



SUPPORT  
GROUP  
NETWORK

## 12th Annual National CJD Conference

Jasper Hotel – Melbourne, Victoria

**Friday 25th October 2019**

2.30pm - 5.30pm

Genetic Family Meeting - Room 9 - Upper Level - Jasper Hotel

**Saturday 26th October 2019**

8.30am - 5.30pm

12th Annual National CJD conference  
Function Hall - Ground Floor - Jasper Hotel

### Keynote Speakers

Professor Brian Appleby, Cleveland, USA  
Professor Steven Collins, Melbourne, Australia  
Professor Catriona McLean, Melbourne, Australia

**Saturday 26th October 2019**

7.30pm - 11.00pm

Conference Dinner - Function Hall  
Ground Floor - Jasper Hotel





**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](mailto:contactus@cjdsupport.org.au)**

**Website: [www.cjdsupport.org.au](http://www.cjdsupport.org.au)**

**We provide:  
24 hour helpline**

**Information package for families**

**Information package for health care professionals:**

**Including our handbook on patient care and a DVD 'Understanding CJD'**

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**We also offer:**

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

**An Annual National CJD conference**

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**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 26TH OCTOBER 2019**

**Pre-function**

**Foyer – ground floor**

**8.30am**

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**Welcome refreshments**  
**Conference registration**

**Function Hall**

**8.45am**

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**Suzanne Solvyns**

Director, CJD Support Group Network - Co-chair, CJD International Support Alliance

**Welcome – Opening comments**

**Memorial Wall**

## **SESSION 1**

### **Prion Diseases**

**Chair – Associate Professor Victoria Lawson**

Department of Microbiology and Immunology, in the School of Biomedical Sciences at The University of Melbourne, Victoria

**9.00am – 9.30am**

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**Professor Brian Appleby**

Director, National Prion Pathology Surveillance Center (NPPSC) USA

“An overview of prion disease”

Q & A - 9.30am - 9.35am

**9.35am – 10.30am**

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**Surveillance and diagnostic updates for Australia**

“The work of the Australian National CJD Registry (ANCJDR)”

**Panel**

**Professor Steven Collins**, Director, ANCJDR

**Professor Catriona McLean**, Neuropathologist, ANCJDR

**Dr Christiane Stehmann**, Coordinator, ANCJDR

**Dr Matteo Senesi**, Research Fellow, ANCJDR

**Dr Victoria Lewis**, Research Fellow, ANCJDR

**Shannon Sarros**, Administration assistant, ANCJDR

**Amelia McGlade**, Research Assistant, ANCJDR

**Dr Christiane Stehmann**

“History and function of the ANCJDR, diagnostics and surveillance methods”

**Dr Matteo Sensi**

“Introduction to the functions of the laboratory, diagnostic tools”

**Professor Catriona McLean**

“Neuropathology - overview of diagnostic and research purposes”

## **Professor Steven Collins**

“Surveillance and prion disease research in Australia”

### **Acknowledgement of memorial donations – ANCJDR**

2018 CJDSGN Memorial donation to ANCJDR for the purchase of an additional freezer \$12490 in memory of Judith Liauw, Douglas Brown, Catherine Heagerty and Shirley Joiner

2019 CJDSGN Special Travel Memorial Award to Dr Christiane Stehmann in memory of Robert Sisson, Chris Hausler, Pamela List, Audrey Marshall and other loved ones lost to CJD

2019 CJDSGN Memorial donation to the ANCJDR for the purchase of an additional FLUOstar Omega for RT-QuIC \$35,600 ‘CJDSGN donation in memory of Mario Papalia’

Q&A - 10.30am - 10.40am

**10.40am - 11.00am**

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**Morning Tea**

**Poster Display**

## **SESSION 2**

### **Update on diagnostic and treatment options**

**Chair: Professor Steven Collins**

Neurologist, Research Fellow, University of Melbourne

**11.00am - 11.30am**

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**Professor Brian Appleby**

“Prion Disease: Diagnosis & Treatment”

Q & A 11.30am - 11.35

**11.35am - 11.45am video**

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**Update from Eric Minikel and Sonia Vallabh**

Broad Institute, Boston USA

“The path to an ASO drug for prion disease”

**11.45am - 11.55am video**

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**Patrick Cauntay**

Assistance Director, Patient Advocacy, Ionis USA

Report on ASO for prion disease

Q & A 11.55am - 12.00pm

**12.00pm - 12.05pm**

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**Update on PRN 100 drug being conducted by Prion Unit, London**

(Human antibody manufactured from the mouse antibody)

**12.05pm - 12.15pm**

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**Dr Chistiane Stehmann**

Coordinator, Australian National CJD Registry (ANCJDR)

“Advancing MRI to improve the detection and accuracy of early prion disease diagnosis”

**Project to be funded by family donations as a CJDSGN Memorial Award of \$50,000**

12.15pm - 12.35pm

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**Dr Gi Tae Kwon**

General Medical Registrar at ACT Health Network

“A neurologist’s view on the challenges of diagnosing prion disease”

Q & A 12.35 - 12.40

**SESSION 3**

**CJDSGN**

**Chair: David Ralston**

Chair of Management Committee, CJDSGN

12.40pm - 1.00pm

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**Suzanne Solvyns**

The CJD Support Group Network - Our structure and purpose

The CJD International Support Alliance

**CJDSGN Awards**

To acknowledge and thank special people who are champions for all affected by prion diseases

**Personal Stories**

1.00pm - 2.00pm

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**Lunch**

**Poster Display**

**SESSION 4**

**CJD and infection control**

**Chair: Joe-anne Bendall**

Infection control advisor, CJDSGN - Infection control consultant, Review

2.00pm - 3.00pm

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**Panel**

**Suzanne Solvyns**

**Donna Cameron**, Infection Control Consultant  
Department of Health and Human Services, Victoria

**Associate Professor Victoria Lawson**

**Professor Steven Collins**

**Michelle Strong**, an at increased risk of CJD patient

**Suzanne Solvyns**

Introduction

**Joe-anne Bendall**

Overview

**Michelle Strong**

Issues for ‘at risk patient ‘ accessing surgery

**Donna Cameron**

Role of health departments

**Associate Professor Victoria Lawson**

Advancements in decontamination detergents

**Professor Steven Collins**

Management of CJD Risk Working Group

**Joe-anne Bendall**

Practical Handbook for CJD infection control guidelines - Revision of infection control guidelines

Q & A

## SESSION 5

### **Report on funding projects and prion disease research in Australia**

**Chair: Professor Andrew Hill**

Head of the Department of Biochemistry and Genetics at La Trobe Institute of Molecular Sciences (LIMS), Melbourne, Victoria

**3.00pm - 4.00pm**

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**Suzanne Solvyns**

How family donations are supporting prion disease research in Australia

#### **Reports on funding grants and awards**

**Dr Victoria Lewis -Collins Laboratory, University of Melbourne**

2018/2019 Memorial Research Award - \$45,000

**'CJDSGN Memorial Award in memory of 'Michael Luscombe'**

Project Title: Matrix metalloprotease mediated prion protein proteolysis: Investigating normal processing and links to prion disease

2019 Memorial Grant - \$55,000

**'CJDSGN 2019/2020 Memorial Grant in memory of Frank Burton'**

**Laura Ellett – Lawson Research laboratory, University of Melbourne**

**2019 Willesee top up PhD Scholarship - \$9400**

**2019 CJDSGN Travel Award in memory of Silva Coelho**

Awarded to Laura Ellett to attend the 2019 Asian Pacific Prion Symposium in Tokyo, Japan

**Dr Cathryn Ugalde – La Trobe University, Melbourne**

2019 Memorial Research Award - \$12560

**'CJDSGN Memorial Award in memory of Fiona Radojev'**

Project Title: Assessing the sensitivity of prion disease-associated exosomal miRNA profiles to therapeutic intervention in organotypic brain slices

2019 Memorial Research Award - \$19476

**'CJDSGN Memorial Award 2019/2020 in memory of Catherine and Michael Heagerty'**

Project title: 'Elucidating the role of non-neuronal brain cells in the pathogenesis of prion disease during'

**Dr Lesley Cheng – La Trobe University, Melbourne (Report by Professor Andrew Hill)**

2019 Memorial Research Award - \$12,000

**'CJDSGN Memorial Award in memory of Adrian Chesterton, Norma Crawley and Danilo Banzon'**

Project Title: Profiling serum derived exosome-associated miRNA as a diagnostic tool for prion disease

## **Wenting Zhao La Trobe University, Melbourne**

### **'CJDSGN Travel Award in memory of Silva Coelho'**

Awarded to Wenting Zhao to attend Prion 2019 in Edmonton, Canada

## **Dr Dhamidhu Eratne –Consultant Neuropsychiatrist, Melbourne Health**

2018 Memorial Research Award - \$57420

### **'CJDSGN Memorial Award in memory of Michael Luscombe'**

Project title: Utility of cerebrospinal fluid neurofilament light chain in Creutzfeldt-Jakob disease

## **Announcement of new applications**

### **Dr Dhamidhu Eratne, Melbourne Health**

2019 Memorial Research Award - \$51,600

### **'CJDSGN Memorial Award in memory of Michael Luscombe'**

Project Title: Utility of blood fluid neurofilament light chain in Creutzfeldt-Jakob disease

## **Associate Professor Victoria Lawson, University of Melbourne**

2019 Memorial Research Award - \$25,000

### **'CJDSGN Memorial Award in memory of Jennifer Duckworth'**

Project title: Treatment of medically relevant prion disease

2019 Memorial Research Award - \$25,600

### **'CJDSGN Memorial Award in memory of Michael John Dempsey'**

(MJD for CJD golf day and dinner)

Project title: The role of co-pathologies in the clinical presentation of prion disease.

2019 Memorial Research Award - \$10,000

### **'CJDSGN Memorial Award in memory of Anne Friswell, Peter Delchau and Pamela Stead'**

Project title: The effect of human strain variation on prevention of prion disease transmission.

**4.00pm - 4.25pm**

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### **Afternoon Tea Poster Display**

**4.25pm - 4.30pm**

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David Ralston - Announcements of round tables

**4.30pm - 5.30pm**

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### **Round Tables**

Health care workers are invited to meet together for discussion time or join families to ask questions of experts

# International Speakers

## Professor Brain Appleby

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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 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 Friend & Advisor Group.

## Eric Minikel and Sonia Vahhabh

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In 2010, Sonia Vallabh watched her 52 year old mother die of a rapid, mysterious, undiagnosed neurodegenerative disease. One year later, Sonia learned that her mother's disease had been genetic prion disease, and that she herself had inherited the causal mutation, making it very likely she would suffer the same fate in 20 years' time. There was no prevention, treatment, or cure available. Despite having no prior training in biology, Sonia and her husband Eric Minikel set out to re-train themselves as scientists and devote their lives to searching for a treatment or cure for her disease. They quit their jobs in consulting, started a scientific blog, began taking night classes and attending conferences, found new jobs in research labs, and eventually enrolled as PhD students in biology at Harvard Medical School. They are now based at the Broad Institute of MIT and Harvard, where they have launched a new therapeutic initiative to discover drugs for prion disease.

# Australian Prion Disease Researchers and ANCJDR Staff

## Professor Steven Collins

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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 Spongiform 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

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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 now the institute Director.

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 in 2019 the Beckman Coulter Discovery Science 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.

## Professor Catriona McLean

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BSc, MBBS, FRCPA, MD, FFSc (RCPA), FAHMS  
Director, Anatomical Pathology, Alfred Health  
Professor, Dept of Medicine CCS, Monash University  
Professor, The Florey Institute of Neurosciences and Mental Health  
Director, Victorian Brain Bank  
Director, Victorian Neuromuscular Laboratory Service

Professor Catriona McLean AO (MBBS, FRCPA, MD, FFSc (RCPA), FAHMS) is Director of Department Anatomical Pathology at Alfred Health, Professor in the Central Clinical School at Monash University, Professorial Fellow at The Florey, Director of the Victorian Neuromuscular Laboratory Service as well as the Director of the Victorian Brain Bank since 2003 and has been involved in brain banking for more than 25 years.

In her voluntary role as the specialist neuropathologist for the Victorian Brain Bank and the Australian National Creutzfeldt-Jakob Disease Registry, Catriona has examined and diagnosed over 2,500 brains consented for research.

Catriona's own research is centred on neurodegenerative diseases, Creutzfeldt-Jakob disease, infectious diseases of the central nervous system, neurotrauma, melanoma, liver cancer, breast cancer and respiratory disease. She has published over 300 scientific papers.

Catriona was appointed an Officer of the Order of Australia (AO) in the Australia Day honour list this year.

## Associate Professor Victoria Lawson

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Victoria (Vicki) Lawson is an Associate Professor in the Department of Microbiology and Immunology, in the School of Biomedical Sciences at The University of Melbourne where she holds a lecturing position in the discipline of Pathology and heads a research group with an interest in transmissible neurodegeneration.

Her research interest is in understanding how protein misfolding in the central and enteric nervous system gives rise to diseases such as prion and Parkinson's diseases, with a focus on diagnosis, treatment and prevention.

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.

Vicki's research group has invested in the development of medically relevant prions which are now being used to test existing and novel methods for diagnosis, treatment and prevention of disease which we hope will improve the lives of patients and their families affected by prion disease.

## Dr Dhamidhu Eratne

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CONSULTANT NEUROPSYCHIATRIST  
DR DHAMIDHU ERATNE BHB MBChB FRANZCP

Dr Dhamidhu Eratne graduated in medicine from the University of Auckland in 2007. After extensive experience in consultation-liaison psychiatry and the psychiatry of old age, he completed his two years of advanced training at the Neuropsychiatry Unit before obtaining his Fellowship of the Royal Australian and New Zealand College of Psychiatrists in 2016. After working as an old age psychiatrist, Dhamidhu was proud to join the Neuropsychiatry Unit in 2017. He is currently completing certificates of advanced training as a fellow in training, in consultation-liaison psychiatry and psychiatry of old age. His interests include young onset dementia, biomarkers, clinical reasoning, education, and the interface between psychiatry, neurology, and the rest of general medicine. As well as his clinical work, Dhamidhu is involved in research of biomarkers in a range of neurodegenerative disease, and is also Research Fellow for a Melbourne Genomics Health Alliance flagship study, investigating the use of whole exome sequencing in complex neurological and neurodegenerative diseases.

## Dr Victoria Lewis

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Vicki has had a keen interest in prion diseases since 2000, when she got her first job as a research assistant (RA) for the ANZJDR. 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. Since completing her PhD, Vicki has continued her prion research, overseas and in Australia, with interests in prion protein proteolytic cleavage, and the relevance of these events to normal prion protein function and prion diseases, presenting her research findings at various national and international conferences. Vicki has been the recipient of an NHMRC Fellowship and University of Melbourne Early Career Researcher Grant, and has been fortunate enough to receive several CJDSGN Memorial Awards/Grants. Vicki is currently a part-time Research Fellow in the Department of Medicine, (RMH) at the University of Melbourne, and has also returned to where it all started, working part-time for the ANZJDR, again involved in aspects of diagnostic testing and collaborative research. Over the couple of decades 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 has been supported by the following CJDSGN awards:**

**In 2015 Vicki received a \$20,000 'CJDSGN Memorial Grant in memory of Ross Glasscock, Robert Craig, Carmelo Tripoli, Arthur Schinck and Arlene Hamilton and a travel award in memory of Silva Coehlo**

**In 2016 Vicki received a \$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)'**

**In 2018 Vicki was awarded a \$50,000 'CJDSGN Memorial Grant (City2Sea 2016 2017) in memory of Stephen (Jake) O'Hara (Team Jake) Jennifer Duckworth (Team Jenny) and others lost to CJD'**

**In 2018 Vicki was also awarded a \$42,000 'CJDSGN Memorial Award in memory of Michael Luscombe'**

**In 2019 Vicki was awarded a \$55,000 'CJDSGN Memorial Grant in memory of Frank Burton'**

## De Matteo Senesi

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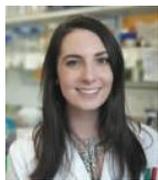


Matteo discovered his passion for neuroscience while studying in Italy through an Experimental Psychology degree at uni. He later joined the Collin's lab in 2011 starting a Doctor of Philosophy (PhD) degree in prion pathology using animal model and behavioural tests to assess the disease progression and how different brain region are affected differently by prions. After spending a year interstate, Matteo returned to the Collins lab in 2017 to run the Australian National CJD Registry diagnostic tests such as the 14-3-3 and RT-QuIC for the diagnosis of prion diseases in cerebrospinal fluid from patients. Matteo received the "International Melbourne Scholarship" to undertake his PhD at the University of Melbourne and received several CJDSGN travel awards to attend scientific conferences and present data derived from his research.

**Matteo received a CJDSGN travel award in 2015 and was awarded a further 2 travel awards to attend international conferences during 2018 in memory of Silva Coehlo. Matteo also received a CJDSGN Special Travel award for RT-QuIC training in Edinburgh in memory of Mario Papalia.**

## Dr Cathryn Ugalde

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Cathryn is a post-doctoral researcher at La Trobe Institute for Molecular Science (LIMS), La Trobe University. She obtained her PhD from the University of Melbourne in 2018 under the supervision of Professor Andrew Hill. During her PhD, Cathryn studied 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 involved developing a way to study neuronal cell death in prion disease using organotypic brain slice cultures. She has extensive knowledge on the mechanisms of protein misfolding in neurodegenerative conditions and has published peer-reviewed articles and presented at national and international conferences in this field.

**Cathryn has been supported by the following CJDSGN awards:**

**In 2016 she received the 'Carol Willesee top-up scholarship award and a CJDSGN travel award in memory of Silva Coehlo.**

**In 2017, Cathryn was the recipient of the CJDSGN Memorial top-up PhD Scholarship in memory of David Matthews and the CJDSGN Memorial PhD Scholarship in memory of Frank Burton. Also, that year, Cathryn presented work at the conference 'Prion 2019' in Edinburgh, Scotland.**

## Dr Christiane Stehmann

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Christiane is the coordinator of the Australian National CJD Registry, responsible for the day to day operations of the group and its interactions with clinicians and patient families.

Christiane graduated from Stuttgart-Hohenheim University, Germany (with honours in biology) and was awarded a PhD from Wageningen University, the Netherlands. Christiane then completed a post doc at University of Melbourne, worked as a Research Scientist at HortResearch in Auckland and then moved into a commercial role with Perkin Elmer managing the high throughput screening and proteomics technologies businesses. A four-year stint with Biotech start up Healthlinx as proteomics laboratory manager further rounded out her business and people skills which she now puts to effective use in her role at the ANCJDR, her most fulfilling role to date.

**Christiane received a CJDSGN Special Travel Award in 2016 in memory of Frank Burton.**

## Laura Ellett

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PhD Candidate and Research Assistant, Department of Microbiology and Immunology, The University of Melbourne.

Laura has over ten 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. She commenced her PhD in 2017 investigating prion strain phenomenon.

**Laura has been supported by the following CJDSGN Awards:**

**In 2016 she received 'CJDSGN Memorial Grant in memory of Susan Maclean, Carmel Petersen, Anne O'Shea, Leslie Cleary, Beryl Hogg, Peter Smith, Sophie Desteno, Pamela Conoulty and Richard Ratliff' which enabled her to continue her research work.**

**In 2017 when Laura began her PhD she was supported by a CJDSGN top-up Scholarship in memory of Frank Burton and in 2018 she received a CJDSGN top-up scholarship in memory of Primo Monaci.**

# Australian Speakers

## Donna Cameron

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**Infection Control Consultant | Communicable Disease Prevention and Control  
Health Protection Branch | Regulation Health Protection and Emergency Management  
Department of Health and Human Services, Victoria**

Donna is an Infection Control Consultant with the Microbiological Diagnostic Unit Public Health Laboratory and Communicable Diseases Prevention and Control Unit at the Victorian Department of Health and Human Services where she provides infection control advice to healthcare facilities and community-based practices, such as beauty therapists and tattoo artists. Among other responsibilities, her role also includes liaising with the Australian National CJD Registry (ANCJDR) for the surveillance of CJD in Victoria and providing infection control advice re CJD to health care facilities as required.

## Dr Ti Gae Kwon

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**BMed MD (UNSW), Postgrad student for Master of Medicine (in Clin. Neurophysiology, USYD)**

Occupation:

Basic Physician Trainee; Currently working as a General Medical Registrar at ACT Health Network

# CJDSGN Committee

## Suzanne Solvyns

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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 stature, 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 organisations around the world and network with researchers and experts who are members of the 'Friend and Advisor Group' of the CJDISA.

Suzanne received an 'Order of Australia Medal' in the 2019 Queen Birthday honour list for her commitment to community health.

## David Ralston

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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. 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 and Ageing 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 retired 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, the Director/National Coordinator. David is also a member of the CJD International Support Alliance as a representative of the CJD Support Group Network - Australia.

## Joe-anne Bendall

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Joe-Anne Bendall has worked in various nursing, management and consultancy positions since 1977. Her infection control career commenced in 1990 and has enabled her to work in private and public hospitals, public health and statewide positions at the NSW Ministry of Health and Clinical Excellence Commission.

Joe first became interested in CJD during her time at the NSW Ministry of Health. She had a rapid learning curve and enjoys supporting Suzanne Solvyns at the CJD Support Group Network.

In 2012, after attending the 5th Annual National CJD Conference, Joe-anne offered her services on a more official basis and was appointed to the Committee of the CJDSGN as an advisor on infection control and since that time has assisted many 'at risk of CJD' patients who have faced discrimination and delays when accessing health care.

Joe is now working as a private consultant on infection prevention and control.

## Gail Glasscock

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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 test 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.

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

Mairin Ummi

Ashley Glasscock

Colleen and Lachie O'Hara

Nadine Solvyns

**The CJDSGN acknowledges the funding provided by the Department of Health that assists towards the cost of this conference**

**We would like to acknowledge and thank the families who work so hard to raise money and those who offer on-going funding support for prion research in Australia**

**Sponsorship for this event provided by Mr Graham Murray and his company, Australian Animal Care Systems Pty Ltd, in memory of his daughter Silva Coelho**



*Dr Dhamidhu Eratne presenting at the Alzheimer's Association International Conference satellite symposium in Sydney - 2019 CJDSGN Memorial Award in memory of Michael Luscombe*





# Still time to join us for the CJD Fun Run 27th October at Emerald Park in Melbourne

CJD Community coming together to promote awareness of CJD  
and raise money for prion disease research in Australia



In memory of Sandra Kernahan

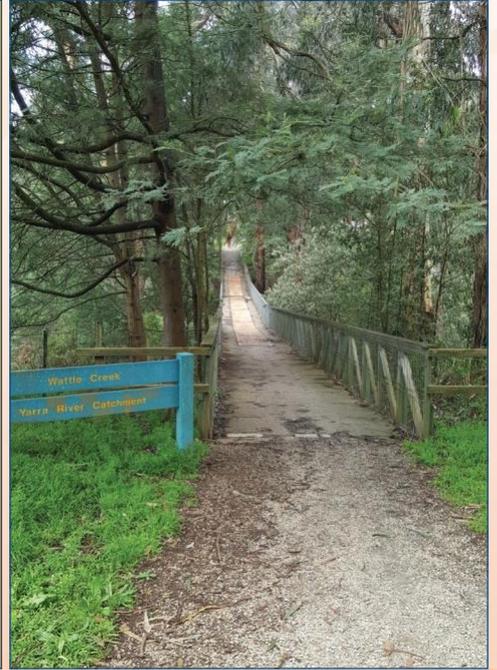
Register **NOW** to join us and be a part  
of the 'sea of orange'

Date: 27th October 2017

Location: Emerald, VIC

Distance options are: 10km and 5km  
PLUS a 2km kids only event

For more information visit  
[www.cjdsupport.org.au](http://www.cjdsupport.org.au)



**CJD**  Fun Run 'And so I ran...'

