

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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AL QAMRA HOLDING

Cystic Fibrosis Conference

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Wednesday, March 20, 2019

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

Chairs: Nilay Baş, 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 Köse

Room B

Christopher Tapley, USA

Sharyn Dagher, USA

Özge Keniş, TUR

16:00 - 16:30 Coffee Break

16:30 - 18:00 Nutrition Workshop

Chairs: Engin Tutar, Güzin 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 Doğru

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
Jacquelien 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 Kenış Coşkun, Kardelen Gençer Atalay, Evrim Karadağ Saygı, 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 Gülen, 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 Sarıoğlu, 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 Ikizoğlu, 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 Ayzıt Kılıç, 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**

Poster Area

"Microbiology and Immunology in CF"
Chairs: Saniye Girit, Nazan Çobanoğlu

- 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, Ilham 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 Çakan, Eren Sarioglu, Batuhan Bascı, 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 Oncel, Aysegül 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 Celebi 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 Selimoglu Sen, Müsemma Karabel
- PP-09** Evaluation of the factors that affecting quality of life of children with cystic fibrosis
Zeynep Kayra Tanrıverdi, Velat Sen, Ismail Yıldız, Hadice Selimoglu Sen
- PP-10** Allergic bronchopulmonary aspergillosis in patients with cystic fibrosis: 13 years experiment at one center
Pakize Cennetoglu, Cansu Yilmaz Yegin, 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 cystic fibrosis patients
Aykut Eşki, Gökçen Kartal Öztürk, Figen Gülen, Esen Demir

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12:10 - 13:10 "Diffuculties 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 Abufouil, 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, Ayşen Başaran, Dilara Fatma Kocacık Uygun, Özgül Alper, Ayşen Bingöl
- PP-16** Characteristics of cystic fibrosis patients diagnosed after false negative cystic fibrosis newborn screening results
Pınar Ergenekon, Emine Atag, Nilay Bas İkizoglu, Cansu Yilmaz Yegit, Ellada Rzayeva, Yasemin Gokdemir, Ela Erdem Eralp, Bulent Karadag
- PP-17** Clinical characteristics of cystic fibrosis patients at our clinic
Aybuke Kacır, Füsun Ünal, Tuba Koçkar Kızılırmak, Gökhane 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

Room A

Charis: Sait Karakurt, Ayşen Bingöl

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

Room A

Oral Presentation Session-2

Chairperson: Bülent Karadağ

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 Sarıoglu, Batuhan Bascı, Beyza Oncel, Yasemin Gökdemir, Ebru Erdem Eralp, Bülent Karadağ

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- 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, Fatima 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



NOTES

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CONTACT INFORMATION



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