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**Cover image** – Nerve cells in culture showing red-stained mitochondria - Photobiomodulation project (Chan Taplinovsky and Armati)
President’s and Directors’ Report

2017 was another successful year for the Foundation and we were able to provide continuing support for research projects in Multiple Sclerosis, Motor Neuron Disease, Peripheral Neuropathy and Pain Management related to Photobiomodulation. Foundation funds have supplemented salaries for researchers and enabled infrastructure purchases for scientists who need expensive but essential equipment.

We are particularly grateful to our benefactors who have continued to support this work. The Sydney Executive Business Association have worked tirelessly to raise much needed funding which will progress this work and their efforts and generosity cannot be overestimated. Moreover, their Annual Fundraising Dinner in Chinatown at the Marigold Restaurant, again proved to be a most enjoyable and successful occasion and many of our benefactors provided auction items and enthusiasm in their bidding.

The last few years have conclusively shown how important Medical Research is in the quest to find better treatments. New immunotherapies, for instance, have recently changed the outlook for formerly incurable conditions such as metastatic melanoma and certain other cancers and exciting new gene therapies are being applied with early success to young patients with spinal muscular atrophy. Foundation scientists and clinicians have participated in the development of new and more effective treatments for MS and Neuropathy. There is no doubt that research is of the utmost importance and with the help of you our supporters, the Foundation will continue its work.

Finally, we especially wish to thank all members of the NRF Council who have given their precious time to attend meetings, review documents and provide wise council. We are indeed privileged that people of such outstanding experience and talent have given their service over so many years. One sad note from 2017 was the death in June of John Armati, who played a most important role in the establishment of the Foundation and as a generous supporter over many years.

Highlights and updates

Associate Professor Michael Barnett was promoted to Professor at the University of Sydney and the Brain and Mind Centre in recognition of his outstanding contributions to teaching and research in the field of Multiple Sclerosis in which he has achieved International standing. Professor Barnett has broken new ground in establishing a multidisciplinary team at the University including neurologists, neuroscientists, physicists, experts in Information Technology and Imaging who are planning national and international collaborative programmes focussed on MR Imaging and aimed ultimately at preventing MS progression. Professor Barnett has submitted a proposal to the NRF Council for substantial support to establish this “Neuroanalytics Platform to Prevent MS Progression” and the Council has approved it. Prof Barnett and his team of MS Researchers have continued their participation in International Therapeutic Trials of new therapies aimed at preventing disease and encouraging repair.

Professor Armati was recognised for her important contribution to neuroscience research, tertiary education and outstanding community service by her appointment as a Member of the Order of Australia. Professor Armati has championed research into the myelin forming cell of the Peripheral Nervous System, a cell essential for normal nerve function and central to many important neuropathies.

Dr. Roberta Chow was also appointed a Member of the Order of Australia in recognition of her dedication to the practise of medicine and pioneering developments in the use of laser therapy (photobiomodulation) in the important field of Pain Management.
Sydney Executive Business Association presented a cheque for more than $40,000 to Professor Armati and Dr Chow to further support their research.

The efforts of Professor Armati and the members of the Cajal Legacy Group to persuade UNESCO to formally recognise the Nobel Prize winning Ramon Y Cajal’s legacy (surviving histological slides of brain and nerve, photographs, paintings, books, etc.) was successful. Having won UNESCO recognition for these priceless treasures the group are now requesting the Spanish Government to house this legacy in an appropriate museum.

Benjamin Chow - President

Patricia Armati
Vice President and Director

John Pollard
Director

Members

Council
- Ms Belinda Jane Hutchinson AM, Chancellor, The University of Sydney
- Dr Michael Spence AC, Vice Chancellor, The University of Sydney
- Professor Arthur Conigrave, Dean, Faculty of Medicine, The University of Sydney
- Mr Benjamin Chow AO, President
- Professor Patricia Armati AM, Vice President and Co-Director
- Professor John Pollard AO, Co-Director
- Professor Robert Ouvrier OAM
- Dr Ruth Kerr OAM
- Mr John Armati OAM
- Mr Tony Carroll KCSG, AM
- Mr. David Jacobs
- Mr Roy Melick
- Associate Professor Michael Barnett
- The Hon Alan R Abadee AM RFD QC
- Associate Professor Stephen Reddel
- Professor Matthew Kiernan
- Ms Melissa Bonevska

Scientific Committee
- Professor John Pollard AO
- Professor Patricia Armati AM
- Professor Robert Ouvrier OAM
- Professor Matthew Kiernan
Honorary Governor
- Ms Rikki O’Neill

Honorary Life Members
- Mr David Jacobs
- Ms Rikki O’Neill
- Dr Ruth Kerr OAM
- Mr John Armati OAM
- Mr Tony Carroll KCSG, AM
Researchers Supported by the Nerve Research Foundation

Academic
- Professor John Pollard AO, BSc (Med) MB BS PhD, FRACP, FRCP
- Professor Patricia Armati AM, BSc, MSc, PhD
- Professor John Prineas AO, MB Bs, FRCP, FRCP (Edin)
- Dr Judy Spies, MB BS PhD, FRACP
- Dr Emily Mathey, BSc (Hons 1), PhD
- Dr Min-Xia Wang MB MD
- Associate Professor Michael Barnett MB BS (Hons 1) FRACP PhD
- Associate Professor Roger Pamphlett, MD, FRACP, FRCPath
- Associate Professor Stephen Reddel MB BS FRACP PhD
- Dr John Parratt MB BS MD

Honorary Research Associates
- Dr Roberta Chow AM MBBS PhD, FRACGP, FAMAC, MApplSci (Med Acu)
- Dr Ambrose Chan BDS Hons (Uni Syd), DipClin.Dent (Uni Syd), MScDent (Uni Syd), FRACDS

Research Associates
- Dr Linda Ly PhD

Senior Research Fellows
- Dr Emily Mathey BSc (Hons) PhD
- Dr Claire Goldsbury PhD

Clinical Trials Staff
Mrs Marinda Taha, Trials Co-ordinator

Technical Staff
- Toan Nguyen
- Neeta Lal BSc Dip. Path
- Ms Hung Jiew Lee, BSc, MSc

Research Staff
- Dr Nidhi Garg
  - NHMRC/MNDRIA co-funded postgraduate award 2017-2017
- Dr Thanuja Dharmadasa
  - MNDRIA PhD top-up Grant 2017-2018
  - Top up award from the Yugilbar Foundation (2017-2019)
  - PhD Top up award from Rotary (2017-2019)
- Associate Professor Cindy Lin
- Dr Rebekah Ahmed (Neurologist)
- Dr Michael Lee (Neurophysiologist & Physiotherapist, Postdoctoral Research Fellow)
- Dr Emma Devenney (Neurologist, PhD candidate)
- Dr Susanna Park (Senior Lecturer)
- Dr Tim Howells (Postdoctoral Research Fellow)
- Jashelle Caga (Health Psychologist, PhD Candidate)
- Hannah Timmins (Research Assistant)
- Dr William Huynh (Neurologist, Postdoctoral Researcher).
• Dr Talai Kaplinovsky PhD (Armati group)
• Margie Zoing (MND CNC)
• Dr Yoshimitsu Shimatani (Neurologist, Japanese visiting researcher)
• Dr Yuichi Noto (Neurologist, Japanese visiting researcher)
• Dr Jose Mattamala Capponi (Neurologist, Chilean visiting researcher)
• Elizabeth Highton-Williamson (Research Assistant)
• Tiffany Li (Research Assistant)
• Nicollellete Thornton (Research Assistant)
• Eleanor Ramsey (Research Coordinator)

Higher degree Candidates:

• Ms Jashelle Caga, 2014 – ongoing (PhD Candidate; Co-supervised with Dr Anne Hodgen)
• Dr Nidhi Garg, 2015 – ongoing (PhD Candidate)
• Dr Thanuja Dharmadasa 2017-ongoing (PhD Candidate)
• Jashelle Caga (Health Psychologist, PhD Candidate)
• Dr Nidhi Garg (Neurologist, PhD Candidate)
• Dr Thanuja Dharmadasa (Neurologist, PhD Candidate)
• Dr Dev Nathani (Neurologist, PhD Candidate)
• Hannah Timmins (Neuroscience, PhD Candidate)
• Elizabeth Highton-Williamson (Neuroscience, PhD Candidate)
• GuYu Gu (Physiotherapist, PhD Candidate)
• Dr Ambrose Chan (PhD Candidate) (Armati group)

Administrative Staff
Mrs Megan Power
Strategy, Achievement of Objectives and Financial Performance Against Budget

The Sydney University Nerve Research Foundation, established in 1985, promotes basic research into the mechanisms and effects of disease of the central and peripheral nervous system by scientists, clinicians and postgraduate students. It assists the formation of patient support groups and aims to increase public understanding of diseases of the nervous system.

Achieving Objectives

The NRF achieves the above goals by its members being awarded nationally competitive grants, supporting postgraduate students, clinical trials, organising invited lectures, conference presentations and seminars.

Fundraising Activity

The NRF did not actively fundraise during 2017 as the Sydney Executive Business Association actively raised over $40,000 for the photobiomodulation project.

The NRF also receives donations and bequests from time to time as well as in response to our Annual Report.

The Nerve Research Foundation does not employ full time administrative staff, this is done by Mrs Megan Power on an ‘as needs’ basis – which minimises such costs and allows us to maximize our donations to fulfill our objectives.

Foundation Governance Statement

The Nerve Research Foundation recognises the importance and benefit of reviewing its adoption and alignment with governance principles and provides the following report

Principle 1 – Lay solid foundations for management and oversight

Nature of the entity

The Nerve Research Foundation is a part of the University of Sydney ABN 15211513464 and not separately incorporated under a state or commonwealth Act. The Foundation is required to gain prior approval for its fundraising activities from the appropriate University delegate. The Foundation’s activities are not-for-profit and covered by the DGR status of the University of Sydney. The University is exempted from the requirement to hold an Authority to Fundraise and obligations upon holders of such an authority but is still required to comply with the balance of provisions of the Charitable Fundraising Act

Roles of board / council and management

The Foundation operates under the authority of the Senate of the University of Sydney, as approved on 21 March 2011 and has no powers of delegation. The Foundation conducts its affairs pursuant to the Foundation Rules and the relevant policies of the University. The Foundation had its annual fundraising plan approved and was able to meet its objectives.

Principle 2 – Structure of the council to add value

The Council of the Foundation in 2017 consisted of the following members:

Benjamin M T Chow AO  
President NRF Council  
Civil Engineer, Property Development, Company Director, Government and University Councils, Council  
Member Sydney Medical School Foundation  
Term of Appointment: 2012 – 2017  
Special Responsibilities: Fund raising in partnership with outside organisations such as Lions Club, The Sydney Business Executive Club, donations and bequests  
Attended all meetings in 2017
Professor Patricia Armati AM
BSc MSc PhD, Vice President and Co-Director and Founder of the NRF
Current Term of Appointment: 2012 – 2017
Special Responsibilities: Oversight of administration of the Foundation and liaison with other Council members and the general public
Attended all meetings in 2017

Professor John Pollard AO
MB BS BSc (Med) PhD FRACP FRCP (Lond), Co-Director and Founder of Nerve Research Foundation
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017

Matthew Kiernan PhD, DSc, FRACP
Bushell Chair of Neurology, Royal Prince Alfred Hospital
University of Sydney
Current Term of Appointment: 2017 - 2017
Special Responsibilities:
Attended all meetings in 2017

The Hon Alan Richard Abadee AM RFD QC
LLB
Retired Judge
Special Responsibilities: Review and advise on legal issues
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017

Associate Professor Michael Barnett
MB BS (Hons I) FRACP PhD
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017

Associate Professor Steven Reddel
MB BS FRACP PhD
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017

Professor Robert Ouvrier AC
BSc (Med) (Hons), MB, BS (Hons), MRACP, FRACP, M.D.
Emeritus Professor
Research in the field of Paediatric Neurology
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017

Dr Ruth Kerr OAM
PhD; B. Leg. Studies; BA; Gr Dip Lib Sc; Cert Tchg
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017
Mr David Jacobs
LLB, LLM
Solicitor; former managing partner of Baker & McKenzie in Australia, former Chairman of Asia Pacific for Baker & McKenzie, former member of the global Executive Committee of Baker & McKenzie, numerous other management roles in Baker & McKenzie
Current Term of Appointment: 2012 – 2017
Special Responsibilities: Review and advise on legal issues
Attended all meetings in 2017

Mr Roy Melick
LLB BA LLM
Special Responsibilities: Review and advise on legal issues
Current Term of Appointment: 2012 – 2017
Attended all meetings in 2017

Ms Melissa Bonevska
Current Term of Appointment: 2017 -
Special Responsibilities: Ex-Officio University (Provost’s nominee)
Attended no meetings in 2017

Council members were elected and/or co-opted at the Foundation’s AGM on 28 February 2012. There is separate nomination sub-committee of Council elected at the Foundations AGM on 4 February 2015 consisting of Matthew Kiernan, Steven Reddel and Ben Chow. The full Council resolves on nominations for co-opting of members to fill vacancies outside of the process of election at the AGM. There was not a performance evaluation of the Council undertaken in the reporting period.

Principle 3 – Promote ethical and responsible decision-making
Council members have been provided with the University of Sydney Foundation Governance Guide, Foundation Rules, Code of Conduct, Work Health & Safety policy and the External Interests policy. All these policies are available on the University’s Policy Register. as are other relevant University policies regarding harassment, grievance procedures and the Delegations of Authority.

Principle 4 – Safeguard integrity in financial reporting
The annual accounts of the Foundation are prepared by the financial staff of the University, signed off by Petrus Swemmer and included in this Annual Report to the Senate. The Foundation is part of the University and therefore does not have its own audit sub-committee. While the Annual Financial Report of the University is audited by the Audit Office of NSW, the Annual Report of the Foundation has not itself been audited.

The Foundation did not undertake any fundraising appeals1 during 2017.

Principle 5 – Make timely and balanced disclosure
The Foundation complied with the reporting and disclosure requirements of the Senate. These include an annual budget and this Annual Report

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1 See s5 Charitable Fundraising Act 1991 (NSW)
Members and Council have been made aware of the processes for disclosure pursuant to the Code of Conduct, External Interests policy, which include protected disclosure to the ICAC, to the Ombudsman or the Auditor General.

**Principle 6 - Respect the rights of shareholders, members, staff, volunteers, clients, & other stakeholders**

The Foundation Council and/or membership consists of members of the community, industry bodies and the University whose input is invited via the Annual General Meeting and Council meetings of the Foundation. The following forums/mechanisms have been held during the year to involve stakeholders in election of the Council, activities of the foundation or other stakeholder participation AGM – March 2017.

Under the Charitable Fundraising Act, the University may be questioned about any appeal on details of the purpose of the appeal such as the appeal target, objectives, distribution of proceeds, and the process to provide answers. During the year the Foundation published information and outlines those activities in this annual report. There were no specific requests for information responded to by the Foundation office. Other enquiries may have been made to other parts of the University.

**Principle 7 - Recognise and manage risk**

The Foundation recognises its activities within University premises or other premises require risks such as health and safety, environmental protection, privacy, trade practices, and compliance with the Charitable Fundraising Act to be considered and managed.

**Principle 8 – Remunerate fairly and responsibly**

No member of a Council is entitled to receive any remuneration for acting in that capacity except reasonable remuneration on a basis which has first been approved in writing by the University Officer (Foundations).

Members of the Foundation Council may be reimbursed for reasonable expenses after written approval of the University Officer (Foundations). Any such instances are recorded in the minutes of the Council.
Research Projects

Peripheral Neuropathy - Neuroinflammation Group at the Brain and Mind Centre

Autoimmunity to the Node of Ranvier in inflammatory diseases of the peripheral nervous system
Emily Mathey, Toan Nguyen, Nidhi Garg, Susanna Park, John Pollard, Matthew Kiernan.

Chronic inflammatory demyelinating polyneuropathy (CIDP) is a paralyzing disorder of the peripheral nervous system (PNS). CIDP occurs when the immune system mistakenly attacks the peripheral nerve. During this process the immune system strips the myelin away from the axon leaving it uninsulated and unable to conduct nerve impulses efficiently. We have been studying the immune response in patients with CIDP and have found that the target of the response in some patients is also directed at and around the node of Ranvier. The node of Ranvier is a gap in the myelin covering of the nerve fibre which seems to be particularly vulnerable to autoimmune attack.

We have developed an assay to screen patient sera for antibody responses to the nodal/paranodal proteins neurofascin 155, neurofascin 186, contactin 1 and gliomedin as well as a panel of gangliosides. We have detected autoantibody responses to some of these molecules in a proportion of patients with CIDP and are now following these patients to monitor nerve function and clinical phenotypes. The presence of these antibodies is associated with certain clinical phenotypes and a lack of response to intravenous immunoglobulin (IVIg.)

We are also developing models to test the pathogenic significance of these antibodies in vivo to determine if they damage the nerve and how they inhibit nerve function. Other studies will assess whether IVIg can prevent this antibody induced nerve damage and if so by which mechanism. Further characterisation of autoimmune responses to these antigens should give greater insight into the pathogenesis of inflammatory demyelinating neuropathies and may help guide diagnosis, treatment options and prognosis.

MULTIPLE SCLEROSIS

Multiple sclerosis is a disabling inflammatory brain disease that afflicts more than 20,000 Australians at the prime of their life. Our group continues to focus research efforts on biomarkers of MS disease activity and progression with a spectrum of blood, imaging and electrophysiological techniques. Clinical research and MS clinical trials are enriched by the participation of patients attending the BMC Multiple Sclerosis Clinic, a partnership of Sydney University, Royal Prince Alfred Hospital and Multiple Sclerosis Australia.

MS Clinical Research
MH Barnett, JD Pollard, J Spies, M Taha, S Reddel, T Hardy, H Beadnell, J Barton, A O’Connell

Our dedicated MS Clinical Trials Unit has continued to provide patients with access to Phase 2-4 trials of cutting edge MS therapies across the spectrum of disease phenotypes. Coordinated by Dr Marinda Taha, the MS Clinical Trials Unit is the largest in NSW and works in close association with the MS Clinic at BMRI.
Our participation in the **iMed/MSBASE clinical database platform** continues to produce high quality, clinically relevant data that has led to 11 high impact publications in 2017 (including Brain and Lancet Neurology) that will guide patient management, and in particular therapeutic strategy and treatment sequencing in MS.

We are excited to announce the publication of our groundbreaking work, undertaken with A/Professor Michael Buckland and his team, investigating the role of circulating “exosomes” as biomarkers in MS. Published in Scientific Reports (a Nature journal), this work is the first demonstration that circulating exosomes are informative biomarkers not only for the diagnosis of MS, but in predicting disease subtype with a high degree of accuracy. Our goal now is to refine the methodology into a clinically useful blood test for application in the MS Clinic.

New collaborations with A/Prof Ollie Jay (Faculty of Health Sciences, University of Sydney) generated novel research into the mechanisms of heat sensitivity in patients with MS. Publication of this research in 2017 highlighted and the use of simple techniques to improve exercise tolerance in heat-sensitive patients with MS.

**MSRA Brain Bank**  
**MH Barnett, M Buckland, Tony Harding and MS Research Australia Team**

Established in 2008, the MS Research Australia Brain Bank continues to expand and provide expertly characterized tissue samples to MS researchers in both Australia and internationally. This crucial platform addresses a major factor limiting progress in MS research in the country. Tissue from donated brains is characterized both with neuroimaging (MRI) and by using microscopy and immunohistochemistry.

*Funding: MS Research Australia, Sydney Local Health District, University of Sydney*

**MS Neuroimaging Research**  
**MH Barnett, T Wang, L Ly, S Liu, S Klistorner, R Oliver, H Beadnall, J Barton, K Kyle**

In collaboration with the Sydney Neuroimaging Analysis Centre (SNAC), based at the Brain and Mind Centre, we have developed novel MRI biomarkers of myelin and axonal integrity in MS. In particular, our group uses advanced imaging techniques such as diffusion MRI to examine the properties of nerve fibre bundles in the brain. In 2017, we made significant technical advances that have identified progressive alteration in diffusion MRI properties in the core of established MS lesions. This work suggests that gradual loss of nerve fibres occurs in chronic MS lesions despite excellent control of brain inflammation; and is the likely pathology that underlies gradual worsening in patients with progressive disease. Translational work is the clinical trial space continued through 2017 with the ongoing VISMS (“Visual System in MS”) and ORIMUS (Optic Radiation in MS) studies.

**Pain Management**

**Photobiomodulation (PBM)**  
**Ambrose Chan Tala Kaplinovsky Patricia Armati –**

This project has continued with the work of PhD candidate, Ambrose Chan exploring the use of a-thermal low level application of photobiomodulation (PBM) delivered by laser devices - including the same Nd/YAG device used in a published clinical trial study (Journal of Dental Research, 2012). A further two clinical trials carried out in collaboration with Sydney Dental Hospital have clearly demonstrated the significant effect on pain levels, root resorption and inflammation when PBM protocols were used during orthodontic procedures. This research has great potential for needle-phobic people especially children. It is a therapy which does not require drugs nor invasive injections. It is anticipated to change dental treatment when the study is completed in early 2018.
Motor Neuron Disease
Amyotrophic lateral sclerosis/Motor Neuron Disease

Roger Pamphlett

In 2017 Associate Professor Pamphlett, working in the Brain and Mind Centre at the University of Sydney, continued looking for both environmental and genetic factors that could underlie amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND). The following studies in 2017 looked for evidence of these factors.

*Epigenetic differences between monozygotic twins discordant for amyotrophic lateral sclerosis (ALS) provide clues to disease pathogenesis*¹

Widespread changes in methylation patterns were found in ALS-affected identical co-twins, consistent with an epigenetic contribution to disease. These DNA methylation findings could be used to develop blood-based ALS biomarkers, gain insights into disease pathogenesis, and provide a reference for future large-scale ALS epigenetic studies.

*Environmental insults: critical triggers for amyotrophic lateral sclerosis*²

Environmental insults are a critical trigger for ALS, particularly in the aged individuals with other toxicant susceptible genes. The identification of ALS triggers could lead to preventive strategies for those individuals at risk.

*Does the index-to-ring finger length ratio (2D:4D) differ in amyotrophic lateral sclerosis (ALS)? Results from an international online case-control study*³

Index-to-ring finger length ratio did not differ between patients with ALS and controls in this study. These findings do not support the hypothesis that exposure to increased prenatal testosterone is a risk factor for ALS. A putative lower 2D:4D has been proposed to explain the link between ALS and exercise, but our results indicate that other exercise-related factors are more likely to explain this association.

*Cross-ethnic meta-analysis identifies association of the GPX3-TNIP1 locus with amyotrophic lateral sclerosis*⁴

We found a significant association of GPX3-TNIP1 with ALS, with replication support from two independent Australian samples (combined 576 cases and 683 controls). Both GPX3 and TNIP1 interact with other known ALS genes (SOD1 and OPTN, respectively). Our results increase our understanding of genetic etiology of ALS.

*Genetic and Pathological Assessment of hnRNPA1, hnRNPA2/B1, and hnRNPA3 in Familial and Sporadic Amyotrophic Lateral Sclerosis*⁵

hnRNPA3 pathology was identified in motor neurons of ALS patients with C9orf72 repeat expansions, implicating hnRNPA3 in the pathogenesis of C9orf72-linked ALS. hnRNPA3 warrants further investigation into the pathogenesis of ALS linked to C9orf72.

ForeFront – Motor Neurone Disease and Frontotemporal Dementia

*Professor Matthew Kiernan*

Professor Matthew Kiernan leads the ForeFront Frontotemporal Dementia and Motor Neurodegeneration Syndrome Program. The team's work is focused on clinical neurology, in particular disease pathophysiology and treatment strategies for neurological disorders.
The team are currently investigating the mechanisms and possible prevention of neurodegeneration in frontotemporal dementia (FTD), motor neurone disease (MND), Kennedy's disease, chemotherapy-induced neurotoxicity, stroke, Machado-Joseph disease, spinal muscular atrophy and other inherited neuropathies.

As the Bushell Professor of Neurology, Professor Kiernan is dually located at the University of Sydney, Brain and Mind Centre and the Royal Prince Alfred Hospital. Professor Kiernan is also the Co-Director of the Brain and Mind Centre - Discovery and Translation.

Professor Kiernan provides academic leadership in neurology and promotes partnerships between researchers and healthcare practitioners to optimise the translation of research into improved healthcare practice and policy.

Motor neurone disease is a rapidly progressive neurodegenerative disorder that is universally fatal. MND causes the nerves and muscles to atrophy leading to paralysis. The recent discovery of the C9orf72 gene has revealed further links between MND and FTD.

The ForeFront clinic offers diagnostic assessment for patients with suspected motor neurone disease or frontotemporal dementia and multidisciplinary symptom management for patients.

Our diagnostic team are able to perform electrodiagnostic studies including electromyography and nerve conduction studies, as well as novel procedures such as nerve and muscle ultrasound, peripheral nerve excitability and transcranial magnetic stimulation, the latter used to study brain function.

For patients diagnosed with motor neurone disease the clinic provides multidisciplinary care plans and ongoing support along with the opportunity to participate in research projects including novel clinical trials. In 2017 our clinic team expanded to include a new physiotherapist and occupational therapist.

The integration of research programs with the clinic enables our research to be driven by an understanding of the needs of primary and allied carers, patients and their families. This integration also facilitates the translation of research outcomes into improved healthcare practice and policy.

Key Achievements

This program of clinics and the associated research program currently receives referrals for patients from across Australia, New Zealand and throughout Asia.

The Fight MND Foundation awarded Professor Kiernan and colleague Professor Steve Vucic $4.75 million, raised from the Freeze at the G (held at Melbourne Cricket Ground) to investigate a new potential treatment for MND. The clinical trial investigating Tecfidera is set to begin in early 2018. Recruitment will be undertaken through the NHMRC Sydney Health Partners Advanced Health Care Centre, with sites at the Royal Prince Alfred Hospital and Westmead Hospital.

Working with international colleagues Project MinE was established to investigate the genetic basis of ALS and to ultimately find a cure for this devastating, fatal neuromuscular disease. Project MinE aims to analyse the DNA of 15,000 ALS patients and 7,500 control subjects. The resulting 22,500 DNA profiles will be compared to work out the origins of MND.
Molecular Heterogeneity in Diffuse Gliomas

RPA Department of Neuropathology, Brain & Mind Centre, University of Sydney

Michael Buckland, Grace Wei, Maggie Lee, Kim Kaufman, John Turchini

RPA Department of Neuropathology, Brain & Mind Centre, University of Sydney

Gliomas are the most common brain tumours of adults and children. They are devastating tumours that are resistant to surgery and chemoradiotherapy, and most are fatal. Unlike more common cancers, we still have no idea of how or why gliomas occur in some individuals. In the last 5 years great progress has been made in defining some of the common genetic lesions associated with glioma growth and progression. An important unanswered question is whether these genetic lesions are present throughout a tumour, or restricted to a subset of tumour cells, and if their distribution changes with treatment or tumour progression.

We have been examining a large number of brain tumour samples in order to define the extent of this ‘molecular heterogeneity’ We are using a variety of techniques to quantify the level of various mutations, as well as visualising the distribution of mutations in individual cells within a tumour. Support from the Nerve Research Foundation has allowed us to apply state of the art deep sequencing techniques to comprehensively examine a panel of over 50 genetic mutations in each sample. Based on our initial results, we have now expanded the study to include over a hundred more samples from Royal North Shore Hospital. This will give us sufficient numbers to perform the definitive study on the nature and extent of molecular heterogeneity. Our work has important implications for how brain tumours are classified and will provide novel insights into the early stages of brain tumour formation.
Publications - Researchers Associated with the NRF


Parkin Kullmann JA, Pamphlett R. Does the index-to-ring finger length ratio (2D:4D) differ in amyotrophic lateral sclerosis (ALS)? Results from an international online case-control study. BMJ Open. 7:e016924.


Parkin Kullmann JA, Pamphlett R. Does the index-to-ring finger length ratio (2D:4D) differ in amyotrophic lateral sclerosis (ALS)? Results from an international online case-control study. BMJ Open. 7:e016924.


**INVITED TALKS**

**Mathey E**

Autoantibody responses to nodal and paranodal antigens in chronic inflammatory neuropathies. Neuroimmunology Australia.

**Kiernan M**

MND Connect, Charles Perkins Centre, University of Sydney, Sydney, Australia, November (2017)

Speaker: "Clinical Trials update"

13th MND Australia Research Conference, Charles Perkins Centre, University of Sydney, Sydney, Australia November 2017 (Chair)

Forefront Scientific Meeting, Grace Hotel, Sydney, 11 October 2017 (Chair)

17th BieMatheynnal Clinical Neurophysiological Workshop of the Australian and New Zealand Association of Neurologists, Sheraton Mirage Resort, Southport, Queensland, September 2017 (Chair/Organizer)

Palliative Care Nurses Australian; 'Cognitive decline and capacity'; August 2017, Adelaide, Australia; (Invited Speaker),

XXIII World Congress of Neurology, 'Tracking Neurodegeneration by TMS', September 2017, Kyoto, Japan, (Speaker/Chairman)

Launceston General Hospital: 'Motor Neurone Disease: current & future therapies', June 2017, Launceston, Australia (Guest Speaker)

ANZAN Annual Scientific Meeting, 'Treatment Strategies in Motor Neurone Disease', May 2017, Gold Coast, Australia (Plenary Speaker)

Cure 4 MND, 'New Horizons in MND', April 2017, Melbourne, Invited Lecture
British Medical Journal (BMJ) Editors Retreat; London, UK, March 2017

MND SA Research Symposium, Adelaide SA, March 2017, 'MND current and future perspectives', (Keynote Speaker)

**Books and Chapters**


## Research Monies granted to Researchers Associated with the NRF

<table>
<thead>
<tr>
<th>Recipient of Grant</th>
<th>Title</th>
<th>Granting Body</th>
<th>Amount of Grant</th>
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<tbody>
<tr>
<td>R Pamphlett</td>
<td>Using trios to find the cause of motor neuron disease</td>
<td>NH &amp; MRC</td>
<td>$600,000 (total) 2012-2017</td>
</tr>
<tr>
<td>M Barnett</td>
<td>Optic Radiation in Multiple Sclerosis</td>
<td>Sydney Neuroimaging Analysis Centre</td>
<td>$501,074.00 2014-2017</td>
</tr>
<tr>
<td>M Kiernan &amp; E Mathey</td>
<td>The clinical and functional significance of autoimmune responses to nodal antigens in patients with inflammatory demyelinating neuropathies.;</td>
<td>GBS/CIDP Foundation International</td>
<td>USD$45,000 2017-2017</td>
</tr>
<tr>
<td>Kiernan M, Lin C, Pollard J, Mathey E, Park S, Vucic S;</td>
<td>Nodal Function in Peripheral Neuroinflammatory Disorders: Target Antigens, Functional Significance and Treatment Response;</td>
<td>National Health and Medical Research Council (NHMRC)/Project Grants.</td>
<td>$605,172 2017-2018</td>
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<tr>
<td>J Rubio, M Barnett</td>
<td>Does neuronal somatic progression influence the progression of MS</td>
<td>MS Research Australia and National Multiple Sclerosis Society (USA)</td>
<td>$73,000 2017</td>
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<tr>
<td>J Rubio, M Barnett</td>
<td>Ultradeep sequencing of oligodendrocyte lineage genes to investigate the role of somatic mutation in MS</td>
<td>Rebecca Cooper Medical Research Foundation</td>
<td>$24,000 2017</td>
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<td>M Barnett</td>
<td>SOAR Research accelerator Fellowship</td>
<td>The University of Sydney</td>
<td>$150000 2017-2018</td>
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<td>M Barnett, J Barton, A Klistorner, T Wang</td>
<td>Vision in Multiple Sclerosis</td>
<td>Sydney Neuroimaging Analysis Centre and Genzme-Sanofi</td>
<td>$600,000.00 2016-2018</td>
</tr>
</tbody>
</table>
1. **Statement of Significant Accounting Policies**
   (a) These financial statements are special purpose financial statements that have been prepared on an accrual basis.
   (b) Income tax is not applicable to activities of the Foundation.

2. **Unrealised Gain/(Loss) on Investments**
   The business model that relates to unitisation supports the classification and measurement of the majority of University financial assets at fair value. The unrealised gains/ (losses) as at 31 December are shown as "Unrealised Gain/ (Loss) on Investments" in the Income Statement. Long term investments are shown at market value in the Balance Sheet.

3. **Accumulated Funds Adjustments**
   Funds relating to the Ignacy Burnett Bequest, accumulating to $440,986 were transferred to the area in charge of its administration.
The University of Sydney

Nerve Research Foundation

Income Statement
for the year ended 31 December 2017

<table>
<thead>
<tr>
<th></th>
<th>Notes</th>
<th>31 December CY2017</th>
<th>31 December CY2016</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>INCOME</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scholarships, Donations and Bequests</td>
<td>22,468</td>
<td>784,275</td>
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<tr>
<td>Investment Income</td>
<td>12,106</td>
<td>17,661</td>
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<tr>
<td>Realised Gain / (Loss) on Investments</td>
<td>4,648</td>
<td>3,681</td>
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<tr>
<td>Unrealised Gain / (Loss) on Investments</td>
<td>90,473</td>
<td>59,340</td>
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</tr>
<tr>
<td>Internal and Other Income</td>
<td>0</td>
<td>545</td>
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<tr>
<td>Total Income</td>
<td></td>
<td>129,695</td>
<td>865,502</td>
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<tr>
<td>EXPENDITURE</td>
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<tr>
<td>Salaries</td>
<td>0</td>
<td>4,369</td>
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<tr>
<td>Services and Utilities</td>
<td>32</td>
<td>173</td>
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<tr>
<td>Contributions to University areas</td>
<td>88,085</td>
<td>50,191</td>
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<tr>
<td>Other Expenses</td>
<td>8,879</td>
<td>2,466</td>
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<td>Total Expenditure</td>
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<td>96,996</td>
<td>57,199</td>
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<td>Surplus / (Deficit)</td>
<td>32,699</td>
<td>808,303</td>
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<tr>
<td>Accumulated Funds</td>
<td>1,948,079</td>
<td>1,212,882</td>
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<tr>
<td>Accumulated Funds Adjustments</td>
<td>3</td>
<td>(440,986)</td>
<td>(73,106)</td>
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<tr>
<td>Total Accumulated Funds</td>
<td></td>
<td>1,539,792</td>
<td>1,948,079</td>
</tr>
</tbody>
</table>
The University of Sydney

Nerve Research Foundation

Balance Sheet as at 31 December 2017

<table>
<thead>
<tr>
<th></th>
<th>Notes</th>
<th>31 December CY2017</th>
<th>31 December CY2016</th>
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</thead>
<tbody>
<tr>
<td><strong>ASSETS</strong></td>
<td></td>
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<tr>
<td>Current Assets</td>
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<tr>
<td>Short Term Investments</td>
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<td>440,767</td>
<td>954,518</td>
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<tr>
<td>Total Current Assets</td>
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<td>440,767</td>
<td>954,518</td>
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<tr>
<td>Non Current Assets</td>
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<td>Total Non Current Assets</td>
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<td>983,567</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
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<td>1,539,792</td>
<td>1,948,079</td>
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<tr>
<td><strong>NET ASSETS</strong></td>
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<td>1,948,079</td>
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<td><strong>EQUITY</strong></td>
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<tr>
<td>Accumulated Funds</td>
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<td>1,539,792</td>
<td>1,948,079</td>
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<tr>
<td><strong>TOTAL EQUITY</strong></td>
<td></td>
<td>1,539,792</td>
<td>1,948,079</td>
</tr>
</tbody>
</table>

I certify that the Income Statement and Balance Sheet of the Foundation have been prepared in accordance with the University’s accounting practices and procedures. These Foundation accounts form part of the University of Sydney’s financial reports.

Petunis Sweeney
Finance Director
Faculty of Health
February 21, 2018
Benefactors
With Special Thanks to our Benefactors and Supporters in 2017 who so generously donated individually or in association with SEBA

- Sydney Executive Business Association (SEBA)
- Ms Alison Chow-Barton
- Mr Jimmy Liu
- Ms Pauline Chan
- Ms Miriam Cheung
- The Hon. Mr John Dowd AO QC
- Mr Ernie Friedlander
- Mr William Hsu
- Miss A. Miu
- Mr Graham Steel

We again thank the Brain & Mind Centre of the University of Sydney for providing research facilities for many NRF associated researchers and the Charles Perkins Centre and Australian Centre for Microscopy and Microanalysis for research facilities related to the PhD project of Ambrose Chan.