

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

<b>Appealing Agency</b>	<b>QATAR RED CRESCENT SOCIETY (QATAR RC)</b>
<b>Project Title</b>	Qualitative Special care to children with PKU Disease 2018
<b>Project Code</b>	OPT-18/H/115030
<b>Sector/Cluster</b>	Health and Nutrition Cluster
<b>Refugee project</b>	No
<b>Objectives</b>	<p>Goal</p> <p>The overall objective is to contribute in improving health, intellectual and nutritional status male and female infants and children suffering from PKU in the Gaza Strip.</p> <p>Project specific objectives</p> <ol style="list-style-type: none"> <li>1. Support children with special illness; PKU</li> <li>2. Secure qualitative feeding pattern of infants and children affected with PKU.</li> <li>3. Enhance better qualitative health and nutritional knowledge amongst affected children, care takers and their improved practices with regards to PKU.</li> <li>4. Promote and advocate PKU at national level.</li> </ol>
<b>Beneficiaries</b>	<p>Total: 120</p> <p>Female: 66</p> <p>Male: 54</p> <p>Children (under 18): 120</p>
<b>Implementing Partners</b>	Ard Ellnsan Association
<b>Project Duration</b>	Jan 2018 - Dec 2018
<b>Current Funds Requested</b>	<b>\$212,760</b>
<b>Location</b>	Projects covering just Gaza
<b>Gender Marker Code</b>	2b - The principal purpose of the project is to advance gender equality
<b>Contact Details</b>	Akram Hassan Nassar, anassar@qrc.org.qa, + 972 59 5699386
<b>Cash transfer programming</b>	<p>Is any part of this project cash transfer programming (including vouchers)? <span style="float: right;">No</span></p> <p>Conditionality:</p> <p>Restrictions:</p> <p>Estimated percentage of project requirements to be used for cash/vouchers: <span style="float: right;">0</span></p>

**Needs**

## Problem Statement

Phenylketonuria (commonly known as PKU) is an inherited disorder amongst the group of inborn errors of metabolism. In this disease increased blood levels of amino-acid “phenylalanine” which is a building block of protein. It is found in all proteins and in some other food items. If PKU is not treated, phenylalanine can build up to harmful levels in the body, causing intellectual disability and other serious health problems.

The signs and symptoms of PKU vary from mild to severe. The most severe form of this disorder is known as classic PKU. Infants with classic PKU appear normal until they are a few months old. If not treated early, these children develop permanent intellectual disability, seizures, delayed development, behavioral problems, and psychiatric disorders.

The occurrence of PKU varies among ethnic groups and geographic regions worldwide. In the United States, PKU occurs in 1 in 10,000 to 15,000 newborns. Most cases of PKU are detected shortly after birth by newborn screening, and treatment is started promptly. As a result, the severe signs and symptoms of classic PKU are rarely seen.

### PKU in the Gaza Strip

Early interest in PKU was paid by the Palestinian health providers in the sequential administrations and ministries but there had been no reliable approach ensuring a sustainable intervention. All trials made were dependent on donated phenylalanine free milk formulae and individual trials made by interested physician who weren't able to continue because the subject wasn't amongst the basic mandate of MOH. The cost of adoption of this disease was a real burden disabling the health providers at the level of governmental and nongovernmental areas. Hence, all interventions made were embraced into preventive aspects and early detection via screening of all new born infants by testing a blood sample using the Guthrie's chart for detection of PKU and thyroid disorders.

Detected cases (66 of them are females and 54 males) of PKU in Gaza receive intermittent supplies of phenylalanine free milk by the MOH in some occasions. Unfortunately, this supply is affected with the financial constraints affecting the MOH and closures. Moreover, the services provided by the MOH within this scope are missing the qualitative component because there is no more support services offered such as health education, special counseling, and regular follow up and reporting.

QRC have experience in such health and nutrition projects. Through the last year QRC and ARD EIInsan association implemented project of supporting PKU male and female patients in Gaza. More than 100 male and female child benefiariate from project, a nutritional feeding pattern, awareness (awareness session, field home visits, TV spokes, brochures), healthy lifestyle, and advocating the health and nutrition status of PKU patients.

### Activities or outputs

## Outputs-Outcomes

### 1. Adequate direct beneficiaries support

- 2,322 tins of phenylalanine free infant formulae provided to male and female children 0-6 months old over 6 months period.
  - 1440 tins of phenylalanine free infant formulae provided to male and female children over 6 months old up to 6 months period
  - 5,120 kg of gluten free flour for PKU male and female patients
  - 36 group awareness sessions conducted for mothers and care takers of male and female infants and children with PKU (once each 2 weeks interval as one for infants' 6months and one for children=6 months old). This sessions for increasing health and nutrition awareness about the PKU, preparation of patient meal, best feeding practices, results of neglecting the treatment of the disease, psychosocial support, treatment of negative energy in male and female PKU patients, ...etc.
  - 360 Home visits to male and female cases assessed as PKU patients.
  - 360 individual counselling held as 3 sessions for each of the 120 PKU children's mothers/care takers over the 6 months period.
  - Recreational activities for male and female children affected with disease (as a part of psychosocial support)
  - 400 handbooks produced and distributed.
  - Radio spokes and SMS to increase the awareness level about PKU as a disease. This step aim is to reach as many people as possible at all society level female or male, elderly people, people with disabilities and children also
- 2.Improvement in clinical condition of male and female infants and children with PKU.
    - 90% of detected male and female cases presented with good general condition.
  - 3.Improvement in male and female PKU older children and infants' caregivers' knowledge regarding PKU
  - 4.Improvement in male and female patient's and caregivers' attitude towards PKU
  - 5.Improvement in feeding practices

## Activities

1. Coordination with relevant institutions, MOH (as health services provider in Gaza)
2. Community meetings with selected affected male and female cases and also NGOs in the filed for assessing needs
  - 2.1 collect information from caregivers (women and men), male and female children and health care provider
  - 2.2 community meetings taking into consideration not only nutritional and health needs but also other factors when assessing needs ( income, demographic factors, household factors, and also if there is disabled in the house and or elderly)
  - 2.3 ensure the community engagement not only in assessing needs but also in designing the action plan and monitoring cases
3. Follow up the already registered 120 male and female PKU cases and open new medical files for the diagnosed new cases for future support if any.

Follow up visits are planned as twice monthly over 6 months period, during which;  
male and female Infants (Under 6months old)

Assessment of general health condition of male and female PKU cases, assessment of patient's mother knowledge regarding PKU, assessment of nutritional status of male and female cases and compliance to (Phenylalanine free formula), assessment of neurological and developmental milestones for male and female cases.

One individual counselling for caregivers each two weeks over 6 months period, sharing in 3 occasions of nutritional health group counselling as once each two months per mother/care giver, home visits and contacting the defaulters or non-responding or less improving male and female cases, and referral for male and female cases in equitable manner when needed to other health specialists\facilities.

Twice monthly provision of 5 tins of Phenylalanine free formula, i.e.10 tins/month for male and female cases in equitable manner.

Children = 6months old,

The same as less than 6 months of age except the support will be for male and female cases; twice monthly provision of 3 tins of Phenylalanine free formula, i.e.10 tins/month.

## Indicators and targets

The target of the intervention is to ensure the availability, acceptability of life saving health service (availability of special formula milk and gluten free flour), to vulnerable male and female children (with metabolic diseases) , in addition to that improve effectiveness of lifesaving health response for vulnerable stratum of population

**Target 1:**

Ensure access to adequate health and nutritional care services to male and female children with PKU in Gaza through the appropriate case management, provision of critically needed formulas for improved diagnosis and through increasing the capacity of community male and female workers and also community awareness

**Indicators:**

Number of male and female children (120) benefiting from improved health and nutritional services from AEI centers and community outreach teams

1. 120 male and female children assessed at AEI centers in Gaza and Khanyounis
2. 120 laboratory investigations performed (health assessment) equally for male and female cases
3. 120 male and female patients provided with gluten free flour and 3722 Phenylalanine free infant and children formula tins, added to that 5120 kg of flour ser
4. 36 group awareness sessions conducted in Gaza & Khanyounis centers (number of participants not less than care givers for 120 male and female PKU patients).
5. 360 individual awareness sessions (number of participants not less than care givers of 120 male and female PKU patients).
6. 360 Home visits (community outreach) for health promotion and psycho social support for male and female cases

**Target 2:** The community, male and female health workers, and also male and female children with PKU as vulnerable community are well prepared to cope with the disease this will achieved through health promotion

1. 400 of booklet will be printed and distributed to targeted male and female cases (PKU from A to Z, feeding practices, psychosocial, how to cope with the disease in emergency)
2. Radio spokes and SMS (the disease results if not treated, the impact of care on health status of male and female child ...)
3. Special event day (nationally)

**2.1 Improvement in male and female PKU older children and infants' caregivers' knowledge regarding PKU**

- 100% recognize the PKU problem and the neurological complications of brain in the neglected conditions.
- 90% recognize that PKU complications are preventable by strict adherence to Phenylalanine and certain proteins diet.
- 100% recognize that PKU is incurable.
- 90% believe that male and female PKU patients can life a healthy life.
- 100% knows the safe food list (Phenylalanine & special proteins free).

**2.2 Improvement in male and female patient's and caregivers' attitude towards PKU**

- 95% of male and female patients and caregivers were committed to the schedule of receiving (Phenylalanine & special proteins free) from AEI.

**2.3 Improvement in feeding practices**

- 90% of male and female infants and older children have their feeding practices of (Phenylalanine & special proteins free) been improved via themselves or their mothers/care takers.

Indicator	Project target
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<b>Qatar Red Crescent Society(Qatar RC)</b>	
<b>Original BUDGET items</b>	<b>\$</b>
project technical staff	24,500
Special Infant Formula (Phenylalanine free)	157,000
direct technical support (awareness, home visit)	3,000
visibility	2,000
AEI operational costs	10,500
overhead costs	15,760
<b>Total</b>	<b>212,760</b>
overhead costs	15,760