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# COMMUNITY INFO DAY SURVEY SURVEY

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SCAN FOR MOBILE SURVEY





### 9:30 am Welcome

### **Professor John Grigg**

Professor John Grigg is passionate about helping children and adults with blinding eye conditions. He is involved in caring for patients, researching new ways to save sight and teaching the next generation of eye doctors. John is Head of the Discipline of Clinical Ophthalmology and Eye Health at The University of Sydney. He also consults at Sydney Eye Hospital and The Children's Hospital at Westmead. With sub-specialties in glaucoma, cataract, paediatric ophthalmology genetic and clinical and electrophysiology, John completed his training at Sydney Eye Hospital and undertook fellowships in Australia and the UK.



### 9:40am Welcome to Country

Uncle Allen Madden

### 9:45 am Keynote Address

### **Emeritus Professor Ron McCallum AO**

Emeritus Professor McCallum AO studied law at Monash University, graduating in 1972. In 1974 he completed a Master of Laws Degree at Queen's University, Canada. It was at this point that Ron developed his interest and expertise in labour and employment law.



After teaching at Monash for 18 years, he moved to Sydney in 1993 where he was appointed to a full professorship at the University of Sydney. Blind since his birth, this appointment made Ron the first totally blind person to be appointed to a full professorship at any Australian or New Zealand university. He served as Dean of the University of Sydney Law School between 2002 and 2007. His expertise in labour law and occupational health and safety saw him appointed as chair or member of various federal and state inquiries.

Professor McCallum was made an Officer in the Order of Australia (AO) in 2006 for his services to tertiary education, for industrial relations advice to governments, for assistance to visually impaired persons and for social justice. In January 2011, Prime Minister Ms Julia Gillard designated Ron as Senior Australian of the Year for 2011.

Professor McCallum was elected as a member of the United Nations Committee on the Rights of Persons with Disabilities which monitors the implementation of the Disabilities Convention. He served from 2009 until the close of 2014.

Ron served as a part-time member of the Administrative Appeals Tribunal from 2013 to July 2019.

In July 2019, Allen and Unwin published his memoir titled "Born At The Right Time" which discusses his life and the changes brought about by new technologies.

He is married to Mary Crock who is Professor of Public Law, University of Sydney. They have one daughter and two sons.

### 10:15am Introducing SSI

### **Briony Glastonbury**

Briony has over 25 years' experience in the healthcare, not for profit and medical research sectors and an extensive background in operations, business and research management and leadership.

She obtained her Master in Health Administration whilst leading a not for profit primary care membership organisation, gaining 10 years' senior management experience. Briony sought to obtain experience in the management of innovative research activities, an area of personal interest, and was subsequently appointed to set up and lead a national clinical trial at the University of Adelaide.

She commenced at the Save Sight Institute, in 2007 having been recruited from South Australia to set up



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and lead an international research post marketing surveillance study on the management of eye disease.

Whilst at the Institute she worked with the new Director to identify a number of areas for improvement, from governance to administration and operations management, and assisted with an organisational restructure. In 2010 Briony became the Institute's Business Manager, now Chief Operations Officer, the most senior professional leadership role in the organisation, working closely with academics and researchers, leading outcomes and driving achievements by drawing on her broad background and experience.

### 10:25am Education Panel – Managing School Transitions

### **Brodie Smith**

Brodie is a 20-year-old sports athlete from Maitland, NSW who is also blind.

Diagnosed with a degenerative eye disease known as Retinitis Pigmentosa, Brodie plays the paralympic sport of Goalball and has represented Australia at a national and international level. In 2017 Brodie won gold at the Youth Goalball World Championships in Budapest. Between work and training, Brodie is also currently studying to become a secondary school teacher in History and Drama at the University of Newcastle.



### Susan Leong

Sue is an Assistant Principal (Vision) with the NSW Department of Education. She leads and coordinates a team of Itinerant Support Teachers Vision based at Bass Hill Public School. Sue has over 30 years' experience in the field of vision impairment as both a Vision Support Teacher and an Orientation and Mobility Instructor.



Highlights in Sue's career include studying and working in the USA and teaching in the UK.

### **Audrey Housbey**

Audrey has 28 years' experience working in the disability sector and is currently working as a National Disability Coordination Officer (NDCO) in western NSW. The NDCO program drives change so that people with disability have equitable opportunity to access, participate and achieve their goals in tertiary education and subsequent employment.



### Claire Mahony

Claire is a Specialist Teacher (Vision Impairment). She works at the Royal Institute for Deaf and Blind Children and works across K-12. Claire has come from a mainstream background, teaching students with learning difficulties and disabilities as well as some time teaching adults at TAFE.



Claire loves the difference that technology is making to her vision impaired students.

### Michael McGuire - Panel Chair and MC

Michael is a husband to the love of his life and the father of two powerful daughters one of who just happens to be deaf and the other who is blind (aged 8 and 3). Between 2 quail, 3 dogs, and 4 chickens they are quite the menagerie.



He has worked in banking IT for 20 years, volunteers for various vision and hearing related organisations that he cares passionately about, and obsessively attends or joins every meet up, Facebook group, parent's group, conference or family camp he can find.

He also has the usual hobbies of spending time with his kids, walking their dogs and filling in NDIS paperwork.



### 11:10am Jenna Jones

Jenna was born with a rare degenerative vision impairment called cone-rod dystrophy. Diagnosed when she was in kindergarten, her parents encouraged her to try all sports, but as her eyesight continued to deteriorate, swimming was the safer option.

At just 13 years old, she made three A Finals and two B Finals and set 11 Australian Age records. She went on to win six gold and three silver medals at the 2015 Australian Championships. She qualified for the 2016 Rio Paralympic Games in five events, where she finished seventh in the 50m freestyle and 100m backstroke finals. Aside from the 2020 Tokyo games, in the future she would like to work as a physiotherapist or work with animals.

### 11:25am MORNING TEA

## 11:55am In the era of technology, when/if do you start braille?

### Vincent Nguyen - Panel Chair

Vincent is passionate about helping people with low vision. He spent a number of years working in low vision and clinical visual electrophysiology clinics. He is currently an academic at UTS teaching low vision in the Masters of Orthoptics program. Vincent's research interest is low vision and electrophysiology.



### Connor McLeod

Blind from birth, and at the time just 12 years old, Connor campaigned the Reserve Bank of Australia to print tactile banknotes. Connor's idea arose after he was given money for Christmas, but could not tell the amount in his hand.



He refused to take no for an answer, even going to Canberra with his mum to deliver his petition with 57,000 signatures to the government. It worked, and in September 2016 the first tactile \$5 note was launched. With a steely resolve, the power of an online army behind him, and a willingness to share his story to help others, Connor has improved the day-to-day lives of 357,000 Australians living with vision impairments.

### Sonali Marathe

Sonali is the manager of Alternative Format Publications at the Royal Institute for Deaf and Blind Children and the President of Round Table on Information Access for People with Print Disabilities. Sonali is passionate about access to information for people with a print disability, in traditional formats such as large print, braille and audio, and in newer and emerging electronic technologies.



### Harzita Hashim

Harzita is an Occupational Therapist with a Masters in Special Education (Sensory Impairment). She has worked in the field of low vision and blindness for almost 30 years and is passionate about early intervention and working with families to support their child's development and the foundation skills needed for lifelong learning. She currently holds the role of Best Practice Lead (Vision) at the Royal Institute for Deaf and Blind Children and works across various disciplines to ensure teams are equipped with the knowledge and practical skills to achieve the best outcomes for children aged 0-18 years who are blind and have low vision.



### 12:40pm Becoming a Yes Woman

### **Simran Goyal**

Simran is a 21-year-old young professional living and working in Sydney. She was diagnosed with Cone Rod Dystrophy at a young age and has overcome



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various challenges throughout her teenage and young adult life. Today she works in professional services for a global firm. In her free time, Simran enjoys pursuing her passion for photography, travel and cooking. Simran lives by a strong belief in saying yes to all opportunities. By sharing her experiences, she is building her own network of "disruptors," who are making a case for change in society's perception of ableism and ability.

### 1:00pm PCC Service Introduction

### **Lorraine Villaret**

Lorraine is SSI's Patient Care Coordinator, a position made possible through the support of the William and Eliza Hall Trust.

She is a Social Worker with a background in the notfor-profit and NGO sector. She brings her experience in disability, carers, mental health, and CALD communities to Save Sight Institute.



### 1:10pm LUNCH

### 2:10pm Research at the SSI – What's new?

### **Professor John Grigg**

Professor Grigg is a group leader of the Eye Genetics Research Unit at the Save Sight Institute. His research interests are genetic eye disease, glaucoma management and electrophysiology of the visual system.



### **Professor Robyn Jamieson**

Professor Jamieson leads the Eye Genetics Research Unit at The Children's Medical Research Institute, The Children's Hospital at Westmead and Save Sight Institute, University of Sydney. Professor Jamieson's research program is focussed aenomic and functional studies aimed at understanding disease causation and progressing to novel therapies in genetic diseases, especially of the eye. Her work has resulted in several novel disease gene and variant identifications, new insights to disease mechanisms, and translation to diagnostic aenomic testing for genetic eye diseases. Applications in genome engineering and new vector technologies are underway for progress towards therapies in blinding eye conditions including those affecting the retina.



### **Professor Stephanie Watson**

Professor Watson is an ophthalmic surgeon specialising in cataract, corneal and laser surgery; with expertise in eye disease in adults and children. She is known for her ground-breaking research in stem cell treatment for corneas. Her work has been featured on ABC's New Inventors and Catalyst.



### Dr Sophia Zagora

Dr Zagora is a Consultant Ophthalmologist at Sydney Eye Hospital and the Children's Hospital at Westmead. She subspecialises in Uveitis (in both adults and children), medical retina and the complex surgical treatment of these diseases. She has undergone fellowship training at Sydney Eye Hospital, Westmead Children's Hospital and Moorfields Eye Hospital. She is heavily involved in clinical research in these areas and is a Clinical Senior Lecturer at the University of Sydney





### **Breakout Sessions**

2:30pm

SUCCEED (Parents)

Ada McCluskey



Ada is а psychologist currently working Homebush in Medical and Dental Centre. With 10 vears' experience, focus is on helping people reach а better understanding of themselves and their relations in Ophthalmology order to be happier and more connected in their lives.

RELATE (Teachers and service providers) **Dr James Smith** and Brodie Smith



Smith Dr has worked as paediatric ophthalmologist in Sydney for 20 years. He is Senior of Staff her Ophthalmologist at UNSW, Jia is also The Hospital Westmead Head Department of at Royal North Shore Hospital.

**ENGAGE** (Young People)

Jia Ni Teo



Jia is a volunteer Mental **Fitness** presenter with the Black Dog Institute. Currently completing a BA of Specialist Psychology Children's a nutritionist (BSc) at and certified life and coach. She is passionate about helping people live well and show up fully in all areas of their life.

### 3:30 pm How Many Fingers Do I See?

### Mia Armsworth

Mia, 18 years of age, is currently studying

Bachelor of Fine Arts at RMIT Melbourne.

This presentation will focus on her educational journey as a student with low vision and how this influenced her art and choice of career. Mia's artwork "How Many Fingers Do I see", was the featured artwork in ART Express, exhibited at the NSW art gallery and Dubbo gallery. Mia is well known for her advocacy for low vision students presenting at many corporate events, speaking at the Black and White Fundraiser, the Reserve Bank Fundraiser and the opening the Vision Australia office at Epping.



3:50 pm Closing Comments

4:00 pm AFTERNOON TEA

### About the Save Sight Institute

The Save Sight Institute focusses on excellence in teaching, research and patient care. Research at the Save Sight Institute relies exclusively on external grants, donations and bequests. For more information visit our website: savesightinstitute.org.au