It is with great honor and happiness that I write to you as the new International Hemophilia Training Centre (IHTC) Committee Chair. I have been a member of this committee for the last eight years. As an IHTC Director, I have had the joy and privilege to see and train many healthcare professionals at the Gulf States Hemophilia and Thrombophilia Center in Houston, USA, as well as see IHTC fellows getting involved with the bleeding disorders community.

Since the program was launched in 1972, over 685 healthcare professionals from 96 countries have benefitted from the program. Following the success of the IHTC Alumni event held at the WFH 2016 World Congress in Orlando, we received over 100 applications from around the world for the 2017 IHTC Fellowship Program cycle. We are also witnessing the results of our new designated IHTCs, with French, Arabic, and English speaking fellows from Africa and the Middle East able to train in Johannesburg, Dakar, and Cairo.

The WFH recently conducted an impact evaluation of the IHTC Fellowship Program for the period of 2011–2015, which allowed us to review the powerful impact and difference that mentors, trainers, and fellows have made to the life of people living with bleeding disorders around the world. Almost all fellows show outstanding commitment to bleeding disorders care, with 90% continuing to work in hemophilia care at the time of the survey and 97% planning to continue in this field for the next five years. In addition, 97% of the fellows have already shared their acquired knowledge and skills with their peers, patients, and families.

The positive impact of the WFH IHTC Fellowship Program in the areas of enhancing medical and paramedical knowledge and expertise, as well as in improving diagnosis, better management, and care of people with bleeding disorders, is a constant motivation to keep this program growing. I am optimistic that more healthcare professionals will continue to benefit from the program in the years to come.
More than 685 fellows, from 96 countries, have been awarded fellowships since 1972.

MAP OF CURRENT IHTCS

There are 31 International Hemophilia Treatment Centres around the world located in 22 countries.

DISTRIBUTION OF FELLOWS BY REGION: 2008-2017

- Middle East & Western Africa (20%)
- Eastern, Central & Southern Africa (9%)
- Central America & Caribbean (13%)
- South America (15%)
- South Asia & East Asia (18%)
- Southeast Asia & Western Pacific (7%)
- Europe (18%)

DISTRIBUTION OF FELLOWS BY DISCIPLINE: 2008-2017

- Hematologists
- Physiotherapists/Physiatrists
- Nurses
- Lab Scientists/Technicians
- Pediatricians
- Adult physicians
- Orthopedic Surgeons
- Dentists/Dental surgeons
- Psychologists/Social Workers
- Other

The goal of the IHTC Fellowship Program is for fellows to implement the knowledge and expertise acquired through their training to improve bleeding disorders treatment in their own country. An impact evaluation was conducted from July to August 2016 and surveyed all fellows who undertook fellowships between January 2011 and December 2015, as well as all WFH national member organizations (NMO) whose country benefitted from one or more fellowships during the same period. The objectives of the impact evaluation were to: determine the involvement of IHTC fellows in the bleeding disorders care; examine how the fellowship specifically helped them to advance care in their countries; and look at possible ways to improve the program so that it can better reach its aims. In total, 125 fellows and 53 NMOs were surveyed. From this group, we received responses from 94 fellows (75% response rate) and 39 NMOs (74% response rate).

Some of the answers are represented in the following graphs.

**IMPLEMENTATION OF WHAT FELLOWS LEARN DURING THEIR TRAINING:**

![Graph showing various categories of implementation](image)

The majority of decisions regarding how hemophilia care is managed are done by the fellows’ hospital or HTC administrations. The vast majority of fellows (84; 89%) reported that their fellowship brought about changes in bleeding disorders care in their hospital or centre. Eight fellows (9%) reported that their training did not result to any changes in the way patients with bleeding disorders were treated.

**HOW THEIR ROLES HAVE CHANGED IN THEIR PLACE OF WORK AFTER THEIR FELLOWSHIP:**

![Graph showing various roles](image)

Respondents were asked if they thought their training had also benefited the bleeding disorders community in their country. Again, a similar trend was observed, with the majority (97%) of the respondents confirming that their fellowship had a positive bearing on the patients.

**Did your IHTC fellowship result in any changes to the way hemophilia care is managed in your hospital/HTC?**

- Yes: 88%
- No: 4%
- Blank: 2%

**Do you think that your training has benefited the patients with bleeding disorders in your hospital/HTC?**

- Yes: 97%
- No: 1%
- Blank: 2%
IHTC-RTW Joint Event: Building Capacity to Address Global Need

At the WFH 2016 World Congress in Orlando, WFH and the International Society of Thrombosis and Haemostasis (ISTH) collaborated for a second time in organizing a joint-alumni event called “Building Capacity to Address Global Need: Working with the WFH and ISTH Fellowship Programs”. The event was open to the public and well attended. Mike Makris, MD, in his role as chair of the IHTC Committee, was the moderator. Panel speakers included Phillippe de Moerloose, MD (Geneva), Evelien Mauser-Bunschoten, MD (Utrecht), Cesar Haddad (Lebanon), and Zhengping Chen, MD (China).

To encourage productive and familial conversations, the meeting took the form of a moderated panel and roundtable discussions. Mentors, trainers, and former fellows of the IHTC and RtW programs from around the world discussed how to raise awareness of the value of capacity building and leadership development in hemophilia, thrombosis, and hemostasis. Participants from over 20 countries took part in this event, with the goal of highlighting the success of the fellows and alumni, as well as in improving care for bleeding disorder patients in their countries.

Groups sat at tables that were limited to ten people in order to keep the conversations familial and ensure that everyone had a chance to speak and share their views. The event concluded with a networking session, leaving the participants with a very optimistic feeling regarding their role in improving care around the world.
The Johannesburg IHTC started training fellows in hemophilia in 2016, following accreditation by the WFH. We have trained nine WFH sponsored and self-funded fellows who have included two nurses, a physiotherapist, two technicians, and four doctors from various parts of Africa including Kenya, Ghana, Zambia, Nigeria, and Mauritius.

Our motivation for the establishment of this IHTC was to reach out to the largely under-resourced African continent and to share our experience and expertise in managing patients with bleeding disorders with our regional neighbours. This objective is evolving very well as evidenced by the increasing number of people with hemophilia diagnosed in the various countries of origin of the fellows.

We have established ongoing collaboration with most of the fellows following their training and meet with them regularly at scientific congresses to plan and consolidate future collaborations. A number of our fellows presented posters at the WFH 2016 World Congress, an indication that we are managing to increase their interest in research and presentation of their learning experiences.

Our academic centre offers comprehensive hematology training not just in hemophilia but also in many other aspects of hematology training. A number of fellows have opted to come back to expand and consolidate their knowledge and experience in hematology.

Our IHTC has been the national co-ordinating centre for the IEQA Program run by the Christian Medical College in Vellore, India. There were 15 participants in the program from South Africa in 2016 and it is anticipated that the program will be expanded to other African countries in the near future. In the last three years, we have hosted a regional basic coagulation course in which 7-10 fellows from various parts of Africa were trained.

It is too early to evaluate the impact of our IHTC training but we are hopeful that it will make a big difference to the people living with hemophilia in our region.
Hemophilia Training And Beyond: An Experience

By Shiva Prasad Shrestha, MD, pediatrician from Nepal and 2016 IHTC fellowship recipient

SHIVA’S STORY:

Namaste…!! I am Dr. Shiva Shrestha from Nepal.

Nepal, a Himalayan landlocked country popularly known as Country of “Mt. Everest” and a country where Buddha was born, is situated between two giant neighbors China in the north and most of its part surrounded by India, the south.

Nepal has dealt with poor health indices for long time. Since the establishment of Nepal Hemophilia Society (NHS) in 1992, there has been the registration of 563 cases of hemophilia, along with the expansion of its services through five different chapters in the peripheral level to broaden the services to the hemophiliacs in the country. One of them is a Chitwan chapter, which I’m involved in.

I’m grateful to IHTC for giving me opportunity to receive four weeks IHTC fellowship training on hemophilia at National Blood Center, Kuala Lumpur, Malaysia, in May-June, 2016. Truth be told, I learnt only a little about hemophilia during my medical schooling and also had limited knowledge and skills in handling a patient with hemophilia even after holding pediatrician degree. After the IHTC training, I believe that I acquired a lot knowledge and skills in hemophilia management. After this training I realized that there should be comprehensive multidisciplinary approach for better care of hemophilia that should include physiotherapist, orthopedicians, dentist, hematopathologist, sociologist, in addition to the physician and pediatrician.

During IHTC fellowship training, I had an opportunity to see a case of hemophilia that was admitted for hematuria and was receiving IV fluids for 48 hours to wash out the clotted blood in the urinary tract to prevent from thrombosis. Factor replacement was given after hematuria is controlled.

During my physiotherapy posting in the IHTC training, which is an integral part in the management of hemophilia, in the Hospital Kuala Lumpur I met a physically disabled young boy of 18 from rural Malaysia who attended hospital lately and was not able to follow up with his physiotherapy. Total hip replacement surgery was not done due to the financial constraint. Similarly, during my training in hemostasis and thrombosis unit, I learnt “hands on training” on how to do factor assay. In the meantime, I found that date expired factor VIII still has retained its efficacy by 90% (250 unit of FVIII after expiry date retains 240 unit of functional FVIII). I carried a few vails of newly expired factors to be used in emergency condition and it worked nicely. In Vellore, India, emergency surgery was performed in the past by transfusing date expired factor concentrates and has saved patients’ lives.

I am thankful to Dato Dr Farah, MD, Director of the hemophilia training centre in Kuala Lumpur for delivering a meaningful lecture regarding hemophilia and its treatment during an afternoon session, along with a master level student posted in the same center. It gave me the theoretical foundation in the sense that if hemophilia could be diagnosed early, the initiations of prompt and adequate treatment, along with adequate factor concentrate replacement, will help to reduce the disability, improve of quality of lives, and increase the life expectancy of the patients. Also, I learned about inhibitors and the related treatment of immune tolerance induction (ITI) protocol, along with the importance of prophylaxis in the long-term management. However, due to the inadequate supply of factor concentrates, we are still using on-demand therapy in Nepal. One additional thing that I saw in the training center is that 500 to 1000 pints of blood are collected from the satellite clinic every day to send to Australia for factor concentrate manufacturing after certain processing is done. Australia supplies the factors in Malaysia in this way.
After returning home from IHTC training, I had to face two cases of uncontrolled bleeding with hematoma formation in the intra-muscular injection site in the deltoid and the patient was admitted to my hospital. We treated the patient with ice compression and tight bandaging for two days. Both were undiagnosed cases, hence we referred this case to the capital city centre for factors assay as there was no such existing facility in my medical college. However, other bleeding profiles are being done here. Later follow up was done and the cases turned out to be severe hemophilia A and managed accordingly.

One more case, 13 year girl attended in the outpatient department with severe menorrhagia who was carrying FVIII treatment with an expiry date of 2014. She had visited various health facilities for two days but none were a convenient place for her injection. Since she was pale and was bleeding for 2 days, I infused that one and bleeding stopped in few minutes. It turns out that she was a known case of von Willebrand disease.

During the Colombo Symposium held in November 21-22, 2016, I had a great opportunity to have extensive discussion on hemophilia and other bleeding disorders. Participants from south Asia region also benefited from the symposium. I could see many chronically disabled people in the symposium and experts discussed their modalities of further treatment.

Thank you IHTC team for such a wonderful program!

Upgrading Care For Patients In Mauritius
By Kavish Chuttooree, nurse from Mauritius and 2016 IHTC fellowship recipient.

My IHTC Fellowship training was scheduled at the Haemophilia Comprehensive Care Centre (HCCC), Charlotte Mexeke Johannesburg Academic Hospital, under the supervision of Prof. Johnny Mahlangu.

It was an outstanding training in which I was exposed to the various aspects in the management of hemophilia.

During the four weeks spent with Sister Bongi Mbele and her staff at the HCCC, it was a great opportunity to learn how patients with hemophilia are managed in a very scientific way using standard protocols by a dedicated team.

The first day was impressive as Dr. Mahlangu showed us the facilities and the “high tech” lab. He helped me a lot to attain my objectives which I set up and had to be timely framed with the duration of my training. Together, we discuss several case studies and he also explained about specific aspects of hemophilia.

It was very fascinating to learn how Sister Bongi empowered patients and parents and made them fully involved in the management of their disorder as it is a lifelong experience. This eventually leads them to home therapy. She gave us a very good insight of how she manages her patients and their relatives and encourages them to adhere to the protocols of the HCCC. Also she covered how all records are maintained using specific tools, whether it is for the register, assessment,
During my first time assessing patients, it was surprising to see the number of patients with inhibitors and von Willebrand disease, as well as to see them doing so well with their treatment.

Every day I was exposed to different cases which widely broadened my knowledge, as the modalities of the treatment were different. Also I had the opportunity to join ward rounds with different hematologists every morning. This gave me an overview of how patients with hemostatic challenges were managed.

Thanks to Alice Banze who made the outreach program a success. During this time, I was able to visit other hospitals and learn how patients were being treated in different set up with sometimes limited resources available to them. She also explained the procedure for doing home visit.

Confidently I can say that with all the knowledge acquired has proved beneficial not only to me but to our patients, our patients organization and other staff who are interested in upgrading care for hemophilia patients in Mauritius.

Finally I would like to take this opportunity to thank the WFH for granting me this fellowship and Haemophilia Association of Mauritius for their support to make this training a success.

Comprehensive Care In Mexico

By Maricela Osorio Guzman, Psychologist form Mexico and 2015 IHTC fellowship recipient

Comprehensive care implies taking care of the patients’ physical, psychological, and social needs. Because the WFH’s IHTC Fellowship Program has this holistic vision of the human health, as a professional dedicated to psychological and emotional health, I received support to strengthen my abilities in this field.

My name is Maricela Osorio Guzman; I am a Mexican psychologist and I work as advisor and volunteer for the Hemofilia Federation of the Mexican Republic (Federación de Hemofilia de la República Mexicana). Since I started my collaboration with the Federación, I realized that the psychological aspect in the healthcare process deserves special attention, since a patient’s disposition, motivation, and beliefs are directly related to therapeutic compliance.
As mentioned before, there are many psychological aspects that surround hemophilia. During consultations a range of topics emerged: fear of the disease, anger for having hemophilia, conflicts between healthy siblings and those with hemophilia, overprotection from mothers, little support from fathers (which is common in Latin American countries), depression in adults, and fear of family break-ups. These were many of the issues which we helped address.

Play therapy with pediatric patients.

Besides spending time in all of the training centre departments, I spent a few hours in the social work department. Here I was able to witness the work done by the representative in the search of resources from private and public entities (projects, support requests, etc.), an extremely important effort to strengthen the institution. I was also able to review some psychosocial manuals on topics such as surgery guides, obtaining healthcare coverage, and advocacy for the patients’ rights in general. I feel very lucky to have been a recipient of an IHTC fellowship because it allowed me to see different approaches which have provided me with lots of ideas to develop. I return to my country with multiple tools to provide assistance to our patients and their families, and I place great value in the learning of the psychosocial aspects addressed.

DO YOU HAVE STORIES TO SHARE?
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CALENDAR OF EVENTS

2017

JUNE

30
ANNUAL GLOBAL SURVEY DATA SUBMISSION DEADLINE

JULY

9
IHTC – REACH THE WORLD ALUMNI EVENT, CITYCUBE BERLIN, ROOM M8

11
WORLD BLEEDING DISORDERS REGISTRY (WBDR) LAUNCH MEETING AT ISTH

OCTOBER

31
DEADLINE TO APPLY FOR 2018 WFH IHTC FELLOWSHIPS
For more information, visit: http://www.wfh.org/en/IHTC_Fellowship_Program

2018

MAY

20-24
XXXIII INTERNATIONAL CONGRESS OF THE WORLD FEDERATION OF HEMOPHILIA, GLASGOW, SCOTLAND

For more information, visit: visit www.wfh.org/congress
WFH AND ISTH FELLOWSHIP PROGRAM EVENT SPONSORED BY BAYER

Building Capacity Globally:
The Impact and Future of the IHTC and Reach the World Programs

Bayer invites you to an Advocacy Symposium, where recognized experts in the global hemophilia community will convene for a discussion on leadership.

In a changing, complex healthcare landscape, it’s no longer enough to be a part of the conversation – we need to lead the dialogue on important topics affecting quality care and access in hemophilia and thrombosis treatment.

This symposium will include introductions to the International Hemophilia Training Centre (IHTC) and Reach the World programs, an interactive panel and audience discussion centered around advocacy and the power of leadership in moving positive change.

We hope that you can join us in affecting positive change in hemophilia and thrombotic disorders through meaningful dialogue and powerful advocacy.

If you would like to attend the IHTC Reach the World Symposium, please select one of the options to receive a calendar invite.

Outlook / Cal
Google Calendar

Agenda
Opening Remarks
13:00-13:10
Bayer speaker: Gregory LaChir, Director, Global Hemophilia Excellence, Bayer

Introduction of the IHTC and Reach the World Programs
13:10-13:15
Bayer speaker: Dr. Rick Ponsard, MD, PhD, Professor of Internal Medicine at the University of Milan, President of IHTC; Dr. Miguel Escalada, MD, Lindner Director, German Haemophilia and Thrombosis Centre; Professor, UTH Health Houston, MD, Andrew Carrel Center

Panel Discussion: The Impact and Future of the IHTC and Reach the World Programs
13:15-14:15
Panelists: Reach the World Mentor Speakers
Dr. Rino Sagratini, Professor and Head of the Department of Hematology at the Allie’s Institute of Hematology, Naples, Italy
Dr. Sunny Reeser, MD, Head of Hematology and Oncology at the University Hospital, Associate Professor at the University of Applied Sciences and Arts, Vienna, Austria
Bristol Panellists: IHTC Mentor Speakers
Prof. Ulrich Müller, MD, Director of Hematology/Dermatology, Dermpath, Martin Kneser, Buxtehude, Germany
Prof. Martin Schudel, MD, Associate Professor of Hematology, University of Munich, Munich, Germany
Dr. Myrsi Al-Batal, MD, Head of the Global Transfusion A.H. Hemophilia Centre, Al Hail Hospital, Oman
Mr. Mojtaba Al-Batal, MD, Head of the Global Transfusion A.H. Hemophilia Centre, Al Hail Hospital, Oman

Closing
14:15-14:30
Bayer speaker: Gregory LaChir, Director, Global Hemophilia Excellence, Bayer

Networking
14:30-16:00

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The WFH IHTC Fellowship Program is solely funded by Bayer.

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