

SPEAKERS

Kathy Bromley and her husband Rob have two children, Michael age 19 and Shannon (AS) age 14. Kathy is a teacher of the deaf and has been working with the Langley School district for the past 22 years.

As a parent, Kathy has been an advocate for both of her children throughout their preschool and school years. Shannon has been involved in horseback riding, Girl Guides, birthday parties, swimming, bike riding, and all the things that keep kids, kids. Kathy has not only been very involved with educating the staff involved with her daughter but also in educating the children who are part of the school community, through the use of a DVD and pamphlet. In addition to the recreational and educational involvement, Kathy has also worked closely with Shannon's many specialists to ensure her continued development.

Kathy's first conference was in Kelowna, one of the first special events hosted by CASS, when Shannon was still a baby. Since then she has attended other conferences hosted by CASS and the ASF and helped to host the children's programming at the conference held in Vancouver in 2000.

Dr. Wendy Robinson earned a PhD in Genetics at the University of California at Berkeley in 1989. Her thesis work was on Disease Associations and Evolution of the Human HLA Region. From 1989 to 1994, Dr. Robinson worked as a post-doctoral fellow at the University of Zurich in Switzerland under the supervision of Professor Albert Schinzel. She had the opportunity to study the genetic basis of Prader-Willi syndrome and Angelman syndrome during this time and this led to her current research interest in human chromosomal disorders. In 1994, Dr. Robinson was recruited to a position as an Assistant Professor in the University of British Columbia Department of Medical Genetics and has subsequently been promoted to Full Professor. She is also the chair of the "Reproduction and Healthy Pregnancy" research program at the Child & Family Research Institute in Vancouver. Her research is currently focused on genetic and epigenetic aspects of reproduction.

Ted Kuntz is a psychotherapist in private practice in Vancouver. Yet the wisdom Ted shares in his presentation doesn't come from his formal training. Rather, it is the result of his journey as the father of a severely disabled child. This deeply personal story is an inspiration for all of us who want to reduce our pain and distress and increase our peace and joy. Ted's passion is to create a peaceful world where we all belong.

Charles A. Williams, M.D. is a Professor of Pediatrics and Genetics, Department of Pediatrics, University of Florida, Gainesville. He is a board-certified pediatrician and clinical geneticist and has a special interest in neurogenetic syndromes and related conditions. The main focus of his research career has been the study of Angelman syndrome. He has published many papers on the genetic and medical aspects of Angelman syndrome and he currently has an active clinical practice involving the follow-up of children and adults with Angelman syndrome. In 1987, he was instrumental in founding the U.S. Angelman Research Group, in Florida, and this entity subsequently evolved into the U.S. Angelman Syndrome Foundation.

Dr. Mary Connolly, is the Division Head and a Clinical Associate Professor in the Department of Pediatrics, Division of Neurology, at British Columbia Children's Hospital. As a pediatric neurologist with specific expertise in epilepsy and EEG, she is involved in clinical and research aspects of epilepsy in children. Dr. Connolly also leads a team involved in pioneering work in the treatment of epilepsy by brain surgery.

Dr. Connolly graduated from Medical School at Trinity College in Dublin, Ireland in June 1981 and was a fellow in Neurophysiology at Children's Hospital, Boston, Massachusetts from 1993 – 1994 and a Fellow of the Royal College of Physicians and Surgeons of Canada in Neurology in 1992.

Dennis Tetreau is the father of Kyle, who has Angelman syndrome and is now 25. Dennis has been an elementary school principal for 25 years. Dennis earned his B.P.E. and obtained teacher training at the University of British Columbia before going on to receive his M.Ed. from the University of Western Washington. He is a member of many committees dealing with special needs children in the school system. He continues many years of working with AS

families throughout Canada on educational issues. Dennis has served as a guest speaker to educational staff on the stages parents go through as their child enters and goes through the school system and on the IEP process. He has authored a pamphlet for parents on the IEP process. Dennis has also written articles for the CASS Newsletter and has had articles published in the Journal of Exceptional Children and in the School Administrator.

Dr. James E. Jan received his M.D. in 1963 from the University of Alberta in Edmonton. He continued his medical and scientific training with a wide variety of fellowships and postings in Paediatric Neurology, Epileptology, Neurophysiology, and received Certification in Electroencephalography. A Child Neurologist, he worked until his retirement in 2001 with children who had various disabilities and has held the positions of Medical Director, Consultant, Professor, Chairman of Professional Advisory Committee, as well as serving as program, professional journal, and foundation reviewer. Dr. Jan is also a researcher and his current title is Senior Research Scientist Emeritus. He has done much research in sleep disorders, particularly with respect to treatment with melatonin. Dr. Jan's distinguished career includes nominations and receipt of many awards and honours, the publication of 7 books, 206 major publications, a wide variety of television and video productions, and 114 presentations. He is still active at Children's Hospital, where he teaches, works in the Neurophysiology Unit, and is involved in several important research projects.

Daniel Collins has been active in the field of community living for over thirty years. He is currently the Executive Director of the Langley Association for Community Living in Langley, British Columbia and has held this position for 17 years. Dan has an undergraduate degree in Science and a Masters in Organizational Development. Dan is also an instructor at Kwantlen University College, where he teaches in the faculty of Community and Health Studies. Dan is the founder and chair of the Langley Social Planning Society, an organization that works to promote full inclusion for all citizens. Dan and his wife have three children, the eldest of whom has autism.

Dr. Edwin Weeber received his doctorate in Neuroscience from the University of New Mexico in 1998. He became interested in Angelman syndrome as a Post Doctoral Fellow while at Baylor College of Medicine in Houston, Texas, where he earned the rank of Assistant Professor in 2002. In 2003, he moved to Vanderbilt University to start his own laboratory in the Department of Molecular Physiology and Biophysics, where he continued his research in understanding the molecular mechanisms underlying AS. In 2007, he moved to the University of South Florida in Tampa, Florida, and currently holds the title of Associate Professor in the Department of Molecular Pharmacology and Physiology. His research interests also include the cognitive disruption underlying neurodegenerative and neuropsychiatric disorders, such as Alzheimer's disease and schizophrenia.

Vickie Cammack and Al Etmanski

Vickie Cammack is a co-founder of Planned Lifetime Advocacy Network (PLAN), a pioneer social enterprise supporting families as they plan for the safety and well being of their family member with a disability. She created PLAN's Personal Network program and is the co-author of "Safe and Secure – Six Steps to Creating a Personal Future Plan for People with Disabilities".

She currently mentors the spread of grass roots PLAN groups in 40 locations globally. Vickie is a founder and active member of the steering committee for Philia – an international dialogue on caring citizenship and welcoming communities. Vickie also co-chairs a national symposium on applied dissemination. For the past 2 years, she has co-led a Canadian exploration on sustainability and social innovation with the J.W. McConnell Foundation. Vickie is also the founding director of the Family Support Institute and has taught and designed curriculum for colleges and universities.

Vickie is a recipient of the Community Living Institute's Leadership Award, the Simon Fraser University President's Club Distinguished Community Leadership Award, and the Meritorious Service Medal of Canada. Vickie's former faculty colleagues at Douglas College established in her name an annual student leadership award. She continues her work through writing, consulting, and lecturing on social networks, organizational transformation, and scaling social innovation. Al Etmanski has been a leading advocate for people with disabilities and their families in Canada for more

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than two decades. He was for eight years the Executive Director of the B.C. Association for the Mentally Retarded (now the B.C. Association for Community Living) before joining with Jack Collins and Vickie Cammack to found the Planned Lifetime Advocacy Network (PLAN). Al is an author, advocacy consultant, and social inventor who specializes in finding innovative non-governmental solutions to social problems. He is the author of “A Good Life – for You and Your Relative with a Disability” and “Safe and Secure – Six Steps to Creating a Personal Future Plan for People with Disabilities”.

Al was one of the first two Canadians to receive a Fellowship from Ashoka, an international organization which searches the world for social entrepreneurs with innovative ideas. He is also the recipient of numerous awards, including the Civic Merit Award by the City of Vancouver, the Simon Fraser University President's Club Distinguished Community Leadership Award, and the Governor General's Meritorious Service Medal. In recent years, Al has become known for his expertise in fostering social enterprise within the civic sector. He is also a parent of five children, one of whom has a disability.

Cathy Dixon BScPT (Physical Therapist)

Cathy graduated from the University of Alberta in 1994 with a degree in Physical Therapy. She has worked for the last 10 years with children having a large variety of disabilities (including Angelman syndrome and Autism). Over the years, she has provided consultation and therapy services to children and their families as well as supporting children in various learning environments (be it inclusive classrooms or separate programming).

Susan Ernst, MD, is an honours graduate of the University of Michigan Medical School and residency program in Obstetrics and Gynecology. After a brief time in private practice, Dr. Ernst returned to the University of Michigan where she is now the Chief of Gynecology services at the University Health Service and is an adjunct instructor in the department of Obstetrics and Gynecology. Since 2003, Dr. Ernst has functioned as the Director of the gynecology clinic for women with developmental disabilities. Along with her clinical and research interest on this topic, Dr. Ernst has a personal interest in this field. She is the parent of an 11 year old, Hannah, who is deletion positive for Angelman syndrome.

Laura Yake is the Executive Director of the Center for Epilepsy and Seizure Education in British Columbia. Her initial involvement began when her daughter developed seizures and Laura was unable to find information through school and community supports on the effects of epilepsy on learning and behaviour in children. In 1998, Laura and Dr. Lionel Traverse (Medical Director of the Fraser Valley Child Development Center, Clinical Associate Professor of Pediatrics at UBC) co-founded the Fraser Valley Epilepsy Society. The Society is now known as the Center for Epilepsy and Seizure Education in B.C. The epilepsy education programs Laura has led the society to develop over the past 10 years have been adopted provincially, nationally, and internationally.

Laura is also the Communications Director with the Canadian Epilepsy Alliance (CEA). Nationally, she works with more than 25 organizations across Canada in the CEA to establish best educational practices for epilepsy education programs. An active member of her community, Laura brings her unique insights on epilepsy to share with our attendees.

Debra M. Dobrez is Executive Director and Founder of Wishing Well nfp, a not-for-profit organization dedicated to providing quality continuing education opportunities for adults with developmental disabilities. She has a Bachelor of Arts from the University of Iowa and over 25 years experience working with individuals with developmental disabilities. Debra has served as a member of the Board of Directors for several local organizations and is a current member of The ARC of Illinois. She has spent the past four years developing and implementing the Day Training Program, Horticultural Therapy Program and Drop-In Center at Wishing Well nfp. She has appeared on Fox News and Channel 2 News Chicago to discuss Wishing Well nfp and the difficulties their organization is facing because of lack of government support in the State of Illinois. Debra enjoys sharing information with parents of individuals with special needs and hopes her program will help enrich the lives of many individuals in the years to come. She is the proud mother of Megan, her

27 year old daughter diagnosed with Angelman syndrome, Adam, her 20 year old son, and Nathan, her 18 year old son. She resides in Manhattan, Illinois with her husband Rick and children, and spends a great deal of time at the Wishing Well Day Training Program facility in Frankfort, Illinois.

Stephen Calculator is a Professor and Chair in the Department of Communication Sciences and Disorders and an Adjunct Professor of Pediatrics at Dartmouth Medical School in Hanover, NH. He earned his doctorate in Communicative Disorders from the University of Wisconsin-Madison in 1980. Stephen has published and lectured extensively in the areas of augmentative and alternative communication (AAC) and inclusive education for students with severe and profound disabilities, drawing upon his ongoing experiences as a consultant to numerous schools and other agencies in the USA and beyond. His greatest contributions have been devoted to enhancing our understanding of the role communication and assistive technology can play in fostering the participation of individuals with severe disabilities in their communities. To this end, Stephen continues to collaborate with school districts and other agencies in developing programs and fostering systems change efforts to accommodate the needs of children with severe disabilities. Dr. Calculator's most recent clinical and research efforts have involved exploring methods of enhancing communication and participation skills of children with Angelman Syndrome in their homes and at school.

Eileen Millar has been teaching Iyengar yoga since 1996. Eileen began practicing Iyengar Yoga in 1992 as a means to find relief from pain after a serious accident. Amazed at how effectively Iyengar yoga helped her regain her strength and mobility, she then completed a three-year teacher training program at Yoga Centre Toronto. She has studied at the Ramamani Iyengar Memorial Yoga Institute in Pune, India, and continues to take workshops with senior Iyengar teachers. Eileen currently lives and works in Abbotsford, BC, where she owns and runs the Studio for Yoga & Wellness. She is known by her students as a gifted and sensitive teacher whose warmth and humour create a wonderful learning atmosphere. She is attentive to the individual needs of students and adapts her teaching to meet those needs. Eileen is a certified holistic practitioner, specializing in aromatherapy, massage, and reflexology.

Brian Salisbury and Jacinta Eni

Brian Salisbury has been the Director of Strategic Planning for Community Living British Columbia [CLBC] since 2005. He has been a faculty member in the Community Support Worker Program at Kwantlen University College and has consulted extensively in Canada, the USA, Australia, and the United Kingdom on various disability policy issues, including individualized funding and independent planning support. From 2001 – 2004, Brian was involved in the planning and development work that led to the creation of CLBC, the Crown Agency responsible for the delivery of supports and services for adults with developmental disabilities and children and youth with special needs and their families.

Jacinta Eni is currently the Project Director of Quality Services Initiatives for Community Living British Columbia [CLBC]. Since September 2006, she has directed the Residential Options Project, an initiative to offer alternative choices to individuals currently living in group homes in BC. Jacinta's previous experience includes a rich history of work in community living, most recently as Executive Director of two successive agencies. Her interests include developing highly individualized options with families and creating personal support networks. Jacinta was formerly an instructor with the Justice Institute of BC.

Dr. Nigel Livingston is the founder and currently the Director of CanAssist (formerly UVATT) at the Faculty of Engineering of the University of Victoria. He is also the father of a special needs child (originally diagnosed as having Angelman syndrome) and has served on the Board of Directors of the Canadian Angelman Syndrome Society. CanAssist is a university based programme dedicated to developing technology, devices, and services which improve the quality of life of those with disabilities. CanAssist engages community volunteers as well as students, faculty, and staff from virtually every discipline on the UVic campus. To date, it has developed over 75 new technologies specifically designed to address the specific needs of users. Over 1,700 students and more than 200 staff and faculty members have been involved in the programme.