



atypical  
Hemolytic  
Uremic  
Syndrome

# aHUS Canada

Supporting patients and families living with aHUS



Syndrome  
Hémolytique  
et Urémique  
atypique

# SHUa Canada

Nous supportons les patients et les familles vivant avec le SHUa

# Welcome!

## aHUS Canada Annual Patient Meeting

Saturday, May 23, 2015



# Introductions

## About aHUS Canada



# Our Board Members

**Michael Eygenraam (ON)**

Vice-Chair

**Sonia Giroto (ON)**

Treasurer

**Margriet Eygenraam (ON)**

Secretary

**Carrie Stogryn (AB)**

Member

**Glenn Stogryn (AB)**

Member

**Nancy Lafleur (QC)**

Member

**Brian Tjepkema (BC)**

Member

# Our Medical Advisors

**Dr. Christoph Licht**

Pediatric Nephrologist – Toronto

**Dr. Anne Laure Lapeyraque**

Pediatric Nephrologist – Montreal

**Dr. William Clark**

Nephrologist – London

**Dr. Christopher Patriquin**

Hematologist – Hamilton

**Michelle Mayne**

Clinical consultant – Toronto

# What we do

- aHUS Canada is a not-for-profit organization formed in November 2012
- Our mission is to support patients and families living with aHUS
- All aHUS Canada board members are either caregivers to aHUS patients, or aHUS patients themselves

# Today's agenda highlights

- **Dr. Licht** – One of our association's medical advisors
  - Many of you already know him as a world renowned researcher
- **Dr. Hladunewich** – A local clinician here to speak about living with aHUS
- **John Bylok** – present the results of last fall's survey of patient experiences
- **Lisa Di Lollo** – Last fall we hired her as our government relations consultant. She has been instrumental in helping us establish connections with gov't. Lisa will be talking about what we have accomplished this past year.
- **Ryan Clarke** – our advocacy consultant
  - will discuss the advocacy tools we can use for the coming year
- **Keegan Johnson** – Special speaker this afternoon who has extensive experience working in rare disease patient groups.
- **Patient** stories and sharing

# aHUS Canada update

Updates since our last  
meeting





# General highlights

- Hired Lisa Di Lollo as our G.R. consultant
- Distributed 2<sup>nd</sup> issue of aHUS Alert/Avis SHUa
- Engaged and supported patients/caregivers
  - Met with aHUS families to strategize their advocacy
  - Secure public access to Soliris for an aHUS patient
- Interim funding of Soliris was announced
- Dr. Tim Goodship Visit (from UK)
  - Met with Ontario MOH and patients
  - Raised awareness of Soliris use in UK



# Government highlights

- Met with various senior policy advisors in Ontario's government
- Met several times with Ontario's E.O. (Suzanne McGurn) and her team
- Presented statement to Ontario's Finance Minister
- Held “Lobby Day” at Ontario's legislature



# Advocacy highlights

- Used provincial advocacy packages and “email tool” on website
  - over 3300 letters sent to date
- Met with numerous MPPs/MLAs
- Over 8000 petitions given to Ontario legislature



# Media highlights

- Many newspaper, radio and TV segments ran
- Several high profile newspaper stories

# Goals for the year ahead

What we are striving to  
achieve in 2015



# General goals

- Encourage other provinces to provide interim funding
  - Engage patients and associations from other provinces
  - Write letters/send info to drug plan managers
- Connect with more patients, caregivers and physicians and provide support, as needed
- Add additional patient stories to aHUS Canada website (“Meet the Community”)
- Recruit new board members for succession plan
- Begin fund raising to gain more independence
- Distribute e-newsletters (aHUS aLERT/aVIS SHUa)

# Government goals

- Continue to engage with government decision makers
  - Reach out to all provinces in Canada
  - Drug plan managers
  - Health Ministers
  - Opposition health critics
  - Premiers

# Advocacy goals

- Engage additional families and physicians to become advocates
- Secure additional meetings with members of provincial parliament (MLAs, MPPs, MNAs)
- Support advocates to meet with their local MPPs/MLAs
- Conduct advocacy activities such as letter writing, petitions, etc.



# Media goals

- Support additional patients/caregivers to advocate through the media
- Sustain disease awareness and pressure on governments through the media by securing additional stories
  - Goal to help communicate the value of drugs for rare diseases and impact of access/lack of on patient