occupied Palestinian territory 2018 (part of 2018-2020 HRP)

Appealing Agency	**THALASSEMIA PATIENTS' FRIENDS SOCIETY (TPFS)**
Project Title	Appeal for lifesaving medical supplies for thalassemia patients
Project Code	OPT-18/H/116410
Sector/Cluster	Health and Nutrition Cluster
Refugee project	No
Objectives	The project goal: To improve health and well-being for thalassemia patients in West Bank and Gaza strip. The specific Objectives: 1. To control the development of vital organs complications caused by high body iron level by supplying adequate iron chelating medications and regular follow up clinical examinations by specialists to ensure early and proper treatment of complications when needed. 2. To holistically educate thalassemia patients on good practice for lifestyle behavior to include regular attendance to treatment and examination, healthy dietary regimen, to improve quality of life and have confidence in a better future. 3. To increase patients and family awareness' about Thalassemia and life style adjustments and to break stigma and discrimination against thalassemia patients.
Beneficiaries	Total: 884 Thalassemia patients Female: 423 Male: 461 Children (under 18): 500 Adult (18-59): 384 Refugees: 361 IDPs: 423 Returnees: 100
Implementing Partners	Palestinian ministry of health - MOH
Project Duration	Jan 2018 - Dec 2018
Current Funds Requested	**$429,821**
Location	Projects covering both West Bank and Gaza
Gender Marker Code	2a - The project is designed to contribute significantly to gender equality
Contact Details	Walaa Shamasneh, Wala@tpfs.ps, +972 0597492935
Cash transfer programming	Is any part of this project cash transfer programming (including vouchers)? Yes Conditionality: Conditional Restrictions: Restricted Estimated percentage of project requirements to be used for cash/vouchers: 16

Needs

This life saving medicine Deferasirox – (EXJADE) has been recently registered in the Ministry of Health (MOH) after a lot of efforts, as it is an alternative to the medicine administrated by pump for 8 hours daily 25 days per month. Currently the medications quantity in MOH stock are 30%, this means that it covers 250 patients only from the total number 884 for thalassemia patients in West Bank and Gaza. The MOH quantity per year is 1,214 packs from Exjade 250mg and 2,962 packs form 500mg and this quantity cover 250 patients. After the dose calculation depends in thalassemia guidelines management, the patients need 4,058 packs from Exjade 250mg and 9,468 packs Exjade 500mg per year, this will cover all patients in Palestine. In this project appeal budget of the quantity around 30% (170 packs from 250mg, and 418 packs from 500mg) of Exjade medication. Where it considers the Specific criteria for selecting patients and guidelines have been implemented in the MOH to assure that patients are provided with the appropriate therapy needed for a better quality of life. Through this project we ensure the availability of medication and increase demanding treatment and lifelong for all thalassemia patients in Palestine. Yet, we need to assure that we can maintain these patients on a longer time period to assure the success of treatment through provide more resources for medications and increase life span for better care. And in the same time we need to focus on patients' behaviours through enhancing healthy practices help them to reduce complications and improve well-being. Especially, most of thalassemia patients die from cardiac arrest and the main cause is shortage of medications. Nevertheless, for the past few years, and with the addition of the new protocol of management, patients have been growing up with an average life expectance of 18 years, compared to the pervious life expectance of 7-8 years before ten years ago. In addition, thalassemia patients' friends' society –TPFS work newly with MOH to develop four specialist centers for thalassemia patients in west bank and Gaza, but the main challenge is unavailability of medications for all thalassemia patients in Palestine.

Activities or outputs

1. TOT training of thalassemia youth on (leadership, behavior change, and social mobilization), through enhancing patients capacity for self-care through adoption of appropriate health and healthcare seeking practices.
2. Development of educational aids and ICE materials related to disease and healthful practices associated with it.
3. Train Health provider in thalassemia units in hospital on the national protocol.
4. Purchase Deferasirox (EXJADE) 250 mg 170 pack, and 500 mg 418 pack.
5. Develop an innovative mobile program as simplify daily control and management to reach all thalassemia patients.

This project will provide the medications increase patients access to acceptable, on time quality health and social services by training all thalassemia patients (both women and men) on therapeutic guide and to give knowledge to patients & parents of children with thalassemia by training them to recognize their signs and symptoms of the disease and how to treat and prevent them, reduce social stigma towards thalassemia patients in rural area that's due to increase access to healthcare centers for treatment.

The monitoring and evaluation will be a participatory process, in which all stakeholders (medical centers, patients, parents, etc.) will be involved in assessing the impact of the project such as quality of life, the social integration, healthier lifestyle, enrolment in schools, involvement in social activities, applying for jobs etc. Data collected will be quantitative and qualitative. The impact of the project on social integration of the thalassemia patients will be measured and assessed. The monitoring and evaluation report will be built on the indicators mentioned in the logical framework.

Monitoring and evaluation is a continuous process, from planning to the time during implementation and post intervention. Lesson learned will collected after each evaluation to be incorporated immediately. Data collected will be sex and age segregated. Pre data and post data will be gathered and analyzed to estimate the success of the project. Biannual reports will be issued and shared with all the stakeholders involved.
Focus group discussions, survey, assessments, and reports from CBOs and other stakeholders will be used to develop the biannual report. In addition, other tools will be utilized all through the project to follow up activities, one of these tools will be field visits where teams of organizations and donors visit the locations and observe implementation on the ground. A quarterly monitoring tool will be prepared to be used and filled regularly by the project coordinator. If needed any major obstacle will be reported to the board and the proper decision will be made.

Indicators and targets

1. 884 of thalassemia patients are adopting appropriate healthcare seeking practices lifestyle.
2. 300 of thalassemia patients have of controlled disease complications.
3. 600 of thalassemia patients have knowledge about how to use the medications in right way.
4. 600 of thalassemia patients are assessed and get treatment by ministry of health services.
5. 423 women with thalassemia disease getting treatment in the thalassemia units in hospitals.
6. 310 pwD (thalassemia disease) enrolled at university/ getting jobs and participating in social activities.

This project plays a key role in promoting the meaning of Thalassemia, how to prevent the disease, how to mitigate the complications of the disease and how to sustain living with the disease. As well in this project there is a deep focus on social aspect of patients with thalassemia. The training targets patients and families to empower them and raise their level of awareness as well as confidence; this will happen through providing life skills based training, and lifestyle based approach concepts. As project tends to train both girls and boys with thalassemia disease. The aim is to reduce social stigma to encourage patients to access health services and get the treatments which influence a better health for patients. Patients suffer from growth retardation, liver problems, osteoporosis, and weakening of the liver and heart conditions depending on the ferritin level and duration of its accumulation. That's consider the thalassemia patients as persons with disabilities. Most thalassemia patients die from cardiac arrest. Nevertheless, for the past few years, and with the addition of the new protocol of management, patients have been growing up with an average life expectance of 18 years, compared to the previous life expectance of 7-8 years 10 years ago increasing the demand for better care and more resources for medicines. We in TPFS have a duty for advocacy with patients and educating public in general also private and public potential employers for equal work for values as well as safe and health working conditions.

Thalassemia patients need medical and social services. The patients need regular blood transfusion in addition to daily medications. While the psychosocial suffering of the patients and their families is of utmost importance, especially when complications are expected due to over accumulation of iron in the body. Usually women with thalassemia suffer more socially. They get marginalized and isolated when the symptoms of the disease become visible. Thus, women with thalassemia need more attention when it comes to psychosocial support.

The gender specific approach recognises differences in gender roles, responsibilities and access to resources, and take account of these when designing interventions (WHO 2017). This project takes into account the gender differences, gender roles and expectations. The project takes into account these differences in designing the activities to make it equally accessible for both genders.

Indicator	Project target

Thalassemia Patients' Friends Society(TPFS)	
Original BUDGET items	**$**
Purchase deferasirox (EXJADE) 250mg	71,203
Purchase deferasirox (EXJADE) 500mg	329,618
Train health provider in thalassemia units	9,000
TOT training of thalassemia youth (lifestyle behaviour)	15,000
Development of educational aids and ICE materials	5,000
Total	**429,821**

Thalassemia Patients' Friends Society(TPFS)	
Current BUDGET items	**$**
Purchase deferasirox (EXJADE) 250mg	71,203
Purchase deferasirox (EXJADE) 500mg	329,618
Train health provider in thalassemia units	9,000
TOT training of thalassemia youth (lifestyle behaviour)	15,000
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