

Country Close Up: India

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Cystic Fibrosis in India

Many medical professionals consider Cystic Fibrosis a disease affecting only the Caucasian population. As such, it was considered extremely rare in the Indian subcontinent until a decade ago. However, recent reports suggest that Indian children do indeed have CF; however, CF in India is still being misdiagnosed and misrepresented.

Due to lack of studies, the precise incidence of CF in the Indian population is unknown. The estimated prevalence in migrant populations in the UK and US vary from 1 in 10,000 to 1 in 40,000. There are no large community based studies that give a clear idea about the disease burden in India, and with the lack of this critical data, CF does not get appropriate attention from policy makers. Even if the prevalence of CF in India is 1 in 10,000 births, there may be 3000 children born with cystic fibrosis annually in different parts of India. Therefore, India would hold the largest population of CF patients in the world today.

Current Status of CF services in India

In most countries in Europe, USA and South America, CF services are well developed and the survival of CF patients has improved significantly.

However, there were no CF services in India until 1999. The All India Institute of Medical Sciences (AIIMS), New Delhi started CF services with funding from International Cystic Fibrosis (Mucoviscidosis) Association, now known as CFW.

Since then, centres have been established at the Post Graduate Institute of Medical Education and Research Chandigarh, and at the Christian Medical College Vellore, Hinduja Hospital Mumbai. These centres offer diagnostic facilities and clinical care to CF patients.

Presently, at AIIMS, a group of doctors are doing research on CF to improve care of CF patients and to find the genetic profile of Indian CF patients. Moreover, AIIMS is currently treating over 200 diagnosed patients.

CF knowledge is limited in India because CF care is not included in medical curriculum. As a result, diagnostic services have not been established throughout the country and a majority of medical graduates may not have even a

single confirmed CF case.

To identify all CF patients in India and to provide them appropriate care, there is need to spread awareness about this illness amongst doctors and society. Increased knowledge will help establish diagnostic and clinical care services in different parts of India. Early diagnosis and appropriate treatment is the key to improve survival and quality of life of these patients.

Why is CFW in India?

In most developed countries there are established CF Associations that help in management of these patients. A long-term outcome for CFW will be to focus on the development of a CF Association working to reach all patients who suffer from CF in India. The main objectives for CFW will include spreading awareness of CF in India, supporting activities that provide care for all CF families, and strengthening the development of an Indian CF Foundation.

CFW will work with partners in India to increase the managerial, financial and advocacy skills of the Indian CF Foundation and support the development of relationships with local NGO networks that target inherited chronic disease. CFW will also work to expand linkages between those local NGO's and the public and private sectors throughout India and the international CF community. As part of the initial steps of spreading information and developing a CF Foundation in India, CFW will work with AIIMS faculty members to identify the true incidence of CF in India.

How can we reach people with CF in India?

CF may still lie unrecognized in such countries as India, Pakistan, Sri Lanka and Bangladesh. Moreover, if clinicians believe that CF is absent from their population, as we have found in India, they will not consider it in a differential diagnosis. A better awareness of CF 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 and this will be the case in India.

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.

Furthermore, India has a very wide spectrum of people with enormous differences in socio-economic status. Any family can seek a consultation with a pediatrician but patients have to use their own resources to pay for investigations and treatment. In India, this is compounded by people's unique socio-economic status and their access to available options for care for reasons of geography. For instance, Dr. Kabra, who treats CF patients AIIMS, garnered better results in his patients by re-organizing his outpatient services so that children had booked appointments to come back on a specific date for follow-up. Clearly, increased awareness coupled with more CF facilities will provide the best opportunity to reach CF patients throughout India and neighboring regions.

At AIIMS, the mean age at diagnosis is 54 months (3-154months). It is suspect that the majority of those affected with CF are dying from malnutrition and respiratory complications before diagnosis. Undoubtedly, medical students need to learn about CF and physicians must be convinced that CF exists in India. This group requires access to appropriate treatment including in particular pancreatic enzyme replacement therapy and the care of the multidisciplinary CF specialized team.

It will be imperative that CFW is able to find funding to continue the valuable services offered by AIIMS to existing CF patients, as well as support new initiatives aimed at improving life expectancy and quality of life for all CF patients in India.

Facts about India

The Indus Valley civilization, one of the oldest in the world, dates back at least 5,000 years. Aryan tribes from the northwest invaded about 1500 B.C.; their merger with the earlier Dravidian inhabitants created the classical Indian culture. Arab incursions starting in the 8th century, and Turkish in the 12th, were followed by those of European traders, beginning in the late 15th century. By the 19th century, Britain had assumed political control of virtually all Indian lands. Indian armed forces in the British army played a vital role in both World Wars.

Nonviolent resistance to British colonialism led by Mohandas Gandhi and Jawaharlal Nehru brought independence in 1947. The subcontinent was divided into the secular state of India and the smaller Muslim state of Pakistan. A third war between the two countries in 1971 resulted in East Pakistan becoming the separate nation of Bangladesh. Despite impressive gains in economic investment and output, India faces pressing problems such as the ongoing dispute with Pakistan over Kashmir, massive overpopulation, environmental degradation, extensive poverty, and ethnic and religious strife.

Location

Southern Asia, bordering the Arabian Sea and the Bay of Bengal, between Burma and Pakistan.

Language

English enjoys associate status but is the most important language for national, political, and commercial communication; Hindi is the national language and primary tongue of 30% of the people; there are 14 other official languages: Bengali, Telugu, Marathi, Tamil, Urdu, Gujarati, Malayalam, Kannada, Oriya, Punjabi, Assamese, Kashmiri, Sindhi, and Sanskrit; Hindustani is a popular variant of Hindi/Urdu spoken widely throughout northern India but is not an official language.