The importance of global collaboration to optimise haemophilia care

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The Hospital for Sick Children Toronto, Canada

- Founded in 1875
- Number of admissions in 2016 = 15,988
- Number of out-patient clinic visits in 2016 = 227,651

Division of Haematology/Oncology/Stem Cell Transplantation

- Paediatric Oncology
  - Leukaemia/Lymphoma Section
  - NeuroOncology Section
  - Solid Tumour Section

- Stem Cell Transplantation Section

- Non-malignant Haematology Section
  - Thrombosis and Haemostasis Programme
  - Haemoglobinopathy Programme
  - Bone Marrow Failure Programme
  - “Benign” Haematology Programme
Number of Fellows who are Haemophilia Academy Alumni (2008–Current) = 10
Your experience as a participant in the Haemophilia Academy

“Attending the Haemophilia Academy changed the trajectory of my career. I was a second year fellow in hematology-oncology hoping to specialize further in hemostasis-thrombosis. I now help run the Joan Hemostasis-Thrombosis fellowship at Nationwide Children’s Hospital in Columbus, OH.”

Riten Kumar (USA), 2009 attendee

“This excellent experience polished my education in thrombosis and haemostasis, and the knowledge I acquired has accompanied me ever since.”

Laura Avila (Argentina), 2010 attendee

“A unique opportunity to learn and share personal experience in the care of patients with haemophilia and other bleeding disorders, in a well elaborated meeting concept and a fantastic environment.”

Mattia Rizzi (Switzerland), 2012 attendee

“International/global cooperation is essential to achieve the best care for patients with haemophilia. The Haemophilia Academy has a very special role in this cooperation. It provided an opportunity to not only learn but as well to develop a precious relationship with people who have been or are becoming dedicated to the best possible care of people with bleeding disorders.”

Ester Zapotocka (Czech Republic), 2016 attendee
Map of China showing locations of the 6 Haemophilia Treatment Centre Collaborative Network of China (HTCCNC) centres

- Population: 1.33 billion
- Size: 9.6 million square km
- Estimated number of persons with haemophilia: 80,000-120,000*

- Initial WFH twinnings occurred with HTCs in Canada:
  - Ottawa (Medical Director Dr Brian Luke)
  - Calgary (Medical Director Dr Man-Chiu Poon)

- China achieved WFH Global Alliance for Progress (GAP) recognition in 2009

HTC, Haemophilia Treatment Centre, WFH, World Federation of Hemophilia
China–Canada Collaborative Group

- Founded in 2007
- Co-Directors of the collaboration:
  - **China**
    - Dr Runhui Wu (Medical Director, Hemophilia Treatment Center, Beijing Children’s Hospital)
    - Dr Jing Sun (Medical Director, Nanfang Hospital, Guanzhou)
  - **Canada**
    - Dr Brian Luke (Ottawa)
    - Dr Victor Blanchette (Toronto)

- **Key initiatives**
  - Exchange training visit of Dr Ningning Zhang (Radiologist, Beijing Children’s Hospital) to train in musculoskeletal imaging at the Hospital for Sick Children, Toronto under the supervision of Dr Andrea Doria
  - Development and testing of a Chinese version of the Hemophilia Joint Health Score (HJHS)
  - Development and testing of a Chinese version of the Hemophilia Quality of Life instrument, the CHO-KLAT
Low dose secondary prophylaxis in China

Overview
- Children (2–18 years) with moderate/severe haemophilia A or B and established joint disease
- 12-week observation period followed by a 12-week low dose secondary prophylaxis period
  - Haem A, factor VIII concentrate 10 IU kg⁻¹ twice weekly
  - Haem B, factor IX concentrate 20 IU kg⁻¹ weekly

Results
- Frequency of joint bleeding significantly reduced
- Moderate improvement in joint function, school attendance, sport participation and daily activities

Follow-up study
- Confirmed benefits of a low dose prophylaxis protocol in a multi-centre setting in China (191 patients, 15 centres)
- Obstacles to overcome: improvement in comprehensive care and in education of patient/parents and healthcare personnel re. benefits of adherence to protocol

Important benefits arising from global collaborations to optimise haemophilia care

- How the Haemophilia Academy promotes global collaboration:
  - Inspiring trainee haematologists to consider a career in haemophilia
  - Creating international networks and opportunities to collaborate
  - Sharing research ideas
  - Highlighting the need for clinical studies

- Clinical trials for new therapies are increasingly dependent on global collaborations

- Studies of different long-term prophylaxis regimens that include objective outcome measures are urgently needed with the goal of improving access to prophylaxis for persons with haemophilia globally