

We are dedicating the 2023 MECFA Annual Report to one of our founding members, Dr. Nisreen Rumman and her many colleagues in the West Bank and Gaza, Palestine.



2023 Annual Report

A MESSAGE FROM OUR FOUNDERS



At MECFA, we believe that everyone born with cystic fibrosis should have access to adequate treatment and essential therapies. This year, especially, our work has been based on connecting with our members to support their efforts on behalf of CF patients. Because of this work, we've met some of the most amazing people, families, CF patients and many dedicated and passionate physicians and allied health professionals. We are grateful to all our sponsors, volunteers and partners who have contributed to our success in 2023. We hope you enjoy this year's Impact Report and continue to follow our progress in 2024.

Christine Noke, CEO/President - Prof. Bulent Karadag, Vice President
Dr. Nisreen Rumman - Prof. Ibrahim Janahi - Prof. Hussein Alkindy - Dr. Muna Kilani

A YEAR WITH UNIQUE CHALLENGES

In 2023 MECFA supported advocacy, education, and diagnostic donations helping hundreds of CF patients across our region. We triumphed over numerous challenges, such as natural disasters, and an ever-expanding network of doctors, patients, and families seeking assistance. By drawing lessons from these challenges and devising inventive resolutions, we will continue to persistently propel CF care and access to essential therapies forward in our region. With growth in mind, we welcomed Dr Muna Kilani to the MECFA Executive Medical and Scientific Committee and Dr Fadi Unsour to our international board of advisors.

In 2024 we will focus on evaluating our diagnostic program, advancing CF team training in multiple member countries, supporting patient organizations, exploring virtual care and assisting CF patients and their families to advocate for access to essential drugs and care.

IMPACT SNAPSHOT

300+

CF medical professionals provided training and support

200+

CF patients gained access to essential drugs and care

3000

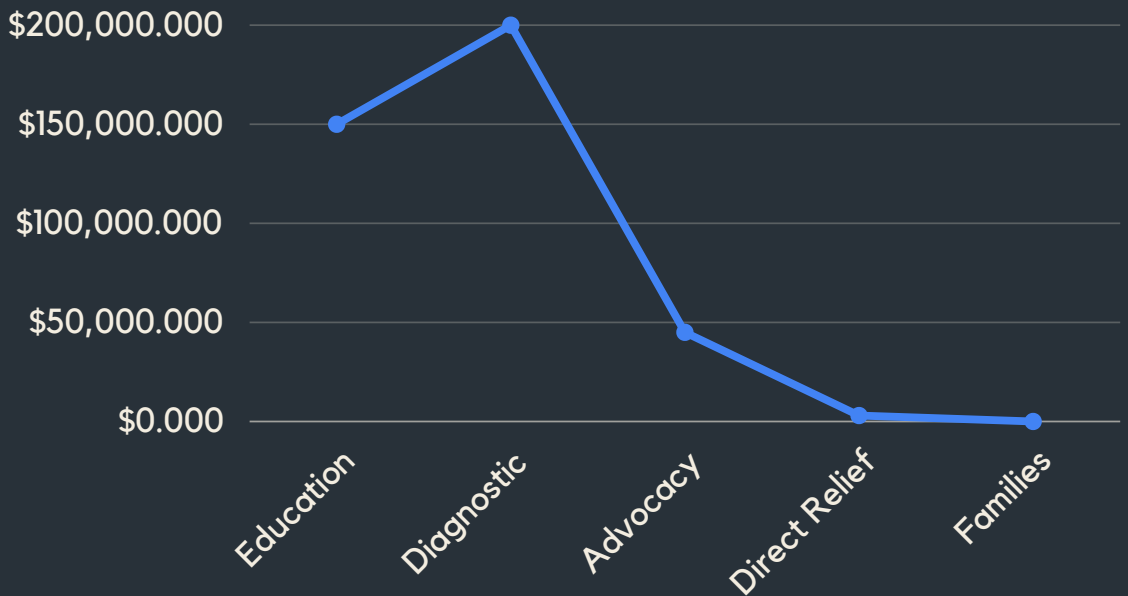
Diagnostic tests and 3 UTSAT diagnostic systems donated



2023 BUDGET

\$ 412,640

In 2023 MECFA focused on three key activities; Education and training for CF teams, Donating diagnostics, and Lobbying for drug and care access. An emergency relief fund was established to aid CF patients in Turkey struck by devastating earthquakes. The Giving Breath Campaign donated 100 nebulizers to people with CF in Jordan and MECFA supported patient organizations in Jordan and Turkey.



PROJECTS

DETAILS

OUTCOME

Advocating

Lobbied the Jordanian MOH for access to essential drugs and the development of 3 CF centers in Jordan.

Patients access to Dornase Alpha, CF vitamins and inhaled tobramycin are now included in the national health budget. The MOH full support for CF Centers at Princess Hamza Hospital, Princess Rahma and King Abdullah University Hospital in Jordan.

Donating Diagnostics

Donated three diagnostic systems and 3000 tests to Tunisia

- State hospitals in the north, central, and south regions of Tunisia have created a diagnostic network in Tunisia.

Giving Breath Campaign

Raised 7K+ through the Giving Breath Campaign—Boston to Jordan.

Donated to the Turkish CF Foundation, KIFDER, to support CF patients effected by the 2023 earthquake

- Created awareness in the international CF community and Jordan.
- 100 Jordanian CF patients have new nebulizers
- A team of CF specialists visited CF patients in the earthquake region of Turkey and provided treatment.



PROJECTS

DETAILS

OUTCOME

Patient and Family support

MECFA hosted a family conference in Amman, Jordan. "Roadmap to Care"

- Over 150 families received targeted education, and joined the CF Family network in Jordan.
- The Minister of Health opened the event by announcing state support for patients care and drug access.

CF Team Training

US CF specialists began quality improvement training with 3 hospitals in Jordan

- A new CF Center was established at the Princess Hamza State Hospital.
- The King Abdullah University Hospital formed a CF team and established a Center.
- Princess Ramallah developed an outpatient CF Center.

CF Bootcamp

MECFA ran our first annual week-long training course at Marmara CF Center

- Clinicians from 7 countries attended the training
- Programs for CF care were started in the 7 participating countries.

CF workshops in Egypt

MECFA sponsored a 3-day parent training course in Ciara.

- Over 70 parents attended.
- Physiotherapy, nutrition, and home care were the focus of the training program.

Advocacy in Egypt

Engaged in lobbying the Egyptian MOH for patients access to essential drugs and care.

- Egypt MOH agreed to allow donations of Vertex modulators to be distributed to patients.
- MOH is considering including CF essential drugs in Eyp.
- MOH requested MECFA start a CF center in a state hospital.

Supporting Turkish Fellow

1 fellow from the Marmara University CF Center was sent to Mott CF Center for training.

- The Turkish Fellow spent 2 months at Mott CF Center in Michigan.
- The Fellow has joined the Marmara CF Team at the largest CF Center in Turkey.

Supporting patient and family local charities

Funded a new website to share information and build a patient and family network in Jordan.

- www.jordancysticfibrosis.com
- Created a database of patients and families who assisted in lobbying for access to drugs.

2023 MECFA Events



Family CF Conference, Amman
Jordan



Marmara CF Course, Istanbul Turkey



Dr Firas Hawari, MOH Jordan

* People with CF will not be allowed entrance to the event due to the health risk of cross contamination.

2023

A ROADMAP TO CARE

CYSTIC FIBROSIS
FAMILY EDUCATION
CONFERENCE

Families that attend will be eligible to receive a voucher for a free Omron C8 nebulizer.



09 JULY
10:00 AM TO
04:00 PM



Speakers from Harvard Boston Children's Hospital multidisciplinary CF Team and CF experts from the University of Utah, Ohio University Nationwide Children's Hospital and the University of Arkansas.

JOIN US AT THE GENEVA HOTEL

Abdallah Ghosheh St., Amman, Jordan
Crystal Ballroom, Floor L1

for family education in the management and care of people with cystic fibrosis. Learn how to access CF care in Jordan, about physiotherapy, CF nutrition, patients cooperation with therapies and the latest developments of CF care in Jordan.

If you have questions please contact our partners in Jordan

Dr Muna Kilani, PHH 0791417450
Prof Faisal Abu-Ekteish, KAUH 0795150611
Dr Eyad Altamimi, KAUH 0797464254

info@mecfa.org



Free bus service from KAUH in Irbid to the Geneva Hotel, Amman. Please arrive on time to ensure your seat availability.

Leaving KAUH 8:00 AM
Leaving Geneva Hotel 5:00 PM



Our fellow host and conference partner
www.jordancysticfibrosis.com



Jordan Cystic Fibrosis Friends Charity
جمعية اصدقاء التليف الكيسي الخيرية الاردنية

We are honored to announce the conference will be opened by H.E Dr. Firas Ibrahim Al-Hawari, Minister of Health of Jordan

MARMARA CF CENTER HOSTS

ISTANBUL, TURKEY

5 DAY CF COURSE

November 20 to 24, 2023

Program participants will undergo basic training in the management of cystic fibrosis and setting up a CF Centre in their own countries. This programme will continue with online meetings between the participants and the Marmara University CF Centre. Participants will be divided into their background experience (physician, dietitian, nurse or physiotherapist) and additional education will be tailored according to this information.

Training will include



Lectures

Covering diagnosis, clinical characteristics of CF, management of CF, airway clearance techniques, nutritional approach, future treatment modalities including modulator therapies and genetics.



In patient/Out patient

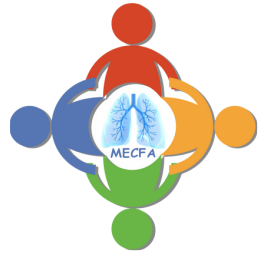
Marmara is the largest CF center in Turkey following 450 pts. 50 CF pts will be seen at the outpatient clinic and 5 hospitalized pts will be followed and the approach to their problems will be discussed.



Practical

Covering bronchoscopy, sweat testing, spirometry and physiotherapy. Discussions on newborn screening, registry and quality improvement studies will be included. At the end of the week, the aim is to create a network among MECFA member countries to improve the standards of CF care in the region.

Sponsored by



CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



Mesitas Medikal Sanayi İc ve Dis Ticaret Anonim Sirketi

Our team at work!



Educating



Advocating



Learning



Sharing



Committing



Evaluating



Growing



Focusing






Giving

We couldn't have done it without your generous *support.*

Thank you

We are grateful to the CF Foundation for their support of our diagnostic and education initiatives, as well as our corporate and public donors and volunteers' countless hours. We are impactful because of you!



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Our Founders



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