

WEBINAR

COLLABORATIONS, CONNECTIONS AND COVID19:
**TWINNING STORIES FROM
NEAR AND FAR**



Deniece Chevannes
Stephanie Pineda
Dr. Patricia Silva, M.D.
Yuri Zhulyov
Santosh Manivannan

Thursday, 17 September 2020



WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

SPEAKERS AND PANELISTS



Deniece
Chevannes



Stephanie
Pineda



Dr. Patricia
Silva



Yuri Zhulyov



Santosh
Manivannan

AGENDA

1. Overview of the Twinning Program
2. Presentation from the twins
3. Q&A

ASK QUESTIONS


Recording

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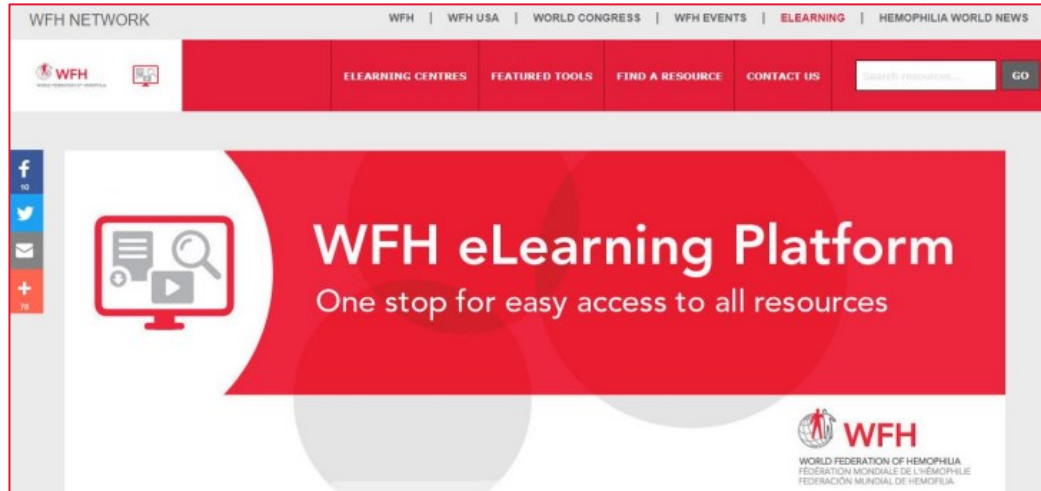
 **WFH**
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Audio Settings ^

Chat Raise Hand **Q&A** ³ Leave



WEBINAR RECORDING



A recording of the webinar will be available on the WFH eLearning Platform.
The webinar will be made available in other languages.

<https://elearning.wfh.org/>

THANK YOU



TWINNING PROGRAM

Stephanie Pineda
Twinning Coordinator



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TWINNING PROGRAM



Short-term partnerships (4 years for HOT and HTC; 2 to 4 years for Youth Group)

Focus on sustainability and capacity building



Annual funding and coaching support from WFH



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WHY TWINNING WORKS

255 Partnerships across **115** countries =

Improved
diagnosis,
care and
treatment
over time

Enriched
knowledge of
healthcare
professionals
caring for
people with
bleeding
disorders

Strengthened
patient
organizations
through
capability
building

Enhanced
outreach
initiatives

Facilitated
resource
sharing

TWINNING PARTNERSHIPS IN 2020

18

Hemophilia
Treatment
Centre (HTC)
Twinning



17

Hemophilia
Organization
Twinning
(HOT)



4

Youth Group
Twinning



HTC TWINNING ACTIVITIES



Training for members of the comprehensive care team



Patient registry development and outreach activities



Development of treatment protocols



Exchange of information and educational materials for health professionals and/or patients



HOT TWINNING ACTIVITIES



Advocacy initiatives and lobbying governments



Patient and family education



Capacity building



Chapter development



YOUTH GROUP TWINNING ACTIVITIES



Leadership Training



Summer camps



Training workshops on peer support groups, good governance, public speaking, etc.



World Hemophilia Day activities

TWINNING AROUND THE WORLD



QUESTIONS?

WEBSITE:

<https://www.wfh.org/en/our-work-global/twinning-program>

EMAIL: twinning@wfh.org

WHEN SOLIDARITY OVERCOMES GEOGRAPHY

Patrícia Silva, MD

Hematologist

Chief of Hematology Unit

Maputo Central Hospital

Mozambique - September 17th 2020



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AGENDA

1. Beginning of Twinning Maputo Central Hospital/UCSD
2. Summary of Twinning activities 2019
3. Twinning activities 2020
4. Challenges and current activities
(constraints of Pandemic COVID19)



1. BEGINNING OF TWINNING MAPUTO CENTRAL HOSPITAL (MCH)/ UNIVERSITY OF CALIFORNIA SAN DIEGO (UCSD)

GOALS and ACTIVITIES

- 1st contact in **2017** with several visits and missions of Dr Annette von Drygalski to Maputo
- Officialization of twinning end 2018
- To date: 9 visits
- Donations including equipment and factor
- Discussion and interaction with patients, during clinic
- Meetings with NMO
- Musculoskeletal Ultrasound (MSKUS) to assess recent joint bleeding or synovitis/arthrosis
- Training and lectures
- Creation of Multidisciplinary team
- Creation of Hemophilia Treatment Center (HTC)
- Meetings with Hospital Directors and with Minister of Health



MUSCULOSKELETAL ULTRASOUND (MSKUS) TRAINING IN 2018



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CLINICAL EXAMINATION AND DAILY FOLLOW UP HEMATOLOGY UNIT



2. SUMMARY OF ACTIVITIES 2019

DONE:

- Training exchange visits between HCPs from MCH and UCSD to augment local expertise
- Training of blood bank staff in production and handling of cryoprecipitate and other factor concentrates and possible training in provincial blood banks

POSTPONED:

- Visits to other provinces for laboratory and diagnostic capacity building

ONGOING:

- Creation of a center and multidisciplinary team for adult and pediatric hemophilia care
- Development of educational materials for health professionals (i.e. presentations, brochures, books)
- Establish a national patient registry and data collection tools



INTRA-ARTICULAR INJECTION ULTRASOUND GUIDED (2019 AUGUST)



PHYSIOTHERAPY TRAINING; MULTIDISCIPLINARY TEAM(2019 AUGUST)



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3. TWINNING ACTIVITIES 2020



DONE

1. Establish protocol for **chemical synoviorthesis** with Rifampicin (using **ultrasound-guided injection**)
2. Continued capacity building of local blood bank to advance the procurement of safe blood products. Installation of freezer and equipment
3. Development and printing of educational materials

ONGOING

1. **Capacity building** on diagnosis and management in one region in Mozambique (Beira) and provinces in central region
2. Establish patient registry, register and obtain ethics approval for World Bleeding Disorders Registry (WBDR)
3. Develop a pathway for laboratory diagnosis in major hospitals in Mozambique, especially central and northern Mozambique
4. Creation **Hemophilia Treatment Center (HTC)** with multidisciplinary team (adult and pediatric). Draft memorandum of understanding to guarantee 2 rooms for management and treatment of patients



4. CHALLENGES AND CURRENT ACTIVITIES (CONSTRAINTS OF PANDEMIC COVID19)



What we have done:

1. **Early March visit of Dr. von Drygalski:**

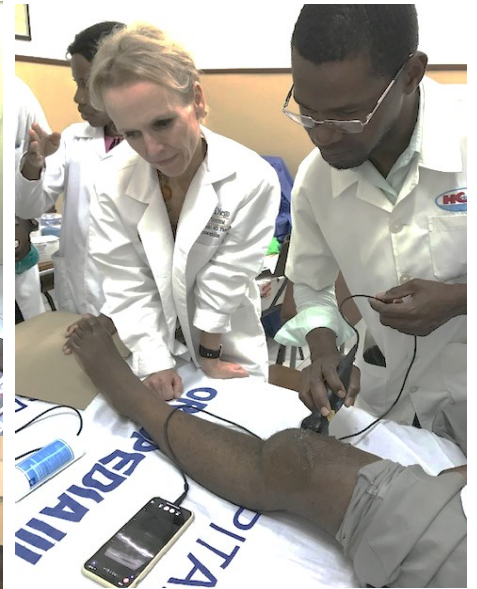
- Intraarticular injection with anti-inflammatory agent (triamcinolone and lidocaine), rifampicin not available
- Lectures and meetings with multidisciplinary team and NMO;
- MSKSU in hemophilic patients

2. **Acquisition and installation of a freezer** for cryoprecipitate production and storage

3. Creation of **educational materials** and printing for to distribute to other central hospitals and general hospitals in the provinces (emergency department, doctors and nurses who deal with hemophilia)

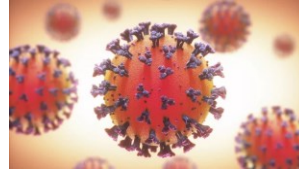
4. Acquisition of a router and zoom account for meetings and training online with health professionals from hospitals in other provinces, **and including professionals from UCSD (Dr. von Drygalski and others)**; also to discuss laboratory diagnosis

JOINT EVALUATION AND INTRA-ARTICULAR INJECTION

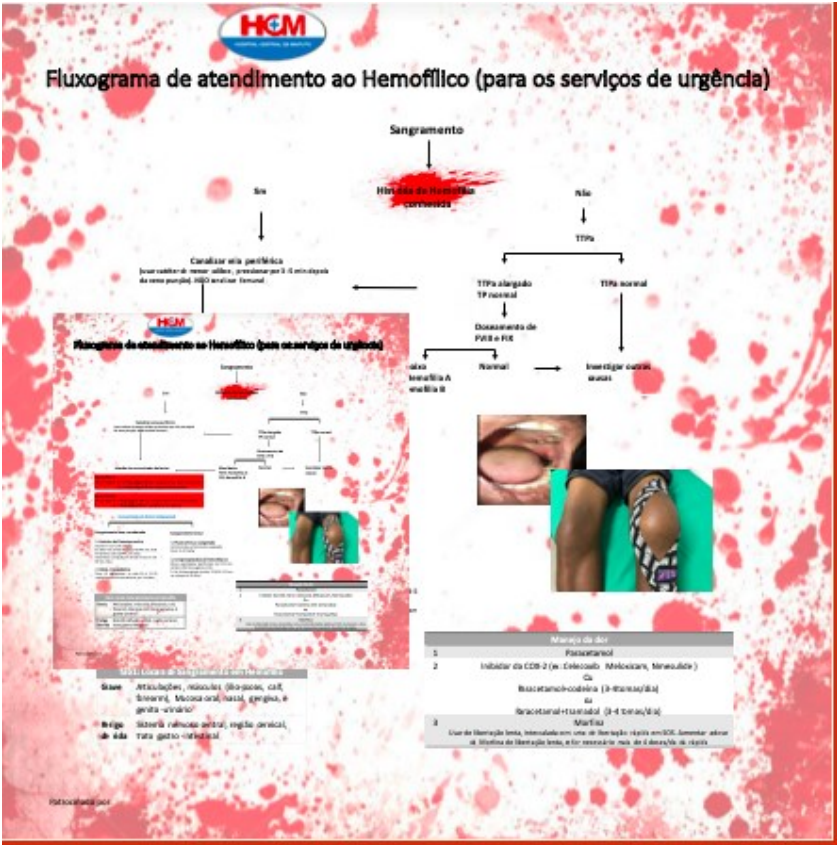


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WORKING IN COVID ERA: WE MUST GO ON



4. ELABORATION OF EDUCATIONAL MATERIALS: POSTER WITH FLOWCHART IN EMERGENCY ROOM; 2 NEW CASES FROM BEIRA





**THANK YOU
OBRIGADA!**



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WFH HEMOPHILIA ORGANIZATION TWINNING PROGRAM RUSSIA – TAJIKISTAN

YURI ZHULYOV / PRESIDENT /
RUSSIAN HEMOPHILIA SOCIETY



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AGENDA

1. Basic information (hemophilia in Tajikistan)
2. Challenges of COVID pandemic
3. Twinning activities
4. Future plans

BASIC INFORMATION

Tajikistan population = 9 million people

Patients with hemophilia A (adults+children) + inhibitory form = 520

Patients with hemophilia B (adults+children) = 60

Patients with Willebrand (adults+children) = 40

Date of establishment of the Tajikistan Hemophilia Society - 22.02.2017

TWINNING ACTIVITIES

Doctor's examination of hemophilia patients in Tajikistan



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TWINNING ACTIVITIES



TWINNING ACTIVITIES

Visits to Tajikistan in 2017 - 2019




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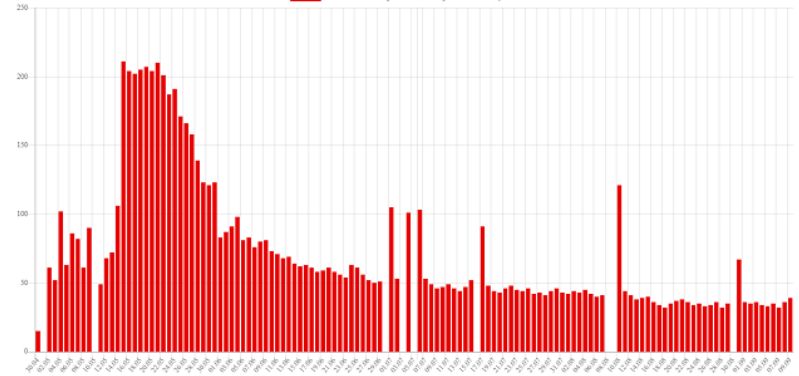
TWINNING ACTIVITIES



CHALLENGES OF COVID PANDEMIC

- Incidence rate 
- Restrictive barriers
- Border closure
- Inability to conduct face-to-face meetings
- Need to change plans, incl. replacing face-to-face meetings to an
online format

COVID statistic in Tajikistan



FUTURE PLANS



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TWINNING ACTIVITIES

- 25/07/2020 - online conference in Khatlon region “COVID-19: impact on hemophilia patients and prevention” - 25 activists and doctors



FUTURE PLANS

ONLINE training for the active/core members of the Tajik NMO on how to work in patient organization and learn on the main treatment concepts for patients

ONLINE conferences “COVID-19: Impact on hemophilia patients and prevention”:

- 19/09/2020 - Khatlon region - 25 activists and doctors
- 17/10/2020 - Gorno-Badakhshan Autonomous region - 20 activists and doctors
- 28/11/2020 - Dushanbe and districts of republican subordination - 30 activists and doctors

FUTURE PLANS

Translate from Russian to Tadjik language and print:

- passport for PWH – 1000 pcs
- Hemophilia in pictures – 300 pcs
- Osipova "Hemophilia gymnasties for PWH" – 300 pcs
- Rakhmanov "Hemophilia treatment in Tajikistan" - 600 pcs



FUTURE PLANS

Planned actions before the end of this year:

- Online training of activists and volunteers
- Constant online communication and consulting activities
- Change and implementation of the advocacy program





THANK YOU!

Website: <https://www.hemophilia.ru/>

INDIA-USA TWINNING PROGRESS DURING THE LOCKDOWN

Santosh Manivannan
Chairman, Youth Group
Hemophilia Federation (India)
Bangalore – September 17, 2020



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AGENDA

1. India - USA Twinning
2. Before the Travel Ban
3. Lockdown and Covid-19
4. Events conducted
5. Looking Forward

INDIA - USA TWINNING

- We have successfully completed 2 years of the twinning program. This year being the 3rd.
- Has been one of the most effective programs in creating and showcasing leadership across the country.
- Has identified and created a dedicated team of Master trainers, who have helped in content creation for the youth training programs.

INDIA - USA TWINNING



BEFORE THE TRAVEL BAN

- I was a part of the Steps for Living facilitation training conducted by the National Hemophilia Foundation at their office in New York from 5th to 7th January.
- We conducted the Annual Youth Meet (AYM) from February 7th to 8th at Kolkata, India.
- The new Youth Committee was elected during the same meeting.
- We conducted a one day training program for the new YC on the 9th of February that focused on self sustainability and development.
- Kenneth Mcelderry from the National Hemophilia Foundation was with us for both the AYM and the YC training program.

BEFORE THE TRAVEL BAN



LOCKDOWN AND COVID-19

- Uncertainty and mixed information about Covid-19.
- A lot of hemophilia treatment centers were converted into Covid centers so it wasn't easy to access AHF.
- Travel bans meant PWH needed a travel pass to reach the hospital which was difficult to get.
- Couriers and shipping were also paused, which lead to more problems as emergency factor supplies at the chapters started depleting and the management of HFI couldn't send more factors to them.

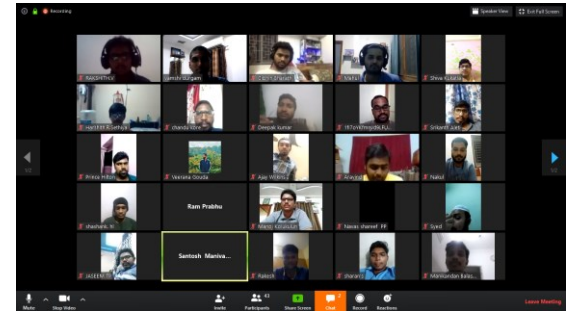
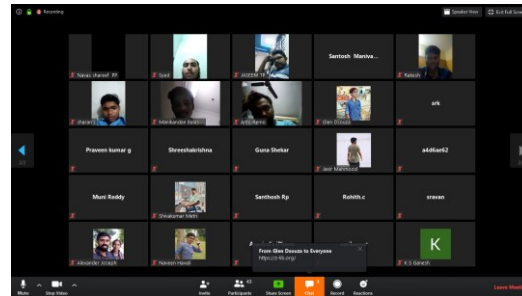
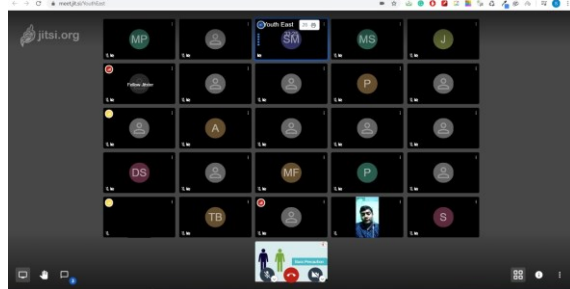
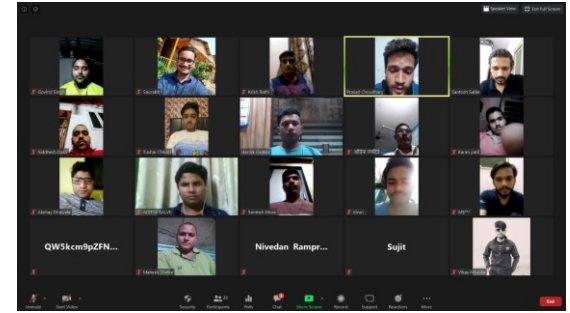
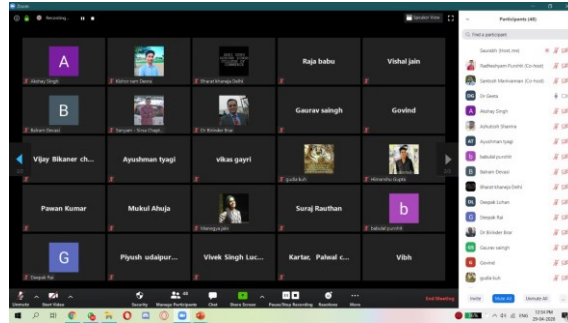
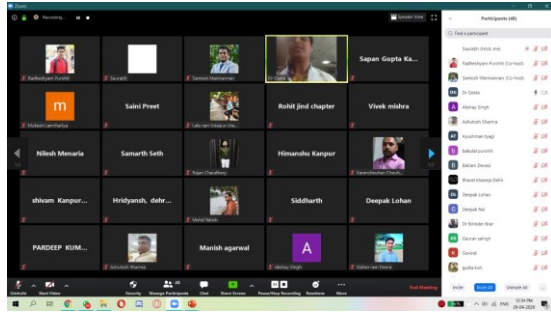
EVENTS CONDUCTED

- So with everything that was happening, we had to figure out how we can help with the situation and help the PWH in coping with everything.
- We let the management at HFI take care of the core medical aspect of Covid-19.
- The main topics that we decided to focus on were:
 - General awareness and Safety measures,
 - Reduction of factor dependence,
 - Mental and physical health
- Thanks to the communication streams that we have built from the beginning of the twinning program, we could reach out to more youth and get them involved in the sessions.

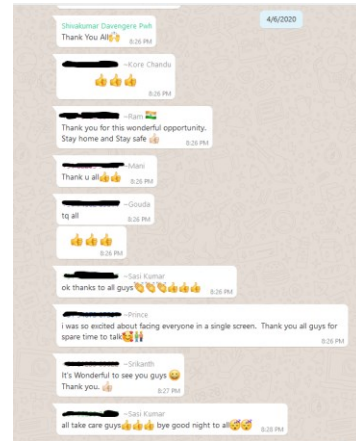
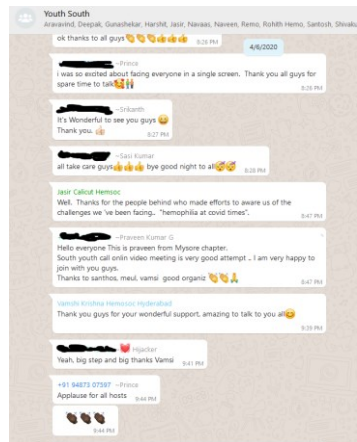
EVENTS CONDUCTED

- We conducted one session on Awareness about Covid and safety measures in each region, North, South, East and West.
- We conducted one session on Physiotherapy and bleed management in each region.
- We conducted a psychosocial webinar with Dr. Richa Mohan and Ed Kuebler as speakers.

EVENTS CONDUCTED



EVENTS CONDUCTED



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LOOKING FORWARD

- We have been in constant touch with NHF regarding the events conducted.
- In our recent call we drew out a plan for the upcoming online regional training programs and master training program as we have decided to suspend all physical meetings.
- We have conducted surveys with all the regions to assess the key points or concepts the youth want to learn as well so we can include sessions that cater to their needs.
- We expect to start the regional training programs in the end of October or the beginning of November 2020.

THANK YOU

Website: www.hemophilia.in

Email: santosh@hemophilia.in



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QUESTION & ANSWER PERIOD

Deniece Chevannes
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**STAY SAFE
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