WEBINAR

ADVOCACY DURING COVID-19: HAVING OUR VOICES HEARD

October 27, 2020

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

SPEAKERS

Cesar Garrido
WFH President

Dawn Rotellini
WFH Board Member and Chief Operating Officer of the National Hemophilia Foundation (USA)

Julie O’Donnell
Global Head of Digital, Evoke KYNE

Alexsandro dos Santos Machado
Professor and member of the Brazilian Federation of Hemophilia

Munira Borhany
Hematologist and Head of Haemophilia Society Karachi (HWSK), Pakistan

James Kago
Board member of the Kenya Haemophilia Association

AGENDA

1) Welcome from the WFH President
2) Advocacy During COVID-19
3) Building a Strong Online Advocacy Community
4) Panel of NMO Speakers:
    - Brazil
    - Pakistan
    - Kenya
5) Q&A
6) Conclusion

QUESTIONS AND TRANSLATION

FOR COMPUTERS AND TABLETS

Please submit your questions in the Q&A box

Please select your language of preference now

Por favor seleccione su idioma de preferencia ahora

Veuillez sélectionner votre langue de préférence maintenant

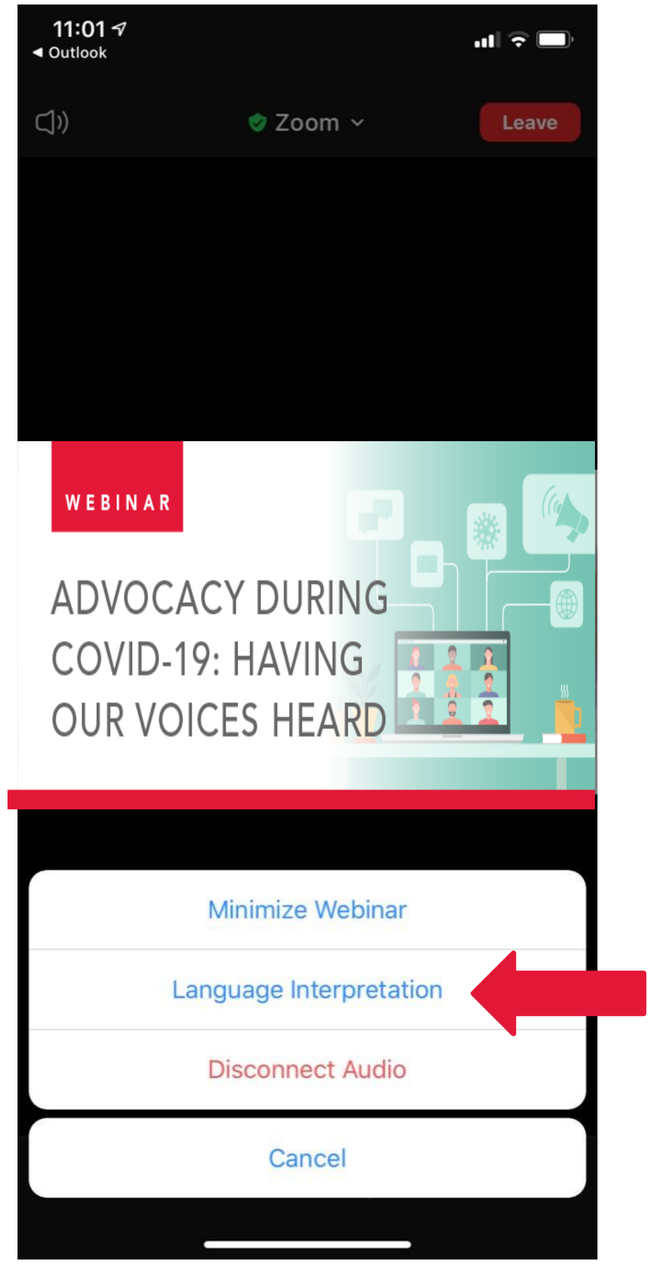
الرجاء اختيار لغتك المفضلة الآن

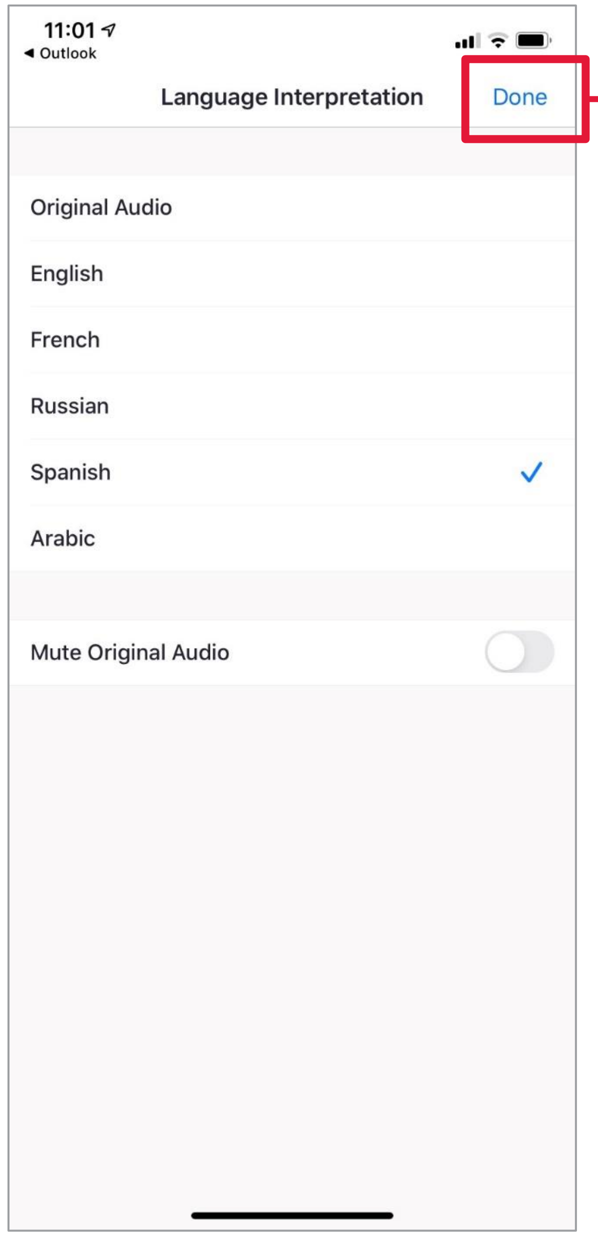
Пожалуйста выберите язык

QUESTIONS AND TRANSLATION

FOR MOBILE PHONES

EN English and 5 language interpretations available!





Spanish ✓

Click on “Done” to select your language

Please click on the 3 dots to select the interpretation channel

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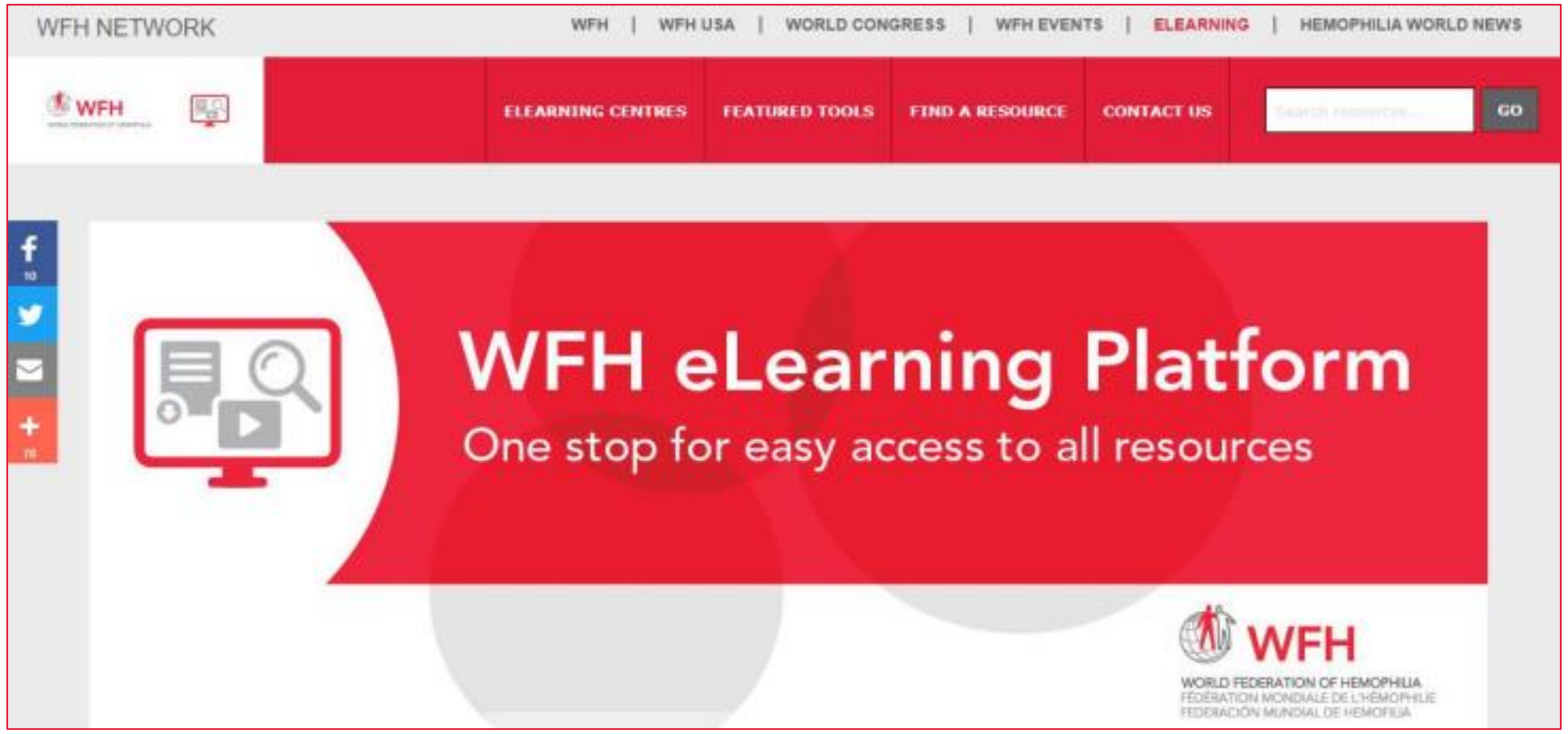
WEBINAR RECORDING

https://elearning.wfh.org/



WFH eLearning Platform

One stop for easy access to all resources

A recording of the webinar will be available on the WFH eLearning Platform

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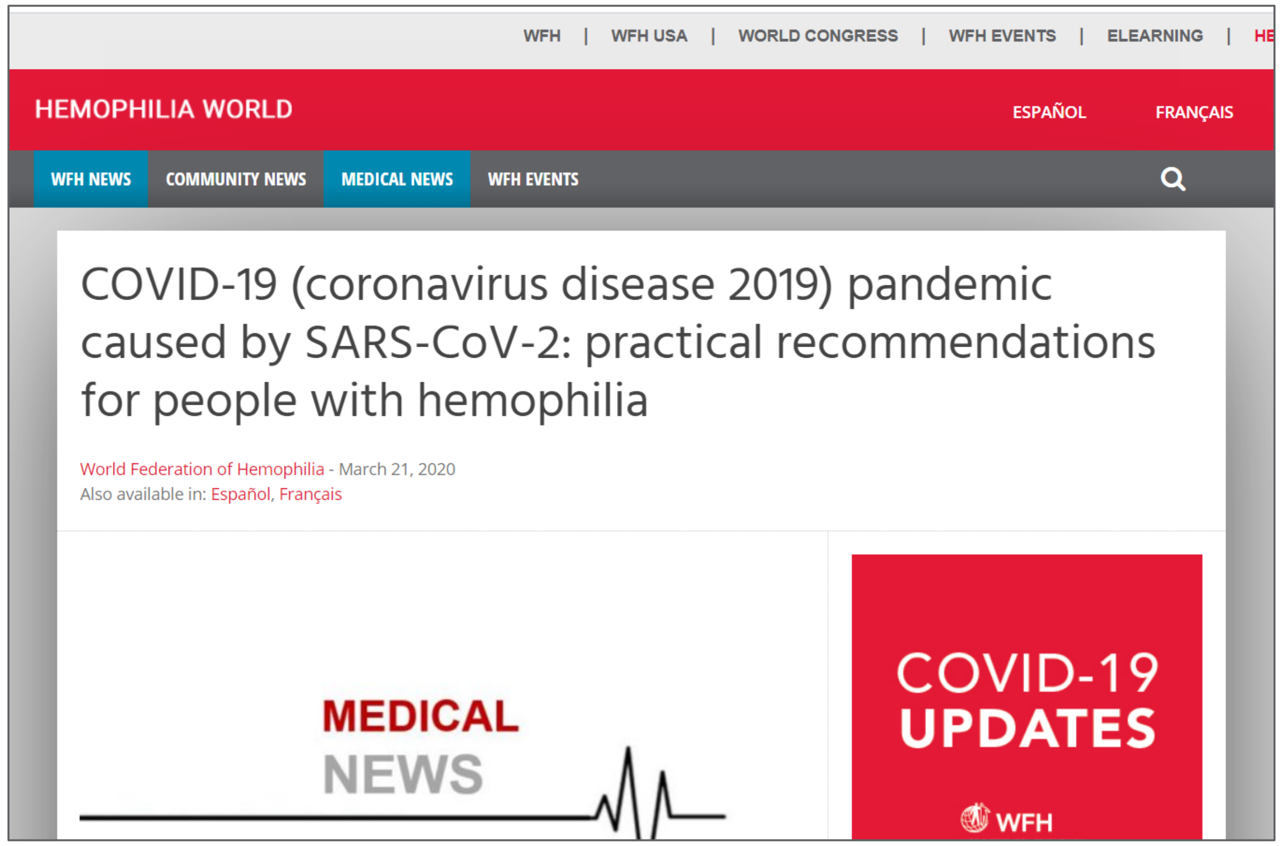
WFH COVID-19 INFORMATION

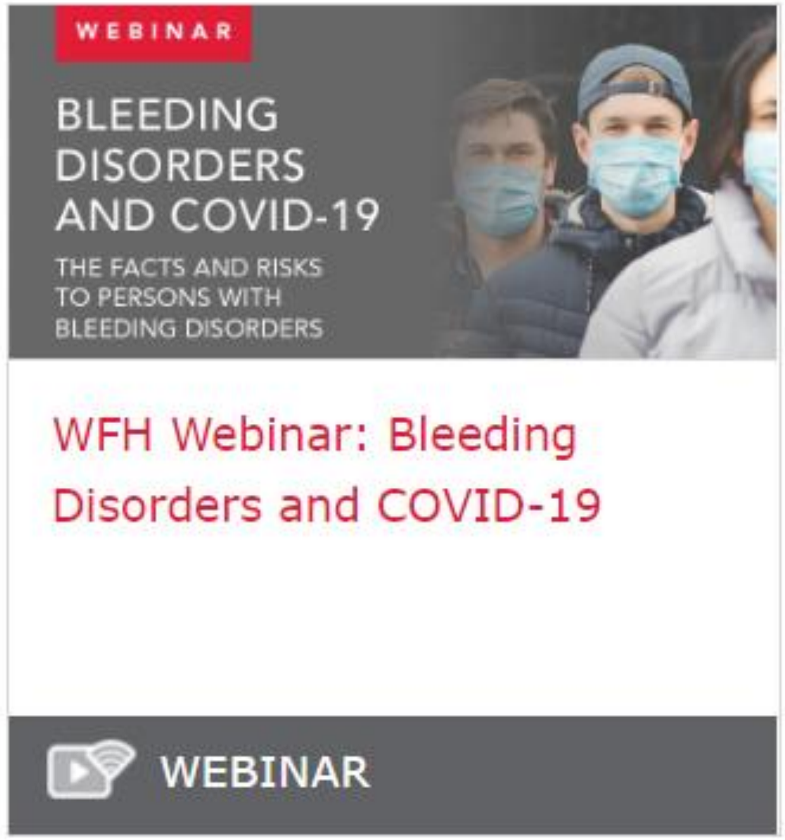
https://www.wfh.org/en/covid-19-communications
https://elearning.wfh.org/



COVID-19 (coronavirus disease 2019) pandemic caused by SARS-CoV-2: practical recommendations for people with hemophilia

World Federation of Hemophilia - March 21, 2020
Also available in: Español, Français

Stepping up and not stepping out: a nursing and psychosocial perspective to COVID-19



WFH Webinar: Bleeding Disorders and COVID-19

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THANK YOU

Hemophilia
of Georgia

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WELCOME

CESAR GARRIDO, WFH PRESIDENT

ADVOCACY DURING COVID-19

Dawn Rotellini

Chief Operating Officer, National Hemophilia Foundation

Member, WFH Board of Directors

October 27, 2020

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AGENDA

- WFH Vision
- COVID-19 pandemic and bleeding disorders community
- Advocacy during COVID-19

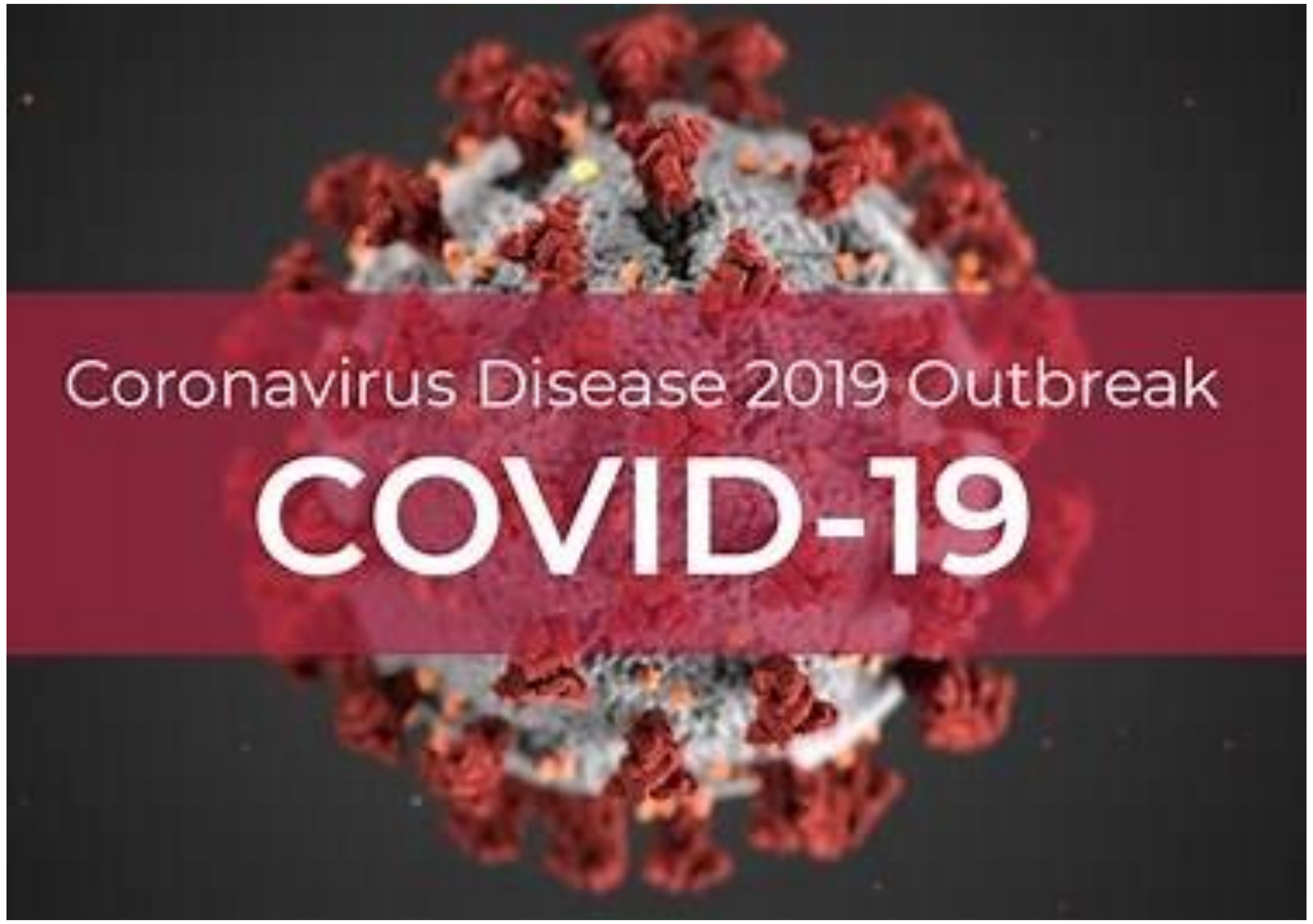
OUR VISION: TREATMENT FOR ALL

- Safe, effective treatment products are available for all people with inherited bleeding disorders.
- Proper diagnosis, management, and care by a multidisciplinary team of trained specialists.
- Expanding services beyond hemophilia, to VWD, rare factor deficiencies and inherited platelet disorders, women with bleeding disorders.


Treatment for all

A Vision for Improvement

IMPACT OF PANDEMIC…



While COVID-19 has had a hugely negative impact on all country's healthcare systems, the crisis will continue:

- Back to the basics
- Protect our standard of care
- Ensure equity in health

But we must stay prepared

- Gather Your Data (again)
- Start Telling Your Stories (again)
- Reach Out To Decision Makers

WFH RESPONSE TO COVID-19 PANDEMIC

- Education on COVID-19 and bleeding disorders through WFH statements and webinars
- Strengthened virtual training and education
- NMO Survey on COVID-19 pandemic and bleeding disorders community
- Financial support to NMOs for internet connectivity, software and equipment for online training and other projects
- Development Grant Program
- COVID-19 Relief Fund
- Strengthening advocacy-geared activities

WHAT IS ADVOCACY?

Influence key individuals, organizations, decision – makers to

MAINTAIN or CHANGE

policies, practices, and standards of care

MAIN STEPS OF ADVOCACY CAMPAIGN

✓ What do we want?	Goals / Objectives
✓ Who can give it to us?	Audience / Decision-Makers
✓ What do they need to hear?	Messages
✓ Who should they hear it from?	Messengers
✓ How do we get them to hear it?	Delivery / Presentation
✓ What do we have?	Resources
✓ What do we need to develop?	New Resources
✓ How do we begin?	First steps
✓ How do we tell if it’s working?	Evaluation

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S.M.A.R.T. GOALS / OBJECTIVE

- Identify the issue, concern or problem
- Determine the S.M.A.R.T. goals / objectives

TARGET AUDIENCE / DECISION-MAKERS

- Identify the people who can help meet your goals
  - ❑ Government officials
  - ❑ Hospital administrator
- Secondary audience
  - ❑ Other key players who can influence the decision-makers
- Identify all key players early
- Do your research
- Understand the issue from their perspective

OPPORTUNITY: HEALTHCARE DELIVERY CHANGES DUE TO COVID

- Home treatment / care
- Home delivery of treatment products
- Home inventory (“emergency reserve”)
- Home infusion support

- Tele-medicine
- Virtual access to multi-disciplinary appointments (Dental, Nursing, Psychosocial, Physical therapy)

- Remote clinics
- Remote laboratory phlebotomy

- What do we want to keep?
- What do we want to go back to the way it was?
- Do we have the arguments and data to support what we want?

MESSAGES

- Concise and persuasive statements, images
- Adapted to your target audience
- Should state:
  - ✓ What you want to achieve
  - ✓ Why you want to achieve it
  - ✓ Positive result of taking action/negative effect of no action
  - ✓ How you propose to achieve the positive result
  - ✓ What action you want the audience to take

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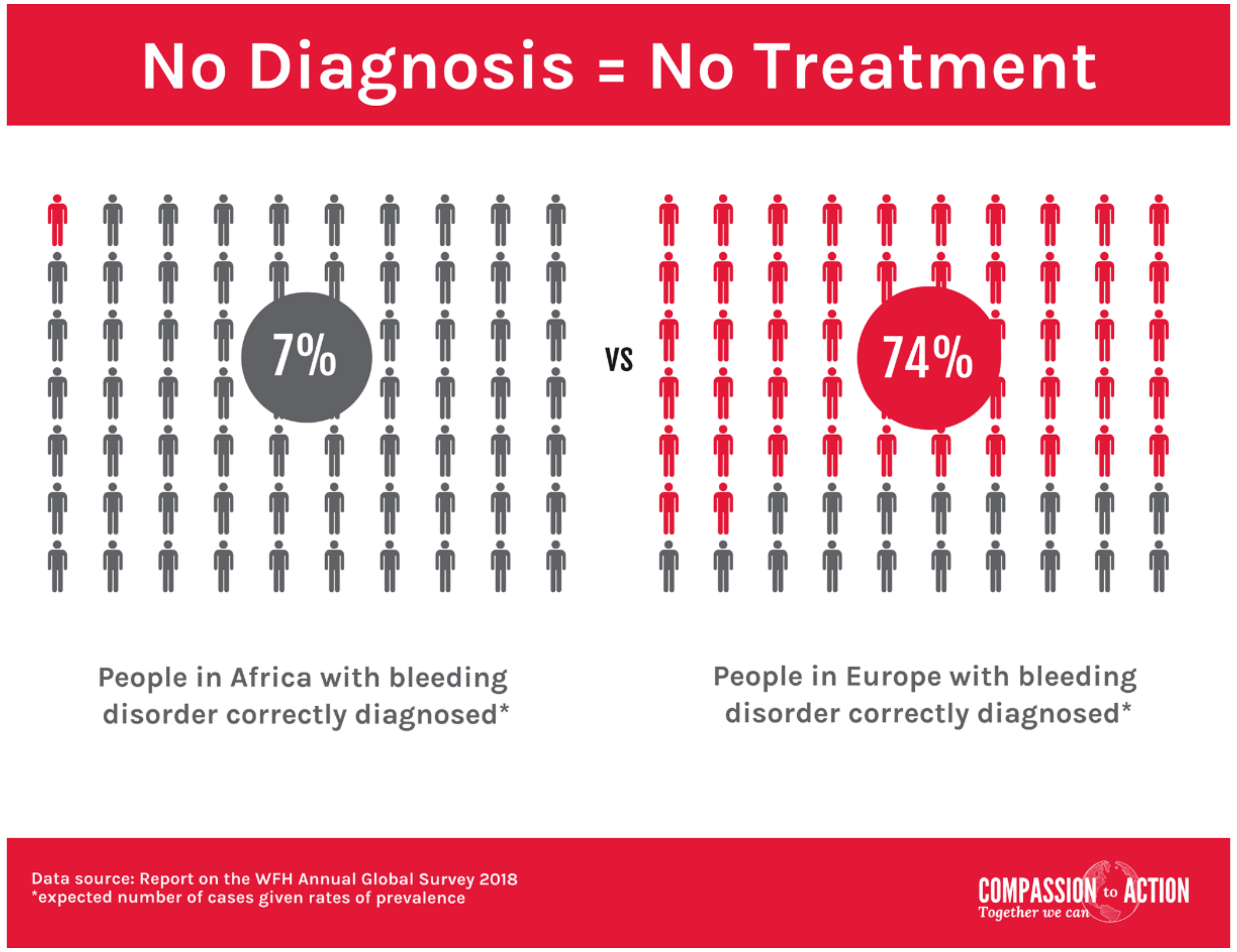
MESSAGES

- **We can tell our stories, but data proves what we are saying**
- Be prepared with **relevant data**
- **Data on number of patients and how they are treated**
- Data on burden of disease (DALY)
- Data on outcome of treatment (EQ-5D)
- Data on cost of treatment
- **Use WHF existing resources: Global Survey and WBDR**

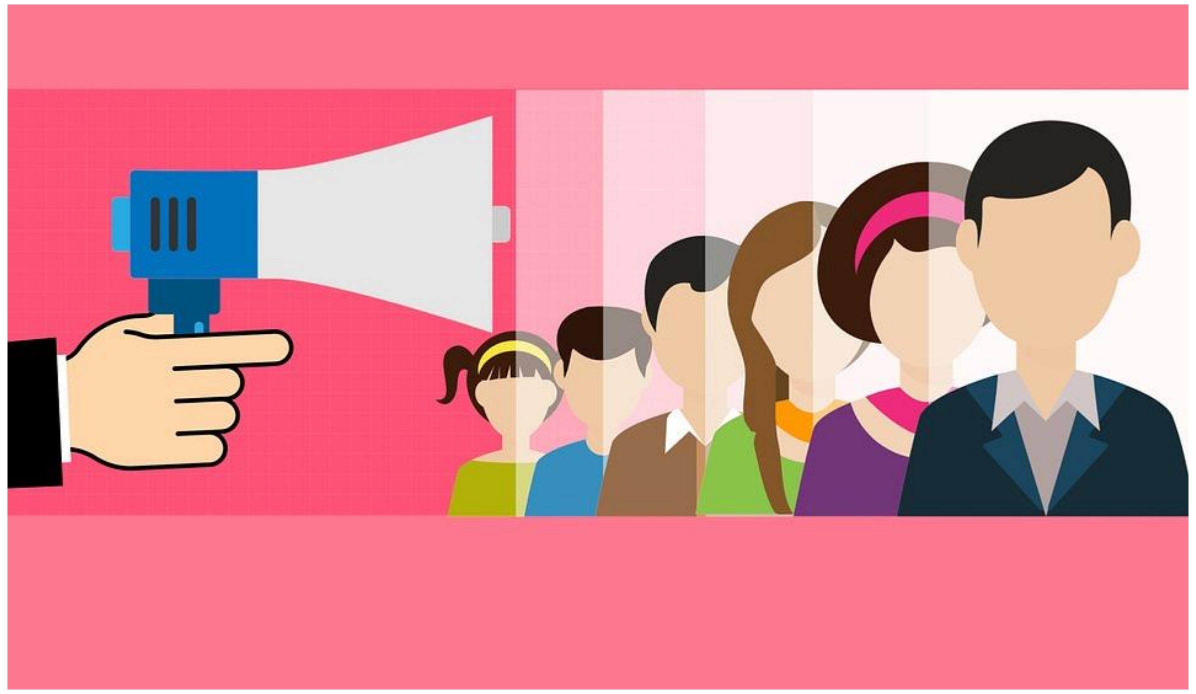


No Diagnosis = No Treatment

Data source: Report on the WFH Annual Global Survey 2018
*expected number of cases given rates of prevalence

MESSENGERS

- Identify the best person(s) to deliver your specific message
- Persons who deliver the message should speak for the groups you represent:
  - ☐ PWBD
  - ☐ Parents/caregivers and carriers
  - ☐ Doctors and other healthcare professionals
  - ☐ Government official



DELIVERY / PRESENTATION

- It is better to suggest solutions than to complain

- Collect information on the issue, such as data, and published resources to support your argument

- Collect stories from people who are directly affected by the issue

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DELIVERY / PRESENTATION

Use the appropriate methods or tools to deliver your message

- In-person and/or virtual meeting
- Special events
- Traditional and social media
- Petitions, letters
- Public demonstration

RESOURCES

Define what resources you already have and what is needed for the advocacy project:

- Financial
- Human
- Informational
- Time

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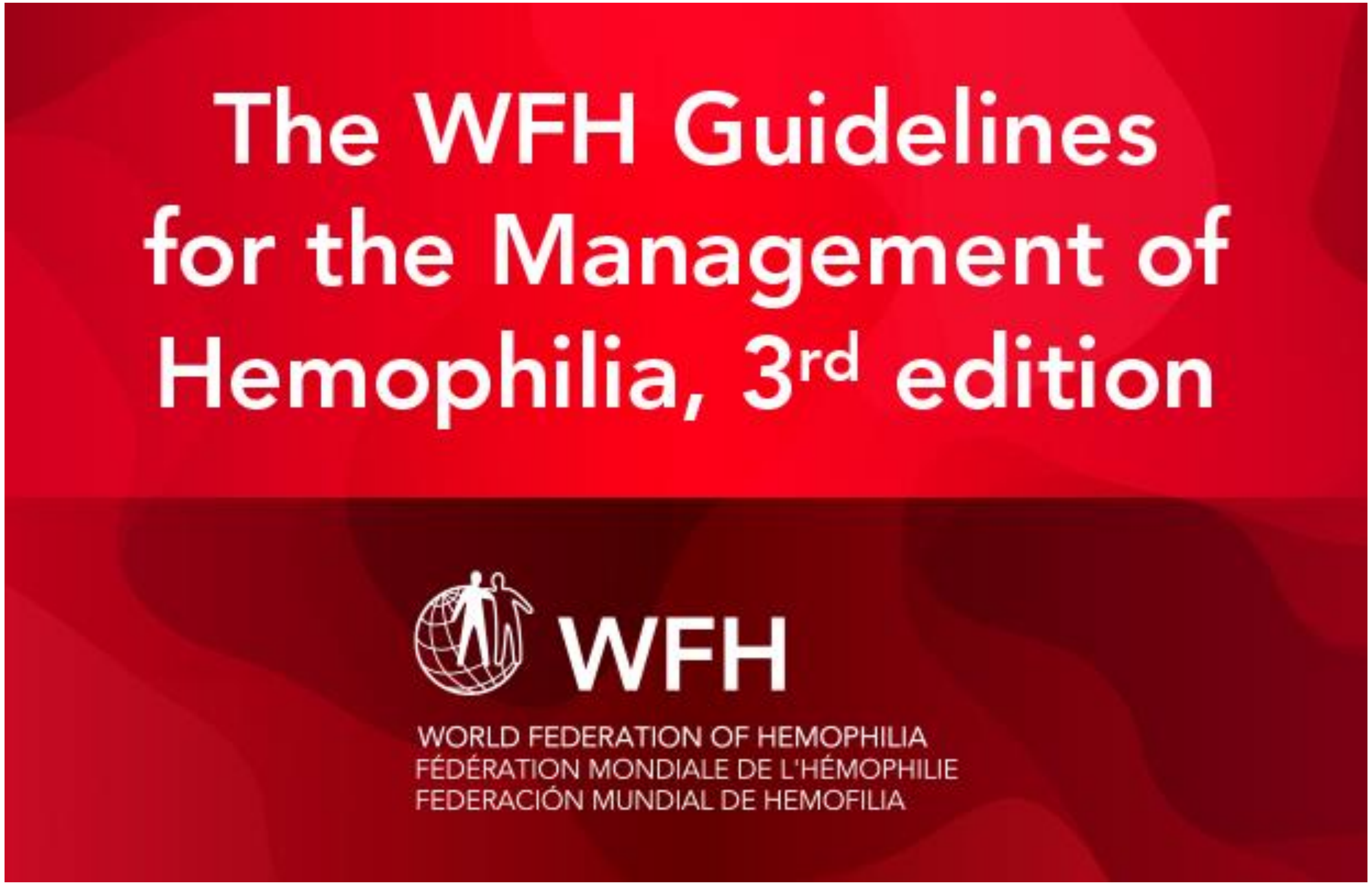
WFH GUIDELINES FOR THE MANAGEMENT OF HEMOPHILIA – 3RD EDITION



The WFH Guidelines for the Management of Hemophilia, 3rd edition

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FIRST STEPS

- Strategy and a plan that serves your advocacy objective/s
- Timing is important
- Design a realistic plan
- Form a core implementing team

EVALUATION

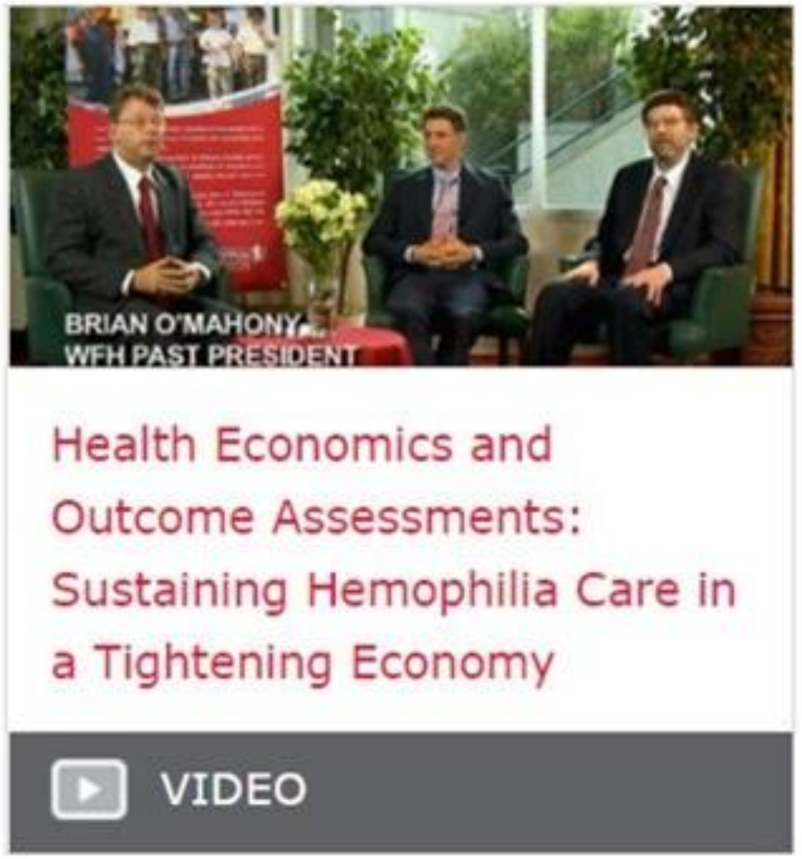
Evaluate your strategy and plan:

- What was achieved
- What worked well
- What needs to be changed
- What difficulties and problems were encountered (if any?)
- What next

elearning.wfh.org/

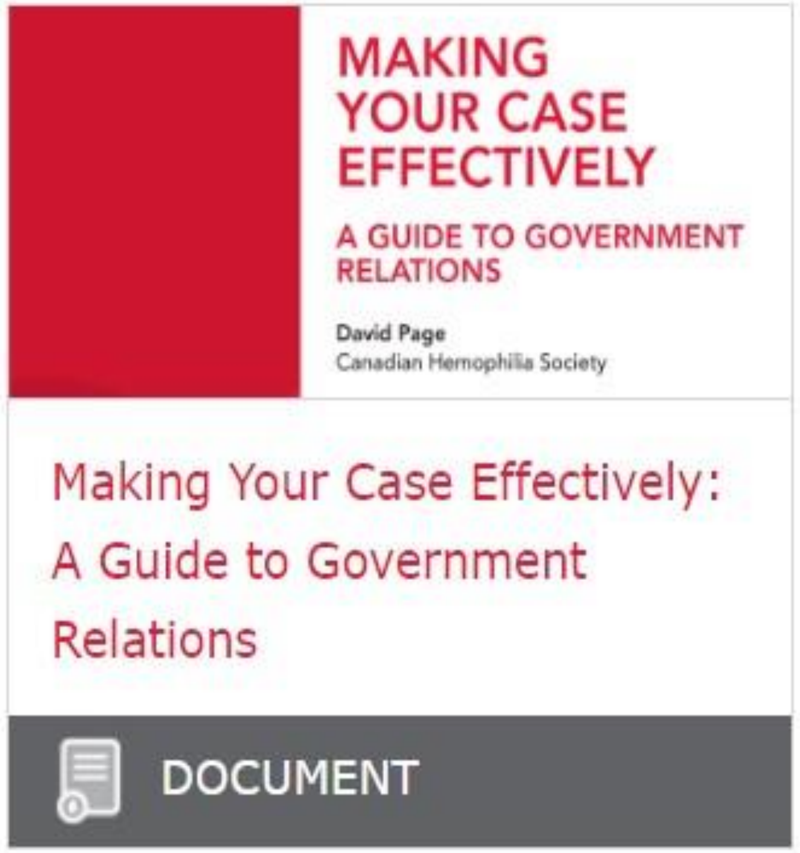
WFH ELEARNING PLATFORM

Hundreds of educational resources (articles, booklets, guides, illustrated handouts, books, binders, videos, and reports) available in multiple languages and free of charge.

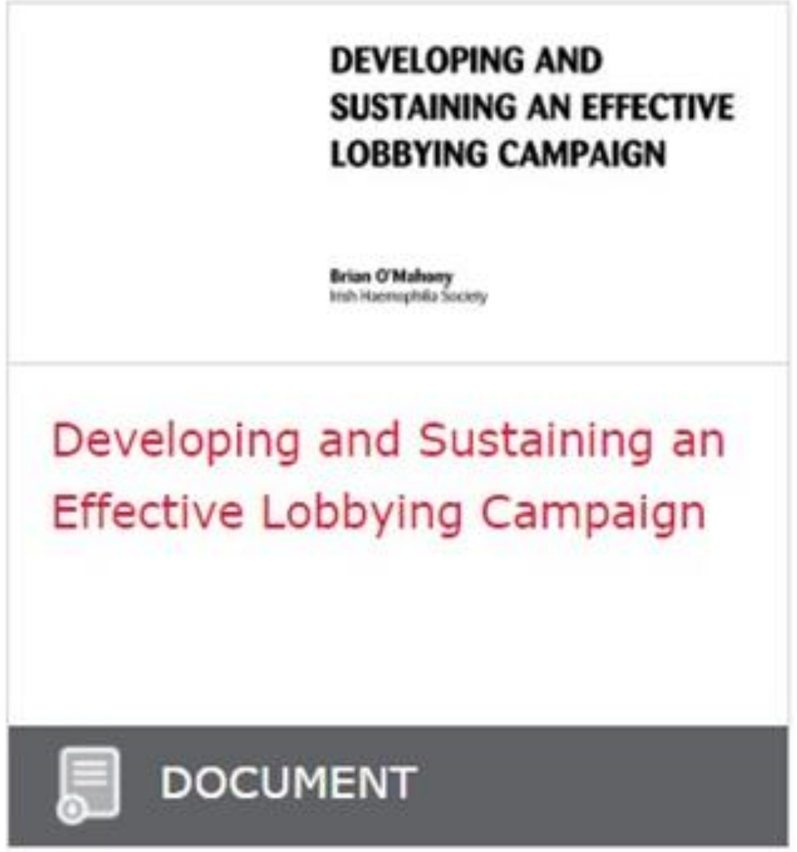


Health Economics and Outcome Assessments: Sustaining Hemophilia Care in a Tightening Economy

Collaboration with National/Governmental Organizations Key in VWD Outreach



Making Your Case Effectively: A Guide to Government Relations



Developing and Sustaining an Effective Lobbying Campaign

THANK YOU!

¡GRACIAS!

MERCI!

شكرا

СПАСИБО

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BUILDING A STRONG ONLINE ADVOCACY COMMUNITY

Julie O'Donnell
Global Head of Digital
Evoke KYNE

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ADVOCACY DURING COVID-19 IN BRAZIL:

Informational Platform of the Hemophilia care Network

Prof. Alexsandro dos Santos Machado
Federaçao Brasileira de Hemofilia

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BRAZILIAN FEDERATION HEMOPHILIA

HISTORY

Founded by a group of family members and caregivers in 1976

GUIDELINES

Advocate for the treatment and quality of life of all people with hemophilia, von Willebrand and other hereditary bleeding disorders

MAIN ACHIEVEMENTS

Since 2011 government investment in prophylaxis, immunotolerance and home treatment has tripled

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DE HEMOFILIA

FEDERAÇÃO BRASILEIRA
DE HEMOFILIA

CHALLENGES

Brazil has continental proportions, with 5 regions, 26 states and the Federal District. There are significant regional differences and social inequality. However, the country has a governmental universal health system that offers free treatment.

AFFILIATED ASSOCIATIONS

The FBH has 25 affiliated associations, which follow the same principles and philosophy and represent the 5 regions of Brazil and 2 other associations in the process of formation.

PWBD CARE

Hemophilia A - 10.821

Hemophilia B - 2.139

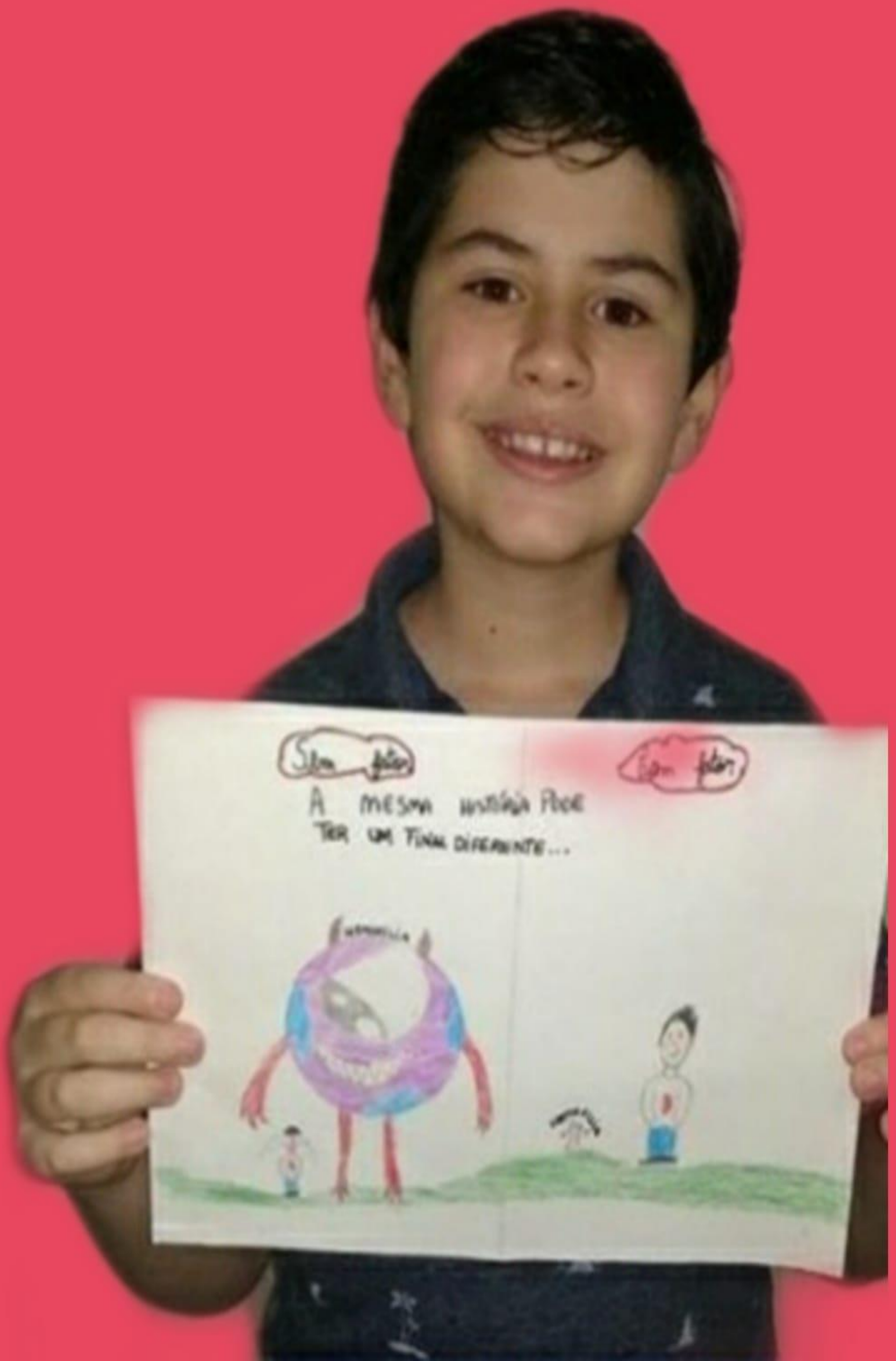
Von Willebrand Disease - 9.462

Rare Coagulopathies - 2.621

Other Hereditary Bleeding Disorders and other hemorrhagic disorders - 2.946

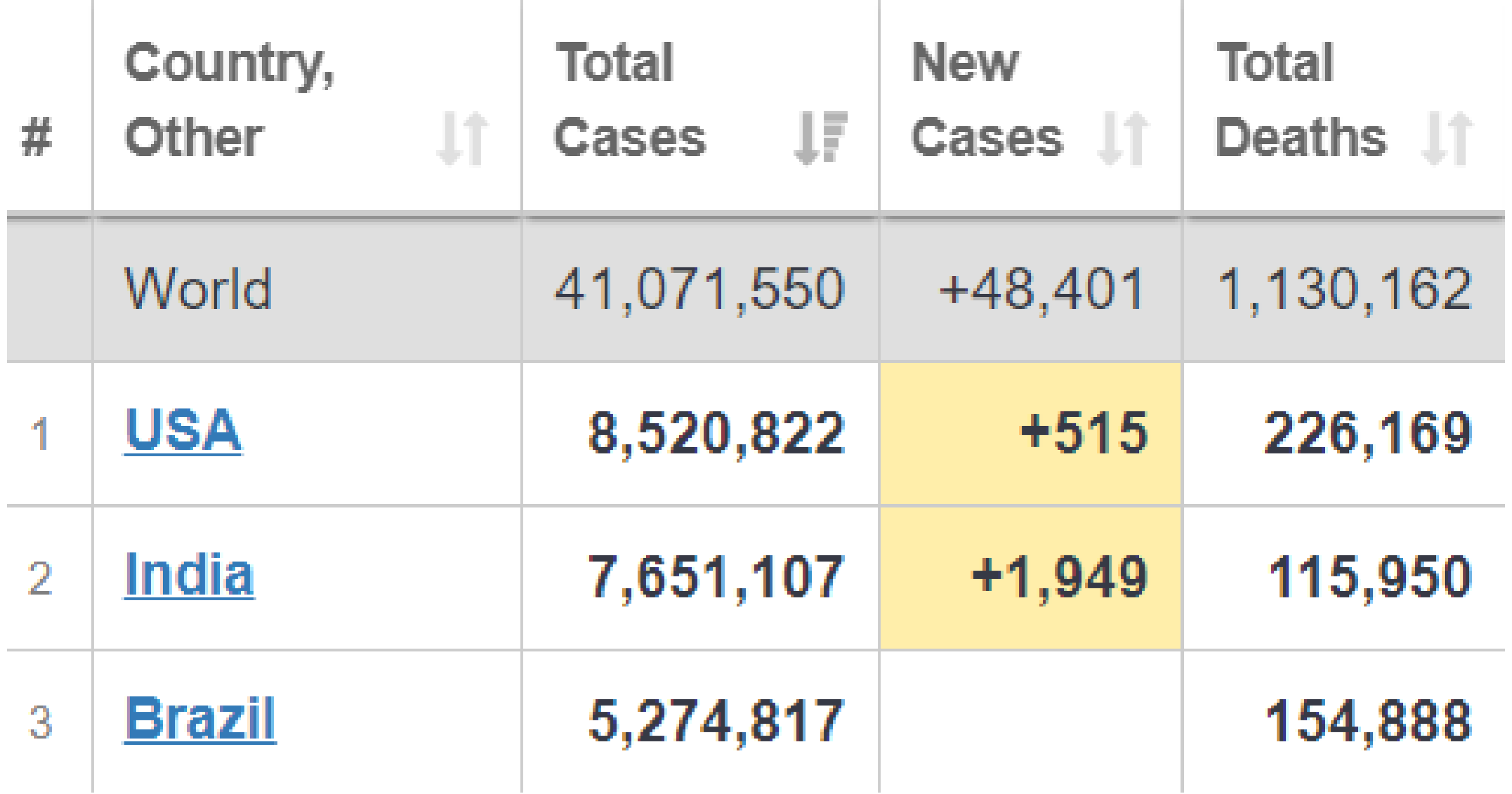
Total: **27.989**

Ministry of Health of Brazil (2019)



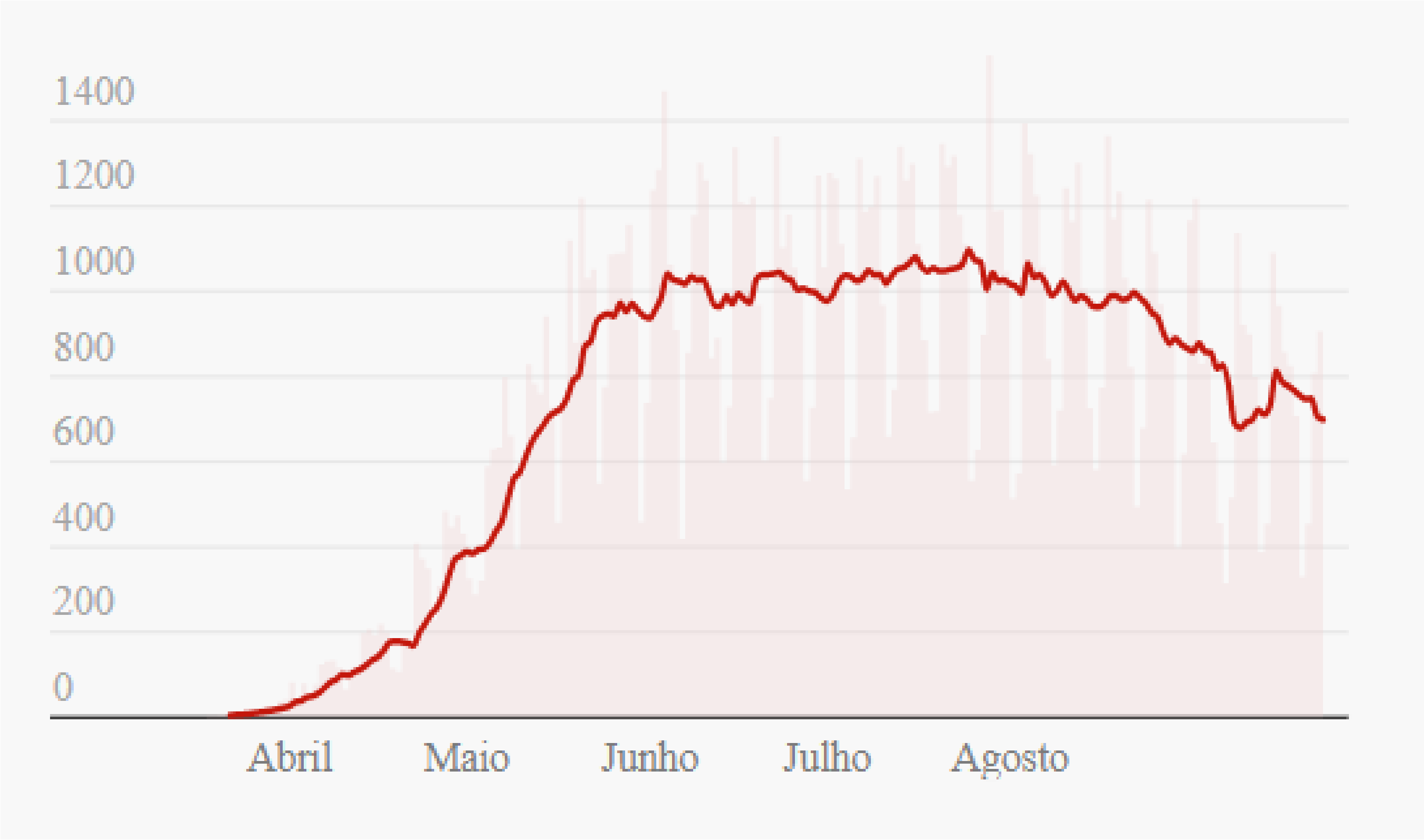
CURRENT COVID-19 SITUATION IN BRAZIL

In the world



#	Country, Other	Total Cases	New Cases	Total Deaths
	World	41,071,550	+48,401	1,130,162
1	USA	8,520,822	+515	226,169
2	India	7,651,107	+1,949	115,950
3	Brazil	5,274,817		154,888

Deaths per day



https://www.worldometers.info/coronavirus
October 21, 2020

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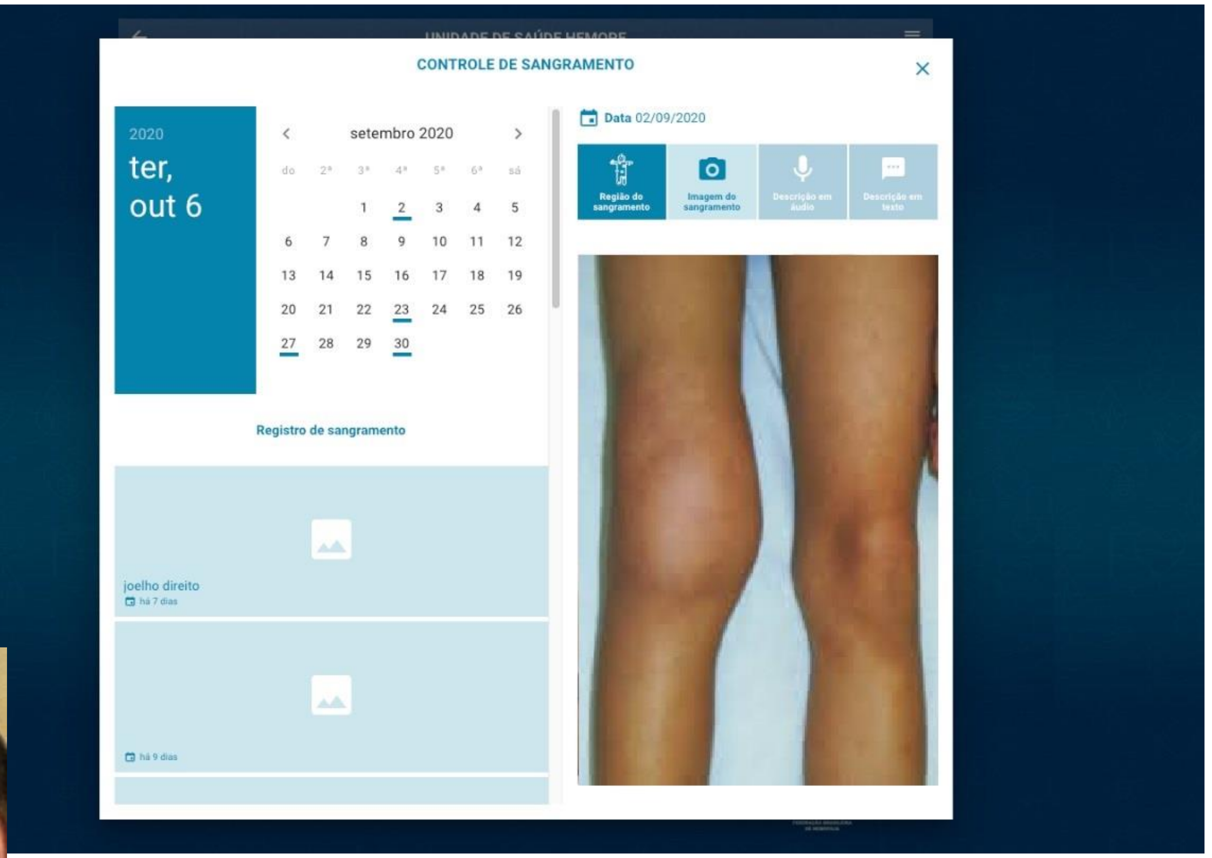
TREATMENT DURING PANDEMIC

Challenges, Innovation and Hope



CONTROLE DE SANGRAMENTO

2020
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out 6

setembro 2020

do	2ª	3ª	4ª	5ª	6ª	sá
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

Registro de sangramento

joelho direito
há 7 dias

há 9 dias

Data 02/09/2020

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Tuguy

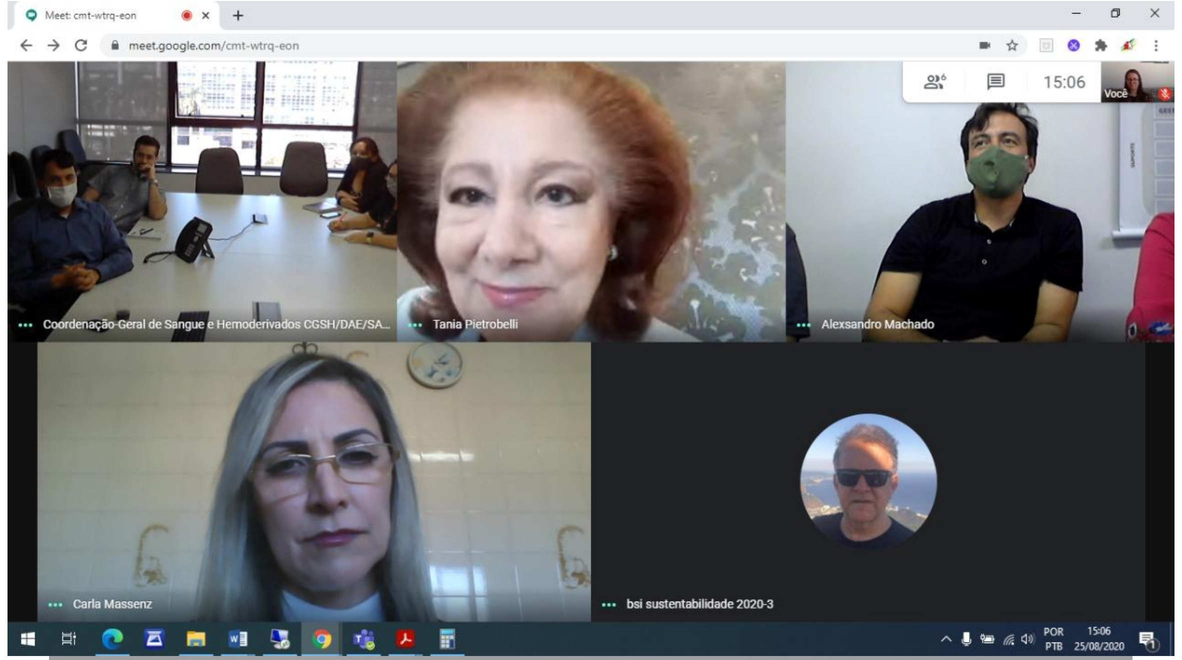
GOALS

With this project, FBH intends to become a reference in the creation of technological devices to assist in remote treatment, in the self-care of patients and in the georeferenced monitoring of clinical processes by blood centers.

NAME

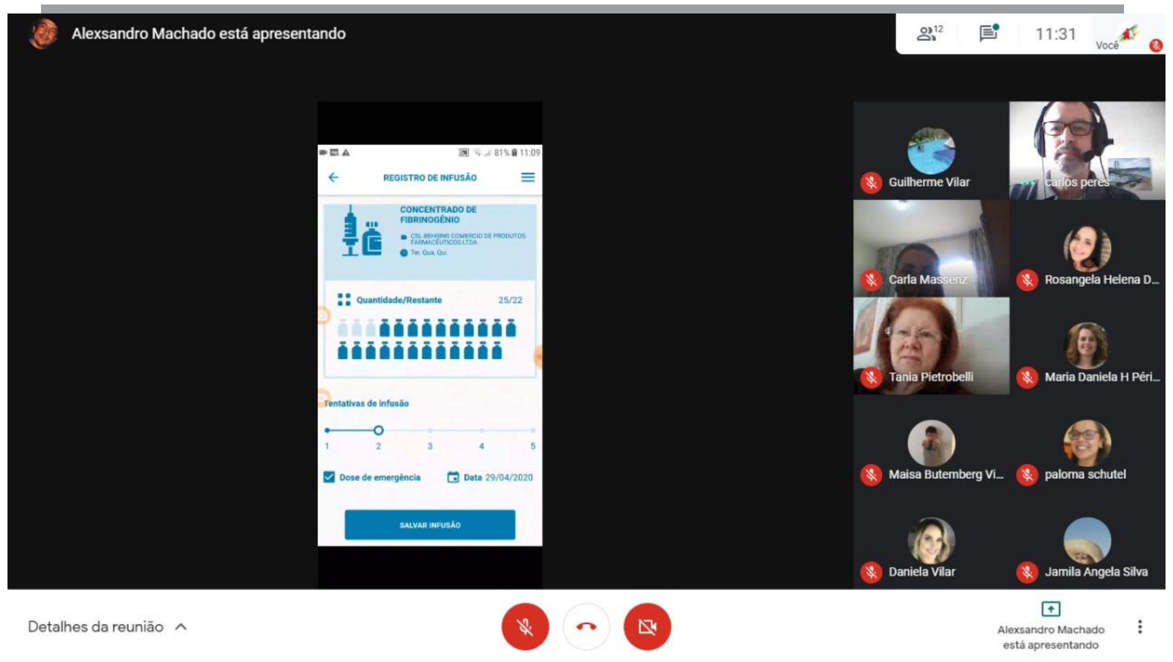
Blood is life in motion. The word blood in Guarani is called *tuguy* and means all the energy flows interconnected in the environment we live in.

ADVOCACY



Tuguy Presentation to the General Coordination of Blood - Ministry of Health

In-person mode training with health professionals from the Blood Center in the state of Pernambuco



Remote mode training with health professionals from the Blood Center in the state of Santa Catarina

TREATMENT DURING PANDEMIC

Challenges, Innovation and Hope

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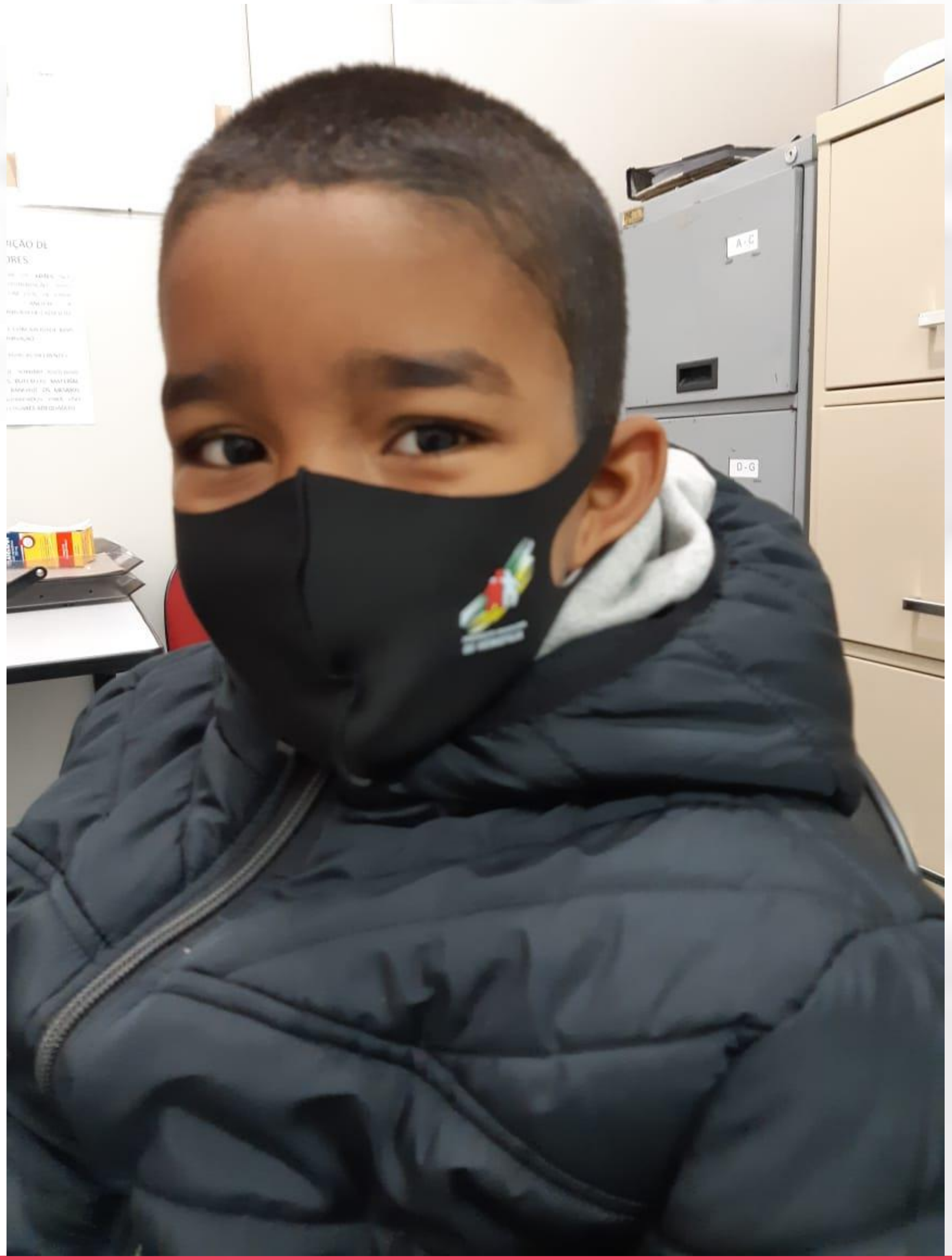

May our careful road visit everyone

> “Never has our world had so much
> communication at its disposal
> and our loneliness
> has never been so dramatic.
> There has never been so much
> road and we have never
> visited so little.”

Mia Couto

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Thank you!

Alexsandro dos Santos Machado, Phd

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Website: hemofiliabrasil.org.br

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ADVOCACY OF HEMOPHILIA SOCIETY, KARACHI CHAPTER FOR LDP TO THE GOVERNMENT

Munira Borhany,
Consultant Haematologist,
National Institute of Blood Disease (NIBD),
Haemophilia Welfare Society, Karachi (HWSK)
Karachi– 20.10.20.

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AGENDA

1. Introduction/Background
2. Efforts of HWSK
3. Advocacy
4. Challenges

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BACKGROUND:

COUNTRY CONTEXT

- Karachi is the largest and most populous cosmopolitan city in Pakistan. It has a population of 20 million out of Pakistan’s total circa 220 million.
- Health is a provincial government responsibility yet there is no government support to Hemophilia/Bleeding Disorders. Pakistan is not a welfare state and there is currently no free healthcare to patients suffering from blood disorders.
- Weak Infrastructure to look after lifelong bleeding disorders.

HEMOPHILIA WELFARE SOCIETY KARACHI (HWSK)

- HWSK was first set up in 1995 – but properly re-established and registered with Sindh Government in 2012. Now part of HFP.

- Over time, HWSK gradually morphed into a Hemophilia Treatment Centre (HTC) providing treatment and care for the broad spectrum of patients with bleeding disorders (PwBDs) in Sindh province

- Currently 10 employees and 2 doctors are working at HWSK.

HWSK REGISTERED PATIENTS ACCORDING TO DISEASE

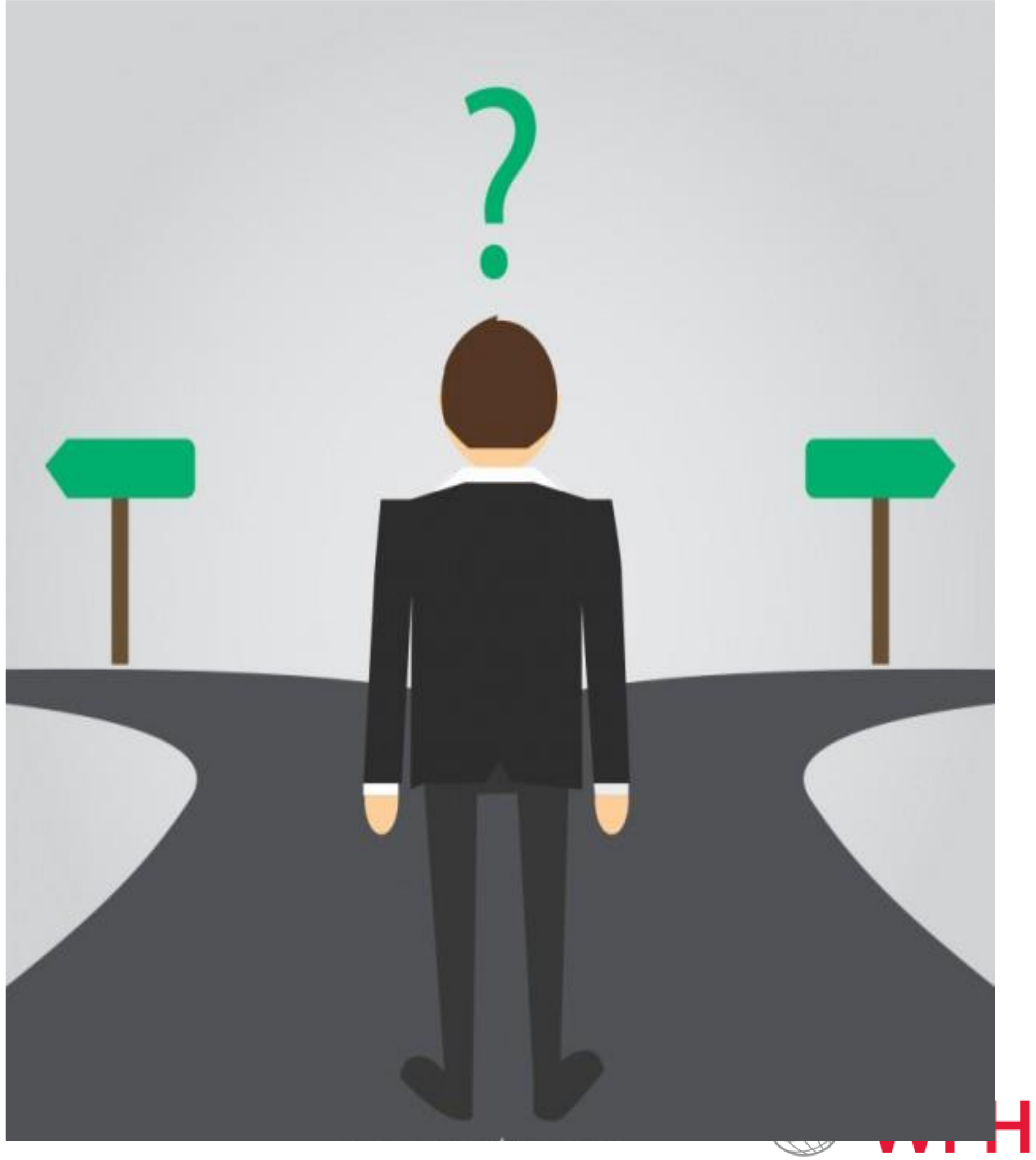
S NO	DISEASE WISE GROUPS	PATIENT QTY
1	Factor I deficiency	6
2	Factor II deficiency	1
3	Factor V deficiency	3
4	Factor V+VIII deficiency	4
5	Factor VII deficiency	4
6	Factor X deficiency	5
7	Factor XIII deficiency	9
8	Fibrinogen	1
9	**Hemophilia A [VIII]**	**532**
10	**Hemophilia B [IX]**	**113**
11	Platelet Dis Bernard	1
12	Von Willebrand	48
	TOTAL PATIENTS	727

CONTEXT: CHALLENGES OF HEMOPHILIA CARE AND TREATMENT

- Access to treatment: No government support. Inhibitors.
- Diagnosis: Costs unfordable to most patients
- Medical Expertise: Lack of training and support
- Patient Education: lack of awareness
- QoL: complications leading to education and job challenges

DILEMMA

Due to the absence of proper treatment facility in the Sindh Province, bleeding disorder patients get complications and especially their joints get damaged and they become crippled overtime.



HWKS Advocacy Plan

- In 2020 - HWSK launched an advocacy initiative with the Govt. of Sindh.
- Target audience is concerned government officials at provincial level: Provincial Health Minister (Dr. Azra) and Director of the Sindh Blood Transfusion Authority “SBTA” (Dr. Durr-e-naz).
- The objective of the initiative is to “make our voices heard” and advocate for improving the QoL of PWBDs - making them active participants/successful contributors society (rather than a burden).

- Two meetings on 13 August and 14 September 2020. Outcome to-date: Government committee assigned to work on a comprehensive plan NMO reps doctors + PWH
- This initiative is part of HFP’s Strategic Plan focused on advocacy for Government support at provincial/federal levels - developed during WFH’s (Brian O’Mahony) visit to Pakistan Nov 2019.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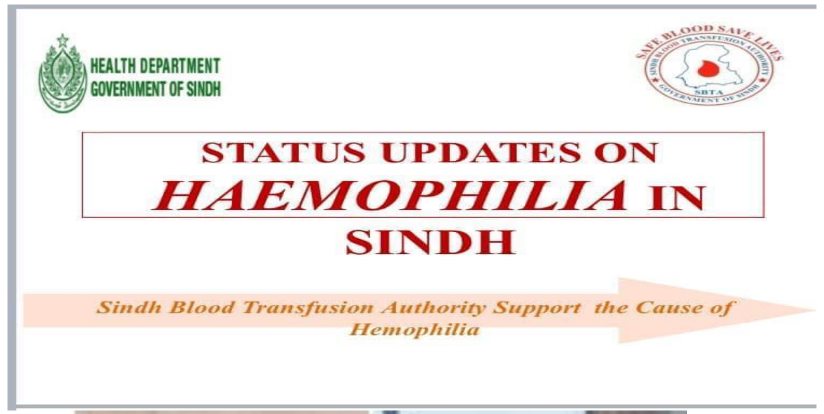
A SPECIFIC ASK: LDP PROPOSAL



HEALTH DEPARTMENT
GOVERNMENT OF SINDH

STATUS UPDATES ON
HAEMOPHILIA IN
SINDH

Sindh Blood Transfusion Authority Support the Cause of Hemophilia

- In 2018, HWSK joined forces with WFH for a Low-Dose Prophylaxis (LDP) program in Pakistan, where 15 children with severe hemophilia A from HWSK were enrolled.
- We presented the results of this study to the higher authorities, who appreciated the progress we were making and ultimately asked us to prepare a project for hemophilia patients.
- Hence, the Karachi team prepared a project with the help of WFH (Rana Saifi, Assad Haffar) and presented it to the Provincial govt.

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The LDP Project

Aim: To start low dose prophylaxis program (LDP) in our 74 hemophilia A and B patients of age less than 5 years

1) Primary Objectives
    - To identify the effectiveness of Low-Dose Prophylaxis (LDP) regimen in patients with severe hemophilia A and B
    - To find out the Annual Bleed Rate (ABR) in patients with Hemophilia on LDP.
2) Secondary Objectives
    - To evaluate the Quality of Life (QoL) in patients on LDP.
    - To evaluate the joint health score and functional independence score in hemophilia patients on LDP.

BUDGET SUMMARY

PROCUREMENT COST

Measure Value Dosage Hemophilia A for [Factor VIII]

Type of Hemophilia	Group by Age	Registered Hemophilia-A Factor VIII	Twice a week 250IUs/ FVIII	Per Month IUs/ FVIII	Per Annum IUs/ of FVIII	Per Annum Cost
Hemophilia A (CFC)	< 5 year	60	30,000	120,000	1,440,000	79,200,000/=
10% CFC IUs for Accidental purpose (FVIII)	-	-	-	-	144000	7,920,000/=

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BUDGET SUMMARY

Measure Value Dosage Hemophilia B [Factor IX]

Type of Hemophilia	Group by Age	Registered Hemophilia-B Factor IX	Twice a week 250IUs CFC IX	Per Month IUs CFC IX	Per Annum IUs CFC of IX	Per Annum Cost
Hemophilia B	< 5 year	14	7,000	28,000	336,000	19,488,000/=
10% CFC IUs for Accidental purpose (FIX)	-	-	-	-	33600	1,948,800/=

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BUDGET SUMMARY

Diagnostic Cost

S. No	Type of Hemophilia	By Age Group (years)	Number of Patients	Diagnostic Cost of Each Patient /Annum	Total Estimated Cost in PKR/per annum
1	Hemophilia-A (Factor VIII)	< 5	60	29,930	1,795,800
2	Hemophilia-B (Factor IX)	< 5	14	29,930	419,020
2	Hemophilia-A&B (Factor VIII &IX)	< 5	74	29,930	2,214,820

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LIMITATIONS

1. In Pakistan, consanguineous marriages are common. Therefore, we have a high number of rare autosomal bleeding disorder patients in our country, but due to the lack of diagnostic services we are unable to even identify them.

2. Similarly, due to unscreened blood products, very high numbers of chronically transfused patients including PWH are infected with Hepatitis B, C, and HIV. Hence, these patients should be screened, treated and vaccinated accordingly.

3. All Hemophilia treatment centers (HTC) should be connected to Regional blood centers (RBCs) so that patients receive properly screened blood products.

4. Plasma present in our RBCs should be used for fractionation to make clotting factor concentrates (CFCs), as done in other countries such as Iran. This will save cost of CFCs, import, and wastage of our plasma.

CONCLUSION

Through the LDP project for children with hemophilia, we hope to lead by example for other chapters/ provincial governments in Pakistan for advocacy, procurement and comprehensive care to improve the quality of life of bleeding disorder patients.

COVID-19 slowed us down but did not stop us from continuing with our advocacy strategy

TAKE-AWAY MESSAGE

“We don’t grow when things are easy, we grow when we face challenges”

Anonymous

The key goal of the society is to adapt the challenges and realities of life with bleeding disorder in the province of Pakistan.

If proper diagnosis & treatment is given, then a lot of things should be under control which may enhance the quality of life of persons with hemophilia.

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HAVING OUR VOICES HEARD

James Kago,

Board Member and Treasurer,

Kenya Haemophilia Association

27th October,2020

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About Us

- Kenya Haemophilia Association was established in 1978
- It is recognized by WFH as the patient organization in Kenya
- In 2014 it was re-registered by the Kenyan Government
- It held an AGM and established two layers of leadership :a) Board of Directors b) Executive committee
- Both teams have a hybrid system: representation: clinicians, patient and parents

Priority Areas

We developed a 5-year strategic plan that has guided our key priorities:

1. Infrastructure Development- establishing of Haemophilia Treatment Centres
2. Diagnostic capability- improve diagnosis by training lab techs and equipping the facilities with diagnostic machines
3. Building the capacity of Health Care Providers through training and exposures to international best practices in management of haemophilia
4. Awareness creation- this is for patients, parents and general public
5. Advocacy- engage policy makers in developing relevant legislations that will support haemophilia management
6. Resource Mobilization/ sustainability- to raise funds to advance our course and activities

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Our Achievements

- KHA has identified 700 patients against an approximated population of 5,000 potential haemophilia patients
- We have established 2 haemophilia comprehensive care centres and 4 haemophilia clinics across the country
- We have trained over 400 Healthcare Providers on haemophilia identification and management
- We have trained over 50 patients and parents on advocacy
- We have held over 10 successful meetings with policy makers at MOH and Parliament

Our Achievements

- KHA submitted a petition to parliament that has been debated and is awaiting adoption
- Jointly with MOH worked on a budget for purchase of factor concentrates
- Factor Concentrates has been included into the Essentials Drug list
- Held a disability registration exercise with National Council of Persons with Disability (NCPWD)
- We had a discussion with the Deputy President, and he has committed to prioritize haemophilia treatment

Our Achievements

- KHA facilitated an MOU between the WHF and the Kenyan government that waived taxes on donated factor
- The Government through MOH and County Governments has provided space to set up Haemophilia clinics
- The Government has committed resources both personnel and financial to manage the haemophilia clinics
- Haemophilia patients have been recognized and registered as persons with disability
- The government has been participating in KHA activities

How COVID-19 Impacted us

The COVID-19 Pandemic impacted us in three ways:

- Disrupted distribution of medical supplies especially factor concentrates – MOH came in handy
- Financial Impact: Most families were unable to fend for themselves. We supported over 73 families
- Hygiene challenges: most families couldn't afford sanitizers and face masks. Through partnerships we gave out over 10,000 re-usable masks.

Key Learnings

Success:
Have a dedicated team that is well trained on advocacy

Challenges:
Resources to carry out a successful advocacy campaign are scarce so prioritize

Opportunities:
Collaborate with other NCDs to have a bigger voice

Read the mood:
Study the governments priorities to know which priority to push for

Recommendations

EVENTS	Involve the government in your activities such as WHD celebrations
SOCIAL MEDIA	Use social media to drum support for your course. Sometimes, a trending event can reach the highest office and get assistance.
SPONSORSHIP	Corporates provide a good fora through their corporate social responsibilities and a partnership with them can assist you to reach a wide audience
PARTNERSHIPS	Forming partnerships with like minded organizations can assist in building up support and have a louder voice. We have partnered with the Sickle Cell Federation of Kenya.

KHA Team at Parliament Building with Hon. David Sankok presenting the Petition

Irene Chami, WFH RM giving a talk during opening of Voi Clinic

Meeting between KHA and Sickle Cell Federation Officials

H.E. First Lady Elizabeth Ongwae during the Opening of Haemophilia Clinic at Kisii County Referral Hospital.

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THANK YOU!

ASANTE!

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QUESTION & ANSWER

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THANK YOU!

¡GRACIAS!

MERCI!

شكرا

СПАСИБО

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