

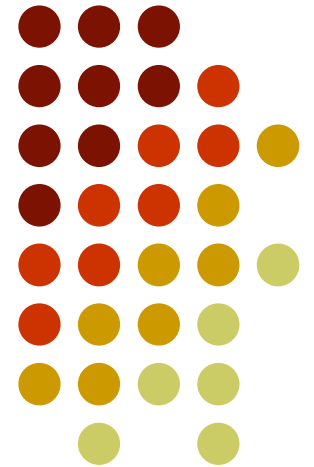
HEMOGLOBINOPATHY PREVENTION PROGRAM IN TURKEY

PROF.DR.DURAN CANATAN

**The President of
Thalassemia Federation of
Turkey**



Talasemi
Federasyonu





The progress of thalassemia in Turkey

1958	Aksoy et al published the first clinical and hematological studies on thalassemia and hemoglobinopathies in Turkey
1971	Çavdar and Arcasoy reported that overall incidence of β -thalassemia in Turkey was 2.1%
1983	Altay et al performed first prenatal diagnostic procedures for hemoglobinopathies
1987	Akar et al showed that the most frequent thalassaemia allele in the Turkish population is the IVS.1.110 mutation
1992	Başak et al reported the spectrum of β-thalassemia mutations occurring in the Turkish population

Slide 2

v3 vaio, 05/11/2007

v4 vaio, 05/11/2007



The progress of thalassemia in Turkey

1993	A law was issued called “ Fight Against Hereditary Blood Disease ” a pilot project was started in the Ministry of Health (MOH) Hospitals such as Antalya, Antakya, Mersin, Mugla regions.
1994	Canatan et al established first thalassemia center of MOH in Antalya.
2000	Turkish National Hemoglobinopathy Council (TNHC) was installed to combine all centres, foundations and associations into one organization controlled by the MOH.
2001	MOH and the TNHC made an inventory of all recorded patients with thalassemia and abnormal hemoglobins in Turkey

Slide 3

v5 vaio, 05/11/2007

v6 vaio, 05/11/2007



The progress of thalassemia in Turkey

2002	Altay published that screening studies for abnormal hemoglobins and β -thalassemia during the last 40 years. These studies revealed most common abnormal hemoglobin was HbS followed by Hb D, HbE, and Hb O Arab.
2002	Written regulations for the Fight Against Hereditary Blood Disease (FAHBD) were published by MOH.
2003	Hemoglobinopathy Prevention Program (HPP) was started in 33 cities with high risk on the 8th of May.
2005	Thalassemia Federation of Turkey (TFT) was established as a secular society organization instead of TNHC.

Slide 4

v9 vaio, 05/11/2007

v10 vaio, 05/11/2007

v11
v12



The progress of thalassemia in Turkey

2007	National Thalassemia Prevention Campaign (NTPC) was organized for public education by Ministry of the Health, Ministry of the Internal Affairs, Ministry of Education, The Presidency of Religious Affairs of the Republic of Turkey and Thalassemia Federation of Turkey .
2007	Teacher Education Program (TEP) was started to teachers on thalassemia education by Ministry of Education and Thalassemia Federation of Turkey .
2009 2010	National Thalassemia Education Seminars (NTES) for health workers have been organized in 18 cities by MOH and Thalassemia Federation of Turkey .

Slide 5

v11 vaio, 05/11/2007

v12 vaio, 05/11/2007

HEMOGLOBINOPATHY PREVENTION PROGRAM

THE AIMS:



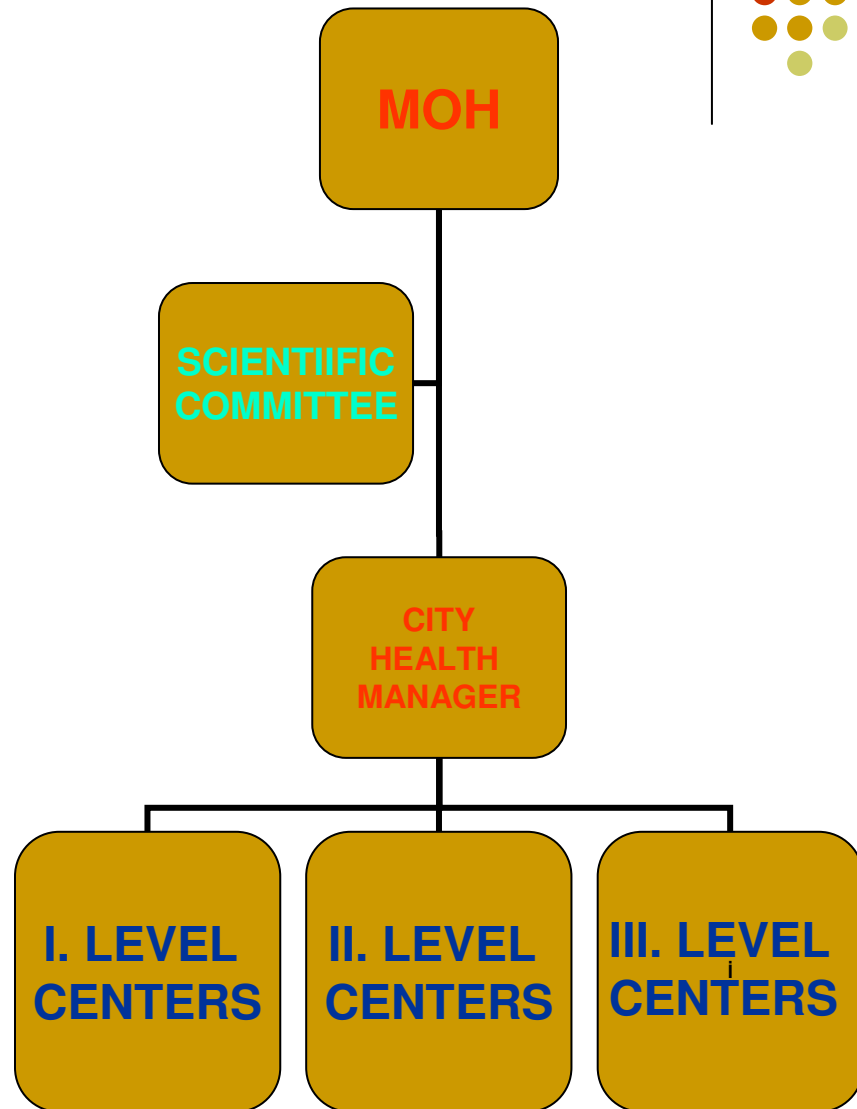
- ❑ to assess the present situation in Turkey,
- ❑ to establish reference centers for prevention and state of the art therapy,
- ❑ to educate the healthcare personnel,
- ❑ to inform the public by using press, media and NGO's
- ❑ to make premarital screening tests, to give genetic counselling to couples and to guide couples with risk to prenatal diagnosis centers.

Canatan D, Kose MR, Ustundağ M, Haznedaroglu D, Ozbaş S:
Hemoglobinopathy control program in Turkey. *Community Genet*,9:124-126, 2006.

HEMOGLOBINOPATHY PREVENTION PROGRAM

Material and methods:

- The General Director of the Mother and Child Health / Family Planning of the MOH was responsible for national HPP depends on the written regulations
- According to regulations, the centers of the project of HPP was separated to three levels.
- **First Level centers** are responsible for diagnosis, public education, screening and genetic counselling.
- **Second Level centers** are responsible for the diagnosis, therapy and follow-up of patients.
- **Third Level centers** are responsible for prenatal diagnosis, mutation analysis or bone marrow transplant centers.





T.C.
SAĞLIK BAKANLIĞI
ANAÇOCUK SAĞLIĞI VE AİLE PLANLAMASI
GENEL MÜDÜRLÜĞÜ

Cilt No :.....
Sıra No :.....
Tarih :...../...../ 20....

HEMOGLOBİNOPATİ MERKEZİ RUHSATI

30.12.1993 tarihinde 3960 sayılı olarak yayımlanan Kalıtsal Kan Hastalıkları ile Mücadele Kanunu'na dayanılarak hazırlanan “Kalıtsal Kan Hastalıklarından Hemoglobinopati Kontrol Programı İle Tanı ve Tedavi Merkezleri Yönetmeliği”ne göre İlinde isimli kuruluşun olarak çalışmasına izin verilmiştir.

LICENCE OF HEMOGLOBINOPATHY CENTER OF MOH

HEMOGLOBINOPATHY PREVENTION PROGRAM

Results:

- ❑ The MOH and the TNHC had six meetings;
 - ❑ for written regulations of HPP
 - ❑ for selection cities with risk
 - ❑ for writing a guide book for centers
- in between 2000 and 2005.



HEMOGLOBINOPATHY PREVENTION PROGRAM

Results:

- The MOH and the TNHC picked up the results of screening in 16 cities between 1995 and 2000.



National Thalassemia Prevention Campaign (NTPC)



- ❑ **National Thalassemia Prevention Campaign (NTPC)** was organized for public education by MOH and TFT in 2007.
- ❑ Thalassemia Federation authority committee, arranged an assembly with
 - ❑ Ministry of the Health,
 - ❑ Ministry of the Internal Affairs,
 - ❑ Ministry of Education,
 - ❑ The Presidency of Religious Affairs of the Republic of Turkeyto take support for the NTPC.

1.400.000
Talasemi taşıyıcısı ve
4.500
Talasemi hastasına
yenilerinin eklenmemesi için...



National Thalassemia Prevention Campaign (NTPC)



- A long vehicle as named "Talotir" was specially designed as an education hall by NOVARTIS
- TALOTIR has been started at Taksim Square in Istanbul on 8 th May, 2007



National Thalassemia Prevention Campaign (NTPC)



- 26 cities in Thrace, Western and Southern Anatolia with high incidence of thalassemia were chosen for program.

1.400.000
Talasemi taşıyıcısı ve
4.500
Talasemi hastasına
yenilerinin eklenmemesi için...

**TALOTIR,
8 MAYIS DÜNYA TALASEMİ GÜNÜ'NDE
YOLA ÇIKIYOR!**

**TAKİP EDİN,
ZİYARET EDİN,
BİLGİLENİN.**

NOVARTIS

www.talasemi.org www.taloclub.net

Talasemi Federasyonu

National Thalassemia Prevention Campaign (NTPC)



- ❑ NTPC contributed very important supportings to HPP in Turkey,
- ❑ **A total 63.000 people** such as
 - ❑ health workers,
 - ❑ students,
 - ❑ teachers,
 - ❑ demarchs,
 - ❑ religion officers

were educated for thalassemia and hemoglobinopathies by scientific committee of TFT.



TEACHER EDUCATION PROGRAM



- ❑ **Teacher Education Program (TEP)** was started to teachers on thalassemia education program by **Thalassemia Federation and Ministry of Education.**
- ❑ **Fourty teachers from 33 cities** were chosen by **Ministry of Education**
- ❑ They have been trained on thalassemia by **Scientific Committee of Thalassemia Federation.**
- ❑ These teachers have educated all students in schools since 2007.



Thalassemia Education Seminars (NTES)



- National Thalassemia Education Seminars (NTES) for health workers have been planned by MOH and TFT in 26 cities in 2009.



Thalassemia Education Seminars (NTES)



- A total 3600 health workers were educated on prevention and therapy of thalassemia and hemoglobinopathies by Scientific Committee of Thalassemia Federation in
- 18 centers in 2009 and 2010





Five International Thalassaemia Summerschools were organized every two years since 2000. A total 3000 persons were educated in ITSS





NTYC



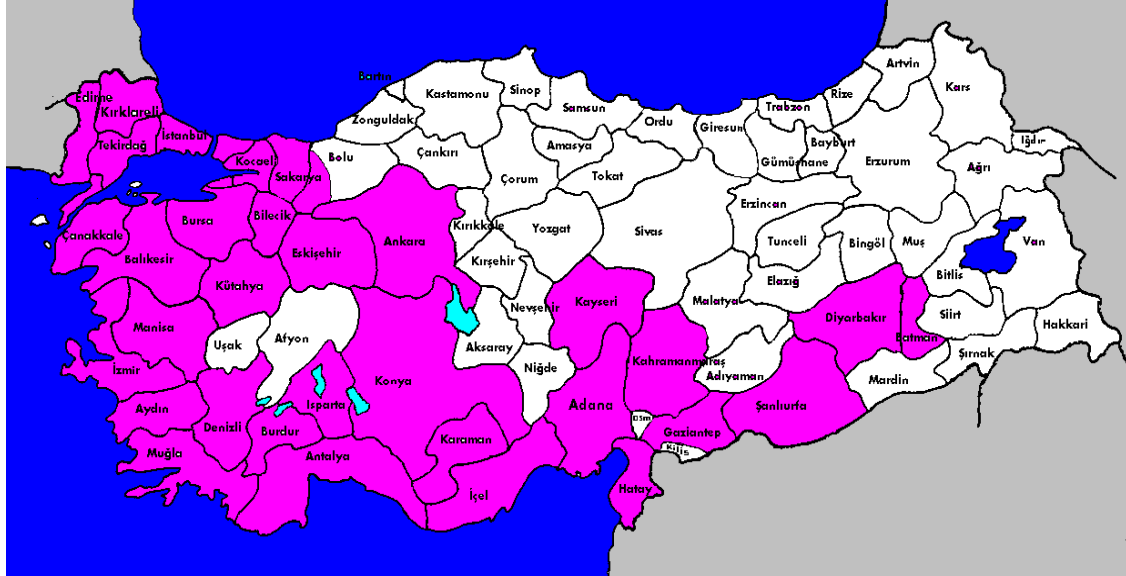
Ten National Thalassemia Youth Camps were organized every year since 2000. A total 2000 thalassemics were educated in NTYC



Hemoglobinopatya Prevention Program



Hemoglobinopatya Prevention Program was started in 33 cities with high risk hemoglobinopathies by MOH on the 8th of May 2003.



Sağlık Bakanlığı AÇSAP Genel Müdürlüğü: Hemoglobinopati Kontrol Programı.

Editörler: Canatan D, Aydınok Y: Talasemi ve Hemoglobinopatiler: Tanı-Tedavi. Sağlık Bakanlığı-Talasemi Federasyonu, Antalya, 2007.



REGISTERED PATIENTS - 2002

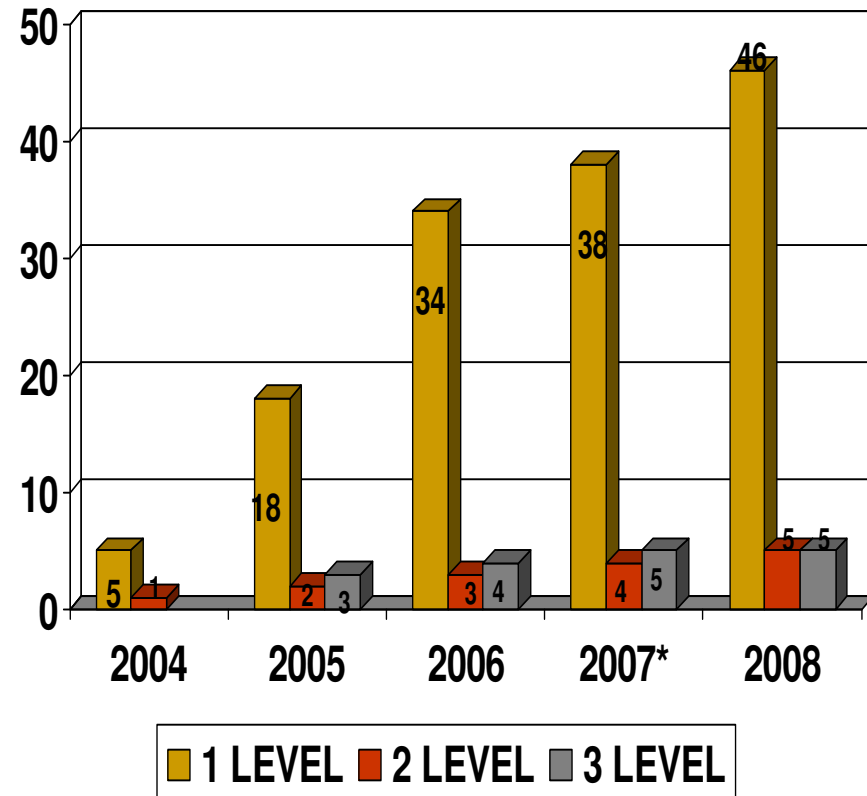
❑ Thalasaemia major:	2573	57%
❑ Sickle cell anemia:	1038	23%
❑ Thalasaemia intermedia:	722	16%
❑ S+Beta Thalaasemia:	90	2%
❑ Other abnormal Hbs:	90	2%
❑ TOTAL	4513	100%

Sağlık Bakanlığı AÇSAP Genel Müdürlüğü: Hemoglobinopati Kontrol Programı. Editörler: Canatan D, Aydınok Y: Talasemi ve Hemoglobinopatiler: Tanı-Tedavi. Sağlık Bakanlığı-Talasemi Federasyonu, Antalya, 2007.

Hemoglobinopathy Prevention Program (HPP)



- According to reports of MOH,
- **46 first level** hemoglobinopathy diagnosis centers,
- **5 second level** diagnosis and therapy centers
- **5 third level** prenatal diagnosis centers were licenced in 30 cities between 2003 and 2008.



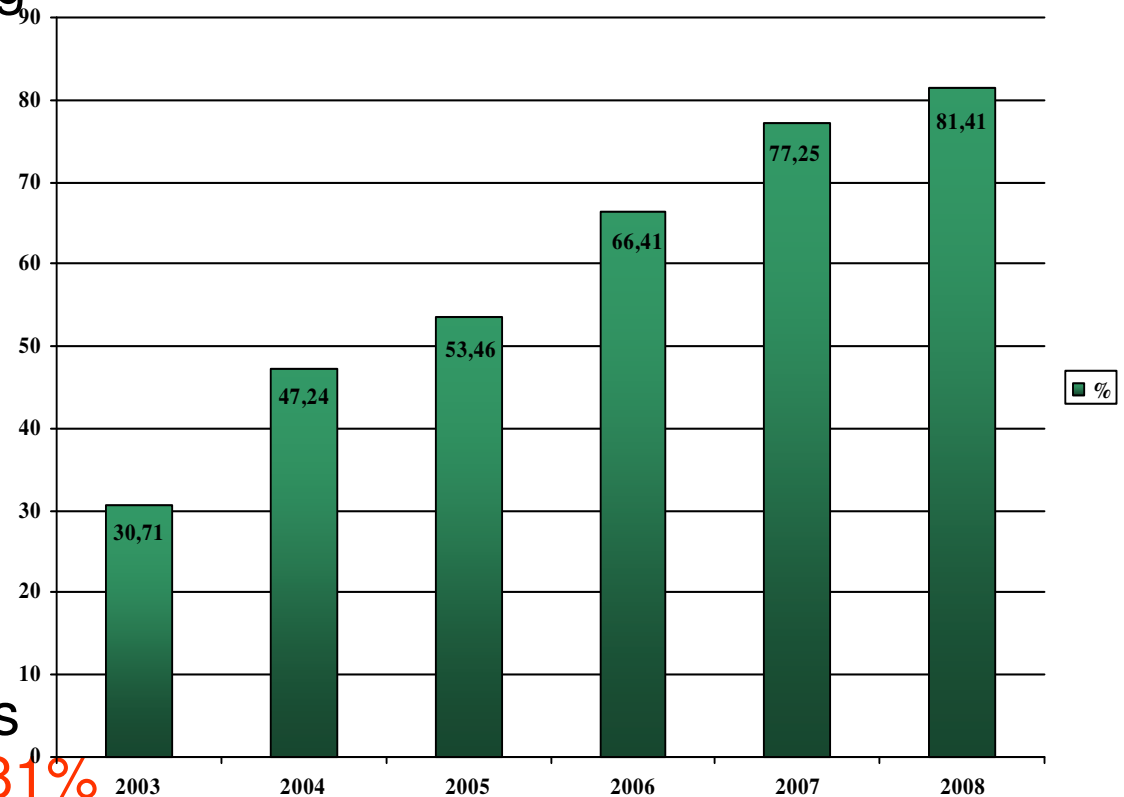
Hemoglobinopathy Prevention Program (HPP)



While premarital screening tests were 30% of all couples in 2003,

- 47% in 2004
- 53% in 2005
- 66% in 2006
- 77% in 2007
- 81% in 2008.

It has been increased continuously between 2003 and 2008 and it was reached from 30% to 81%



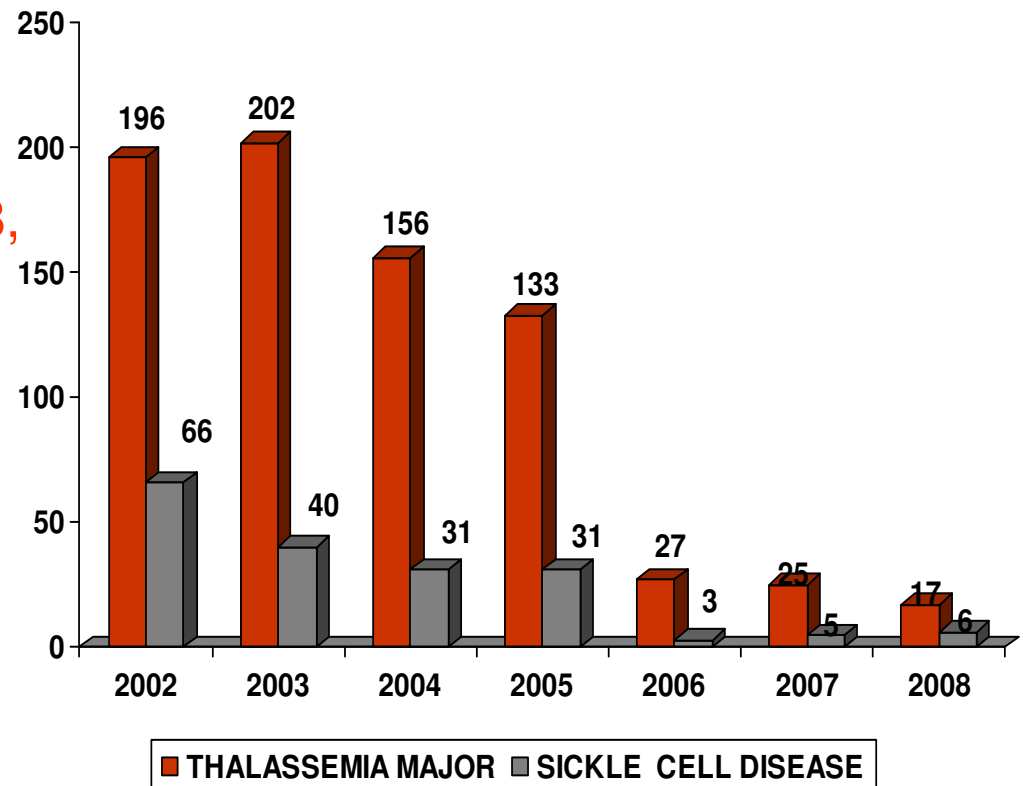
Ministry of Health. Mother and Child Health General Director.

Hemoglobinopathy control program (Editör: Canatan D). J Hem Onc- Special Topics 2010;3(1):5-8

Hemoglobinopathy Prevention Program (HPP)



- The number of new born with thalassemias and hemoglobinopathies was **272 in 2002**,
- It decreased to **23 in 2008**,
- While an expected the number of new patient was **400** per year, it was dropped to **23 in 2008**.
- As a result there has been an **90 % reduction** in new affected births





In conclusion;

- ❑ premarital screening tests were 30% of all couples in 2003.
- ❑ it increased continuously during HPP and it has been reached 81% in 2008.
- ❑ As a result there has been an 90 % reduction in new affected births in Turkey.

Acknowledgments

I would like to thank to all our scientists for the progress of thalassemia in Turkey



- ❑ Ministry of the Health
- ❑ Ministry of the Internal Affairs
- ❑ Ministry of Education
- ❑ The Presidency of Religious Affairs of the Republic of Turkey
- ❑ MOH Scientific Committe Members
- ❑ Thalassemia Federation Scientific Committe Members

Novartis Oncology for financial supports
to all our projects



Talasemi Federasyonu

1. Adana-Çukurova Kalıtsal Kan Hastalıkları Derneği
2. Ankara -Talasemi Derneği,
3. Antalya- Akdeniz Kan Hastalıkları Derneği
4. İstanbul- Talasemi Araştırma ve Uygulama Derneği
5. İzmir-Ege Talasemi Derneği
6. Gaziantep Talasemi Derneği – Gaziantep
7. Mersin Hemoglobinopati Derneği – Mersin
8. TADAD-Talasemi Dayanışma Derneği – İstanbul
9. Siirt Talasemililer Derneği – Siirt
10. Muğla Talasemi Derneği – Muğla
11. Batman Talasemililer Derneği – Batman
12. Kayseri Talasemililer Derneği – Kayseri
13. Akdeniz Anemi ve Orak Hücre Anemi Hastalıkları Derneği – Adana
14. Konya Talasemi Derneği- Konya
15. İzmir Talasemi Derneği- İzmir
16. Muğla Talasemi Derneği- Muğla
17. Tarsus Hemoglobinpati Derneği- Tarsus
18. Pamukkale Talasemi Derneği- Denizli
19. Aydın Talasemi Derneği- Aydın

**Kışla Mh Güllük Cd Antelsan İş
Merkezi Antalya,
Tel-faks:+90.242.2434046**

**Web Adresi:
www.talasemifederasyonu.org.tr**