

Role of medical universities in management of hemophilia in IRAN

Mohammad Aghighi MD - MPH
Director of Department of
Transplantation and Special Disease
MOH
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Introduction

- Iran, in the Middle East, comprises 30 provinces and covers an area of 1.648 million sq. kms.
- The population is around 70 million and life expectancy is 69.96 years
- gross national product (GNP) is reported to be 2767 US\$ per capita in 2005 [IMF GDP PER CAPITA RANKING: WWW.IMF.ORG]
- The total health expenditure of GNP is 6% [World factbook/Iran:www.CIA.org]
- General population # 70,000,000
- People With Hemophilia # 7000 [# 0.0001 of GP]

Organization for hemophilia in IRAN

- Hemophilia management in Iran was organized in Imam Khomeini hospital of Tehran University of Medical sciences in early 1960`s,
- MOH has been the sponsor of management of hemophilia during the last 40 years,
- In Iran at present time, 41 medical universities are responsible for implementing different treatment and prevention programs of Ministry of Health in all the provinces

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- In each university, one is to oversee and coordinate affairs of hemophilia , thalassemia, hemodialysis and transplanted patients in different wards which are covered by that special university and are in direct contact with MCTSD

Management Center of Transplantation and Special Diseases MCTSD (2001)

Mission:

- provision of the products and services
- policy making
- strategic planning to achieve and establish
higher standards of treatments

National advisory committee on blood diseases : 2003

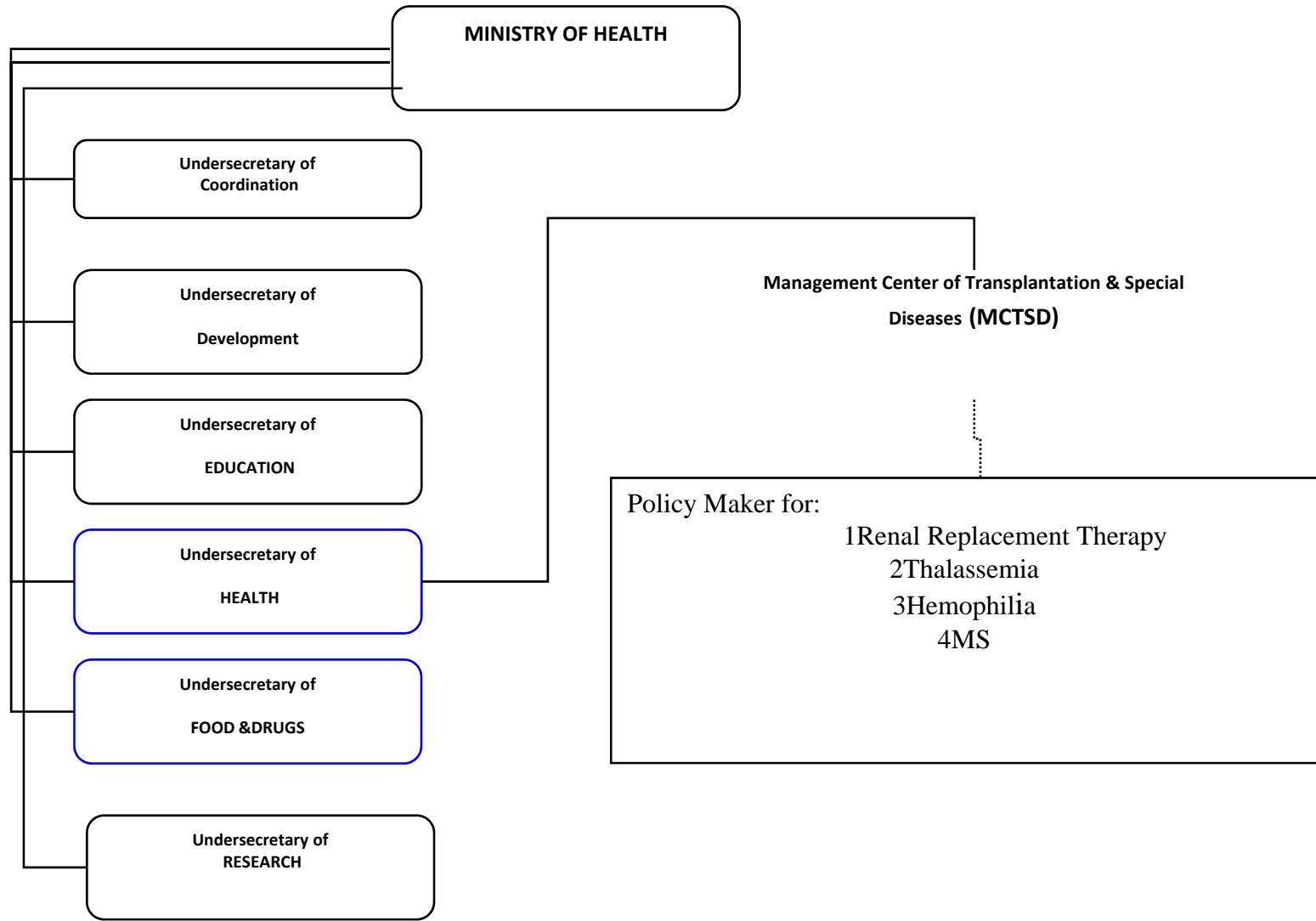
- Consist of academic attendant of Medical Universities

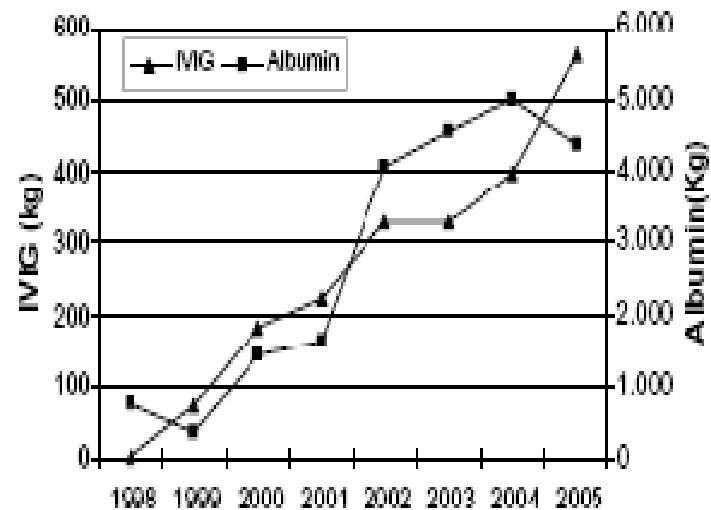
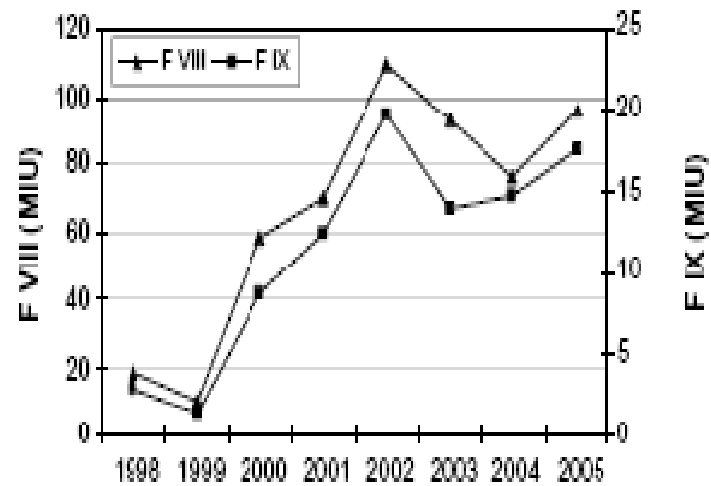
As recommended by World Federation of Hemophilia (WFH):

[GIANGRANDE, P.L., BLACK, C.](#) *WORLD FEDERATION OF HAEMOPHILIA PROGRAMS IN DEVELOPING COUNTRIES. SEMIN THROMB HEMOST. 2005; 31(5):555-60.*

the mission of this committee is introduction of scientific, specific and practical programs to be used as tools to furthering treatment of hemophilia and related disorders which covered sensible dosing and equitable distribution of resources to gain the maximum benefit from scarce resources

Figure-1: MOH Organization

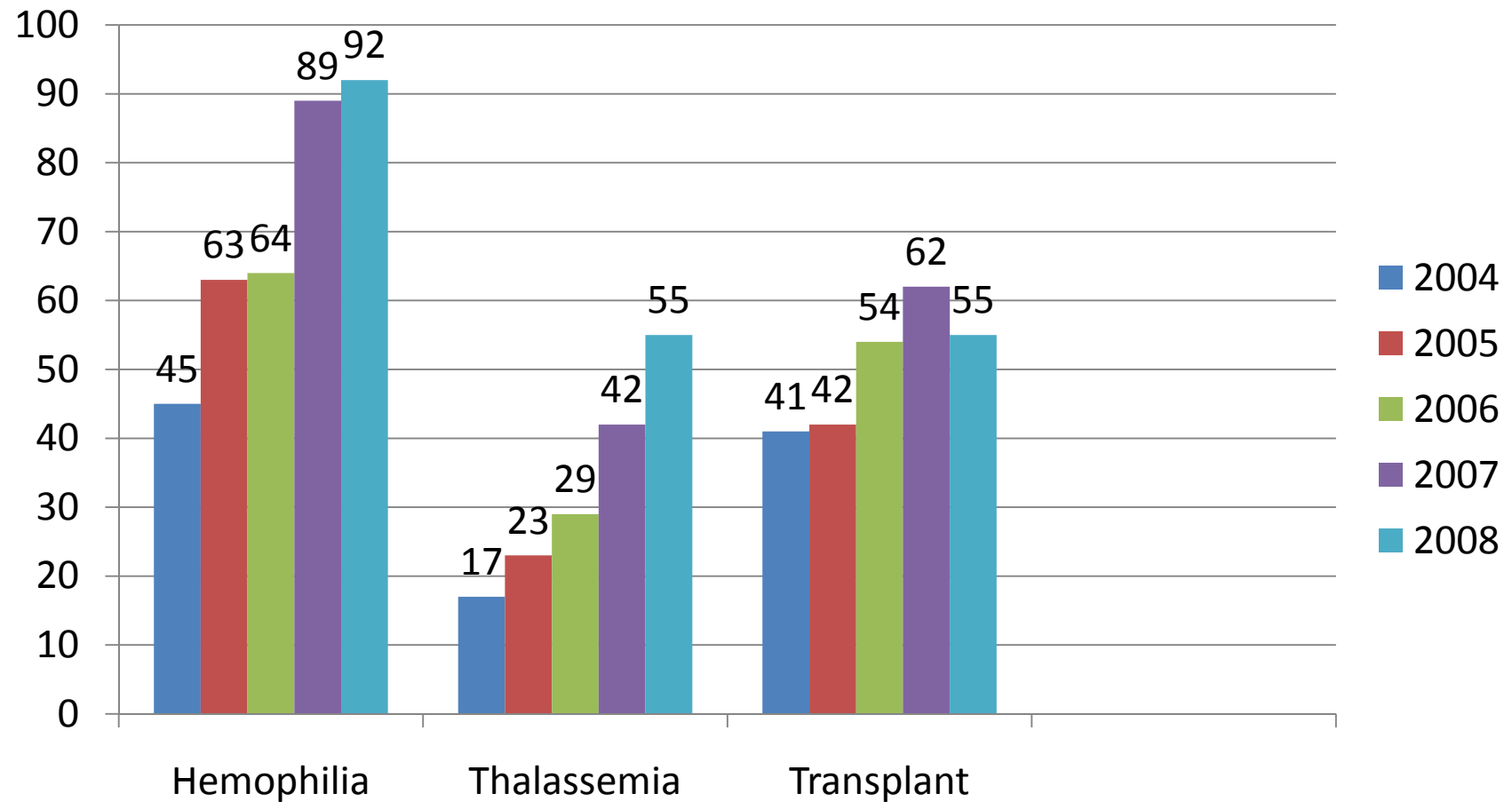




Increase in consumption of PD medicines in IRAN is not limited to hemophilia ; and is an actual governmental policy for upgrading the quality of medical care

Fig. 2. Consumption of plasma derived medicines in Iran 1998–2005.

Medicine expenditure in different special diseases in IRAN (1,000,000 US \$)



- **Iran-2008:**
 - Per capita factor VIII usage:1.7**
 - Per capita factor IX usage :0.2**
- **WFH Annual report 2006 :**
 - Per capita factor VIII usage (GNP between US\$2000-US\$10,000): 0.90 IU**
 - Per capita factor IX usage (GNP between US\$2000-US\$10,000): 0.20 IU**

ACTIVITIES AND ACHIEVEMENTS OF
MCTSD IN CLOSE RELATIONSHIP WITH
MEDICAL UNIVERSITIES
ACCORDING TO PRINCIPLES OF
HAEMOPHILIA CARE:

- 1) A Central Haemophilia Organisation with supporting local groups
- 2) National Haemophilia Patient Registries
- 3) Comprehensive Care Centres and Haemophilia Treatment Centres
- 4) National guideline for hemophilia management
- 5) Partnership in the Delivery of Haemophilia Care
- 6) Safe and Effective Concentrates at Optimum Treatment Levels
- 7) Home Treatment and Delivery
- 8) Prophylaxis (Preventative) Treatment
- 9) Specialist Services and Emergency Care
- 10) Management of Inhibitors & ITI
- 11) Education and Research

- Both the early and more recent UK and American guidelines state that haemophilia care should be centralized in designated HTC.
- Comprehensive Care Centres (CCCs) and Haemophilia Treatment Centres (HTCs) should be established to ensure that people with haemophilia have access to the full range of clinical specialties and appropriate laboratory services.
- The concept of a CCC derives from the WFH, which specifies that a CCC should care for at least 40 people with severe haemophilia.

A CCC should:

*B. T. COLVIN, et al. European principles of haemophilia care European principles of haemophilia care
Haemophilia (2008), 1–14*

1. provide **24-h service with experienced staff**;
2. provide inhibitor care;
3. have access to an immune tolerance service,
4. provide safe and effective factor concentrate.
5. provide 24-h, hospital based, experienced medical cover with one or more whole-time equivalent doctors;
6. have designated & hospital-based nursing staff to co-ordinate treatment, treatment supplies, the home treatment program and patient and family education;
7. provide community liaison,
8. have a laboratory that : provides 24-h assay cover and the potency of inhibitors in a timely manner ; subject to external quality assurance;

A CCC should(Continue):

9. have available a dedicated physiotherapy service;
10. have access to :a social worker; dedicated data management
11. have access to : rheumatology and/or orthopaedic services; dental services; all surgery services ; obstetric and gynaecology services ;
12. if children are treated, have a paediatric Accident & Emergency department, paediatric day care, a paediatric ward and paediatric nurses;
13. have access to a genetics laboratory; genetic counselling;
14. be able to care for patients with HIV and hepatitis C infection;

A CCC should(Continue):

15. be accessible for people with disabilities;
16. follow-up patients regularly;
17. provide home treatment for patients;
18. be able to provide prophylaxis, especially for children and where otherwise indicated;
19. keep reliable records;
20. carry out clinical audit. Internal audit is essential; external audit is desirable;
21. undertake medical education;
22. participate in research; have broad experience in haemostasis

IN IRAN:

- Comprehensive Care Centers & Hemophilia Treatment Centers : Mainly in Hospitals affiliated to medical universities
- Out patient clinics : mainly Charities and NGOs