



Thalassemia Patients' Friends Society (TPFS) – Palestine



for a palestine free of thalassemia



WHO WE ARE

Thalassemia Patients' Friends Society (TPFS) is a non-profit non-governmental organization, established in 1996 by a group of patients, their families and medical professionals concerned about Thalassemia in Palestine.

MISSION

“Towards a Palestine free of Thalassemia “

HISTORICAL PERSPECTIVE

- TPFS was officially established and registered by the Ministry of Interior in 1996.
- The first board was elected in 1997 by the general assembly of 700 members that include patients, family members and supporters. Election of new board is done every two years. Despite the political problems and chaos in the country, elections were conducted in 1999, 2001, 2004. Plans are underway to elect a new board by the general assembly in the current year 2008.
- TPFS was granted a full membership in the Thalassemia International Federation (TIF) in 2001 with full membership rights including voting and right of nomination to the TIF executive board of directors.
- TPFS became a member of the Arab Group for Blood Diseases in 1997 and attended al meetings of the group since then.
- TPFS established 4 day care units linked to major governmental hospitals for patients care between the years 2000 - 2002, and handed them over to the Ministry of Health to assure sustainability.
- About 800 officially registered members currently constitute the general assembly and distributed among all TPFS branches in all districts of West Bank. Each branch is directed by an elected local committee that attends to the specific needs of the patients in the district and help execute the TPFS national plans and activities.



OBJECTIVES

1. Organize and coordinate national educational campaigns to raise the awareness of the public about the disease to minimize the incidence of having new Thalassemia patients.
2. Improve the quality of treatment and care for patients. This is achieved by mobilizing local and international resources to improve the professional level of the medical staff through specialized local and international workshops and training programs.
3. Provide urgently needed supplies including blood, medications, pumps, transfusion filters.....etc, through fundraising and mobilizing local and international resources including medical and charitable organizations.
4. Conduct research on various subjects related to Thalassemia.
5. Lobbying policy makers at all levels to ensure the approval of premarital testing law for Thalassemia to control the birth of new patients.

STRATEGIC PLAN FOR TPFS

1. Health education and promotion (concentrating health, media)
2. Continuation of Pre-marital screening.
3. Networking with other organizations and ministries of concern as part of multi-sector collaboration.
4. Lobbying and Advocacy.
5. Improve patients' care by facilitating medical care and allocation of emergency needs when possible.

THALASSEMIA IN PALESTINE

*There are around 800 β -Thalassemia patients in the Palestinian territory in the west bank and Gaza strip.

Distribution of patients and their characteristics in 2007 is as follows:

| Area | District | # Pts | Aver. age (years) | Age range | New births in 2007 | Attending university | Working/employed |
|--------|----------|-------|-------------------|-----------|--------------------|----------------------|------------------|
| North | Nablus | 100 | 13 | 1-75 | 3 | 5 | 6 |
| West | Tulkarem | 80 | 12 | 5-33 | 0 | 3 | 2 |
| Bank | Qalqilia | 43 | 13 | 1-32 | 1 | 2 | 0 |
| | Toubas | 16 | 11 | 3-26 | 0 | 1 | 0 |
| | Jenin | 125 | 12 | 2-33 | 0 | 2 | 0 |
| Center | Ramallah | 52 | 15 | 4-36 | 0 | 3 | 4 |
| | Jericho | 7 | 15 | 3-26 | 0 | 0 | 4 |
| South | Hebron | 78 | 15 | 4-50 | 0 | 5 | 4 |
| Gaza | Gaza | 300 | NA | NA | NA | NA | NA |

* Patients' deaths in WB between 2005-2007 = 24.

* The prevalence of the B-Thalassemia trait is estimated 4-7% depending on the district (TPFS) which translates to more than 120,000 carriers in the population

* Consanguineous marriages in Palestine contributes to about 76% of Thalassemia cases.

HOW DOES TPFS HELP THALASSEMIA PATIENTS.

1. Educationally

* organize training workshops for patients and their families on the proper handling of Desferal® and the use and maintenance of the electronic pump usage. nutrition, hygiene, ...etc.

* Translation and distribute of TIF publications.

* Arrange for patients representatives to attend the international Thalassemia



patients forums organized by TIF to present their meet patients from other countries to exchange ideas and learn from their counterparts of how to live with disease and be aware about the recent developments in testing methodology and managements protocols.

- * Educate school teachers and counselors on the disease and the the proper way to dealing and support Thalassemia patients.
- * Publish a regular newsletter under the name “ Amal” to inform patients, volunteers, supporters and the community about the activities of TPFs, patients news, upcoming events and new developments in the world of Thalassemia.

2. Medically

- * Co-ordinate with doctors to follow-up and evaluate patients’ conditions.
- * Facilitate blood transfusion for patients in local hospitals.
- * Fundraising and mobilizing resources to secure the availability of all needed supplies for then proper treatment fo patients including medicines (Desferal, hormones, disposable supplies), specialized medical tests, and modern therapeutic protocols..

3. Socially

- * Hold periodic social activities in collaboration with other local youth groups for patients to integrate them into society.
- * Cooperate with local organization to assist families of patients due to their economic hardships.
- * Lobby public officials and policy makers for patients’ rights of full treatment and social integration and support.
- * Facilitating the participation of adolescent patients into training programs such as human rights, health education, leadership, computer skills, and

- other related activities with various youth organizations to help them develop their skills and eventually become active members in society.
- * Annual recreational programs and activities for Thalassemia patients in all TPFS branches on the occasion of the international Thalassemia day on **May 8th** of each year.
 - * Organize an annual community activity during the month Ramadan to gather all patients and their families with all supporting groups, personnel and volunteers to increase the ties between them and to strengthen the involvement of all participants in a big Thalassemia family.

TPFS MAJOR PROJECTS

- * Educational campaigns for youth (15-25).
- * Training workshops for medical personnel including doctors, lab technicians, nurses, students in medical fields & health workers.
- * National community awareness campaigns.
- * Prenatal testing in cooperation with the expert clinical staff and the molecular genetics laboratory at A1-Makassed Charitable Islamic Hospital in Jerusalem to screen for diseased fetuses in inflicted families in the early weeks of pregnancy.
- * Establishing a comprehensive database on premarital testing and patients' profiles to establish evidence-based recommendation for advocacy and lobbying.
- * Develop special projects for submission to international and local private organization to generate funds for their implementation





CHALLENGES

- * Due to the current political situation, most patients suffer from inaccessibility to the proper health services.
- * Most Thalassemia families are hit hard by the economic hardships facing the entire population which adds to the already medical hardship facing them including, but not limited to, less availability of resources to improve their health situation and their economic status.
- * The absence of a true central blood bank to ensure the availability of high quality of blood for transfusion (fresh, safe and fully matched blood)

- * Severe shortage comprehensive periodic evaluation programs of patients vital organs (glabnds, liver, bones and heart) and the inavailability of the needed medicine (ex. hormone replacement therapy) and other medical supplies for proper patients care.
- * Severe shortage of specialized physicians (Hematologists, Endocrinologists) & nurses to provide the optimum treatment for patients.
- * Absence of a detailed well defined treatment protocol for use by local treating physicians in the designated medical centers.
- * Presence of certain misconceptions about the pre-marital testing in some closed communities.



HOW CAN YOU HELP

- * Participate and support the awareness and educational programs about Thalassemia in Palestine.
- * Participate in blood donations campaigns for Thalassemia patients.
- * Support patients' needs including donation, help to mobilize resources for patients care, provide social and psychological support for patients and their families in your city, town or neighborhood.
- * Volunteer and cooperate with TPFS to join efforts aimed to provide Thalassemia patients and families the treatment and support they deserve.

For financial support,

TPFS Bank Account / Arab Bank No. 611693 El-Bireh.

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