



## Country Close-Up

### **Cystic Fibrosis In Jordan**

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The Hashemite Kingdom of Jordan, with Amman as its capital city, gained independence in 1946 and the nation of 6 million inhabitants has a constitutional monarchy with a representative government. Jordan, being centrally located, is a well-travelled bridge between east and west, sea and desert. It is located in Western Asia and shares borders with Palestine, Saudi Arabia, Syria, Iraq and Lebanon. Jordan's coastline spans 26 kilometers on both the Dead Sea and Gulf of Aqaba. The country is part of a region considered to be the Cradle of Civilization, therefore, it is rich with tradition and history. Jordan has evolved over the centuries into a modernized country where a majority of the population speaks Arabic; however, English is also widely used.



Despite having a free market economy, Jordan is a resource-poor country. Tourism constitutes a major sector in the economy because Petra is one of the new seven wonders of the world. However, the country has other tourists spots including: the ancient Roman city of Jarash, and religious sites in Madaba, Mount Nebo and the River of Jordan. Visiting the Dead Sea and Gulf of Aqaba is extremely popular during the winter. Interestingly, the dead sea is the lowest point on Earth because it is 405 meters below sea level; the water is 9 times saltier water than ocean water.

Jordan is ranked as having some of the highest quality of life in the Arab World. The country also has one of the highest standards of living in the developing world with a highly educated population with access to advanced healthcare services in both urban and rural areas.



Medical tourism is an important aspect in the region and worldwide. Jordan has an advanced health care system, although services remain highly concentrated in Amman. In fact, Queen Rania Alabdulla Hospital is ranked as the number one specialized children's hospital in the region. It is part of the Royal Medical hospital system that provides medical services for most of the population across Jordan.

### **CF care in Jordan**

Cystic fibrosis was first recognized in Jordan in 1984. Since that time, cases of CF have increased which reflects the high consanguinity rate in Jordan. However, there are no studies at the national level to document the prevalence of the disease. With our limited resources, we aim at a survival of above 30 years in our patients. The mean age of diagnosis at our center is 5 months but the delay in diagnosis is seen in those who are referred from other centers or from other specialties.

We differ from other developed countries because more of our patients present with recurrent hyponatremic dehydration that can be fatal especially in hot summer weather. We also tend to see patients presenting in infancy with *Pseudomonas* colonization. These two factors may be explained by the lack of a neonatal screening program as well as the lack of awareness of the disease by physicians.

CF patients seek treatment at different centers in Jordan including: University Hospitals, Ministry of Jordan and the Royal Medical Services. The latter being mostly at Queen Rania al Abdulla hospital for Children, where the majority of the CF population is treated.

Presently, our CF clinics administer treatment to 115 patients. We run joint clinics with the endocrine and gastroenterology hepatology clinics. Our treatment protocol includes monthly out-patient visits, regular admission for patients with *Pseudomonas* colonization to hospital every 3 months for intravenous antibiotics, physiotherapy and assessment nutritional status. We use inhalational Gentamicin antibiotic because we lack colistin and tobramycin.

Our genetic testing uses the Ennogenetics, INNO-LiPA, Belgium kits for 36 gene mutations. This gives a 30% positivity in our cohort which means we definitely have different gene mutations that may have an impact on the disease course.

We face many difficulties:

1. Medications--especially enzyme replacement or creon capsules because of the expense and lack of coverage through medical insurance.
2. Lack of a neonatal screening program.



3. Lack of identified gene mutation in our population that may be helpful in atypical and borderline cases.
4. Lack of one specialized center to look after all cases at a national level.
5. Lack of well-trained CF nurses to help children and families.
6. Lack of DNase, colistin and tobramycin inhalation treatment because of the cost effectiveness of using these treatments in low-income countries such as ours.

At Queen Rania Alabdullah Hospital, we are now starting to look to other specialized centers in our region and all over the world for further cooperation, for sharing experiences, for support and for guidance with our CF programme.