

# MECFA

Road to the future

A young child, shirtless and wearing shorts, sits on a ground of dirt and gravel. The child's expression is somber and they are looking down. The word "POVERTY" is written in large, white, sans-serif capital letters across the center of the image. The entire scene is framed by a white L-shaped graphic element in the top-left and bottom-right corners.

POVERTY

One in four children in the Arab world live in poverty, often deprived of life's most basic necessities such as proper housing or safe water, according to a study released by the U.N. children's agency UNICEF in 2017.



WAR

There are over 61 million children living in countries affected by war in MENA out of a total child population of nearly 166 million. One in every three are affected by ongoing conflicts and violence. In this region, living in war is becoming the “new normal” for millions of children..



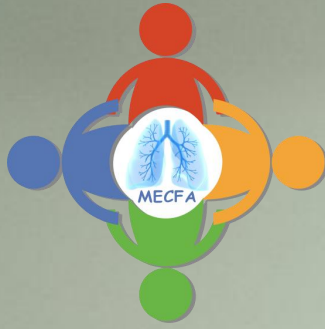
# REFUGES

More people have been forced to flee their homes by conflict and crisis than at any time since World War II. The UN reports shows 53% of displaced people are children.

# CF IN THE MIDDLE EAST



- ✓ Life expectancy is still averaging below 15 in most countries
- ✓ 1/3 of children diagnosed are suffering without access to essential drugs and equipment
- ✓ There are no western standard CF centers
- ✓ And a limited number of trained CF clinicians and allied health
- ✓ Underdiagnosed and misdiagnosis is still a major problem
- ✓ No CF national or regional CF registries that have data from all patients diagnosed.
- ✓ Turkey is the only country with an NBS program.



# WE DECIDED

MECFA and our members have decided to believe that we can change these statistics.

We have decided to join together, to share knowledge and resources.

We have decided to be pioneers in the fight against CF in the Middle East.

We have decided that we will find a way to make a difference.



IF WE HAD  
THE  
ANSWERS,  
WE  
WOULDN'T  
NEED MECFA.



WE HAVE TO  
WALK  
BEFORE WE  
CAN RUN.

1. Diagnostics
2. Access to Essential Drugs and Equipment
3. Education

# WHAT'S WE CARE?



**Diagnostics** – We work with our members to facilitate access to appropriate diagnostics by networking with stakeholders, sponsors and lobbying health ministries.

**Drugs and Equipment** – MECFA works with our partner CF-IDEA ([www.cfdrugs.org](http://www.cfdrugs.org)) and pharma friends to open the door to less costly drugs and equipment. We support lobbying efforts and help facilitate donations whenever possible.

**Education** – Through CF specialized course, conference and workshops we are building CF teams and supporting our members to develop CF Centers that are following gold standards.

Visit the MECFA website to learn more about We Care [www.mecfa.org/wecare](http://www.mecfa.org/wecare)



# RESEARCH

In 2018 MECFA awarded cash to the top two abstracts and oral presentations at the MECFC 2018.

In 2019 MECFA will support small QI projects

Projects considered for support should aim to achieve one or more of the following:

- ✓ Improve pulmonary function
- ✓ Improve Nutrition and BMI
- ✓ Implementing infection control measures
- ✓ Screening for mental health for patients and family
- ✓ Organizing and structuring the CF clinics:
  - ✓ *Pre-clinic huddle, using pre-clinic survey that patients/parents complete,*
- ✓ Post clinic review
- ✓ Reviewing patients in a monthly staff meetings

We will be sending out a call for proposals to MECFA members in 2019.



# THE MAMI PROJECT

PILOT AND FEASIBILITY PROGRAM TO DEVELOP A  
CYSTIC FIBROSIS CARE CENTER OF  
EXCELLENCE IN TURKEY

Marmara CF Center, Istanbul, Turkey  
UNIVERSITY OF Michigan Collaboration

*Prof Bulent Karadag and Prof. Samya Nasr are leading the  
project.*



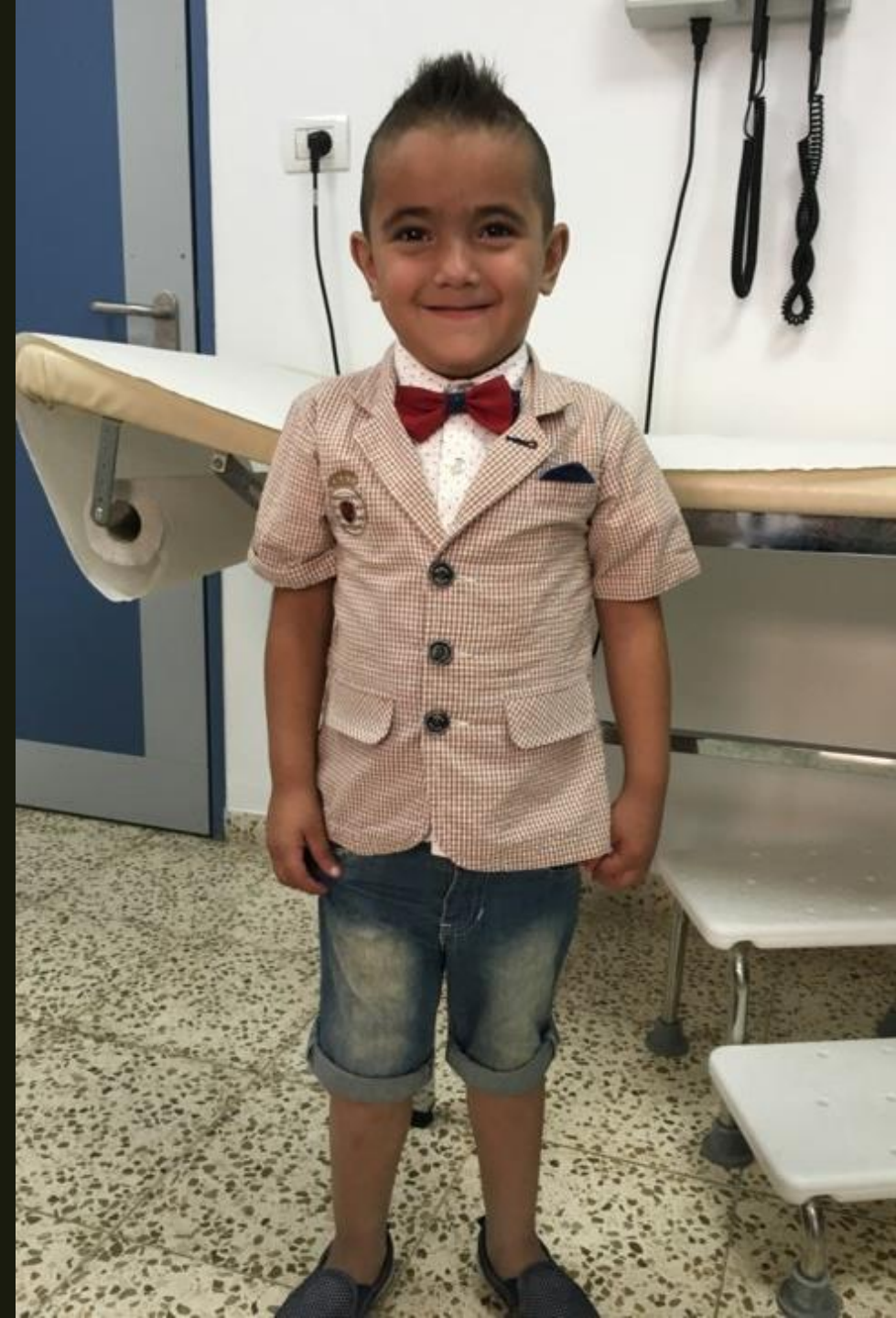
# PALESTINE CAPACITY BUILDING PILOT PROGRAM

DR NISREEN RUMMAN

This program falls under the We Care program and is our first pilot project launching this initiative

## *Program Objectives:*

1. Partnering with the Caritas Baby Hospital and Gaza Government Hospital to improve standards of care in Bethlehem and Gaza.
2. Support lobbying the MoH to provide inhaled antibiotics, vitamins, nebulizers and hypertonic saline.
3. Facilitate diagnostic equipment for the Government Hospital in Gaza.




When 'i' is  
replaced By 'we'

Even  
'illness'  
Becomes  
'Wellness'

# TEAMWORK

We cannot achieve our goals if we do not work together.

Thank you to everyone who works to make MECFA a success.



**Cystic Fibrosis Team**  
**Volunteer Mission To Gaza**  
**February 2019**