MIDDLE EAST CYSTIC FIBROSIS ASSOCIATION

Annual Report 2017

Cystic Fibrosis in the Middle East

Cystic fibrosis is a chronic inherited disorder that causes severe damage to the lungs, digestive system and other organs in the body. It is estimated that 70,000 people live with CF, but sadly we know many go undiagnosed in the Middle East and globally. However, improvements in screening and treatments mean people with cystic fibrosis may now live into their mid- to late 30s, on average, and some are living into their 40s and 50s.

The novel CFTR-targeting therapies have shown to correct CFTR dysfunction and improve pulmonary function in many patients. These treatment options have greatly increased the quality of life for CF patients. While CF requires daily treatment routines, some people with the condition attend school and work full time. Today when children are diagnosed with CF, parents have hope that we are moving ever closer to finding a cure.

The Middle East has made progress in the treatment and diagnosis of CF patients. However, lack of medical awareness and limited experience with the disease helps explain delayed and low diagnosis. Instead of a CF diagnosis, patients are treated for the common symptoms such as recurrent chest infections, asthma-like disease, chronic diarrhea and failure to thrive. Further complicating diagnosis is the numerous genetic mutations that cause CF, and the fact that some patients often experience limited or late-onset of symptoms. Yet, the primary barrier for diagnosis is the lack of diagnostic tools and experienced technicians in regional healthcare facilities.

Newborn cystic fibrosis screening has been adopted by many western countries, with the objective of early diagnosis and early intervention to delay or even prevent organ damage. Research indicates that early intervention prolongs life expectancy and improves quality of life. In addition, this approach has shown long term cost-effectiveness in countries where cystic fibrosis is more common. However, implementing this approach in the Middle East is hindered by a lack of economical cost-effective studies. It should be noted that Cystic fibrosis has huge economic impact on patients, families and healthcare system. Lack of supporting data along with a lack literature about the disease has thus far hindered the Middle East's opportunity to reduce costs while improving the lives of CF patients.

Medications are numerous, expensive and time-consuming. Patients who develop end-organ damage are offered organ (e.g. lung, kidney and/or or liver) transplantation. These procedures are costly, require waiting lists and organ donations. Additionally, while transplantation extends the lives of some recipient, the yield is still suboptimal for others. Hence, efforts have been directed towards screening for the disease, to allow early intervention, to slow organ damage and to increase life expectancy.

In some countries such as Saudi Arabia, there is relatively a high level of care provided but in countries such as Palestine, there is still little to no treatment offered and patients die in early childhood. There are only three known CF patient organizations working to increase awareness and offer aid to patients; CF Lebanon (CFLB.org), CF Turkish patient org, KIFDER (kifder.tr.com) and CF Palestine (CF Palestine.com) but these organizations struggle against many obstacles. MECFA is the only regional medical and scientific organization bringing together disease knowledge, research data and medical professionals from the region.

**Information provided by Dr Yazan Said, Consultant, Allergy/Immunology and Pediatric Pulmonology, King Fahad Specialist Hospital, Dammam..*

MECFA 2017 ANNUAL REPORT

OVERVIEW OF MECFA

The Middle East CF Association is a nonprofit organization with headquarters in Izmir Turkey. MECFA operates with a Board of Trustees who manage the day to day operations working to support the MECFA Medical and Scientific Executive Committee and Working Groups. The MECFA Medical and Scientific Committee is a community of clinical professionals committed to improving the survival and quality of life for people born with cystic fibrosis in the Middle East. MECFA plays an important role in developing a network between CF health professionals, patients, and other groups affiliated with rare disease. Our members engage in high quality medical practice treating cystic fibrosis patients, they guide research, newborn screening and data collection and work towards implementing EU and NA CF standards of care in the Middle East. MECFA offers opportunities that help translate scientific and medical progress into the efficient delivery of effective medical care. MECFA works to develop resources that guide our members in advancing CF care in the region.

MISSION

Working to improve quality of life and life expectancy for people living with CF and those born in the future in the Middle East.

VISION

All patients born with cystic fibrosis living in the Middle East and surrounding countries are diagnosed early and have access to quality care, medication and equipment that extend their life expectancy and improve quality of life.

KEY AREAS OF FOCUS

- ✓ Increasing life expectancy and quality of life for CF patients regionally through improved access to:
    - ○ CF Care Centers
    - ○ Trained interdisciplinary care teams
    - ○ Required drugs and equipment and
    - ○ Advanced therapies.
- ✓ Increasing early diagnosis through Newborn Screening.
- ✓ Developing a CF regional patient registry.
- ✓ Supporting research and clinical trials in the region.
- ✓ Increase awareness about CF and Rare Diseases in the region.

Visit us and learn more
www.mecfa.org (English) www.mecfa-tr.org (Turkish)
Facebook.com/mecfassoc
Twitter.com/mecfa

Middle East Cystic Fibrosis Association
Executive Office
Akdeniz Mah.Cumhuriyet
Bulvarı No:95 K:6/61
Alsancak Konak-İZMİR
TURKEY

Email: info@mecfa.org
A registered medical and scientific nonprofit organization in the Republic of Turkey.

MECFA Medical and Scientific Executive Committee

Prof. Ibrahim Janahi

Qatar

Prof. DR. Bulent Karadag

Turkey

Dr. Nisreen Rumman
Palestine

Dr. Hussain Al-Kindy
Oman

International Medical Advisors

Dr. Harry Heijerman,
Netherlands

Prof. Dr. Kris De Boeck,
Belgium

Prof. Samya Nasr
USA

Prof. Milan Macek
Czech Republic

Letter from the CEO

Dear Friends of MECFA,

It is with great pleasure on behalf of the Board of Trustees and Scientific Committee and staff that I present the 1st MECFA annual report. It has been an honor to serve as CEO of this newly developed organization entirely focused on improving the lives of people who suffer with CF.

The MECFA Medical and Scientific Board members have all worked tirelessly to ensure that our first year of operation has been a great success and I am grateful and honored to work with such prestigious and dedicated clinicians. With the help of our talented staff and partners, MECFA is positioned to be a leader in advancing CF care and improving patient outcomes in the Middle East.

In 2017 we achieved many milestones such as hosting the 1st Middle East CF Conference, held a CME workshop with the Saudi Pediatric Pulmonology Society, developed the MECFA 3 -year strategic plan, launched a website in English and Turkish and started an awareness campaign via social media. MECFA has also launched a program to survey the region that will reveal where MECFA support is needed to increase diagnosis, access to therapies and optimal treatment.

MECFA has organized several working groups to help us carry out the goals in our strategic plan. The MECFA working groups are open to all members and we invite clinicians and allied health professionals to become members of MECFA. Visit www.mecfa.org to learn more.

We have determined key areas of focus such as developing CF Care Centers who are staffed with interdisciplinary teams working within European and North American standards. Early Diagnosis must be a priority if we hope to identify patients in infancy and begin treatment to extend and improve their lives. MECFA and our partners are developing programs that will include training, diagnostics and access to basic medication and equipment. A CF patient registry will be a future focus as well as advancing CF research and clinical trials.

We know the road ahead is challenging but all of us at MECFA believe our potential is limitless.

Sincerely,

Christine Noke, CEO MECFA

MECFA Medical and Scientific Executive Committee planning session.

Istanbul, Turkey September 2016.

Our 2017 programs

EDUCATION

MECFA Education Working Group Chair, Dr. Yazan Said

Dr. Said and the MECFA Education Working Group is focused on bringing quality CF education to the region. We do this by offering an annual conference, CME workshops and tailored workshops aiding CF Center development and interdisciplinary team care.

1st Middle East CF Conference – MECFC 2017

The 1st Middle East Cystic Fibrosis Conference hosted by MECFA and our partners took place in Muscat, Oman, February 2017. The conference offered international CF experts as keynote speakers and covered a wide range of topics in the management of cystic fibrosis. A full 2 and half day Allied Health program was run parallel to the Medical and Scientific program. There were over 250 delegates from the region.

The MECFC 2017 offered a unique opportunity for clinicians in the region to share their knowledge and current treatment advancements with international CF experts. It was the first CF conference in the region to include partners such as the CF Foundation and the European CF Society, both of whom played an important role in the conferences success. Regional partners: Saudi Pediatric Pulmonology Society, Oman Respiratory Society and Arab Pediatric Pulmonology Association, assisted MECFA by developing our network of regional clinicians and allied health professionals. We look forward to continuing to work with our partners on future educational offerings.

List speakers and topics MECFC 2017

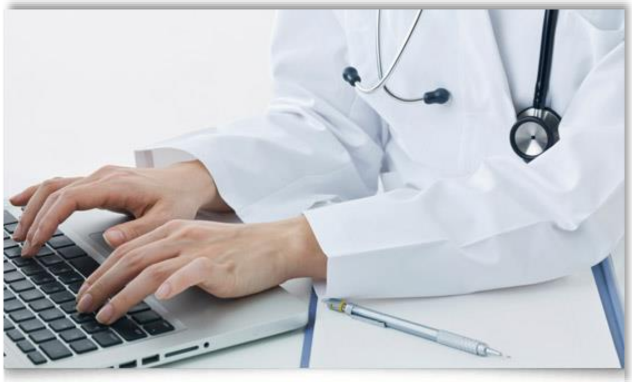
Dr Adel Alharbi, President of MECFA
Prof, DR Kris De Boeck, President of the ECFS
Dr Preston Campbell, CEO CFF
Dr Harry Heijerman, Adult Pulmonologist
Alex Elbert, CFF Registry Director
Dr Nisreen Rumman, Board Member MECFA
Dr Bruce Marshall, Director of Clinical Affairs CFF
Dr Carsten Schwarz, Adult Pulmonologist
Dr. Yazan Said, MECFA Board Member
Dr Hussein Alkindy, MECFA Board Member
And more…………

The Middle East Cystic Fibrosis Association (MECFA) – Facing Challenges together
The European CF Society – Collaborating for Success
The Cystic Fibrosis Foundation (CFF) – Adding Tomorrow and Living Today (video)
CF Center Development and Management – European Standards
CF Center – The Middle East Experience CF Newborn Screening
Sweat Chloride Testing – infant to adult
Genetic Testing in CF and Pitfalls
CF Registries, introduction to PortCF

And more……….

REGIONAL SURVEY – DEVELOPING CF CARE CENTERS

CF Center Development Working Group Chair, Dr. Nisreen, Rumman



The CF Center Development Committee is headed by Dr. Nisreen Rumman, a leading CF pediatric pulmonologist in Palestine. The CFCDW main goal is to support the development of CF Centers staffed with trained clinicians and allied health professionals. As a newly established association, our first step is to organize a questionnaire to be circulated to MECFA member countries to indicate the status of cystic fibrosis care in the region. We will also collect basic data to evaluate the current number of diagnosed patients, to gather information on Newborn Screening in the region, to assess the health status of patients, to understand access and treatment protocols and to identify existing genetic data. This questionnaire will enable us to have a background for a standardized newborn screening program (NBS) in the region. It will provide the basis for a CF Patient Registry and clearly identify what is needed to aid in the development of CF Centers and interdisciplinary CF care teams. It will also provide data that reveals an overall current picture of CF in the region.

MECFA Member Countries participating in the program

Armenia Azerbaijan Bahrain Egypt Iran Iraq Jordan Kuwait Lebanon Pakistan Palestine Qatar Saudi Arabia Syria Turkey UAE and Yemen.

Phase I Activities

1. Develop a questionnaire requesting basic data such as: Neonatal screening status, health care services available to CF patients, level of support from national health services, treatment protocols, number of currently diagnosed patients, genetic data (mutations), age and health status of current patients. (Please note: As new patients are identified the questionnaire will be utilized to continually gather updated data.)

2. Launch a secure section of the MECFA website containing the questionnaire to collect data online. An electronic form will be emailed to the MECFA network of clinicians and health officials that will allow them to submit the completed form to our online secure database in one easy step.

3. Share the online questionnaire with MECFA member countries and clinicians.

4. Continue to involve clinicians and health officials in the region to participate in the program.

5. Apply due diligence to ensure participants complete forms and submit accurate data.

6. Process, organize and analyze data.

NEWBORN SCREENING

MECFA NBS Working Group

Chair Prof. Dr. Bulent Karadag

Prof. Bulent Karadag, Vice President of MECFA and Chair of the MECFA Neonatal Screening program, is a member of the Advisory Board and Steering Committee of the Turkish national NBS program that was implemented in January 2015. Prof. Karadag is also a member of the European Newborn Screening Working Group. He is sharing his experience and using published evidence-based guidelines to implement a standardized NBS program in the Middle East region.

A NBS program in the Middle East will enable standardized CF care in the region while generating reliable data to the MECFA CF Registry and increase the quality of healthcare provided to CF patients.

Specific aims of the MECFA CF Neonatal Screening Committee:

1. To support the implementation of Newborn Screening (NBS) for CF in the Middle East countries,
2. To monitor performance and compare protocols to optimize effectiveness,
3. To encourage enrolment of all infants identified through NBS in clinical trials, and
4. To determine the optimal management of infants with an equivocal diagnosis following newborn screening.

Broader objectives:

1. To work in an open and inclusive manner
2. To encourage membership in the MECFA
3. To encourage participation from neighboring countries,
4. To increase the collaboration with ECFS Neonatal Screening Working Group

Phase I

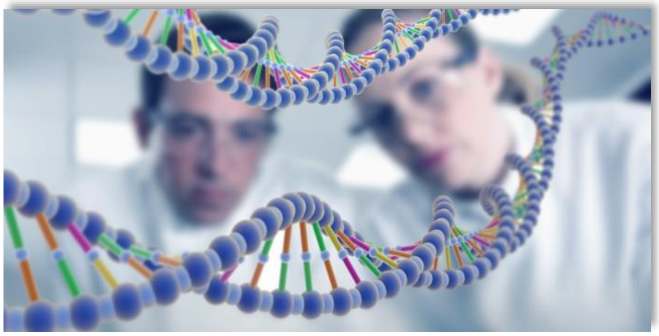
Phase 1 will be implemented through the survey being run by the MECFA CF Center Development Committee and data will be shared with the NBS committee. The CFCD questionnaire will gather data that indicates Neonatal Screening status, includes a request for basic data such as: health care services available to CF patients, level of support from national health services, treatment protocols, number of currently diagnosed patients, genetic data (mutations), age and health status.

NBS Program Future Goals

Adding genetic analysis to the NBS protocols should be the next step. The genetic variances across the countries should be detected and an individual country based approach implemented in that area. In the end, the best possible protocol for each region can be identified and implemented.

RESEARCH AND CLINICIAL TRIALS

MECFA Research and Clinical Trials Committee Chairperson, Prof. Dr. Ibrahim Janahi



Prof. Janahi is a member of the MECFA Executive Board and leads CF research in Qatar and is the Director of the only CF Care Center in Qatar.

The Middle East CF community is growing. Patients are being diagnosed earlier and more frequently. The region offers new mutations and has a substantial number of patients using the newly FDA approved cystic fibrosis (CF) drugs that target the genetic defect that causes CF. This combined with state of the art medical facilities, laboratories and access to government funding, the Middle East will contribute vastly to on-going research that we hope will one-day lead to a cure.

The goal of the MECFA Research and Clinical trial committee is to support research and sponsor researchers in the region. We plan to focus on both young researchers and collaborations with existing research and clinical trial groups to promote mutation identification. At present, a MECFA research grant program is in discussion and we hope to launch the program soon. Moreover, we will host our first CF research poster session at the MECFC 2018 Annual Conference.

The MECFA feels that by bringing attention to the Middle East CF community, we will enable our patients to participate in clinical trials which will further serve the community by improving medical treatments, quality of life and patient life expectancy.

*Independent research in the Middle East**

Qatar: Identification of I1234v mutation in Qatari population- CF large families were investigated- Case studies of deceased patients with CF were reported.

KSA: Geographical distribution of CF patients in Saudi Arabia / Studies targeting mutations in the CFTR gene.

Bahrain: Identification of the incidence rate of CF/identification of present mutations

Jordan: Incidence and prevalence of CF patients in Jordan

Lebanon: Identified the distribution of CFTR mutations/ discovered a new mutation in the Lebanese population

Oman: Novel Mutation in the CFTR Gene of Cystic Fibrosis Patients in Oman

**MECFA is not involved with the independent research listed in the 2017 AR. However, we strive to promote all research in the region and raise awareness. We welcome information about ongoing research and clinical trials. Email us details at info@mecfa.org.*

AWARENESS

MECFA launched a social media campaign to spread awareness about CF and to promote MECFA. With 95% of Middle East internet users active on social media or direct messaging, MECFA is confident we can reach our target audience; especially since this finding is uninfluenced by nationality, gender, or age.

A MECFA social media awareness campaign takes advantage of a region with high social media presence and smartphone usage by incorporating all necessary platforms to connect with clinicians, allied health professionals, public health officials, patients, families and the public at large.

Middle East Cystic Fibrosis Association

Increasing awareness and disseminating knowledge about the treatment of cystic fibrosis in the Middle East

Call for MECFC 2018
CF Research Abstracts now open!

MECFA CLINICIANS CARE

Join the MECFA team, become a member today!

Events:
2nd Middle East CF Conference 2018 - visit our conference pages to learn more about this event.

Become a MECFA Member and receive free

MECFA maintains a presence on Facebook, Twitter, YouTube, LinkedIn and Instagram to share news and information daily with our followers. We have an active blog and newsletter that provides the latest medical news, a forum to discuss the new therapies being developed and researched and a calendar of ongoing events that provide education to CF clinicians and allied health professionals.

MECFA launched www.mecfa.org in January 2017 to disseminate information about Cystic Fibrosis to clinicians, allied health professionals, patients and families. Due to its importance, the website is continually updated to ensure the information we provide is current.

Visit our website to connect to our multiplatform social media campaign.
www.mecfa.org (English) www.mecfa-tr.org (Turkish)

Looking Ahead

MECFA PATIENT REGISTRY

A future goal for MECFA is to develop a CF Patient Registry connecting the region to share data that will lead to improved outcomes for patients while expanding disease research.

A CF patient registry can be a powerful tool to observe the course of disease; to understand variations in treatment and outcomes; to examine factors that influence prognosis and quality of life; to describe care patterns, including appropriateness of care and disparities in the delivery of care; to assess effectiveness; to monitor safety and harm; and to measure quality of care. Through functionalities such as feedback of data, registries are also being used to study quality improvement.

> "Registries are invaluable in the improvement of care, especially for people with chronic diseases" *Dr. Donald Berwick, a professor of health care policy at Harvard and Director of the Institute for Healthcare Improvement, a nonprofit consulting firm.*

Currently, Turkey and Saudi Arabia are the only two countries in the region that have CF patient registries. It will be important to work closely with these countries as we take the first steps in building a MECFA CF Patient Registry. The pertinent information the registry provides will benefit the whole region.

PARTNERS IN PROGRESS

MECFA actively works to build our network with partner organizations, clinicians and allied health professionals.

Qualifications for MECFA Members

To become a member, you must be a clinician, allied health professional, Medical student or Allied Health student working with cystic fibrosis patients in the Middle East Region. There are no fees to join MECFA. Please fill out our membership form and submit it for review by MECFA Board Members.

Become a MECFA partner organization

Organizations who wish to partner with MECFA should contact us at info@mecfa.org. We encourage participation and are open to mutually beneficial collaboration.

Please visit our website to learn more about MECFA membership www.mecfa.org/members

2nd Middle East
Cystic Fibrosis Conference
Izmir, TURKEY

22-24 March 2018 İzmir Ege Palas Hotel

Featuring International Speakers

Preston Campbell, USA
Isabelle Fajac, France
Harry Heijerman, Netherlands
Samya Nasr, USA
Milan Macek, Czech Republic
Barry Plant, Ireland
Adel Alharbi, Saudi Arabia
Nisreen Rumman, Palestine
Bülent Karadağ, Turkey
Basil Elnazir, UAE
Ibrahim Janahi, Qatar
Asma Nuaimi, UAE
Dimitri Declercq, Belgium
Hussein Alkindy, Oman
Esen Demir, Turkey
Imran Nizami, Saudi Arabia
Yazan Said, Jordan
And more...

Gain Latest Insights On

Establishing CF Centers- Standards
Managing Centers & Care Teams
Multi-systemic Nature of CF
Monitoring of CF patients
Genetics of CF in the Middle East
PA infection –management
Clinical experience of CFTR
Organoids, the road to optimal care
End stage Lung Disease,
Lung Transplantation
Fertility and Pregnancy Issues
Lean CF care (cost effective)
Progressive CF disease in adults
Nutrition in CF: different age groups
Social challenges of CF in Palestine
Research and Clinical Trials
CF Grand Round - Challenging cases
And more...

Target Audience

Pediatric Pulmonologists
Adult Pulmonologists
Gastroenterologists
Pharmacists
Nutritionists
Physiotherapists
Nurses

Allied Health Workshops

Nurses knowledge and clinical skills
Physiotherapy anno 2018
How to eat well in CF
Airway Clearance Techniques
Inhalation Therapy
Infection prevention and control
Musculoskeletal assessment,
posture and exercise
Improving adherence

CF Research Abstract submission deadline February 15, 2018
www.mecfa.org info@mecfa.org

2nd Middle East CF Conference – MECFC 2018

"Developing CF Care in the Middle East"

March 22nd – 24th 2018

Izmir - Turkey

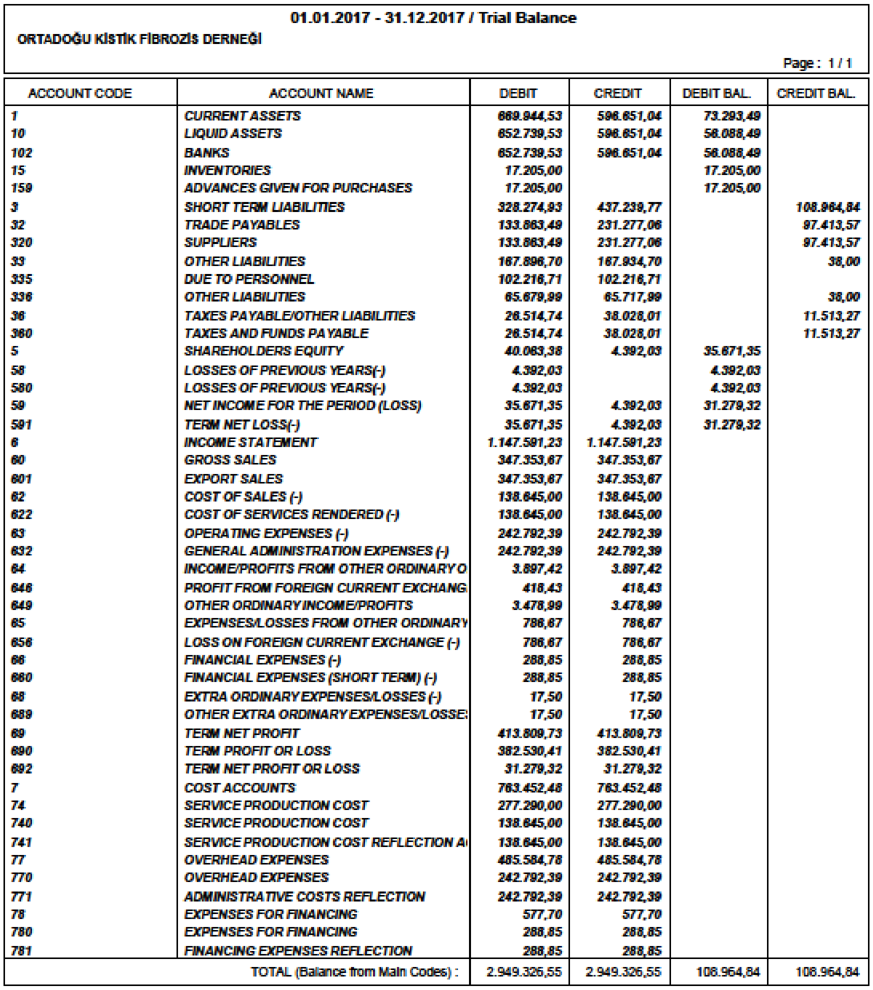
MECFA is looking forward to hosting the MECFC 2018 in the beautiful city of Izmir, home to MECFA's headquarters. Our program is tailored to the needs of the region with a focus on ***Developing CF Care in the Middle East***. We are honored to welcome the President and CEO of the US based CF Foundation, Dr. Preston Campbell and incoming President of the European CF Society, Prof. Isabell Fajac as keynote speakers. Included on our list of speakers is the internationally known Geneticist, Prof. Milan Macek, Dr. Harry Heijerman, Dr. Barry Plant and more. We will also welcome back our Allied Health team from Belgium.

In addition to our Medical and Scientific Program, we will host a half day workshop on nutrition and physiotherapy for parents. Once again, we will partner with KIFDER, the Turkish patient organization, to help parents in the region better understand the disease, its symptoms, and treatment options. We expect over 300 delegates and exhibitors from leading CF pharmaceutical and equipment companies.

List of speakers and topics

Adel S. Alharbi, Saudi Arabia
Samya Nasr, USA
Prof Elif Dagli, Turkey
Preston Campbell, USA
Isabelle, Fajac, France
Harry Heijerman, Netherlands
Milan Macek, Czech Republic
Ibrahim Janahi, Qatar
And more……

Establishing CF Centers- Standards
Managing Centers & Care Teams
Multi-systemic Nature of CF
Monitoring of CF patients
Genetics of CF in the Middle East
PA infection –management
Clinical experience of CFTR
Organoids, the road to optimal care
End stage Lung Disease,
And more…….

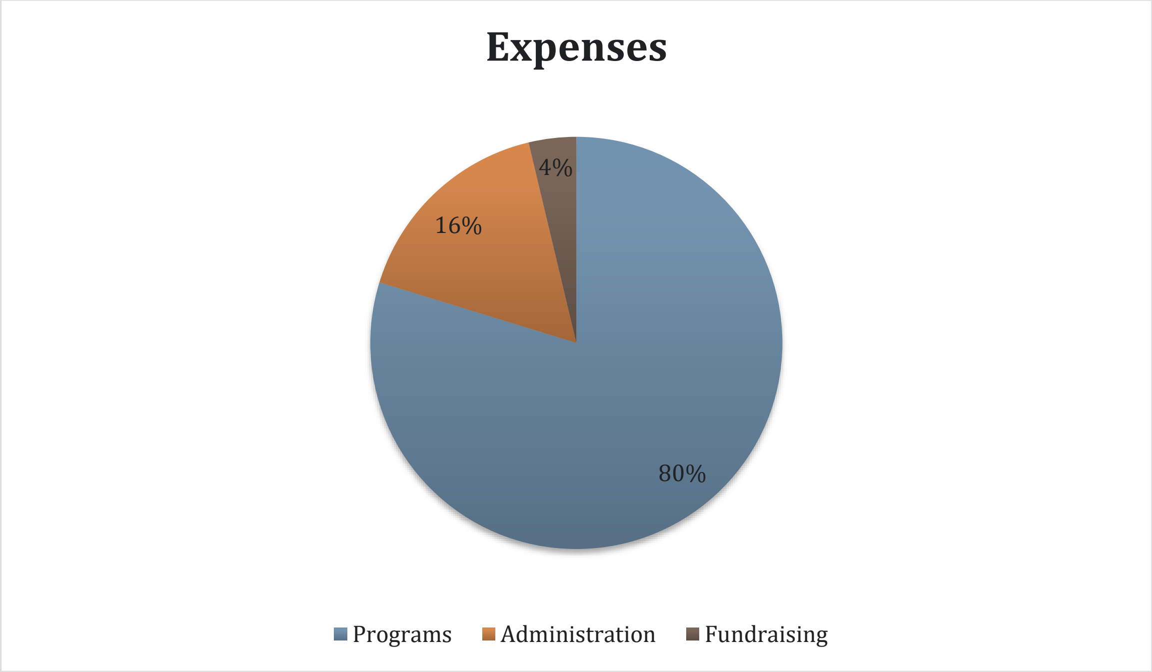


01.01.2017 - 31.12.2017 / Trial Balance

ORTADOĞU KİSTİK FİBROZİS DERNEĞİ

Page : 1 / 1

ACCOUNT CODE	ACCOUNT NAME	DEBIT	CREDIT	DEBIT BAL.	CREDIT BAL.
1	CURRENT ASSETS	669.944,53	596.651,04	73.293,49	
10	LIQUID ASSETS	652.739,53	596.651,04	56.088,49	
102	BANKS	652.739,53	596.651,04	56.088,49	
15	INVENTORIES	17.205,00		17.205,00	
159	ADVANCES GIVEN FOR PURCHASES	17.205,00		17.205,00	
3	SHORT TERM LIABILITIES	328.274,93	437.239,77		108.964,84
32	TRADE PAYABLES	133.863,49	231.277,06		97.413,57
320	SUPPLIERS	133.863,49	231.277,06		97.413,57
33	OTHER LIABILITIES	167.896,70	167.934,70		38,00
335	DUE TO PERSONNEL	102.216,71	102.216,71		
336	OTHER LIABILITIES	65.679,99	65.717,99		38,00
36	TAXES PAYABLE/OTHER LIABILITIES	26.514,74	38.028,01		11.513,27
360	TAXES AND FUNDS PAYABLE	26.514,74	38.028,01		11.513,27
5	SHAREHOLDERS EQUITY	40.063,38	4.392,03	35.671,35	
58	LOSSES OF PREVIOUS YEARS(-)	4.392,03		4.392,03	
580	LOSSES OF PREVIOUS YEARS(-)	4.392,03		4.392,03	
59	NET INCOME FOR THE PERIOD (LOSS)	35.671,35	4.392,03	31.279,32	
591	TERM NET LOSS(-)	35.671,35	4.392,03	31.279,32	
6	INCOME STATEMENT	1.147.591,23	1.147.591,23		
60	GROSS SALES	347.353,67	347.353,67		
601	EXPORT SALES	347.353,67	347.353,67		
62	COST OF SALES (-)	138.645,00	138.645,00		
622	COST OF SERVICES RENDERED (-)	138.645,00	138.645,00		
63	OPERATING EXPENSES (-)	242.792,39	242.792,39		
632	GENERAL ADMINISTRATION EXPENSES (-)	242.792,39	242.792,39		
64	INCOME/PROFITS FROM OTHER ORDINARY O	3.897,42	3.897,42		
646	PROFIT FROM FOREIGN CURRENT EXCHANG	418,43	418,43		
649	OTHER ORDINARY INCOME/PROFITS	3.478,99	3.478,99		
65	EXPENSES/LOSSES FROM OTHER ORDINARY	786,67	786,67		
656	LOSS ON FOREIGN CURRENT EXCHANGE (-)	786,67	786,67		
66	FINANCIAL EXPENSES (-)	288,85	288,85		
660	FINANCIAL EXPENSES (SHORT TERM) (-)	288,85	288,85		
68	EXTRA ORDINARY EXPENSES/LOSSES (-)	17,50	17,50		
689	OTHER EXTRA ORDINARY EXPENSES/LOSSE	17,50	17,50		
69	TERM NET PROFIT	413.809,73	413.809,73		
690	TERM PROFIT OR LOSS	382.530,41	382.530,41		
692	TERM NET PROFIT OR LOSS	31.279,32	31.279,32		
7	COST ACCOUNTS	763.452,48	763.452,48		
74	SERVICE PRODUCTION COST	277.290,00	277.290,00		
740	SERVICE PRODUCTION COST	138.645,00	138.645,00		
741	SERVICE PRODUCTION COST REFLECTION A	138.645,00	138.645,00		
77	OVERHEAD EXPENSES	485.584,78	485.584,78		
770	OVERHEAD EXPENSES	242.792,39	242.792,39		
771	ADMINISTRATIVE COSTS REFLECTION	242.792,39	242.792,39		
78	EXPENSES FOR FINANCING	577,70	577,70		
780	EXPENSES FOR FINANCING	288,85	288,85		
781	FINANCING EXPENSES REFLECTION	288,85	288,85		
	TOTAL (Balance from Main Codes) :	2.949.326,55	2.949.326,55	108.964,84	108.964,84



Our partners for progress

CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

ecfs
European Cystic Fibrosis Society

الرابطة العمانية للجهاز التنفسي
OMAN RESPIRATORY SOCIETY

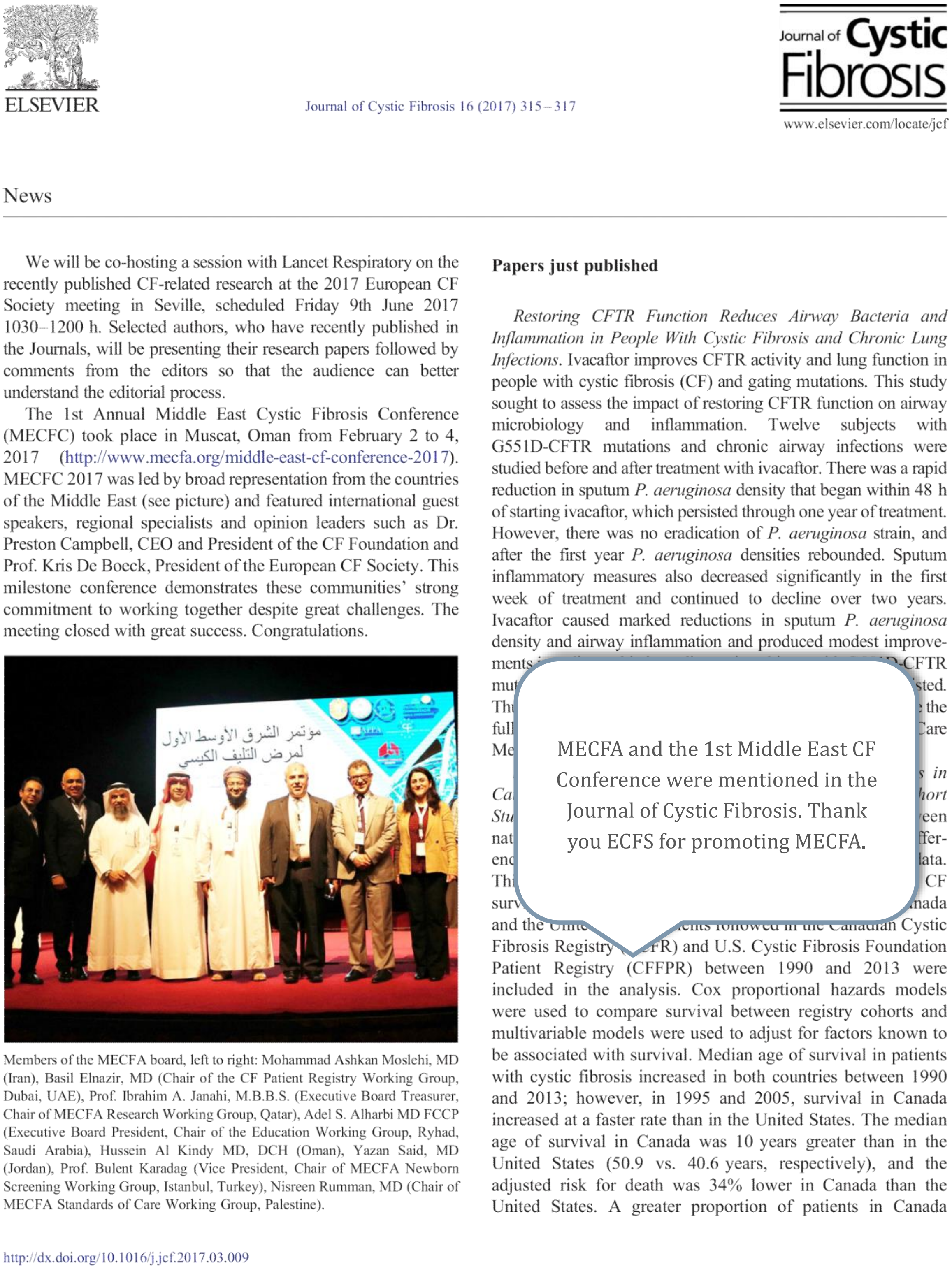
Saudi Pediatric Pulmonology Association
SPPA
الجمعية السعودية لطب الصدر لدى الأطفال

Arab Pediatric Pulmonology Association
APPA
الجمعية العربية لأمراض الصدر للأطفال

جامعة السلطان قابوس

Members of the MECFA Committee members with European CF Society President, Prof. Dr. Kris De Boeck and members of the Oman Respiratory Society at the

1st Middle East CF Conference
Muscat Oman, February 2017



ELSEVIER

Journal of Cystic Fibrosis 16 (2017) 315–317

Journal of Cystic Fibrosis

www.elsevier.com/locate/jcf

News

We will be co-hosting a session with Lancet Respiratory on the recently published CF-related research at the 2017 European CF Society meeting in Seville, scheduled Friday 9th June 2017 1030–1200 h. Selected authors, who have recently published in the Journals, will be presenting their research papers followed by comments from the editors so that the audience can better understand the editorial process.

The 1st Annual Middle East Cystic Fibrosis Conference (MECFC) took place in Muscat, Oman from February 2 to 4, 2017 (http://www.mecfa.org/middle-east-cf-conference-2017). MECFC 2017 was led by broad representation from the countries of the Middle East (see picture) and featured international guest speakers, regional specialists and opinion leaders such as Dr. Preston Campbell, CEO and President of the CF Foundation and Prof. Kris De Boeck, President of the European CF Society. This milestone conference demonstrates these communities' strong commitment to working together despite great challenges. The meeting closed with great success. Congratulations.

Members of the MECFA board, left to right: Mohammad Ashkan Moslehi, MD (Iran), Basil Elnazir, MD (Chair of the CF Patient Registry Working Group, Dubai, UAE), Prof. Ibrahim A. Janahi, M.B.B.S. (Executive Board Treasurer, Chair of MECFA Research Working Group, Qatar), Adel S. Alharbi MD FCCP (Executive Board President, Chair of the Education Working Group, Ryhad, Saudi Arabia), Hussein Al Kindy MD, DCH (Oman), Yazan Said, MD (Jordan), Prof. Bulent Karadag (Vice President, Chair of MECFA Newborn Screening Working Group, Istanbul, Turkey), Nisreen Rumman, MD (Chair of MECFA Standards of Care Working Group, Palestine).

http://dx.doi.org/10.1016/j.jcf.2017.03.009

Papers just published

Restoring CFTR Function Reduces Airway Bacteria and Inflammation in People With Cystic Fibrosis and Chronic Lung Infections. Ivacaftor improves CFTR activity and lung function in people with cystic fibrosis (CF) and gating mutations. This study sought to assess the impact of restoring CFTR function on airway microbiology and inflammation. Twelve subjects with G551D-CFTR mutations and chronic airway infections were studied before and after treatment with ivacaftor. There was a rapid reduction in sputum *P. aeruginosa* density that began within 48 h of starting ivacaftor, which persisted through one year of treatment. However, there was no eradication of *P. aeruginosa* strain, and after the first year *P. aeruginosa* densities rebounded. Sputum inflammatory measures also decreased significantly in the first week of treatment and continued to decline over two years. Ivacaftor caused marked reductions in sputum *P. aeruginosa* density and airway inflammation and produced modest improvements [illegible] CFTR mut[illegible]sted. Thu[illegible] the full[illegible] Care Me[illegible]

[illegible] *in Ca*[illegible]*hort Stu*[illegible]een nat[illegible]ffer-enc[illegible]lata. Thi[illegible] CF surv[illegible]nada and the [illegible] Canadian Cystic Fibrosis Registry [illegible]FR) and U.S. Cystic Fibrosis Foundation Patient Registry (CFFPR) between 1990 and 2013 were included in the analysis. Cox proportional hazards models were used to compare survival between registry cohorts and multivariable models were used to adjust for factors known to be associated with survival. Median age of survival in patients with cystic fibrosis increased in both countries between 1990 and 2013; however, in 1995 and 2005, survival in Canada increased at a faster rate than in the United States. The median age of survival in Canada was 10 years greater than in the United States (50.9 vs. 40.6 years, respectively), and the adjusted risk for death was 34% lower in Canada than the United States. A greater proportion of patients in Canada

MECFA and the 1st Middle East CF Conference were mentioned in the Journal of Cystic Fibrosis. Thank you ECFS for promoting MECFA.

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We are grateful to our partners and sponsors for their continued support. At MECFA we understand the importance of collaborating with industry leaders to achieve our goals and we strive to develop relationships that are mutually beneficial. * If you or your company have interest in collaborating with MECFA, contact us at info@mecf.org.

Is your company interested in running an event to sponsor MECFA?
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*See the MECFA Sponsor and Corporate Partner Policy on page 14.

Board of Trustees

For a list of the MECFA Board of Trustees please email Mr. Nihat Bac at info@mecfa.org.

MECFA Sponsor and Corporate Partnership Policy

The Medical and Scientific Executive Committee and Board of Trustees has adopted a policy to govern interaction between MECFA sponsors, corporate partners and the clinicians who serve on the MECFA Executive Committee and Working Groups. For-profit entities that develop, produce, market or distribute drugs, devices, services or therapies used to diagnose, treat, monitor, manage, and alleviate Cystic Fibrosis, referred to in this Policy as "Companies," also strive to help patients live longer and healthier lives. Companies invest resources to bring new drugs, devices and therapies out of the laboratory and to the patient while maximizing value for shareholders.

We adopt this Code to reinforce the core principles that help us maintain actual and perceived independence. Adopting this Policy helps to ensure that MECFA's interactions with Companies and Sponsors will be for the benefit of patients and members and for the improvement of care in our respective specialty field of Cystic Fibrosis.

Signing on to this Policy is voluntary for members but a condition for the MECFA Board of Medical Directors.

Clinicians and Board Members that sign on to the Policy will be identified on the MECFA website. www.mecfa.org

Board Members that sign on to the Policy should adopt policies and procedures to guide MECFA and Companies interactions in accordance with the Policy. Board Members will interpret and implement the Policy in the context of MECFA organizational structure and their policies and procedures.

Clinicians that sign on to the Policy are encouraged to comply with as many Principles as possible at the time they sign on, and should set a reasonable timeframe for adopting the policies and procedures required to comply with any remaining Principles. At their individual discretion,

Board Members may choose to adopt policies that are more rigorous than the Policy. Board Members should regularly evaluate their success in adhering to the Code. Board members will be encouraged to affirm annually to MECFA that they continue to adhere to the Code.

A full version of this policy and MECFA policies are available at www.mecfa.org/policy

Get in touch with us

Christine Noke Chief Executive Officer	Sebnem Tuna Executive Assistant	MECFA Medical and Scientific Committee
		
cnoke@mecfa.org	**sebnem@mecfa.org**	**info@mecfa.org**

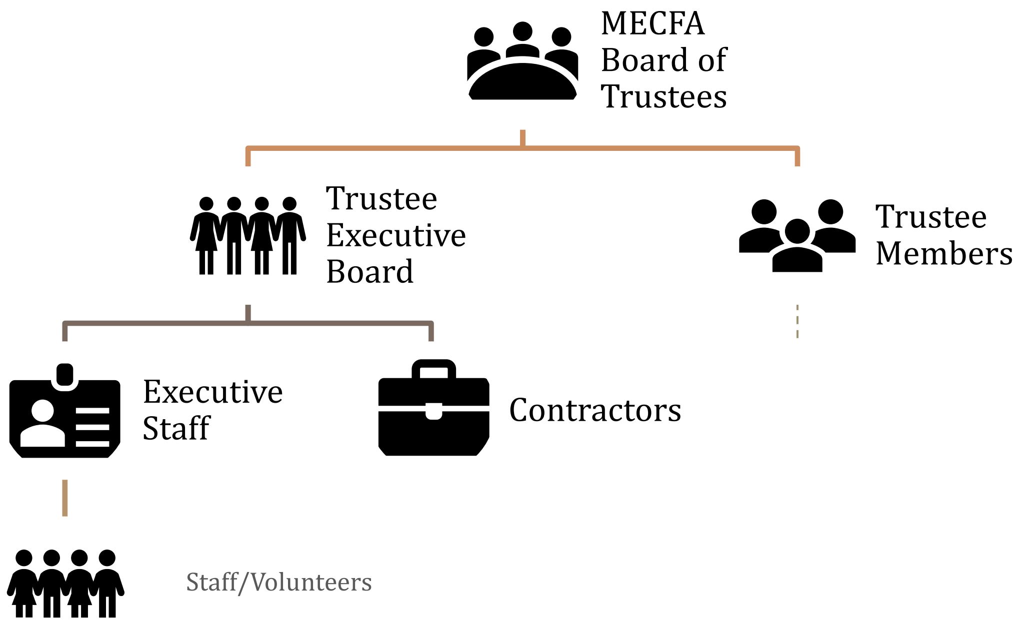
MECFA Organization Structure

MECFA Board of Trustees and Executive Management (Turkish citizens only)

The board of trustees is responsible for;

1. Legal compliance of MECFA- this includes filing annual reports, monitoring committee activity, policies, procedures and bylaws
2. Staff/contractors – contracts and salaries
3. Finances – annual audit (On or before April 15), quarterly reviews, bookkeeping
4. Reporting activities to the Medical and Scientific Committee
5. Holding an annual assembly
6. Reporting to sponsors and partners – financial transparency, operating procedures. The CF Foundation has agreed to work closely with the Trustee Executives and Executive Staff to ensure transparency and due diligence.

Board of trustees has an executive board with 5 volunteer members and 15 voting members.



Executive Management – Staff

MECFA staff is managed by the Board of Trustees. Salaries, contracts are determined by the Board of Trustees and stakeholders who fund operations. Staff works to support the Medical and Scientific committee and the Board of Trustees.

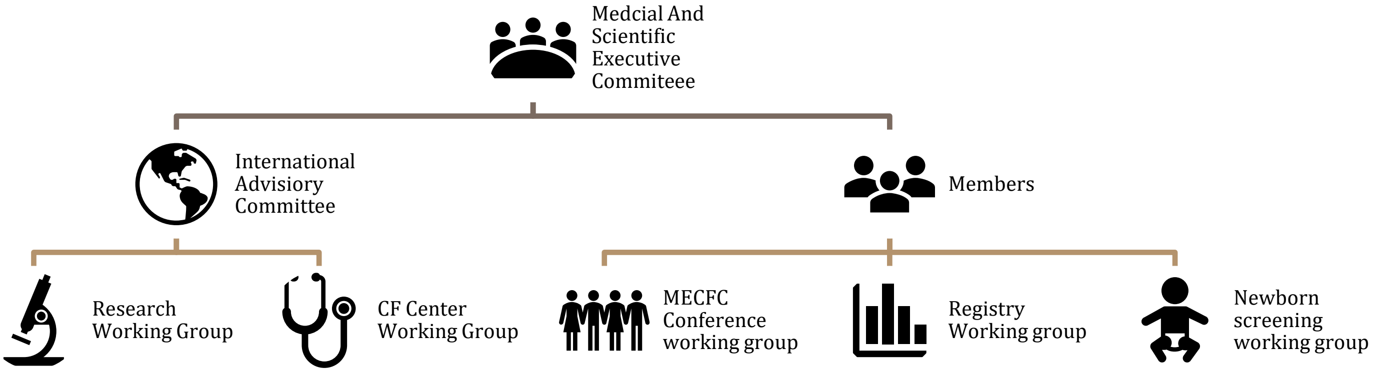
Christine Noke – CEO (Consultant)

Sebnem Tuna – Executive Assistant (Employee)

Medical and Scientific Executive Committee

The Committee is responsible for;

1. Programs
2. Publications
3. Reporting to stakeholders
4. Promoting and networking
5. Fundraising
6. Financials/ – Decides how funds will be dispersed for programs
7. Working Groups
8. International Advisory Committee
9. Members



Medical and Scientific Members

Name-First	*Name-Last*	*Credentials*	*-Country*
Lobat	Shahkar	MD	Iran
Ghamartaj	Khanbabaee	MD	Iran
Seyed Javad	Sayedj	MD	Turkey
PINAR	ATA	MD	Turkey
Turhan	Kahraman	PhD	Turkey
serdar	al	MD	Turkey
Kilian	Petry	Allied Health Professional	Turkey
Seda	Sirin kose	MD	Turkey
Nermin	Gürcan	Allied Health Professional	Turkey
Kayan	Atabeh	MD	Palestina
nevin	uzuner	MD	Turkey
Nihat	Sapan	MD	Turkey
Şule	Taş Gülen	MD	Turkey
Arif	Kut	MD	Turkey
H. Uğur	Özçelik	MD	Turkey
SANEM	ERYILMAZ	MD	Turkey
Derya Ufuk	Altıntaş	MD	Turkey
sevgi	pekcan	MD	Turkey
Yeliz	Bursalı	Allied Health Professional	Turkey
gülfinaz	bahtiyar	Allied Health Professional	Turkey
Nagehan	Emiralioglu	MD	Turkey
Esra	Işık	MD	Turkey
Esma	Balcı	Allied Health Professional	Turkey
Ferda	Ozkinay	MD	Turkey
Ertan	Timuçin	Allied Health Professional	Turkey
SELİME	ÖZEN	MD	Turkey
nazanin	Farahbakhsh	MD	Iran
GÖKCEN	SIMSEK	Allied Health Professional	Turkey
ECE	OZDOGRU	Allied Health Professional	Turkey
Sirmen	KIZILCAN CETIN	MD	Turkey
handan	duman şenol	MD	Turkey
Pelin	Elibol	MD	Turkey
Nazlı Zeynep	Uslu	MD	Turkey
DEMET	CAN	MD	Turkey
Tuba	Tuncel	MD	Turkey
rafat	allawi	MD	Palestina
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Zeynep Seda	Uyan	PhD	Turkey
Figen	Gülen	MD	Turkey

hakan	yazan	MD	Turkey
Esin	Akçael	PhD	Turkey
gökay	çelik	Allied Health Professional	Turkey
sinem	özen	Allied Health Professional	Turkey
ERKAN	ÇAKIR	MD	Turkey
Aylin	Özgen Alpaydın	MD	Turkey
ALİ	ÖZDEMİR	MD	Turkey
Refika	Ersu	MD	Turkey
Nilay	Bas Ikizoglu	MD	Turkey
seda	sirin kose	MD	Turkey
Gökçen	Kartal Öztürk	MD	Turkey
Buse	Özcan Kahraman	Allied Health Professional	Turkey
Aylin	Tanrıverdi	Allied Health Professional	Turkey
Sema	Savcı	PhD	Turkey
Ismail	Ozsoy	Allied Health Professional	Turkey
Gamze	Alcı	PhD	Turkey
Kübra	Özgüler	PhD	Turkey
Gizen	Atakul	MD	Turkey
Sanem	Eren Akarcan	MD	Turkey
Pervin	Korkmaz Ekren	PhD	Turkey
Seda sevilay	Koldaş	Allied Health Professional	Turkey
Gamze	Alci	PhD	Turkey
Burak	Aksu	MD	Turkey
mehmet mucahit	guncu	PhD	Turkey
Derya	Kocakaya	MD	Turkey
Beyza	Asker	MD	Turkey
Ebru	Fidan	MD	Turkey
Şehnaz	OLGUN YILDIZELİ	MD	Turkey
seda sevilay	koldaş	Allied Health Professional	Turkey
Aysegul	Karahasan	MD	Turkey
AMAL	NASSAR	Allied Health Professional	Palestina
Shajan	Mokyel	Allied Health Professional	Saudi Arabia
Mustafa	Divyapıcıgil	MD	Turkey
soheila	Khalilzadeh	MD	Iran
Aykut	Eşki	MD	Turkey
Sanem	Eryılmaz Eşref	MD	Turkey
Laila	Qarawi	MD	Palestina
Ibrahim	Shamasneh	MD	Israel
Daoud	Abushama	MD	Israel
Mai	Alsadi	MD	Palestina
Muna	Dahabreh	MD	Jordan

M. ZUHDI	ALIMAM	MD	Saudi Arabia
Bülent	Karadağ	MD	Turkey
Serife Seyda	Pirincci	PhD	Turkey
Ela	Erdem Eralp	MD	Turkey
FATIMA	YUCEL	PhD	Turkey
Bengu	ERGENOGLU	MD	Turkey
Pelin	ÇIRTLIK	MD	Turkey
Esen	Demir	MD	Turkey
Yasemin	Gokdemir	MD	Turkey
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Muna	albimani	Allied Health Professional	Oman
BAO PING	XU	MD	China
Hao	Wang	MD	China
ashraf	alshanti	Allied Health Professional	Palestina
RADHIYA	AL OMAIRI	Allied Health Professional	Oman
Majid	Al Salmani	PhD	United Kingdom
Sylvana	Zoghbi	MD	Lebanon
Nasser	Alhajri	Allied Health Professional	Oman
غازي	محمد اللطيف	MD	Oman
Dr Ganji	Shivalingam	MD	Oman
Amjad	Tuffaha	MD	Qatar
Inaq	Jass	MD	Israel
Majid	Al Jabri	MD	Oman
Sara	Loubani	MD	Canada
AAMIR	ALSHAHRABALLY	PhD	Oman
محمد	مزيد	MD	Saudi Arabia
Jaber Sadiq	Al Lawati	MD	Oman
Soheila	Khalilzadeh	MD	Iran
Asmahan	Al Barram	Allied Health Professional	Oman
SHEETAL	SHAH	Allied Health Professional	Oman
samya	salah	Allied Health Professional	Palestina
Marium	Mohammed	MD	Oman
Soheila	Khalilzadeh	MD	Iran
Amjad	Tuffaha	MD	Qatar
Wessam	Gad El HAk	MD	Qatar
Hussam	Inany	MD	United States
DR. Amjad	alshanti	PhD	Palestina
ashraf	alshanti	Allied Health Professional	Palestina

Pervin	Korkmaz Ekren	Doktora	Turkey
Sanem	Eren Akarcan	Medikal Doktor	Turkey
gizem	atakul	Medikal Doktor	Turkey
Kübra	Özgüler	Doktora	Turkey
Gamze	Alci	Doktora	Turkey
İsmail	ÖZSOY	Yardımcı Sağlık Profesyoneli	Turkey
Sema	SAVCI	Doktora	Turkey
Aylin	TANRIVERDİ	Yardımcı Sağlık Profesyoneli	Turkey
Buse	Özcan Kahraman	Yardımcı Sağlık Profesyoneli	Turkey
Gökçen	Kartal Öztürk	Medikal Doktor	Turkey

MECFA 2017 ANNUAL REPORT

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A registered medical and scientific nonprofit organization in the Republic of Turkey.