

NFSO Biannual Provincial Meeting Insert

When/Where: Sunday Oct 23rd, 2011, at Days Hotel Conference Centre, 185 Yorkland Blvd, Toronto

RSVP: on-line at <http://goo.gl/8ewvg> or phone 1-866-843-6376

Childcare: There is a separate room with adult supervision for the kids to use during speaker presentations.

Overnight rooms for Sat: there are a limited number of rooms with two double beds tentatively held on a first come basis or call the hotel at 416-502-6870

Busing: We are planning a bus with stops in London, Brantford and possibly Kitchener. If interested please call **ASAP** for more details and/or to guarantee your seat.

Tentative agenda

- 9:00 – 9:30 Registration and Coffee and time to network
- 9:30 – 9:45 Welcome & Opening remarks
- 9:45 – 10:00 **ICEBREAKER** – networking with your neighbours
- 10:00 – 10:45 **Andrea Shugar**, genetic counselor, Hospital for Sick Children
- 10:45 – 11:00 ***** QUESTION PERIOD *****

- 11:00 – 11:15 BREAK
- 11:15 – 11:45 **Vedant Arun**, researcher
- 11:45 – 12:00 Personal Stories and electro desiccation presentation
- 12:00 – 12:10 **Presentations** and Awards

- 12:10 – 1:00 LUNCH
- 1:00 – 1:10 Raffle – part 1
- 1:10 – 1:55 **Video clip** – I have NF – a documentary
- 1:55 – 2:15 small group discussion on video

- 2:15 – 2:25 BREAK
- 2:15 – 2:40 **Charity business**, presentation of financials, voting,
- 2:40 – 2:55 raffle – part 2
- 2:55 – 3:00 Thank you and **Closing remarks**

******* Question period is a time for you to share *your* questions. They will be addressed by Andrea Shugar, and/or any doctors present who are willing to assist. You can send questions to us in advance by email, bring them to the meeting, ask them anonymously using our questions box located near registration, or ask them from the floor during question period. We will try to answer as many as we can, but sometimes with NF, there just isn't an answer.

Guest Speaker Bios and Overview

Andrea Shugar , MS, CGC,CCGC Genetic Counsellor, Clinical Genetics – is a genetic counselor in the Division of Clinical and Metabolic genetics at the Hospital for Sick Children and has been in practice since 1992. She received her undergraduate degree from U of T and her master of science in genetic counseling and biological sciences from the University of Cincinnati. Andrea is the past president of the Canadian Association of Genetic Counsellors, and was on the first Certification Board of Canadian Genetic Counsellors. In her current position at the Hospital for Sick Children, Andrea teaches and supervises graduate -level genetic counselling students, provides genetic counseling to paediatric patients and their families and is involved in establishing a new multi-disciplinary for clinic 22q-11 deletion syndrome (velocardiofacial syndrome). Andrea has a special interest in research ethics and issues surrounding predictive testing for adult onset disorders and the multi-disciplinary care model.

Andrea will speak about the genetics of NF, it's association with other conditions, and she will share some results from a clinical research project that looks at NF1 symptoms in very young children and to identify who may benefit from DNA testing. She will then try to address your questions and concerns.

Vedant Arun - was fascinated by the cancer paradigm through highschool and his undergraduate studies. He initially joined the research group of Dr Mark Minden to study protein interactions in Acute Myeloblastic Leukemia. Vedant later joined Dr. A Guha's neurooncology lab to study a similar protein-protein interaction. Vedant is a PhD candidate who is published for his lead in the current study of the NF1 - LRPPR C interaction and as part of a research team with Dr Guha studying rapamycin in MPNST. Vedant has been a frequent speaker and guest at our NFSO meetings. I apologize to him, if in attempting to simplify his studies, I have omitted or altered important information.

Vedant will present "NF1 and café-au-lait macules:What's the link?" This is a summary of his current research looking at protein interactions associated with NF1 and Leigh's syndrome (French Canadian variant). This research revealed a deep insight into a possibly novel etiopathogenesis for the cognitive disorders. It has opened the door to exploring a unique underlying cause of cognitive dysfunction in NF1 from the perspective of a very intriguing molecular phenomena.