



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 Meeting

Saturday, April 26, 2014



Introductions

About aHUS Canada



Who we are

Tracy MacIntyre (ON)

Chair

Kevin MacIntyre (ON)

Member

Michael Eygenraam (ON)

Vice-Chair

Carrie Stogryn (AB)

Member

Sonia Giroto (ON)

Treasurer

Glenn Stogryn (AB)

Member

Margriet Eygenraam (ON)

Secretary

Nancy Lafleur (QC)

Member

Brian Tjepkema (BC)

Member

Our advisors

Medical Advisory Committee

Dr. Christoph Licht

Pediatric Nephrologist – Toronto

Dr. Anne Laure Lapeyraque

Pediatric Nephrologist – Montreal

Dr. William Clark

Nephrologist – London

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

- 9:15 – 9:45 a.m. aHUS Canada Update
- 9:45 – 10:00 a.m. Alexion Update
- 10:00 – 10:15 a.m. Break
- 10:15 – 11:45 a.m. Clinical Update/Discussion
- 11:45 – 12:30 p.m. Lunch/Check-Out
- 12:30 – 12:45 p.m. OneSource Update
- 12:45 – 1:30 p.m. Intro to Advocacy/Drug Approval Process
- 1:30 – 2:00 p.m. Intro to Advocacy Through the Media
- 2:00 – 2:15 p.m. Break
- 2:15 – 2:45 p.m. Ensuring Your Engagement
- 2:45 – 3:45 p.m. Sharing Stories
- 3:45 – 4:00 p.m. Closing

aHUS Canada update

Updates since our last meeting



General highlights

- Recruited three leading aHUS specialists as medical advisors
- Expanded aHUS Canada's board of directors to include members from AB and QC
- Distributed information cards at CAG and CSN conferences
- Launched first issue of aHUS Alert/Avis SHUa
- Engaged and supported patients/caregivers across Canada
 - Helped secure exceptional access to Soliris for an aHUS patient in Winnipeg

Government highlights

- Letters sent to provincial drug plan managers regarding negative CDR recommendation for Soliris
- Letters sent to ministers of health
- Meeting with Ontario Minister of Health's senior policy advisor
- Meeting with Ontario's opposition health critic
- Meetings with provincial drug plan managers
 - Diane McArthur (Ontario)
 - Michelle Evans (Alberta)
- Engaged support of Julian Fantino (Vaughan MP)

Advocacy highlights

- Provincial advocacy packages added to website
- “Email Your Premier & Health Minister” tool on website
 - over 700 letters sent to date
- Met with Durhane Wong-Rieger from CORD to discuss synergies between our groups and for guidance in meetings with drug plans
- Met with numerous MPPs/MLAs

Media highlights

- News releases distributed nationally in response to CDR and NEJM publication
- Participated in two Rare Disease supplements in the National Post
- Media interviews conducted with key outlets in Vancouver, Edmonton, Winnipeg, Toronto, Vaughan, Brampton and Ottawa
- Story ran on Global National in April 2014

Goals for the year ahead

What we are striving to achieve in 2014



General goals

- Distribute quarterly e-newsletters (aHUS aLERT/aVIS SHUa)
- Publish a brochure on diagnosis and treatment of aHUS
- Add additional patient stories to aHUS Canada website (“Meet the Community”)
- Connect with more patients, caregivers and physicians and provide support, as needed

Government goals

- Secure additional meetings with government decision makers
 - Drug plan managers
 - Second meeting with Diane McArthur in May 2014
 - Alberta Health Minister Fred Horne
 - Ontario Premier, Minister of Health and opposition health critic (pending election outcome)

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 petitions, postcards, etc.

Media goals

- Support additional patients/caregivers/physicians to advocate through the media
- Sustain disease awareness and pressure on governments through the media by securing additional stories
- Educate reporters on aHUS at a media briefing at CORD Toronto workshop on May 2
 - Goal to help communicate the value of drugs for rare diseases and impact of access/lack of on patient

Alexion update

John Haslam

General Manager

Alexion Pharma Canada



Clinical update & discussion

Dr. Christopher Patriquin

Hematologist, McMaster University



OneSource update

Melanie Laviolette, RN

Associate Program Manager, OneSource



Introduction to advocacy and the drug approval process

Ryan Clarke

Advocacy Solutions



Introduction to advocacy through the media

Joanne Koskie

Cohn & Wolfe



Ensuring your engagement



What you can do now

- Visit your MPP/MLA/MNA
 - advocacy packages and one-on-one support
- Engaging your network
 - “Email Your Premier & Health Minister” tool
 - Collect signatures on a petition (Ontario)
- Local media outreach
 - media training and one-on-one support

Sharing stories

Tell us about yourselves!



Thank you for coming

We look forward to working with you!

