



**Haemophilia Academy**

# **The importance of global collaboration to optimise haemophilia care**

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# The Hospital for Sick Children Toronto, Canada

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- 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

# Thrombosis and haemostasis Fellows at SickKids 2008–Current



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● Number of Fellows who are Haemophilia Academy Alumni (2008–Current) = 10

# Your experience as a participant in the Haemophilia Academy

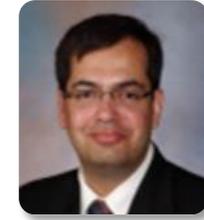


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"Attending the Haemophilia Academy **changed the trajectory of my career**. I was a second year fellow in hematology-oncology **hoping to specialize further in hemostasis-thrombosis**.

**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*



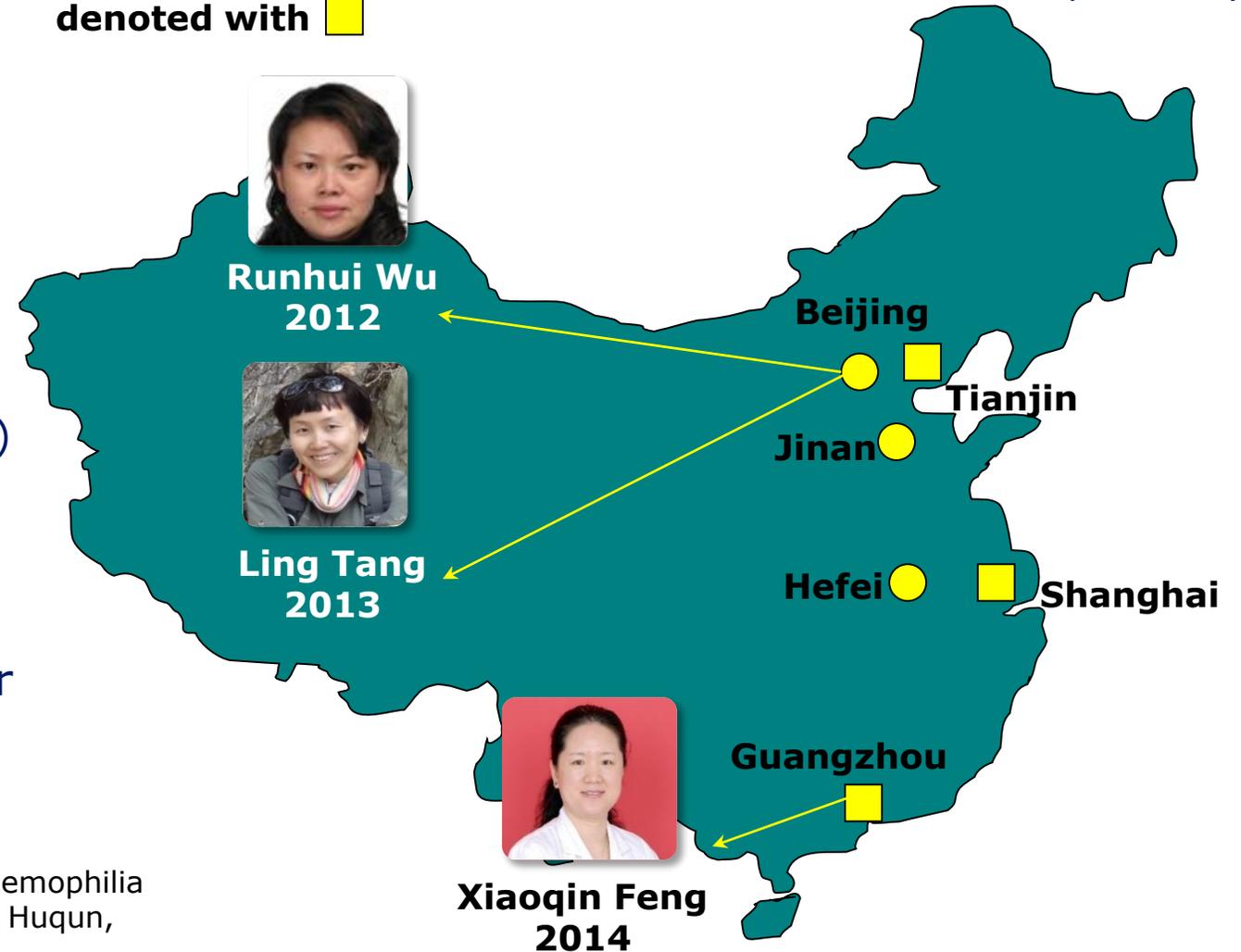
# Map of China showing locations of the 6 Haemophilia Treatment Centre Collaborative Network of China (HTCCNC) centres



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- Population: 1.33 billion
- Size: 9.6 million square km
- Estimated number of persons with haemophilia: 80,000-120,000\*
- Initial WFH twinings occurred with HTC 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

WFH twinning centres denoted with 



HTC, Haemophilia Treatment Centre, WFH, World Federation of Hemophilia  
\*Current situation and diagnosis of hemophilia children in China, Huqun, *Journal Of China Pediatric Blood And Cancer*, 2010,15(2)

# China–Canada Collaborative Group

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Haemophilia Academy

- 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<sup>1</sup>
- 12-week observation period followed by a 12-week low dose secondary prophylaxis period
  - Haem A, factor VIII concentrate 10 IU kg<sup>-1</sup> twice weekly
  - Haem B, factor IX concentrate 20 IU kg<sup>-1</sup> 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)<sup>2</sup>
- Obstacles to overcome: improvement in comprehensive care and in education of patient/parents and healthcare personnel re. benefits of adherence to protocol

1. Wu R, Luke KH, Poon MC, et al. *Haemophilia* 2011;17:70–74

2. Tang L, Wu R, Sun J, et al. *Haemophilia* 2013;19:27–34

# Important benefits arising from global collaborations to optimise haemophilia care

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Haemophilia Academy

- 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

