



CF Gaza: The Cystic Fibrosis Program in the Gaza Strip

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Significance of the program

Cystic fibrosis in Gaza or the West Bank has never been studied or researched scientifically. Because of this, there are no available statistics regarding the incidence or mortality from this disease in Palestinian people. It has been noted in recent times that some children had been diagnosed with CF and had been hospitalized in Gaza. The stories about the sad plight of these children highlighted many severe shortages in the sector, namely:

- lack of good diagnostic services,
- lack of essential medications,
- lack of specialized knowledge in doctors and nurses in how to care for children with CF, especially a lack of proper hygiene protocols to avoid cross infection.
- lack of dietary advice and dietary supplements
- lack of psychological support for families and advice on how to manage the child's condition at home

The difference in health outcomes and survival between the children treated “outside” and children treated in Gaza was painfully obvious, and highlighted the great deficit in our hospitals' ability to treat cystic fibrosis. The region's inability to provide necessary treatments and diagnostic services has clearly impacted negatively on mortality rates and caused increased suffering for families of children with CF patients need a team of medical and other health professionals working together to provide treatment and rehabilitation so that these children can lead a life like other children. This team needs to be well trained and qualified to deal with a disease which is chronic and which will need management for the rest of the patient's life.

We realized that establishing an association that was able to ensure these patients were provided with the treatment, consultation, and support that they need was not only a duty but also a humanitarian and national responsibility. It was clear that this plan needed to be adopted by people responsible for health affairs in Palestine.

We learned about a lot of successful experiences from neighboring countries that had such facilities and had succeeded in making enormous progress in the CF patients' condition and allowed them to have a better life with less suffering from disease and its consequences.

Why have a CF program in Gaza Palestine?

The whole idea of launching a CF program or structure here in Gaza arose out of the experiences and efforts of two fathers; Ashraf Shanti and Mahmood Yaqoubi. Ashraf has two boys; Muhammad and Mustafa al-Shanti , aged 4 years, 3 years respectively, and one deceased infant who died of CF at the age of 72 days. Mahmood has a 4 year old boy with CF. Both fathers met each other on regular visits with their children to the Out



Patient Department in Nasser Pediatric Hospital, where they shared their suffering and came up with the idea of a CF program for Gaza and discussed the idea with their friend, Dr. Mahmood Shamaly M.D. The CF Program was launched in early 2008, with 40 registered patients so far and the number is increasing.

Aims of the CF program

The cystic fibrosis patients and friends association in Gaza aims to provide full high quality health services from diagnosis, consulting, treatment, psychological and social rehabilitation for patients, consistent with the patients' needs and the severity of the disease.

Based on that, the project has the following objectives:

- 1.) To provide a comprehensive medical team specialized and well qualified to treat cystic fibrosis patients (doctors, nurses, nutritionists, physiotherapists, psychiatrists, psychologists, laboratory and pharmaceutical technicians).
- 2.) To provide an appropriate space and to fully equip a department for those who require extra care.
- 3.) To open an advisory clinic to assist, advise, and offer therapeutic services for people with CF.
- 4.) To equip an advanced medical laboratory able to diagnose and follow up the patients with the appropriate equipment.
- 5.) To diagnose the carrier cases and explore the family history of CF, whether prior to marriage or during pregnancy to make sure that the infant doesn't carry the CF gene or is affected by CF.
- 6.) To provide medical treatment for patients by local, international, governmental, or non-governmental health associations at a reasonable price or for free, so that every patient has access to essential medication under the supervision of a pharmacist.
- 7.) To establish a research center so that the association can record CF cases and follow up cases to study results of treatments and outcomes.
- 8.) To publish an annual report that helps to improve the quality of services provided for patients and that is useful for doctors.

Achievements

- CF program Gaza managed to provide funds for a suitable space that is on a rent contract.
- CF program Gaza, managed to find interested volunteers (nurse, M.D, physiotherapist, psychologist and nutritionist to work with the program)
- CF program Gaza, through advertisement managed to open its door for 40 CF patients so far.
- CF program staff have conducted visits to CF families at home and in hospital wards.
- CF patients are currently seen at the program clinic for clinical examination by our medical staff on a weekly basis and they also have thorough laboratory investigations on quarterly basis.
- CF program Gaza managed to provide CF patients with the following items free of charge through local and international NGOS:



- A hygiene kit to each CF patient provided by the Palestinian Red Crescent Society (PRCS)
- milk provided by the Palestine Children's Relief Fund
- medicines (dar Al Shifa Pharmaceutical company)
- food kit of \$100 value provided by the United Nations Development Program

Finally, with the help of Dr David Shoseyov, M.D, a Pediatric Pulmonologist, the CF program Gaza, managed to organize a 6 months study period for Gaza medical staff at the Hadassah Mt Scopus University Hospital in Jerusalem so that our motto: *Let us live with careful attention like everybody else* truly becomes a reality.

