

# Macedonian CF Association

How patient association and healthcare  
authorities can join forces to improve  
access to care

# INTRODUCTION

- Snezana Bojcin,  
founder and actual president of  
**Macedonian CF Association**

# INTRODUCTION

- **Macedonian CF Association**

Founded: 2002

Active since: 2006

Members: 81

[www.cf.mk](http://www.cf.mk)

- **Healthcare authorities (HA):**

- Ministry of Health (MoH)

- Health Insurance Fund of Macedonia (HIFM)

- Drug Bureau

- University Hospital Pediatric Clinic

## Starting Point - 2002

- Not enough hospital rooms
- No room isolations
- Ambulance positioned in a middle of a CF ward
- No existing CF Protocol
- No inhalation drugs available in the country
- Poor choice of iv therapy on a ward as well as not enough for those who need it
- Enzyme therapy available but not systemized
- Hyper caloric food and multi vitamin supplements are not available
- No educated CF physiotherapist
- No educated CF psychologist
- **Parents more eager to hide the illness than to try to fight for better treatment**

# How to improve the situation

## ➤ BASIC

- Collaboration
- Coordination
- Good relation and
- Support from the manager of a CF ward

## How to improve the situation

- Donations
  - *It will cover only minor and temporary needs of CF patients.*
- CF Association's engagement
  - *Association's don't have an institutional power for introduction of new specific CF drugs nor for improvement of hospital relations and conditions.*
- Waiting for HA to improve situation
  - *There is no time to wait for CF patients. There is a necessity for changes as soon as possible.*



## How to improve the situation

### **ONLY ONE SOLUTION**

Patient association and healthcare authorities **MUST** join forces to improve access to care



## How to work together?

### **Building trust – Creating a win-win situation**

- Raising a public awareness
- Regular meetings and updates with authorities
- Projects
- Donations



# How to work together – Raising a public awareness

- **TV**
  - All kind of programs treating health topics
  - Debate shows
  - News
- **DAYLY NEWSPAPERS**
  - Regular report on all association's activities: pre and after event
- **ACTIVITIES**
  - Concerts
  - City walking
  - Visiting the Parliament and Women Parliamentarian's Group
  - Always present on all kind of happenings organized by the other associations
- **WEB PAGE / SOCIAL NETWORKS**

## How to work together – Raising a public awareness

- FEEDBACK

- Increased public awareness for CF
- All promised and realized acts from HA/CF Association are becoming a public issue
- Parents and patients are now encouraged to speak aloud about the CF impact in their daily life routine

*e.g. video created by Nikola*

*<http://www.youtube.com/watch?v=EACtbZW5IFE>*

# How to work together – REGULAR MEETINGS

- **CF ASSOCIATION – University Hospital Pediatric Clinic**
  - What are CF patients needs
  - What CF Association can offer
  - What Pediatric Clinic can offer
- **CF ASSOCIATION – MoH**
  - What are CF patients needs
  - What do Pediatric Clinic need
  - Legislation and possibilities
- **CF ASSOCIATION - NHIF**
  - What are CF patients needs
  - Financial possibilities
  - What CF Association can offer

# How to work together – REGULAR MEETINGS

- **CF ASSOCIATION – Drug Bureau**
  - What are CF patients needs
  - Legislation in the important and urgent cases
- **CF ASSOCIATION – Pharmaceutical companies or their distributors**
  - What are their plans and expectations
  - What are CF Patients real needs

# How to work together – REGULAR MEETINGS

- FEEDBACK

- At the very beginning meetings are rare and only on initiative of the CF Association
- Nowadays meetings with HA are almost regular on initiative of a both sides and depending on needs.
- All involved are proposing and looking for the solution of the actual problem



# How to work together - PROJECTS

The good investment is coming back

- **Joint Project with MoH:**  
Building a CF center for children and adults with CF planned to be finished 2015. It will lay on up to 700m<sup>2</sup> and will function as by recommendations in **“Standards of care for patients with cystic fibrosis: a European consensus”**.
- Physiotherapist will be included in the CF team and education will be planned.
- Planned educational program for medical staff (psychologist, nutritionist, cf doctor, adult cf pulmonologist, nurses)



## How to work together - DONATIONS

- Organized by the CF Association
  - To improve the well-being of CF patients.
  - To demonstrate dedication on partnership with HA.
  - To leave a space for capital investments on HA in overall improving of a CF care in the country.

# How to work together - DONATIONS

- Feedback:
  - Donations:
    - up to 10.000 euro in medical and non-medical equipment provided for the ward.
    - up to 16.000 euro worth medical equipment from CFW.
    - up to 5 .000 euro worth medical equipment from CFE.
    - up to 4.200 euro worth medical equipment from public project financed by Macedonian private company



# How to work together - RESULTS

- **Introduction of an important drugs** free of charge for all CF patients :
  - Enzyme therapy regulated
  - 3 expensive inhalation drugs included in a regular therapy
  - Liver drug included
  - Hepatitis B vaccination included
- Defined **Conditional Clinic Budget** for inhalation drugs in CF patients
- **Obligatory** Clinic CF Protocol
- About **30% increased number of patients** on an inhalation therapy

## How to work together – FUTURE PLANS

- Ongoing project: **Patients CF Register** (in collaboration with CF Center, CF Association, MoH, Agency Directorate for Personal Data Protection)
- Ongoing project: **Lobbying for new specific drugs** (anti-MRSA therapy, anti-fungal therapy, iv therapy, hyper caloric food and multi vitamins supplements) on the List of free of charge drugs for CF patients
- Ongoing project: Play a role in raising a **public awareness on a National Transplantation Program** as we are appearing as a partners and supporters with the initiators.
- Take a main role in **constituting an umbrella association for rare diseases** in Macedonia

# THANK YOU!

I hope that in the very near future we will be honored to welcome you in our small but also beautiful and hospitable country.



**And I would like to stress that all this above would be impossible without the two most important supporters and persons in my life**

**My daughter**



**My husband**

