



HUMANITARIAN AID PROGRAM



IMPACT REPORT 2022



The WFH Humanitarian Aid Program: **A BEACON OF HOPE FOR PEOPLE WITH BLEEDING DISORDERS**

Hello friends,

The WFH Humanitarian Aid Program exists to support emerging countries along their journey to sustainability in inherited bleeding disorders care. This support comes in the form of predictable treatment product donations, education, training, and government lobbying assistance.

We're able to do this thanks to the dedication of our staff and the commitment of our partners: WFH national member organizations (NMOs), hemophilia treatment centres (HTCs), healthcare professionals (HCPs), and sponsors.

In 2022, the Program delivered support to those who needed it in a number of different ways. We donated 197 MIUs of factor and 3,261,800 mg of non-factor replacement therapy. We helped treat 25,000+ patients with hemophilia A and B. We helped 3,964 patients begin or continue prophylactic treatment (2,854 through factor replacement therapy and 1,110 through non-factor replacement therapy). 41,700+ bleeding episodes were managed, and 1,400+ surgeries were performed thanks to the donations we provided. And today, we can say with great pride that we have supported 112 countries since the inception of the Program in 1996. We also supported people with bleeding disorders who are being impacted by the war in Ukraine: as of the end of 2022, we had provided 8.5 million IUs of factor to Ukrainians and Ukrainian refugees. This kind of support will continue until the war ends and life goes back to normal in Ukraine.

Also, for the very first time, the Program was featured in *The Lancet Haematology*, one of the most prestigious medical journals in the world. "Achieving access to haemophilia care in low-income and lower-middle-income countries: expanded Humanitarian Aid Program of the World Federation of Hemophilia after 5 years", authored by the WFH Humanitarian Aid Advisory Committee, chronicles the recent impactful work we have done around the world.

In 2022, we continued to work to increase diagnosis, improve education and training, and advocate with governments. We were also able to resume in-person meetings and sessions—while concurrently increasing our virtual offerings. By doing this, we were able to maximize the accessibility of our offerings while also fostering relationships through face-to-face interaction.

Our goals for next year include continuing to deliver care to where it's needed, increasing the number of children on prophylaxis by 5%, and training specialists on immune tolerance induction (ITI), ultrasound diagnosis, and synovectomy. Our long-term goals include maintaining a sustained level of treatment products in recipient countries, encouraging health authorities in recipient countries to invest in procuring treatment products, beginning donations of upcoming novel therapies, and testing the feasibility of offering donated gene therapy products.

The success of the WFH Humanitarian Aid Program is a direct result of a collective effort between the WFH, pharmaceutical partners, governments, and the global bleeding disorders community. On behalf of everyone at the WFH, thank you for your support and for your conviction in us.

3,964

patients on prophylactic treatment

+1.5 billion

IUs distributed since inception of Program in 1996

25,000+

people with inherited bleeding disorders (PWBDs) treated

41,700+

bleeding episodes managed

1,400+

surgeries facilitated



Assad E. Haffar, MD, MSc

WFH Medical &
Humanitarian Aid Director



CASE STUDY

Morocco

FACTOR DONATED IN 2022
1.4 million IUs

PATIENTS TREATED IN 2022
100



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In Morocco, WFH support has strengthened collaboration with the government and key stakeholders over a period of many years. Thanks to these efforts, the Ministry of Health has drawn up a national plan for the management of hemophilia and other bleeding disorders. The ministry has also increased the purchases of treatment product by hospitals, purchasing more than 9 million IUs of factor in 2022. This large purchase meant that WFH Humanitarian Aid Program donations became a supplement to government purchases, rather than the primary source—a huge step forward for the Moroccan bleeding disorders community.

IMPACT IN ACTION

The WFH Humanitarian Aid Program works to improve the lives of PWBDs, giving them a quality of life that previous generations would not have thought possible.

The Program operates based on three key action pillars: supporting outreach and identification, improving quality of life, and enabling sustainable care. These pillars drive our main support activities: delivering donated factor and non-factor replacement therapy, conducting training events and providing logistics support.

1 Supporting outreach and identification by...

- Training general HCPs on how to recognize bleeding disorders
- Supporting initiatives with local organizations to find new patients
- Encouraging our partners to increase laboratory diagnosis by providing both educational and logistics support

2 Improving quality of life by...

- Collaborating with physicians to provide critical factor and non-factor replacement therapy donations
- Making life-changing surgery possible through sustainable and predictable treatment donations
- Facilitating access to care for new and existing PWBDs by working with NMOs and HTC

3 Enabling sustainable care by...

- Supporting the launch of medical facilities so that NMOs and HTCs can provide patients with lasting care
- Demonstrating to governments the value of treating PWBDs with appropriate and adequate treatment to support advocacy initiatives
- Informing and training healthcare practitioners (HCPs) on new classes of treatment and new treatment methods in line with the WFH Guidelines for the Management of Hemophilia, 3rd edition



**DELIVERING
CARE**



**MAKING SUSTAINABLE
CARE POSSIBLE**



**ADVOCATING
FOR CARE**

CASE STUDY

Nigeria

FACTOR DONATED IN 2022
4.3 million IUs

NON-FACTOR REPLACEMENT THERAPY DONATED IN 2022
232,500 mg

PATIENTS TREATED IN 2022
232



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David Aremu has severe hemophilia A. His condition went undiagnosed for many years, and as a result, he had internal bleeds, including bleeds in his legs that impacted their development. David felt alone and hopeless—until he was introduced to Megan Adediran, the Founder and Executive Director of the Hemophilia Foundation of Nigeria. Soon, he was able to access prophylactic treatment made possible by donated non-factor replacement therapy provided by the WFH Humanitarian Aid Program. This treatment has kept him more consistently healthy and has allowed him to attend school regularly.



DELIVERING CARE

In 2022, the WFH Humanitarian Aid Program provided 197 million IUs of clotting factor concentrates and nearly 3.3 million mg of non-factor replacement therapy around the world. Since the inception of the program in 1996, a total of 1.5 billion IUs have been distributed worldwide.



Key Performance Indicators (KPIs)

Acute bleeds treated

versus people with hemophilia (PWH) on prophylaxis



Because more patients are on prophylaxis, the number of acute bleeds dropped significantly in 2022.

Note: The WFH Quality Management System (QMS) and Standard Operating Procedures (SOPs) ensure that the WFH Humanitarian Aid Program respects all good distribution practices (GDP) requirements.

CASE STUDY

Suriname

FACTOR DONATED IN 2022
1 million IUs

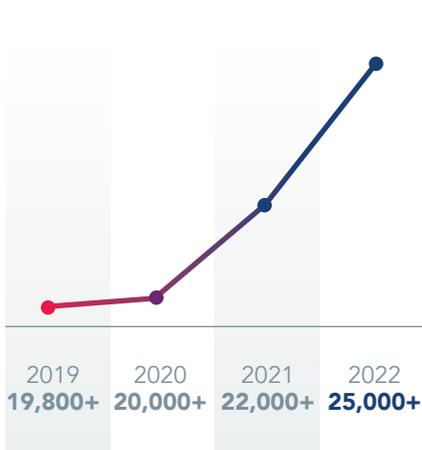


Click here to read the full story or scan the QR code

Sheldon Simson is a 40-year-old man who was diagnosed with severe hemophilia A when he was three months old. During his childhood, he developed permanent joint damage to his ankles, knees, and elbows. Things changed dramatically for Sheldon when the WFH Humanitarian Aid Program began providing donated factor to his country in 2021. He went from having rare access to factor to being able to begin a prophylactic treatment regimen. Simson's story is proof that change is almost immediate even at the initial stages of the WFH Humanitarian Aid Program work in a country.

25,000+

Hemophilia A and B patients treated (cumulative) in 2022



2,803

People with hemophilia (PWH) on prophylaxis under 10 years of age (cumulative) in 2022



1,400+

Surgeries in 2022



MAKING SUSTAINABLE CARE POSSIBLE

Training, logistics and compliance support are the other key pillars of the WFH Humanitarian Aid Program. These activities provide the education and guidance that countries need to develop their infrastructure to provide lasting support.

In-person training

With the COVID-19 pandemic becoming more manageable for many countries, in-person training resumed in 2022 to leverage the networking opportunities that come with multi-day meetings. Two highlights this year were training workshops in Nairobi (Kenya), and Jakarta (Indonesia), both of which led to posters that were presented at the 16th Annual Congress of the European Association for Haemophilia and Allied Disorders (EAHAD).

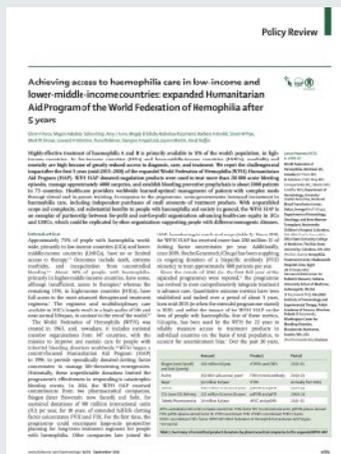
Webinars and online education

In 2022, the Program continued with online training to maximize the accessibility of knowledge-transfer and ensure that all regions received training. These sessions covered topics that were not delivered through in-person events, such as training for lab work, bedside rounds, and front-line doctors and second line treaters. Thematic training was also re-started in 2022 and included the introduction of training for surgeries.

Logistics support

Getting donated factor to where it needs to be quickly and efficiently is a difficult task—and ongoing pandemic issues continue to make the process challenging. Fortunately, the Program continues to develop creative solutions to limit the risk of potentially catastrophic interruptions in factor donations.

Key Performance Indicators (KPIs)	2019	2020	2021	2022	2019 to 2022 % change
Shipments	331	257	318	269	-18%
Vials	321,553	254,706	633,453	422,400	+31%
Gross weight (tons)	58	46	113	82	+43%
Compliance assessments	18	20	20	21	+17%



LANCET ARTICLE

In September 2022, the progress of the Program was showcased in an article in *The Lancet Haematology*, authored by the WFH Humanitarian Aid Advisory Committee. "Achieving access to haemophilia care in low-income and lower-middle-income countries: expanded Humanitarian Aid Program of the World Federation of Hemophilia after 5 years" looks at the encouraging progress that has been made by the Program over the first five years.



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or scan the QR code



CASE STUDY

Guyana

FACTOR DONATED IN 2022
555,000 IUs

PATIENTS TREATED IN 2022
11



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Growing up in Guyana at a time when knowledge of hemophilia was limited was difficult for Mohammad, a 42-year-old with hemophilia A. His mother put him up for adoption because she thought his spontaneous bruising was a sign of witchcraft. As he grew up, frequent bleeds permanently reduced flexibility in his joints. This kind of lack of awareness is something the WFH Humanitarian Aid Program is helping to change. The Program is working with the Guyana Hemophilia Society (GHS) and HCPs to increase education and provide local HTC's with treatment product. This change has allowed Mohammad to be put on prophylactic factor replacement therapy. Now, his life has been transformed: he no longer fears bleeds and he can live a normal life.

The KAP model

Last year, the WFH Humanitarian Aid Program introduced a new evaluation tool to enhance our evaluation method for training initiatives. Called the **Knowledge Attitude Practice (KAP)** model, the new tool helps the WFH Humanitarian Aid Program team evaluate the lasting impact of training. The model looks at the sharing of Knowledge, the Attitude of

participants after training has been completed, and the Practice of applying the knowledge learned. The model helps us answer important questions about what difference training is making, and if levels of care are increasing. Full reporting on the KAP model will be available for the 2023 WFH Humanitarian Aid Impact Report

ADVOCATING FOR CARE

The WFH Humanitarian Aid Program plays a leadership role in global advocacy by working with NMOs to advocate with governments to recognize and support their bleeding disorders communities. Ultimately, government buy-in is required for a country to be able to provide fully sustainable care to its bleeding disorders community. Here are three videos which demonstrate the work the WFH Humanitarian Aid Program is doing around the world.

Cambodia



The WFH Humanitarian Aid Program support has drastically transformed care in Cambodia. Where once PWBDs were almost never diagnosed, now, they are properly treated and put on prophylaxis. The sharing of knowledge between healthcare practitioners (HCPs) also means that the country is becoming more self-sustaining for the treatment of PWBDs.



[Click here to watch the video](#)
or scan the QR code

Sri Lanka



At one time, the National Hospital in Colombo, Sri Lanka was only able to give its patients with bleeding disorders minimal treatment. Physicians were not able to perform surgeries or special treatments. "Now our centre is the main [hemophilia treatment] centre [in Sri Lanka] which treats all the complicated hemophilia injuries and hemophilia surgeries," says Visaka Ratnamalala, MD.



[Click here to watch the video](#)
or scan the QR code

Egypt



One of the key elements of sustainable care is government support. That's why a key part of the WFH Humanitarian Aid Program is working with decision makers to get that governmental buy in. In the case of Egypt, those efforts have paid off, and patient quality of life has significantly improved.



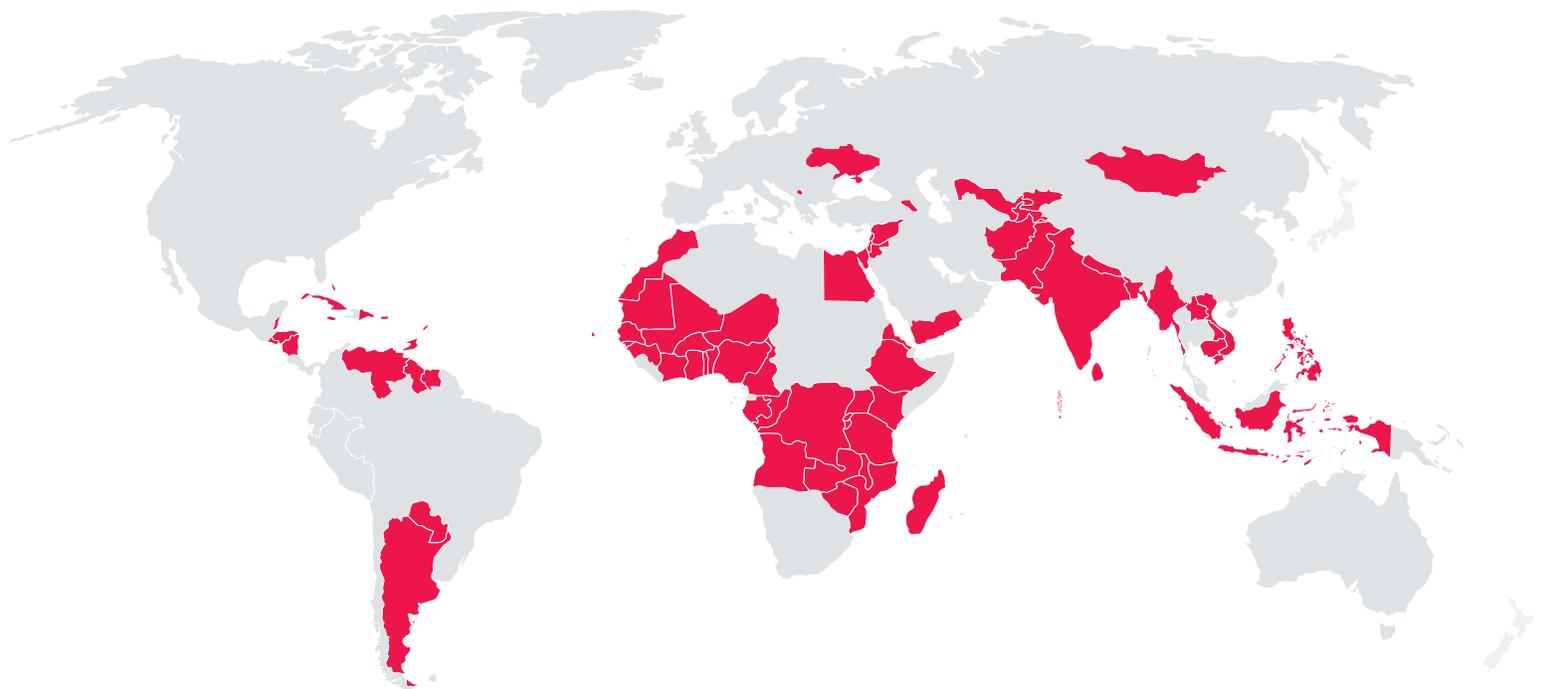
[Click here to watch the video](#)
or scan the QR code

Countries that collaborated with the WFH in 2022

Received donations

(72 countries)

- | | | | | | |
|--------------|------------------------------------|-------------|------------|-------------------------------------|---------------------|
| Afghanistan | Cameroon | Guinea | Madagascar | Pakistan | Tanzania |
| Angola | Cuba | Guyana | Malawi | Palestine | Togo |
| Argentina | Democratic Republic of Congo (DRC) | Honduras | Maldives | Paraguay | Trinidad and Tobago |
| Armenia | Dominican Republic | India | Mali | Philippines | Uganda |
| Bahamas | Egypt | Indonesia | Mauritania | The Republic of Congo (Brazzaville) | Ukraine |
| Bangladesh | El Salvador | Ivory Coast | Mongolia | Rwanda | Uzbekistan |
| Barbados | Eritrea | Jamaica | Morocco | Senegal | Venezuela |
| Belize | Ethiopia | Jordan | Mozambique | Sri Lanka | Vietnam |
| Benin | Gabon | Kenya | Myanmar | Suriname | Yemen |
| Bolivia | Gambia | Kosovo | Nepal | Syria | Zambia |
| Burkina Faso | Ghana | Kyrgyzstan | Nicaragua | Tajikistan | Zimbabwe |
| Burundi | | Laos | Niger | | |
| Cambodia | | Lebanon | Nigeria | | |



● Donations

WORKING TOGETHER

to support Treatment for All

The WFH Humanitarian Aid Program improves the lack of access to care and treatment by providing much-needed support to people with inherited bleeding disorders in developing countries. By providing patients with a more predictable and sustainable flow of donations, the WFH Humanitarian Aid Program makes it possible for patients to receive consistent and reliable access to treatment and care. None of this would be possible without the generous support of our sponsors.

Founding Visionary Contributors



“At Sanofi, our goal has always been to provide reliable access to therapy, diagnosis, and care for people living with hemophilia. We are committed to improving access to healthcare, beyond just a one-time donation. As Founding Visionary Contributors to the WFH Humanitarian Aid Program with Sobi, we help ensure a predictable and sustainable supply of factor replacement therapy to patients and their families—to create a more equitable world for people living with rare blood disorders.”

—Bill Sibold, EVP and Head of Specialty Care, **Sanofi**



“Sobi remains committed to improving access to care for people with hemophilia around the world, and we are proud to continue our support of the WFH Humanitarian Aid Program as Founding Visionary Contributors with Sanofi. We understand that hemophilia treatment can only make a meaningful difference to communities if access to therapy is predictable and sustainable over the long-term. It is a true privilege to be a part of this collaboration and to witness the profound impact it continues to have.”

—Guido Oelkers, CEO and President, **Sobi**

Visionary Contributors



"At Bayer we are guided by our vision of 'Health for All, Hunger for None'. This is why we are very proud to work in close collaboration with the WFH Humanitarian

Aid Program to provide support and access to treatment for people with hemophilia where it is most needed. As part of our long-standing commitment to the global hemophilia community, the strong alliance between the WFH and Bayer is a great opportunity for us to make a life changing difference in people's lives."

—Martin Renze-Westendorf, Global Therapeutic Area Head for Hemophilia, **Bayer**



Genentech
A Member of the Roche Group



"Supporting global hemophilia communities in their efforts to improve the lives of people living with hemophilia A is a top priority for Roche. Improving the healthcare systems and working towards greater government engagement in all countries is as important as creating more access to therapies. Life-changing therapy types can contribute to improving the quality of lives of people with hemophilia A and their families. We are grateful for being able to collaborate with the WFH on the WFH Humanitarian Aid Program, and so help to address the great need for more access to therapies, particularly in low-income countries."

—Daud Chaudry, Global Head of Hemophilia, **Roche**

CSL Behring

"Protecting the health and wellbeing of our patients, communities and people around

the world is paramount to Our Promise to those living with rare and serious diseases. Through collaborative actions such as our donation of 500 million IUs of coagulation factor replacement therapy to WFH and other values-driven partnerships, we are able to further foster a healthier, more sustainable and equitable planet. The WFH Humanitarian Aid Program embodies Our Promise, and we are grateful for the opportunity to partner with an organization that extends our purpose to improve patients' quality of life."

—Paul McKenzie, CEO and Managing Director, CSL Limited, **CSL**

Leadership Contributor

GRIFOLS

"It is an honour to join with the WFH Humanitarian Aid Program and other healthcare companies to address the needs of individuals living with bleeding disorders in low- and middle-income countries who may not otherwise have access to blood clotting factors and other treatments. With a family legacy of more than 110 years of working to improve the health and well-being of people around the world, the continuing contribution of Grifols to the WFH Humanitarian Aid Program underscores our commitment to global public health."

—Christopher Healey, Senior Vice President, Corporate Affairs, **Grifols**

Contributor



"At Takeda, we continue to be inspired by progress made by the WFH in its vision to ensure equitable Treatment for All. For example, the achievements in Morocco are a testament to the success of the WFH multistakeholder partnership approach—an approach we wholeheartedly support."

—Giles Platford, President, Plasma Derived Therapies Business Unit, **Takeda**



"We affirm the WFH philosophy of "Treatment for All" and are proud to contribute to the treatment of hemophilia patients by participating in the WFH Humanitarian Aid Program. In Japan, an export of blood products was restricted, but the law was amended in 2018. We are honoured that our first partner under the new export rules is the WFH."

—Takahide Ishikawa, President, **Japan Blood Products Organization (JB)**

Community Partners



"Hemophilia of Georgia is proud to stand side-by-side with the WFH in support of people across the globe that suffer from a bleeding disorder. We share a common goal: that care is about much more than medicine. Supporting the WFH Humanitarian Aid Program provides not only life-saving medication, but training and education and sustainable quality care to improve lives."

—Edith A. Rosato, CEO, **Hemophilia of Georgia**

WFH Humanitarian Aid Program

KEY PERFORMANCE INDICATORS

Key Performance Indicators (KPIs)

	2018	2019	2020	2021	2022
Operational metrics					
Patients treated by donations (cumulative)	18,458	19,792	20,048	22,159	25,183
Total donations in MIUs	191	241	146	307	197
Total donations in mgs	n/a	n/a	809,220	2,562,750	3,261,800
Number of countries receiving donations	62	73	69	74	72
Mean age of PWH receiving treatment	20	22	22	21	21
Total number of infusions related to acute bleed treatment	103,458	119,658	68,889	159,458	63,492
Impact metrics					
Number of countries doing surgeries	26	25	25	26	22
New countries doing surgeries	3	0	0	2	2
Total number of surgeries	685	789	856	838	1,461
Life and limb-saving surgeries	62	112	121	83	72
Number of acute bleeds treated	58,458	64,722	51,401	62,349	41,771*
Impact metrics (cumulative)					
Number of PWH on prophylaxis	1,546	1,622	1,804	2,836	3,964
PWH on prophylaxis under 10 years of age	834	1,053	1,145	1,251	2,803
Activity metrics					
Number of workshop attendees	240	250	691	1,468	470
Virtual	–	–	691	1,468	364
In-person	250	250	–	–	106

The WFH would like to thank all our sponsors—and particularly Sobi and Bayer—for their proactive donations to the Ukrainian bleeding disorders community during the early stages of the war in Ukraine.

* Because more patients are on prophylaxis, the number of acute bleeds dropped significantly in 2022.

CASE STUDY

Pakistan

FACTOR DONATED IN 2022
12 million IUs

NON-FACTOR REPLACEMENT THERAPY DONATED IN 2022
490,000 mg

PATIENTS TREATED IN 2022
1,548



[Click here to read the full story or scan the QR code](#)

As the awareness that women and girls can also have a bleeding disorder expands, humanitarian aid is increasingly going to females who have conditions like VWD. Wajiha Javid, from Pakistan, was six when she was diagnosed with VWD. When she entered puberty, she began having severe menstrual periods and was put on prophylactic treatment, but she still suffered from continued severe menstrual periods. After a consultation with her specialists, the difficult decision to proceed with a hysterectomy was made to improve her quality of life. Even though the procedure was not the ideal outcome for her, she now has a chance at a normal life with continued prophylactic treatment.



Your continued support helps us

Increase quality of care

.....

Increase the number of patients treated

.....

Improve quality of life

.....

Enhance diagnosis

.....

Advocate for better care

.....

For more information, please contact us at:

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