

Luke's Journal

of Christian Medicine & Dentistry
Vol. 21 No. 2 September 2016



CHRISTIAN MEDICAL
& DENTAL FELLOWSHIP
of AUSTRALIA Inc.

**Book Review:
Fearfully and
Wonderfully
Made**

**A Christian
Perspective on
Prenatal Genetic
Screening and
Diagnosis in
Australia:
National Ethics
Committee
CMDFA**

**Perinatal
Palliative
Care**

**Journey
of Love:
The Challenge
of an Unborn
Life**

**Some reflections
on unborn life**

Life before birth

www.cmdfa.org.au



Published by the
Christian Medical and Dental Fellowship of Australia Inc.
ABN 95 084 292 464

Please submit all contributions to:

THE EDITORS
Dr Paul Mercer
Ph: 07 3348 9940
Email: silkymedical@ozemail.com.au

Dr Catherine Hollier
Ph: 02 4957 5242
Email: cmdfanewcastle@gmail.com

Subscription and change of address details to the National Office listed below.

SUB-EDITORS Sue Furby
EDITORIAL COMMITTEE Professor Warwick Britton (NSW)
Dr Richard Chittleborough (SA)
Drs David and Denise Clarke (Vic)
Dr Alan Gijbers (Vic)

CMDFA

MEMBERS OF COUNCIL OF REFERENCE

Dr Allan Bryson [NSW] MBBS, BSc
Professor Graeme Clark, OA, MD (Hon), PhD, MB, MS, FRACS, FRCS, FTSE
Dr Ken Hayes [Qld] MBBS, FRACP
Emeritus Professor Louise Brearley Messer AM, BDSc, LDS, MDSc(Melb),
PhD(Minn), GradDipDiv(ACT), FRACDS, FICD
Professor Philip Mitchell [NSW] MBBS, MD, FRCPsych, FRANZCP.
Professor Kim Oates [NSW] AM, MD, MHP, FRACMA, FRCP, FRACP, FAFPHM, DCH.
Dr Michael Payne [NSW] BDS (Hons).
Dr Geoffrey Pike [SA] AM, MBBS, DTM&H, FRACGP
Dr Robert Pollnitz [SA] FRACP.
Professor Ian Puddey [WA] MBBS, FRACP, MD
Professor Anthony Radford, SM (Harvard), FRCP (Edin), FRACP, FRACGP,
FFCM, FAFPHM, DTM&H (Liverpool)
Dr David Simpson, MBBS, FRACOG, FRCP(Edin)
Professor Laurence Walsh, BDSc, PhD, DDSc, FFOP(RCPA)
Dr Grace Warren, AM, MD, MS, FRCS, FRACS, D.TM & H (Syd.)

CHAIRMAN

Dr Ross Dunn
Ph 07 3822 6459 Mobile: 0427 045 991
Email: chair@cmdfa.org.au

NATIONAL OFFICE

Unit 35A / 9 Hoyle Avenue
Castle Hill NSW 2154
PO Box 877
Baulk ham Hills NSW 1755
Ph: 02 9680 1233 Fax: 02 9634 2659
Email: office@cmdfa.org.au

BUSINESS MANAGER

David Brown
Contact through the National Office

NATIONAL SECRETARY

Dr Yvonne Lai BDSc(WA)
Email: yvonne.yl.lai@gmail.com
Email: secretary@cmdfa.org.au

NATIONAL TREASURER

Dr Richard Allan (PHD Economics)
Email: office@cmdfa.org.au

ReGS (Recent Graduates & Students)

Dr Joel Wight (recent graduates)
Email: joel.c.wight@gmail.com
Dr Jacki Dunning(students)
Email: jacki.elizabeth.dunning@gmail.com
Email: students@cmdfa.org.au

BRANCH SECRETARIES

NSW and ACT:
Richard Wong
Email: nsw@cmdfa.org.au

QUEENSLAND:
TBA
Email: qld@cmdfa.org.au

SOUTH AUSTRALIA (and NT):
TBA
Email: Lai0051@hotmail.com

WESTERN AUSTRALIA:
Bianca van der Nest
Email: biancamay.vdn@gmail.com

VICTORIA (and TAS):
Elise Chen
Email: victoria@cmdfa.org.au

About Luke's Journal

This Journal is published three times a year by the **Christian Medical and Dental Fellowship of Australia Inc. (CMDFA)**. The views expressed in the articles are those of the authors and not necessarily those of the CMDFA. Articles are reviewed by the editors and members of the editorial committee. Material published in the Journal is subject to copyright. Requests for permission to reproduce any part thereof for purposes other than private study should be directed to the editors. Additional copies for passing on to interested colleagues can be obtained from the national office or Branch Secretaries.

Subscription of **Luke's Journal** is given to members of CMDFA. It is also offered to libraries and hospitals at the price of \$55 per year including postage within Australia. Enquiries and notice of change or address should be directed to the national office.

About CMDFA

Membership of CMDFA is open to graduates and students of medicine and dentistry. Information about activities of CMDFA can be obtained from the website at www.cmdfa.org.au or from Branch Secretaries. Further information and application details are available through the national office.

Graphic design by Ivan Smith, Lilydale, Vic.
Printed by Amazon Printing, Warrnambool, Vic.
Stock photos: www.dreamstime.com

Back Issues

Back issues are available for the following Journals:

Vol 19 No 1	Apr 2014	Historytaking and Historymaking
Vol 19 No 2	Sept 2014	Integral Mission or Holistic Transformation
Vol 20 No 1	Feb 2015	"You are What You Eat"
Vol 20 No 2	Nov 2015	Standing Together in the Public Square
Vol 21 No 1	Apr 2016	Family Matters

These back issues are free for financial members of the CMDFA. The cost is \$5 for friends of CMDFA or non-financial members (including postage). Please write to the national office making cheques payable to CMDFA Inc.

Other issues may be obtained from your Branch Secretary or from the national office.

Life before Birth



Like most GPs I have a pregnancy wheel reliably stored on my desk. When the diagnosis of pregnancy has been established it comes into use in predicting the birthday. Calculating this date is mostly an exciting and breathtaking moment for parents.

For most of human history, the nine months of expectation for birth has been a hidden frontier, an arm wrestle for life itself. Apart from a few glimpses of this gestational lifetime in the stories of Jeremiah, John the Baptist and Jesus and Mary, the Scriptures are silent. Conception gets a few honourable mentions, but the apocryphal book Sirach perhaps offers the most meaningful insight when we read "To fear the Lord is the beginning of wisdom; she is created with the faithful in the womb" (Sirach 1v14).

With modern science and technology, gestational life is becoming more transparent. The mapping of the human genome is central to this growing awareness. CMDFA's ethics working group has recognised this important new space in developing a position paper, "The ethics of prenatal genetic diagnosis" (Dr Joseph Thomas, lead collaborator). It is the centrepiece for this edition of Luke's Journal. Other materials have been prepared around this paper. Hayley Thomas has offered a piece reflecting on the core biblical understanding of the "Image of God." A number of members came forward with stories around the related ethical challenge of abortion. The medical advances in prenatal life will change the

'landscape' of the ethics of medically-indicated termination.

Change in the 'amniotic world' is rapid. In 2007 the discovery of CRISPR as a genetic scissor has triggered new possibilities for genetic treatment and in the past twelve months CRISPR has been used to edit genes within embryos. Because of the human genome project, the genetic links of some 5,000 conditions have now been established. The cost of sequencing is also quickly falling to levels which will inevitably see many clinical applications. Some of these will be prenatal.

Apart from genes, our knowledge of epigenetics is also expanding rapidly. Prenatal life is not immune from external influences. A mother's health and lifestyle choices do influence outcomes. Infections can influence development and human capacity such that pre-pregnancy and antenatal immunisations are desirable. Avoiding certain foods, alcohol and tobacco, all can influence genetic expression. Maternal psychological trauma and then positive nurturing capacity are also strongly linked to mental health outcomes and resilience for the developing prenatal. Indeed the pre- and postnatal environments merge in providing a nurturing epigenetic context which generally leads to healthy human growth and development.

continued page 7

Contents

Theme

- 4 The Image of God
– Hayley Thomas
- 8 A Christian Perspective on Prenatal Genetic Screening and Diagnosis in Australia: National Ethics Committee Christian Medical and Dental Fellowship of Australia
- 19 A Tough Life
– Sarah Luthy
- 20 A Meeting of the Sanhedrin
– James White
- 21 Book Review: Fearfully and Wonderfully Made by Megan Best
– Andrew Moore
- 22 Prenatal Screening
– Jonathan Morris
- 24 Book Review: Defiant Birth: Women Who Resist Medical Eugenics
– Su Lynn Cheah
- 25 Obituary: Kenneth Robert Hayes
- 26 The Visible and the Invisible - Part I: The Invisible moving the Visible
– Joseph Thomas
- 30 Book Review: The Language of God by Francis Collins
– Megan Best
- 32 Journey of Love: The Challenge of an Unborn Life
– Heidi Best
- 35 Emily's Voice – Paul O'Rourke
- 36 Perinatal Palliative Care
– Anthony Herbert
- 39 Crisis Pregnancy Centres Around Australia
- 40 Some reflections on unborn life
– John Whitehall
- 42 Diamond Pregnancy Service
– Tyler Schofield

Luke's Journal

Themes for Next Editions:

A 20th Anniversary Luke's Journal
– **Health & Hope**
– copy by October 2016

Mentoring: Passing the Baton On
– copy by March 2017

The Image of God

by Hayley Thomas

Hayley graduated from the University of Qld in 2011, before working as a resident at Redcliffe Hospital and the Lady Cilento Children's Hospital. Following her second year of residency, she completed a Graduate Diploma of Christian Studies at Sydney Missionary and Bible College. She is currently working as a GP registrar in the northern suburbs of Brisbane.

'So God created mankind in his own image, in the image of God he created them; male and female he created them.'

(Gen 1:27, NIV)

The affirmation that humankind bears the image of God is a deeply held Christian belief, and foundational to a Christian understanding of the nature of humanity. Bearing the image of God confers a unique intrinsic dignity upon all human beings. This has significant and broad-ranging practical implications. It has, for example, frequently underpinned Christians' respect for and protection of the weakest and most vulnerable members of society.

The doctrine of the image of God is present throughout the Bible, being introduced in its first chapter, and further developed and revealed in the New Testament. Yet, despite widespread agreement on the importance of the doctrine, historically Christian theologians have held a

variety of views on its meaning. This article briefly explores Scriptural references to and theological understandings of the image of God, before reflecting on some of its implications.

"...humanity's creation in the image of God has moral implications."

The Image of God in Scripture

While there are a relatively small number of references to the image of God in Scripture, the concept nevertheless holds a prominent place within it. It features in the Bible's first chapter, underpinning the Biblical perspective on humanity. The New Testament continues to expand the concept in light of Christ and believers' relationship to Him.

Biblically, the image of God is introduced in Scripture's first reference to humankind (Gen 1:26-27). In Gen 1:26, God proposes making humankind in 'our' (his own) image and likeness, and 1:27 contains a double affirmation that he did so. The Hebrew word translated 'image' is *tselem*, which comes from the root 'to carve' or 'to cut', often denoting a three-dimensional representation.¹ The word translated 'likeness', *demuth*, comes from the root 'to be like' and refers to similarity.² Together, this suggests that to be created in the image of God is to be 'like God and [represent] ... God'.³ Additionally, this first reference to creation of humans in the image of God is closely related to their creation

as male and female (Gen 1:27) and the mandate to be fruitful and rule over creation (Gen 1:26, 28).

Genesis 5:1 reaffirms that, 'When God created mankind, he made them in the likeness of God'. Genesis 5:3 continues that Adam's son Seth was in his 'image' and 'likeness'. This suggests that the image of God is transmitted from one generation to the next.⁴ It also implies a similarity between the image of God in man and the resemblance between a parent and their child.⁵

The final explicit Old Testament reference to the image of God occurs in Genesis 9:6. Because humans bear the image of God, this verse mandates against 'shed[ding] human blood'.⁶ This indirectly establishes that man still bears the image of God following the Fall, a point which has historically been disputed by some theologians.⁷ It also clearly illustrates that humanity's creation in the image of God has moral implications.

While there are no further explicit references to the image of God in the Old Testament, these few references at its opening are foundational to a Biblical understanding of humanity. The image of God may also be alluded to in other Old Testament passages such as Psalm 8, whose reference to God's creation and exaltation of humankind may recall our creation in His image.⁸

In the New Testament, the doctrine of the image of God reemerges and is further developed. Like Genesis 9:6, James 3:9 reinforces the ethical implications humankind's creation in the image of God, as it condemns



cursing others on this basis. In keeping with the progressive nature of revelation, the New Testament also introduces aspects of the image of God that are not previously evident. Specifically, Christ is revealed to be the perfect image of God, who as His only begotten Son reflects Him uniquely and with a perfection that is unmarred by sin (2 Cor 4:4; Col 1:15; implied by John 14:8-9; Heb 1:3). Additionally, the New Testament reveals that Christians are being progressively conformed to Christ's image (Rom 8:29; 1 Cor 15:49; 2 Cor 3:18; Col 3:10). This suggests that while all people bear the image of God through creation, Christians in some sense bear a unique likeness to Christ, the perfect image of God, through the process of sanctification.

A theological model of 'the image of God in the fourfold state of man' helps to clarify this relationship of the image of God in humankind to redemption history.⁹ It suggests that at creation, man possessed 'The Original Image' of God. At the Fall, this image was retained, but marred by sin, which now stains humankind but is clearly foreign to the nature of God ('The Perverted Image'). This concept helps to address the question often posed by skeptics of how humankind, in the midst of our imperfection, disease and sinfulness, can possibly bear the image of a perfect God. With redemption, however, the image of God in man is

gradually renewed to an even more complete and perfect state than at creation, as believers are conformed to become like Christ ('The Renewed Image'). This process is ongoing, and is finally completed at glorification ('The Perfected Image').

The Image of God in Theology

It is clear, then, that the image of God is a recurring and developing theme within Scripture. Yet, it is not

distinguish humanity from animals.¹² It includes positions that identify the image of God with psychological characteristics such as rationality, free will and self-consciousness; spiritual traits such as possession of a soul; physical characteristics (rarely); or a combination of these.¹³ In early church history, the image of God was frequently equated with human reason and free will. For example, Thomas Aquinas stated that 'man is

"...the image of God is a recurring and developing theme within Scripture. Yet, it is not specifically defined, retaining an element of mystery."

.....

specifically defined, retaining an element of mystery. Historically, this has engendered significant theological discussion. Several understandings of the image of God have been suggested, which can be broadly classified as substantive, relational and functional (or royal) views.¹⁰

The substantive view identifies the image with one or more attributes, characteristics or qualities possessed by humanity that we uniquely share with God.¹¹ This view has been historically dominant, seeking to define the image of God by identifying God-like characteristics that

said to be the image of God by reason of his intellectual nature',¹⁴ such that 'to be the image of God belongs to the mind only'.¹⁵ In the modern period, while other understandings of the image of God have gained in prominence, the substantive view has continuing significance. However, the understanding that it consists only of reason, freedom and self-consciousness is now almost universally rejected, with the recognition that this was founded primarily upon Hellenistic philosophy.¹⁶ Instead, most modern proponents

continued over page



of the substantive view of the image take a holistic approach. Erickson, for example, argues that the image of God is not limited to psychological attributes, but consists in all of the communicable attributes of God.¹⁷

In contrast to the substantive view, the relational view of the image of God suggests that it consists not of specific attributes, but rather in the human experience of relationship with God and others.¹⁸ This view has become prominent in twentieth century theology with the rise of neo-orthodoxy, and was developed through the work of theologians Barth and Brunner.¹⁹ Barth suggested that the parallelism between the statements that God created mankind in his image in Genesis 1:27, and the following assertion that he created them male and female, suggests that the image of God is reflected in relationships.²⁰ He also believed that God's use of 'us' and 'our' in his self-discourse in Genesis reflects His relational, Trinitarian nature, and that it was significant that his first use of this language (Gen 1:26) occurred immediately prior to the statement that humans are created in His image.²¹ Brunner, a contemporary of Barth, defined the image as the ability of mankind to respond to God.²² This relational view of the image remains prominent in modern theology.

Finally, the functional, or royal, view defines the image of God as something that mankind does, rather

"...the image of God in humanity affords us a special and unique dignity."

.....
than something that we are or that we experience.²³ This view has a long history and has recently increased in popularity. Specifically, this view often defines the image as the dominion of humankind over creation, such that we function as the coregents or representatives of God on earth.²⁴ This is based upon the close connection between the creation of humankind in the image of God and the command to rule and subdue in Genesis 1:26-28.²⁵ Additionally, it is argued that the royal view reflects Ancient Near Eastern cultural understanding, in which 'image of God' was a throne name for monarchs, and kings would erect images of themselves throughout their provinces to represent their claim to dominion.²⁶

These varied understandings of the image of God each have strengths and weaknesses, and may all have something to offer our understanding of what it means to image our Creator. Genesis 5:3 seems to imply that an appropriate metaphor for the image of God may be the resemblance between a parent and their child. This is suggested by the modern theologian Grudem, who takes a holistic, though non-specific, view of the image of God

as being 'every way in which man is like God'.²⁷ Perhaps, however, the best way to perceive the image of God is to look to Christ.

Why Does it Matter?

While these varied understandings of the image of God are interesting to reflect upon, our view of the image is of more than theoretical importance. It has significant practical implications.

Clearly, the image of God in humanity affords us a special and unique dignity. This is a dignity that is not based on our abilities or status, but rather, it 'is derivative: it comes from Him whose image we bear'.²⁸ This should shape our perception of ourselves and others, and also the way in which we treat each other. For example, as Genesis 9:6 makes explicit, the image of God in humanity necessitates a special respect for and protection of human life. For in a sense, to harm one made in God's image is an assault against Him; Hoekma goes so far as to suggest that 'To touch the image of God is to touch God himself; to kill the image of God is to do violence to God himself'.²⁹

The clear Biblical assumption is that the image of God is universal in humanity, though present in a special and renewed form in those who are being conformed to Christ's image. Some understandings of the image of God, however, subtly fail to align with this. For example, a possible weakness of the functional view is that equating the image with something

Life before Birth – from page 3

That Sirach locates the emergence of “wisdom” in this prenatal context is a compelling voice for the maternal bio-psycho-socio-spiritual health of expectant women. Wisdom is the wonderful mixing of science, experience, compassion and love. It is likely that wisdom in adult life contributes to the epigenetics of coming generations. Francis Collins, the Human Genome project lead investigator, has stated “It is humbling for me and awe-inspiring to realise that we have caught the first glimpse of our own instruction book, previously known only to God.”

What Collins describes as an ‘instruction book’, the then-US President, Bill Clinton nominated as “the most wondrous map ever produced by humankind.” This human genome map was made available to the world in June 2000 without restrictive patents. It unlocks the contours of around 30,000 human genes which develop the 100 trillion cells that go to make a human life. The Bible uses the word “glory” to describe the creative genius of God laid bare in the human genome. The way humanity handles this genomic data will be contested, but full of potential for health.

This edition of Luke’s Journal invites us into the prenatal life stage of the human genome we all are. It is an era of life shared by Jesus and his mother Mary. It is a fragile, vulnerable stage in the life cycle that calls for compassionate, thoughtful, evidenced-based medical interventions and at times surgical skill. The possibilities are endless. Enjoy this “Life before Birth” edition.

Paul Mercer
Editor

that humans do may suggest that it is not present in those who cannot exercise these functions.³⁰ Similarly, while most current proponents of the substantive view see it in a holistic light, one historically dominant version of this view equated the image with characteristics such as reason and self-consciousness. Any understanding of the image of God that contradicts its universality implicitly undermines the protection afforded to some members of society – and these are frequently the most vulnerable, such as the very young and the disabled.

Conversely, while the relational view has its weaknesses, having been criticised as being influenced by existentialist philosophy and on textual grounds, this view does seem particularly sensitive to the Trinitarian nature of God, and also to the centrality of love in the life of Christ, the perfect image of God.³¹ It also provides scope for a unique covenantal element in the understanding of the image. This provides a framework for the understanding that our personal value is intimately related to God’s love for us. Again, this has practical relevance. Specifically regarding beginning of life issues (though not in the context of discussing the image of God), Wyatt has argued that ‘the covenant relationship of loving commitment does not depend on reciprocity...the critical issue is not whether the fetus is aware of God but whether God is aware of, and committed by grace to, the fetus’.³²

The image of God, then, underpins a Christian understanding of humanity. While the nature of the image retains an element of mystery, seeming to resist a unidimensional definition, clearly to be created in God’s image imparts a unique dignity upon humanity. This is not a dignity that is earned, self-dependent or restricted to a select few, but rather conferred by the act of a loving and Sovereign Creator. This should shape our view and treatment of one another, particularly for those of us who ‘are being transformed into [the] image [of Christ]’ (2 Cor 3:18), the perfect image of God. ●

Bibliography

- Acquinas, Thomas. “The Summa Theologica of Saint Thomas Aquinas.” Translated by Fathers of the English Dominican Province. Vol. One. Rev. ed. Chicago: Encyclopaedia Britannica, Inc, 1952.
- Allison, Gregg R. *Historical Theology*. Grand Rapids: Zondervan, 2011.
- Barth, Karl. *Church Dogmatics*. Translated by JW Edwards, O Bussey and Harold Knight. Vol. 3: The Doctrine of Creation Part 1, Edited by GW Bromiley and TF Torrance. Edinburgh: T&T Clark, 1958.
- Bird, Michael F. *Evangelical Theology*. Grand Rapids: Zondervan, 2013.
- Bray, GL. “Image of God.” In *New Dictionary of Biblical Theology*, edited by T Desmond Alexander and Brian S Rosner. Nottingham: IVP, 2000.
- Brunner, Emil. *The Christian Doctrine of Creation and Redemption*. Translated by Olive Wyon Church Dogmatics. London: Lutterworth Press, 1952.
- Erickson, Millard J. “The Image of God in the Human.” In *Christian Theology*. 3rd ed., 457-474. Grand Rapids: Baker Academic, 2013.
- Grudem, Wayne. *Systematic Theology*. Leicester: IVP, 1994.
- Henry, C F H. “Image of God.” In *Evangelical Dictionary of Theology*, edited by Walter A Elwell. 2nd ed. Grand Rapids: Baker Academic, 2001.
- Hoekema, Anthony. *Created in God’s Image*. Grand Rapids: William B. Eerdmans, 1994.
- Middleton, J Richard. *The Liberating Image*. Grand Rapids: Brazos Press, 2005.
- Richardson, Alan. *Genesis 1-11 Torch Bible Commentaries*. London: SCM Press, 1953.
- Wyatt, John. *Matters of Life and Death*. Nottingham: IVP, 2009.

References

1. Anthony Hoekema, *Created in God’s Image* (Grand Rapids: William B. Eerdmans, 1994), 13.; J Richard Middleton, *The Liberating Image* (Grand Rapids: Brazos Press, 2005), 45.
2. Hoekema, 13.; Middleton, 46-47. Historically, a distinction has been made between these two terms, however they are now understood to be synonymous. (GL Bray, “Image of God,” in *New Dictionary of Biblical Theology*, ed. T Desmond Alexander and Brian S Rosner (Nottingham: IVP, 2000), 575.; Middleton, 28.; C F H Henry, “Image of God,” in *Evangelical Dictionary of Theology*, ed. Walter A Elwell (Grand Rapids: Baker Academic, 2001), 592.)
3. Wayne Grudem, *Systematic Theology* (Leicester: IVP, 1994), 442.
4. Alan Richardson, *Genesis 1-11, Torch Bible Commentaries* (London: SCM Press, 1953), 54, 90-91.
5. Grudem, 444.
6. Hoekema, 16.
7. Millard J. Erickson, “The Image of God in the Human,” in *Christian Theology* (Grand Rapids: Baker Academic, 2013), 469-470.
8. Hoekema, 17-19.
9. *Ibid.*, 82-96.
10. Erickson, 460.
11. *Ibid.*
12. *Ibid.*; Hoekema, 22.
13. Erickson, 460-461, 470-471.; Michael F Bird, *Evangelical Theology* (Grand Rapids: Zondervan, 2013), 658.
14. Thomas Aquinas, “The Summa Theologica of Saint Thomas Aquinas,” 1.Q93.A.4.
15. *Ibid.*, 1.Q93.A.6.
16. Middleton, 18-20.
17. Erickson, 461, 471.
18. *Ibid.*, 463-465.;
19. Bird, 659.
20. Karl Barth, *Church Dogmatics*, ed. GW Bromiley and TF Torrance, trans., JW Edwards, O Bussey, and Harold Knight, vol. 3: The Doctrine of Creation Part 1 (Edinburgh: T&T Clark, 1958), 184-187.
21. *Ibid.*, 182-185.
22. Emil Brunner, *The Christian Doctrine of Creation and Redemption*, trans. Olive Wyon, Church Dogmatics (London: Lutterworth Press, 1952), 56.
23. Erickson, 465.
24. *Ibid.*, 466.; Bird, 659-660.
25. Erickson, 466.
26. Bird, 659-660.; Middleton, 25-29.
27. Grudem, 444.
28. John Wyatt, *Matters of Life and Death* (Nottingham: IVP, 2009), 56.
29. Hoekema, 16.
30. Erickson, 465-466, 470.
31. Gregg R Allison, *Historical Theology* (Grand Rapids: Zondervan, 2011), 336.; Hoekema, 22.; Wyatt, 160-161.; Erickson, 465.; Middleton, 49-50.
32. Wyatt, 166.

A Christian Perspective on Prenatal Genetic Screening and Diagnosis in Australia

National Ethics Committee Christian Medical and Dental Fellowship of Australia

Authors

Dr Joseph Thomas

Dr Michael Burke

Dr Paul Mercer

Dr Megan Best



Background information Technological advances in the 21st century have given us an unprecedented and increasing ability to predict fetal outcomes.

This predictive ability has brought new dilemmas in decision making. Today's families and their doctors face a range of issues that were inconceivable a generation ago. With early scans and other tests, we can now diagnose a wide range of congenital abnormalities, potentially leaving parents with decisions affecting life and death.¹ Over the course of a few decades, medical care has evolved from being primarily therapeutic and preventive to now also include prediction of risks.

In addition to rapid medical and technological progress in the last few decades, there have been powerful socio-cultural changes that alter the way we reflect on life and living. These include the increased presence of women in the workforce, with a consequent delay in the age at which they marry and start bearing children, a decrease in family size and a shift from the extended family to the nuclear

family,² as well as activism and legal changes related to termination of pregnancy. Computerisation has led to greater health literacy throughout the population. Consequently, medical care, technological progress and risk prediction offer new challenges to patients and their doctors.

Modern technology is an ally in improving outcomes for the mother and the child; however, as Christians, we need to make sure that our application of science and technology is ethical. While at times Christians have feared new scientific understandings, we see that science, when ethically practised, can lead to enhanced medical practice. However, in order to determine whether a practice is ethical by biblical standards, we first need to understand the facts involved. In this paper we will give an overview of the current practices in prenatal genetic screening and diagnosis then examine the ethical issues involved and how the Christian doctor may approach them.

Screening in Pregnancy

there are many screening and diagnostic tests available to assess maternal and fetal health to ensure improved perinatal outcomes. Screening tests are easily performed and cost-effective investigations used among large population groups to separate those who are at low risk from those who are at high risk of a disease. Screening tests provide a risk ratio, which reduces the number of people who need to progress to expensive and potentially dangerous diagnostic tests.

Most screening tests in pregnancy are well established. Maternal tests include routine tests such as blood group, rhesus status, presence of syphilis, HIV, hepatitis B, cytomegalovirus and toxoplasmosis, and prior exposure to measles, mumps and rubella, as well as monitoring of maternal full blood count, liver and kidney function and blood sugar levels. Fetal testing includes the various ultrasounds, e.g. the morphology scan at 20 weeks gestation. Most of these investigations are motivated by a desire to improve maternal and fetal wellbeing. The focus of this paper is on issues related to prenatal genetic screening and prenatal genetic diagnosis. These more recent tests have at times been controversial and raised challenging ethical questions.

Prenatal Genetic Screening and Diagnosis

The human karyotype has 46 chromosomes: 22 pairs of autosomes and a pair of sex chromosomes, one set from the biological father and the other set from the biological mother. Genetic disorders result from either a disorder in the number of chromosomes (e.g. Down syndrome [trisomy 21] or Turner syndrome [XO]), or structure of the chromosomes (e.g. duplications/deletions/translocations/ring chromosomes). In addition, there are single gene disorders such as gene repetition disorders and uniparental disomies. Genetic or DNA testing screens for the predisposition an individual has for any of the inherited disorders and is diagnostic in many



clinical contexts. It can determine a person's parentage/ancestry. Genetic tests may include biochemical testing of the markers/products of the gene or testing for the defective gene itself. A gene defect does not necessarily mean a disease state. Whether the disorder is expressed is influenced by both the nature of the disease (dominant or recessive) and the type of genetic disorder (homozygous or heterozygous). The complexity may increase due to different mutations being possible in the same gene and the actual expression of the gene disorder in an individual.

The currently available prenatal tests are:

Screening tests

- Combined first trimester screening (combining maternal blood testing and a scan of the fetus)³
- Second trimester maternal serum screening⁴
- Non-invasive prenatal testing (analysing cell-free fetal DNA from maternal blood)^{5,6}

Diagnostic tests

- Chorionic villus sampling (for chromosomes and DNA extraction)
- Amniocentesis (for chromosomes, DNA extraction and other biochemical tests)
- Microarray panels (comparative genomic hybridisation or new

generation sequencing) of fetal DNA⁷

Second trimester structural anomaly scanning (morphology scan) is used for both screening and diagnosis. The number of diseases that can be screened for and diagnosed using these tests is increasing. Genome-wide prenatal testing is likely to be available soon. In the case of a negative result from screening, it is assumed

the case of a positive diagnosis and in the absence of any treatment or cure, outcomes include a decision by the parents to continue the pregnancy and prepare for ongoing care of the child, or a decision to terminate the pregnancy. Perinatal palliative care is an option for some parents whose child may have a severely life-limiting condition (e.g. Edward syndrome or Patau syndrome). The pace of research related to prenatal genetic conditions

“As Christians, we need to make sure that our application of science and technology is ethical.”

that the pregnancy will continue without intervention. In the case of an indeterminate result or a positive test from screening, further assessment is recommended to establish a diagnosis. The parents have the choice to undertake diagnostic testing or to decline. Counselling is advised before the decision is made.

In the case of a positive diagnosis, all available treatment options should be offered. These may or may not be accepted by the parents. Some will choose to continue the pregnancy under careful management, usually in a tertiary care setting. Access to tertiary care is often determined by geographical location in Australia. In

and their treatment is progressing rapidly⁸; for example, it is now a possibility that Down syndrome⁹ will be treated through silencing the extra chromosome 21.¹⁰

Definitions

Modern technology and the availability of advanced life-support from 23 weeks of intrauterine life onwards have blurred perinatal timeline definitions. The following medico-legal definitions are accepted in the Western world.

Pre-viable gestation

Beginning of biological life

The potential for biological life as

continued over page

we know it begins at conception, and establishes itself progressively at implantation, at viability and at birth. The criteria for miscarriage have been revised to ensure that the beginnings of biological life are given sufficient margin so no errors are made in diagnosis.¹¹ A heartbeat seen by ultrasound scan is the first sign of life in an embryonic disc.

Embryonic period

The time from a missed period or positive home pregnancy test up to 12 weeks gestation, by which time most fetal organs are formed; the fetal period dates from 12 weeks to birth.

Fetal period, weeks 12 to 22

Functionally, three fetal periods are recognised; if the fetus is born prematurely in the pre-viable period up to 22 weeks, resuscitation is normally not recommended.

Peri-viable gestation

In the peri-viable fetal period from 23 weeks to 25 weeks and 6 days, parental wishes in regard to resuscitation are taken into consideration.

Viable gestation

Beyond 25 weeks and 6 days, the fetus is considered to be viable (able to live outside of the womb with technological support and resuscitation).¹²

Birth

A birth is defined by the World Health Organisation as a gestation of over 20 weeks or 500 g (though many developing countries consider this a miscarriage, with criteria for birth being after gestation of 28 weeks or birth weight of 1000 g).¹³ It is a legal requirement to register all births after 20 weeks in Australia.

“Wrongful birth”

The concept of ‘wrongful birth’, where an unplanned child is born through medical negligence – and the parents may sue the negligent doctor to recover the costs of raising the child to maturity – was upheld by an Australian High Court by a 4:3 majority.¹⁴ Legislative changes to counter this have been proposed in the United States.¹⁵ The terms ‘wrongful birth’,

‘wrongful pregnancy’ and ‘wrongful conception’ have been variously defined, sometimes interchangeably. Strictly, what is ‘wrongful’ is the negligence, not the birth; but the label is convenient shorthand. This implies that parental intent is a prerequisite for rightful birth, and hence implies diminished status of the fetus where there is no parental intent.

Controversies in Definitions

Medicine and biology study human structure and function as well as the mechanisms in human formation. While we have elucidated the entire human genome and understand many of the mechanisms that are involved in the formation of a human being, there is still a vast amount that we do not understand. Although our understanding of the genetic and epigenetic interplay has increased in quantum leaps in the last decade, there are many more inroads still to be made before we can understand the many mysteries of cellular mechanisms. Defining human life purely in terms of biology, i.e. biochemistry, chromosomes, structure or function, is reductionist and has limitations.

Biochemical definitions

The potential for life begins with the fusion of an oocyte (n chromosomes) and a sperm (n chromosomes) to form a zygote (2n chromosomes). The exact mechanisms involved in the crossover of chromosomes (from the sperm and oocyte), spindle formation and the migration of the chromosomes to the polar bodies are not well understood. These cells rapidly multiply to separate out into the outer cell mass (trophoblastic cells/chorionic cells), which forms the placenta and membranes, and the inner cell mass, which forms the embryo/fetus. The trophoblastic cells release human chorionic gonadotropins which signal the uterus and the ovary to prepare for implantation and pregnancy. Evidence of pregnancy is biochemical, and many pregnancies are lost at this stage.

Chromosomal definitions

Once implantation occurs, some pregnancies continue without an embryonic pole. Ultrasound

examination can allow the diagnosis of an “anembryonic pregnancy” to be made. Most losses in early pregnancy are likely to be from chromosomal abnormalities. The euploid human fetus is defined as 46,XX or 46,XY. Trisomy of the sex chromosomes (XXX, XXY or XYY) or of chromosome 21 is compatible with life but there are many trisomies of the autosomal chromosomes that are not compatible with life. The triploid/tetraploid pregnancy (69,XXX/92,XXX) that results in a partial molar pregnancy where a fetus is seen, is not compatible with life. The diploid (46,XX/46,XY) 2n chromosomes in the case of dispermy, where no chromosomes are derived from the ovum, results in a molar pregnancy where there is no recognisable fetus. It cannot be attributed any human characteristics even if the biochemistry and the karyotype are normal.

Structural definitions

The anomaly scan conducted at 18 to 20 weeks gestation aims to identify fetuses with a structural abnormality. It is a challenge for fetal medicine specialists to define the level of scanning required to define structural normality, and almost all reports contain a disclaimer. A fetus with anencephaly (no skull with brain tissue exposed) cannot have cortical function even though the pregnancy continues normally and the fetus could be born alive. A twin pregnancy can result in an acardiac fetus, which starts with a heart and head in early pregnancy but develops into a mass of tissue that is chromosomally normal (46,XX/XY) but structurally incompatible with life (although parents may want to name the twin). Therefore, structural characteristics from scans are inadequate to define human life. A structural abnormality may allow a child to be born alive but to only survive for a short time.

Functional definitions

In instances where the fetus has a normal head and a normal heart, the absence of kidneys or conditions that cause hypoplastic lungs are also incompatible with continuing life. Functionally, there are conditions



where the fetus is structurally normal but does not move at all (fetal akinesia syndrome) and cannot breathe once it is born. It is difficult to define what functions have to be present as a minimum to define a human.

Limitations of any definition

These examples highlight the difficulty in defining a human being using any particular biological parameter. Regardless of how we define a human being or when we define the beginning of life, there are some issues that will invariably challenge our views and may not have an easy answer. We can see the difficulty of attributing human characteristics to biochemical evidence of pregnancy or to an embryonic sac from fertilisation or to a molar pregnancy. Moreover, to be chromosomally normal does not ensure sufficient structural normality to necessarily result in a live baby (e.g. anencephaly or Potters syndrome). The fallenness of the reproductive processes (as with all of creation) results in abnormalities that can exist at the biochemical, chromosomal, structural and functional level. To attribute human characteristics or to define human life in terms of karyotype/genome or in terms of structure/function would be to do it an injustice.

Professional Guidelines for Prenatal Screening and Diagnosis

All doctors in Australia are required to comply with professional ethical standards. Several professional organisations have published guidelines on the topic of pregnant women and the disclosure of screening test availability, of which all doctors involved in antenatal care should be aware.

College guidelines

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) has a statement on prenatal screening for Down syndrome, Edward syndrome and neural tube defects with professional requirements for all obstetricians and gynaecologists on their website. An excerpt is copied below:

Pre-test counselling and information

- 1.1 All pregnant women should be advised of the availability of prenatal screening as early as possible in pregnancy to allow time to discuss the options available and facilitate an informed choice.
- 1.2 Information on the relative advantages and disadvantages

of the available screening tests should be provided to pregnant women (and their partners). Information should be provided in a way that is easily understood and culturally appropriate. Information should include details of the nature, purpose, limitations and consequences of screening. The offer of screening needs to take into account both the tests that are available to the woman and the stage of her pregnancy. There should be information on:

- 1.2.5 The understanding that a termination of pregnancy would be available in the event an abnormality was diagnosed, and that the mode of termination available will be influenced by gestational age. There should be an assurance that continuation of the pregnancy is a valid option should an abnormality be diagnosed, and that couples would receive appropriate counselling and care in preparation for birth.¹⁶

Australian Medical Council guidelines

The need for doctors to provide all available information on genetic screening to pregnant patients is supported by the Australian Medical Council's *Good Medical Practice: A code of conduct for doctors in Australia* (2009). The relevant sections are quoted below:

- 2.2 Good patient care
Maintaining a high level of medical competence and professional conduct is essential for good patient care. Good medical practice involves:
- 2.2.6 Providing treatment options based on the best available information.
- 2.2.12 Ensuring that your personal views do not adversely affect the care of your patient.
- 2.4 Decisions about access to medical care

continued over page

Your decisions about patients' access to medical care need to be free from bias and discrimination. Good medical practice involves:

2.4.6 Being aware of your right to not provide or directly participate in treatments to which you conscientiously object, informing your patients and, if relevant, colleagues, of your objection, and not using your objection to impede access to treatments that are legal.

2.4.7 Not allowing your moral or religious views to deny patients access to medical care, recognising that you are free to decline to personally provide or participate in that care.

In the context of the guidelines above, it is imperative that all physicians involved in the care of pregnant women become conversant with prenatal screening and diagnosis, regardless of the cultural, religious and ethical views held by doctor or patient. As discussed in the Christian Medical and Dental Fellowship of Australia (CMDFA) Ethics Statement on Christian Conscience in Healthcare, we each need to decide how such requirements impact on our choices for where we practice medicine.

Ethical Issues in Prenatal Genetic Screening and Diagnosis

Introduction

Western ethics has been traditionally based on Judeo-Christian values. In modern pluralistic Australia these values are not universally held, and the diversity of views can lead to ethical conflicts for Christian doctors.¹⁷ Furthermore, even within a Christian understanding, the right thing to do in any given situation may not be immediately apparent.

Genetic screening and diagnosis allow for improved monitoring of pregnancy and possible antenatal treatment of identified pathological conditions. A diagnosis of Down syndrome may mean that plans for a home birth need to be changed owing to the increased



risk of complications at the time of the delivery. It also makes it possible for parents to prepare their home for long-term care of a child with special needs. Therefore a high regard for the moral status of the fetus does not preclude testing. One assumption underlying genetic screening and diagnosis is that genetic abnormality may lead to termination of pregnancy. The decision of whether to use the technology is complex. The numerous ethical dilemmas associated with prenatal genetic screening and diagnosis make it even more difficult.

The Inherent Value of a Fetus

In current secular medical literature, there is no consensus regarding the moral status of the fetus. This situation is made more complicated in the fetal medicine setting, where the question of 'fetus as patient' arises.

The basic question here is whether we should regard the fetus as a person and thus deserving of legal protection. In secular literature it is due to the potential for maturity, or the idea of maturity increasing with development, that value may be conferred on the nascent human. This

view is reflected in legislation which allows termination of pregnancy under certain circumstances. Obviously the fetus cannot exert autonomy on its own behalf. Therefore Chervenak and McCullough¹⁸ argue that, although the fetus cannot have autonomy-based protection, it could have a beneficence-based protection when the fetus is considered a patient. They further argue that the only basis upon which a pre-viable fetus can attain the status of a patient is when a pregnant woman makes a decision to confer this status onto the fetus. Under our current law, the woman is free to confer or withhold this status. Furthermore, having conferred, she is free to withdraw this status from the pre-viable fetus at any time without justification, according to her own values and beliefs.

Once a fetus has reached viability, this balance changes and some authors suggest that a direct relationship between fetus and the doctor now exists which is not dependent on maternal preference. This relationship would demand that the doctor consider the best interests of the fetus on the basis of beneficence. Chervenak and McCullough suggest that the

mother should also realise that there is a beneficence-based obligation to the fetus which constrains her autonomy,¹⁸ for example, by prohibiting termination of a viable fetus. This view is obviously not universal and not supported by legislation.

Informed Consent

Informed consent will be important for the pregnant woman, as whether screening is done depends entirely on her choice, although ideally this would be a family decision.

Many prenatal genetic screening tests need to be done early in a normal pregnancy, so general practitioners often order them before the mother has had her first visit with an obstetrician. This means the doctor ordering the test may not have specialist knowledge of the conditions being tested. He or she may not be able to explain fully what is involved,¹⁹ and explanation of health risks is known to be difficult in any setting.²⁰ Often there will be time constraints, and it may be difficult to provide comprehensive genetic counselling, such as the statistical complexity of sensitivity and specificity of screening tests, in a busy general practice.²¹

General practitioners in Britain reported that it was difficult to raise possible adverse outcomes with someone who is excited at finding out she is pregnant. Although doctors offered women a choice, they knew they consciously offered genetic screening tests as routine and in a positive light due to lack of time, while being aware that a key motivation for women's positive perceptions of screening was their sense of obligation to undertake any test that would benefit their unborn baby.²² There is a need to better equip all doctors in this complex and fast-changing area.

Currently, evidence suggests that many women undergoing these tests do not understand their purpose. An Australian study²³ found that 31% did not know that miscarriage was a possible consequence of diagnostic

testing subsequent to an increased risk screening result, and only 62% correctly identified that termination of pregnancy would be offered if Down syndrome were diagnosed.²³

Apart from the ethical problems involved with inadequate disclosure of all the facts, it means that women may not think through the implications of a positive diagnosis before undergoing the testing. Informed consent will also require comprehensive explanation of the results at each stage of the screening and diagnosis process, including the meaning of genetic risk, the nature of the genetic abnormality diagnosed, the concepts of variation in phenotype and genotypes, and practical information about living with disability. Currently, such information is not routinely given.²⁴ Some authors suggest it is not feasible to give so much information in a way that is meaningful to the mother. Confusingly, some authors have complained that women are already given too much information regarding

“The capacity of the patient to meaningfully engage with even more diverse and complex measures of risk will further stress the doctor–patient relationship.”

prenatal genetic screening, which gives them too many choices and impairs their decision-making ability.¹⁸ This problem will only become more complex as the testing becomes more comprehensive as genetic technology improves. Furthermore, given that our understanding of genetics is incomplete, we do not know the significance of many variations seen in genome-wide testing. This further highlights the difficulties of what women need to be told before such tests are offered.

Medical standards of patient confidentiality make it necessary for the woman to give the doctor permission before he can share such information with other parties, including the father of the fetus. Any attempts by family members to coerce the woman are also an ethical problem

which the doctor should attempt to counteract.

De Jong and colleagues have suggested that informed consent may become more difficult with the introduction of non-invasive prenatal testing.²⁵ They raise the possibility that, because non-invasive testing is easy and safe and can be performed early in pregnancy, both testing and selective abortion may become 'normalised'. It is also possible that the reduced risks involved may mean that less care will be taken with informed consent. This is particularly important, as, with widening of scope of testing and increased sensitivity of ultrasound scans, women may get unexpected results for conditions for which they did not know the fetus would be tested, and thus may not be prepared to handle. De Jong and colleagues suggest that this easy, safe, and early technique combined with testing a much broader range of abnormalities (including milder disorders or likely no disorder) will challenge the notion of prenatal

screening serving reproductive autonomy. The capacity of the patient to meaningfully engage with even more diverse and complex measures of risk will further stress the doctor–patient relationship. The support of all involved by medical experts in genetic interpretation is likely to increase.

Nature of Conditions Detected

Prenatal genetic screening and diagnosis was initially aimed at identifying serious conditions present at birth. With rapid broadening of the scope of genetic testing – including genome-wide molecular tests – conditions which are treatable, adult-onset or only partially penetrable (such as hereditary cancers) are now also the focus of investigations. While recommendations have been made

continued over page

that prenatal diagnosis not be used for minor conditions or characteristics, the question of who decides what a minor condition is is not clear.²⁶

This raises the possibility of a pregnancy being terminated for conditions which may never develop, or are treatable, or, if they do not develop until adulthood (at least 20 and up to approximately 80 years later), may be treatable by the time they occur. While many commentators suggest termination is done in the interests of the child (to avoid suffering), as the interval of anticipated disease-free life increases this is more difficult to justify.

Fetal Therapy

In the event of a positive diagnosis, treatment of the fetus, including in-utero intervention, can be an option. Maternal–fetal surgery has significant implications and complications can occur acutely, postoperatively, for the duration of the pregnancy, and/or in subsequent pregnancies. It is a highly technical procedure with potential for significant morbidity and possibly mortality, even in the best and most experienced hands. Maternal consent is required for any intrauterine procedure. Treating the fetus puts the mother at risk, both in intrauterine minimally invasive procedures and open fetal surgery. Even simple transplacental therapy of the fetus has side-effects for the mother that can require intensive care admission for monitoring. Where the benefit for the fetus and the mother conflict, in our community it is generally the mother who decides which should be the goal of treatment.

When neither death nor the absence of cognitive development is certain, aggressive management of the fetal condition as consented to by the mother is the ethical standard of care in obstetrics.¹⁸ However, there are instances where the parents may not agree with the medical recommendations, and there have been no court orders to date in Australia where maternal autonomy has been challenged to enforce fetal testing or therapy.

Complications of Termination for Fetal Abnormality

Prenatal testing and selective abortion to avoid the birth of a seriously impaired child is widely accepted in our community. One study²⁶ found that 79% of Americans believed that abortion should be available in this instance. Public surveys suggest that the birth of a child with a severe genetic disorder is thought to bring to a family distress, psychological harm, emotional harm and suffering, loss of opportunities, loss of freedom, isolation and financial costs.²⁷ Concerns have also been expressed regarding the impact on the parent–child relationship and the distress of watching a wanted child die, despite the best palliative care available. However, the evidence suggests that termination of a wanted child on grounds of a genetic disorder may not lead to the best outcome for parents.

“There is concern that the use of prenatal genetic screening and diagnosis sends a negative message to those already living with disability.”

.....

Medical termination for fetal abnormality in a wanted pregnancy is quite different from abortion of an unwanted pregnancy. It represents the loss of future hopes and entails the risk of severe and complicated grieving.²⁸ Women whose infants are diagnosed with a congenital anomaly can experience an emotional crisis²⁹ and consideration of end-of-life decisions can entail ambivalence between commitment to the pregnancy and the need to avoid the burden of disability.³⁰ A significant proportion of women undergoing termination for fetal abnormality can experience pathological levels of distress,³¹ more complicated when they were not anticipated due to inadequate information.³⁰ The long-term posttraumatic stress response and grief

can last for years³¹ and is comparable to the experience³² of having a stillborn child.³² More research is needed to understand the long-term implications of this experience, but the assumption that early detection and termination of fetal anomaly is beneficial for women has been questioned.³³ This has important implications for the adequacy of information-giving for proper informed consent to exist.

There is concern that the easy availability of genetic screening and termination of pregnancy may reduce antenatal parental bonding. Whether an abnormal or normal result eventuates, does the idea of children needing to ‘measure up’ impair the parents’ ability to learn to love their child unconditionally? Does a false negative result make it harder for parents to accept a child born with a genetic abnormality?

In the event of a life-limiting genetic abnormality, while there is no doubt about the distress which results from perinatal death of a wanted child, many parents who have opted for neonatal palliative care have the comfort of knowing they did all they could for their child for as long as they could. Adequate counselling and support needs to be provided for those families that embrace and care for a child with disabilities. Such an experience can bring unexpected rewards as well as unanticipated challenges.

Discrimination

As already mentioned, prenatal genetic tests are usually justified in terms of maximising meaningful reproductive choice. This includes the opportunity to avoid parenting a child with a serious genetic disorder. However, there is concern that the use of prenatal genetic screening and diagnosis sends a negative message to those already living with disability. There is debate regarding whether prenatal diagnosis and selective abortion constitutes discrimination against the disabled, some suggesting that, if it is used as a tool to eradicate disabilities it does discriminate, and others suggesting that this is not a conclusive argument against the practice. De Jong and

colleagues suggest that if abortion decisions remain personal and are not made instruments of societal goals to reduce the number of children with congenital disability, they are morally justified. However, some media reports have suggested that with the increased ease of testing, prenatal genetic screening and diagnosis may move from an optional extra aimed at increasing maternal freedom, to an obligation for mothers which, when rejected, is seen as negligent behaviour at risk of burdening the community with disabled offspring.

While termination of the fetus with a diagnosed genetic abnormality may be seen as an act of mercy by many people in our community, the fact that the whole genetic diagnosis process is oriented towards the autonomy of the mother raises the possibility that termination can sometimes be done to avoid anticipated suffering by the parents if they are obliged to raise a child with special needs, whether or not this suffering actually ensues. Members of the disability community have expressed dismay that others may think their lives are not worth living.³⁴

Autonomy of the Child

Prenatal testing has implications for the future autonomy of the child. Testing before birth removes the right of the child not to know their genetic makeup. Many people at risk of a genetic disorder (e.g. 80% of those at risk of Huntington disease) choose not to be tested to avoid the worry of impending disease, or to avoid the need to inform other parties, such as employers or insurance companies, of their genetic status. These options will no longer be possible if the testing has already been done. Solutions to this conflict between the rights of the child and the rights of the mother have been offered in the secular literature. They include: limiting the scope of testing, avoiding the detection of risk for late-onset diseases; or allowing women to undergo these tests only if they have expressed the clear intention to abort an affected child (as the right to self-determination cannot be violated if the child does not live). As long as the right to information to allow women

autonomous choice is valued so highly in our healthcare system, it is unlikely that any of these options are workable.

Medico-Legal Aspects

There are several factors which work together in the current medico-legal environment to create pressures for the doctor who has the responsibility of offering genetic testing to the patient.

- i. Our legal system is based on secular values and strongly supports the autonomy of the mother in genetic testing. This can be emotionally difficult for the medical practitioner who does not agree with her choices. It is also at odds with biblical directives of the responsibilities of parenting for both mothers and fathers. (Ps 103:13).
- ii. Consumerism and the threat of legal action by the parents if something is missed increase the risk of overinvestigation. It often allows screening tests to creep into medical practice without evidence-based benefit, rigorous debate and understanding. Obstetric specialists in Australia can be sued up to 20 years after the birth of a child for problems arising from the pregnancy and birth. As a result, medical actions can be influenced by medical defence organisations and College guidelines as they are applied to for support.
- iii. The costs involved in developing genetic tests combined with the demands of consumerism may mean that genetic tests are offered online prematurely, before they are validated. Furthermore, direct testing via the internet means that consumers are without the benefit of counselling before and after results are given, possibly resulting in unnecessary distress and confusion.

Public Health Perspectives

Health screening of populations is aimed at early detection of disease to allow for prevention or early treatment.⁵ The aim of prenatal screening is to provide information for pregnant women on fetal wellbeing.



The pregnant woman uses this information to make choices whether to continue a pregnancy, seek fetal therapy if indicated, or undergo a medical termination. However, population screening also needs to be proportional. This means that which conditions should be tested for and why is not judged entirely on the balance of benefits and burdens for participants, but also for the society as a whole.

The principle of justice requires that there is equity of access to screening programs; but in a country such as Australia, where such tests are government funded, there needs to be consideration of the costs of screening, particularly in the context of financial constraints. As the number of available tests increases and the range of conditions tested for broadens, doctors and other stakeholders will need to find a balance between which disorders have sufficient impact on society to justify screening and which ones do not. This will be difficult, as there is no consensus regarding what parameters will guide such decisions. Furthermore, these decisions are likely to be revisited and revised as technology and its costs continue to change.

An Approach to Reading Scripture for Prenatal Ethics Introduction

There are many procedures involved in prenatal genetic screening and

continued over page

diagnosis and the subsequent management pathways that need to be considered carefully from a biblical framework. Undoubtedly, the current ethical climate in obstetric care will create dilemmas for many Christian doctors. As scripture is silent on many issues that face us in the 21st century, ethical principles need to be derived. We live in what is called the “post-modern” era. It is a time of both serious challenge to faith and a fresh opportunity to engage in ethical discussion through the Christian principles found in scripture.

Historically, Christians have made and, undoubtedly, will continue to make mistakes or misread scripture, even in the company of others. Prior to the Reformation, the Church as an institution took responsibility for making final theological decisions for the faithful. The Reformation has opened the scope of authority, with at times a loss of the moderation of the whole Catholic faith. We also issue caution. The primary message of scripture is about the love of God for the world. This love is centred in Jesus of Nazareth and his death for our salvation. Through this Christ event, we are called to a transformed way of life, to Christification. We are not advocating an “extractionist” approach to scripture outside of such a living way.

Burridge makes these observations. “The New Testament is not a general answer book with all the answers to our ethical dilemmas. However, many of the key issues of human moral experience do appear, such as issues of violence, the state, obedience, power, war and peace; human sexuality, marriage, divorce, relationships; money, wealth and poverty, debt; life and death and the value and meaning of life.” We will therefore need to be cautious about applying biblical commands about these areas directly to our contemporary moral debates. Before we can use the biblical material, we have to deal with differences between the New Testament and Old Testament over, for example, violence (holy wars versus ‘turn the other cheek’), or whether all the laws are



now binding on Christians, including things like ceremonial or purity law or circumcision. Similarly, polygamy is accepted in the patriarchal narratives, yet Jesus refers to Gen 2 on ‘one flesh’ as God’s original intention (Mark 10: 6).

In view of these concerns, Burridge makes the following proposal:

- Any attempt to apply biblical texts to ethical concerns will need to begin with the best available exegesis — to find out what this text is actually saying, taking into account historical background, genre etc.
- Equally, the reader needs to be aware of his or her own background as a filter and to make allowances for both the filter in the text and our self in the reading. To avoid negative ‘group think’, Burridge makes this suggestion. “An approach to New Testament ethics requires the interpretive community to be open and diverse; inclusive of those who might disagree with us, but who are still making their response of discipleship as we follow Christ together.”
- In a spirit of prayer, some conclusions may be provisional and thus frustrating to those who want “clear moral guidance.”

This paper seeks to provide helpful insights for Christian colleagues to approach Scripture while seeking answers or guidance for ethical concerns in health or dental care. We

acknowledge a need to read Scripture with eyes respectful to past approaches and conclusions while recognising the challenges and benefits of reading scripture in our post-modern context.

It is important to recognise at this point that our reading of scripture is to be undertaken with open dependence on the Holy Spirit. It is the person of God as the Spirit who leads us into all the truth of Jesus and the love of the Father.

A Christian Approach to Ethics – An Example

Allen Verhey is an ethicist who has sought to develop an integrated biblical approach to this challenge. His text, *Reading the Bible in the strange world of medicine*³⁵ develops the following considerations.

Genesis 1:26–27 states that human beings are created in the image of God. This causes Verhey to reflect ethically in a chapter ‘The human-genome and the kingdom of God’ and put forward an ‘orientation’ that we need to consider in the prenatal context. We should ‘orient’ ourselves not only to the values we may hope to achieve in scientific study but also and fundamentally to the values we display, i.e. our personal ethics, our transforming Kingdom lives. We should orient ourselves not only towards mastery but also toward wonder and the celebration of creation. We ‘image’ God as embodied souls. We are not separate from our bodies; and in this context, Verhey makes the comments, “We must orient ourselves to attend to whole selves. Genetic reductionism and determinism do not fit the story. We may not be reduced either to our genes or to simple transcendence over them.” “We must orient ourselves to respect for the bonds of marriage.” He says “We image God in marriage ... in self-giving commitments of fidelity to care for our partners and for our children — even when they do not turn out quite like we expected ... Parenting involves the uncalculating commitment to nurture.” Verhey gets to the idea that to image God would be to sustain care for the weak and the helpless and the little ones who do not

measure up. This is certainly a very important aspect of what is happening in antenatal diagnosis and treatment. His final comment is interesting: "The solution for our world is neither simply to maximise freedom nor to eliminate it. To coerce faith or fellowship violates the freedom God gives. We must orient ourselves toward respect for freedom."

Scriptural Principles for Prenatal Ethics

Reading scripture for ethics in our post-modern context starts with faith and an openness inspired by the Holy Spirit. Consequently, we identify that the following approach may help us. There are cultural and literary genre issues with all biblical texts. The best information can help start the conversation around ethical concern. Ethics in scripture is always a linking of ideas, wisdom and a transformed/transforming life. For Christians, ethics starts in the community of faith where it can be grounded from the rhythm of worship/liturgy and the fruit of the Spirit at work among the people of God.

God's truth providentially extends beyond the church. In humility, Christians must be subject to 'a chastened understanding of public criticism' if they are to participate wholeheartedly in bioethical debate (with medical/dental colleagues and others). As suggested by theologian Richard Niebuhr, "The gospel of the crucified Lord constitutes a 'permanent revolution' in our understanding of God, the world and ourselves". We may need to accept a 'provisionality' of ethical understanding and at times revise dogmatic decisions.³⁶ There is always value in respecting the ethical understanding of the people of God who have preceded us, .e.g. papal encyclicals and international consultations.

For Christian doctors, the doctrine of man being made in the image of God will have an impact on these decisions. Genesis teaches us that human beings were made in the image of God (Gen 1:26–27), and despite the fall, we retain this likeness (Gen 9:6). However, we also know that as a result of the fall, the image is tarnished and our reasoning

is flawed. Abnormalities can exist from the beginning of human development and we cannot always repair the damage. But our understanding allows us to place value on all human beings, not because of who or what they are, or what they can do, but because of the God in whose image they are made. Therefore, genetic aberrations will not change the innate value of human fetuses. As embodied souls we understand the complexity of human nature and reductionist views of human beings can be rejected.

"our understanding allows us to place value on all human beings, not because of who or what they are, or what they can do, but because of the God in whose image they are made"

.....

We image God also as social and relational beings. This is not surprising given the Trinitarian understanding of God for Christians. We are not autonomous individuals in this sense, and where possible family members beyond the mother alone should be involved in healthcare decision making. This will be influenced by our biblical view of parenthood, which sees children as a gift from God to be gratefully received, rather than a product of manufacture which can be rejected when imperfect (Ps 127:3–5). We need to remember that God has already redeemed us through the saving work of Christ Jesus, and that all creation will one day be free from suffering (Revelation 21: 4).

Conclusions

We write this at the commencement of a major change in the medical science of screening, diagnosis and management in the prenatal setting. The genetic revolution will lead to greater knowledge and, paradoxically, also often greater uncertainty. While

knowledge will continually expand, the wisdom required to respond to this knowledge is mediated through the unsatisfactory prism of inherent uncertainty, or risk. This risk will be continually quantitatively improved but may not be currently clear in many cases.

Christians are inherently people who accept the imperfection of life and the associated imperfection of knowledge. We see this as an opportunity to join together with the Creator in contributing to the enhancement of what is created imperfect, each a flawed masterpiece as we inherently all are (Romans 3:23).

Others in our society may grasp at this notion of perfection which would exclude pain and suffering due to disease, death and the impact of evil in an imperfect world. This is illusory for both Christians and others. Antenatal screening and its associated science cannot protect us from the uncertainties and disappointments of life. Nevertheless, our science is understandable as people at work using God-given talents to serve others.

We seek to respectfully and humbly engage with our patients. We seek to act in accordance with the teaching and example of Jesus, the great healer who most fully understood the needs and frailties of each person he encountered. "For a Christian doctor or dentist ... the ethics of a truly transformed character will constantly challenge our clinical choices. The clinical context is also a context of grace where the reconciling, healing, peace desiring work of God will become surprisingly apparent".³⁷

Christians have been given a mandate to side with the oppressed, the needy and the vulnerable. This was part of Jesus's manifesto (Luke 4:18–19). The care of orphans, widows, aliens and the poor is a recurring theme in the Old Testament (Isaiah 10:8). This mandate calls us to extend care to the fetus in its vulnerable state, and to offer prenatal diagnosis and treatment where indicated. The reality of our lives is the

fallenness of our world, which disrupts all relationships, even at the level of chromosomes and genes. Parents will continue to demand prenatal genetic testing, either for knowledge or decision making regarding the continuation or discontinuation of pregnancy.

The Christian doctor could approach his or her personal role in this controversial area with the following reasoning. Given that prenatal genetic screening is legal and standard practice in Australia, the doctor who wants to continue in obstetric care needs to accept the role of working within this system. The role of conscience in medicine has been explored in an earlier CMDFA publication.³⁸ It is important to have Christian doctors in all areas of healthcare, and more so in this difficult area where there will be the opportunity to encourage parents to consider all options available to them, first in whether they want tests at all, and if so which ones. To decline prenatal genetic screening or diagnostic tests is a valid option for parents. Again, when or if an abnormality is found, the Christian doctor should encourage parents to consider all options available to them before making management decisions. Often multidisciplinary consultations give parents a balanced opinion about the anomaly seen and the management options available. There may be no simple answer to this complicated question.

Each situation and each pregnancy is different and Christian doctors need to prayerfully consider the issues surrounding prenatal genetic screening and diagnostic testing and the results from such testing. We can always offer comfort and care, hoping to restore disrupted relationships at all levels in a redemptive way. Issues in prenatal genetic screening and diagnosis challenge all doctors, and great wisdom and compassionate care for parents is required when reproductive abnormalities occur.

Addendum

In this paper, we have sought to clarify the questions and uncertainties that greater yet imperfect knowledge have created in the field of prenatal

screening and diagnosis. This is not positioned as a definitive checklist of mandated approaches, as this is not possible, but rather as an unravelling of the tangle of issues that face those working in the field of prenatal screening and diagnosis. We recognise that in critical areas of life there could be differences in Christian thinking and practice. The views expressed in this paper have been arrived at after discussions within the National Ethics Committee of the CMDFA and may not necessarily reflect the personal opinions of the individual members of the committee nor of individual members of CMDFA as a whole. ●

We gratefully acknowledge consultative input from Dr Frank Garlick.

Approved by CMDFA Board 5th September 2015.

References

1. L. C. Doczy, R. Trawogor and A. Gedik. Anencephaly and right to life. *Lancet* 1993; 342: 1558-1559. DOI 10.1016/S0140-6736(05)80136-9.
2. A. Hayes, R. Weston, L. Qu and M. Gray. Families then and now: 1980-2010. Australian Institute of Family Studies. <http://www.aifs.gov.au/institute/pubs/factsheets/fs2010conf/fs2010conf.html>.
3. D. Wright, K. Spencer, K. K. Kagan, N. Topping, O. B. Petersen, A. Christou, J. Kallikas and K. H. Nicolaides. First-trimester combined screening for trisomy 21 at 7-14 weeks' gestation. *Ultrasound Obstet Gynecol* 2010; 36: 404-411. DOI 10.1002/uog.7755.
4. D. N. Saller, Jr. and J. A. Canick. Maternal serum screening for fetal Down syndrome: clinical aspects. *Clin Obstet Gynecol* 1996; 39: 783-792.
5. R. D. Wilson. Cell-free fetal DNA in the maternal circulation and its future uses in obstetrics. *J Obstet Gynaecol Can* 2005; 27: 54-62.
6. N. D. Avent, T. E. Madgett, D. G. Maddocks and P. W. Soothill. Cell-free fetal DNA in the maternal serum and plasma: current and evolving applications. *Curr Opin Obstet Gynecol* 2009; 21: 175-179. DOI 10.1097/GCO.0b013e3283294798.
7. L. G. Shaffer and J. A. Rosenfeld. Microarray-based prenatal diagnosis for the identification of fetal chromosome abnormalities. *Expert Rev Mol Diagn* 2013; 13: 601-611. DOI 10.1586/14737159.2013.811912.
8. P. Helguera, J. Seigle, J. Rodriguez, M. Hanna, G. Helguera and J. Busciglio. Adaptive downregulation of mitochondrial function in down syndrome. *Cell Metab* 2013; 17: 132-140. DOI 10.1016/j.cmet.2012.12.005
9. S. Guidi, F. Stagni, P. Bianchi, E. Ciani, E. Ragazzi, S. Trazzi, G. Grossi, C. Mangano, L. Calza and R. Bartsaghi. Early pharmacotherapy with fluoxetine rescues dendritic pathology in the Ts65Dn mouse model of down syndrome. *Brain Pathol* 2013; 23: 129-143. DOI 10.1111/j.1750-3639.2012.00624.x.
10. J. Aleccia. Could it be a 'cure'? Breakthrough prompts Down syndrome soul-searching. NBC News, 11 Aug 2013. <http://www.nbcnews.com/health/could-it-be-cure-breakthrough-prompts-down-syndrome-soul-searching-6C10879213>.
11. G. Condous. Ultrasound diagnosis of miscarriage: new guidelines to prevent harm. *Australas J Ultrasound Med* 2011; 4: 2.
12. J. W. Kaempf, M. Tomlinson, C. Arduza, S. Anderson, B. Campbell, L. A. Ferguson, M. Zabari and V. T. Stewart. Medical staff guidelines for periviability pregnancy counseling and medical treatment of extremely premature infants. *Pediatrics* 2006; 117: 22-29. pii 117/1/22. DOI 10.1542/peds.2004-2547.
13. Organisation for Economic Co-operation and Development. OECD Health Data 2013 Definitions, Sources and Methods. Perinatal Mortality, 2013.

14. H. C. Australia. Cattanach v Melchior. In Book Cattanach v Melchior, Editor (ed)^(eds). City, 2003.
15. K. D. Wilcoxon. Statutory remedies for judicial torts: the need for wrongful birth legislation. *Univ Cincinnati Law Rev* 2001; 69: 1023-1053.
16. Royal Australian and New Zealand College of Obstetricians and Gynaecologists. College Statement: C-Obvs 4. Prenatal screening tests for trisomy 21 (Down syndrome), trisomy 18 (Edwards syndrome) and neural tube defects. <http://www.ranzcog.edu.au/womens-health/statements-a-guidelines/college-statements-and-guidelines.html?showall=&start=1>.
17. M. D. Hans-Martin Sass. Asian and Western bioethics: converging, conflicting, competing? *Eubios Journal of Asian and International Bioethics* 14: 12-22.
18. F. A. Chervenak and L. B. McCullough. Ethical issues in perinatal genetics. *Semin Fetal Neonatal Med* 2011; 16: 70-73. DOI 10.1016/j.siny.2010.10.004.
19. H. Harris. The primary care perspective of quality in clinical genetics service – United Kingdom as an example. Springer, 2010.
20. D. R. Timmermans. Prenatal screening and the communication and perception of risks. In: Prenatal screening and the communication and perception of risks. Editor (ed)^(eds). City, 2005.
21. C. Nagle, S. Lewis, B. Meiser, J. Gunn, J. Halliday and R. Bell. Exploring general practitioners' experience of informing women about prenatal screening tests for foetal abnormalities: a qualitative focus group study. *BMC Health Serv Res* 2008; 8: 114. DOI 10.1186/1472-6963-8-114.
22. V. Tsianakas, M. Calnan, K. Atkin, E. Dormandy and T. M. Marteau. Offering antenatal sickle cell and thalassaemia screening to pregnant women in primary care: a qualitative study of GPs' experiences. *Br J Gen Pract* 2010; 60: 822-828. DOI 10.3399/bjgp10X532602.
23. H. J. Rowe, J. R. Fisher and J. A. Quinlivan. Are pregnant Australian women well informed about prenatal genetic screening? A systematic investigation using the Multidimensional Measure of Informed Choice. *Aust N Z J Obstet Gynaecol* 2006; 46: 433-439. DOI 10.1111/j.1479-828X.2006.00630.x.
24. R. A. Harris, A. E. Washington, D. Feeny and M. Kuppermann. Decision analysis of prenatal testing for chromosomal disorders: what do the preferences of pregnant women tell us? *Genet Test* 2001; 5: 23-32. DOI 10.1089/109065701750168644.
25. A. de Jong, W. J. Dondorp, C. E. de Die-Smulders, S. G. Frints and G. M. de Wert. Non-invasive prenatal testing: ethical issues explored. *Eur J Hum Genet* 2010; 18: 272-277. DOI 10.1038/ejhg.2009.203.
26. J. R. Botkin. Fetal privacy and confidentiality. In: Fetal privacy and confidentiality, Editor (ed)^(eds). City, 1995, 32-39.
27. J.-F. Morejon. Prenatal Diagnosis. In Book Prenatal Diagnosis. Editor (ed)^(eds). City, 1996, 22-23.
28. A. Kersting, M. Reutemann, P. Ohrmann, E. Baez, W. Klockenbusch, M. Lanczik and V. Arolt. Grief after termination of pregnancy due to fetal malformation. *J Psychosom Obstet Gynaecol* 2004; 25: 163-169.
29. A. Fonseca, B. Nazare and M. C. Canavarro. Parental psychological distress and quality of life after a prenatal or postnatal diagnosis of congenital anomaly: a controlled comparison study with parents of healthy infants. *Disabil Health J* 2012; 5: 67-74. DOI 10.1016/j.dhjo.2011.11.001.
30. H. H. Bijma, A. van der Heide and H. I. Wildschut. Decision-making after ultrasound diagnosis of fetal abnormality. *Reprod Health Matters* 2008; 16: 82-89. DOI 10.1016/S0968-8080(08)31372-X.
31. M. J. Korenromp, G. C. Christiaens, J. van den Bout, E. J. Mulder, J. A. Hunfeld, C. M. Bilardo, J. P. Offermans and G. H. Visser. Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenat Diagn* 2005; 25: 253-260. DOI 10.1002/pd.1127.
32. K. Schutt, A. Kersting, P. Ohrmann, M. Reutemann, U. Wesselmann and V. Arolt. [Termination of pregnancy for fetal abnormality — a traumatic experience?]. *Zentralbl Gynaekol* 2001; 123: 37-41.
33. K. Leithner, A. Maar, M. Fischer-Kern, E. Hilger, H. Löffler-Stastka and E. Ponocny-Seliger. Affective state of women following a prenatal diagnosis: predictors of a negative psychological outcome. *Ultrasound Obstet Gynecol* 2004; 23: 240-246. DOI 10.1002/uog.978.
34. A. Asch. Prenatal diagnosis and selective abortion: a challenge to practice and policy. *Am J Public Health* 1999; 89: 1649-1657.
35. A. Verhey. Reading the Bible in the strange world of medicine. Eerdmans, 2003.
36. D. Migliore. Faith seeking understanding. Eerdmans, 2004; 33 (citing Niebuhr R).
37. P. Mercer. Glimpses of conscience in clinical care. *Luke's Journal* 2013; 18: 19.
38. Christian Medical and Dental Fellowship of Australia. Conscience in medicine. *Luke's Journal* 2014; 18.



A Tough Life

by Dr Sarah Luthy

Sarah is a GP obstetrician who has spent many years working in Aboriginal health. She spent 3 years working in Arnhem Land in the Northern Territory and is currently working at Atoifi Adventist Hospital in the Solomon Islands. Email: sarahluthy1@gmail.com

She has been in labour for days in a remote community.

Pushing since yesterday but the baby is stuck. If she is lucky, her baby will still be alive and she can have a symphysiotomy. This is where a cut is made through the pubic bone so that the pelvis can spring open. If she is unlucky, the baby will already be dead. If she is very unlucky, she will die alongside her baby. After walking several hours to a little village, she finally manages to get flown to a hospital in a MAF (Mission Aviation Fellowship) plane. But when she arrives at the hospital, it is too late for her child who has now passed away. She is living in remote PNG, a 3rd world country where life expectancy is 61 for males and 65 for females¹ compared to 80 and 84 in Australia.² For an unborn child the

odds of survival are drastically lower than in Australia. Here, death and suffering are commonplace, but in the face of adversity and no welfare system, the people still have hope. What little money they make from their gardens and roadside stores is used to pay for schooling and health care. It is a life that is used to death and suffering.

“We know that every unborn child is precious, whatever their nationality.”

After a day of labouring in still silence, she sits on the hospital bed with her head bowed down as her dead baby lies next to her. No tears. No sobs. She is used to death. She is used to suffering. It looks like a normal healthy baby girl but she had passed away a few days ago in utero. At her antenatal visit earlier in the week, the midwife in the remote clinic couldn't find a heartbeat. She had been transferred with a MAF plane to deliver in a small remote hospital. Another unborn child that does not get a chance in life. Her only wish had been to be a mother. All hope has been lost. Last week she

had been at her brother's funeral. He passed away from a sudden heart attack at 32 years of age. And before that, it had been the funeral of her younger cousin who had been found lifelessly hanging from a tree branch after having taken his own life. Life expectancy for a male is 63, and 68 for a woman.³ No it's not in PNG – this is a 1st world country. Our country. These are the circumstances facing the indigenous population in the Northern Territory.

Two completely different countries – one with limited resources and a massive amount of poverty and another a wealthy first world country with a good health care system and yet the similarities are remarkable. We know that every unborn child is precious, whatever their nationality. And the loss of this life is a time of terrible pain, sorrow and suffering. A grievance carved so deeply into each woman's heart, that it will stay with them for life.

These women show us that we need compassion for our world and our nation. A compassion that goes beyond just a feeling and leads us to action. ●

References:

1. WHO PNG health statistics 2015 <http://www.who.int/countries/png/en/>
2. AIHW data 2011 - 2013 - <http://www.aihw.gov.au/deaths/life-expectancy/>

A Meeting of the Sanhedrin

In the chambers of the modern temple
The leaders and multidisciplinary team meet
Teachers, elders and makers of the law
Illuminated by incandescent light

An image of a baby projected
Whole, but broken; present yet absent.
The unborn child of a young woman
pregnant and no room for the night.

No money for the return journey.
Unsupported; a rural person;
Complex social situation;
Social work involved.

“An impossible burden”,
To a bejewelled physician.
“And from a country town”,
“There won’t be enough support” says
a sophisticated, urban and privileged few.

“In such situations people choose to terminate”
Is the suggestion offered as counsel.
Betrayed with words, tears under pressure flow
The suggestion agreed; a plan to proceed.

“Does anyone feel they cannot support the family
in their decision?”

“I do not find a case against this child.”
We have saved others;
The defect repaired;
Ability partially restored.

“The same has been done for less”.
Callous is the reply of hearts hardened,
Surprised by the naivety of innocence
Quickly dismissed as untrained ignorance.

“It’s not about the child; it’s about the mother.”
The child has no rights under state law.
By our law this baby can die
On the agreeance of two witnesses.

“We will get a second opinion.”
The psychologist referral is sought.
Must be done urgently, or late
Termination will not be a lawful procedure.

Then the whole assembly arose and referred
the decision to mental health governors,
Saying “this woman has requested a termination.
Do you find any reason that this be denied?”

Was there ever a mother ready for a child?
Ready for unknown difficulties let alone known ones?
How about releasing the child to the hands of another,
Exchange a burden for mercy and grace in a time of need?

A compelling report from another jurisdiction:
Mental health unbecoming child-rearing;
Adoption would worsen mental health;
Patient shows capacity for medical decisions.

What is disability, ability?
Burden, convenience?
Normal, abnormal?
Capacity to make a terrible choice?

What effect such a choice on already poor health?.....
The loss of a possible bright future;
Childhood and birthdays and colouring in;
Grandchildren, friendship and support in old age.

Even a future restricted to some degree
Would be a light shining in dark places
Showing that all is not ability, true relationships
surpassing that of physical disparity.

But the decision is made and the rituals begin.
Priests and priestesses chosen for the occasion.
Ceremonial gowns donned and a table prepared.
Medical elders enter in confidence; this is their rite.

Hands washed clean,
Foeticide is planned.
A spear placed in the side.
Blood and water flow.

The innocent dies at the hands of the guilty.
My God, my God why have we forsaken you?
It is finished? A modern ritual complete
Once darkness comes over the sterile surface.

We say we save others; can we save ourselves?
First do no harm is the maxim decreed.
No abortifacents said the philosopher.
Messiah child would we have terminated Thee?

By Dr James White, currently RMO, Newcastle.

This poem was written when he was a 4th year medical student and attended a case conference for a child in utero diagnosed with a structural abnormality. His was the voice of ‘naivety’:

“I do not find a case against this child.”

Book Review

Fearfully and Wonderfully Made

by Megan Best

A woman has just fallen pregnant and needs a battery of tests as part of their antenatal care. A couple is seeking advice on 'what next' because they are having difficulty falling pregnant. A young woman is pregnant and doesn't want to be.

These are regular scenarios in my practice as a GP and they regularly cause me heartache. As Christian doctors, we know they all have gigantic ethical impact. We can feel a responsibility to say something to save a life, or stop a death, and at the same time sensitively and carefully inform our patients of some of their legal options. As you know, legal and Christian are not the same thing today. Patients today find the direction of flow in obstetrics towards convenience and self-centredness. Our patients are often bewildered and confused, and don't realise they have choices.

I am very glad I have read Megan's book and can't recommend it to you highly enough. It's a long read (508 pages) but every page is worth the effort. She is meticulous in her research. I cannot begin to think how long it must have taken her to put this book together and can only suppose she has had a lot of help from colleagues – both medical and theological. There was so much that I found helpful and interesting. Of particular note, her review of history through the ages on society's views of abortion helps us see how the unravelling of a Christian view of procreation has occurred in the West. There are sections throughout "for doctors" which are of a more technical nature. There are all sorts of practical applications which will help us as we advise couples suffering from infertility. She is scientific and backs up her findings with evidence. She is wonderfully compassionate and pastoral. It is a book for Christian couples, pastors, and I believe most of all, Christian doctors.

Megan takes the reader in a logical sequence from the biology of



"It is a book for Christian couples, pastors, and I believe most of all, Christian doctors."

.....

pregnancy through to the complex scientific minefield of human embryo research. However, I feel the real strength of this book is in putting together both medical facts and an evangelical ethical framework. We necessarily need both medical knowledge and a biblical ethic if we are to have any hope of helping our patients and their families in this very complex and changing field. I'll let you read the book and find this out for yourself, but on the medical side, for example, she examines every type of contraception on the market, and soon to be on the market! I have already used the book as I counsel women on which contraception they might like to use. On the ethical side, in the first few chapters Megan teaches a framework for thinking ethically which is holistic and theologically biblical.

What do we mean by holistic? Take having a child as an example. Having a

child is not in itself sinful. It is a godly, sacrificial, other-person centred action. God creates life and gives himself for his creation in redemption. And he tells us to "fill the earth". But is it always, entirely right? What if the main motive in having a child is to make my life fulfilling and worth it? What if having a child is my life's dream, my all in all? Then it becomes an idol. The child replaces God, and we risk making our child's life a misery because they will never be able to meet all the expectation we have placed on them. Megan recognises and teaches that motivations and Christian character are just as important as the act. Motivation, intentions, consequences, as well as actions are important.

Ethics is a fascinating subject. It's the sharp edge of life where we think and act and interact with the world, using our knowledge of God and life to make decisions. We need the Bible and we need each other (pastors, church, commentaries, testimonies, theologians and historians). We need to be students of the Bible, we need to develop in Christian character (put on virtues, take off vices). We need development of a Christian world view to think things through in a gospel context, and we need prayer that God's Spirit will give us wisdom and grace. As doctors we also need accurate, evidence-based medical knowledge. Megan Best's book, *Fearfully and Wonderfully Made* is a gift from God. She has achieved so much in this one book. We will do well to read it. ●

by Andrew Moore

Andrew graduated as a medical doctor in 1993 and after working for 2 years entered Moore College where he completed a Bachelor of Divinity and MA in Theology, and was involved in Anglican ministry full-time for 10 years. He returned to general practice in 2010 and completed his FRACGP. He is a GP in Maroubra. Andrew is affiliated with the Royal Hospital for Women antenatal shared care programme and enjoys all nature of family medicine.

Prenatal Screening

by Jonathan Morris

Jonathan Morris is a clinical academic and Professor of Obstetrics and Gynaecology at the University of Sydney. He is a Maternal Fetal Medicine Specialist and practises at Royal North Shore Hospital, Sydney. He is the Director of the Kolling Institute of Medical Research and also the current President of the Perinatal Society of Australia and New Zealand. Together with his wife and four boys he attends North Sydney Anglican Church, St Thomas'.

"I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well.

My frame was not hidden from you when I was made in the secret place, when I was woven together in the depths of the earth."

Psalm 139:14-15

Compared to the Psalmist's world the antenatal period, whilst still a period of mysterious awe, is also now one in which there is now an unprecedented ability to appreciate not only the appearance but also the genetic sequence of the unborn. Indeed the practice of maternity care has been transformed by modern imaging and sequencing such that the initial interaction with health professionals is one that is dominated by discussions about testing for anomaly rather than congratulatory anticipation. It is salutary to reflect on the rapidity with which not only the health professionals but also society more widely has embraced the



almost universal adoption of tests that screen for anomaly without any deep reflection of the appropriateness of the tacit implication – that disability is unwanted in our modern world. In times when the message of equality and acceptance is trumpeted in our parliaments, schools, universities and workplaces and homes, it is plain that this does not pertain to the unborn disabled child. Medical practice and contemporary social mores increasingly suggest that one's significance is determined by their genetic sequence. The sequencing of the human genome, isolation of fetal

DNA from the maternal circulation, preimplantation genetic diagnosis and mitochondrial manipulation are all techniques that are upheld as scientific advances of wide social benefit.

Scientific progression with respect to prenatal diagnosis and genetic enhancement will be relentless. Although still somewhat in its own nascence, in Australia its first forays have proceeded in the absence of any significant societal reflection and discourse about the world that it threatens to shape. Indeed one wonders if we have lost the capability

for such cogitation – the issues are weighty and cannot be debated in 140 characters or reduced to an emoji or two. Should there be a brake placed on any technologies? Or already have we entered an era perhaps heralded by Aldous Huxley who wrote in *Brave New World* of “Bokanovsky’s Process” as one of the major instruments of social stability? In the opening chapter Huxley introduces us to the laboratories in which dozens of duplicate perfect beings are created from a single

inconsistent with the biblical account of our origins. In contrast with the rest of the created order though, mankind is an image bearer of God and has been the recipient of life breathed into him. This is fundamental to our identity. We wonder, we create, we reflect on salvation and eternity, we can ask questions about ourselves – these qualities are divine-like qualities reserved for those creatures who are made in the image of their divine creator.

become fully human he had to take on that human form from the very beginning.

Accepting these truths are sufficient to inform the approach to many of the bioethical dilemmas with which we are faced. As Christians, we must question any practice that produces excess embryos, or manipulates or enhances them if this leads to the wanton destruction of those that are considered to be of less worth. Such pursuits have been likened to a modern Tower of Babel, Man making man in his own image.

The pursuit is arguably futile and should be called for the folly that it represents: An illustration of this is the sperm bank that was accrued from high achieving individuals, including Nobel prize winners in the 1990s. One of the children so conceived said the following:

“It was a screwed up idea making genius people. The fact that I have a huge IQ does not make me a person who is good or happy. I don’t think that being intelligent is what makes a person. What makes a person is being raised by a loving family. (http://www.slate.com/articles/life/seed/2001/03/the_nobel_sperm_bank_celebrity.html)

More sobering is the human society that CS Lewis anticipated when he wrote in *The Abolition of Man*, “What we call ‘Man’s power over nature’ turns out to be a power exercised by some men over other men with Nature as the instrument... The man-moulders of the new age will be armed with the powers of an omniscient state and an irresistible scientific technique. We shall get, at last, a race of conditioners who really can cut out posterity in what shape they please... It is not that they are bad men. They are not men at all... They have stepped into the void. Nor are their subjects necessarily unhappy men. They are not men at all. They are artifacts. Man’s final conquest has proved to be the abolition of man”.

There has never before been such a time when there is a need to think deeply and biblically about life before birth. ●

“It is salutary to reflect on the rapidity with which not only the health professionals but also society more widely has embraced the almost universal adoption of tests that screen for anomaly without any deep reflection of the appropriateness of the tacit implication – that disability is unwanted in our modern world.”

conceptus. The fiction that was penned in 1931 no longer seems the fantasy it once was, nearly a century on. With the landscape of IVF in Australia being one in which private equity and profit drives much of the activity, issues about the boundaries that should be placed on beginning of life issues area are as urgent as they are emergent.

What is a Christian health professional’s view about these matters?

How do we arrive at a faithful Christian worldview? The Bible does not speak of cell-free DNA, preimplantation genetic diagnosis and mitochondrial disorders after all.

What the Bible is not silent on are matters relating to the uniqueness of human beings and personhood. It is clear from the opening chapters of the Bible that the pinnacle of creation, the final creative act prior to the seventh day of rest was the making of man in the image of our triune God. Whilst not a scientific account, there is sufficient in Genesis to counter scientific detractors. Man was made from the dust of the ground and shares the common chemicals which are found in the rest of creation. The similarity in the genetic code between ourselves and other life-forms is not

Such a hallmark elevates the human being to one of infinite worth and it is necessary to establish at what point the image of God is acquired by his image bearers. This is profound as the acquisition of the image of God is the point in time when the significance of that life in its fullest, eternal sense begins. Whilst debated for centuries, it seems incontrovertible that human life begins at the point of conception. All arguments to the contrary are founded in rationalistic convenience. It is ironic indeed that the popular secular press were unable to conclude anything else when scientists recently captured the bright flash of light that is emitted at the time the oocyte is fertilised : “Human life begins in a bright flash of light as a sperm meets an egg, scientists have shown for the first time, after capturing the astonishing ‘fireworks’ on film” – proclaimed the *Daily Telegraph* (<http://www.telegraph.co.uk/science/2016/04/26/bright-flash-of-light-marks-incredible-moment-life-begins-when-s/>).

Psalm 139 describes the intimacy between the Creator and the Psalmist, David, and seems to identify no time in the womb when he was unknown to God. The fact that details of Jesus Christ’s conception are recorded in Scripture remind us that for God to

Book Review

Defiant Birth: Women Who Resist Medical Eugenics

ed. Melinda Tankard Reist, Spinifex Press 2006

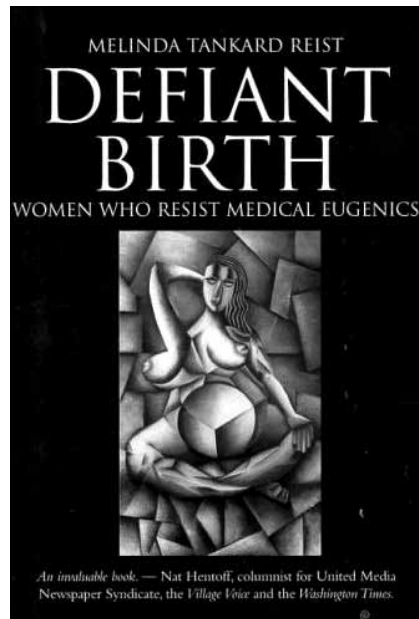
At its heart, *Defiant Birth: Women Who Resist Medical Eugenics* is a lovingly gathered collection of stories about women who choose to be mothers in the face of stigma against themselves and their so-called defective, unborn children.

Underpinning this selection of poignant tales is the thesis that eugenics as a philosophy is pervasive in modern society, and that it is driven and promoted by the medical profession. Contemporary antenatal screening practices, with their pro-abortion assumptions, are the most overt demonstration of a broader pro-eugenist attitude that is widespread and deceptively insidious.

It's hard to read Reist's 60-page introduction as anything other than a polemic. Dense, emotive and profusely referenced, her essay provoked in me – a doctor-in-training whose involvement with obstetrics has been minimal – instant defensive indignation. Doctors, alleges Reist, promote a eugenics agenda in the guise of helping and empowering women. They cherry-pick the information they give, compelling women to terminate their genetically-abnormal unborn children. Where mothers choose to carry such pregnancies to term, the norm is for healthcare professionals to oppose and shame them.

Reist's research is extensive and multifaceted. She brings the spotlight onto a number of important and oft-avoided issues: the fallibility of medical prognosis, the troubling trend towards genetic determinism, the cost-benefit mentality of current healthcare systems and how this economic imperative discriminates against those with a disability. However, at some points, her argument overreaches – is it truly necessary, for instance, to warn impressionable readers off antenatal ultrasounds?

But it's the nineteen women whose stories are told here that form the



real substance of this book. Their perspectives are as complex and nuanced as they are emotionally compelling. Their backgrounds are diverse – there are mothers from New Zealand, Singapore, England, Australia and the United States. They come from all walks of life - there are stay-at-home mums, students, researchers, a physician, a nurse. Their attitudes towards medical professionals vary – there are anecdotes regarding kind and caring midwives as well as dismissive and disparaging radiologists and genetic counsellors.

There is much to reflect upon in their experiences. Several of these women recount giving birth to completely normal, healthy babies, despite fetal abnormalities being detected on ultrasound. One mother, Heather Arnold, speaks of being repeatedly counselled that the "standard of care" is to abort. The narrative of a physician-mother, Lise Poirier-Groulx, who finds herself pregnant with a baby who has Down's Syndrome, is infused with courage and grace, but also illustrates clearly the information privilege that belongs to the medically trained: "We had made the decision early on in the pregnancy not to undergo the routine amniocentesis because we knew we would not go through with an abortion if the baby

had been diagnosed with a handicap." As Reist points out earlier in the book, how much does the average pregnant woman understand of amniocentesis? How many have agreed to undergo such testing without understanding that it is the precursor on a decision tree that may lead to termination of pregnancy?

Some of the most interesting chapters are written by mothers who themselves have a disability – and encounter tremendous opposition even when their disability is not genetically-based and cannot be passed on. Not only are women encouraged not to mother disabled children, but disabled women are also encouraged – sometimes coerced – into not becoming mothers.

Reist reminds us in her afterword that we live in a society that "despises suffering and doesn't know how to deal with pain and death." At its core, *Defiant Birth* is a celebration of women who have learned to sit with pain and suffering with grace and joy - imperfect and beautiful mothers who have given birth to imperfect, precious children.

Although Reist's purpose in writing this book is to provide courage to other women, there's plenty here for Christian doctors to respond to. We too must learn to deal with pain and death, and accept that it cannot always be obliterated or averted. We must learn to sometimes step out of the medical model and its preoccupation with what is normal and what is not. We must learn to recognise and resist eugenic thinking in our health services and clinical education, understanding that it is not always overtly presented to us as such. And we must listen to and support our patients when they choose to have children who are perceived as imperfect, recognising the disproportionate power that health professionals wield in dealing with society's most vulnerable. ●

About the reviewer: Su Lynn Cheah is a psychiatry registrar who works in Newcastle, Australia.

Obituary

Kenneth Robert Hayes

28/08/1928 ~06/07/2016

Kenneth Robert Hayes had a rich and long life and medical career spanning 51 years. Born in Brisbane, the fourth and last child, he had a tough early life. His three siblings died and his father unexpectedly left the family in 1934 although he did share some memorable holidays before he died in 1942. Ken was raised by his mother and maternal grandmother, two strong women.

He was educated at Ithaca Creek State School where his mother taught and then at Brisbane Grammar School (1942-5) where as Dux of the school, he won an Open Scholarship, placed 4th in the State. He studied Medicine on a State Social Service Fellowship graduating with 1st Class Honours in 1951. He fulfilled his seven year bond: one year at RBH, two years in Augathella, three years in Tully and one year as a Medical Registrar at RBH.

Early in 1949, he met Nancy Watkin, a Science Student at the University who completed an MSc in Biochemistry in 1952. They were engaged in 1953, married in January 1954 and had three children, seven grandchildren and four great-grandchildren. Family and a stable home were important to him and family holidays were memorable midst his heavy work schedule.

On returning to Brisbane in 1958 and having decided to train as a Physician, he became a Teaching Medical Registrar at RBH. In May 1960, he successfully completed the FRACP (Fellow of the Royal Australasian College of Physicians) and was appointed as a Visiting Physician at RBH in 1961 where he served for 35 years. After General Practice at Everton

Park he moved to Wickham Terrace as a Consultant Physician (1966) supplemented by work at AMP for 3 years. He was appointed to Prince Charles Hospital as a Visiting Physician, satisfying his interest in Respiratory Disease also working there until 1996. He maintained private practice at Wickham Terrace, Everton Park and Mitchelton/Arana Hills till inadequate sight (bilateral Macular Degeneration) and soon after a stroke (December, 2003) brought medicine to an end. He transitioned to new interests e.g. history society and ongoing engagement in current affairs. Despite visual impairment, Ken remained a ravenous reader (with the aid of a machine) and listener of news of all types and interesting audio books.

“[Ken] had a long association with CMDFA mentoring Christian medical students and encouraging many to think about what it means to be a Christian doctor.”

.....

Ken was a thorough clinician and great diagnostician (even of his own AAA!) with a brilliant and methodical mind who taught and inspired many including two children, one grandchild and the many students and young doctors assigned to his team. He was always reading and learning new things, sticking to the tried and proven

– good evidence based medicine. He encouraged all in pursuit of excellence in study and to use the gifts God had given, taking the opportunities given. He had a long association with CMDFA mentoring Christian medical students and encouraging many to think about what it means to be a Christian doctor.

He was also a faithful church member (58 years at Stafford Presbyterian then Uniting Church), elder (and mentor to many), member of Presbytery and active part of a Home Fellowship Group. He had great commitment to medicine, church and the many other organisations of which he was a faithful member, serving people in these areas with integrity, loyalty and perseverance, touching many lives. He loved reunions being a great one for remembering dates and past events. He was a person of occasion, a true gentleman and fine man.

He set an example of faithful Christian life and marriage, always seeking to grow and continue to think through his faith (even to the end). He faced his final months of failing health with courage and grace as he grappled with the loss of his independence. He understood his sinful nature before God and his need to rely solely on Jesus as his Lord and Saviour and so when he faced death he did so with the hope of resurrection and eternal life.

For those of us grieving our loss, we rejoice that he is now at peace and with God. We honour Kenneth Robert Hayes as husband, father, grandfather, great grandfather, friend, school mate, medical colleague, Christian brother but most importantly and the only one that counts for eternity, child of God. ●

The Visible and the Invisible moving the Visible

by Joseph Thomas

Dr Joseph Thomas is a Senior Specialist in Maternal Fetal Medicine and Obstetrics at the Mater Mothers Hospital in Brisbane. After training at the Christian Medical College Vellore, he worked at the Bangalore Baptist Hospital and Asha Kiran Hospital, Orissa, India till 2003. He subspecialised in Maternal Fetal Medicine in Adelaide after which he moved to Brisbane. He is passionate about human formation and currently he and his family worship at the Creek Road Presbyterian Church.

A fusion of science and theology is challenging, but to live a life where science and theology are compartmentalised contradicts the integrity that we see all around us.

Much about science is considered visible and demonstrable, while much about theology is assumed to be invisible and not demonstrable. I make an attempt in this article to integrate the science of fetal medicine I know with the theology I believe, and to thus illuminate the apparent relationship between the invisible and the visible. I begin this endeavour with a paragraph that looks like utter nonsense:

GGCTCACCTTGGCGTCGCGTCCGGCGGCA
AACTAAGAACACGTCGTCTAAATGACTTC
TTAAAGTAGAATAGCGTGTCTCTCTCC
AGCCTCCGAAAACTCGGACCAAAGATCA
GGCTTGTCCGTTCTTCGCTAGTGATGAGAC
TGCGCCTCTGTTCTGACCAATTTAGGT
GAGTCAAACCTCTCTTAAAGTAGAATAGC
GTGTCTCTCTCCAGCCTCCGAAAAAC
TCGGACCAAAGATCAGGCTTGTCCGTTCT
TCGCTAGTGA

Genotype

This is part of the genetic code, even though it does not make sense to me as I read it. Yet it appears that on

the day I was conceived, 'something' was able to read, not only the above but about 6 billion similar characters making up the 3 billion base pairs of my genome (if printed ~1.5 million A4 pages of the code). I began as a large cell formed from the union of genetic material from my mother and my father. To begin the reading and understanding of my genome there were no bar code readers, scanners, or sensors! My formation was not powered by mother boards or quad processors; it was not brought about by any hardware or software. But 'something' got my DNA to auto-read, auto-correct, and auto-construct to make me into a ball of totipotential stem cells. To confuse matters further, there was an additional side booklet of instructions that worked simultaneously in the mitochondria called the mitochondrial DNA. This DNA worked independently of my nuclear chromosomal genome, yet participated in making me complete. The truth is, I would not have survived but for the mitochondrial DNA, and it is likely that there is a critical role played by the cytoplasmic DNA in initiating various process of fertilisation.¹

Phenotype

My cells were choreographed into an outer cell mass which made my placenta (which resourced raw materials from my mum), and an inner cell mass which eventually became my body. My cells not only read my genomic instructions but also coordinated their activities, jostling around and telling each other what to do. (This is referred to as "cell talk.") Cells had to give way to one another, most of them modifying as they rolled into or over each other to make my endoderm, my ectoderm, and my mesoderm – the three basic layers of my body. This trilaminar disc then started showing signs of life.² One of the first signs of my life was my heartbeat. This happened at around 3 weeks from conception – the first in-

utero system to start off which can be documented with modern transvaginal ultrasound scanners. To get my heart started, a military-like operation in three areas of development needed to be coordinated: the central pump, the vessels, and the blood cells. First my heart had to form itself into three layers from the mesodermal cells, going through bizarre twisting and twirling movements, and directing the left side and the right side (I believe the traffic controller here is a gene called lefty1) to form 4 chambers, 4 valves, and inflow and outflow channels.^{3,4} If anything went wrong here I would have been a dead duck, resulting in a miscarriage! Simultaneously, I was making vascular channels called arteries and veins. These vessels are formed as thick cords of cells with the cells in the middle 'told' to die or lyse so that the cords become channels. The third formation involved my blood cells which formed in my yolk sac and my liver and migrated into the blood vessels. To begin functioning, electrical wiring and switch coordination were added to the mix to get synchronised pumping of my heart, which will go on till one day (hopefully not too soon) my pump stops.⁵ The auto-rhythmicity and coordination of the heart even before the nervous system is formed is astonishing; it has led some authors to claim that the heart has a mind of its own.⁶

Genome, the Epigenome and The Phenome⁷

The genome appears to have a mind of its own as well, with only the relevant parts of the codes revealed at appropriate times, while other parts of the instructions are kept hidden so that my cells know what to do, when and how to do it, and when to stop. This occurs with the uncoiling of the chromosomes so that the relevant instructions are read and the rest of the chromosome remains supercoiled.⁸ This genome is my complete set of deoxyribonucleic acid

Invisible - Part I



(DNA), a chemical compound which contains the genetic instructions needed to develop and direct the activities of my organs, encoded with all the information needed to make me into a living functional human being.⁹ An international collaborative project spread over many research laboratories published the complete human genome in 2003. This set of 3 billion base pairs is unique for each and every individual (except identical twins) with about 0.1% of the genome being different among individuals.¹⁰ This has to be the best DIY (Do It Yourself) manual ever – it resources its own raw materials, makes the parts, assembles them, disposes of all that's not needed, and turns on the right switches for the various pumps and motors at the right time! In fact, this manual has to be fail-safe. If it wasn't, I would have been a non-starter much before D-Day (birth). I am not sure if it is hardware with software or a software that makes its own hardware, but this instruction we call the genetic code has been explained in a book titled *The Language of God* by Francis Collins, Director of the Human Genome Project.¹¹ The genetic code is not strictly followed as written but has several factors that modify it. I am told that each gene has varying penetrance and expressivity under the influence of modifier genes¹

and various environmental factors that affect the outcome.^{12,13} Many are now researching the epigenome described as 'the thing that is not included in my genome'. ("Epi" means upon, outside of or above genetics). Practically, it means gene regulation phenomena, by means of DNA methylation, histone modification, and miRNA.¹⁴ The final result of all the transcription of the genetic codes, the influence of the modifier genes and the environmental factors, is my phenome, which is what my mother got to hold on D Day. Though my genotype and my phenotype have contributed to me being who I am, there are several more tangible (visible) and intangible (invisible) aspects interacting. I don't know if my parents had any idea of who they were giving birth to. The question of who I am is vexatious; surely there are visible (tangible) aspects and invisible (intangible) aspects to who I am. I am told that my parents decided to have a child; nature, I presume, did the rest. Even though much progress has been made with understanding early human formation through in-vitro fertilisation, the exact mechanisms that initiate various processes in fertilisation and embryonic formation are still not fully explained.¹⁵ The more I wonder, the more I know we have no clue as to what exactly my DIY manual, i.e.

the genome does. Was there more to my conception than what nature or nurture does? If not just nature or nurture, what else goes into my origins which may actually answer the question of who I am?

"From the Invisible to the Visible"

My origin (conception) is more complex than what we currently detail. A very small zygote not visible to the naked eye (0.1mm diameter) is where my genome begins to make my phenome. I would not be wrong if I stated that I was formed from almost nothing. I could paraphrase my beginning as something that was 'formless and near empty, with complete darkness present in the *depths of my mother's womb*, and the Spirit of God hovering over the *cytoplasmic* waters of the zygote where my chromosomes played a microcosmic dance to form my unique genome (one in 7 billion and still counting)'. The parallels with Gen 1:2 are intentional, depicting a re-creative act of God.

In John's gospel, chapter 3:5-8, Jesus makes a link between the original creation, and each of our own beginnings in our mother's wombs.

continued over page

Jesus says, "You're not listening. Let me say it again. Unless a person submits to this original creation – the 'wind-hovering-over-the-water' creation, *the invisible moving the visible...*" Jesus continues "When you look at a baby, it's just that: a body you can look at and touch. But the person who takes shape within is formed by something you can't see and touch – the Spirit – and becomes a living spirit (*The Message*).

In paraphrasing this from the everyday language of Jesus's time to our everyday language, Eugene Petersen highlights the notion of the "*invisible moving the visible*". The concept of the 'invisible' is complex, however it is a reality that we need to contend with, as an ever shrinking space. What was invisible a few decades ago is no longer invisible since we have tools and instruments that make the previously invisible clearly visible. The tools one uses for this could be debated and the reality deduced from those tools could also be argued. However, my life before birth was invisible to everyone in the sixties, but now there is hardly any baby whose life before birth remains invisible in the western world. Most mothers now have 3 to 4 ultrasound scans through their pregnancy and much that was previously invisible and unknown is now visible and known.

There is much more that will be revealed in years to come as science and technology improve. However, I am uncertain as to whether we will ever be able to make visible all the processes involved in early human formation. David in Psalms 139⁶ acknowledges the authorship of God over all creative and re-creative acts in human formation. I must admit that, like me, David was clueless as to the mechanisms involved. We have been able to elucidate the numerous mechanisms that process human reproduction, including clues to the 'cell talk'⁷ and attempts to delineate the interface at which the genome, phenome and the spirit interact.^{8,16}

Genome, Phenome and Pneumone

Pneuma is Greek for "spirit or wind" and I think my pneumatype influences,

even overrides, my genotype and my phenotype. Somehow I don't think anyone will be able to discern or describe the exact mechanism or interface at which these mechanisms occur.⁹ Though we are willing to see the "invisible move the visible," science will find it difficult to define the exact relationship between my pneumatype (spirit), my genotype and my phenotype. Some of the invisible that will remain could very well be the interface between the "spirit, mind and body."

"Most mothers now have 3 to 4 ultrasound scans through their pregnancy and much that was previously invisible and unknown is now visible and known."

.....
It is likely that the *pneuma* will be the most critical determinant in deciding who I am and who I become. Some clue to this is offered to us in John 1:13 when Jesus states that those who receive Him become "children born not of natural descent, nor of human decision or a husband's will, but born of God". (NIV 2011) This verse suggests that there is something more than all the genetics and laws of inheritance and reproduction that I have studied. As a fetal medicine specialist, I have refused to accede to the spiritualisation of this verse which explains it away as applying only to our spirit and not to our body. If Jesus had to state it three times, covering all three possible areas of my ancestry ("not natural, not parental/human, not paternal but divine" there must be a deeper understanding that I need to delve into.

Somehow, somewhere, sometime, I believe my 'pneumone' begins to take formation even as my 'genome' gives expression to my 'phenome'. I propose that the word 'pneumone' be used for the full expression of the person's

'pneuma', similar to the use of the word genome for the full expression of the person's genes and the word phenome as the full expression of the person's phenotype. In as much as the expression of my genotype is dependent on numerous mechanisms, similarly the expression of my pneumatype is also dependent on many variables. The original intention of this pneumatype was, I presume, for it to be fully expressed with 100% penetrance with no variance or with only healthy variances. However, as part of the Fall (Gen 3) there must have been a significant loss/mutation and or pathologic variation which has prevented the 100% expression of both the genotype and the pneumatype.

This disruption in relationship between God and man in the Garden of Eden has, I suggest, resulted in variances, such that there is very little resemblance now between the 'pneumatype' of man and the original 'pneumatype' that God intended. The onset of mutations, variations in the genes, single gene disorders, multifactorial disease inheritance, and the triggering of the aging gene occurred, I believe, after the Fall. The disruption in the pneumatype had immediate consequences as well as consequences that manifested over time with changes in the genotype and the phenotype of mankind. The mission of Jesus Christ as stated in Rom 8:29 is for us to be restored to the original pneumatype or as stated the Image of the Son (The Pneuma) who is the exact representation of Our Father in heaven.¹⁰

Existential Genome and Phenome, Transcendental Pneumone

I did not get my whole genome tested (this is now a possibility) and have no clue as to what it is. I am also not certain of what mutations and what copy number variants I carry. I have no idea of what in-utero programming occurred in my mother's womb. In addition to the interactions between the 'epigenome' genome and my resultant phenome, I am told that phenotypic and functional changes occur from ongoing programming

changes depending on my thought life. My limbic system can profoundly influence my hypothalamo-pituitary-adrenal axis and make me a hypertensive if I constantly nurture anger, anxiety, impatience, and thoughts of revenge. On the other hand, if I nurture love, joy, peace, patience, kindness, and self-control, I will be able to reduce and induce changes in my cardiovascular system to reduce my risk of the metabolic syndrome.¹¹ I am reminded of the passage in Galatians chapter 5¹² that speaks of this as the fruit of the spirit (pneuma). Peptides, neuro-transmitters and various other mechanisms are postulated to be responsible for this interface.

This interaction between the 'invisible' thought life and the visible cardiovascular changes is accepted by most clinicians. Regardless, when it comes to the interface between my 'pneumone,' my genome, and my phenome, more questions are raised than answered. Though unlikely to be proven, it is likely that the pneumone is the predominant driver of the genome and the resultant phenome. I am aware that my phenome will continue to deteriorate till one day it will be returned to its elements. Undoubtedly the phenome, the 'visible' body, was resourced and put together by the 'invisible'. My genome with all the now possibly fully decoded instructions may in fact give out its last instructions, tantamount to shutting down systems with no further instructions to be given. Both my genome and my phenome have served their existential purposes and then the question arises, is that my 'end'? There is no doubt that when there is multiple organ failure and all systems shut down my 'phenome' or body is dead and the genome so intricately tied up with the phenome also dies. We are then left to ponder what happens to the pneumone. The Bible (I Cor 15: 42-44)¹³ indicates that there is a transcendental aspect to my life when my 'pneumone' continues an existence beyond the existential phenome.

The questions of mechanisms and interfaces belong to the material world that we are comfortable with,

however the 'invisible' world, though a shrinking space, still has much that remains hidden. There cannot be any mechanisms postulated for the transcendental pneumone or how 'the invisible and the visible' interact since we understand so little of what we see, much less of what we do not see. However, the death and resurrection of Jesus Christ gives us a foretaste of what is to come. The fact that the risen Christ was able to walk through closed doors (as a pneumone) yet at the same time was able to be touched (as a phenome) underscores the interaction between the invisible and the visible as well as the integrity inherent to our lives. Just because I cannot understand or explain the mechanisms involved in this (I am told it is as dissimilar as a plant to a seed) it would be foolish of me to discount it as non-existent.¹⁴

Conclusion

I have attempted to bring together the science I know and the theology I believe, resulting in a holy fusion which integrates the existential and the transcendental world in which we live. There are several consequences to this, the least is that I do not live a dichotomised, schizophrenic life, and the best is that I begin to get insights into the 'Language of God' and into the world He has created with awe and wonder. Acknowledging the existential and temporal nature of my genotype and my phenotype as well as the transcendence of my pneumatype, I hope that I will continue to affirm the 'Fatherhood of God' the 'brotherhood of all mankind' and the need for all of us to recognise and facilitate the variables that are likely to restore not only our genotypes and our phenotypes but also our pneumatypes to their original intended form. ●

References

1. Modifier genes can affect penetrance, dominance, and expressivity. A genetic modifier, when expressed, is able to alter the expression of another gene. Modifier genes can affect transcription and alter the immediate gene transcript expression, or they can affect phenotypes at other levels of organization by altering phenotypes at the cellular or organismal level. A **phenome** is the set of all phenotypes expressed by a cell, tissue, organ, organism, or species. Just as the **genome** and proteome signify all of an organism's genes and proteins, the phenome represents the sum total of its phenotypic traits.
2. The phenotype is the descriptor of the phenome, the manifest physical properties of the organism, its physiology, morphology and behavior.
3. Gen1:2 Now the earth was formless and empty, darkness was over the surface of the deep, and the Spirit of God was hovering over the waters.
4. I do admit that more questions are raised than answered,

e.g what is the Spirit of God doing when fetal formation is abnormal or when a miscarriage occurs.

Jn 3:5-8 (NIV) Jesus answered, "Very truly I tell you, no one can enter the kingdom of God unless they are born of water and the Spirit. Flesh gives birth to flesh, but the Spirit gives birth to spirit. You should not be surprised at my saying, 'You must be born again.' The wind blows wherever it pleases. You hear its sound, but you cannot tell where it comes from or where it is going. So it is with everyone born of the Spirit."

6. Ps 139: 13-16 For you created my inmost being, you knit me together in my mother's womb. I praise you because I am fearfully and wonderfully made... My frame was not hidden from you when I was made in the secret place, when I was woven together in the depths of the earth. Your eyes saw my unformed body, all the days ordained for me were written in your book before one of them came to be.
7. Eccrine, paracrine, autocrine, juxtacrine and endocrine signals
8. The influence or control individuals can have on their DNA – who and what they are and will become – is further illuminated in HeartMath founder Doc Childre's theory of heart intelligence. Childre postulates that "an energetic connection or coupling of information" occurs between the DNA in cells and higher dimensional structures – the higher self or spirit. Childre further postulates, "The heart serves as a key access point through which information originating in the higher dimensional structures is coupled into the physical human system (including DNA), and that states of heart coherence generated through experiencing heartfelt positive emotions increase this coupling."
9. Questions arise as to what happens when the conceptus is malformed or miscarries and if all of that can be postulated to be a result of the fall.
10. Rom 8:29 For those God foreknew he also predestined to be conformed to the image of his Son, that he might be the firstborn among many brothers and sisters.
11. <http://www.stress.org/stress-hypertension-and-the-metabolic-syndrome>
12. Gal 5:22-23 But the fruit of the Spirit is love, joy, peace, forbearance, kindness, goodness, faithfulness, 23 gentleness and self-control. Against such things there is no law.
13. I Cor 15: 42-44 So will it be with the resurrection of the dead. The body that is sown is perishable, it is raised imperishable, it is sown in dishonor, it is raised in glory, it is sown in weakness, it is raised in power, it is sown a natural body, it is raised a spiritual body
14. The world has embraced the virtual reality of the Google glasses and the augmented reality of the 'pokemon go' however we have a long way to go before the reality of the invisible world is embraced

Publications 2014/2015

1. J. M. Cummins. The role of maternal mitochondria during oogenesis, fertilization and embryogenesis. *Reprod Biomed Online* 2002; 4: 176-182.
2. U. o. UTAH. Stem Cell quick reference. In *Book Stem Cell quick reference*, Editor (ed)^(eds). City, 2016.
3. LEFTY1 left-right determination factor 1 [Homo sapiens (human)]
4. Embryology Cardiovascular System Development. https://embryology.med.unsw.edu.au/embryology/index.php/Cardiovascular_System_Development.
5. T. Kiserud. Physiology of the fetal circulation. *Semin Fetal Neonatal Med* 2005; 10: 493-503. DOI S1744-165X(05)00068-5 [pii] 10.1016/j.siny.2005.08.007.
6. Heart intelligence. <https://www.heartmath.org/articles-of-the-heart/the-math-of-heartmath/heart-intelligence/>.
7. C. R. Scriver. After the genome – the phenome? *J Inherit Metab Dis* 2004; 27: 305-317. DOI 10.1023/B:BOLI.0000031100.26546.6e 5268029 [pii].
8. N. Gilbert and J. Allan. Supercoiling in DNA and chromatin. *Curr Opin Genet Dev* 2014; 25: 15-21. DOI 10.1016/j.gde.2013.10.013 S0959-437X(13)00150-0 [pii].
9. The Human Genome Project Completion: Frequently Asked Questions. <https://www.genome.gov/11006943/human-genome-project-completion-frequently-asked-questions/>.
10. How big is the Human Genome. <https://medium.com/precision-medicine/how-big-is-the-human-genome-e90caa3409b0>.
11. F. Collins. *The language of God*. Free Press, 2006.
12. J. H. Nadeau. Modifier genes in mice and humans. *Nat Rev Genet* 2001; 2: 165-174. DOI 10.1038/35056009.
13. I. Lobo. Same Genetic Mutation, Different Genetic Disease Phenotype. In *Book Same Genetic Mutation, Different Genetic Disease Phenotype*, Editor (ed)^(eds). City, 2014.
14. J. B. Bae. Perspectives of international human epigenome consortium. *Genomics Inform* 2013; 11: 7-14. DOI 10.5808/GI.2013.11.1.7.
15. M. Okabe. Mechanism of fertilization: a modern view. *Exp Anim* 2014; 63: 357-365. DOI DN/JST.JSTAGE/expanim/14-0026 [pii].
16. You Can Change Your DNA. <https://www.heartmath.org/articles-of-the-heart/personal-development/you-can-change-your-dna/#more-5743>.

Book Review

The Language of God

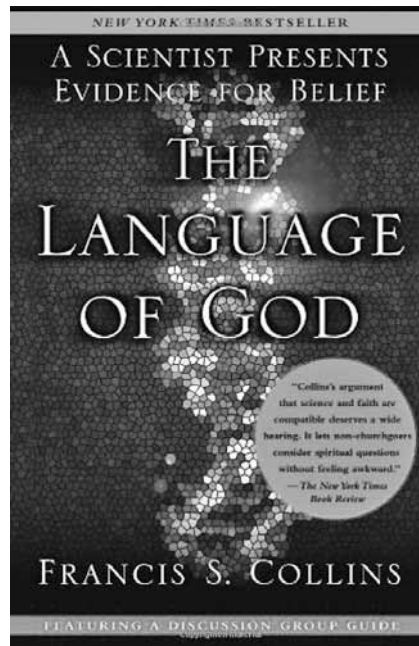
By Francis Collins

The interface of faith and science is often discussed by passionate Christians and scientists who have poor understanding of their opponents' subject.

It was therefore with anticipation that I began reading this volume, written by a man with a foot in each camp, intent on instructing both sides on how they can get along with the other. Dr Francis Collins, a respected scientist, aims to dispel the notion that belief in God requires suspension of reason, and also that the principles of faith are in fact not just consistent, but indeed complementary to the principles of science. In this book he explores a pathway towards an intellectually honest integration of natural and spiritual perspectives.

I have heard Dr Collins speak about his background in the past, noting that although he is often asked how a Christian could become a geneticist, in fact the question should be the other way around. Collins is well known as the director of the Human Genome Project, an international research collaboration initiated in 1990 which led to the completed mapping of the DNA sequence of the entire human genome in April 2003. He is involved with the ongoing task of determining the function of the estimated 20,000 genes identified. He is very familiar with the double helix and tends to break into poetry each time he comes to reflect on its beauty and elegance. He studied physical chemistry before training in medicine and genetics. His scientific credentials are unquestionable.

Early in the book, Collins explains his own journey to faith while at medical school. He was so challenged by the faith he saw in some of his patients that he was compelled to consider the possibility of a spiritual realm, for which he proceeded to review the evidence, as is a scientist's wont. He was greatly influenced by the writings



“Scientific discoveries do not need to remove God from the equation, they merely show us something of how he operates.”

.....
of CS Lewis, in particular his discussion of the moral law. So when he decided the time was right to embark on a contribution to the science and religion debate, it is not surprising that he adopted a similar style. Indeed, at one point I felt as if I was reading ‘CS Lewis does quantum mechanics’. It is a tribute to Collins’ teaching skill that he is able to explain complex scientific theory in a way that makes it accessible to the general reader. I found the description of his actual conversion sadly abstruse, but then so it is for many writers, including Lewis, in my view. The final step of faith cannot be made in light of reason. However, this does not prevent Collins from achieving his goals as listed. His faith will be unquestioned by those who

share it, and his scientific arguments may help those who do not share it to be less wary of exploring it for themselves.

Francis Collins has a big picture of God. Throughout the book he encourages us to seek answers – the God whose creation astonishes him in its sophistication will not be threatened by our questions. He rightly addresses the need to resolve philosophical questions before material ones can be dealt with (he deals with common philosophical objections to Christianity, where his allegiance to Lewis is obvious), since the result of questioning what is possible informs what we are able to observe in our experience. Having established the feasibility of the supernatural, he then launches into an analysis of the origins of the universe with obvious relish.

The astronomical and biblical accounts of Genesis are shown to be consistent in Collins’ treatment of Big Bang Theory, and the Anthropic Principle provides him with an argument in favour of a creator. He then moves on to Quantum Mechanics and the Uncertainty Principle, Cosmology and the God Hypothesis. While he recognises that no scientific observation can reach the level of absolute proof of the existence of God, for those willing to consider a theistic perspective, he gives food for thought. Certainly, it is soon obvious how he envisages a satisfying harmony between science and religion and his confidence that if both are true, full synthesis must be possible.

Next in his sights is the issue of evolution. One of the things I appreciated in this book was Collins’ recognition of the problem of semantics in the science/religion divide. Tired stereotypes are dismissed by clarifying the terms involved in these discussions, and even inventing new ones. The evolution debate is a prime example. Think of the different

understandings of the meaning of the word 'theory'. Though no-one knows how life started on earth, Collins guides us through some possibilities and argues strongly against a 'God of the gaps' approach. Attributing the unknown bits to God means that new knowledge demands a theological revision. It does a disservice to religion and is not necessary. Naturalistic explanations, including molecular mechanisms and natural selection, are compatible with a creator God. Scientific discoveries do not need to remove God from the equation, they merely show us something of how he operates.

Darwin's theory of evolution is, according to Collins, the most contentious issue in the discourse he is addressing. References to Creationism (redefined), literal interpretations of Genesis, and the dangers of insisting that young people ignore modern research are included in a loving entreaty to the evangelical Christian church to resist assuming an automatic attitude of antagonism towards scientific truths. Battles for the gospel cannot be won on a flawed foundation and indeed they may damage faith in the process. Intelligent Design (also redefined) and (of course) the implications of recent developments in genomics that support evolution theory are also explained.

However, Collins reminds us that to be human involves more than just our DNA. In fact, science alone cannot by its legitimate methods adjudicate the issue of God's superintendence of nature either way. Richard Dawkins is brought in to illustrate this point. Collins suggests that atheism, in light of the evidence, is less rational than faith in God. He ends the main text by calling for a truce. He challenges scientists to reconsider the spiritual worldview, and exhorts believers to not attack but seek out new scientific knowledge, remembering in the words of Copernicus, 'To know the mighty works of God...surely...this must be a pleasing and acceptable mode of worship to the Most High, to whom ignorance cannot be more grateful than knowledge'.

This was a satisfying conclusion to a well-argued thesis. You can imagine

my dismay when I proceeded to read an appendix which abandoned careful logic in favour of scientific expedience. Focussing on some of the bioethical dilemmas in current public debate, the appendix begins well with an enthusiastic discussion of the promise of the genomic revolution, a topic close to Collins' heart and one which he covers well. We then have a superficial discussion of ethical theory before embarking on stem cells and cloning. Well. It is true that regenerative

"Collins reminds us that to be human involves more than just our DNA."

medicine holds great promise and should be supported, but that does not mean that the ends justify the means (see Rom 3:8). In his enthusiasm to see the benefits of human embryonic stem cell research proceed, Collins suggests that, although an embryo is a potential human life, it is difficult to be sure when that life should be protected. In short, he argues that by allowing IVF, we are endorsing conditional destruction of embryos and therefore



can justify the use of excess frozen IVF embryos in destructive research. He also offers reasons why we should not object to destructive research on human embryos created by cloning. He does not commit himself to a view on the ethics of preimplantation genetic diagnosis (which involves the discarding of human embryos) and hesitates to endorse faith-based

bioethics. I won't go into the flaws of his moral reasoning, suffice to say he does not seem to have thought through the implications of his comments. An embryonic human surely remains human and holds its moral value regardless of location, genetic makeup and intended use. Indeed, recognition of these premises has subsequently led to scientific breakthroughs which have obviated the need for human embryo destruction.

We finally see how he got into trouble at the end of this section, when he articulates his desire to find a consensus between those who wish to justify questionable moral acts in attempts to follow the mandate to heal, and those who wish to follow the moral obligation to do no harm. The stem cell debate is a good example. I appreciate his desire to find the compromise position, as he has done in the body of the book. However, I think he has missed the point here. When one side determines right from wrong on the basis of the consequences of their actions, and the other side observes absolute values where some things should never be done regardless of consequences, there is no consensus position. They will always disagree because they are looking at different parts of the equation. We must be vigilant to make sure we do not compromise our own values in the search for consensus.

So, what is my final judgement? With his reasoned approach, Collins has made a valuable contribution to the faith vs science debate. I found it to be an easy read, and expect that his scientific credentials and accessible explanations for non-scientists will do much to ease Christian hostility to science, and scientific hostility to the church. I would recommend this book to both groups, though I would probably tear out the appendix before giving it to them. ●

Dr Megan Best, PhD, MAE, BMed(Hons), AssocDegTh, GradDipQHR, ClinDipPall Med, is a consultant bioethicist and assistant lecturer in medical ethics at UNSW.

This book review is published with the permission of CASE Magazine.

Journey of Love:

The Challenge of an Unborn Life

By Heidi Best

It was a day of excited anticipation. Our second child's 20 week anatomy scan!

At the time, we were living in the picturesque city of Dunedin, New Zealand, where my husband Adrian was undertaking specialist training in dentistry. Sitting in the dark sonography room, we nervously chatted to the trainee sonographer who, although understandably slow at her task, was very attentive and kind. Time flew by and, before long, Adrian had to leave to pick up our daughter Téa from childcare.

Shortly after Adrian had left, the sonographer called on her supervisor for help in examining baby's heart. I lay silent and still in the dark. As I read the acronyms being typed on the screen, tears trickled down my cheeks. I knew these acronyms well, having worked as a paediatric and neonatal intensive care nurse with ten years' experience in Melbourne and Perth, Australia. The sonographer looked up, "I'd like you to return later today to repeat these images with our paediatric radiologist. Can you bring your husband with you?" As my heart sank deeper I asked to know the gender, trying to grasp at anything positive. Baby was a girl, a sister for Téa. I walked away in tears. Alone. Staring at the black and white images in my hand. One thing I knew for sure: life had changed forever for our family and a major upheaval was looming on the horizon. Adrian met me in the car park and I tearfully broke the bad news to him, hoping the sonographers had got it all wrong.

But the story only got worse. Later that day, as Adrian and I held hands tightly, the paediatric radiologist broke more bad news to us. Our daughter had a complex congenital cardiac condition: double outlet right ventricle (DORV)

with a ventricular septal defect (VSD). More shock! Open heart surgery and its myriad of inevitable and potential complications. We had a strong belief in Jesus, but never had we needed his strength more than now.

As soon as we arrived home I emailed my previous work colleagues from Melbourne's Royal Children's Hospital, consulting with an experienced cardiac surgeon and paediatric intensivists. They were very sympathetic and advised us to wait and have another cardiac ultrasound at 26 weeks gestation, this time by an experienced paediatric cardiologist. This would allow for a better picture of her condition. But a mother's heart and mind can't wait that long – in my head I was already planning a return to Melbourne for our daughter's birth and open heart surgery.

"Termination? In-utero intra-cardiac potassium injection and a still-birth? It was not an option I wanted to consider."

.....

Then came the greatest of dilemmas. "Termination is a good option for cases like these," suggested the obstetrician at our 21 week appointment. Termination? In-utero intra-cardiac potassium injection and a still-birth? It was not an option I wanted to consider. "We're hoping baby's condition might be surgically correctable," I replied. "Okay, well let's at least perform an amniocentesis," he encouraged, arguing that the presence of a chromosomal disorder might alter our decision. We opted to proceed with amniocentesis, though not because we wanted to terminate the pregnancy but, rather, because it might add

valuable information about baby's postnatal prognosis. It was an incredibly unpleasant experience, not only physically and mentally, but especially emotionally. Finally, some good news: baby was healthy in every way, except for her terribly malformed heart.

The push for termination continued. At 23 weeks we received a letter in the mail giving us two days to fly up to Auckland for a scheduled appointment with Fetal Medicine and Cardiology at Starship Hospital. "But I thought we were waiting until 26 weeks," I queried anxiously. To which the cardiac liaison nurse replied insistently, "No, you should be scanned before 24 completed weeks." The implications were obvious: to be scanned prior to the 25th week left the door ajar for termination, as the legal 'cut-off' date for medical termination in New Zealand is generally 24 weeks.

On the plane to Auckland, Adrian and I decided on a name for our little girl: Amelie Sophia Best. Amelie, meaning *striving and hardworking*, and Sophia, meaning *wisdom*. Now we felt even more connected to her than ever before. She wasn't just a fetus – she was a *person*.

As we sat in the darkened ultrasound room, twelve health professionals piled in to watch Amelie's cardiac scan, intrigued by her rare condition. We sat in shock and disbelief (yet again!) as the senior cardiologist and cardiac nurse broke more bad news to us. Not only did Amelie have DORV and a VSD, she also had transposed ventricles, pulmonary atresia, malformed valves and a hypoplastic left ventricle (statistically, this embryological glitch was a 1:100,000 chance occurrence). No amount of corrective surgery could save her. All that surgery could offer her was a torturous young life and early death. Despite this, the cardiologist proposed staged palliative surgery, but his words were like distant echoes in

my head and I heard very little for the rest of that appointment.

As Adrian and I walked back from the hospital to our hotel, I felt numb. I wanted to step in front of a passing bus so that I wouldn't have to make a decision for my baby's life and impending death. My mind skipped ahead to what Amelie's life might be like on a road of palliative surgery: multiple major open heart surgeries, many complications, and great restrictions on her life. Would she even survive the first stage? Many babies I had cared for had not. I declared to Adrian, "Why did they only offer us palliative surgery? Why was palliation not presented as an option?"

I cried every day, *all day*, for three straight weeks. I was exhausted. My heart physically ached. I prayed to God that He might dry my eyes, even for a little while. We contacted the Melbourne cardiac surgeon again, now with a detailed ultrasound report. He generously took the time to consult with his experienced peers. In a long email, he outlined our three options, all of which led to an early death for Amelie – we just had to choose one. How on earth do you choose a death for your child?

Option one, often chosen (30%): attempt staged cardiac palliative surgery in the hope she might survive long enough to receive an early heart transplant in childhood. But the prognosis, so we were told, was bleak at best. Moreover, most families choosing this pathway end in separation or divorce. My head and heart reeled.

Option two, by far the most commonly chosen (70%): terminate the baby. Should we choose to return to Melbourne to terminate Amelie, we could legally do this any time until 40 weeks gestation (full term!). But not only did the thought of actively killing my baby shake me to my core, it also gave God no further opportunity to perform a healing miracle (which we and many around the world were praying for fervently!). It would be a quick, painful death, that is all.

Option three, by far the least commonly chosen in the West (<



Heidi Best: 37 weeks pregnant with Amilie.

1%): let nature take its course by choosing palliation. This would mean no intervention except for palliative medical care. This option came with an element of uncertainty about how long Amelie might live after birth, though we knew it would likely be only a matter of weeks because she was 'duct-dependant.' Her suffering would be a day or so, and her death fast.

In our hearts, Adrian and I knew that regardless of our decision, Amelie would suffer and die early. It was simply a matter of deciding *how* she would suffer and die. I wouldn't wish that decision upon my worst enemy! This was the hardest decision of our lives. I prayed that Adrian and I would

be in unity with our decision and that God would bring peace for us upon making a decision. I knew that ethical decisions such as these can cause great divide in opinion, even within one's own extended family (as we later discovered). But after much prayer and tears, we chose palliation for our Amelie. We prayed earnestly that Christ would show us how we could endure the suffering with her, just as Mary endured watching Jesus on the cross.

God granted us peace in our decision. It truly was a peace that surpassed all human understanding and enabled me to carry on with Amelie's pregnancy

continued over page

JOURNEY OF LOVE

despite the emotional heartache. Of course, the tears continued. But we wanted Amelie to experience life for whatever length was God's will. Whilst she was on placental bypass she didn't know she was unwell. She had joy – kicking, bouncing, and sucking her thumb, warm and cosy inside me. And we wanted to know her, and her, us. We wanted her to know our loving embrace, our affectionate gaze, our caring voices, and my breastmilk. And we wanted to see her little personality. She was very much a wanted and welcome baby. So, for the remainder of my pregnancy I hugged my belly a lot, sang to her, recorded her fetal heartbeat on my mobile phone, and endured pregnancy complications – all with great joy and without complaint.

At 32 weeks we flew as a family to Perth, Australia, to be cared for by the Palliative Care Team at King Edward Memorial Hospital and to share Amelie's life after birth with our extended family who resided there. We had further cardiac scans confirming

the 24 week diagnosis, and our Perth cardiologist supported our decision of palliation for Amelie.

Amelie Sophia Best was born on the 19th of January 2012, a healthy 3.3kg at 39 weeks 3 days. She was born via normal vaginal delivery by induction of labour. She was quiet and contemplative after birth and, despite looking slightly purple, she was perfect in every other way. After an emotional delivery and a special dedication service for her, we took her home with support from the palliative care service. We shared six and a half precious days with our Amelie and made many wonderful, treasured family memories – a bath with Daddy and Téa, a shower with Mummy, lots of Mummy's milk, lots of cuddles with family and friends, a thumbprint necklace, an outing to the zoo on day three, and watching the Australian Open tennis championship with Daddy. Though the final 26 hours of her life were incredibly hard and painful for her and us, despite palliative medical care, she endured the dying

process and we held her every second of the journey, surrounded by family. She was not alone and she was deeply loved. Our beautiful baby girl passed into Jesus' loving arms on Australia Day, the 26th January 2012 – forever known to us as 'Amelie's Day.' ●

Heidi and Adrian Best have four gorgeous children (3 daughters and a son), though raising three. Heidi trained as a Registered Nurse and Midwife and works in the field of Paediatrics (NICU and PICU). She has a passion for international and public health having completed a Grad Dip in Intercultural Studies in 2004, and a MPH and Trop Med in 2007. She has also worked as a University lecturer and clinical tutor in the School of Nursing, Dunedin, NZ, and studied a Grad Dip in Tertiary Education in 2013. Adrian is an oral and maxillofacial surgeon and has a degree in Christian theology. Though originally residing in West Australia, they've lived and studied in Melbourne for 7 years and Dunedin for 5 years. They currently call Perth home.

URGENT PERSONNEL NEED!!

General Practitioner for Centre De Santé Et De Léprologie (Health and Leprosy Center), Danja, Niger

Convinced that no one should live and die without hearing God's good news, the Center for Health and Leprosy seeks to share the Gospel with some of Niger's most marginalized people: those with leprosy.

We seek to express Jesus' love and compassion by providing excellent medical care in one of the poorest countries in the world while at the same time making the Good News of Jesus Christ known. The role of Doctor is essential to providing care to the daily visitors to the outpatient clinic, to the small obstetric ward, and to the patients with leprosy.



We can take short-term doctors or those willing to serve a year or more. It would be ideal if the doctor can speak French, but translators are available. Long-termers would need to study French before coming.

Niger is rated last on the Human Development Index, making it the poorest country in the world. According to WHO, there are only 0.2 doctors per 10,000 people.

Perhaps God is calling you to join the CSL-Danja team in reaching the lost while meeting human needs!

Brief Job Description

- Provide qualitative general clinical and leprosy services.
- Do rounds in the men's and women's leprosy service wards to insure good wound care and aid with debriding wounds and skin grafting.
- Do consultations with those in the outpatient and in-patient departments who have been screened by the nurses and are in need of more acute care.
- Be available to consult with the midwives in the obstetric department and to supervise simple obstetric cases. Complicated deliveries are referred elsewhere.
- Coordinate and refer patients to the physiotherapy department.

For more information, please contact Nancy DeValve at niger.personnel@sim.org Steve Brown at CSL-Director@sim.org

Emily's Voice

By Paul O'Rourke

Paul O'Rourke is the CEO of Emily's Voice. He is the former CEO of Compassion Australia, has a Master's Degree in child development and authored several books, including the provocative, *Why Satan Hates our Kids: How Children are Suffering and Why The Church Should Care*.



EMILY'S VOICE
Fall in love with the unborn
www.emilysvoice.com

Another about an adoptee who loves her life and would like to meet her biological mother to say "Thank you, thank you for my life. You've given me an incredible gift." Then there's Gavin who wondered how they would cope when his bride conceived on their honeymoon. He declares: "Seventeen years later, we've just had our seventh child, and I reckon I coped just fine."

Other stories highlight the physical features that are evident in the womb and which carry us through life: our heart, hands, hair and feet.

We recognise that the ads are being seen by thousands of women and girls who have already experienced the shame and regret of abortion. The campaign is not unlike other public health advertising such as the Sun Safe message, Quit smoking advertising or Motor Accident Authority campaigns. These campaigns will evoke painful memories for those who have lost a loved one to melanoma, a car accident or smoking-related cancer. Though for some there will be painful memories, our ads are motivated by love – love for mothers and their unborn children, hoping to prevent that pain and regret.

We know that many women make an irreversible choice at a time when they are vulnerable, without all the facts about consequences and often under pressure from others. The purpose of the ads is to restart the conversation about life in a contemporary, relevant, and yet sensitive, way.

The broadcast and social media ads direct viewers to the www.notbornyet.com website where visitors can learn more about pregnancy, abortion, child development, pregnancy and post-abortion grief. The website provides links to pregnancy support centres in each State and Territory. The campaign started almost nine years ago in the Darling Downs of Toowoomba. The ads can now be seen in several regional centres in Queensland and NSW, as well as throughout Tasmania and Western Australia. ●

Emily's Voice is using the beauty, dignity and humanity of the unborn, together with real, personal stories, to protect women and save babies. This culture-changing media campaign on TV, radio, billboards and social media is now being seen in four States by 4.5 million people. And they work.

Galaxy Research has confirmed that 22% of Queenslanders and 25% of Tasmanians, 16-24, have changed their views on abortion after seeing the ads. These include women like Stacey, who was living in a women's shelter in Launceston when she saw *Emily's Voice* ads on TV and received a little feet pin in the mail. The little feet are the shape and size of an unborn child at 10 weeks from conception. The ad featured Madeleine, who "chose" to end her pregnancy at just eight weeks, a decision she profoundly regrets. Stacey took notice, moved back home and gave birth to Oliver who is now six months.

One of the dozen or so ads features Nikki, who came to Australia a few years ago from the Philippines and discovered she was pregnant. Her distraught mother asked the GP what they should do. The female doctor replied that young Australian women in such circumstances would have an abortion. When Nikki replied that abortion was against her values, the doctor replied: "Yeah, but you've already had sex outside of marriage. Isn't that also against your values?" She told Nikki that continuing the pregnancy would be selfish as being

a single mother would bring shame, embarrassment and financial pressure to the family. The doctor wanted to make it easy and cheap: she told Nikki that if she was under nine weeks she could have a chemical abortion at home. Rattled by the doctor's confident judgment, Nikki's mum Bernadette, who also was against abortion, suggested having a termination may be for the best on this occasion.

"...many women make an irreversible choice at a time when they are vulnerable, without all the facts about consequences and often under pressure..."

Then they went for an ultrasound.

A tiny body with a beating heart lit up the screen in the darkened room. And the light came on in Bernadette's own heart and mind when the radiographer said: "Look, there's your grandchild." And the result is three-year-old Nahla.

The *Emily's Voice* ads speak to the reasons why about 97% of women consider abortion: the financial, emotional and social concerns of one-in-three Australian women.

There are ads about a young man who gets his then-student girlfriend pregnant and realises he needed to "man up and take responsibility".

Perinatal Palliative Care



By Anthony Herbert

Dr Anthony Herbert is a paediatrician who specialises in palliative care. Since commencing practice as a consultant in Brisbane in 2008, he has developed an interest in peri-natal palliative care. He is also the current chair of the Queensland Branch of the Christian Medical and Dental Fellowship of Australia.

Perinatal palliative care programs are being established around the world.¹

Perinatal palliative care is a compassionate model of support that can be offered to parents who find out during pregnancy that their baby has a life-limiting condition. As prenatal testing continues to advance, more families are finding themselves in this heartbreaking situation. Perinatal palliative care incorporates the philosophy and expertise of palliative care into the care of this new population of patients. For parents who receive a life-limiting prenatal diagnosis and wish to continue their pregnancies, perinatal palliative care helps them embrace whatever life their baby might have, before and after birth.

This support begins at the time of diagnosis, not just after the baby is born. It can be thought of as “hospice in the womb” (including birth planning and preliminary medical decision-making before the baby is born) as well as more traditional palliative care on the post-natal ward or at home after birth (if the baby lives longer than a few minutes or hours).

Palliative care can also include medical treatments intended to improve quality of life, including consideration of surgery. This approach supports families through the rest of the pregnancy, through decision-making (before and after birth) and through their grief. Perinatal palliative care empowers families to make meaningful plans for their baby’s birth, life, and death, and offers dignity to the baby and their family.

Epidemiology

Congenital malformations can be multiple, severe and lead to miscarriage, stillbirth or a shortened lifespan. Often these conditions are diagnosed on the 18 week morphology scan (but not always). Conditions include:

- Major structural abnormalities in the brain (e.g. anencephaly,

hydranencephaly and holoprosencephaly).

- Chromosomal abnormalities (e.g. Trisomy 18 and Trisomy 13).²
- Severe complex congenital heart malformations (e.g. hypoplastic left heart syndrome).
- Severe neuromuscular conditions (usually diagnosed post-natally, although there may be suspicion of a neuromuscular condition with reduced foetal movements or polyhydramnios).
- Severe renal abnormalities (+/- pulmonary hypoplasia).
- Life-threatening skeletal dysplasia.

Language

Severe birth defects diagnosed antenatally are often described as being “incompatible with life”. However, some children with these conditions do live longer (weeks to months to years). In this context, the terminology “life-limiting” or “life-shortening” condition may be preferable. Support groups and social media reveal these exceptions and are changing our perspective on how to best manage these conditions. I recently worked with some parents expecting a child with anencephaly. They had found a Facebook support group that had given them information

which would help them maintain the dignity of their baby at the time of birth and also sound advice on how to best manage nutrition after birth.

Dr John Lantos, a medical ethicist at Children's Mercy Hospital in Kansas City says that support groups on social media can empower parents by allowing them to share stories, compare treatments, and present their physicians with information that challenges the medical literature.³ Lantos acknowledges that there is the risk of giving families false hope if an online support group only shows happy-looking children learning to walk and talk. However, sometimes it is good to see that there can be positive outcomes. Parents of a child with Wolf-Hirschhorn syndrome, a rare genetic syndrome, was told their child would be unlikely to live past the age of 2 years.⁴ They were also told that she would not talk, walk or have a personality. Their daughter is now 14 years of age and, although mentally and physically delayed, she can attend school and is an integral part of their family.

Uncertainty and the Role of Hope

A recent study published in the *Journal of the American Medical Association* from Ontario, Canada illustrates how rare many of these conditions are, and that many babies unfortunately do die from these conditions.⁵ The study focused on trisomy 13 and trisomy 18 – genetic conditions that typically cause mental impairment, facial and organ abnormalities, respiratory problems, congenital heart disease amongst other problems. Over two decades, 428 babies were born. Only 65 (approximately 15 %) lived for at least a year. A small number (29 children or 6.7 %) lived for at least 10 years. There is little previous research on these children surviving this long, and in this context these conditions are not always as lethal as health professionals have advised families. While each child had significant disability (both physical and intellectual), this study did not include information on the survivor's quality of life. This would be an area of fruitful research for the future.

Parents can prepare for the delivery of a baby with a life-limiting condition

in various ways. Health professionals may help families by using a parallel planning process. This means helping to prepare the family for two very different scenarios – the death or the survival of their child. Going through the processes of routine antenatal care (including keeping results of ultrasound scans, developing relationships with obstetric staff and bonding with their in-utero baby) can also help establish some normality. This allows the family to make some positive memories from a difficult experience, which will remain with them for the remainder of their lives.

“It is important families are supported in a compassionate and non-judgmental way as they make these difficult decisions.”

.....

Such a process outlines the best case scenario (in terms of duration and quality of life) and the worst case scenario. Families should be allowed to maintain some hope – including hope for a miracle. At the same time, there is also a need to prepare them for the reality of the situation and to consider the worst case scenario. Parents may then make informed decisions about what medical interventions they do or do not want following the birth. It is important families are supported in a compassionate and non-judgmental way as they make these difficult decisions.^{6,7} In this context it is helpful to explore both the parent's fears and hopes.⁶ This can be done by doctors, midwives, social workers and psychologists.

Some families may turn to their faith, community or pastoral carers at such a time.⁷ Over time, parents can describe an eventual acceptance of their situation and work through the many emotions inherent in such trying circumstances. Parents can modify their hopes for having a healthy infant to other hopes, such as having time with their infant, holding their infant or taking them home.⁸ In such difficult circumstances, families can find a

sublime joy, and what is sometimes called post-traumatic growth, in offering dignity and parental love to a child with significant disability.⁹ Consideration of other siblings in the family and how best to support them is also critical.

Cases of Prognostic Uncertainty

In 2009, one boy I was involved with did better than expected after birth. His diagnosis was that of hypoplastic left heart syndrome. Without surgery, many of these babies will die within 2 weeks (usually when their patent ductus closes). Even with surgery, the mortality is very high and treatment often involves multiple surgeries (leading to a uni-ventricular circulation) and prolonged hospitalisations. This boy remained stable and at his assessment at 6 months his cardiac physiology was better than expected. He was able to maintain a bi-ventricular circulation and graduate from the palliative care service.

I also looked after one of a set of twin boys in 2010. This baby also had hypoplastic left heart syndrome. His brother was healthy. Initially the two of them stayed in the nursery as they were born premature at 33 weeks. However, it was felt that heart surgery would be very risky and the parents wanted to focus on his quality of life. He eventually roomed in with his parents and then went home where he died peacefully at approximately 3 weeks of age. His healthy twin brother fed and grew in the nursery and went home a few weeks later. Contrast this outcome with that of a tragic hospital mistake involving similar twins in Melbourne. This case saw a healthy 32-week old foetus accidentally aborted instead of his seriously ill twin who had a cardiac condition.¹⁰

A Family's Perspectives

Some of the themes expressed above are demonstrated in this letter of thanks sent to the paediatric palliative care service at my hospital.

We would just like to express our deepest gratitude to your team for the help and support you have provided our family since we had Jake¹¹ in September of last year.

continued over page

I have done quite a lot of research on Trisomy 18 and have found that many other countries consider Trisomy 18 as incompatible with life and offer little or no comfort for the baby. In reading how cruel these hospitals can be, we are so very aware of how fortunate we were.

Fifty-six days we got to spend with Jake. Fifty-six days of love, joy and memories. Some parents are not even given a choice (sic) thanks to the amazing team that you have. You offered us help, time, comfort and love. We also got your sympathy but in a way that sympathy should be given.

Not for one second were we made to feel as if we were making wrong decisions.

We were also lucky enough to receive a gift of Jake's handprints and footprints. They are absolutely beautiful and something we will forever cherish.

We cannot express how grateful we are.

Conclusion

Perinatal palliative care offers a family a positive alternative to termination of pregnancy when their child is diagnosed with a life-limiting condition in utero. Routine antenatal care can continue, while the parents plan for how they will manage the birth of their baby. The internet provides significant information for parents, and health professionals can help parents access and interpret reliable information. While it is important to allow hope to be present, health professionals also need to assist parents to deal with the reality of the situation. This will require time, and is usually best done by consistent people within the health care team. Significant collaboration between obstetric, maternal-foetal medicine, paediatric and palliative care staff may be required. The family's general practitioner is also integral to this process. Support should continue during the time of and beyond delivery, including bereavement support and support for the siblings of the child. ●

Useful Websites

<http://perinatalhospice.org/>
<http://www.pnpc.org.au/>

References:

1. <http://perinatalhospice.org/>
2. Trisomy 21 (Down Syndrome) would not be referred to perinatal or paediatric palliative care routinely as these children are not necessarily expected to die during childhood. On occasion, if they have cardiac complications (e.g. an inoperable heart lesion, or heart failure) or respiratory failure, they may require palliative care support.
3. Lantos JD. Trisomy 13 and 18 – Treatment Decisions in a Stable Gray Zone. *JAMA* 2016; 316(4):396 – 8.
4. Tanner, L. Severe birth defects not as lethal as docs once said: Study. <http://bigstory.ap.org/article/e5ae7f721be9480cb66ba676217b387e2/severe-birth-defects-not-lethal-docs-once-said-study> Viewed August 7, 2016.
5. Nelson KE, Rosella LC, Marchant S et al. Survival and Surgical Interventions for Children with Trisomy 13 and 18. *JAMA* 2016; 26 (3): 396 – 8.
6. Mancini A. Perinatal Palliative Care. <http://www.icpcnconference.org/wp-content/uploads/2016/06/Perinatal-palliative-care-Mancini.pdf> Viewed August 7, 2016
7. Redlinger-Grosse K, Bernhardt BA, Berg K, Muenke M, Biesecker BB. The decision to continue: the experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *Am J Med Genet* 2002 Nov 1;112(4):369-78.
8. Wool C. State of the Science on Perinatal Palliative Care. *JOGNN* 2013; 42: 372 – 82.
9. Black B, Sandelowski M. Personal growth after severe fetal diagnosis. *Western Journal of Nursing Research*, 2010; 32(8), 1011-1030.
10. Akerman P, Ferguson J. Tragic mix-up in which a baby was mistakenly aborted in Melbourne will be investigated. <http://www.theaustralian.com.au/news/health-science/a-tragic-mix-up-in-which-a-baby-was-mistakenly-aborted-in-melbourne-will-be-investigated/story-e6frg8y6-1226205411782> . Viewed August 7, 2016.
11. The name of the patient has been changed to maintain anonymity.

Luke's Journal Survey

Luke's Journal is the journal for the Christian Medical and Dental Fellowship of Australia (CMDFA). There are 3-4 editions each year and these are mailed out to CMDFA members. Past issues can be accessed at: <http://www.cmdfa.org.au/Resources/luke-s-journal>. **Please help us improve *Luke's Journal* by filling in this 3 minute survey.**

Gender

- Male Female

Age

- <25 25-35
- 35-50 50-70
- 70+

Are you in

- Medicine (graduated)
- Medical Student
- Dentistry (graduated)
- Dental Student
- Other: _____

What is your email?

How often do you read *Luke's Journal*?

- Every issue
- Some issues
- One issue
- I've never read *Luke's Journal*

How much of each issue do you read?

- Cover to cover! (All of it)
- Most of it
- A few pages
- Not interested

What is your favourite section of *Luke's Journal*?

- Editorial
- Topical articles
- Fire in the belly
- Advertisements
- Classifieds

How would you prefer to receive it?

- Paper version only
- Electronic version only
- Electronic and paper version
- Free electronic and extra fee for paper version

How important is *Luke's Journal* to your CMDFA membership? (circle)

1 2 3 4 5

Not important

Extremely important

Complete, cut out and mail to:
CMDFA National Office, PO Box 877,
Baulkham Hills NSW 1755

Would you be interested in joining the *Luke's Journal* (LJ) team?

- Yes, sign me up! (ensure correct email in question on left)
- No thank you

What is your name? (optional – complete only if you want to be contacted re contributing to the LJ team) _____

What is your phone number? (optional – complete only if you want to be contacted re contributing to LJ team) _____

Crisis Pregnancy Centres Around Australia

The author of this list would like to remain anonymous

GPs are often the first “port of call” for a young woman who is distressed at finding out she is pregnant.

After a positive home pregnancy test, a woman may still be in a state of shock when she sees her family doctor to have the test confirmed and to discuss her options.

It is important to explore the woman's feelings in regards to the pregnancy. If she seems to be considering abortion, then it is important to explore the underlying pressures which may be driving her in that direction. Many women find themselves pregnant only to be abandoned by their male partner, or to face pressure from their boyfriend to undergo abortion. In other cases the woman faces domestic violence, issues relating to drug or alcohol addiction or financial difficulties.

A significant proportion of these women actually believe that abortion is wrong but are in such desperate circumstances that they are contemplating an abortion, despite their own ethical beliefs.

It is critical to listen to these women's stories, to provide empathy and to give them gentle encouragement. Referring them to a pregnancy support centre which has a life-affirming ethos can literally make the difference between a woman aborting or keeping her child.

Even putting aside moral concerns, women who continue unwanted pregnancies to term generally have significantly better mental health outcomes compared to women who abort, as demonstrated by longitudinal studies such as that of Fergusson and colleagues.^{1,2} Many women who initially regard their pregnancy as a disaster (or at least unwanted), once they reach a point where they decide

to continue the pregnancy, their perspectives change. By the time they're 3-4 months pregnant, the baby becomes very much wanted. In contrast, a high proportion of women who undergo abortion suffer long-term depression or grief.

A woman may only ever tell a doctor that they are pregnant just before they decide to abort. It is a matter of life and death. Make sure you give the woman the opportunity and time to consider all the possibilities before making a decision.

Pregnancy support centres provide confidential and free counselling as well as practical assistance (financial help, emergency accommodation or referrals to welfare agencies). Above all these centres provide what these girls need most, which is hope. ●

Following is a list of crisis pregnancy centres throughout Australia:

WESTERN AUSTRALIA

Pregnancy Problem House
www.pregnancyproblemhouse.com
Phone: 1300 200 406

SOUTH AUSTRALIA

Pregnancy Help South Australia
www.pregnancyhelpsa.com.au
Phone: 0403 760 200

QUEENSLAND

Priceless Life Centre
www.priceless.org.au
Phone: 1800 090 777

Eva's Place (Toowoomba)
www.evasplace.org.au
Phone: (07) 4642 1910

ACT

Karinya House
www.karinyahouse.asn.au
Phone: (02) 6259 8998

NEW SOUTH WALES

Sara's Place
www.sarasplace.org.au
Phone: 1300 851 592

Diamond Pregnancy Support
www.diamondpregnancy.com
Phone: (02) 8003 4990

Lilyrose Pregnancy Support
(Coffs Harbour)
www.lilyrose.org.au
Phone: 0423 227 917

Zoe's Place (Newcastle)
www.zoesplace.org.au
Phone: 0402 744 055

Women's Life Centre Albury (Albury)
www.womenslifecentrealbury.org.au
Phone: (02) 6040 7910

Zoe Support Mildura (Mildura)
www.zoesupport.com
Phone: 0488 963 963

VICTORIA

The Babes Project
www.thebabesproject.com.au
Phone: 1300 140 212

Open Doors
www.opendoors.com.au
Phone: (03) 9870 7044

TASMANIA

Babymum Australia
www.babymum.org.au
Phone: 0488 996 633

Esther's House
www.estershhouse-pps.com
Phone: 0479 055 777

NORTHERN TERRITORY

Pregnancy Problem House
www.pregnancyproblemhouse.com
Phone: 1300 200 406

References

1. Abortion in young women and subsequent mental health. Fergusson DM, Horwood LJ and Ridder EM *Journal of Child Psychology and Psychiatry* 47:1. (2006) pp 16-24 www.onlinelibrary.wiley.com
2. Abortion and mental health disorders: evidence from a 30-year longitudinal study. Fergusson DM, Horwood LJ and Boden JM *Br J Psychiatry* 2008 Dec 193(6): 444-51 www.bjprcpsych.org

Some reflections on unborn life

by Dr John Whitehall

John Whitehall is Professor of Paediatrics at Western Sydney University. His 50 year career began at Sydney University, continued through developing countries and western Sydney as a general paediatrician, then specialised in neonatology. For some 15 years he was Director of Neonatal Intensive Care in Townsville, which included ante-natal diagnosis, resuscitation, management and transportation of premature, dysmorphic and sick neonates. He remained involved in developing countries, teaching modules on 'Tropical Paediatrics' in a Masters programme. Currently, he teaches, leads research and has duties in general paediatrics.

I graduated in 1966 and have spent much of that time involved with newborn babies.

In the old days, in-utero life could only be pondered. In recent years, the baby can be measured, monitored, investigated and photographed in all its beauty. Apart from an appreciation of the aesthetics of an unborn sucking its thumb, is there anything else I have learned as a paediatrician and then neonatologist?

There must be a Creator...

As I learned more of the complexity of developmental biology, so increased my awe at Creation. That there must be a Creator is an intellectual conclusion for me, not a matter of faith. I cannot accept that all that complexity... life... could arise from blind mutational accident. That is not to say my interest is restricted to the intellect. My heart is

moved by biology. I love to see those flashes of red Doppler that reveal a beating heart at six weeks; the unfolding of a brain; the spreading of little fingers; the demonstration of consciousness by startle. Unexpectedly, as I get older I find joy in reading the texts that discuss the molecular mechanisms of development. I am a much more committed student than ever in trying to understand how 'all things were made through Him... in Him was life'. Now, to revisit the old song, 'every time I hear a newborn baby cry' at delivery 'I know why I believe' in a Creator. This yelling creature could not have come by accident!

Those with ears to hear...

I learned I wanted to impart something of the wonder of this Creation to my students. But how could it be sparked in souls exposed to teratogenic effects of post-modern Western unbelief, Eastern mysticism, and Middle Eastern relativism, while bathed in the official 'biopsychosocial' model? I worried about this at first, understanding the

"I am glad we are encouraged to look forward to a time when 'God shall wipe away all tears from their eyes; and there shall be no more death...'"

.....

privilege of lecturing was not to be abused by inappropriate 'preaching'. I learned I needed to commit these lectures in prayer and then have faith in the words of Mark that '...there is nothing hidden which will not be revealed'. In other words, for those with ears to hear, the wonder of Creation will be revealed by the facts: embryology speaks for itself.

No answers to imperfections...

I have learned no answer to the imperfections of Creation. With the writer to the Romans (Chapter 8), I can hear it 'groaning as a woman in

labour' and am appalled by myelomeningocele, stillbirths and infections. I cling to the promise of its restoration in the glory of God and am comforted that the Spirit understands our ignorance and pain, and prays for us when we lack the words, or even the effort. I am glad we are encouraged to look forward to a time when 'God shall wipe away all tears from their eyes; and there shall be no more death, neither sorrow, nor crying, neither shall there be any more pain: for the former things are passed away'.

'Mustard seed' faith...

I have learned, in the meantime, that we are to have faith that little, seemingly inconsequential acts, the size of 'mustard seeds', are fundamental to the coming Kingdom. When sitting with parents and their dead child and wondering what on earth might be said, it is reassuring that eternal effects might be wrought by the 'mustard seeds' of agape and brotherly love.

A mother's love...

I have concluded that the writer of Proverbs must have been a man excluded from the delivery suite, otherwise he would have added to his special four... a gliding eagle, a slithering snake, a navigating boat and the love of a man for a woman... the love of a mother for her newborn.

Almost every time I go to a delivery, I perceive a spectacle of the transformation when a mother beholds her newborn. There seem to be three related births in the room: a baby, then a mother, then a family.



The tragedies...

Therein, however, I have observed tragedy. Though the black and white images of ultrasound are beloved by mothers, they do not seem to invoke the 'new birth' of motherhood. One story should suffice: the ultrasound revealed a cleft lip in a boy. The pregnancy was aborted. The child was dressed in a blue shawl with matching beanie. The mother took over four days to say goodbye to the corpse which was in and out of the fridge. I don't think she ever really noticed the little cleft in the lip which had once seemed so dreadful. Though quoting out of context, it appears to me the birth of baby involves 'a new creation' in which 'old things have passed away... (and) all things have become new'. Hence the tragedies of abortion.

Consciousness and pain...

This leads to another thing I have learned: the obfuscation of language in which a life might be deemed, by others, to be 'not worth living'. This conclusion is followed by reassurance that no pain will be felt in or after the process of rending that life asunder. Despite neurological development soon after conception, the startling of foetuses by noise, the dislike of needles by very premature babies and those with grievous abnormalities of their brains, the sophistry is maintained that 'consciousness' is necessary for the perception of pain.

This sophistry is emphasised by the old limerick...

"My journey with the unborn has been a sacred experience..."

.....

*There was a young lady from Deal
Who said 'although pain is not real
If I sit on this pin
And it punctures my skin,
I dislike what I fancy I feel'.*

Regarding the unborn, the last line may be altered to 'I dislike what they fancy I don't feel'.

I have, however, found no limerick regarding the necessity of some mothers to meet regularly to mitigate their consciousness of sustained post-termination pain.

How to handle termination?...

All this leads to another thing I have not learned: how to handle the termination. I have seen my role as neonatologist as an advocate for the unborn but how should I handle a loss? How much sadness should be displayed? How much confirmation that everything was for the baby's best interests? Is it best simply to stay away? But, often, there must be discussion of the deformity.

An imperfect poem may reveal my sense of failure when I met the half closed eyes of another little boy

dressed in blue retrieved from the refrigerator...

*With tiny hands crossed on your chest,
Can I believe you are at rest
Untroubled by the chance denied
To judge yourself the pain described?*

*"Too young," they said,
"for formèd thought."
Were any formless dreamings caught
When those intrusive waves of sound
Proclaimed the defect they had found?*

*Some musings on a life to live?
Of joys to share and love to give?
Some commission in plans divine?
Some contribution wholly thine?*

*"Too much for anyone to bear",
"Life not worth living", some declare.
"More merciful to terminate
And wrench in love from defect's fate."*

*As I examine you, little one,
And I ponder what has been done,
I stand transfixed by half-closed eyes.
Do they forgive? Do they despise?*

In summary

In summary, writing these words makes me realise my journey with the unborn has been a sacred experience: the wonders of Creation, the tragedy of the Fall, the imperfection of human nature, the transformation of Love, the need for Agape love, and the promise that small seeds may grow into great trees to be revealed in the Kingdom to come. It is been more Biblical than I realised! ●

Diamond Pregnancy Service

by Tyler Schofield

Dr Tyler Schofield is a GP and church planter in Newcastle (Gospel Church). Ten years ago he helped a non-medical friend with the early planning of Pregnant Alternatives. As a GP he prayerfully strives to point needy people to Jesus by illustrating applied gospel hope as the ultimate remedy for brokenness in life. He felt honoured when someone recently dubbed him a 'Gospel Practitioner'.

Diamond Pregnancy Service's story is an inspiring portrayal of faith in action.

In the past decade, hundreds of women and families who questioned whether or not to have a child were given the support and help they needed to thrive as parents. The service is quite extraordinary in its scope – comprising a comprehensive provision of quality counselling, fostering a community of expectant and new mums, and ongoing personal support.

About Diamond Pregnancy Support

Based in Sydney's western suburbs (Macquarie Fields and Kingswood), Diamond Pregnancy Services offer compassionate support and counselling to women and families facing unplanned pregnancies. At a time of fear and uncertainty, women are offered practical help and genuine hope while they work out what they should do. From first contact, throughout pregnancy and in the first year following birth, Diamond provides an extraordinary level of support, training and mentoring to help women navigate this pivotal time of life. They support women to build a network



of support that provides long-term solutions through emotional, practical and spiritual support.

Diamond's Story

Diamond's comprehensive counselling and pre- and post-natal support program germinated from one young woman's determination and self-funded efforts to help unexpectedly pregnant women. Founder Jenny Smyth generously shared the personal story of what motivated her to establish their remarkable charity in a recent interview for *Luke's Journal*.

At the age of sixteen, Jenny learned that when she was conceived, her young parents were firmly instructed by doctors to terminate the pregnancy. Her father refused to terminate in light of his religious beliefs, deciding instead to wed his pregnant girlfriend. Years later, while studying ethics at University, on the subject of unplanned pregnancies Jenny heard "a lot of judgement and not a lot of options". Jenny considered that if she was to have fallen pregnant at that time, the harsh religious views of her father would have likely meant substantial

persecution or even homelessness for her.

Galvanised by the gravity of this thought and her parent's own story, Jenny began to look at local models of support in Australia. She decided there was a need for a charity to support women who lacked options in pregnancy and needed genuine support.

She took the extraordinary step of shifting to the US where she visited numerous pregnancy support services, volunteered and worked in crisis pregnancy centres to learn what model could best suit Australia. Using her own funds, Jenny registered as a not-for-profit charity and established a Board of Directors. She began to study counseling "so I could help until I could find someone more skilled".

10 years later, Diamond Pregnancy Support is staffed by an entirely Christian team including two professional counsellors, social workers, case workers, chaplains and a team of volunteers to help with mentoring and event support. Only

two staff receive part time wages and volunteer the remainder of their time.

After years of Jenny supporting the service on her own, Diamond is now financially supported by a small number of generous local Christian doctors who privately fund its activities, council grants and annual fundraisers. Other doctors provide 'in kind' support – obstetricians and GPs offer wholistic care in bulkbilled consultations and deliveries. These doctors are often needed for second opinions and care of women distressed by insensitive initial consultations with other doctors.

Unplanned Pregnancy Counselling

For women who initially engage for support, Diamond's counsellors thoughtfully explore what she is considering with the pregnancy. They spend time clarifying what sort of support she would like. Generally, pregnancy is not the only issue with ninety percent of unplanned pregnancies complicated by prominent issues such as the threat of becoming homeless, major relationship issues, parental reactions, or concerns that pregnancies may ruin a woman's career, studies or other significant plans. Diamond's volunteers and counsellors spend time building a relationship, getting to know the woman's fears, hopes and dreams. Recognising that "a lot of younger

mums just need support", they offer fortnightly support groups and mentor catchups on alternate weeks. Diamond also supplies support for dads. For women who have gone through abortions from other services, Diamond provides free post abortion counselling.

"Diamond Pregnancy Support has seen many women continue pregnancies that would otherwise have been terminated."

Diamond's experience is that the nine months of pregnancy are a highly transformative time with significant growth and problems which can be worked through. Women who receive this time of support are found to thrive. Even the small number of mums who embarked on the formal process to adopt their babies out to other families decided, as they approached delivery, that they were adequately supported, confident and ready to care for their own child.

Practical Support

One thing that really makes Diamond shine is the practical and community support they offer. Ninety percent of

women join with their *Mum 2 Mum* mentoring program, building parenting and life skills through regular guest speakers and personal mentors for each mum (teaching things from breast feeding and budgets, to bonding and creating a sense of security). The *Diamond Empowerment Program* is offered to mums of babies 6-12 months of age to help women in developing future skills for work and study. They partner with the local TAFE to provide one day courses and have a one-to-one mentor through the whole year. Through partnership with other organisations, Diamond is able to assist new mums with specific needs – goods and clothing, referrals, personal counselling, one-on-one support and addressing other needs. Women are also assigned a caseworker for the whole process – "including taking them home from hospital, getting settled afterward, taking them to interviews, helping them shop and just generally being with them to help". It is an extraordinary level of support.

Building on the faith and actions of one young woman committed to making a difference, Diamond Pregnancy Support has seen many women continue pregnancies that would otherwise have been terminated. Every year Diamond supports hundreds of new mums and dads to flourish in parenthood.

www.diamondpregnancy.com



INSTRUCTIONS FOR CONTRIBUTORS

Members of CMDFA are invited to submit articles or letters to the editors for publication in **Luke's Journal**. Articles may or may not be on the advertised theme. Writers may wish to discuss their potential contribution with the editors or their state editorial representative before submitting.

Articles, letters, book reviews and lengthy news items should be submitted (preferably in electronic form) to the **editors** with a covering letter requesting their consideration for publication. Photos supplied should be high res JPEGs.

Advertisements and short news items should be submitted directly to the **sub-editor**. See page 2 for contact details.



SMBC
SYDNEY MISSIONARY & BIBLE COLLEGE

WHY BIBLE COLLEGE?

The world of medicine and dentistry is full of unique opportunities as well as particular challenges for Christians. Being well prepared for what God has in store for you - whether a busy hospital career, a private practice or the overseas mission field - requires a solid foundation in God's word.

What is the relevance of theology to the medical world? How can you think biblically through ethical issues? How do you cross cultures with the gospel? Setting aside a year, or more, to study and discuss and think at Sydney Missionary & Bible College (SMBC) will help lay a foundation for a lifetime of serving Christ, wherever he leads you. Studying at SMBC gives you in-depth teaching of the Bible alongside renowned mission expertise. All this is done in the context of an enriching community of fellow students and highly experienced lecturers.

Be inspired by what some of our graduates have to say about their time at SMBC...

FIND OUT MORE AT SMBC.COM.AU



Brendan So

One of the main reasons why I chose to study medicine was for the opportunities it would allow for sharing the gospel in a medical missionary context. I was able to take a year off medicine to study at SMBC full-time. It was an immensely enriching and rewarding experience, and one that I will carry with me for the rest of my life. I feel equipped to handle the Bible more effectively, but more than that, I really feel that I have a far greater appreciation and understanding of what cross-cultural missionary work involves. How should a doctor balance life between clinical work and ministry? Is it even legitimate to separate the two? What does it actually mean to contextualize the gospel to another culture? If these are questions you've thought about yourself, I could not recommend SMBC more highly to you.



Hayley Thomas

I wanted to spend dedicated time studying God's word, growing to know him more, and building a foundation for whatever he has for me in the future. During my year at SMBC, I enjoyed consistently hearing God's word taught faithfully, and having dedicated time to delve into it in study. This was complemented by the blessing of building relationships with staff and students - seeing the Christian life modelled and walking alongside others. I also benefited from the chance to reflect on the relevance of theology to a specific area of medicine, as I completed a research project in medical ethics. My time at SMBC has equipped me with knowledge to think more systematically about the Bible and theology, has broadened my exposure to mission, and has challenged me to grow in my own Christian walk.



Steven Naoum

My year studying at SMBC was certainly the most significant year of my life. On reflection it equipped me greatly for every endeavour I have undertaken since as I have sought to live as a child of God in his world in all I do. Spending a year completely focused on God, his goodness and sovereignty, and dwelling day after day on his word - what he has said and done throughout history - was the best decision I have made!

Study was rigorous and of a very high standard, and I still say this having completed a PhD and being half way through specialist clinical training. But it wasn't just a thing of the head - my heart and will were continually challenged - both in the classroom and by living in the college community.

