USHER IN FOCUS

Webinar Series

USHER KIDS AUSTRALIA

usherkidsaustralia.com

USHER BASICS

SESSION 1

Professor Margaret Kenna - Boston Children's Hospital
What is Usher Syndrome? What is Retinitis Pigmentosa?
30 MINUTES

Lanya McKittrick & Krista Vasi - Usher Syndrome Coalition USA
The Global Usher Community, The Importance of Registries
30 MINUTES

Q&A
Usher Basics with Margaret and Lanya
30 MINUTES

SESSION 2

Professor Alex Hewitt - Ophthalmologist and Research Scientist
The Genetics of Usher Syndrome, Australian Research Efforts
45 MINUTES

USHER CLINICAL GUIDELINES

SESSION 1

Associate Professor Valerie Sung - Paediatrician, Royal Children's Hospital Melbourne
Paediatric Hearing Loss Investigation Guidelines, Genetic Testing
30 MINUTES

Dr Fiona Barker - Vestibular Specialist
Vestibular Dysfunction in Usher Syndrome Type 1 Patients, Supporting Gross Motor Development in Usher Syndrome Patients
30 MINUTES

Q&A
Usher Clinical Guidelines with Valerie
30 MINUTES

SESSION 2

Dr Sandra Staffieri - Paediatric Orthoptist
Assessment of Retinitis Pigmentosa, Eye Appointments and Eye Care, The Importance of Regular Eye Monitoring
45 MINUTES

Q&A Ask an Eye Specialist with Sandra
30 MINUTES

EARLY SUPPORT FOR USHER KIDS

SESSION 1

Emily Shepard and Hollie Feller - UsherKids Australia
Parent Perspective on Pathways to Primary School, Finding the Right Supports & Early Intervention for Children with Usher Syndrome
30 MINUTES

Dr Bronwen Scott - Orientation & Mobility Specialist
Early Orientation & Mobility Skill Development
30 MINUTES

Q&A Early Support for Usher Kids with Hollie, Emily and Bronwen
30 MINUTES

SESSION 2

Dr Karen Wolffe - Career Education Consultant for Students with Vision Impairment, Texas, USA
Skills for Life - Supporting School Age Kids with Usher Syndrome - Social Impacts and Early Career Skill Development
45 MINUTES

USHER SUPPORT

SESSION 1

Robin Forbes - Genetic Counsellor, VCGS
Supporting the Whole Family Unit
30 MINUTES

Associate Professor Helen Bourke-Taylor - Monash University
Healthy Mothers- Healthy Families
30 MINUTES

Q&A Usher Support with Robin and Helen
30 MINUTES

SESSION 2

Carly Fredericks - Ava's Voice, USA
Facilitating Social Connections with Other Usher Kids, Mentoring for Children with Usher Syndrome, Early Advocacy Skills for Children with Usher Syndrome
45 MINUTES

USHER LIVED EXPERIENCES

SESSION 1

Maggie Sandles - Teen with Usher Type 1
My Journey with Usher Syndrome
30 MINUTES

Molly Watt - Young Adult with Type 2
My Journey with Usher Syndrome
30 MINUTES

Q&A with Molly
30 MINUTES

SESSION 2

National Disability Insurance Agency
Supporting Children with Usher Syndrome Through the National Disability Insurance Scheme (NDIS)
30 MINUTES

Q&A with NDIA Rep
30 MINUTES

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Our online webinar series took place on 14th-18th September 2020 in conjunction with celebrations for International Usher Syndrome Awareness Day on September 19th.

The webinars included the latest updates on global clinical research efforts, clinical guidelines, how to support your Usher syndrome student in the classroom and more. You can now access the recordings and Q&A sessions to watch in your own time.

With a range of Australian and International leaders in support for children with Usher syndrome joining us to present, we believe this is a must for families and health care professionals caring for children with Usher Syndrome in Australia.

Your registration allows access to all 15 presentations, 7 Q&A sessions, presentation slides, resource lists and transcriptions. All videos include captions and Auslan interpreting. For families in Australia, you can claim the cost of your registration through your NDIS plan.

REGISTRATION DETAILS:

Family Member Registration **$95.00**

Professional Registration **$175.00**

Go to www.usherkidsaustralia.com to register

ABOUT USHERKIDS AUSTRALIA

UsherKids Australia is a not-for-profit charitable organisation that was established in 2016 as a parent-led support group established to enhance the lives of children diagnosed with Usher syndrome and their families in Australia.

UsherKids Australia's mission is to ensure children diagnosed with Usher syndrome and their families have access to an informed, committed and caring community of clinicians, service providers, educators, researchers and peer support networks to allow them to thrive in their everyday endeavours.

UsherKids Australia has Charity and Deductible Gift Recipient (DGR) status from The Australian Charities and Not-for-profits Commission (ACNC). All donations over $2 are tax deductible.

ACCREDITATION

The content of these webinars has been developed in conjunction with a variety of Continuing Professional Development (CPD) programs. See our website for more details www.usherkidsaustralia.com

Australian College of Audiology Approval No.202065 · a.g.bell · audiology australia CPD2021 023 Category 1.2 12 CPD points · ASGC · aitsl · NAPD · orthoptics australia · Orientation + Mobility Association of Australasia · Speech Pathology Australia

USHER KIDS AUSTRALIA

Enhancing the lives of children with Usher Syndrome in Australia through information, collaboration and connection.

IDENTIFY

Ensuring all those with Usher syndrome are known to our community to assist the collaboration of research efforts both here in Australia and globally.

EDUCATE

Providing information to newly diagnosed families, as well as educating health care professionals, educators and support staff on the needs of our children to maximise inclusion and best clinical practice.

SUPPORT

Providing support to families, children, siblings, health care professionals, communities, sporting clubs, schools, service providers and all those who are part of the care and education of children with Usher syndrome to ensure they have the knowledge, resources and skills to assist our children to thrive in their everyday endeavours.

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Professor Margaret Kenna

Professor Margaret Kenna is Director of the Hearing Loss Program in the Department of Otolaryngology and Communication Enhancement at Boston Children's Hospital, Professor of Otolaryngology at Harvard Medical School, co-founder of the Cochlear Implant Program, and a founding member of the Harvard Hereditary Deafness Center. Professor Kenna is also a founding Board Director of the Usher Syndrome Coalition in USA and has a longstanding commitment to the global Usher community through her extensive research in the area.

What is Usher Syndrome? What is Retinitis Pigmentosa?

Professor Margaret Kenna will identify the basics of Usher syndrome and the variation in clinical presentation of the 3 different subtypes of the condition. Sample audiograms will be used to highlight the similarities and differences between other common causes of hearing loss in the paediatric population, and when referral for further testing is warranted. The presentation will also explore the genetics of Usher syndrome, autosomal recessive inheritance patterns, vision impairment caused by retinitis pigmentosa and the implications of a dual sensory loss on the development of the child. Availability of hearing technology and audiological outcomes for the paediatric patient will also be a highlight of this presentation.

Krista Vasi

Krista Vasi is the Executive Director at the Usher Syndrome Coalition, a global organisation working to find and support every individual and family affected by Usher syndrome. Krista joined the Usher Syndrome Coalition in an official capacity in 2013 after volunteering since 2008, bringing a wealth of experience in public administration, development, fundraising and management to the community.

Lanya McKittrick

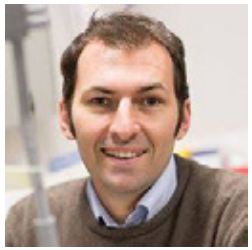
Lanya McKittrick is the newly appointed Chair of the Usher Syndrome Coalition in the USA after many years on the Board of Directors. She co-founded the Hear See Hope Foundation to raise awareness and funding for Usher research and to support families through their Usher journey after two of her children were diagnosed with the condition. Lanya also holds a Ph.D. in Special Education with a focus on deafblind research.

The Global Usher Community & the Importance of Registries

The Usher Syndrome Coalition is a global organisation with the mission to raise awareness and accelerate research for the most common genetic cause of combined deafness and blindness. The Coalition also provides information and support to individuals and families affected by Usher syndrome. Krista Vasi will detail the history and growth of the organisation, and the benefits of connecting the global Usher community to ensure families and clinicians can exchange knowledge about best practices, leading to better outcomes for people with Usher syndrome.

Dr. Lanya McKittrick will discuss the importance of international registries for rare diseases such as Usher syndrome as the work of researchers can be jeopardized because they have access to too few people with Usher syndrome. The goal of the USH Trust is to voluntarily register everyone with Usher syndrome, worldwide, and to be the bridge between the research community and the Usher syndrome community. By encouraging patients to register with the USH Trust, they will become part of the largest global network of individuals with Usher syndrome and have the opportunity to contribute to the world's understanding of Usher syndrome, will be ensured of receiving information on the latest research, treatments and clinical trials, and will be the first to learn about opportunities to participate in research.

Professor Alex Hewitt



Professor Alex Hewitt is a Principal Research Fellow at the Menzies Institute for Medical Research and the School of Medicine at the University of Tasmania, as well as Principal Investigator at the Centre for Eye Research Australia. He is a practising ophthalmologist and in 2016 received a Research Excellence Award as the top ranked NHMRC Practitioner Fellowship applicant in Australia for his work on patient-specific stem cell lines and emerging gene-based therapies.

The Genetics of Usher Syndrome & Australian Research Efforts

Professor Hewitt will present the very latest on clinical research being undertaken in various research laboratories in Australia addressing strategies to slow or halt the progression of retinitis pigmentosa, the eye disease associated with Usher syndrome. He will explore the importance of genetic testing and tracking the natural progression of the disease and how these contribute to research efforts. Professor Hewitt will explain the medical interventions designed to correct the mutation or error in the Usher syndrome-causing gene as well as discuss the stages in research including preclinical studies and clinical trials, with timelines to give the audience a realistic overview of the advancements of research.

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Associate Professor Valerie Sung

Associate Professor Valerie Sung is a consultant paediatrician and senior research fellow at the Murdoch Children's Research Institute. Dr Sung is founder and chair of the Childhood Hearing Australasian Medical Professionals (CHAMP) Network which developed national guidelines for managing childhood hearing loss, as well as Director of the Caring for Hearing Impaired Children Clinic (CHIC) at the Royal Children's Hospital, Melbourne.

Paediatric Hearing Loss Investigation Guidelines & Genetic Testing

Associate Professor Sung will discuss the development of the Paediatric Hearing Loss Investigation Guidelines designed to streamline the management of children with hearing loss. A working group of 15 Childhood Hearing Australasian Medical Professionals (CHAMP) network members developed the guidelines to ensure early-stage medical management is improved to offer families correct and timely testing and reduce potentially unnecessary tests and referrals. The network is now developing the parent resource to reflect the CHAMP guidelines, as well as developing education materials for other clinicians.

Dr Sung will discuss the implications of early diagnosis of conditions such as Usher syndrome and the opportunity for improved clinical care.

Dr Fiona Barker

Dr. Fiona Barker is a registered Clinical Scientist from the Princess Margaret Hospital in London who, over an 18 year career has developed a focus on the assessment and management of vestibular problems, dizziness and imbalance. She has a certificate in evidence-based psychological therapy and has a special interest in the consultation process and in the psychological impact vestibular problems can bring. Dr Barker is also involved in training Clinical Scientists as a lecturer on balance courses in the UK and internationally.

Vestibular Dysfunction in Usher Syndrome Type 1 Patients & Supporting Gross Motor Development

The vestibular system is important for the development of gross motor function in children. Children with Usher syndrome Type 1 typically have a dysfunctional vestibular system, causing a delay in acquisition of gross motor skills such as head control, sitting and independent walking.

Dr Barker will discuss the early assessment and rehabiitation of vestibular function in children. She will then cover strategies that allied health teams can develop with families to ensure the safe promotion of gross motor development in children.

Dr. Karen Wolffe

Dr. Karen Wolffe is a world renowned expert in the early development of career skills in youth with visual impairments. She worked with the American Foundation for the Blind as Director of Professional Development and CareerConnect from 2000 to 2010. Prior to that, she was a faculty member in the Department of Special Education at the University of Texas (UT) where she also directed the Job Readiness Clinic, an applied learning lab for people with disabilities looking for work and university students studying to become rehabilitation counsellors or special education teachers.

Skills for Life - Supporting School Age Kids with Usher Syndrome, Social Impacts & Early Career Skill Development

Dr. Wolffe will present strategies for early skill development of children with dual sensory loss with the goal for all children is to reach their potential, to grow up happy, healthy, and to be productive citizens.

She will discuss strategies for developing social engagement skills and early career skills for children with Usher syndrome.

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Dr. Sandra Staffieri

Dr. Sandra Staffieri is a Senior Clinical Orthoptist at Melbourne Children's Eye Clinic and the Royal Children's Hospital. Having recently completed her PhD at the University of Melbourne, Dr Staffieri is a Research Fellow at the Centre for Eye Research Australia.

Assessment of Retinitis Pigmentosa, Eye Appointments and Eye Care & the Importance of Regular Eye Monitoring

Dr. Staffieri will present the assessment of retinitis pigmentosa in a paediatric patient and how clinicians can work with families to provide the best outcomes from eye appointments. She will discuss the importance of regular eye monitoring to track the progression of the disease to allow appropriate strategies and supports to be introduced to manage the reducing visual field.

Emily Shepard

Emily Shepard is a co-founder and Director of UsherKids Australia. Emily is passionate and committed to improving the lives of children with Usher syndrome and their families by providing evidenced-based information and education to the range of healthcare practitioners supporting children with the condition. She has brought her perspective as the mother of a child with Usher syndrome, as well as her management skills to successfully lead the not-for-profit organisation.

Hollie Feller

Hollie Feller is a co-founder and Director of UsherKids Australia. She is a fierce advocate for early diagnosis of Usher syndrome through genetic testing, the education of clinical professionals as well as support for families around the country to share research and information about the current generation of USH kids. Hollie established the not-for-profit organisation in 2016 after her son was diagnosed with Usher syndrome.

Parent Perspective on the Pathway to Primary School, Finding the Right Supports & Early Intervention for Children with Usher Syndrome

Ms Shepard and Ms Feller will look at the pathway to primary school from a parent perspective of a child with Usher syndrome, including consideration of communication options, managing the various appointments and therapy, finding the right early supports through early intervention, and options available in primary school education.

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Robin Forbes

Robin Forbes is a Genetic Counsellor at the Victorian Clinical Genetic Service, Royal Children's Hospital, Melbourne. Her extensive experience has led to the development of best practise models for multidisciplinary clinics for children with complex genetic conditions.

Supporting the Whole Family Unit

Robin Forbes will explore the common themes relating to families with children diagnosed with genetic conditions, including the communication of genetic information with immediate and extended family, as well as the impact on unaffected siblings and fathers when the focus often falls on mothers and the child with the genetic condition.

Robin will also discuss the consequences telehealth can have on the communication of sensitive information, and how health care providers can work to ensure the best mental health and wellbeing outcomes for the entire family unit.

Associate Professor Helen Bourke-Taylor

Helen Bourke-Taylor is an occupational therapist and Associate Professor at Monash University, Melbourne Australia. Helen is a Fellow of the Occupational Therapy Australia Research Academy and her research has led to the development of Healthy Mothers Healthy Families (HMHF), a research based program designed to support, empower and encourage mothers of a child with a disability to learn about, and create a healthy lifestyle that fosters their own health and well-being, alongside a healthy, happy family life.

Healthy Mothers Healthy Families

Associate Professor Helen Bourke-Taylor will discuss the research that identifies mothers of children with a disability as having a higher risk for compromised health and wellbeing, and the catalyst for the development of the Healthy Mothers Healthy Families (HMHF) program. She will address the service changes that provide mothers with information about their own health and need for health enhancing activities, as well as education that empowers mothers to manage and master their child's disability and needs.

Dr. Bronwen Scott

Dr. Bronwen Scott has worked as an Orientation & Mobility (O&M) specialist for 30 years. Her qualifications include a Bachelor of Psychology, Graduate Diploma of Orientation and Mobility, Master of Education (Special Education), and a Doctor of Education. Dr Scott is a lecturer at Macquarie University in the Master of Disability (Sensory Disability) course, teaching the Orientation and Mobility Fundamentals and Inclusion and Professional Collaboration in Sensory Disability units. She also works as an independent O&M specialist in Melbourne and is passionate about creating opportunities for people with vision impairment to meet their goals for independence.

Early Orientation & Mobility Skill Development

Dr. Scott will discuss the principles of orientation and mobility and how the early introduction of skills can assist the safety and independence of children with retinitis pigmentosa. She will describe the role of the O&M specialist throughout the course of childhood, how education staff can ensure the inclusion of children with Usher syndrome throughout their education, and how to maintain involvement in all aspects of community life safely and independently.

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Carly Fredericks

Carly Fredericks is a Family Specialist for the New Jersey Consortium on Deaf-Blindness at The College of New Jersey. She is also the Program Coordinator for iCanConnect/NJ, the Deaf-Blind Equipment Distribution Program that provides telecommunications equipment for individuals with combined hearing and vision loss. Carly is the founder of Ava's Voice, an internationally recognised organisation committed to empowering youth with Usher syndrome by educating families and school communities on the needs of those with living with the condition.

Pamela Aasen

Pamela Aasen is the proud parent of Ethan & Gavin, who have Usher syndrome 1b. Pam has 25 years experience in special education working with diverse communities in the U.S., Canada and the Dominican Republic. In advocating for her own children she has successfully lead parent engagement initiatives and worked with parents in partnership to become advocates for their children in the process of finding appropriate family-centered care and ensuring an appropriate education. She is currently a Parent-Leader for the NJCDB, a Project Leader and Family Resource Specialist for the SPAN Parent Advocacy Network's Early Hearing Detection and Intervention Program, a board member of USH Partner Ava's Voice and one of the facilitators of the monthly Family 2 Family Community call for parents of children with Usher syndrome.

Facilitating Social Connections with Other Usher Kids, Mentoring for Children with Usher Syndrome & Early Advocacy Skills for Children with Usher Syndrome

When Carly's daughter was diagnosed with Usher syndrome, she established Ava's Voice, a charity dedicated to empowering youth and educating families and school communities on the needs of students with Usher syndrome. In this presentation, Carly will give an overview of the services and supports beneficial to children with Usher syndrome in various educational settings, as well as ideas on encouraging early advocacy skills in both children and families . She will explore ways to build impactful relationships between families and providers, to improve the outcomes for children.

Maggie Sandles

Maggie is 17 and always up for a challenge. She doesn't accept "no" and is now embracing the opportunities her Usher diagnosis has opened up to her, mainly (fingers crossed), a spot in the crew rowing for Australia at the Paralympics. There have been some rocky years for sure, however, mustering her own style of support has helped her navigate her way forward.

My Journey with Usher Syndrome

Join Maggie as she weaves you though her lived experience of Usher Syndrome Type 1C. Now 17, she will reflect on her early years growing up profoundly deaf and pretty wonky on her feet, and then share some of her raw and challenging years post diagnosis.

Maggie shares some pearls of wisdom regarding the way she navigated her way forward and what support was worthwhile and what was obstructive.

Molly Watt

Molly Watt has used her life experiences as an individual with Usher syndrome to become a sort-after accessibility/ usability consultant and keynote speaker. Through the Molly Watt Trust, she and her family work to raise awareness about the condition, and also to support people with Usher syndrome by donating helpful devices. She is actively involved in the subject of inclusion to give people with Usher syndrome a voice and a platform to share their experiences.

My Journey with Usher Syndrome

Molly will provide valuable insight into growing up with Usher syndrome and how her experiences, both good and bad, have shaped the person she is today. She will discuss in detail the topic of accessibility, and the importance of schools, universities and workplaces being inclusive for those with disabilities. Molly will highlight the ongoing need for those with the condition to continually advocate for their required supports and accommodations.

She is very passionate about developments in technology and will address how ongoing advances and developments in this field can be 'game changers' for those with Usher syndrome. Along with an increase in general awareness, as well as support and understanding from those around you, people with Usher syndrome can manage their lives successfully and independently.