



C J D
C O N F E R E N C E
1 6 T H A N N U A L N A T I O N A L

24th & 25th October 2025

The Victoria Hotel
Melbourne, VIC

PROGRAM

www.cjdsupport.org.au



PROGRAM SCHEDULE

FRIDAY 24TH OCTOBER, 2025

2:30PM - 5:30PM

GENETIC FAMILY MEETING

- Collins Room, The Victoria Hotel

SATURDAY 25TH OCTOBER, 2025

9:00AM - 5:00PM

16TH ANNUAL NATIONAL CJD CONFERENCE

- The Victoria Room, The Victoria Hotel

7:00PM - 10:00PM

COCKTAIL PARTY

- Miss Morgan (within Mr Munro Dining Room), The Victoria Hotel



SPEAKER BIOS

To find out more about our speakers and view a digital version of our program, please scan the QR code to visit the **CJD Support Group Network website**.

The CJDSGN acknowledges the funding from the Department of Health that assists towards the cost of this conference.

SATURDAY 25TH OCTOBER 2025

9:00AM

WELCOME

SUZANNE SOLVYNS

Director/National Coordinator, CJDSGN

Executive Director, CJD International Support Alliance (CJDISA)

9:05AM

MEMORIAL WALL

In memory of those loved ones lost to CJD/prion disease.

SESSION 1

CHAIR - PROFESSOR STEVEN COLLINS

Director, Australian National CJD Registry (ANCJDR)

Medical Director, CJDSGN

9:10AM

A TRIBUTE TO PROFESSOR MICHAEL ALPERS - 'KURU'

PROFESSOR COLIN MASTERS

The Florey Institute, The University of Melbourne

Director, Australian National CJD Registry (ANCJDR)

9:40AM

'INTRODUCTION TO PRION DISEASES' – UNIMAGINATIVE BUT ACCURATE!

PROFESSOR RICHARD KNIGHT

Emeritus Professor of Clinical Neurology, University of

Edinburgh, UK

10:20AM

CARING TODAY, TREATMENTS TOMORROW: WORK AT THE UK NATIONAL PRION CLINIC

PROFESSOR SIMON MEAD

Consultant Neurologist and Clinical Lead of the NHS National Prion Clinic

Professor of Neurology and Deputy Director of the MRC Prion Unit at UCL

UK CJD Support Network Committee Member

10:50AM

SESSION 1 Q&A

11:00AM

MORNING TEA

SESSION 2

CHAIR - ASSOCIATE PROFESSOR VICTORIA LAWSON

Department of Microbiology and Immunology, School of Biomedical Sciences, University of Melbourne

11:20AM

TRANSLATING THE JARGON: CJD FOR THE NON-DOCTOR

DR SARAH HOLPER

Clinician-Scientist, The Royal Melbourne Hospital
Assistant Medical Director, CJD/SGN

11:40AM

THE PUBLIC RISK ASSESSMENT AND THE LOOKBACK PROCESS

DONNA CAMERON

Infection Control Consultant, Communicable Disease,
Communicable Disease Prevention and Control Health Protection
Branch, Victoria Department of Health

12:00PM

PANEL

AUSTRALIAN NATIONAL CJD REGISTRY (ANCJDR)

Professor Steven Collins – Director, ANCJDR

Professor Colin Master - Director, ANCJDR

Dr Sarah Holper - Clinician-Scientist, The Royal Melbourne Hospital

Dr Christiane Stehmann - Coordinator, ANCJDR

Dr Matteo Senesi - Research Fellow, RT-QuIC, ANCJDR

Dr Victoria Lewis – Head, Molecular Diagnostics, ANCJDR

Shannon Sarros - Research Assistant/Assistant Quality Manager

INTRODUCTION TO THE ANCJDR TEAM AND THEIR ROLES

12:20PM

THE IMPORTANCE OF NEUROPATHOLOGY INVESTIGATION TO UNDERSTAND PRION DISEASE

PROFESSOR STEVEN COLLINS

12:30PM

ATYPICAL CASES OF CJD/PRION DISEASE

DR VICTORIA LEWIS

Postdoctoral Prion Research Fellow, University of Melbourne
Head, Molecular Diagnostics, ANCJDR

12:40PM

UPDATES ON RT-QUIC

DR MATTEO SENESI

Postdoctoral Research Fellow, University of Melbourne
Research Fellow, RT-QuIC, ANCJDR

12:50PM

ANCJDR VIDEO

12:55PM

SESSION 2 Q&A

1:00PM

LUNCH

SESSION 3

CHAIR - SUZANNE SOLVYNS

2:00PM

MEMORIAL WALL

In memory of those loved ones lost to CJD/prion disease.

2:05PM

FAMILY PANEL

**EXPERIENCING PRION DISEASE THAT HAS SHAPED AND
CHANGED LIFE FOCUS**

2:25PM

CJDSGN AWARDS



WE APPRECIATE YOUR FEEDBACK

Are you enjoying the conference? Is there something you would like more information about?

Please scan the QR code to fill out our evaluation form on the CJD Support Group website. Your submission will be anonymous.

SESSION 4

CHAIR - DR DEBRA SCOTT

Medical Officer – Executive Management Committee/ Palliative Care & Patient Care Advisor, CJDSGN

2:30PM

PRNP TESTING - DIAGNOSTIC AND PREDICTIVE TESTING AND ADVANCES WITH PREIMPLANTATION GENETIC TESTING (PGT)

SHERIDAN O'DONNELL

Associate Genetic Counsellor, Hunter Genetics

2:50PM

A PERSONAL STORY

3:00PM

Q&A

3:05PM

PRION DISEASE RESEARCH UPDATES IN AUSTRALIA

ASSOCIATE PROFESSOR VICTORIA LAWSON

3:25PM

Q&A

SESSION 5

CHAIR - PROFESSOR RICHARD KNIGHT

3:30PM

PANEL

DRUG DEVELOPMENT AND SUPPORTING STUDIES

INTRODUCTION

PROFESSOR RICHARD KNIGHT

3:35PM

VIDEO

ASSOCIATE PROFESSORS ERIC MINIKEL AND SONIA VALLABH

Prion Alliance

3:40PM

A PILL TO TREAT PRION DISEASE

DR PATRICK SHARP

Scientific founder of Gate Bioscience

4:00PM

PRN100 TREATMENT IN THE UK: AN UPDATE
PROFESSOR SIMON MEAD

4:10PM

SPARC - LONGITUDINAL STUDY
GENEVIEVE LOFTUS-HILL

Co-ordinator, Longitudinal Study, Florey Institute
Co-ordinator, Study of At Risk of Prion Disease Cohort (SPARC)

4:25PM

PRIONATRISK, GLOBAL COLLABORATION
PROFESSOR SIMON MEAD AND DR CHRISTIANE STEHMANN

4:35PM

SESSION 5 Q&A

4:40PM

CLOSING SESSION

ACKNOWLEDGEMENT OF FUND-RAISING EVENTS
INTERNATIONAL CJD AWARENESS DAY
SUZANNE SOLVYNS

4:45PM

AFTERNOON TEA AND ROUND TABLE NETWORKING WITH
SPEAKERS

5:00PM

CLOSE

Thank you to the CJD families who work so hard to raise money for research and those who continue to support the CJDSGN in providing much needed funding for diagnostic and research projects and studies.

NOTES

