

3rd Middle East



Cystic Fibrosis Conference



"Working towards optimal CF care in the Middle East"

21-23 March, 2019

Marriott Hotel Sisli, Istanbul / Turkey

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MINI PROGRAM

3rd Middle East

"Working towards optimal CF care in the Middle East"

Cystic Fibrosis

Conference

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AL QAMRA HOLDING

Cystic Fibrosis Conference

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Wednesday, March 20, 2019

13:00 - 14:30 Pre-Conference Workshop 1

Chairs: Nilay Bař, Ela Erdem



Room B

Sweat chloride testing

Nico Derichs, ECFS Diagnostic Network WG Coordinator, DEU

14:30 - 16:00 Pre-Conference Workshop 2

Physiotherapy Workshop

Chairs: Zeynep Seda Uyan, Mehmet Kse

Room B

Christopher Tapley, USA

Sharyn Dagher, USA

zge Keniř, TUR

16:00 - 16:30 Coffee Break

16:30 - 18:00 Nutrition Workshop

Chairs: Engin Tutar, Gzin Cinel

Room B

Sandra Bouma, USA

12:00 - 18:00 MECFA Annual Business Meeting

MECFC 2020 Organizing Committee Meeting

Room C

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Thursday, March 21, 2019

08:00 - 17:00 Registration

Lobby

08:45 - 10:05 Session I: CF: An International Approach

Room A

Chairs: Esen Demir, Elif Dağlı

08:45 - 09:00 Conference opening and welcome

Bülent Karadağ, TUR

09:00 - 09:15 MECFA – Road to the future

Christine Noke, MECFA CEO, USA

09:15 - 09:40 The Cystic Fibrosis Foundation (CFF) – Adding tomorrow and living today

Preston Campbell, USA and Bruce Marshall, USA (video)

09:40 - 10:05 European Standards of Care

How did we make and maintain them?

Carlo Castellani, ITA

10:05 - 10:40 Coffee Break

10:40 - 12:00 Session II: Where and How to Start- Standards of Care

Room A

Chairs: Nural Kiper, Derya Altıntaş

10:40 - 11:00 Survey of CF care in Middle East – Results

Hussein Al Kindi, OMN

11:00 - 11:30 Developing CF Centers in the region – The MaMi project

Samya Nasr, USA

11:30 - 12:00 Combating cross contamination in clinical care-the

rules of hygiene

Bülent Karadağ, TUR

12:00 - 13:30 Lunch Break

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Thursday, March 21, 2019

13:30 - 14:00 Recent Advances in CF

Room A

Chairs: Demet Can, Deniz Dođru

CRMS/CFSPID

Carlo Castellani, ITA

14:00 - 14:30 Update on ongoing studies in CF

Samya Nasr, USA

14:30 - 15:10 Lobbying for CF care in the Middle East

Ibrahim Al Janahi, QAT

İlknur Özgür Görgün- President of KIFDER, TUR

15:10 - 15:25 CF and Asthma: How to treat?

Bülent Karadağ, TUR

15:25 - 15:45 **Coffee Break**

15:45 - 17:35 Session III: Genetics and Lobbying for CF

Room A

Chairs: Uğur Özçelik, Ayşe Tana Aslan

15:45 - 16:35 CF genetics in the Middle East

In Oman, Hussein Al Kindi, OMN

In Qatar, Atqah Adulwahab, QAT

In Turkey, Pınar Ata, TUR

16:35 - 17:05 Optimizing CF diagnosis by personalized characterization

of inconclusive CFTR genotypes

Nico Derichs, DEU

17:05 - 17:35 Genetics of CF – current status

Milan Macek, CZE

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Friday, March 22, 2019

09:00 - 10:30 Session IV: Emerging topics in CF

Room A

Chairs: Haluk Çokuğraş, Fazilet Karakoç

09:00 - 09:30 Therapeutic drug monitoring and pharmacokinetics in CF
Daniel Touw, NLD

09:30 - 10:00 The important role of patient organizations: CF Europe
Jacquelin Noordhoek, NLD

10:00 - 10:30 Update on new drugs for CF and the Rainbow project
Hendrikus Heijerman, NLD

10:30 - 11:00 **Coffee Break**

11:00 - 12:10 Oral Presentation Session 1

Room A

"Clinical Characteristics of CF in the Middle East"

Chairs: Arif Kut, Nagehan Emiralioglu

11:00 - 11:10 **OP-01** Caregiver burden of the children with cystic fibrosis
Özge Keniş Coşkun, Kardelen Gençer Atalay, Evrim Karadağ Saygi, Ela Erdem, Yasemin Gökdemir, Bülent Karadağ

11:10 - 11:20 **OP-02** Forced Expiratory Volume in the first second (FEV1) decline in siblings with cystic fibrosis
Mehdi Alizadeh, Hoseinali Ghaffaripour, Marayam Hasanzad, Noushin Baghaee, Habib Emami, Korush Fakhimi Derakhshan

11:20 - 11:30 **OP-03** Prospective evaluation of vascular changes in acute respiratory infections in patients with cystic fibrosis
Gökçen Kartal Öztürk, Aykut Eşki, Figen Çelebi Çelik, Seçil Conkar, Ahmet Keskinoglu, Figen Gulen, Esen Demir

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- 11:30 - 11:40 **OP-04** Infection control knowledge and practices among cystic fibrosis patients and their families
Can Akın, Ayça Çakan, Eren Sarioğlu, Batuhan Başçı, Gamze Alçı, Ayşegül Karahasan
- 11:40 - 11:50 **OP-05** Non-tuberculous mycobacterial infections in children with cystic fibrosis- a cystic fibrosis center experience in Turkey
Cansu Yılmaz Yeğit, Almala Pınar Ergenekon, Emine Atağ, Nilay Baş İkizoğlu, Yasemin Gökdemir, Ela Erdem Eralp, Berrin Ceyhan, Kaya Köksalan, Bülent Taner Karadağ
- 11:50 - 12:00 **OP-06** Cystic fibrosis and sinonasal problems
Erdal Sakallı, Ayşe Ayzit Kılınç, Haluk Çokuğraş
- 12:00 - 12:10 **OP-12** Our experience in cystic fibrosis newborn screening programme
Tugba Ramasli GURSOY, Zeynep Reyhan Onay, Tugba Sismanlar Eyuboglu, Ayse Tana Aslan, Busra Sultan Kibar, Sevgi Pekcan, Melih Hangul, Mehmet Kose, Isil Irem Budakoglu

12:10 - 13:10 Thematic Poster Session
"Microbiology and Immunology in CF"
Chairs: Saniye Girit, Nazan Çobanoğlu

Poster Area

- PP-01** Evaluation of microorganisms and their resistance in the respiratory tract specimens of patients with cystic fibrosis and the correlation of antibiotic resistance with clinical findings and pulmonary function tests
Mukaddes Kılıç Sağlam, Canan Baydemir, Zeynep Seda Uyan

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- PP-02** Plasma IgG4 levels in clinically stable adult cystic fibrosis colonized with pseudomonas aeruginosa
Atqah Abdulwahab, Mona Allangawi, Merlin Thomas, Illham Bettahi, Sivaraman K Siveen, Jayakumar Jerobin, Prem Chandra, Abdul Badi Abou Samra, Manjunath Ramanjaneya
- PP-03** Mycobacterium simiae infection in cystic fibrosis: A case report
Hakan Yazan, Lina Al Shadfaan, Erkan Cakir
- PP-04** Epidemiology of pseudomonas aeruginosa among cystic fibrosis patients
Gamze Alci, Aysegül Karahasan, Can Akin, Ayça Cakan, Eren Sarioglu, Batuhan Basci, Beyza Oncel, Yasemin Gökdemir, Ela Erdem Eralp, Bülent Karadağ
- PP-05** Genotypic relatedness of pseudomonas aeruginosa strains isolated from sputum samples of Cystic Fibrosis patients in Marmara University Hospital CF center
Gamze Alci, Ayça Çakan, Can Akin, Batuhan Başçı, Eren Sarioglu, Beyza Öncel, Ayşegül Karahasan
- PP-06** Non-tuberculosis mycobacteria in cystic fibrosis patients
Dilber Ademhan Tural, Nagehan Emiralioğlu, Ebru Yalçın, Deniz Doğru Ersöz, Uğur Özçelik, Nural Kiper

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12:10 - 13:10 "Different Aspects of CF"

Poster Area

Chairs: Şebnem Özdoğan, Sedat Öktem

- PP-07** A case of allergic fungal rhinosinusitis at cystic fibrosis
Figen Çelebi Çelik, Sercan Göde, Zübeyde Yıldırım Ekin, Gökçen Öztürk Kartal, Aykut Eşki, Hüdaver Alper, Figen Gülen, Esen Demir
- PP-08** Evaluation of bone metabolism in children and adults with cystic fibrosis by using falangeal quantitative ultrasound
Velat Sen, Abdurrahim Dusak, Hadice Selimoğlu Sen, Müsemma Karabel
- PP-09** Evaluation of the factors that affecting quality of life of children with cystic fibrosis
Zeynep Kayra Tanrıverdi, Velat Sen, İsmail Yıldız, Hadice Selimoğlu Sen
- PP-10** Allergic bronchopulmonary aspergillosis in patients with cystic fibrosis: 13 yeas experiment at one center
Pakize Cennetoglu, Cansu Yılmaz Yegit, Almula Pinar Ergenekon, Nilay Bas, Ela Erdem Eralp, Yasemin Gokdemir, Tamer Bulent Karadag
- PP-11** Cystic fibrosis presenting as arthropathy: A case report
Yazan Zeyad Abed, Omar Khaleel Abu Shamma, Nisreen Rumman, Anas Muhanna, Ahmad Qaaqour
- PP-12** Presentation of four cases of allergic bronchopulmonary aspergillosis in cyctic fibrosis patients
Aykut Eşki, Gökçen Kartal Öztürk, Figen Gülen, Esen Demir

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12:10 - 13:10 "Difficulties in management of CF in the Middle East" Poster Area
Chairs: Erkan Çakır, Tuğba Şişmanlar

- PP-13** A profile of children with cystic fibrosis in Gaza
Bakr Abu Jarad, Afnan Abufoul, Hanan Abukumail, Rania Abusamra
- PP-14** The effect of ivacaftor on adult cystic fibrosis patients at Royal Hospital in Oman
Zakia Ali Al Rashdi, Nasser Al Busaidi
- PP-15** Association between CFTR mutation classes and cystic fibrosis severity markers in children
Abdurrahman Erdem Başaran, Aysen Başaran, Dilara Fatma Kocacık Uygun, Özgül Alper, Aysen Bingöl
- PP-16** Characteristics of cystic fibrosis patients diagnosed after false negative cystic fibrosis newborn screening results
Pinar Ergenekon, Emine Atag, Nilay Bas Ikizoglu, Cansu Yilmaz Yegit, Ellada Rzayeva, Yasemin Gokdemir, Ela Erdem Eralp, Bulent Karadag
- PP-17** Clinical characteristics of cystic fibrosis patients at our clinic
Aybüke Kacır, Füsün Ünal, Tuba Koçkar Kızılırmak, Gökhan Baysoy, Sedat Öktem
- PP-18** *Clinical and socio-demographic evaluation of cystic fibrosis*
Hakan Yazan, Lina Alshadfaan, Erkan Çakır

13:10 - 14:00 Lunch Break

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Friday, March 22, 2019

14:00 - 17:30 Session V: CF in Middle East

Room A

Chairs: Figen Gülen, Sevgi Pekcan

- 14:00 - 15:30 CF in Iran, Mohammadreza Modaresi, IRN
CF in Egypt, Nader Fasseeh, EGY
CF Jordan, Samah Awad, JOR
CF Turkey, Yasemin Gökdemir, TUR
CF in Omani and Pakistan/Indian patients, Hussein Al Kindi, OMN
- 15:30 - 16:00 Home-made therapies for CF; a recipe for lower cost treatments
Daniel Touw, NLD
- 16:00 - 16:30 The challenges of treating CF without essential drugs and equipment
Samah Awad, JOR
- CF-IDEA, A nonprofit solution to high cost therapies
Christine Noke, USA
- 16:30 - 17:30 Physiotherapy in CF-US and Middle East Experience
Christopher Tapley, USA
Özge Keniş, TUR

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Saturday, March 23, 2019

09:00 - 10:30 **Session VI: CF Care in Adults**
Charis: Sait Karakurt, Ayşen Bingöl

Room A

09:00 - 09:30 CF in Adults – What is different ?
Hendrikus Heijerman, NLD

09:30 - 10:10 CF Adult Care, challenges in the Middle East
Derya Kocakaya, TUR
Mona Al Lingawi, QAT

10:10 - 10:30 GI and nutrition
Deniz Ertem, TUR

10:30 - 10:50 **Coffee Break**

10:50 - 11:50 **Top 6 Abstract on Cystic Fibrosis**
Oral Presentation Session-2
Chairperson: Bülent Karadağ

Room A

10:50 - 11:00 **OP-07** Managing the respiratory care of children with CF in Gaza
Bakr Abu Jarad, Afnan Abufoul, Hanan Abukumail, Rania Abusamra

11:00 - 11:10 **OP-08** Distribution of microorganisms isolated from cystic fibrosis patients
Gamze Alci, Aysegül Karahasan, Can Akin, Ayça Cakan, Eren Sarioglu, Batuhan Basci, Beyza Oncel, Yasemin Gökdemir, Ebru Erdem Eralp, Bülent Karadağ

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Saturday, March 23, 2019

- 11:10 - 11:20 **OP-09** Respiratory virus analysis in cystic fibrosis patients with acute respiratory exacerbations
*Pinar Ergenekon, Rabia Can Sarinoglu, Cansu Yilmaz Yegit,
Yasemin Gokdemir, Ela Erdem Eralp, Guner Soyletir, Bulent Karadag*
- 11:20 - 11:30 **OP-10** Importance of isoforms of immunoreactive trypsin in newborn screening for cystic fibrosis
*Bengü Ergenoğlu, Esin Akçael, Ş. Şeyda Pirinççi, Ali İhsan Manav,
Erdal Ataç, Fatıma Yücel*
- 11:30 - 11:40 **OP-11** The effect of the family empowerment program on disease management skills of parents with children with cystic fibrosis: A randomized controlled trial
Hatice Donmez, Fatma Taş Arslan, Sevgi Pekcan
- 11:40 - 11:50 **OP-13** Impact of Body Composition and Nutritional Status on Health Outcomes in Adult Cystic Fibrosis Patients
*Nazlı Zeynep Uslu, Derya Kocakaya, Şehnaz Olgun Yıldızeli,
Emel Eryüksel, Şeyma Görçin Karaketir, Berrin Ceyhan*
- 11:50** **Closing Remarks,**
Bülent Karadağ, TUR

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CONTACT INFORMATION



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