



ST. JOHN'S DRAVET DAY

Saturday, April 8, 2017

2M240, FACULTY OF MEDICINE
Memorial University of Newfoundland



Video conference link with PGCRL Salter Auditorium Hospital for Sick Children, Toronto, Ontario

AGENDA

- 9:00 **REGISTRATION/COFFEE** (2M240, St. John's)
- 9:20 **WELCOME AND OPENING REMARKS**
Patti Bryant, Co-Chair, dravetCanada
- 9:30 **NAVIGATING NEW WATERS ****
Rhonda Noseworthy, BSW, RSW
- 10:00 **PRIMARY CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES: WHAT SUPPORTS ARE IN PLACE IN NL? ****
Dr. Katherine Stringer, MBChB, CCFP, FCFP
- 10:30 **NUTRITION BREAK**
(What follows is the video conference with the Hospital for Sick Children. We will be muted during presentations and able to ask questions after each)
- 10:45 **WELCOME AND OPENING REMARKS in Toronto**
Guida Quaglia Clozza, Co-Chair, dravetCanada
- 10:50 **DIAGNOSIS AND TREATMENT OF DRAVET SYNDROME: FROM SEIZURES TO SCN1A AND EVERYTHING IN BETWEEN**
Dr. Elizabeth Donner
- 11:30 **LONG TERM OUTCOMES FOR DRAVET SYNDROME****
Dr. Danielle Andrade
- 12:15 **NUTRITION BREAK**
- 12:30 **STRATEGIES FOR DEVELOPING GENE THERAPY FOR TREATING DRAVET SYNDROME**
Dr. David Hampson
- 1:00 **PHYSIOLOGY AND PHARMACOLOGY OF CANNABIS; EPLINK ADULT CBD TRIAL****
Dr. McIntyre Burnham
- 1:30 **CANNABINOIDS FOR CHILDHOOD EPILEPSY:WHAT DO WE KNOW?; SICK KIDS CBD TRIAL**
Dr. Blathnaid McCoy
- 2:00 **A FAMILY'S PERSONAL JOURNEY ****
Barry and Shannon Pogson
- 2:15 **LUNCH** (2M240)
- 3:15 **WHAT DO WE KNOW ABOUT SUDEP IN DRAVET SYNDROME****
Dr. Elizabeth Donner
- 4:00 **TRANSITIONING FROM PEDIATRIC CARE TO ADULT CARE****
Dr. Danielle Andrade
- 4:30 **THANKS AND CLOSING REMARKS in St. John's**
(What follows is the Ontario-specific portion of the day, and we are welcome to remain on the feed for the duration. The directly preceding presentation is also Ontario-specific, but a good example of a realized transition program.)
- 4:45 **NAVIGATING THE SCHOOL AND SOCIAL SYSTEM FROM PRE-SCHOOL TO ADULT LIFE****
Joe Trovato , Jon Greenaway and Lezlee Lindon
- 5:45 **PANEL DISCUSSION**** – Dr. Danielle Andrade, Dr. Elizabeth Donner, Dr. Blathnaid McCoy and others
- 6:15 **CLOSING REMARKS**
Guida Quaglia Clozza