



2019 Community Forum: Knowledge without Borders Final Program Schedule

9:30 – 9:50 am: Introductions by Community Council Members

A Word from our Sponsor – Cerebral Palsy Foundation

Speaker: Ms. Rachel Byrne

Ms. Byrne's Bio: Rachel Byrne is the Executive Director at the Cerebral Palsy Foundation. She has been working in the field of pediatric rehabilitation and cerebral palsy research for the past 14 years. Rachel has a background in physical therapy, with a particular interest in neuroplasticity and motor learning. Her early career as a clinician in Australia delivering physical therapy services in schools, hospitals and private practice is focused on knowledge translation and the impact on a person's ability to participate in their community across the lifespan.

In her current role at the Foundation, she has continued her research interest in evidence-based practice, knowledge translation, early detection and interventions and population studies for cerebral palsy. Rachel was instrumental in developing the Early Detection Network, as well as the *Just Say Hi* school inclusion curriculum, which is now being expanded nationally. In the last 10 years she has given multiple presentations at international conferences and managed large multi-site research projects.

9:55-10:15 am: Regenerative Medicine and Cerebral Palsy

Speaker: Dr. Iona Novak

Dr. Novak's Bio: Professor Iona Novak is the Head of Research of the Cerebral Palsy Alliance Research Institute, located at the Brain Mind Centre, in the University of Sydney Australia. Iona is a Fulbright Scholar, and has won Western Sydney University Chancellor's Award for Alumni of the Year and The University of Sydney Award for Professional Achievement. Iona co-founded the Cerebral Palsy Alliance Research Institute for the purpose of: prevention, cure and treatment of cerebral palsy. Driven by an internal belief that healthcare truly has the potential to change lives, Iona has pursued projects and roles with the greatest possible impact on children and families today and tomorrow's world. For example, co-founding the Australian Cerebral Palsy Register. Iona is passionate about evidence-based practice; knowledge translation, neuroplasticity; stem cells and neuroregenerative clinical trials. Iona leads a collaborative research team that is currently conducting the world's largest ever, cerebral palsy early intervention trial, exploring whether harnessing neuroplasticity can reduce the severity of disability

10:20-11:05 am: Weakening and Strengthening and Spasticity...Approaches to Management in CP

Speakers: Dr. Darcy Fehlings, Dr. Jennifer Ryan, Mr. Jason Gray

Dr. Fehling's Bio: Dr. Darcy Fehlings is Head of the Division of Developmental Paediatrics and is a Professor in the Department of Paediatrics, at the University of Toronto. Dr. Fehlings is a Senior Clinician Scientist in the Bloorview Research Institute and leads a large cerebral palsy clinical program at Holland Bloorview Kids Rehabilitation Hospital, Canada's largest children's paediatric rehabilitation hospital. Her research focuses on the innovation and evaluation of interventions for children with cerebral palsy. Professor Fehlings is the lead investigator of an Ontario Brain Institute integrated neuroscience network focused on children with cerebral palsy (CP-NET). She leads the Greater Toronto Area site of the National CP Registry and is a member of the International CP Genomics Consortium. She has been an active member of the American Academy for Cerebral Palsy and Developmental Medicine (AAPDM)

since 1998 and served as President in 2015 and has played a leadership role in developing the AACPDm Care Pathways.

Dr. Ryan's Bio: Dr. Jennifer Ryan is a Research Lecturer in the Department of Public Health and Epidemiology at RCSI (Royal College of Surgeons in Ireland). She also holds a position as a Senior Lecturer in Physiotherapy at Brunel University London. She has degrees in Physical Therapy and Medical Statistics. Jennifer's interests encompass physical activity, exercise, and burden of chronic disease among people with cerebral palsy. She has led trials examining exercise or physical activity for people with cerebral palsy and multiple sclerosis. Jennifer was lead author on a Cochrane systematic review of exercise for cerebral palsy. She was a member of the Physical Activity and Disability Expert Group (PADEG) for "Physical activity for general health benefits in disabled adults: Summary of a rapid evidence review for the UK Chief Medical Officers' update of the physical activity guidelines" and is contributing a section on exercise for cerebral palsy to an updated edition of the American College of Sports Medicine's Guidelines for Exercise Testing and Prescription.

Mr. Jason Gray's Bio: Mr. Jason Gray is a young adult with spastic diplegic cerebral palsy. Mr. Gray has extensive personal experience with many of the support services offered to and utilized by those with cerebral palsy. Early on he received early intervention services, special education services and extensive physical and occupational therapies. He ultimately was integrated into a regular educational setting and successfully graduated from high school. Despite health issues and reading challenges, Mr. Gray went on to earn an Associate of Arts degree in Childhood Development from Fullerton Community College and a Bachelor of Science degree in Child and Adolescent Studies from Cal State University. He is currently attending Cal State University, Los Angeles, working towards earning his teaching credentials in Adapted Physical Education. In addition to furthering his education, Mr. Gray has been a member of the local Special Olympic Softball team and volunteers at several elementary schools in the East Whittier City School District A.P.E. classes. He also works with his mother for their nonprofit, Collaborative Action & Unity in Special Education. He lives in Whittier, CA with his parents and younger brother.

11:10 am - 12:15 pm: Adaptive Sports Panel and Demonstration

Speakers: *Carolina Schaber, Dr. Phoebe Scott-Wyard, Adaptive Athletes and their parents*

Ms. Schaber's Bio: Carolina currently works as the Clinical Director of the Southern California Cerebral Palsy Center at Rady Children's Hospital San Diego. She has more than 30 years of clinical and business experience. She earned her bachelor's in nursing from CSU Fresno, and after completing her nursing degree, she spent the next seven years in the pediatric critical care setting. Carolina earned a master's of business administration degree from the University of San Diego. The next 15 years of her career were spent working with various biotech companies, specializing in marketing and new product development. Carolina is part of the AACPDm adaptive sport committee and enjoys spreading the word about the benefits of adaptive sports.

Dr. Scott-Wyard's Bio: Dr. Phoebe Scott-Wyard is a rehabilitation medicine specialist at Rady Children's Hospital-San Diego and an assistant professor at UC San Diego School of Medicine. She is double board-certified in pediatrics and physical medicine and rehabilitation. Originally from Maine, Dr. Scott-Wyard completed her undergraduate degree in behavioral biology at Johns Hopkins University before attending medical school at Western University of Health Sciences here in Southern California. She completed a combined residency in pediatrics and physical medicine and rehabilitation at Cincinnati Children's Hospital Medical Center and University of Cincinnati. She served two years as a Peace Corps volunteer in Ecuador and is fluent in Spanish. Dr. Scott-Wyard is especially interested in treating children with limb differences. Before coming to Rady Children's, she served as the medical director of the Child Amputee Prosthetics Project clinic at Shriners Hospital in Los Angeles for six years. She is also a board member at large for the Association of Children's Prosthetic and Orthotic Clinics, the only professional organization for pediatric amputee care. She has served as a volunteer for the Challenged Athlete's Foundation and Angel City Games.

Adaptive Athletes and their Parents:

Katrina Schaber, Former Team USA Adaptive Alpine Skier, Adaptive Rock Climbing

Tatiana Crenshaw, Team USA Adaptive Rock Climbing

Helen Crenshaw, Mother Tatiana Crenshaw

Tessa Taylor, 6 years old, Recreational Para Athlete

Janis Taylor, Mother of Tessa

12:15 pm: Lunch Break

1:15-1:45 pm: Visual Ability in Children with Cerebral Palsy

Speaker: *Belinda Deramore Denver*

Ms. Denver's Bio: Ms. Denver is a candidate within the Doctor of Philosophy program at Australian Catholic University, North Sydney campus. She is an occupational therapist, has a 2016 Career Development Grant from the Cerebral Palsy Alliance Research Foundation and is currently working part time as a lecturer within the Bachelor of Occupational Therapy program at ACU. Belinda graduated from the University of South Australia with degrees in psychology and occupational therapy, and has worked as an OT in tertiary and community pediatric services across South Australia, New South Wales and Victoria. Her interest in working with children with cerebral palsy and children with visual impairments has led to her research in the area of vision, and the primary outcome from her PhD research is the development of the Measure of Early Vision Use (MEVU).

1:45-2:00 pm: A Word from our Premier Sponsors – CP Now and Orthopedic Institute for Children/UCLA

Speakers: *Ms. Christina Youngblood and Dr. Eileen Fowler*

Ms. Christina Youngblood's Bio: CP NOW Foundation – Ms. Youngblood is a parent volunteer who coordinates the education initiatives and distribution of educational materials for CP NOW. She is part of the team of parents who came together to develop CP NOW's first resource guide, The CP Tool Kit. Christina hopes to make an impact on the CP community by helping CP NOW advance programming that changes the way CP is diagnosed, treated and thought of by the general public.

She is Mom to Devin who was born prematurely and diagnosed with CP at 11 months old. Devin developed CP and epilepsy because of a brain bleed he had at the time of birth. Today Devin is an active boy who is a straight A student, loves music, video games and anything with wheels that goes fast.

Dr. Eileen Fowler's Bio: Center for Cerebral Palsy at UCLA/OIC – Dr. Fowler's research focus is in motor disorders in cerebral palsy. She is the Director of the Kameron Gait and Motion Analysis Lab and the Director of Research and Education for the UCLA/OIC for Cerebral Palsy. She is also faculty in the Tarjan Center at UCLA. She was the President of AACPD in 2016. Her research addresses mechanisms responsible for impaired motor function and promising interventions. Her team developed clinical and biomechanical methods to evaluate selective voluntary motor control in patients with spastic cerebral palsy. She is currently examining the effect of selective motor control exercise camps on motor function and brain tracts. Additional research studies included exercise strengthening and fitness.

2:05-3:30 pm: Healthcare Advocacy- Navigating the System

Speakers: Dr. Erik Levey, Dr. Susan Biffi, Ms. Kim Hudson and Ms. Kristeen Payne

Dr. Levey's Bio: Dr. Levey went to the University of Pennsylvania School of Medicine. He did his residency in Pediatrics and a fellowship in General Academic Pediatrics at Johns Hopkins and then worked at Kennedy Krieger Institute in Baltimore for about 18 years. Over that time period, he worked in a number of programs including cerebral palsy, spina bifida program, feeding disorders, chronic pain as well inpatient rehabilitation. He is now Chief Medical Officer at Health Services for Children with Special Needs, a small Medicaid health plan for children and young adults with SSI in Washington, DC. He has always had an interest in improving the transition for youth with childhood-onset disabilities to adulthood. He was part of group with the American Academy of Pediatrics that did a consensus statement on health care transition in 2001. He served on the Governor's Interagency Transition Council in Maryland. He has given local and national presentations on transition.

Dr. Susan Biffi's Bio: Dr. Biffi is currently working as a pediatric physiatrist with the Rehab medicine team at Rady Children's Hospital serving an in and outpatient population, she previously established a pediatric physiatry program at Kapi'olani Medical center for Women and Children in Hawai'i. Prior to that she worked at Children's Hospital Colorado for many years as part of the Rehab Team. Before entering medical school, she was a pediatric physical therapist for 10 years. She has been very lucky to work with children with disabilities and their families in lots of different settings over more years than she cares to count!

Ms. Kristeen Payne's Bio: Ms. Payne is a social worker and a parent of a child with Cerebral palsy. She works at Rady Children's Hospital in San Diego in the Orthopedic and Rehabilitation clinics.

Ms. Kim Hudson's Bio: Ms. Kim Hudson has a Masters in Social Work and has over 20 years' experience working with individuals with disabilities and chronic health issues. She also is an adult patient with cerebral palsy.