

An Open Letter To Our Representatives In Australian Parliament

We are 60 Australian doctors, medical researchers, ethicists and health experts with a long interest in the treatment and prevention of inherited disease, writing to you as individuals to express our strong support of proposed legislative changes to legalise mitochondrial donation.

Mitochondrial disease is devastating and debilitating. It can cause major organ failure, blindness, deafness, brain disorders, muscular problems and early death. It targets all ages but is especially cruel to our young at the early stages of their life.

There are no cures for mitochondrial disease and a lack of effective therapies.

Mitochondria are the 'batteries' of cells in the body, creating energy. Allowing mitochondrial donation - a specialised IVF treatment that replaces faulty mitochondria with healthy mitochondria - will greatly reduce the risk of a child inheriting the disease.

World class clinical, reproductive medicine and ethics expertise is available in Australia to support this technology, but it is currently not legal to do so.

The Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021 represents an opportunity for the law to keep in step with advances in science and reproductive medicine. Most importantly, it gives Australians with this inherited disease the chance to raise a healthy family.

The approach to mitochondrial donation outlined in Maeve's Law will give Australians access to modern health technologies through a controlled and regulated framework. This process has been supported by rigorous evaluations in the UK and by international organisations.

Maeve's Law outlines a staged approach with a clinical trial being undertaken prior to introduction into clinical practice.

The licencing requirements within the Bill provide for appropriately strong control and regulation while the law has a range of provisions and safeguards for families that consider mitochondrial donation.

We emphasise that this legislation has gone through comprehensive local consultation and review, including a Senate Inquiry in 2018; an NHMRC expert committee review through 2019-2020; a Department of Health consultation in March 2021; and a Senate Committee Inquiry in August 2021. Uniquely, the public engagement processes included Citizen's Jury and Citizen's Panel consultations. These suggested that, following informed consideration of benefits, risks and ethical issues, a clear majority of Australians would be in favour of legislative change.

Our medical research programs are recognised as among the best in the world, and we continue this legacy by supporting it with thoughtful, modern regulation.

We recommend you vote Yes, and that Parliament approves Maeve's Law.

Yours Faithfully,

Signed.

**Prof Ian Alexander BMedSci MBBS (Hons) PhD
FRACP (Paeds) FAHMS**

Professor in Paediatrics and Molecular Medicine, The
University of Sydney

**Dr Shanti Balasubramaniam MBBS MRCPCH (UK)
FRACP**

Sydney Children's Hospitals Network

Prof Samuel Berkovic AC FRACP FAA FRS FAHMS

Director, Epilepsy Research Centre,
The University of Melbourne

Dr Kaustuv Bhattacharya MBBS FRACP MD (res)

Senior Lecturer, Discipline of Genomic Medicine, The
University of Sydney

Tiffany Boughtwood BSc MBA

Managing Director, Australian Genomics

**Prof Jeffrey Braithwaite PhD FIML FACHSM FAAHMS
FFPHRCP [UK] FAcSS [UK] Hon FRACMA**

Founding Director, Australian Institute of Health
Innovation, Macquarie University

Dr Drago Bratkovic MBBS FRACP HGSA

Unit Head, Metabolic Clinic, Women's and Children's
Hospital Adelaide

Dr Kevin Carpenter PhD FHGSA FFSc(RCPA)

CEO, Human Genetics Society of Australasia

Prof John Carroll PhD

Director, Monash Biomedicine Discovery Institute and
Dean of Biomedical Sciences, Monash University

Dr Fleur Cattrall MBBS FRANZCOG CREI

Medical Director, Melbourne IVF

Prof John Christodoulou AM FRACP PhD

FFSc(RCPA) FRCPA FAHMS

Genetics Theme Director,
Murdoch Children's Research Institute

Prof Ian Chubb AC FAA FTSE

Secretary for Science Policy,
Australian Academy of Science

Prof David Coman MBBS MPhil FRACP

School of Medicine, The University of Queensland

Dr Ryan Davis PhD

President, Australian Society for Medical Research

Dr Chris Degeling PhD

Senior Fellow, Australian Centre for Health Engagement,
Evidence and Values, University of Wollongong

Prof Martin Delatycki MBBS FRACP PhD

Medical Director, Victorian Clinical Genetics Services

Dr Tracy Dudding-Byth BMed FRACP PhD

Conjoint Associate Professor, School of Medicine and
Public Health (Medical Genetics), The University of
Newcastle

A/Prof Carolyn Ellaway MBBS PhD FRACP CGHGSA

Sydney Children's Hospitals Network

A/Prof Michael Fahey MBBS PhD FRACP

Head of Paediatric Neurology and Director of
Neurogenetics, Monash Health

Prof Aleksandra Filipovska PhD

Harry Perkins Institute of Medical Research

Dr Janice Fletcher MBBS BSc MD FRACP FRCPA

Genetic Pathologist and Clinical Geneticist

**Prof Ian Frazer AC FRS FAA FAHMS MB ChB(Edin)
MD(Melb)**

University of Queensland Diamantina Institute

Prof Clara Gaff PhD FHGSA

Executive Director,

Melbourne Genomics Health Alliance

Prof David Gardner PhD FAA

Scientific Director, Melbourne IVF

Dr Roula Ghaoui FRACP PhD

Consultant Neurologist,
Royal Adelaide Hospital

Dr Christopher Gyngell PhD

Team Leader, Biomedical Ethics Group,
Murdoch Children's Research Institute

Dr Matilda Haas BSc(Hons) PhD

Research Projects & Partnerships Manager,
Australian Genomics

Dr Maina Kava MD DCH DNB FCPS FRACP

Paediatric Neurologist and Paediatrician (Metabolic
Division), Perth Children's Hospital

Prof Edwin Kirk MB BS PhD FRACP FRCPA

FFSc(RCPA)

University of New South Wales

Dr Julian Koplin PhD

Biomedical Ethics Research Group,
Murdoch Children's Research Institute

Prof Nigel Laing AO PhD FAHMS FFSc (RCPA)

FHGSA

Head, Preventive Genetics, Centre for Medical Research,
The University of Western Australia

Dr Joy Lee MD, FRACP

Department of Metabolic Medicine,
The Royal Children's Hospital Melbourne

Dr Doug Lingard AM MB ChB FRANZCR

Chair, Mito Foundation

A/Prof Karinne Ludlow PhD

Faculty of Law, Monash University

Prof David Mackey AO MBBS FRANZCO FRACS MD

FAHMS

Lions Eye Institute,
The University of Western Australia

A/Prof Alison McEwen PhD FHGSA

President, Human Genetics Society of Australasia

Dr Jim McGill AM MBBS(Hons) FRACP FRCPA

Biochemical Genetic
Pathologist, Pathology Queensland

Prof Robert McLachlan AM PhD FRACP

Monash University

Prof Catherine Mills PhD

Director, Monash Bioethics Centre

Prof Megan Munsie PhD

Melbourne Medical School,
The University of Melbourne

Prof Ainsley Newson BSc(Hons) LLB(Hons) PhD

Professor of Bioethics,
The University of Sydney

Prof Kathryn North AC FRACP MD DMedSci FAHMS

Director, Murdoch Children's Research Institute

Prof Mike Ryan PhD

Pro Vice-Chancellor (Research),
Monash University

Dr Suzanne Sallevelt MD PhD FRACP

Women's and Children's Hospital Adelaide

Prof Julian Savulescu BMedSci MB BS MA PhD

FAHMS

Head, Biomedical Ethics Group,
Murdoch Children's Research Institute

Prof Ingrid Scheffer AO FRS FAA FAHMS

President,
Australian Academy of Health and Medical Sciences

Prof John Shine AC PresAA FAHMS(Hon) FRS

President, Australian Academy of Science

Dr Nicholas Smith MBBS (HON) DCH FRACP PHD

Head, Dept. Neurology and Clinical Neurophysiology,
Women's and Children's Health Network Adelaide

Dr Sharyn Stock-Myer PhD

Virtus Health Specialist Diagnostics

Dr Diana Stojanovski PhD

The University of Melbourne

Dr David Stroud Dr rer nat

The University of Melbourne

Prof Carolyn Sue AM MBBS PhD FRACP FAHMS

Executive Director, Kolling Institute

Dr Michael Tchan BMedSc MBBS PhD FRACP

Genetic Medicine, Westmead Hospital

Prof David Thorburn PhD FHGSA FFSc(RCPA)

FAHMS

Murdoch Children's Research Institute

Prof Dominic Thyagarajan MD FRACP

Professor of Neuroscience, Central Clinical School,
Monash University

A/Prof Ian Trounce PhD

Centre for Eye Research Australia

Prof Alan Trounson AO PhD FRCOG FRANZCOG

FATSE FAHMS

Emeritus Professor Monash University and Distinguished
Scientist, Monash University and Hudson Institute of
Medical Research

Prof Nigel Turner PhD

Head, Mitochondrial Bioenergetics Lab,
University of New South Wales

Dr Matthew Wallis FRACP MBBS BSc

School of Medicine and Menzies Institute of Medical
Research, University of Tasmania

Prof Robert Williamson AO FRS FAA FAHMS

The University of Melbourne