Global Cystic Fibrosis Initiative "Bridge of Hope Program"

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CF Bridge of Hope

Improving the health and life of CF patients in underdeveloped areas of the world. Leave no Person with CF Behind.

CF Bridge of Hope

A non profit organization started in 2012

Mission: To improve the health and life of patients with CF in underdeveloped area of the world

Ultimate Goal: To work with local physicians in these countries to improve the standard of care for patients there.

Why do we need "Bridge of Hope"? **Developing countries:** *Lack of knowledge of healthcare providers *Outdated medical care * 40 years difference *Limited access to medical care * financial limitations * distance *Unavailability of medications * due to sanctions * unaffordability

Phases of treatment process for each patient in the program

- Phase 1 Selection of candidates
- Phase 2 Evaluation
- Phase 3 Treatment and education
- Phase 4 Continuation of management in the home country and collaboration with the local health-care provider(s)
- Phase 5 Annual returns until local resources are established

Phase 1 – Pre-arrival to the United States

- Patient contacts the program
- Patient selection that is mainly based on clinical stability since this is an outpatient therapy
- Paperwork filing to obtain a non-immigrant travel visa to the United States
- Coordination of travel and accommodations

Phase 2 – Arrival in New York/Connecticut

- Initial evaluation that includes:
 - Blood tests: complete blood count, electrolytes, liver function test, HbA1c, vitamin A, D, E levels, PT, lgE level, oral glucose tolerance test (>10 years of age), DNA mutation analysis (if not available)
 - Repeat sweat test
 - Sputum/deep throat culture
 - Pulmonary function test
 - Chest radiograph (if indicated)

Evaluation by MD,ND,RN,SW,RD,RT members of the CF team

Phase 3 – Treatment and Education

- If antibiotic therapy is needed decide oral vs IV
 - If decided on IV therapy then a percutaneous line is placed for a 14 day outpatient therapy.
- Pulmonary function test is repeated to assess the efficacy of treatment.
- Education:
 - Obtain and educate usage of necessary equipment (vest, nebulizers).
 - Obtain a 1 year supply and educate usage of medications, enzymes, vitamins, and nutritiona supplements.

Phase 4 – Collaboration upon returning to home country

- Regular clinical report from the patient.
- Collaboration with the local health-care provider(s).
- Medical recommendations if there is a change in clinical status
 - Such as an exacerbation.

Phase 5 – Regular returns to the US

Return every 6 to 12 months for re-assessment and provision of medications until local resources are established.

The program maintains low cost by:

- Probono work by Cravath, Swaine and Moore law firm and Drs Raissi and Sadeghi.
- Outpatient therapy with discounted rates for laboratory tests and IV antibiotic infusion at Stamford Hospital in Connecticut, USA.
- Maintenance medications/nutritional supplements obtained at no cost either through assistance programs, donations or samples and vouchers
- Community volunteers by Wi-ACT (Wilton Interfaith Action Committee).

Estimated Costs per patient

- Estimated cost for the initial work up is approximately \$150,000.
- Cost to the "Bridge of Hope" program is approximately \$10,000.
- Cost to the patient can vary from zero to \$3,500 (depends on the financial status of the patient).

Country of Origin of Patients who have received assistance through the program as of 2017

- 🧕 Georgia
- Iran
- Ecuador
- Dominican Republic

Obstacles still remain

Obtaining visa's going forward

Obtaining medications for treating P.A.
Cayston

Area physicians and their willingness to collaborate on care

Vision for the Future

"...leave no individual with CF behind."

www.cfprojectinc.org

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