

CF Worldwide Program in Armenia

Program Description

Cystic Fibrosis Worldwide with its 56 member countries, medical advisors and multiple international CF working groups offers educational workshops to parents, patients and medical professionals and aids in the development of specialized CF care centers globally. By spreading education about CF among medical professionals, parents and patients we create a long-term difference that will have resounding effects on patient's lives for years to come. Educational workshops are the cornerstone to forging solid programs that can be replicated in countries around the globe. The development of specialized CF care centers contribute to long-term survival of patients and the development of standards of care. Through continued evaluations and analysis of the programs and participants, we can successfully tease out program strengths and weaknesses ensuring continued success.

Needs Assessment

Exact data on the incidence of CF in Armenia is unknown, but there are some reasons to think that it's one of the most common inherited disorders in region.



Despite this fact, primary diagnostics of CF and treatment of the disease continue stay non integrated and insufficient. Most of the treatment and follow-up are accomplished in different hospitals and clinics throughout Armenia. The diagnoses is made based on the clinical picture, sweat test (on Gibson –Cooke method) and sometimes, though very rarely, upon genetic investigation. (The screening panel consists of only 25

mutations). It is necessary to develop a centralized CF center and is a top priority in improving the lives of patients living in Armenia.

Education about CF at the Medical University is not adequate therefore;



- A broad mass of clinicians (especially paediatricians and family physicians) are inadequately informed about the severity of the problem, new approaches for diagnostics, new research and available treatment and medication.

The Ministry of Social Maintenance grants a pension for disability (about 8 EUR per month) to persons with CF. This pension allows them to receive state-paid medical care. Today in Armenia patients have free access to life – saving drugs such as Kreon-10000 and acetylcystein, they also receive “Alfare” donated by “Nestle” which is distributed by clinicians. Currently there are 27 diagnosed patients but suspected 50 or more.



Building a CF Center

A center for CF is being developed at the Yerevan State Medical University Hospital by the order of the Minister of Health. The center was created by efforts of the health care nonprofit organization “Doctors and Children” and with the support of Cystic Fibrosis Worldwide.

Cystic Fibrosis Worldwide has collaborated once again with Project CURE and Counterpart International to secure hospital supplies and furnishing to be shipped to Yerevan, Armenia by the end of October. We are now working to raise funds to support the costs of this shipment and to purchase in addition to the donated supplies, a Spiro Meter and Pulse Oxy-Meter. Through the kind generosity of Wescor, Macroduct diagnostic equipment has been donated and will be included in the future shipment. For more information, please visit:

<http://www.projectcure.org/>,
<http://www.counterpart.org/>, and
<http://www.wescor.com/>.



We are readily seeking support for this shipment and to purchase additional equipment. Please donate here and help us aid people with CF in Armenia. www.cfww.org/donate.asp



Educational Activities

“Cystic Fibrosis management: Considerations for improved care in Armenia”

Yerevan State Medical University hosted a four-day series of workshops and lectures given by experts from around the world:

- Chest Physiotherapy Courses (inhalation therapy, airway clearance therapy, physical exercise, and on-on one consults with patients and families)
- Nutrition Courses (one on one consults with patients and families)
- Importance of non-profit organizations in improving CF care
- Genetics and pathogenesis of CF
- Treatment of lung disease in CF
- Gastrointestinal problems in connection with CF
- Registry activities of Eurocare CF and ECFS

The following materials were also printed and distributed to participants (Physicians, Pulmonologists, Nutritionists, Gastroenterologists, Caregivers (Nurses, Nutritionists, Physiotherapists), Medical University Students, Patients, and Parents) and will also be available at www.cfww.org

- Nutritional Handbook translated into Russian
- Distributed to seminar attendees
- Posters with daily care regime for patients