
Overseas Haematology Laboratory Experience



Mary Byrne St. James's Hospital, Dublin
IEQAS Annual Meeting 7th October 2021

Overseas Haematology Laboratory Experience

- Development of a partnership between Haemophilia Treatment Centres and Haemophilia Patient Organisations in established and emerging centres throughout the world
- Organised and facilitated by the World Federation of Hemophilia
- Multi-disciplinary partnership
 - Medical
 - Nursing
 - Laboratory
 - Dental
 - Physiotherapy
 - Other allied health professionals
 - Patient Organisations



WORLD FEDERATION OF HEMOPHILIA

- ****Treatment for all****
 - Improve and sustain care for people with inherited bleeding disorders around the world

 - Ensure every person living with Haemophilia, Von Willebrand disease, rare coagulation factor deficiencies and women with bleeding disorders have access to world class care and recognition of their condition





WFH

WORLD FEDERATION OF HEMOPHILIA

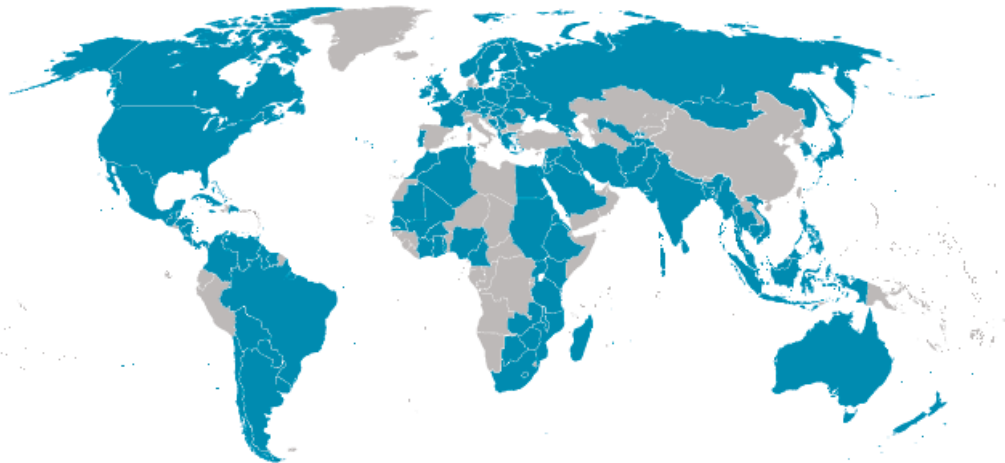


WFH

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

October 2020

Annual Global Survey 2019



■ Countries included

■ Countries not included

KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY (2019)

NUMBER OF COUNTRIES
in this survey



115

RESPONSE RATE
from WFH National
Member Organizations



82%

(115/140)

NUMBER OF IDENTIFIED PATIENTS



324,648

People with hemophilia..... **195,263**
Hemophilia A..... **157,517**
Hemophilia B..... **31,997**

Hemophilia type unknown **5,749**
von Willebrand disease **80,302**
Other bleeding disorders..... **49,083**

**FACTOR VIII
USAGE PER CAPITA**

1.058 IU

(0.174 – 4.312) Median (IQR)
(101 countries, 72% of world population)



**FACTOR IX
USAGE PER CAPITA**

0.155 IU

(0.017 – 0.673) Median (IQR)
(93 countries, 66% of the world population)

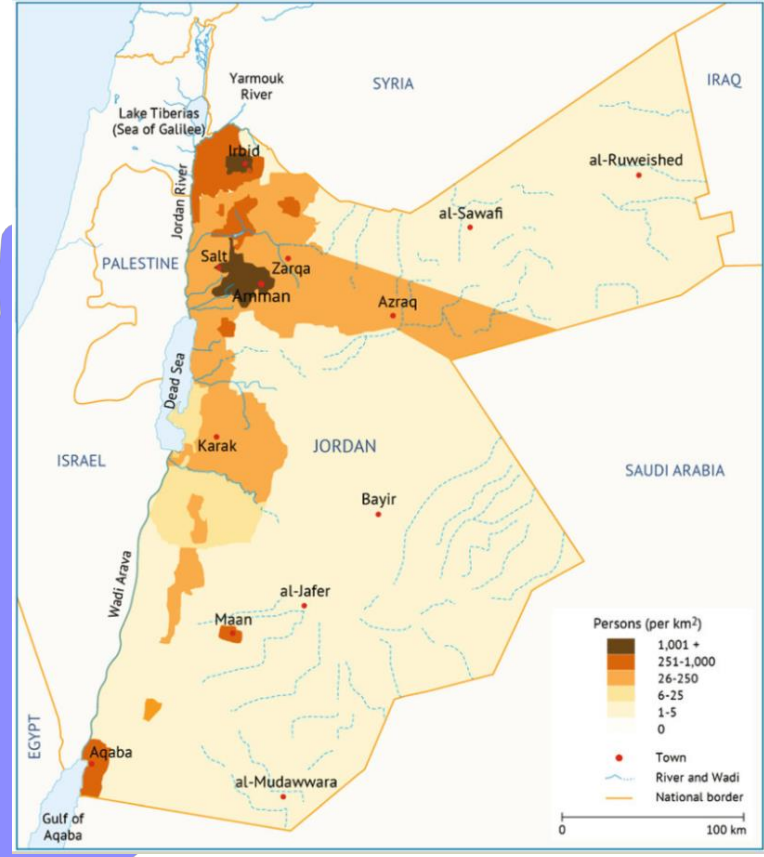
- Twinning programme
 - Partnership between established and emerging Haemophilia treatment centres and patient organisations
 - Developing and developed countries
 - Assist emerging centres to improve diagnosis and treatment of patients
 - Exchange of knowledge, experience, skills
 - Share resources
 - Advocacy initiatives
 - Strengthen patient organisations
 - Mutually beneficial relationship

■ Twinning programmes

- ❑ >20 Years
- ❑ 255 Partnerships
- ❑ 115 Countries
- ❑ 93 Haemophilia Organisations
- ❑ 157 Haemophilia Treatment Centres
- ❑ 5 Youth Group Twinning Partnerships

- ❑ **Amounting to 1075 total years of twinning partnerships**

Twinning partnership: Ireland and Jordan



Population (2021)

Jordan 10,269,021

Ireland 4,982,907

www.comparea.org accessed September 2021

Population distribution:

November 2019





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Country	Population	People with Haemophilia	People with VWD	People with other bleeding disorders
Ireland	4,941,444	915	1,644	1,305
Jordan	10,101,694	447	259	255

Country	Haemophilia A	Haemophilia B	Haemophilia type unknown	VWD	F1	FII	FV	FV+FVIII	FVII	FX	FXI	FXIII	Bleeding disorder – type unknown	Glanzmanns Thrombasthenia	Bernard Soulier syndrome	Platelet disorders (other/unknown)
Ireland	664	251	0	1644	88	3	175	1	220	153	271	11	0	14	4	365
Jordan	341	106	0	259	1	4	12	0	51	21	37	17		112		

Establishment of twinning programme

- Joint assessment visit for Haemophilia Treatment Centres and Haemophilia Patient Organisations 2018
- Action plan developed
- First formal twinning visit September 2019

Al Bashir Hospital, Amman



- Al Bashir Thalassaemia and Hemophilia Centre
 - The Jordanian Association for Thalassemia and Hemophilia

- National Haemophilia service in Ireland
 - Comprehensive care centres
 - National Coagulation Centre, St James's Hospital
 - Children's Health Ireland, Crumlin
 - Irish Haemophilia Society

Twinning visit 2019

- Paediatric and adult Clinic
- Pharmacy
- Laboratory
- Ministry of Health
- Meeting with patient organisation
- Day Symposium
 - The Second International Medical Conference on Hemophilia, Thalassemia and Sickle Cell disease



Pre visit planning essential !!



- Prior to visit:
- Contact made with laboratory staff to determine needs and wishes for visit
 - Review of coagulation factor assays
 - Coagulation factor inhibitor assays
 - Von Willebrand screens

- Determine availability of reagents locally
- Source reagents and send to Jordan
- Ensure reagents are compatible with laboratory equipment and resources
- Plan workshop

Laboratory visit



Laboratory Visit: Year 1

- Coagulation screens
 - Fibrinogen
 - D Dimer
 - Mixing studies
 - Factor Assays
 - Thrombophilia screens
 - No Von Willebrand Screens
 - No genetic analysis
- Stago analysers
 - Waterbath
 - Freezer (-20°C)
 - Centrifuge
 - On-line test requesting and reporting of results
 - IQC schedule
 - EQA programme with Stago

Laboratory Visit: Year 1

- Review of mixing studies and factor assay procedures
- Discussion of principle of method and reagents required for coagulation factor inhibitor testing
- Practical demonstration of inhibitor testing



Laboratory Visit: Year 1

- Planning for future:
 - Expansion of IQC schedule
 - Expansion of EQA participation
 - Secure supply of reagents



Laboratory Visit: Year 1



- Planning for future visits:
 - Full repertoire of factor assays and with multi-dilutional assays
 - Inhibitors
 - Screens and quantitation
 - Von Willebrand Factor
 - VWF antigen and VWF function
 - Thrombophilia screens:
 - Develop and agree local guidelines with clinicians for appropriate testing

International Medical Conference on Hemophilia, Thalassaemia and Sickle Cell disease



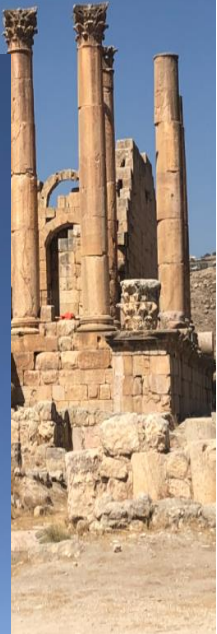
- Diagnosis of Von Willebrand Disease
- Testing and Diagnosis of Inhibitors in Haemophilia
- Novel Therapies in Hemophilia: Where Are We Now and What Does the Future Hold
- Multidisciplinary Approaches to Managing Haemophilia
- Transition from Pediatric to Adult Haemophilia Care: Management and Key Considerations

Twinning partnership through COVID-19 travel restrictions

- In-person visits not possible since 2019
- Keep up momentum for partnership

- Regular webinars and meetings
- Exchange of information
- Collaboration and discussion of many aspects of service provision
- Plan for a resumption of in-person visits
- Continuation of partnership development





Thank you !



- Al Bashir Hospital in Amman
- World Federation of Haemophilia twinning programme
- National Coagulation Centre, St James's Hospital
- Children's Health Ireland, Crumlin
- Irish Haemophilia Society