

NF Empowerment, MBNF Guest Speakers



Reggie Bibbs spent the first 40 years of his life in hiding. He was concerned about how his particular disfigurement affected people that didn't know him. He was less concerned about how they made him feel as he was concerned about how he made them feel. He struggled to find a way to spread awareness and let people know that he, at heart, was no different than anyone else. Reggie is the Just Ask Foundation founder. He wanted people to "Just Ask" about his condition – and ask they did! This simple concept and Reggie's caring heart has been successful in raising NF awareness to the public for over 25 years.

Dr. Jan Friedman is a medical geneticist who has been involved in clinical and epidemiological research regarding neurofibromatosis for more than 30 years. His research has led to seminal advances in improving the diagnosis of NF, and in formulating recommendations for genetic and clinical diagnosis that have led to enhanced standards of patient care. His key research discoveries of novel molecular and cellular hallmarks that distinguish types of NF, benign tumours that typically arise in these patients, are providing new insights into the pathogenesis and progression of NF.



Suzanne Lendvoy is an Occupational Therapist from Regina. She has been in private practice for over 20 years. Suzanne's recent experience includes pediatrics, ergonomics and vocational rehabilitation. She changed her OT practice to include more pediatrics as she realized that she needed to use some OT skills with her son, who was diagnosed with NF1 at the age of 7. (He is now 15 years old.) Suzanne has certification in Ayres Sensory Integration, Floortime, Integrated Listening Systems and Cogmed Working Memory Training. She provides assessment and treatment regarding areas such as fine and gross motor activities, sensory processing, visual motor and visual perceptual difficulties. She works with children, their caregivers and their teachers regarding difficulties related to autism, ADHD, dyspraxia, sensory processing,

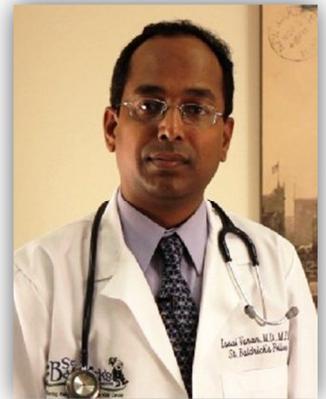
developmental coordination disorder, developmental delays, Fetal Alcohol Spectrum disorder, and other developmental conditions.

NF Empowerment, MBNF Guest Speakers



Courtney Willoughby is in her third year of a Bachelor of Science to pursue her Nursing Degree. Courtney desires to be a pediatric nurse working on a medical surgical unit at the Stollery Children's Hospital. She hopes to give back to children going through similar medical diagnoses or illness. Courtney was diagnosed with NF 1 at three years of age; she is currently 21 years old and writes Courtney's Column, which is shown first to our Manitoba NF Support Group. She is an administrator on our Facebook Page.

Dr Issai Vanan is a Physician-Scientist and a Pediatric Neuro-Oncologist at CCMB. Dr Vanan received his basic medical education in India (Bangalore Medical College / PGIMER). He completed his Pediatric Hem-Onc and Pediatric Neuro-Oncology fellowships in New York (Cohen Children's Medical Center of New York). His main research interests are in translational Neuro-Oncology with special emphasis on Radiation and Chemotherapy sensitivity of Pediatric Brain tumors and Novel Neuro therapeutics. He is a St Baldrick's Cancer research scholar and his research is also supported by CCMB foundation and MMSF. Prior to being recruited to CCMB, he was an attending physician in the Department of Pediatrics at Steven and Alexandra Cohen Children's Medical Center of New York.



Desirée Sher is the Executive Director of the BCNF and a life coach. She is passionate about helping people embrace their power and uncover their true potential to transform their lives. She uses her personal stories of loss and pain to give others hope and to help them shine. She is the editor of INSPIRE! magazine and just released her first book, Refuse to Sink. She shares her life with her young daughter Maya and her grown sons, Taylor and Connor.