

Cystic Fibrosis Association Mexico

BASIC INFORMATION	
Full name of the organization	Cystic Fibrosis Association Mexico
Local name of the organization	Asociación Mexicana de Fibrosis Quística, AC AMFQ
Year of establishment	1982
Scope	National
Contact person	Guadalupe Campoy - Director General
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Address	Yacatas 86 Planta Baja, Col. Narvarte, Del Benito Juárez, CP 03020, México D.F.
Website	http://fq.org.mx/home/index.php?id=1
Twitter	@amfqmx
Facebook	https://www.facebook.com/pages/Asociaci%C3%B3n-Mexicana-de-Fibrosis-Qu%C3%ADstica-AC/136778199710516
PURPOSE	
Legal form	NGO
Governance	Governing Board
Purpose of organization	Establish means for diagnosing cystic fibrosis (CF) in a timely manner and to support patients and their families, informing them about the condition and care.
Leader	Ing. Alvaro Héctor Ojeda Santana
Financing	Private donations
Key objectives	<ul style="list-style-type: none"> ➤ Improve and expand CF diagnostic methods ➤ Give patients access to specialized treatment and disease management/control ➤ Encourage research on CF ➤ Medical education and outreach ➤ Promote the creation of accredited centers of CF diagnosis and treatment. ➤ Promote the creation of the CF National Registry
Therapeutic areas	Cystic Fibrosis
Past projects/activities	In Mexico only 15% of those born with CF are diagnosed. For this reason it is necessary to establish Accredited Diagnostic Centers in Pediatric Hospitals in Mexico, the

	<p>centers must be strategically placed in the country to prevent transport of patients over long distances, accurate diagnosis of the disease, reduce the average age at diagnosis and hence the morbidities associated with the disease, to improve the quality and life expectancy of patients.</p> <p>In order to generate a National Registry of Patients with CF the creation of Specialized Care Centers where patients receive comprehensive interdisciplinary care was urgent. In November and December 2013 we opened the first 9 centers in our country</p>
Upcoming projects/activities	<p>A fundamental part of the AMFQ is training physicians/health professionals on the understanding and management of the disease, diagnostic methods, clinical and current treatment. We seek methods to disseminate and raise awareness about CF among parents, patients, physicians, health professionals and public in the country.</p> <p>National Reference Center. Create a regulatory framework for regional centers to issue regulations for the proper diagnosis and treatment of cystic fibrosis and conduct periodic review of national treatment guidelines, interdisciplinary patient care, pulmonary rehabilitation, basis for generating a lung transplant program.</p>
Specific activities	Raise awareness on CF, publish Handbook of CF for parents, coordinate the periodic review of National Treatment guidelines, conduct national awareness campaigns.
ASSESSMENT	
Visibility	High, TV shows and campaigns
Contact with policy-/decision-makers	Very active - works well with policy makers especially the Ministry of Health and can serve as an example to other groups.
NOTES	
Coalition memberships	Member: Red de Acceso, CEMEFI, AFQ, Mexican Network of Cystic Fibrosis, Latin-American Federation of CF.
Sponsors	Roche and Solvay (Abbott), Novartis
Other	They are interested in receiving training to improve their work with stakeholders