



Please join us on March 4th at 11:30 AM to 5:00 PM at Toronto Marriott Downtown Eaton Centre Hotel, 525 Bay Street, Toronto <http://www.marriott.com/hotels/travel/yyzec-toronto-marriott-downtown-eaton-centre-hotel/>

Register : <http://giving.tsalliance.org/site/Calendar?id=100621&view=Detail>

Agenda :

11:30AM– 12:00 PM Registration & Refreshments and Snacks

12:00 PM– 12:45 PM Maria Zak, MN, NP-Paediatrics, Co-Director, TSC Clinic SickKids Hospital- Seizures/ Update on TSC Clinic

12:45 PM – 2:00 PM – Dr. John Bissler - Kidney Related Issues related to TSC and Treatment

2:00PM – 2:15PM Break

2:15PM – 3:30 PM Dr. Gipson, Behavioural Issues related to TSC and TAND

3:30 PM - 4:15 PM Stacy Hewson – Genetics

4:15 PM – 5:00 PM – Parents Forum – Meet and Greet

Bio's

Dr. John Bissler – Kidney issues related to TSC and Treatment

Dr. Bissler is the Federal Express Chaired Professor of Excellence at the University of Tennessee and is the chief of Pediatric Nephrology at Le Bonheur Children's Hospital and St. Jude Children's Research Hospital. He also is the Director of the Tuberous Sclerosis Center of Excellence. Prior to working at Le Bonheur Children's Hospital, Dr. Bissler was the Clark D. West Chaired Professor at Cincinnati Children's Hospital Medical Center, and associate program director for Research and Academic Careers. Dr. Bissler has been the principal investigator on important studies aimed at the treatment of tuberous sclerosis renal disease, and maintains basic and clinical investigation programs as well as a busy clinical program.

Stacy Hewson – Understanding TSC Genetics

Stacy Hewson is a Genetic Counsellor at the Hospital for Sick Children, working in Division of Clinical and Metabolic Genetics for the last 17 years. She received her Master of Science degree in Genetic Counselling from the McGill University in 1998 and a Master of Science degree in Molecular Biology from McGill in 1996. She obtained certification by the Canadian Association of Genetic Counsellors in 1998 and by the American Board of Genetic Counseling in 1999. She is actively involved in the University of Toronto M.Sc Program in Genetic Counselling in both a clinical supervisory and lecturer capacity. She has a special interest in patient advocacy for rare disease and has been facilitating a parent peer support group for the last 5 years. She began working in the TS clinic at SickKids in 2017. She has been invited to speak to many organizations including, Canadian Association of Genetic Counsellors (CAGC), National Gaucher Foundation of Canada, The Canadian MPS Society and Canadian Fabry Association.

Maria Zak, MN, NP-Paediatrics, Co-Director, TSC Clinic SickKids Hospital- Seizures/ Update on TSC Clinic

Maria is a Nurse Practitioner in the Division of Neurology at the Hospital for Sick Children (SickKids) and an Adjunct Lecturer at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto. Maria joined the Division of Neurology in 2004 after a fifteen year tenure in surgery including 9 years and a clinical nurse/manager/coordinator of the Orthopaedic Clinic. She has worked as a Nurse Practitioner in the Paediatric Stroke Program and in the Epilepsy Program. She is co-founder of the Comprehensive Tuberous Sclerosis Clinic at SickKids. Her main areas of clinical focus are paediatric epilepsy – children with drug-resistant epilepsy - the ketogenic diet, tuberous sclerosis and some general neurology. Maria is a co-investigator on many studies. Areas of interest include the impact of the internet and social media on patient/parental medical decision making, cannabinoids in the treatment of drug-resistant epilepsy, and tuberous sclerosis in which she is involved in setting up a patient registry that will facilitate research, and research ethics. Maria is active in graduate nursing education and many organizations including the Association of Child Neurology Nursing. She is also a member of the Research Ethics Board at SickKids.

Dr. Tanjala Gipson, Director, TAND Unit LeBonheur Children's Hospital; Director, Neurodevelopmental disabilities clinic

Dr. Gipson is both a child neurologist and neurodevelopmental disabilities specialist. She founded the TSC Center of Excellence at Kennedy Krieger Institute and established an interdisciplinary model of care for children and adults with TSC-associated neuropsychiatric disorders. She has now moved to Le Bonheur Children's Hospital and the Boling Center for Developmental Disabilities at the University of Tennessee Health Sciences Center in Memphis, TN where she has established a clinical and research unit dedicated to TSC-associated neuropsychiatric disorders.

