CJD SUPPORT GROUP NETWORK

10th Annual National CJD Conference

Jasper Hotel – Melbourne, Victoria

Friday 17th November 2017
2.30pm to 5.30pm
Genetic Family Meeting – Room 3-4 Upper level – Jasper Hotel

Saturday 18th November 2017
8.30am
Welcome refreshments and registration
8.45am – 5.30pm
10th Annual National CJD Conference – Function Hall

Keynote Speakers
Professor John Collinge, UK
Professor Robert Will, UK
Associate Professor Brian Appleby, USA
Associate Professor Gianluigi Zanusso, Italy

Saturday 18th November 2017
7.00pm to 11.00pm
Conference Dinner – Room 8 Upper Level

CJD SUPPORT GROUP NETWORK

The CJD Support Group Network (CJDSGN) is a national non-profit organisation offering support, information and assistance to:

Individuals at 'increased risk of developing CJD' their family members and friends.

Patients suffering with suspected CJD or other prion diseases, their family members and friends.

Call: National Toll Free Number 1800 052 466

Email: contactus@cjdsupport.org.au

Website: www.cjdsupport.org.au

We provide:
24 hour help line.
Information package for families.

Information package for health care professionals: including our handbook on patient care – DVD 'Understanding CJD'.

We also offer:

A national education and awareness program including free presentations and in-services for hospitals and facilities.

An Annual National CJD conference.

We connect family members to share experiences and provide mutual support.

We assist families to fundraise to support CJD Research in Australia.

To donate:
http://www.cjdsupport.org.au/fundraising/donate-online/

SATURDAY 18TH NOVEMBER 2017

Pre-function
Foyer – ground floor

8.30am

Welcome refreshments
Conference registration
Poster Displays

Function hall

8.45am

Suzanne Solvyns
Director, CJD Support Group Network
Co-chair of the CJD International Support Alliance
Welcome

SESSION 1

Prion Diseases
Chair – Professor Steven Collins
Director of the Australian National CJD Registry (ANCJDR)
Medical Director of the CJDSGN
Neurologist and Principle Research Fellow, University of Melbourne, Victoria

9.00am – 9.30am

Associate Professor Brian Appleby
Director of the National Prion Disease Pathology Surveillance Center at Case Western Reserve University, Cleveland, USA

"Overview of human prion diseases"

Q & A – 9.30am – 9.35am

9.35am – 10.05am

Professor Robert Will
Clinical neurologist, Department of Clinical Neurosciences, Western General Hospital Edinburgh, UK

"Why do people get CJD?"

Q & A – 10.05am – 10.10am

10.10am – 10.40am

Associate Professor Gianluigi Zanusso
Associate Professor in Neurology, University of Verona, Italy

"New perspectives in Creutzfeldt-Jakob disease diagnosis"

Q & A – 10.40am – 10.45am

10.45am – 11.05am

Morning Tea
Poster Displays

SESSION 2

Prion disease – Research into treatment options
Chair – Professor Andrew Hill
Head Department of Biochemistry and Genetics, Director, RFA Understanding Disease,
La Trobe University, Victoria

11.05am – 11.15am

Brian Appleby
"Overview of prion disease treatment"

11.15am – 11.25am

Doxycline
Gainluigi Zanusso
"Presymptomatic treatment in subjects at risk of developing FFI"

11.25am – 11.55am

Professor John Collinge
"Progress towards effective treatment for prion infection and disease"
Professor of Neurology and Head of the Department of Neurodegenerative Disease at the UCL Institute of Neurology, Director of the UK Medical Council's Prion Unit, London UK

Q & A 11.55am – 12.10pm

SESSION 3

CJD Surveillance, Diagnostics and PRNP Genetic testing in Australia
Chair – Associate Professor Victoria Lawson
University of Melbourne, Victoria
Head, Lawson Research Group, University of Melbourne

12.10pm – 12.30pm

Professor Steven Collins
Director of the Australian National CJD Registry
Medical Director of the CJDSGN
Neurologist and Principle Research Fellow, University of Melbourne, Victoria

"Australian Human Prion Disease: update and some related research activities".

12.30pm – 12.50pm

Professor Martin Delatycki
Clinical Director, Victorian Clinical Genetics Services, Melbourne, Victoria

"PRNP genetic testing for families in Australia"

Q & A – panel 12.50 – 1.00pm
Professor Steven Collins
Professor Martin Delatycki

1.00pm – 2.00pm

Lunch
Poster Displays

SESSION 4

The human side of prion diseases
Chair – David Ralston
Chair, Management Committee
The CJD Support Group Network

2.00pm – 2.05pm

CJDSGN Awards – Suzanne Solvyns
CJDSGN Awards – Acknowledging special people who have become champions for all affected by prion diseases. Thank you for your commitment and passion!

Professional's stories of being touching by prion diseases

2.05pm – 2.20pm

Jennifer Cooke
Journalist /Editor
The Hotel California

2.20pm – 2.35pm

Michelle Gentle CN

"Dealing with an at Increased Risk Patient"

2.35pm to 2.50pm

Debra Scott GP

'Caring for a suspected CJD patient"

Q & A 2.50pm – 3.00pm

3.00pm – 3.15pm

Personal Stories

We thank the following family members who have experienced the devastating journey of dealing with a loved one with CJD or other prion disease. Thank you for your dedication to others and your commitment to make a difference and promote awareness of this rare and always fatal disease.

Catherine Grasso
Kate Duckworth

3.15pm – 3.25pm

Suzanne Solvyns

"The CJD International Support Alliance and the faces of those we represent"

3.25pm – 3.45pm

Afternoon Tea

SESSION 5

Supporting our prion researchers in Australia
Chair – Dr Simon Drew
Senior Research Fellow, University of Melbourne, Victoria

3.45pm – 4.30pm

Suzanne Solvyns – Introduction
"And so I ran……." Team Prion – City2Sea 2017

What you, the families and friends of CJD patients have contributed to our research teams: Overview of memorial donations in 2016-2017.

CJDSGN Memorial Grants, Awards and equipment purchases for 2017 – Total $134,000

Research funding reports for 2017 – 2018

CJDSGN Memorial Grants to Hill Laboratory, Department of Biochemistsry Genetics LIMS, La Trobe University, Melbourne, Victoria.
Reported by Professor Andrew Hill, Dr Lesley Cheng and Cathryn Ugalde.

Project: miRNA Analysis in human prion disease.
$51750 – CJDSGN Memorial Grant in memory of Lorraine Seabrook

Consumables for above project
$5000 – CJDSGN Memorial Grant in memory of Frank Burton

Equipment for above project (cell counter)
$4210 – CJDSGN Memorial Grant in memory of Norma Crawley

PhD Scholarship for Cathryn Ugalde – 2017
$14804 – CJDSGN Memorial Scholarship in Memory of Frank Burton

PhD top-up Scholarship for Cathryn Ugalde – 2017
$3250 – CJDSGN top-up scholarship in memory of David Matthews

CJDSGN Memorial Grants to Lawson Research Laboratory at the University of Melbourne
Reported by Associated Professor Victoria Lawson and Laura Ellett

Project: 'Mouse model of sporadic CJD'
$40,000 – CJDSGN Memorial Grant in memory of Frank Burton

PhD top-up Scholarship for Laura Ellett – 2017
$5000 – CJDSGN top-up scholarship in memory of Frank Burton

CJDSGN Memorial Scholarships to Collins Laboratory at the University of Melbourne
Reported by Abu Mohammed Taufiqual Islam and Simote T Foliaki

Carol Willesee PhD Scholarship $5000 – 2017 – Awarded to Taufiqual Islam

Poppy's Crusade PhD Scholarship $5000 – 2017– Awarded to Simote Foliaki

Announcement of funding grants to be awarded in 2018

4.30pm – 5.30pm

Round Tables
An opportunity to speak with individual speakers and experts

International Speakers

Professor John Collinge

John Collinge is Professor of Neurology and Head of the Department of Neurodegenerative Disease at the UCL Institute of Neurology. He is also Director of the UK Medical Research Council's Prion Unit, a highly multidisciplinary research unit focussing on human prion disease, and leads the National Prion Clinic at the National Hospital for Neurology and Neurosurgery in London. His laboratory demonstrated in 1996 that the new human prion disease, variant CJD, was caused by the same prion strain as that causing BSE in cattle and has made many of the key contributions to understanding the prion diseases since 1989. In addition, he has made wider contributions in the genetics of neurodegenerative disease, including frontotemporal dementia, Alzheimer's disease and motor neurone disease. He has a particular interest in therapeutics of prion and Alzheimer's disease and is developing both small molecule and immunotherapeutics. He has a major interest in the wider implications of prion-like mechanisms and their relation to the accumulation and toxicity of misfolded host proteins in neurodegeneration. More detail on his research can be found at www.prion.ucl.ac.uk. He is a Fellow of the Royal Society, a Founder Fellow of the UK Academy of Medical Sciences, an Inaugural Senior Investigator of the Faculty of the National Institute for Health Research and an Honorary Fellow of the American Neurological Association. He was awarded a CBE by HM the Queen for services to medical research.

Professor Robert Will

Professor RG Will is a clinical neurologist who works at the Department of Clinical Neurosciences, Western General Hospital Edinburgh, UK. He has a long-term interest in Creutzfeldt-Jakob disease, having carried out a research project on the epidemiology of CJD from 1979-1982 and having founded the National CJD Surveillance Unit, UK in 1990 and acted as its Director for 10 years.

He has written a number of papers on CJD and was involved in the identification and characterisation of variant CJD and the discovery that this condition was transmissible through blood transfusion. He currently coordinates the European and Allied Countries Surveillance System for CJD, while continuing to work at the UK surveillance unit.

At Prion 2007 in Edinburgh, Professor Will attended the second CJD International Support Alliance meeting and became a founding member of the Friends and Advisory Group of the CJD International Support Alliance.

Brian S. Appleby, M.D.

Dr. Appleby is a neuropsychiatrist with clinical and research interests in prion diseases (e.g., Creutzfeldt-Jakob disease) and young-onset dementias.

Dr. Appleby received a B.A. in biology and philosophy from Goucher College and a M.D. from Georgetown University School of Medicine. He completed a psychiatry residency at The Johns Hopkins Hospital, where he also completed a geriatric psychiatry fellowship. Following his training, he founded and directed the Johns Hopkins Creutzfeldt-Jakob Disease (CJD) Program and was co-director of the Frontotemporal Dementia and Young-Onset Dementia Clinic. He joined University Hospitals-Cleveland Medical Center in 2013 and is Associate Professor of Neurology, Psychiatry, and Pathology at Case Western Reserve University School of Medicine. He is Director of the National Prion Disease Pathology Surveillance Center at Case Western Reserve University and Medical Director of the CJD Foundation and a member of the CJD International Support Alliance Friends & Advisor Group.

Gianluigi Zanusso, M.D., Ph.D.

Dr. Gianluigi Zanusso graduated *cum laude* in Medicine and Surgery in 1990 and obtained the board in Neurology *cum laude* in 1994. He received his Ph.D. degree in Neuroscience in 1999. From 1995 to 1998, he attended a postdoctoral training at the Department of Neuropathology, Case western Reserve University, Cleveland, OH, USA. Since 2014, he held the position of Associate Professor in Neurology at the University of Verona.

Human and animal Prion disorders are his primary research field focusing on intravital diagnostics. In 2003, he reported on the involvement of olfactory pathway in sporadic Creutzfeldt-Jakob disease (sCJD). In 2004, in a collaborative study, he identified a sporadic form of bovine spongiform encephalopathy (BASE). In 2007, described a novel subtype of sCJD. In 2014, he set up a new test for intravital diagnosis of sCJD using nasal brushing. Dr Gianluigi is a member of the CJD International Support Alliance Friends and Advisor Group.

Australian Prion Disease Researchers and Experts

Professor Steven Collins

Steven Collins is a neurologist who is Director of the Australian National Creutzfeldt-Jakob Disease Registry (ANCJDR), as well as Professorial/Senior Principal Research Fellow in the Department of Medicine, the University of Melbourne and a National Health & Medical Research Council Practitioner Fellow. Professor Collins is also appointed to the Department of Clinical Neurosciences and Neurological Research, St Vincent's Hospital, Melbourne, where he heads the Mitochondrial & Autoimmune Neurological Disorders diagnostic laboratory, a NATA accredited, national referral service. After graduating from the Faculty of Medicine, the University of Melbourne, in 1982, he undertook clinical neurological training in Melbourne and Adelaide before undertaking post-graduate research studies in mitochondrial diseases, followed by post-doctoral fellowships in clinical neurology at the Mayo Clinic, Rochester Minnesota USA and electromyography at the University of Western Ontario, London, Ontario, Canada. Stemming from his role as Director of the ANCJDR, he holds or has held membership in a number of national committees (most notably, the Transmissible Spongifrom Encephalopathy Advisory Committee) advising on a range of issues, including clinical and infection control matters for CJD and related disorders. The ANCJDR is the national referral service for diagnostic testing of prion diseases, including CSF for 14-3-3 proteins and in 2014 this and Alzheimer Disease CSF biomarker testing was subsumed under the NATA accredited National Dementia Diagnostics Laboratory, of which Professor Collins is co-director. Since 1997, Professor Collins has overseen, coordinated and represented the participation of the ANCJDR in a large international CJD surveillance consortium (EUROCJD). Through the ANCJDR Professor Collins undertakes both epidemiological and basic scientific research into prion diseases and supervises a number of post-doctoral fellows and PhD students. In addition, Professor Collins undertakes translational research into Alzheimer's disease as well as participates as principal investigator in Alzheimer's disease clinical trials.

In 2008 Professor Collins became a member of the Friends and Advisory group of the CJD International Support Alliance and in 2009 he took on the role as Medical Director of the CJD Support Group Network assisting the network to support CJD families in Australia

Professor Andrew Hill

Professor Andy Hill gained his BSc(Hons) in Biochemistry and Molecular Biology from Victoria University of Wellington in New Zealand and his PhD at Imperial College, London. He held post-doctoral positions in the MRC Prion Unit (London) and in the Department of Pathology at the University of Melbourne as a Wellcome Trust Prize Travelling Research Fellow. Andy joined the Department of Biochemistry and Molecular Biology at the University of Melbourne in 2002 and moved his lab into the Bio21 Institute when it opened in 2005. In 2015, Andy moved his laboratory to the La Trobe Institute of Molecular Sciences (LIMS) at La Trobe University where he is also Head of the Department of Biochemistry and Genetics.

Andy has held a National Health and Medical Research Council (NHMRC) Senior Research Fellowship and an Australian Research Council Future Fellowship (Level 3). He has been the recipient of several awards and prizes including a Victorian Young Tall Poppy Award in 2006, and the Edman Award (2005) and, in 2010, the Merck Research Excellence Medal from the Australian Society for Biochemistry and Molecular Biology. In 2014 Andy became a member of the Friends/Advisors Group of the CJD International Support Alliance. In 2016 Andy was elected President of the International Society of Extracellular Vesicles (ISEV) which is a research area his group has used in the study of prion disease.

Associate Professor Victoria Lawson

Victoria Lawson is an Associate Professor in the Department of Pathology at the University of Melbourne, with over 20 years' experience in investigating how infectious agents are transmitted and cause diseases such as AIDS and prion disease.

Her research has identified regions of the prion protein that are essential for the protein misfolding that defines the disease and the contribution glycosylation has in this process. She has identified evidence of disease in peripheral tissues of animals affected with prion disease and been involved in studies that are using new imaging paradigms to detect disease in the central nervous system, which will aid in the development of treatments. Her research was instrumental in the validation of a surgical instrument cleaning product which is now used by many hospitals in Australia to reduce the risk of prion disease transmission through surgery.

Professor Martin Delatycki

Professor Martin Delatycki studied medicine at the University of Melbourne before completing his paediatric training at The Royal Children's Hospital. He went on to train in clinical genetics at the Victorian Clinical Genetics Services followed by a PhD studying the nervous system disease Friedreich ataxia at the Murdoch Childrens Research (MCRI). He is currently Medical Director or Victorian Clinical Genetics Services and Co-Director of the Bruce Lefroy Centre at MCRI.

Dr Simon Drew

Simon Drew's research aims to characterise the properties of proteins involved in neurodegenerative diseases, including their interaction with metal ions, cell membranes and free radicals. By first studying model systems in detail, hypotheses are generated regarding biological function that can be tested in cell and animal models. He graduated with a PhD in physics in 2002, followed by postdoctoral research in medical imaging (2002–2004) and biological chemistry (2004–2006) at the University of Queensland. From 2006–2009 he worked as research fellow in the Department of Pathology, The University of Melbourne, then as a research fellow at the Max Planck Institute for Bioinorganic Chemistry, Germany from 2010-2011. Since 2012, he has headed a biophysics laboratory at the University of Melbourne. His interests in prion disease focus on development of neuroimaging contrast agents and identifying spontaneous prion generation by free radical mechanisms that may be of relevance to sporadic CJD.

Dr Victoria Lewis

Vicki has had a keen interest in prion diseases since 2000, when she got her first job as a research assistant (RA) for the ANCJDR. As an RA Vicki ran various diagnostic tests and collaborative research projects, and it was during this time that she decided to undertake a PhD in prion research. Under the supervision of Steve Collins, Vicki Lawson and Andrew Hill, Vicki's PhD focused on understanding the nature of infectious prion species and prion disease susceptibility. Nearing the end of her PhD studies Vicki was lucky enough to be awarded a prestigious NHMRC CJ Martin Fellowship, which allowed Vicki to carry out research overseas, based at the University of Leeds (UK), and then return to Australia to continue her work. Since her return, Vicki has been awarded a University of Melbourne Early Career Researcher Grant (2013) and a CJDSGN Memorial Award (2015), and has presented her research findings at various national and international conferences. Vicki is currently a Research Fellow in the Department of Medicine, RMH, and the University of Melbourne. As well as co-supervising two PhD students, Vicki continues to have strong research interests in prion protein proteolytic cleavage, and the relevance of these events to normal prion protein function and prion diseases. Over the last 15 years Vicki has made significant contributions to prion research, in particular to the areas of prion disease epidemiology and diagnostics, prion strain pathogenesis and prion protein proteolysis.

Vicki was awarded a 2016 $25,000 CJDSGN Grant 'CJDSGN Memorial Grant in memory of: Sandra Kernahan, Stephen (Jake) O'Hara, Catherine Heagerty, Grasso family, Victoria Larielle, Barbara Childerhouse, Marilyn Hart and Pamela Thomas (City2Sea)'.

Dr Lesley Cheng

Dr. Lesley Cheng is presently a Postdoctoral researcher at the La Trobe Institute for Molecular Science (LIMS), La Trobe University. She is working towards developing a minimally invasive blood test for the early detection and monitoring of neurodegenerative diseases such as Alzheimer's disease, Parkinson's disease and Prion disease. She uses next-generation sequencing to profile small RNA molecules isolated from extracellular vesicles called 'exosomes' that travel in the bloodstream and are used as a source of disease indicators.

Ms Laura Ellett

Research Assistant, Department of Pathology, The University of Melbourne.Laura has eight years of experience in prion research. She has worked as a Research Assistant under the supervision of Associate Professor Victoria Lawson since 2008. She graduated from a Bachelor's Degree with honours in Biochemistry at La Trobe University in 2007.

Abu Mohammed Taufiqual Islam

Abu Mohammed Taufiqual Islam is currently doing a PhD under Professor Steven John Collins research group in Dept. of Medicine (RMH), The University of Melbourne. His PhD project is focused on characterizing the prion neurotoxicity by using Biochemical, Electrophysiological, and Biophysical technique. He did his masters major in Neurodevelopmental Biology from Department of Systems Immunology College of Bio-Medical Science, Kangwon National University, Republic of Korea. In his bachelor, he successfully finished Bachelor of Pharmacy (Hons.) from Department of Pharmacy, International Islamic University Chittagong, Bangladesh.

Taufiqual was the recipient of the 'CJDSGN Memorial PhD Scholarship in memory of Sandra Kernahan (2016).

Simote T Foliaki

Simote T. Foliaki is from Tonga. Simote graduated with BSc (Hons) in animal science from the East-West Center at the University of Hawaii.

He is currently a third year Ph.D. student at the University of Melbourne. Simote's Ph.D. project is to assess the acute synaptotoxicity of misfolded prion proteins using an electrophysiological paradigm.

Simote was selected to give an oral presentation at Prion 2016 in Tokyo Japan and was awarded the 'CJDSGN Travel Award in memory of Silva Coelho (2016) to assist with travel costs to this international event.

Cathryn Ugalde

Cathryn is a PhD student in the Department of Biochemistry and Molecular Biology at The University of Melbourne where she is supervised by Professor Andy Hill, Associate Professor Vicki Lawson and Associate Professor David Finkelstein. For her project, Cathryn studies how misfolded proteins, such as prions, damage brain cells and how we can target these neurotoxic pathways for therapeutic intervention. A large component of her project has been to develop a new way to study cell death using organotypic brain slice cultures.

Cathryn was the 2016 recipient of the Carol Willesee PhD scholarship. Earlier this year, Cathryn presented some of her work at the conference *'Common Mechanisms of Neurodegeneration'* in Colorado, U.S.A and conducted several lab visits to prion research institutes including the Centre of Prions and Protein Folding Diseases in Alberta, Canada. For her travels Cathryn was awarded the 'CJDSGN Travel Award in memory of Silva Coelho (2016).

Jennifer Cooke

Jennifer Cooke is an award-winning journalist and author who has worked in Sydney, Hong Kong and Washington DC over the last 35 years for newspapers including the Sydney Morning Herald and the South China Morning Post. She also worked on the Secrecy for Sale probe into tax havens for the International Consortium of Investigative Journalists in the United States.

Her first book, Cannibals, Cows & the CJD Catastrophe, won the 1999 Eureka Science Book Prize. She has co-authored two other books in the true crime genre and edited a newsmagazine for general practitioners. She would really like to write a romance novel, if only she could find the time.

Jennifer has befriended and assisted people at risk of CJD for 25 years now and is also a founding member of the CJD International Support Alliance Friend and Advisor Group.

Michelle Gentle

Michelle is currently Clinical Nurse and Evening Coordinator in the Neuro Sciences Unit of Mater Private Hospital in Brisbane.

With over 35 years' experience in nursing generally and theatre in particular she brings a wealth of hands-on experience to her talk today.

She has worked in theatre setting across many disciplines including maternity, ENT and neurosciences.

Over the time in Neuro surgery she has seen many innovations, many developments and many new issues and concerns arise.

Debra Scott

Debra Scott is a General Practice Registrar, having recently finished College Fellowship examinations. She works in the Southern Highlands, Bowral, NSW in clinical practice. Debra completed a Bachelor of Science (Advanced Biology), majoring in physiology and psychology, through Macquarie University and completed her MBBS through Sydney University (2008). She has worked in many hospitals around NSW, spent 6 months as a Radiation Oncology Registrar at St George Hospital and has obtained a Diploma in Child Health. Debra will be completing dual specialty training, commencing Palliative Medicine Advanced Training in 2018 and plans to complete a PhD in Neurology in the future.

CJD Support Group Network – Committee

Suzanne Solvyns

Director, CJD Support Group Network

Suzanne first heard about Creutzfeldt-Jakob disease (CJD) in the early 90's, when a media report announced that 2100 Australians, who had been treated with human pituitary hormones for infertility and short statue, were now at an increased risk of developing CJD. This followed the deaths of four women who had died from Iatrogenic CJD due to contaminated pituitaries in batches of human pituitary hormones in Australia.

Suzanne became a founding member of the CJD Support Group Network (CJDSGN) in 1993 as NSW Co-coordinator and in 2004 was appointed Director. She was instrumental in the expansion of the network to offer support and assistance to all Australians affected by prion diseases.

Since early 2008, conducting a national education program has helped to educate health care professionals about CJD and other prion diseases, promote the work of the CJDSGN and emphasise the need of CJD patients and their families as well as the need for equity of care for at risk patients.

When the CJD International Support Alliance (CJDISA) was formed in 2006, Suzanne took on the role as co-chair of the alliance, a role that today still provides the opportunity to work with like organizations around the world and network with researchers and experts who are members of the 'Friend and Advisor Group' of the CJDISA.

David Ralston

Chair, The Management Committee of the CJD Support Group Network

At the age of 15, David was referred by his family doctor to the Endocrine Clinic at a large Sydney hospital after it was observed that he was much shorter than his younger brother, and very short for his age. After a lengthy series of tests, David was approved to receive injections of human growth hormone (hGH). Fortunately for David, he responded very well to the treatment, appeared to have no side effects and was able to pursue his passion for sport and eventually his university studies.

In 1992, David received a letter from the National Department of Health advising him to consult the treating doctor who supervised his hormone treatment. At this meeting David was informed that some of the human hormone product that was used in the program had been contaminated, and several Australians had died as a consequence of their treatment. As a result, David was at increased risk of developing CJD. This not only caused David great concern, but the news was also very worrying to his parents who gave consent for his treatment all those years before, thinking at the time that they were doing the right thing.

David attended support group meetings in Sydney in an effort to find out more about CJD, a disease about which very little was known at that time. As a result of attending these support meetings, opportunities arose to participate in other state and national meetings and David was appointed as a recipient member of the National Pituitary Hormone Advisory Council, advising the Minister of Health and Ageing at a national level.

When the CJD Support Group restructured and expanded its role in 2004, from supporting people who were at risk of CJD through hormone treatments to providing support for Australians affected by all types of CJD, David joined the management committee. David, a secondary school teacher, and his wife Lynne have four daughters and live in Sydney.

In a voluntary capacity, David acts as Chair of the Management Committee of the CJD Support Group Network and assists Suzanne Solvyns in her role as director. David is also a member of the CJD International Support Alliance as a representative of the CJD Support Group Network – Australia.

Gail Glasscock

Committee Member, CJD Support Group Network

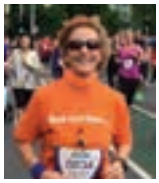
Gail Glasscock lost her husband Ross in December 2008 after he was diagnosed with suspected CJD. Until that time she had no knowledge of CJD apart from the media coverage in the 1990's when the world became aware of the variant form of CJD, commonly referred to as 'Mad Cows Disease'.

When all tests indicated that Ross was suffering with CJD, her knowledge soon grew. His diagnosis was a very slow process but once suspected CJD was the diagnosis she became aware of classical CJD and the various forms it may involve. After autopsy results confirmed that Ross had died of CJD, Gail was anxious to know as soon as possible if he had suffered with a genetic form of CJD as Ross and Gail have three children. If so, the related implications of this for the children and other family members became a primary concern for the whole family.

She was fortunate to have access to prompt genetic testing through a genetic service. The service ruled out a genetic cause within 2 weeks. This timely process, along with the support offered by the service was invaluable. Hopefully the future involvement of genetic services will make both support and counselling readily available to all families when needed.

Gail is currently a committee member of the CJD Support Group Network as a representative of families affected by sporadic CJD.

Josephine Farlekas



Committee Member, CJD Support Group Network

Josephine Farlekas is married with two children and four grandchildren.

She first found out about CJD when her father passed away in 1992. At the time not a lot of information was available about this disease and nothing was mentioned about familial CJD. Over the next few years other members of her extended family passed away after suffering with CJD and that is when the family realised that they were dealing with the genetic form of the disease.

In 2005 her eldest brother passed away also from CJD and she started to think seriously about having the genetic testing done to find out if she carried a genetic mutation. Finally in 2009 she made the decision to be tested and when the test results came back as positive for the mutation of E200K she actually felt a sense of relief that she could stop thinking about it and get on with her life.

In 2012 her second brother shared with her that he was suffering with memory loss and feared that he may in the early stages of CJD. Sadly he passed away in June 2012 and in 2014 she lost a first cousin also to familial CJD. This brings the number of deaths to this terrible disease to nine for Josephine and her family.

Although at times Josephine finds it a challenge living with this monster lurking in the dark, she loves her life and is determined to enjoy every precious moment.

Josephine is currently a committee member of the CJD Support Group Network as a representative of genetic family members.

We would also like to acknowledge the following people who have also assisted and contributed to the success of this conference

Lauren and Lillian Ralston

Brandon Solvyns

Catherine Grasso

Kate Duckworth

The CJD Support Group Network is a registered charity supporting the work of the CJD research teams in Australia.

The CJD Support Group Network would like to thank the families and friends of those affected by CJD and other prion diseases for your continued and generous donations in memory of loved ones lost to this devastating group of prion diseases.

Your amazing support is very much appreciated by the CJDSGN, the ANCJDR and the research teams in Australia.

#seaoforange #goteamprion

The CJDSGN acknowledges the funding provided by the Department of Health that assists toward the cost of this conference.

We would like to acknowledge sponsorship for this event and on-going funding support for prion disease research in Australia provided by Mr Graham Murray and his company, Australian Animal Care Systems Pty Ltd, in memory of his daughter 'Silva Coelho".