



MIH Foundation

Mediterranean Institute of Hematology

A presentation by
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on behalf of
Prof. Ilja Gardi
Commissioner of MIH Foundation

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Thalassemia

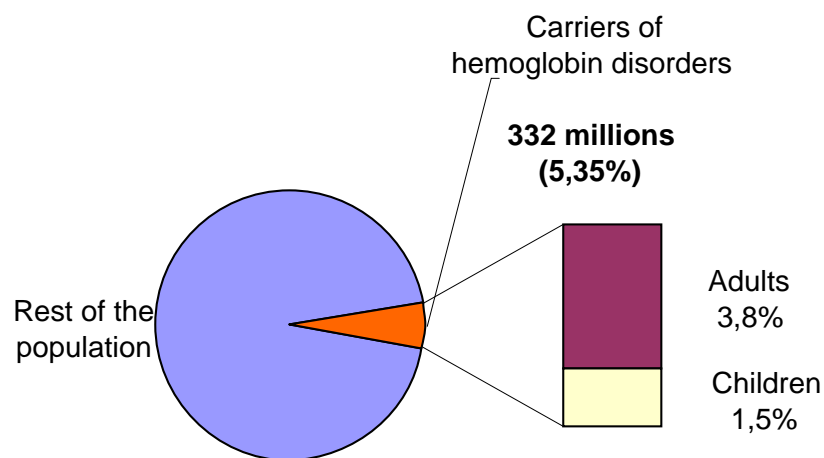
- Thalassemia (or Mediterranean anemia) is **the most widespread single genetic disease in the world today**
- It is estimated to affect **up to 270 ml. people** worldwide; in the Mediterranean area, there are **15 to 25 ml.** of healthy carriers
- Approximately **300,000 to 400,000 babies** are born each year with severe forms of blood disorders as **thalassemia** and **sickle cell anemia**

Source: Prof. D.Weatherall; Public Health Bulletin, WHO 2001

Prevalence estimates of hemoglobin disorders

Global estimates

Incidence of hemoglobin disorders on world population in 2002 (estimated)



National estimates

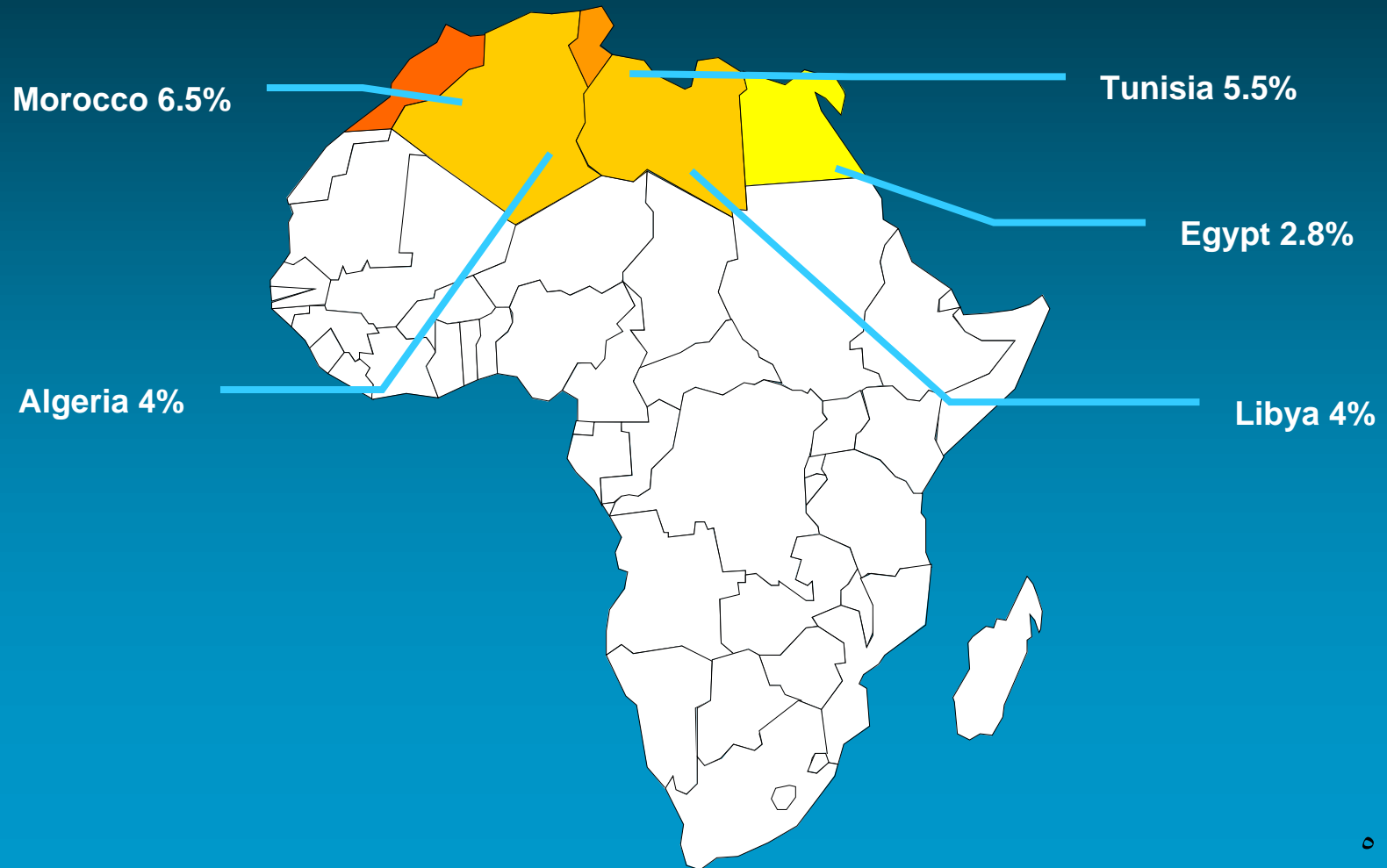
Algeria	4%
Egypt	2,8%
Morocco	6,5%
Libya	4%
Tunisia	5,5%
Iraq	6%
Iran	4%
Saudi Arabia	9,6%
Bahrain	13%
Lebanon	4%
UAE	5%
Turkey	2,5%
India	3,9%
Pakistan	4,5%
Bangladesh	5%
Albania	6%
Greece	8%
Italy	4,6%

NB: projections based on estimates made in the **beginning of the nineties**; population data of the same period

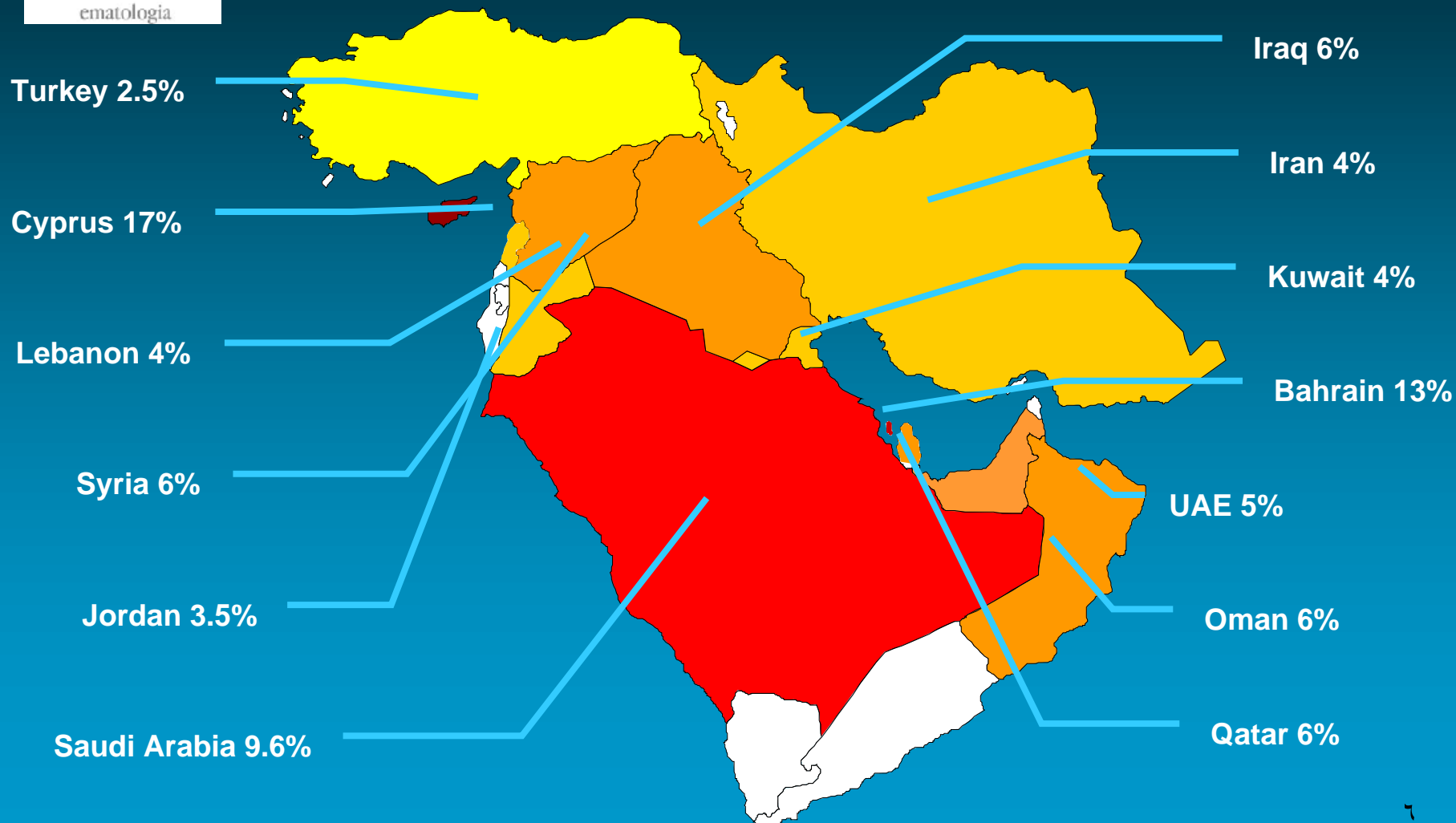
Hemoglobin disorders



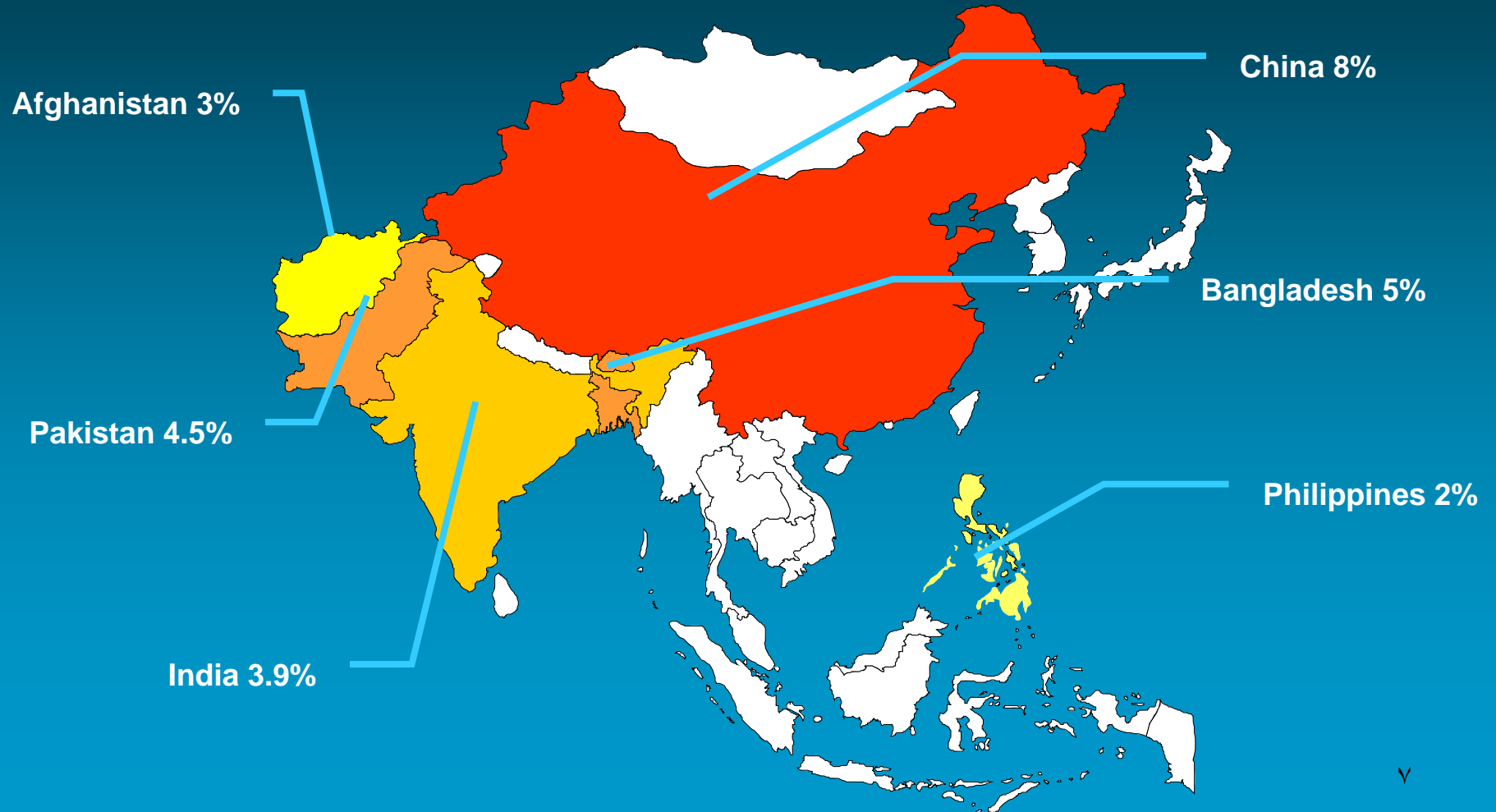
Hemoglobin disorders



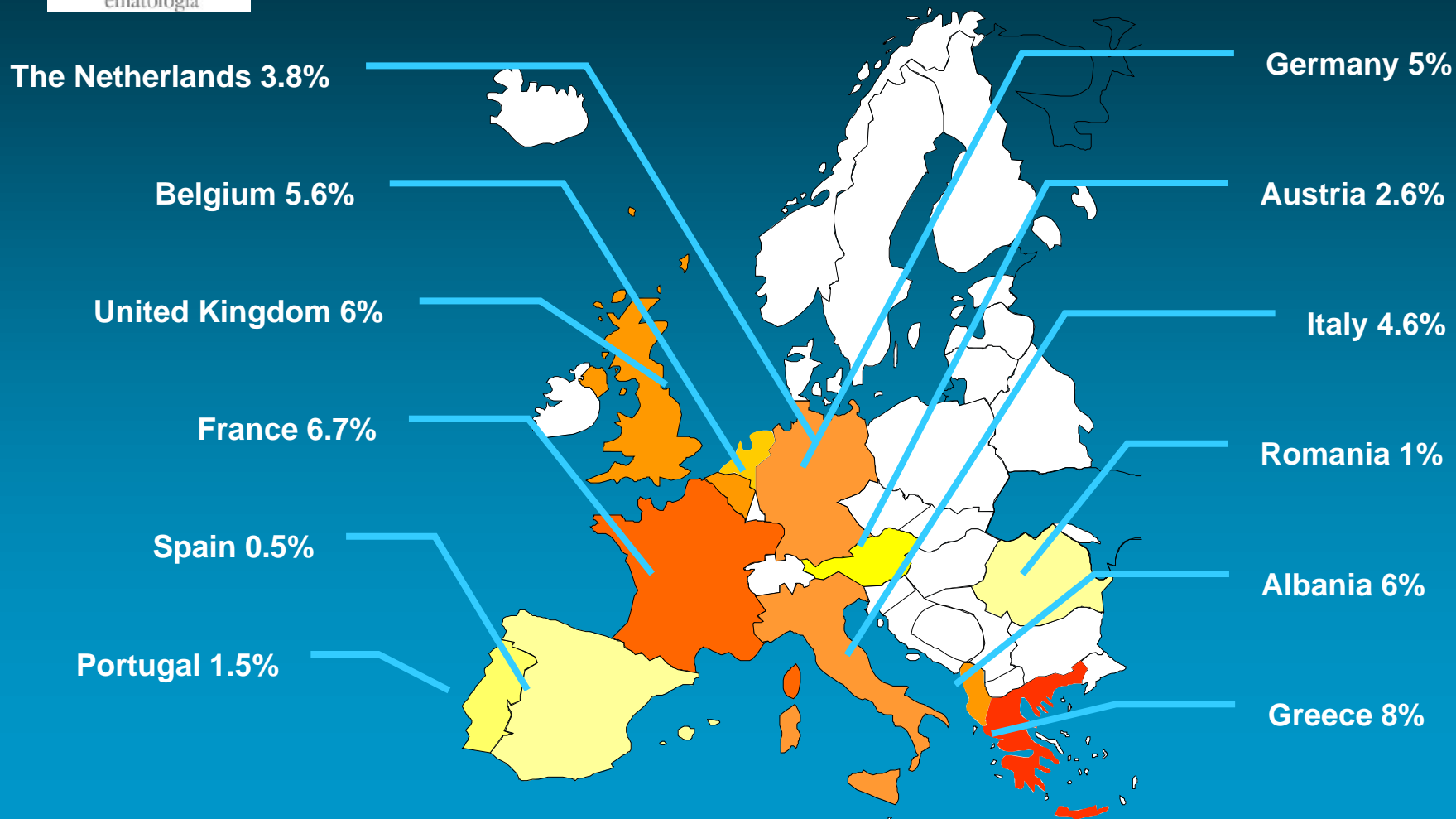
Hemoglobin disorders



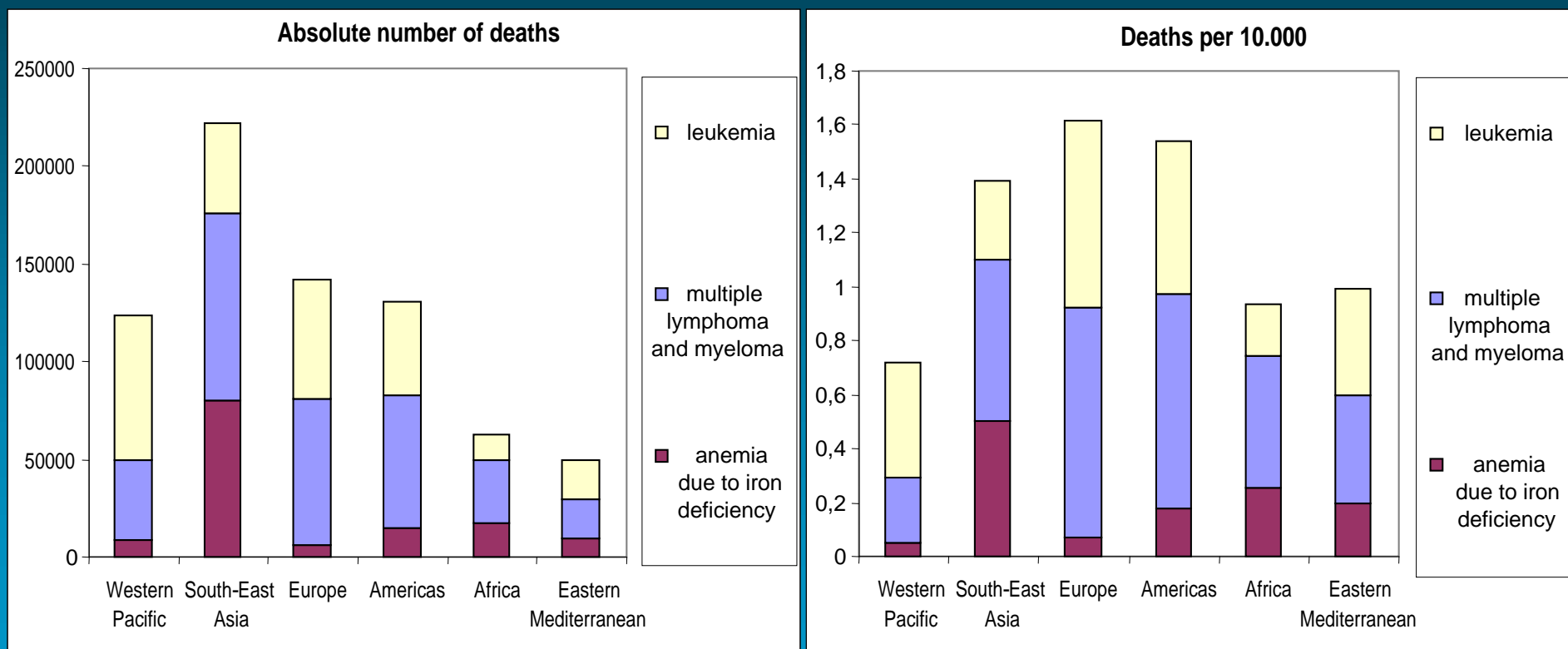
Hemoglobin disorders



Hemoglobin disorders



Mortality rate due to pathologies within MIH activity area



Data taken from "World Health Report 2003" (WHO) - Updated 2002

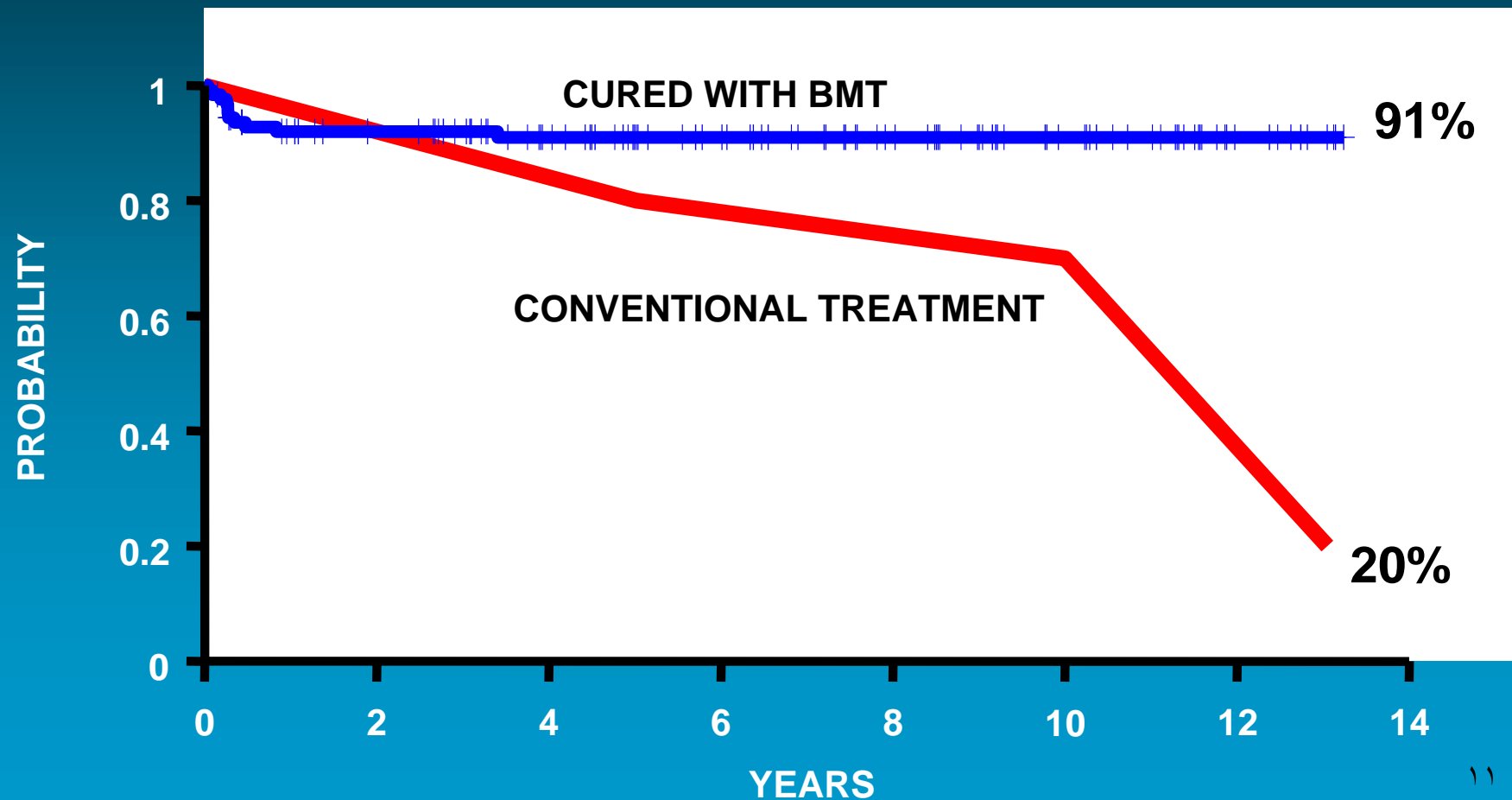


Thalassemia, the cure: Bone Marrow Transplant

- It is the **only known absolute cure available** for many blood disorders, including Thalassemia
- The success rate of BMT *in low risk thalassemic patients* has now reached **over 90%**
- On a strictly financial point of view the **apparently high cost** of the BMT procedure largely compensates the costs of **long years of conventional (only palliative) treatment**

BMT effectiveness

FIVE YEARS OLD

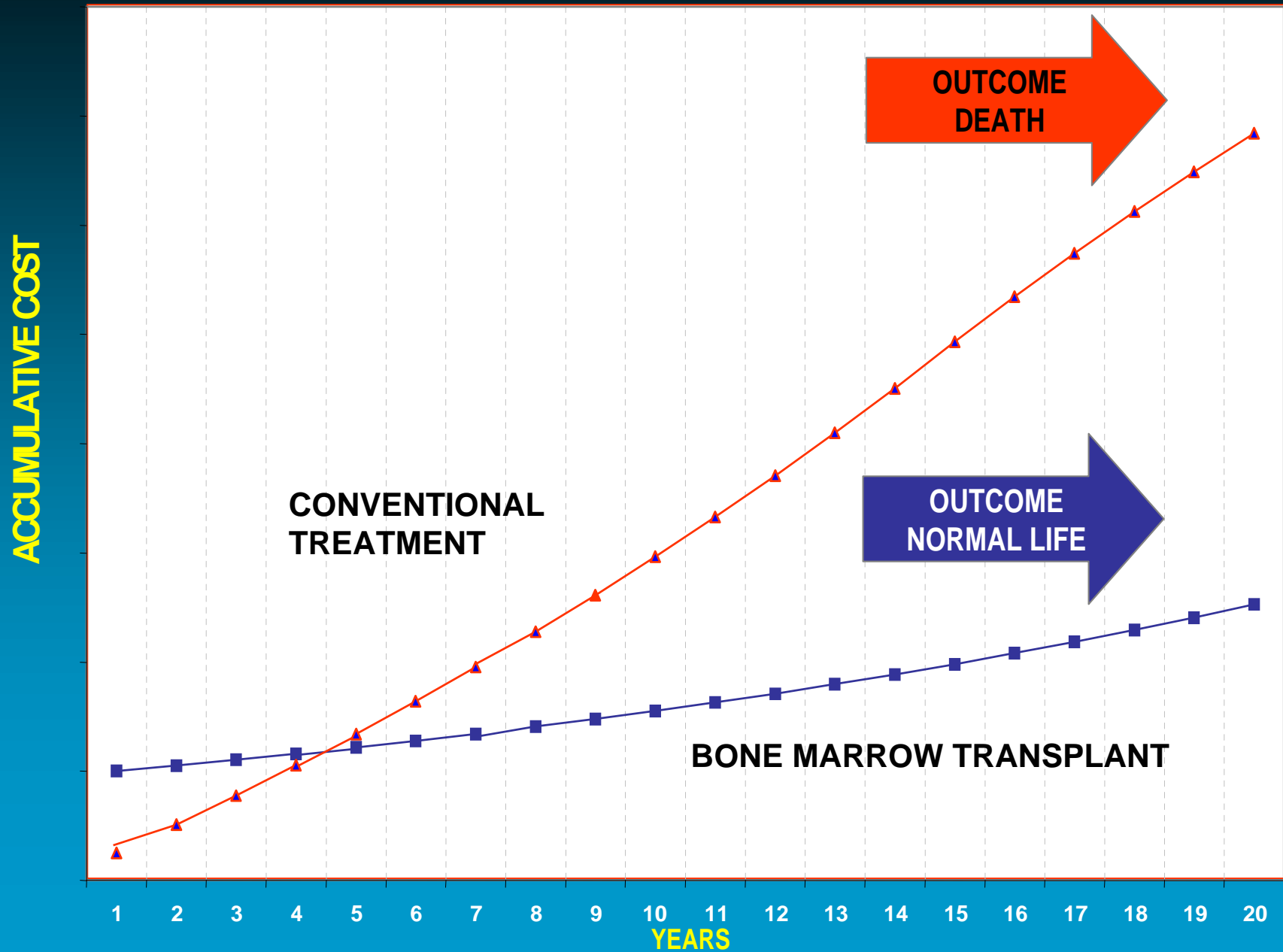




BMT financial convenience

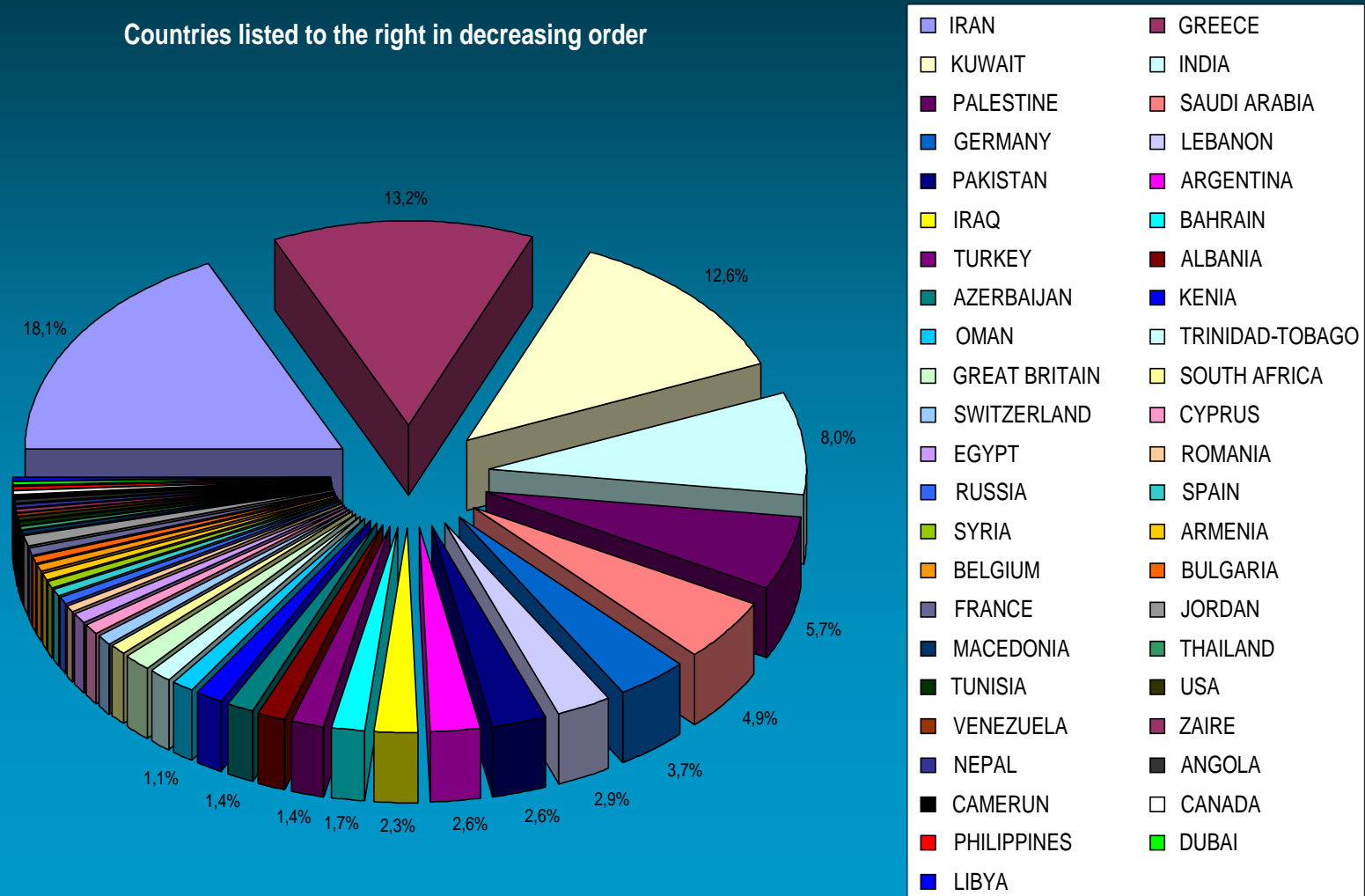
- Conventional treatment (blood transfusions and daily administration of iron chelating drug to remove the excess of iron from the blood) per patient: **US\$ 30,000** annually for an average period of **15 years** = **US\$ 400,000**
- Cost of the **most expensive bone marrow transplant** provided by MIH: **US\$ 200,000**
- After bone marrow transplant in infancy, **the cost of treating the disease CEASES**

Cost / Benefits



Foreign Countries of origin of Prof. Lucarelli's patients (from 1981)

Countries listed to the right in decreasing order





MIH Foundation: a brief biography

- An “International Thalassemia Project” was proposed in **2001** at G8 Summit of Genoa as an international development initiative
- MIH was created in **March 2003** by the Italian Government, through the Ministry of Foreign Affairs, the Ministry of Health, the Ministry of Economy and Finance, and the Lazio Region
- The MIH Foundation combines medical-scientific experience:
 - **Prof. Guido Lucarelli** in hemoglobinopathies (in particular Thalassemia)
 - and*
 - **Prof. Franco Mandelli** in onco-hematological diseases



MIH Foundation: a snapshot

- **Philosophy:** MIH Project is an instrument for the Italian foreign policy, developed through a health activity and based on the assumption that *“[professional] knowledge is the merit of who has pursued it, but belongs to whomever needs it”*
- **Final goal:** transfer of specialized clinical know-how and technologies to partner countries, promoting the creation of an international network of specialized BMT and healthcare centers
- **Means:** cure of foreign hematological patients in Italy; training of specialized healthcare medical/technical personnel coming [preferably] from the same partner countries (training on the job); research in order to develop and consolidate our professional know-how in the field of hematological diseases cure



MIH activity area

- As MedChild, MIH chose as its area of activity an “expanded Mediterranean” which includes Europe, the MENA region and all the other countries situated around the Mediterranean, together with the nearest “hematological crisis areas”, specifically China and the most part of South-East Asia. In detail:
 - Europe: Italy, Austria, Belgium, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Latvia, Lithuania, Luxemburg, Malta, the Netherlands, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, UK
 - EU applicant countries: Bulgaria, Croatia, Romania, Turkey
 - Balkans: Albania, Bosnia Herzegovina, Macedonia, Serbia & Montenegro
 - North Africa: Algeria, Egypt, Libya, Morocco, Tunisia
 - Near and Middle East: Afghanistan, Bahrain, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, UAE, Yemen
 - “Crisis areas”: Bangladesh, China, India, Maldives, Pakistan



MIH working methodology

- **1st step:** institutional agreements between the Italian Ministry of Foreign Affairs (or Ministry of Health) and the Government of a partner country
- **2nd step:** MOU and operative agreement between MIH and a specific local health institution or hospital individuated by local authorities (location of the BMT center; definition of clinical and training programs)
- **3rd step:** implementation of the programs (cure of selected children coming from partner country in Italian centers [funded by MIH]; training of specialized healthcare medical/technical personnel; *in parallel*, activation of the MIH “hub & spokes” centers in the partner country)
- **Outcome:** complete transfer of specialized clinical know-how and technologies to the partner country, which thus officially becomes part of the MIH international network



MIH Foundation: primary objectives

- Increase the cure activity in Italy (providing adequate accommodation to young patients and their families) and, in parallel, in partner countries (building where possible a first level of BMT centers – “hubs” – and in each partner country a further level of “spoke” centers for primary health care and palliative treatment of hematological patients)
- Promote the development and organization of health systems dedicated to the cure of hematological diseases
- Create an IT infrastructure for the connection of all MIH centers, together with an international network dedicated to e-medicine
- Implement and develop specialized scientific research, concurrent with cure



Structure of the MIH international network

Hub centers (hospitals or university clinics of excellence):

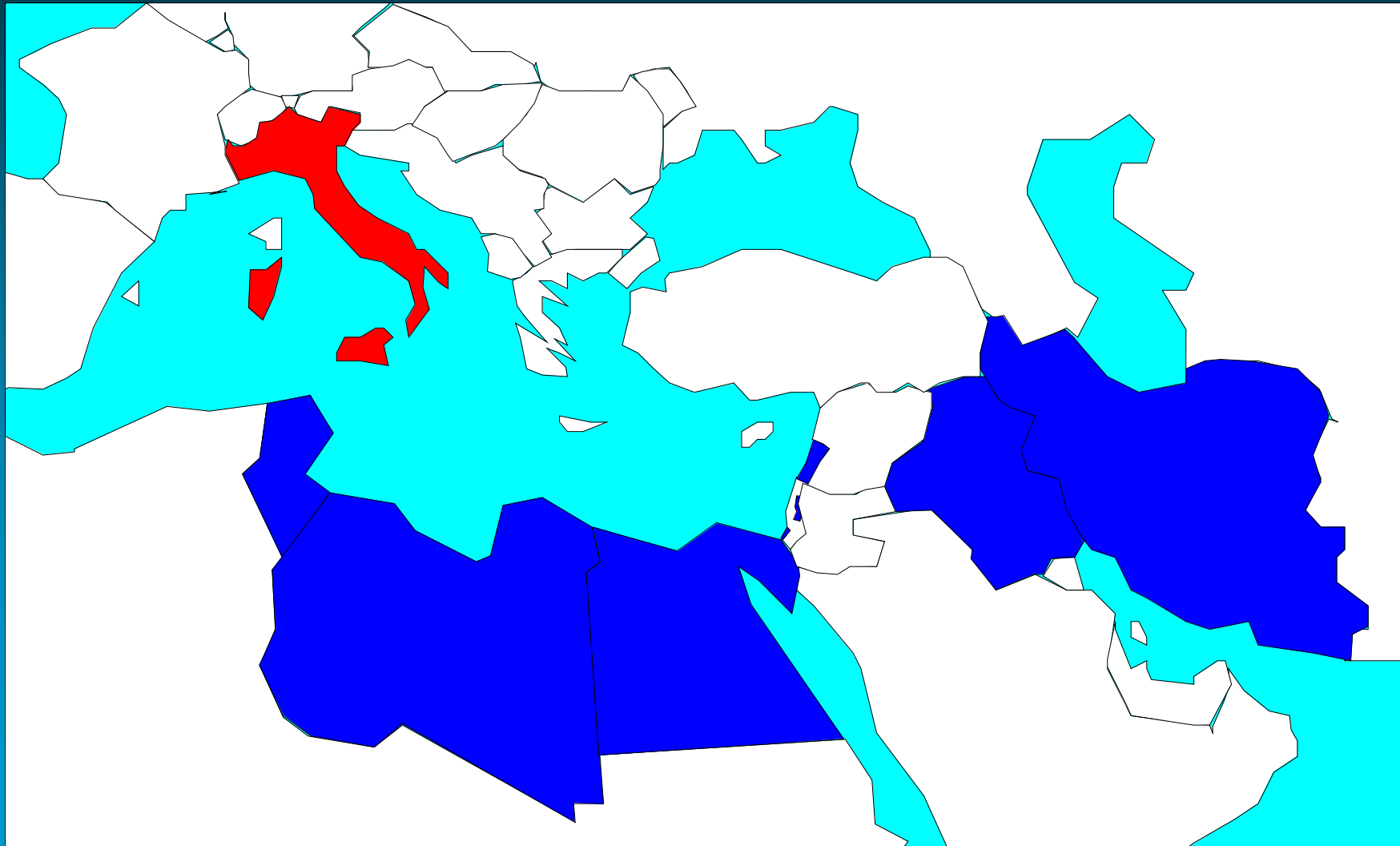
- technological equipment for BMT
- professional skills of high specialized level
- qualification for training of specialized healthcare medical/technical personnel
- epidemiological observatory
- strong network connections with MIH Italian centers

Spoke centers (healthcare centers or outpatients clinics):

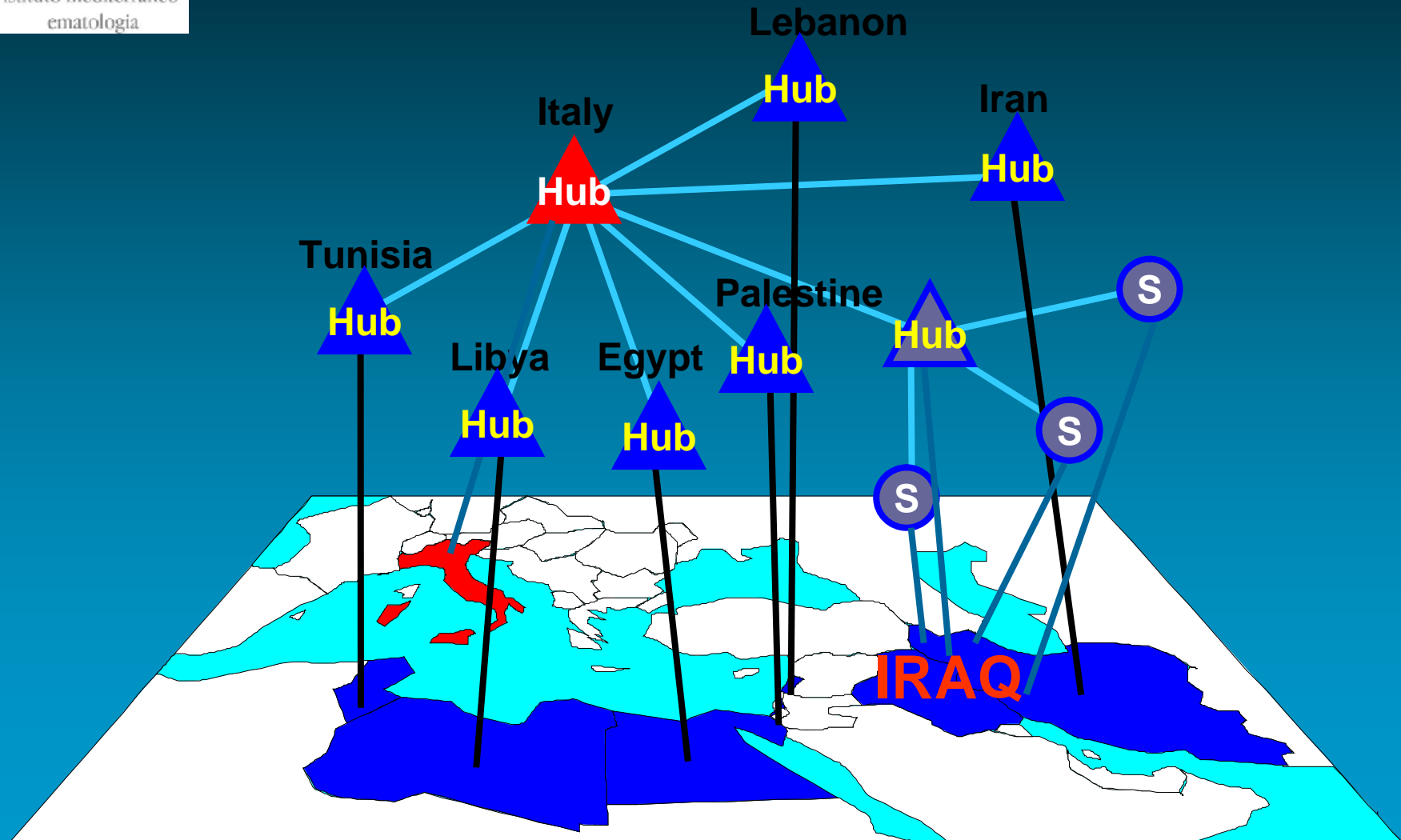
- prevention, palliative and stabilization (follow-up) treatments
- selection of patients to be cured in the MIH Italian centers
- supplying of primary health information and education
- collection of epidemiological data
- strong network connections with the relevant “Hub center”



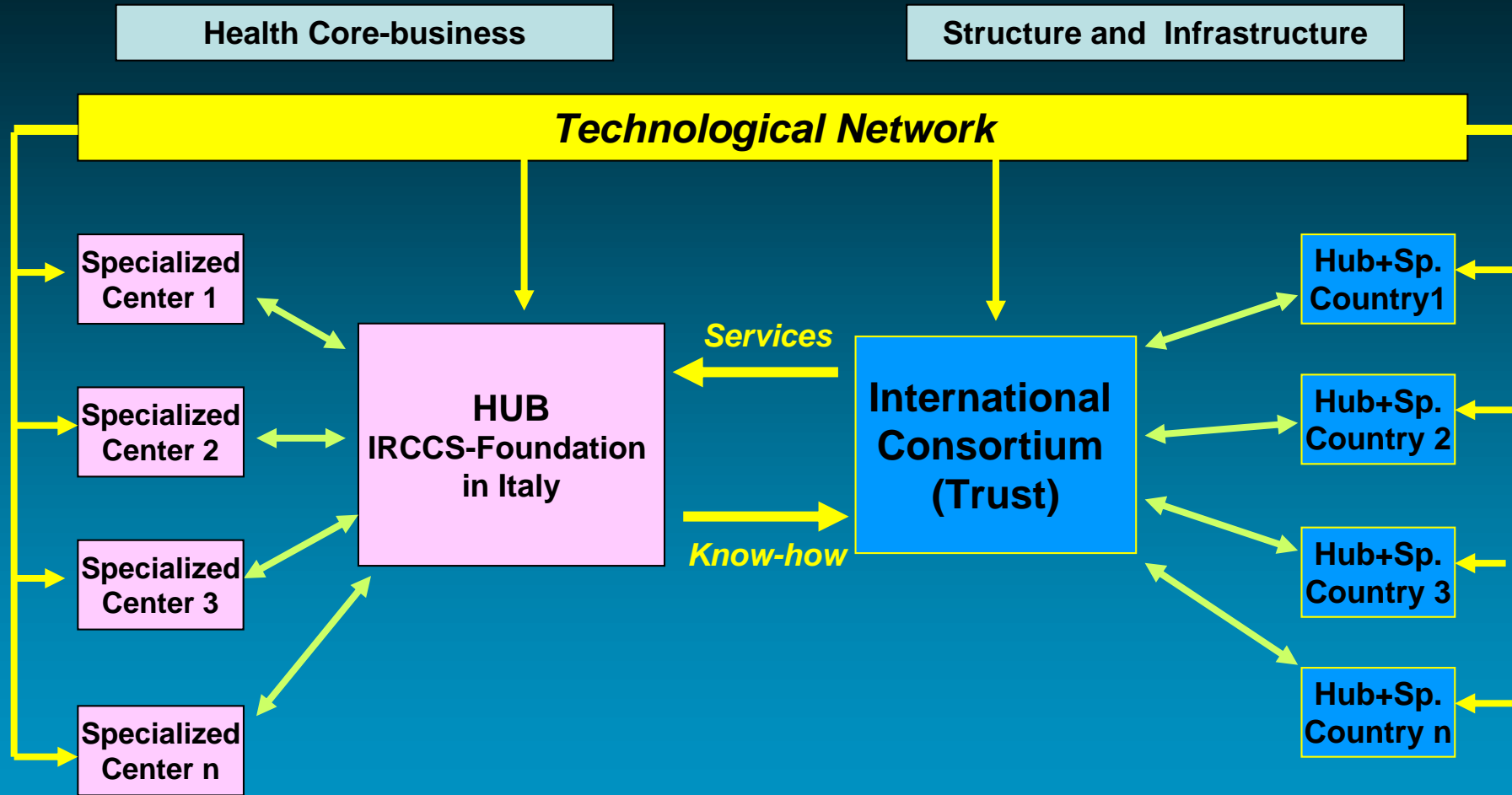
MIH international network: a connection model



MIH international network: a connection model



Overall MIH network



Cure, Training and Research in Italy

Know-How transfer and Hub health Centers implementation



MIH national and international partners

The national network for cure, training and research

- Formal partners:
 - MIH Centro Principale (Rome), Gaslini Foundation (Genoa), San Raffaele Hospital (Milan), Meyer Hospital (Florence)
- Partnerships to be formalized:
 - University Clinic of Ferrara, Bambino Gesù Hospital (Rome), Cervello Hospital (Palermo), Cagliari Hospital (Sardinia Region)

The international network for cure, training and research

- First target partner countries:
 - Egypt (Cairo Medical University Hospital), Iraq, Palestine, Lebanon, Tunisia, Iran
- Future partnerships:
 - Morocco, Algeria, Syria, Saudi Arabia, Turkey, Romania, China, India, Pakistan
- Special agreements (under way):
 - United Arab Emirates (al-Wasl Hospital), Maldives



Main “cultural” implication of MIH international project

- Giving adequate reception and hospitality to young patients and their families (different origins, geographical provenience, cultural/religious backgrounds, socio-economic conditions)
- Giving adequate reception and hospitality to professionals (research and training)
- Striking up and keeping on optimal terms relationships with patients, accompanying persons and professionals during (and after) the care/training cycle, personally and inside working teams
- Encouraging and implementing new, progressively broader bilateral and multilateral cooperation agreements



The MIH International Studies Center

- **Major goal:** projecting and realization of “Dossiers” on actual and future partner countries. In detail:
 - collection of all useful statistical data (demographic, socio-economic, political and health-related)
 - collection of all useful clinical data (general and specifically focused on diseases within MIH sphere of interest)
 - survey of relevant legislations (children’s rights, specially in the field of health)
 - in-depth study of cultural and religious topics
- **Two outcomes:** 1) clinical planning
2) management of “human resources”



The two-lane road of MIH

- First lane: building of a clinical network of excellence for Mediterranean children
Strong connection with Gaslini Foundation and its network
- Second lane: building of a multi-disciplinary Mediterranean network, inclusive of all aspects specifically concerning the life of Mediterranean children (rights, culture, religion, education, social relationships, environment, games, etc.)
Strong connection with MedChild Foundation and its network

MIH Foundation

