



AACPDM

2020 Virtual Community Forum Final Program

Adaptive Sports and Recreation Panel

Clayton Frech - Disability Advocate & Social Entrepreneur

Clayton is a disability advocate and social entrepreneur, with a passion for diversity and inclusion across all sectors of society. He is the CEO & Founder of Angel City Sports and is Chairman of the Board of Directors for Adaptive Sports USA. In addition to serving as a board member and strategic advisor to a number of companies, he is currently launching the Ampla Institute, a career development and planning firm dedicated to helping people optimize their career potential. More importantly, he is the father of an aspiring Paralympian, Ezra Frech, 15 year old on Team USA and plans to medal in the Tokyo Paralympics.

Cathryn Gray – University of Michigan Adaptive Track Athlete

Cathryn is from Atlanta. She has cerebral palsy and is an internationally ranked adaptive track and field athlete in the F35 class and a 4.0 student. She has been designated a US Paralympic High School All American in track and field and also Women's Sports Foundation National Ambassador/Travel and Training Grant recipient. She has competed in Spain in the World Paralympic Games, was the only female named as a US Paralympic Track and Field All American, in addition to being the 2017 javelin and discuss national champion. She currently holds the national record for javelin. 2019 All American.

Cynthia Frisina – Community Council Member, Parent Advocate, and Cerebral Palsy Foundation Vice President of Partnerships

Cynthia Frisina is a global expert on disability advocacy, family education and partnerships. Cynthia also served as the Executive Director of one of the leading US Paralympic Sport Clubs, transforming it into a leader in the field of adaptive sports, recreation and training. Cynthia's leadership resulted in being honored by the United States Olympic Committee as the Rings of Gold Outstanding Sports Program in the US two years in a row and brought humanitarian adaptive sports programs to Africa, South America and the Middle East. Cynthia serves on the global advisory board for the Cerebral Palsy International Sports & Recreation Association (CPIIRA), and several other advisory boards in the field including the American Academy for Cerebral Palsy and Developmental Medicine (AACPD). She holds a BA from University of Illinois and Masters degrees from Northwestern University.

Cindy Housner – Executive Director, Great Lakes Adaptive Sports Association

Cindy is the founder and Executive Director of the Great Lakes Adaptive Sports Association (GLASA), a nationally recognized adaptive and Paralympic sports club that provides sports programs to youth and adults, including veterans, who have a physical or visual disability. Cindy is the current Track Coach for Team GLASA. Additional credentials include: 2019 Co-Leader Team USA Paralympic Junior World Championships; Games Director for the Great Lakes Regional Games and Adult National Open 2006-present; Member of the Athletics for All National Task Force; Co-Team Leader 2015 and 2018 International Wheelchair and Amputee Sports Foundation; World Junior Games, Team USA; Past Board Member of Wheelchair and Ambulatory Sports, USA; Former Executive Director for the Wheelchair Athletic Associations; Games Director of the 2010 National Junior Disability Championships; and Team USA Athletic Manager for Seoul Paralympic Games.

Patrick Lawrence – Challenged Athlete Foundation, Senior Programs Manager

Patrick has been at CAF since September 2015 and was introduced to adaptive sports as an athletic trainer for USA Volleyball's Sitting Volleyball programs. After careers in healthcare, recreation management, and sports medicine, discovering adaptive sports combined all of the things that he feels passionate about. At CAF, he oversees several grant programs, the High School Adaptive Sports Program, and Community Outreach. The opportunity to support individuals with physical disabilities in their athletic and recreational pursuits is a reflection of his own belief that being active is an essential part of life that should be accessible to people of all abilities.



Quinn Waitley – Adaptive Surfer and Athlete

My name is Quinn Waitley and I am many things. I'm a daughter, sister, disabled, Athlete, surfer, and speaker.

I come from a big athletic family. Did I mention we're all girls, my parents David and Heidi Waitley had three girls but by the ages of eight, six and two; they wanted to try for one more, hoping for a boy they were very surprised to find that they were getting identical quadruplet girls. Yes I'm on of the four, because of my miracle birth along with my sisters. We were premature and I was born with Spastic Quadriplegia Cerebral Palsy, in short terms I'm unable to walk so I use a wheelchair to get around.

Yes, my life is challenging but that didn't stop my parents and sisters from treating me like any other kid growing up. I did everything my sisters did just in a different way, the result of this made me into fierce competitor. Growing up I played many sports but my favorite is surfing.

Three years ago, I made the US National adaptive surf team for the first time, this year in 2020 it was third time competing. My favorite part of competing is surfing with my friends and introducing people to adaptive community and sports

Jen Lyman- Community Council Chair, Parent Advocate, Recreation Therapist

Bower Lyman – Multi-Sport Recreational Athlete

Bower Lyman, is a 15 year old, New Orleanean who has quadriplegic cerebral palsy, visual and communication impairments. He is a healthy, happy teenager who loves Mardi Gras, Music Festivals, working out, bike riding, race-running, eating sushi, swimming, school and so much more. He and his parents enjoy travelling to beaches in Costa Rica, skiing in Colorado, and exploring the rivers and bayous of Coastal Louisiana.

Bower's mom, Jen, is passionate about ensuring that individuals with complex cerebral palsy have the opportunities to actively participate in meaningful experiences that promote self-expression, optimal health, lead to lasting friendships, and that are challenging, fun, and inclusive. Jen is currently the Chair of the American Academy for Cerebral Palsy and Developmental Medicine's Community Council and she serves on the boards of the CP Now and Camp Dream Street. Jen is a recreation therapist and a yoga instructor. Jen, Bower and Chris Lyman live in New Orleans with their new puppy Everest.

Resources Discussed:

Angel City Games: <https://www.angelcitygames.org/>

Great Lakes Adaptive Sports Association: <https://www.glasa.org/>

Challenged Athlete Foundation: <https://www.challengedathletes.org/>

Cerebral Palsy International Sport and Recreation Association: <https://cpisra.org/>



Robotics and Advanced Rehabilitation Technology: Virtual Reality, Robotic Walkers and Early Powered Mobility

Deborah J. Gaebler-Spira, MD: Professor PMR, Pediatrics Shirley Ryan Ability Lab, Northwestern Feinberg School of Medicine

Contact Information: dgaebler@sralab.org

Dr. Deborah Gaebler-Spira completed a Pediatric Residency at University of Chicago and Physical Medicine and Rehabilitation Residency at Shirley Ryan AbilityLab (formerly Rehabilitation Institute of Chicago). She combined the two fields at Shirley Ryan AbilityLab and has been there for the past 30 years. She is a Professor of Physical Medicine and Rehabilitation and Pediatrics at the Northwestern Feinberg School of Medicine. Her main clinical practice has been working with children with cerebral palsy and their families.

Dr. Gaebler serves on the Pathways Awareness Foundation Roundtable, is past President of the American Academy of Cerebral Palsy and Developmental Medicine, past Physical Medicine and Rehabilitation Liaison to the American Academy of Pediatrics Council on Children with Disabilities and has held leadership positions in the Illinois Chapter of the American Academy of Pediatrics Council on Children with Disabilities. She is happy to serve on the Scientific Advisory Council as medical chair for the Cerebral Palsy Foundation. Her research is focused on outcomes for children with cerebral palsy and interventions that improve function.

Elaine Biddess, PhD, PEng: Senior Scientist, Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital and Associate Professor with the Institute of Biomaterials and Biomedical Engineering at the University of Toronto

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Dr. Biddiss is a senior scientist in the Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital and an Associate Professor with the Institute of Biomaterials and Biomedical Engineering at the University of Toronto.

She is dedicated to creating innovative solutions that support young people with disabilities to achieve their goals in both recreation and rehabilitation. She embraces an interdisciplinary design approach and enjoys the challenges of integrating engineering, medicine, arts, and design. Elaine received a master's degree in mechanical engineering at the University of Toronto before pursuing doctoral studies in biomedical engineering at the Institute of Biomaterials and Biomedical Engineering and a postdoctoral fellowship with the School for Health and Related Research at the University of Sheffield.

Anna M. McCormick, MD, FRCPC: Pediatrics and Physical Medicine and Rehabilitation: Medical Director of Rehabilitation, The Children's Hospital of Eastern Ontario / University of Ottawa

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Dr. McCormick is one of few individuals in Canada to be dual Royal College certified in Pediatrics and Rehabilitation Medicine. She is the Division Chief of Developmental Medicine and Rehabilitation at the Children's Hospital of Eastern Ontario where she has been in practice for over 20 years. She is a consultant at the local Children's Treatment Center and The Ottawa Rehabilitation Center and an Associate Professor with the University of Ottawa.

Dr. McCormick has developed a fellowship program in Pediatric Rehabilitation. Her research interests include the use of technology to optimize function, transition to adult care, spasticity management and connecting patients with research through involvement with database projects.



**Cole Galloway, PT, PhD, FAPTA: Professor, Dept of Physical Therapy,
Biomechanics and Movement Science Graduate Program, University of Delaware**
Contact Information: jacgallo@udel.edu

Dr. Galloway's "blue-collar futurist" approach guides his collaborative work on supporting individuals in the co-creation of their world through mobility. His interests in human behavior, families, music, comedy, design thinking and social justice mix effortlessly with his professional background of rehabilitation, neuroscience, child development, human-machine interaction, dynamic systems concepts and open source culture.

His team's research and device development work — focused on the key role of social mobility in life — serves to unapologetically challenge the out of date cultures of pediatric and adult rehabilitation with a highly hopeful set of alternative products and processes. His current focus is on the impact of modified ride on cars, bodyweight harnesses placed in the real world, swarms of smart toys and on the research and manufacturing power of k-12 STEM/STEAM classrooms.

He works within Go Baby Go – a +150 chapter research, education and advocacy human rights movement composed of researchers, clinicians, families and a wide range of lay communities. His approach of combining high tech and low tech into "go tech" has garnered 20 yrs of funding, awards and partnerships with top tier organizations including the NIH, NSF, the Robert Wood Johnson Foundation, the Smithsonian's American History Museum, the medical, toy and mobility tech industries such as Fisher-Price, Mattel and Toyota.

Resources Discussed:

Go-Baby-Go: <https://sites.udel.edu/gobabygo/>

<https://www.facebook.com/UDGoBabyGo>

Article - [Technological Advancements in Cerebral Palsy Rehabilitation](#)

Technological Advancements in Cerebral Palsy Rehabilitation



Fabiola Reyes, MD^{1*}, Christian Niedzwecki, DO²,
Deborah Gaebler-Spira, MD³

INTRODUCTION

In the last decade, technology applications in the field of neurorehabilitation have grown at a rapid pace. This growth is driven by robust engineering research, commercial development of neurorehabilitation products, and through new applications of rapidly expanding technological advances to the field of health care.¹⁻³ As a result,

Disclosure Statement: D. Gaebler-Spira is a consultant for Rehabtek, a rehabilitation robotics company. The other authors have nothing to disclose.

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Understanding Dystonia: Diagnosis and Treatment

Bhooma Aravamuthan, MD, DPhil

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Dr. Aravamuthan is an Assistant Professor of Neurology and pediatric movement disorders specialist in the Cerebral Palsy Center at St. Louis Children's Hospital and the Washington University School of Medicine. She completed her research doctorate at the University of Oxford in England, medical school and pediatrics residency at Washington University in St. Louis, and child neurology and movement disorders fellowships at Boston Children's Hospital and Massachusetts General Hospital before returning to Wash U as faculty. She leads the Cerebral Palsy Research Network Committee on Dystonia Quality Improvement, founded and directs the Child Neurology Society Cerebral Palsy Special Interest Group, and is Vice Chair of the American Academy of Neurology Intellectual and Developmental Disabilities Section. Her research on objective dystonia diagnosis methods has been recognized with early career investigator awards from the Child Neurology Society and the American Neurological Association.

Metformin: A Potential Future Treatment for Cerebral Palsy?

Darcy L. Fehlings, MD, MSc, FRCP(C)

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. She is the inaugural holder of the Bloorview Children's Hospital Foundation Chair in Developmental Paediatrics. Dr. Fehlings is a Senior Clinician Scientist in the Bloorview Research Institute. Her research focuses on the innovation and evaluation of interventions for children with cerebral palsy. She is the lead investigator of an Ontario Brain Institute integrated neuroscience network focused on children with cerebral palsy (CP-NET) and leads the CP Discovery Project in the Canadian NeuroDevNet Networks of Centres of Excellence. She is a past president of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM).

Donald Mabbot, PhD

Dr. Mabbott received his PhD in developmental psychology at the University of Alberta in 1998 and then completed a post-doctoral fellowship in paediatric neuropsychology at The Hospital for Sick Children (SickKids). Dr. Mabbott is Head of Neurosciences and Mental Health Program and Senior Scientist within the Research Institute at SickKids and a Professor in the Department of Psychology at the University of Toronto. Situated at the intersection between clinical neuroscience, developmental neuropsychology, and regenerative medicine, Dr. Mabbott's research program seeks to: (a) understand how perturbed brain development manifests as cognitive impairment in children – particularly in survivors of paediatric brain tumours, and (b) discover how neuroplasticity in the developing brain can be harnessed for neural recovery and cognitive restoration in children with acquired brain injury. His work has been instrumental in documenting the thinking and learning problems children and adolescents treated for brain tumours experience, and the underlying damage to brain structure and function that cause these problems. He is now conducting exciting new work to find ways to foster brain repair and cognitive recovery following acquired brain injury in children, including harnessing neuroplasticity from physical exercise and employing drugs that stimulate the growth of new brain cells.



Complex Care: A family journey

The Shrader Family

Wade and Carol Shrader are parents to Benjamin, Mason, Claire, and Cate. In 1997, Benjamin, Mason, and Claire were born three months early changing the direction of their lives (could the birth of triplets do anything less?).

Benjamin and Mason were diagnosed with Cerebral Palsy in 1998. It was this diagnosis that would lead Wade to specialize in Pediatric Orthopedic surgery. Today, he runs the A.I. DuPont Hospital for Children's Center for Cerebral Palsy.

In 2008, an 11-year-old Mason created a blog – The Blessing Counter – and encouraged Carol to share their story. His willingness to have his story told so that even just one family could find hope inspires her still.

The triplets graduated from college in 2019. Benjamin is currently working on a local senate campaign and is an advocate for voting rights for the disabled. Mason is in his second year of graduate school at Texas Tech University. He is getting his masters in Classical Archeology and his main research is in disability in the ancient world. Claire, the triplet without CP, began Occupational Therapy school at Thomas Jefferson University in August. And Cate – born when the triplets were 8 -- just started high school.

It is the Shrader family's goal to remove helplessness and hopelessness from the diagnosis of Cerebral Palsy.

Charmaine Wright, MD

Leading multi-disciplinary teams has been a highlight of Dr. Charmaine Wright's career. A dual-trained internal medicine and pediatric primary care physician, she attended Harvard for college, medical school, and residency. Following residency, she completed a Robert Wood Johnson Clinical Fellowship at the University of Pennsylvania and joined faculty. As a med-peds primary care physician caring for complex patients, medical educator mentoring residents, and health services and clinical researcher dedicated to improving health disparities, she is passionate about implementing teams and programs that work for our most vulnerable patients. She works to bridge the gap between pediatric and adult care for patients with childhood-acquired medical conditions. She joined Christiana Care Health System as the Director of the Center for Special Health Care Needs. She serves on the board of the Easterseals Delaware and Maryland Eastern Shore. Over the past year, the Center for Special Health Care Needs has grown beyond its signature Primary care, Down Syndrome, Hemophilia, and Cystic Fibrosis programs to also include Sickle Cell, Cerebral Palsy, Women's Health, Developmental Psychiatry, Gastroenterology, Urology, and Mary Campbell Center programs.

She is a member of Christiana Care's Employee Resource Group Diversabilities, working hard as of late to end discrimination of all kinds and improve the health of people with disabilities.

She lives in Delaware with her husband Sean, kids Lydia Luke and Logan, and a dog Sunny Montego. Their families are from Jamaica and they think outside of Delaware, the beaches there are the best! She enjoys reading, riding (bikes), and eating.

Lynne Fogel – Moderator, Community Council Member

Lynne Fogel lives near Columbus, Ohio and is mom to two lovely girls - Natalie, age 15, and Erica, age 18. Erica is a senior in high school and has spastic quad CP with dystonia and cortical vision impairment. Lynne came to Community Council via Pedal with Pete, with whom she has partnered in the past to provide adapted bikes to kids with CP in Central Ohio. She has run a parent support group, CP Parent Columbus (an official chapter of Reaching for the Stars), since 2004 and volunteers as a parent mentor in the Connecting Families program at Nationwide Children's Hospital. Lynne has served on the Parent Advisory Council of the Children with Medical Handicaps program of the Ohio Dept. of Health since 2014. She has worked part-time as the Central Ohio Family Support Specialist for Ohio Family 2 Family Health Information Center since 2016.



Healthcare Advocacy, Monday, Sept. 14 5:00 EST/4:00 CT

Jason Edinger, DO

Jason Edinger, DO, FAAP, FAAPMR is a Pediatric Rehabilitation Medicine physician in the Department of Physical Medicine and Rehabilitation at the University of Pittsburgh Medical Center and practices at UPMC Children's Hospital of Pittsburgh. He is the medical director of the Cerebral Palsy Clinic and Acquired Brain Injury Clinic and is passionate about helping children and young adults with cerebral palsy, brain injury and neuromuscular disorders achieve independence and optimize their participation in society. He serves as the Medical Director of the Technology Assisted Children's Home Program, a program designed to serve children that require medical technology to live outside of the hospital. Dr. Edinger is a co-founding member of Camp Inspire, an overnight camp specially designed for children on ventilators. He also volunteers time to other programs both national and international. He is the proud father of two little girls, Clara (4 years) and Samantha (9 months).

Jan Willem Gorter, MD, PhD, FRCP(C)

Jan Willem Gorter, MD, PhD, FRCP(C) Physical Medicine and Rehabilitation, is a Professor in the Department of Pediatrics. He is Director and a scientist at [CanChild Centre for Childhood Disability Research \(www.canchild.ca\)](http://www.canchild.ca) and holds the Scotiabank Chair in Child Health Research at McMaster University. He is visiting professor in Pediatric Rehabilitation in Utrecht, The Netherlands.

Jan Willem has training in pediatric and adult rehabilitation medicine (physiatry) with a special clinical and research interest in transitional services and life course health development. His research focuses on the themes of family, function, friends & fun (daily activities and participation) with a special interest in physical activity promotion (fitness) and in transitions from adolescence to adulthood (future).

Jan Willem's vision is to enhance the physical health, mental health and well-being of children and youth with disabilities/chronic health conditions and their families through interventions carefully tailored, timed and integrated into health services. He leads a research program that advances the knowledge of health development of people with disabilities, and that enhances research capacity through mentoring and training. Jan Willem's research is frequently published in peer-reviewed articles in leading journals.

Alexis Nichols, Self Advocate

Alexis Nichols is a motivational speaker and advocate for people with disabilities. Born with Cerebral Palsy and acquiring many other medical complexities, she has much experience navigating the disability and medical field. She sits on various boards and councils representing people with disabilities and continually shares her message that "you define your disability, your disability doesn't define you." Cerebral Palsy has been one of her biggest blessings in life and she is thankful to be able to share her experience with you.

Brenda Agnew, Parent Advocate

Brenda is the proud mother of two boys, Chase and Maclain. Her son Maclain has severe Cerebral Palsy and profound hearing loss as a result of a condition known as Kernicterus, a brain injury that results from untreated jaundice. Professionally she is a client liaison for a law firm, a local school board trustee, and a caregiving consultant.

She tirelessly advocates for better systems and programs for children with special needs. Brenda has been appointed to the Community Council for the American Academy of Cerebral Palsy and Developmental Medicine and is an active member for volunteer organizations such as CP-Net, CHILD-BRIGHT Citizen Engagement Committee, and the Burlington Accessibility Advisory Committee.

Resources Discussed:

Advocacy Resources -

My Transition App-

<https://www.canchild.ca/en/research-in-practice/current-studies/apply-the-mytransition-app-in-transition-applyit-study/mytransition-app>

[MyTransition App | CanChild](#)

Most childhood health care providers talk to children and adolescents about taking on more responsibility for their own health as they age, yet many providers report having neither the tools nor appropriate resources to foster smooth transitions for patients and their families to the adult system

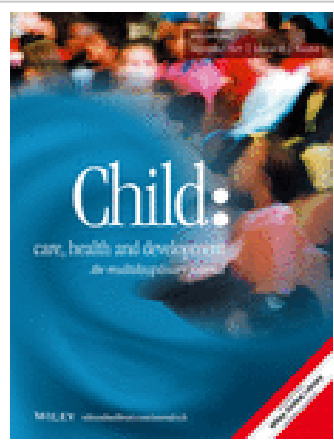
www.canchild.ca

Video on Transition -

https://youtu.be/Sv5_c0EaAhE

Article on Transition -

<https://onlinelibrary.wiley.com/doi/full/10.1111/cch.12705>



[Beyond stereotypes of cerebral palsy: Exploring the lived experiences of young Canadians - Hanes - 2019 - Child: Care, Health and Development - Wiley Online Library](#)

INTRODUCTION. Health—formally defined by Huber et al. as “the ability to adapt and self-manage”—is a multidimensional concept integrating physical, emotional, social, and environmental aspects of people’s lives (Huber et al., 2011; Kim & Fox, 2006; World Health Organization, 2002). For people with childhood-onset disabilities such as ... cerebral palsy (CP), health challenges continue

onlinelibrary.wiley.com