

Who is Cystic Fibrosis Worldwide

Cystic Fibrosis Worldwide (CFW), formed after the merger of the International Association of Cystic Fibrosis Adults and the International Cystic Fibrosis (Mucoviscidosis) Association, is dedicated to improving quality of life and life expectancy for persons living with cystic fibrosis globally. CFW has over 60 member countries with a number of members coming from developing parts of the world. With these new memberships comes an awareness of the desperate situation facing those who have cystic fibrosis, caregivers or medical professionals in developing countries.

Cystic Fibrosis Worldwide reaches out to these countries by working to help develop affective cystic fibrosis treatment and care. This includes helping to organize much needed medications, clinical development, training and education of health care providers, parents and people with CF and spreading awareness of cystic fibrosis at the government and community levels. We seek to find people with CF who are living in countries where cystic fibrosis is thought to not exist and offer them hope for better tomorrows. It is our objective to find a solution that will bring long-term benefits to the existing persons with cystic fibrosis and to those people with CF who will be born in the future, leaving no people with CF behind. Until a cure is found, we will strive to provide humane situations for those who are currently suffering from cystic fibrosis globally.

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While the earliest clear medical descriptions date from the 1930's, CF obviously existed prior to this date but was un-recognized. Its clinical characteristics individually resemble those of other diseases such as pneumonia, bronchiectasis, failure to thrive, and celiac disease. Indeed, where these conditions are prevalent CF may still lie un-recognized. Moreover, if clinicians believe that CF is absent from their population they will not consider it in a differential diagnosis. A better awareness of and the increasing availability of diagnostic tests- the sweat test and/or DNA tests - frequently leads to the identification of a higher number of affected individuals.

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In the last two decades, CF has been increasingly diagnosed in Latin America, the Middle East, and populations derived from the Indian subcontinent that have emigrated to Western Europe, thus implying the presence of CF in significant numbers among the citizens of India and Pakistan who have remained in their homeland. As Eastern Europe recovers from the shift away from communism, they are faced with the demands to meet their countries health care needs independently. CF is often viewed as an incurable disease affecting too few in numbers to be considered a priority. All developing countries face the

challenge of bringing CF to the front when most countries are already staggered by the growing numbers of HIV patients, Tuberculosis and ever present malnutrition. In these situations commanding an audience concerned with CF is an enormous challenge to newly developed CF patients organizations.

CF is a multi-organ disease and children with CF need multidisciplinary team care in CF Centers regularly. This multidisciplinary team should consist of a CF Nurse, Pediatric Pulmonologists, Pulmonologists, Gastroenterologist/Nutritionist, Nurse, Physiotherapist, Microbiologist and Psychologist/Social worker who have been trained in the specific needs of patient care. Daily home care that requires both parent and patient participation is also needed to ensure the patients experience a better quality of life and life expectancy.

Cystic Fibrosis Worldwide is working to bring care to patients who are in desperate need across the globe.

"If we don't care, who will?"