Working together
Examples of the cooperation among Healthcare professionals and patients organizations in Hungary

25.05.2018
Bratislava, SK

Geza Marsal
President
Hungarian Association of Cystic Fibrosis Patients
HUNGARIAN CF REGISTRY
www.cisztasfibrozis.hu

TEAMWORK
Maintained by the Hungarian Association of Cystic Fibrosis Patients, strong cooperation with CF centers and professionals

CORE TEAM
Dr. Ujhelyi Rita  
Dr. Csizsér Eszter  
Hornyák-Kovács Attila  
Marsal Géza  
country representative  
sponsor, coordinator  
data manager  
country data manager

CERTIFICATION
Approved by the Medical Research Council  
(11.05.2011)

APPEREANCES
Presenting results on the annual scientific meetings and publications in HU and in EU
WHAT WE DO

Purpose of the CF registry

MEASUREMENT
Measuring, surveying, comparing aspects of CF and its
treatment and providing data for the actual scientific purposes

REPRESENTATION OF INTEREST
Advocacy work through providing clear picture about the
status of the Hungarian CF patients and their care

STRATEGY MAKING
Answering the current questions with facts depending of the
needs of the decision makers.

INTEGRATION
Successful collaboration with the ECFS Patients Registry
since 2008
ECFS Patients Registry project
More than 42,000 people with CF
33 participating countries
History

- Hungarian Registry was established in 2007

- It was the classical story, the greatest center wanted to know how many patients were treated and what were the actual status with them

- We went through the standard evolution:
  - 1, summarize documents on paper
  - 2, create excel sheets
  - 3, MS Access (desktop) database
  - 4, centralized SQL server with reporting capabilities
National Registry

- We have 18 (!) different locations in the country where the CF Patients are being taken care

- This means 18 different data sources what we had to consolidate

- It was obvious from the very beginning that we are not able to handle the various data sources and parameters without strong centralization

- This led the decision to create one National Registry:
  - It could show us how the patients are moving among the centers
  - It helps to avoid the duplicated patients through the centrally generated patients ID
  - It show us where are the coverages or common errors in the CF care system in HU
NUMBER OF PATIENTS BY CENTERS

CF CARE
There are 18 different locations in Hungary where CF care is currently available.

CENTERS
The biggest centers are Heim Pál Hospital (children) and Korányi Institute (adult). Both are located in Budapest.

MULTICENTER PATIENTS
In some cases patients are registered at two or more centers in the same time. The reason of this is mostly the running transition from the pediatric care to the adult center or the distance of the centers.
Structure

Center 1

Data sent via web

Data sent via excel

www.digitalbevaring.dk

Fixing errors, creating unique IDs

Central SQL Database

Reporting services, Custom reports, publications

Center 2
Challenges

- It was very hard to proof the usefulness or its meaning **without result**
  In the first time it looked like the work what the centers invested in the data reporting it was not worth it -> resistance

- We tried to show as much as we can from the actual years data in order to show the potential of the future usage of the registry

- After two years of data collecting we could provide historical data and we joined to the ECFS PR project. Joining the international community helped us to **convince all the participants** especially the resisting members

- We used our custom parameter list in the dataset but we realized we **don’t need to reinvent the hot water**:
  - Implemented the ECFSPR parameter set:
  - easier data export, clear definitions, apple to apple comparison
Registry data

HU - 2015
DISTRIBUTION BY GENDER

TOTAL NUMBER OF PATIENTS: 567
Men: 302
Women: 265

AVERAGE AGE
Men: 17.8 years
Women: 16.4 years

- Men: 25%
- Women: 18%
- Boys: 28%
- Girls: 29%
NUMBER OF PATIENTS BY GENDER

- Men
- Women
- Boys
- Girls
AVERAGE AGE BY GENDER

- Men
- Women
- All patients
# Number of Patients Approaching Age 18

## Patients to Adult Care

Number of patients who are going to be handled by adult centers in the following years

## By Centers

<table>
<thead>
<tr>
<th>Location</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>BP - Heim Pál</td>
<td>4</td>
</tr>
<tr>
<td>BP - Korányi</td>
<td>3</td>
</tr>
<tr>
<td>Debrecen</td>
<td>1</td>
</tr>
<tr>
<td>Győr</td>
<td>1</td>
</tr>
<tr>
<td>Miskolc</td>
<td>2</td>
</tr>
<tr>
<td>Mosdós</td>
<td>1</td>
</tr>
<tr>
<td>Szeged</td>
<td>4</td>
</tr>
<tr>
<td>Szombathely</td>
<td>2</td>
</tr>
<tr>
<td>Törökbálint</td>
<td>1</td>
</tr>
<tr>
<td>Zalaegerszeg</td>
<td>1</td>
</tr>
</tbody>
</table>

![Graph showing the number of patients approaching age 18 across years]
AGE STRUCTURE

Number of patients

Age (years)
Most / least populated counties in Hungary:

- Pest: 69
- Jász-Nagykun-Szolnok: 19
- Nógrád: 5
Average age by counties

- BAZ: 16,68
- Szabolcs: 14,71
- Hajdú-B: 16,26
- Budapest: 21,97
- Pest: 18,64
Things what we still needs to solve

- The data reporting is based on the consensus of the 18 care center, there are no regulations or instructions by the law makers or by the healthcare system / government

- Hungary is still working on the implementation of the neonatal screening (we have been informed about the beginning of the pilot project by the middle of 2018)

- We are working hard on the introduction of the new version of the HU registry which will be operated by the National Health Insurance Fund of Hungary and protected by the newly created legislation

- We hope we could make mandatory the reporting of the new diagnoses into the registry, based on the neonatal screening project and to harmonize the financing system according to the data from the HU registry
NATIONAL KORÁNYI INSTITUTE
REBUILT CF CENTER
DEAR FRIENDS AND COLLEAGUES!

On behalf of The Hungarian Association of Cystic Fibrosis Adults, it is a great pleasure to invite the representatives of the following countries, who are involved in the care of patients (children and adults) and/or delegates of organizations of patients and parents to the first CF Better Together conference which will be held in Gárdony - Hungary 28 September - 01 October 2017.

Albania, Bosnia-Herzegovina, Bulgaria, Croatia, Czech Republic, Kosovo, Macedonia, Moldova, Montenegro, Romania, Serbia, Slovakia, Slovenia, Ukraine

Four persons from each country are invited with full board. Registration will be opened on 01.05.2017 till 01.07.2017 on the http://www.bettertogetherhu site.

AIM OF THIS MEETING At this conference, we will try to establish a new forum for the discussion of the best and most recent basic and applied science and to introduce the Hungarian practice in the care of cystic fibrosis patients and the development of the long transplantation center in Budapest. The aim of this event is to create a new way in terms of communication and to offer an opportunity in cooperation for the invited countries. The programs will reflect these priorities and bring together both clinical teams and patients associations from the invited countries.

PROGRAMME Interactive discussions, workshops and professional exhibition are planned. Sightseeing in Budapest and visits to CF centers are also included in the program.

IMPORTANT INFORMATION Date of the meeting: evening 28/09/2017 - morning 01/10/2017 Location: Gárdony, Tihany street 17, Hungary

LANGUAGE: English Scientific topics: Care of cystic fibrosis patients. Long transplantation cystic fibrosis, meeting with patients associations and pharmaceutical companies.

The meeting is sponsored by the Ministry of Human Capacities of the Hungarian Government.

ORGANIZING COMMITTEE
Hungarian Association of Cystic Fibrosis Adults
H-1045 Budapest Szépü József u. 19.
http://www.bettertogetherhu
http://www.cysticfibrosis.hu

CONTACT PERSONS
Esther Csizmadia MD - csizmadiaesther@gmail.com
Achim Holzer MD, PhD - holzerachim@gmail.com
Zsuzsa S. Nagy - zsuszanasay@gmail.com
Geza Mészáros - geza.meszaros@gmail.com
KEY MESSAGES

1. TEAMWORK
   Segregation of duties

2. DATA QUALITY
   A chain is only as strong as its weakest link

3. COMPARABILITY
   The comparison of CF populations is essential for the development of standards for clinical practice

4. TRUST
   The aim of the registry is to encourage the development instead to initiate meaningless criticism
Thank you for your attention!

Geza Marsal
geza.marsal@gmail.com
http://www.cysticfibrosis.hu