

IHTC ALUMNI NEWSLETTER

MESSAGE FROM MIKE MAKRIS INTERNATIONAL HEMOPHILIA TRAINING CENTRE (IHTC) COMMITTEE CHAIR

Welcome to the first edition of the World Federation of Hemophilia (WFH) IHTC e-newsletter. We hope that this will be a useful vehicle for IHTC fellowship alumni to stay connected and get the latest updates on IHTC news and events.

The newsletter will highlight stories of past IHTC fellows who have gone on to share what they learned during their IHTC fellowship training. We will also provide updates on WFH research and activities, including the new WFH Clinical Research Grant Program (visit www.wfh.org/crgp for more details).

By creating a strong link between the WFH and IHTC alumni, we hope to keep the WFH connected to its volunteers and help extend the educational experience of all fellows, past, present and future, beyond their training.

IHTC: DECADES OF PROGRESS

Founded in 1972, more than 585 fellows from 85 countries have been awarded fellowships. Since its founding, the aim of the program has remained the same: to train people in how to provide comprehensive care using practical methods so that they can then implement these strategies in their home countries. Today, there are 28 IHTCs that provide training in 19 countries.

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As the number of applications grows every year, the WFH continues to strive to provide appropriate and adequate training that match the IHTC fellows' language and specialization background. We are working towards adding more IHTCs that could train in Spanish, Arabic, French and Russian. In addition, there is also a need for more centres that can provide solid curricula in dentistry and physiotherapy.

The number of IHTC fellowship alumni continues to increase, and it is our desire to provide a stronger network of trained professionals that can share best practices and ideas, as well as provide global leadership to improve and sustain care for people with inherited bleeding disorders. We hope that this e-newsletter will inspire and motivate you in your work. We encourage you to use this platform to stay connected with us. Share your stories! We want to know how your IHTC fellowship training has helped further your career, and how you have helped the bleeding disorder community in your country.

Enjoy, and we hope to hear from you soon!



PROFESSOR MIKE MAKRIS, MD
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IHTC OVERVIEW

In 1972, the World Federation of Hemophilia (WFH) launched the International Hemophilia Treatment Centre (IHTC) Program, conceived by medical secretary Anthony Britten, MD, a doctor with severe hemophilia. For Dr. Britten, the centres would bring “inspiration to many, and leadership to all of us.” The IHTC Fellowship training program provides clinical, laboratory, and paramedical training

at one of the following designated international hemophilia training centres (IHTC). The program started with 15 training centres, growing to 28 IHTCs in 19 countries.

The goal of the IHTC Fellowship Program is to provide training for people working in hemophilia in the developing parts of the world by giving an intensive period of training in the diagnosis and management of hemophilia, and other inherited bleeding disorders. Many of the past

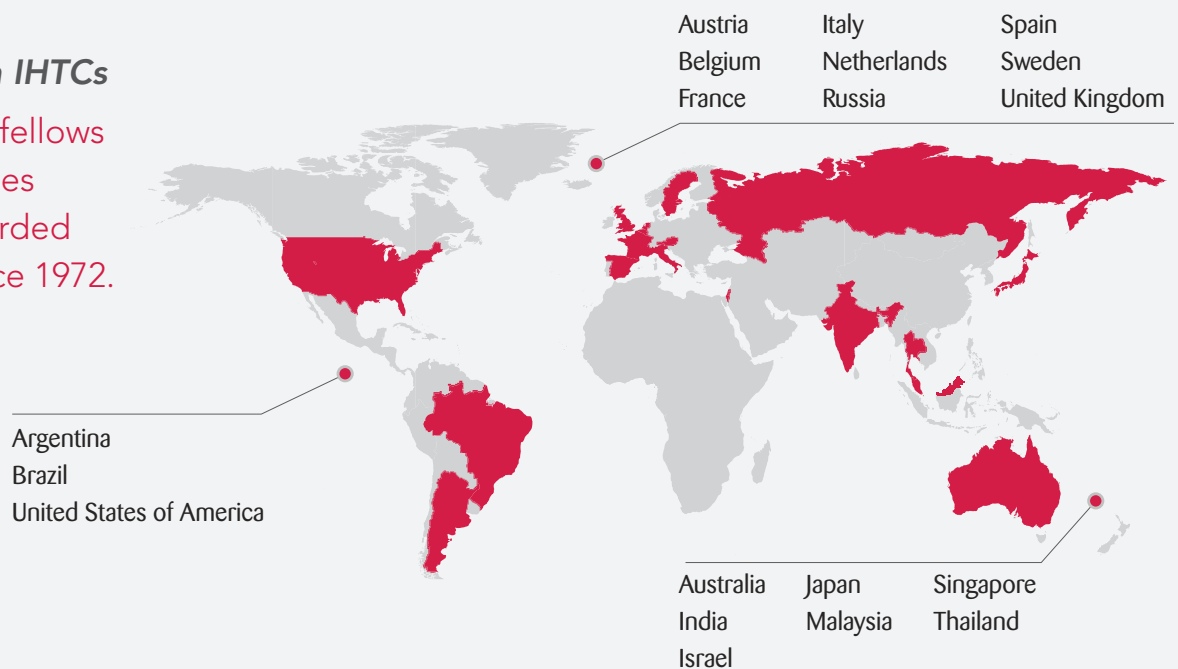
(Left): IHTC Fellow Dr. Olivera Serbic Nonkovic (Serbia) with the staff from the Katharine Dormandy Haemophilia Centre and Thrombosis Unit from the Royal Free Hospital, as well as the members of the UK Hemophilia Society on World Hemophilia Day.

(Right): Dr. Cedric Hermans, IHTC Director and Dr. Catherine Lambert of the Haemostasis and Thrombosis Unit, Cliniques universitaires Saint-Luc, Brussels, with IHTC Fellows Mr. Dje Bi Zinzi Stanislas and Dr. N'Dogomo Meite (Ivory Coast).

IHTC fellows have gone on to become leaders in hemophilia care in their own countries. The vast majority of those trained continue to care for patients with bleeding disorders.

Countries with IHTCs

More than 585 fellows from 85 countries have been awarded fellowships since 1972.



IHTC OVERVIEW

The IHTC Fellowship program covers the costs of the following: economy class return airfare or train ticket, visa application, travel medical insurance, as well as accommodations and meals during the training. Directors of the selected IHTCs will help to arrange for accommodation and meals. The duration of the fellowship is from four to six weeks.

Interested potential applicants should discuss the application form with their hospital and their national hemophilia member organization (NMO).

APPLICANTS SHOULD:

Have strong medical references

Have a strong recommendation from their officially recognized national hemophilia member organization (NMO)

Be committed to improving hemophilia treatment after completion of the training period

Have a working knowledge of one of the following languages: English, Spanish, French or Russian

A new application form is posted on the WFH website on September 1, and the application package must be received at the WFH headquarters by October 31 of each year.

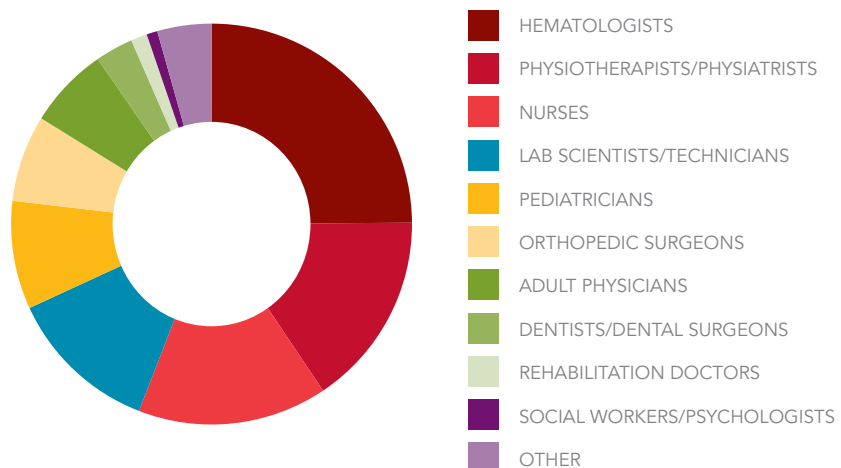
For more information on the IHTC Fellowship Program, please visit: http://www.wfh.org/en/IHTC_Fellowship_Program

A list of the 2014 fellows is also available here: http://www.wfh.org/en/IHTC_Fellowship_Recipients (this is also available in Spanish and French).

DISTRIBUTION OF FELLOWS BY REGION: 2006-2013



DISTRIBUTION OF FELLOWS BY DISCIPLINE: 2006-2013



2013 IHTC FELLOWSHIP BREAKFAST SYMPOSIUM

The WFH and Bayer HealthCare, sponsor of the WFH IHTC Fellowship Program, have been exploring ways to celebrate the outstanding achievements of all those involved in the program over the years, as well as opportunities for IHTC fellows from around the world to meet one another, share experiences and reconnect with their training providers.

In the second half of 2011, WFH conducted an impact evaluation on fellowships undertaken between 2006 and 2010. Fellows and NMOs alike identified a need for greater communication and support in the post-fellowship period, allowing them to: stay connected with the WFH and other fellows; implement what they learned; and be informed of the WFH

events and other training opportunities.

In July 2012, during the WFH World Congress in Paris, France, WFH and Bayer HealthCare organized the first ever IHTC networking reception. The event was well received and well attended by IHTC alumni and IHTC Directors, and led to the idea of creating an IHTC Alumni Network.

In early June 2013, a questionnaire was prepared by WFH and sent to 240 IHTC alumni asking for their feedback about whether they would like to receive more information from the WFH, what type of information they preferred, and in what form. Results from the survey were tabulated in the last week of June, and a brief summary was presented at the IHTC Fellowship Breakfast

Symposium, which took place during the ISTH Congress in Amsterdam. WFH received 102 responses from 48 countries. The vast majority reported that they would like to stay more connected to the WFH, and 76 percent indicated a preference for an alumni e-Newsletter.

During the IHTC Breakfast symposium, Prof. Mike Makris presented a brief overview of the WFH IHTC Fellowship Program, when it started, how many fellows have been trained to date, and the program's structure. The symposium also featured presentations by an IHTC Director and two past fellows. Dr. Miguel Escobar from the Gulf States Hemophilia and Thrombophilia Center in Houston (USA) spoke about the experience of his centre in

the IHTC Program since 2000 and their approach to training fellows from different countries and disciplines. Dr. Nguyen Thi Mai (Vietnam) and Dr. Claudia Djambas Khayat (Lebanon), both IHTC alumni, spoke about their fellowship experiences, the status of care in their country prior to training, reasons for participating in the program, what they learned in training, how the fellowships increased their knowledge of hemophilia care and management, and how they have been able to institute changes to improve bleeding disorder care in their own countries.

We are planning another symposium in Melbourne and encourage all IHTC alumni attending the WFH Congress to come and learn and network with fellow alumni.



The World Federation of Hemophilia (WFH) International Hemophilia Training Centre Fellowship Program Breakfast Symposium

The World Federation of Hemophilia (WFH) and Bayer HealthCare cordially invite you to a breakfast symposium and networking event to discuss the WFH International Hemophilia Training Centre (IHTC) Fellowship Program.

Where: Melbourne Convention and Exhibition Centre
Room 210
1 Convention Centre Place
South Wharf 3006
Melbourne

When: Tuesday, May 13, 2014
07:00 - 09:00

More Information: Breakfast will be provided.

RSVP: If you are interested in attending, please RSVP to Stephanie Pineda at ihtc@wfh.org by April 25, 2014.

This event may be videotaped or photographed for use in promoting the WFH IHTC Fellowship Program by Bayer or WFH. By attending, you are granting permission for your participation to be included in program promotion.

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ALUMNI SPOTLIGHT



DR. NGUYEN THI MAI

Undertook her fellowship in January-February 2006 in the IHTC in Bangkok (Thailand). Currently Head of the Hemophilia Centre, National Institute of Hematology and Blood Transfusion, in Hanoi, Vietnam.

Dr. Nguyen Thi Mai's work in Hanoi is a testament to the type of skills one can develop and the success one can achieve through an IHTC fellowship. In 2006, she joined the program in Bangkok where she gained experience in hemophilia care and treatment. Some of the skills she learned during her fellowship included how to better organize a hemophilia program in her own country, the importance of patient and caregiver training, and how advocacy and research can be used to advance care.

After completing her fellowship, Dr. Mai returned to Vietnam and began

developing programs to help improve treatment in her local community. In the last eight years, she has developed guidelines for the diagnosis and treatment of hemophilia, made strides in generating greater awareness of hemophilia, and helped forge connections between those in the community. Dr. Mai has also published her work and created a website, hemoviet.org.vn.



DR. CLAUDIA DJAMBAS KHAYAT

Undertook her fellowship in July 2006 at the Royal Free Hospital in London (UK). Currently, Pediatric Hematologist at the Hotel Dieu de France Hospital, St. Joseph University, in Beirut, Lebanon.

Dr. Claudia Djambas Khayat also began her IHTC journey in 2006, but at the Royal Free Hospital in London. There she gained the experience she needed to drive change back in Beirut. During her time in the IHTC Fellowship Program, Dr. Khayat gained a better understanding of joint bleeding, treatment options, and the importance of physiotherapy and a multidisciplinary approach. She also learned the importance of a good data registry strategy and of employing a community approach in caring for persons with hemophilia.

After finishing the program, Dr. Khayat returned to Beirut where she began implementing multidisciplinary consultations at her local centre. She has also worked to improve data registry at her centre and developed a three-year education program for patients, nurses and first-line doctors. Dr. Khayat drafted the first version of treatment guidelines for hemophilia in her community and conducted a genetic study of FVIII gene and genetic counseling. She is currently a pediatric hematologist at the Hotel Dieu de France Hospital in Beirut.

CALENDAR OF EVENTS

APRIL

17 WORLD HEMOPHILIA DAY

MAY

11-15 WFH WORLD CONGRESS

Melbourne, Australia

13 IHTC BREAKFAST SYMPOSIUM

Melbourne, Australia

AUGUST

31 WFH CLINICAL RESEARCH GRANT PROGRAM

Deadline for submissions



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www.wfh.org

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WFH **50** YEARS OF ADVANCING TREATMENT FOR ALL

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