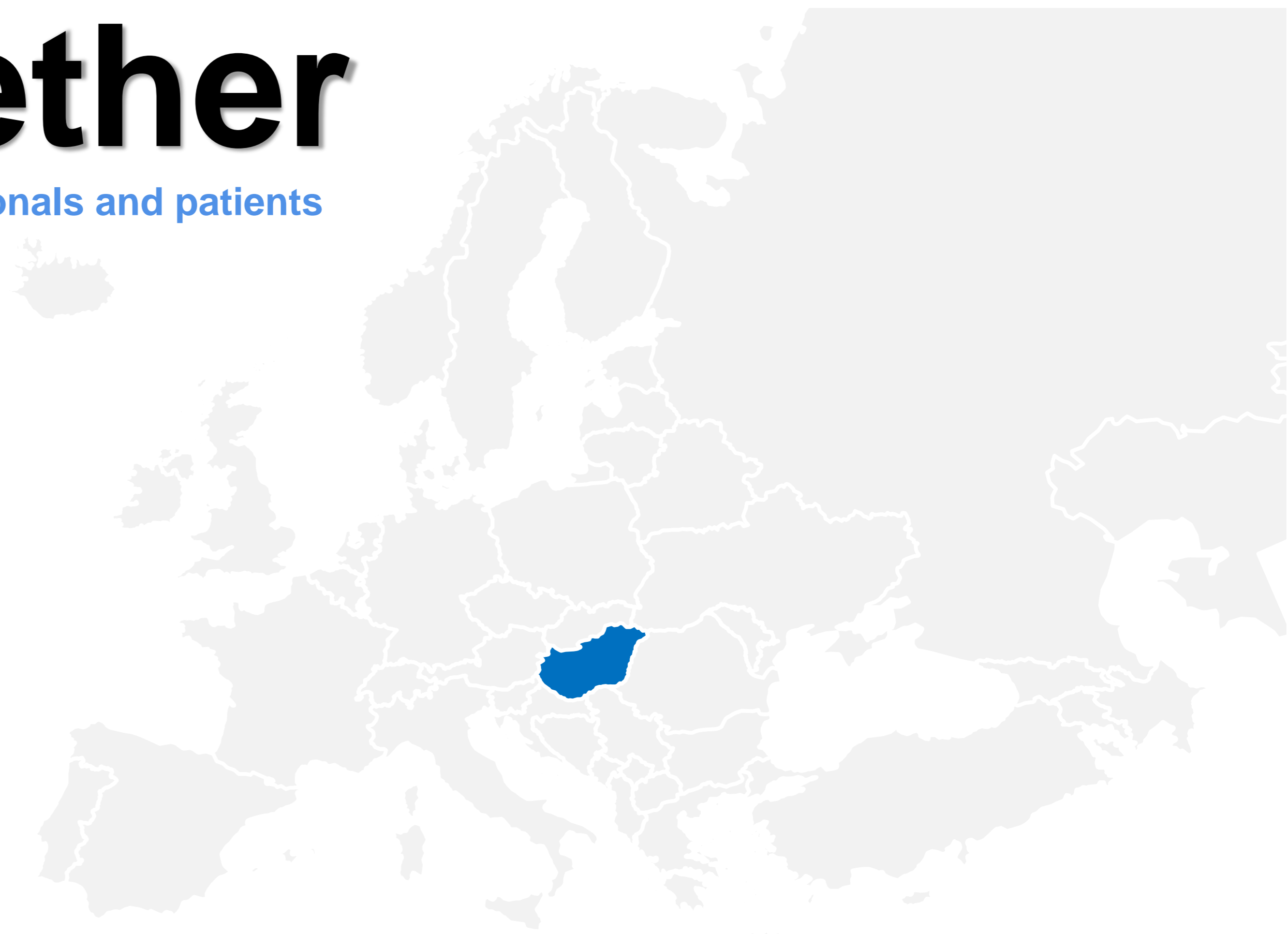


# Working together

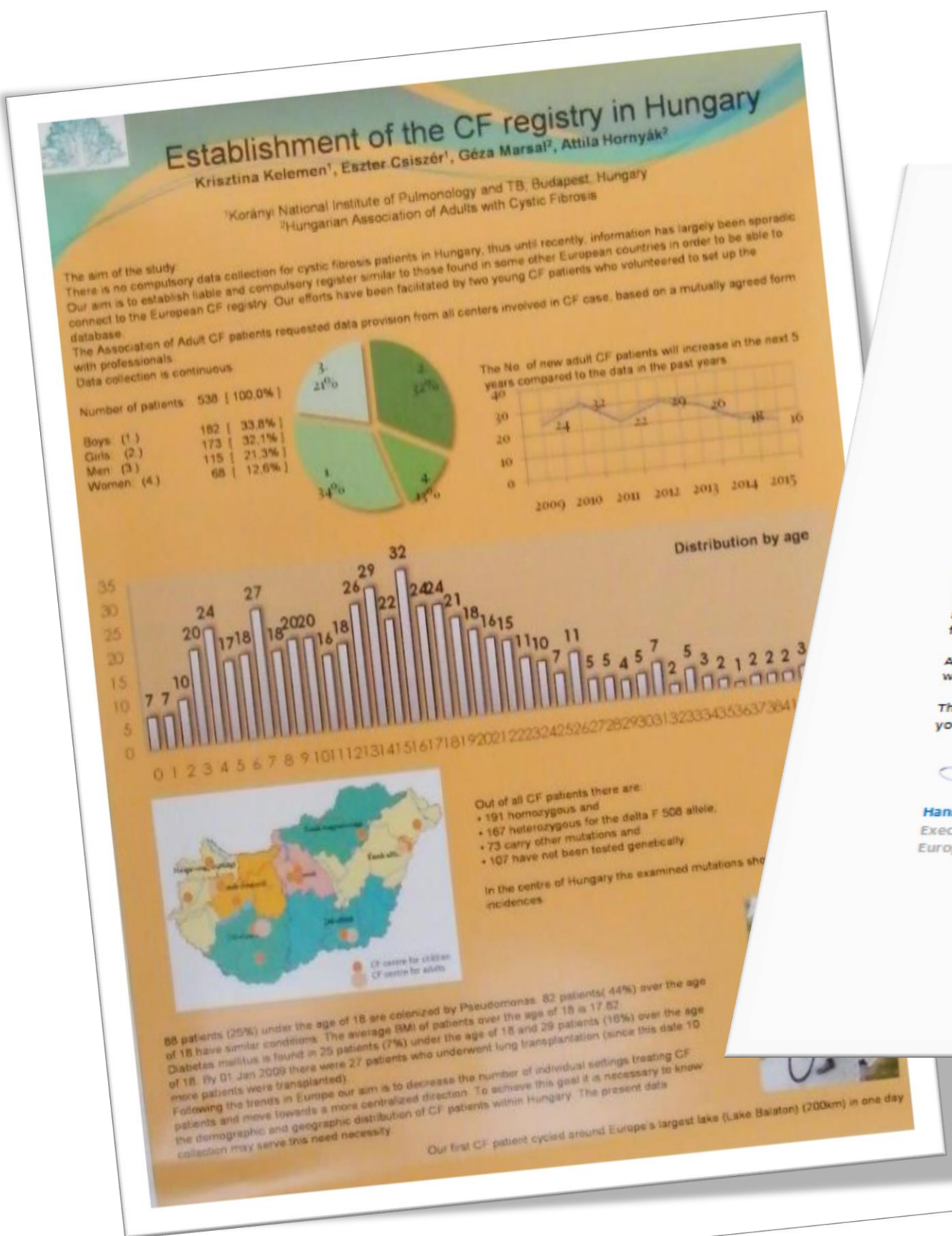
Examples of the cooperation among Healthcare professionals and patients organizations in Hungary





# HUNGARIAN CF REGISTRY

[www.cisztasfibrozis.hu](http://www.cisztasfibrozis.hu)



To whom it may concern

August 20, 2012

The European Cystic Fibrosis Society Patient Registry (ECFSPR) is a common platform for data collection on CF patients in Europe. The main objectives of the ECFSPR are to promote and innovate standards of care for CF and facilitate public health planning through the collection and comparison of information on CF in the participating European countries. This can only be attained by provision of high quality data for epidemiological research and for identification of patients suitable for clinical trials.

In the annual ECFSPR report of 2009 18,999 patients from 20 countries were reported. Hungary is one of the countries participating in the ECFSPR and that provided data for the report 2009. For detailed information I refer you to our website [www.ecfs.eu/files/webfm/webfiles/File/ecfs\\_registry/ECFSPR\\_Report10809\\_v22012.pdf](http://www.ecfs.eu/files/webfm/webfiles/File/ecfs_registry/ECFSPR_Report10809_v22012.pdf).

With this letter we would like to inform you that we have a successful cooperation with Hungary, with Rita Ujhelyi as country representative of Hungary in the ECFSPR Steering Group, and Géza Marsal as data manager. Their efforts to develop a common database from the data you have sent them is valuable. Therefore we would like to encourage the centres that do not have the customized ECFSPR software program, to send the anonymised data directly to Géza Marsal, who will enter these data into ECFRecord. In this way Géza Marsal will be able to conduct the necessary and appropriate data analyses in order to send the Hungarian data successfully, as they did formerly, to the ECFSPR.

At the moment the ECFSPR is developing a new software system for data collection, which hopefully will be ready in the summer of 2013.

Thank you for your consideration,  
 yours sincerely,

*Hanne Vebert Olesen*  
 Hanne Vebert Olesen  
 Executive Director  
 European Cystic Fibrosis Society Patient Registry

European Cystic Fibrosis Society Patient Registry  
 Herestraat 49 - 3000 Leuven - Belgium  
 +32 484 34 32 edpr@usc.eu  
 www.ecfs.eu



## TEAMWORK

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



## CORE TEAM

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

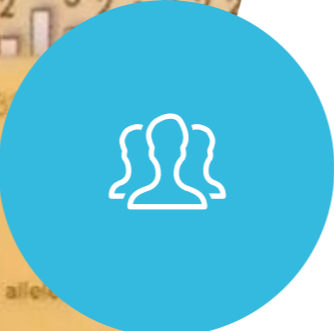
### MEASUREMENT

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



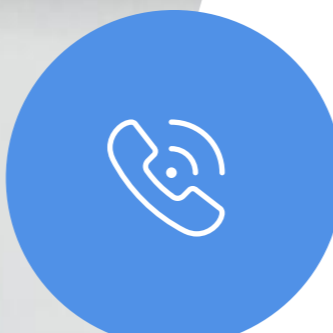
### STRATEGY MAKING

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



### INTEGRATION

Successful collaboration with the ECFS Patients Registry since 2008



### Establishment of the CF registry in Hungary

Krisztina Kelemen<sup>1</sup>, Eszter Csizsér<sup>1</sup>, Géza Marsal<sup>2</sup>, Attila Hornyák<sup>2</sup>

<sup>1</sup>Korányi National Institute of Pulmonology and TB, Budapest, Hungary  
<sup>2</sup>Hungarian Association of Adults with Cystic Fibrosis

The aim of the study  
There is no compulsory data collection for cystic fibrosis patients in Hungary, thus until recently, information has largely been sporadic. Our aim is to establish reliable and compulsory register similar to those found in some other European countries in order to be able to connect to the European CF registry. Our efforts have been facilitated by two young CF patients who volunteered to set up the database.  
The Association of Adult CF patients requested data provision from all centers involved in CF case, based on a mutually agreed form with professionals.  
Data collection is continuous.

Number of patients: 538 (100.0%)

Boys (1.)	182	33.8%
Girls (2.)	173	32.1%
Men (3.)	115	21.3%
Women (4.)	68	12.6%

The No. of new adult CF patients will increase in the next 5 years compared to the data in the past years.

Distribution by age

Out of all CF patients there are:

- 191 homozygous and
- 167 heterozygous for the delta F 508 allele
- 73 carry other mutations and
- 107 have not been tested genetically.

In the centre of Hungary the examined mutations incidences.

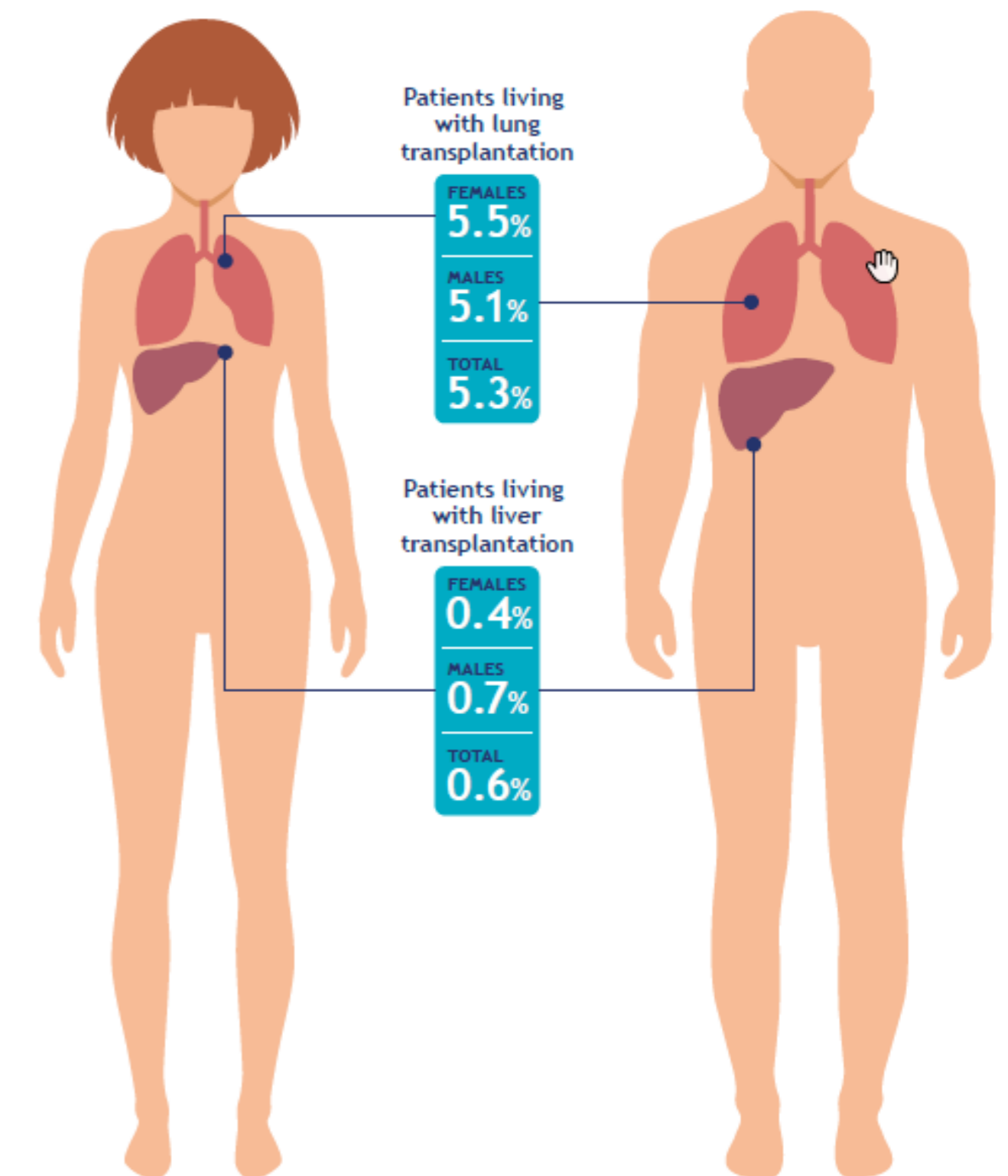
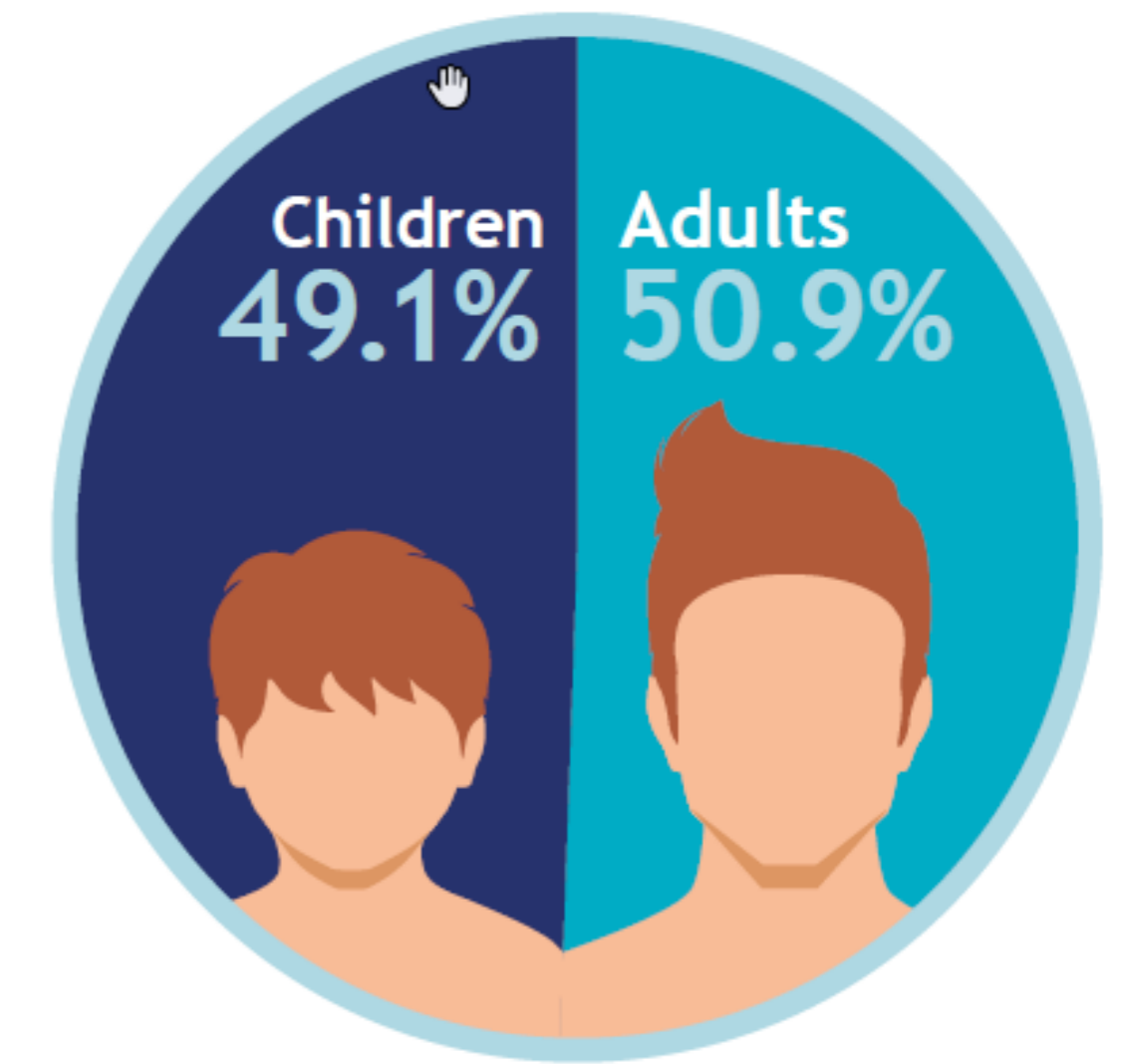
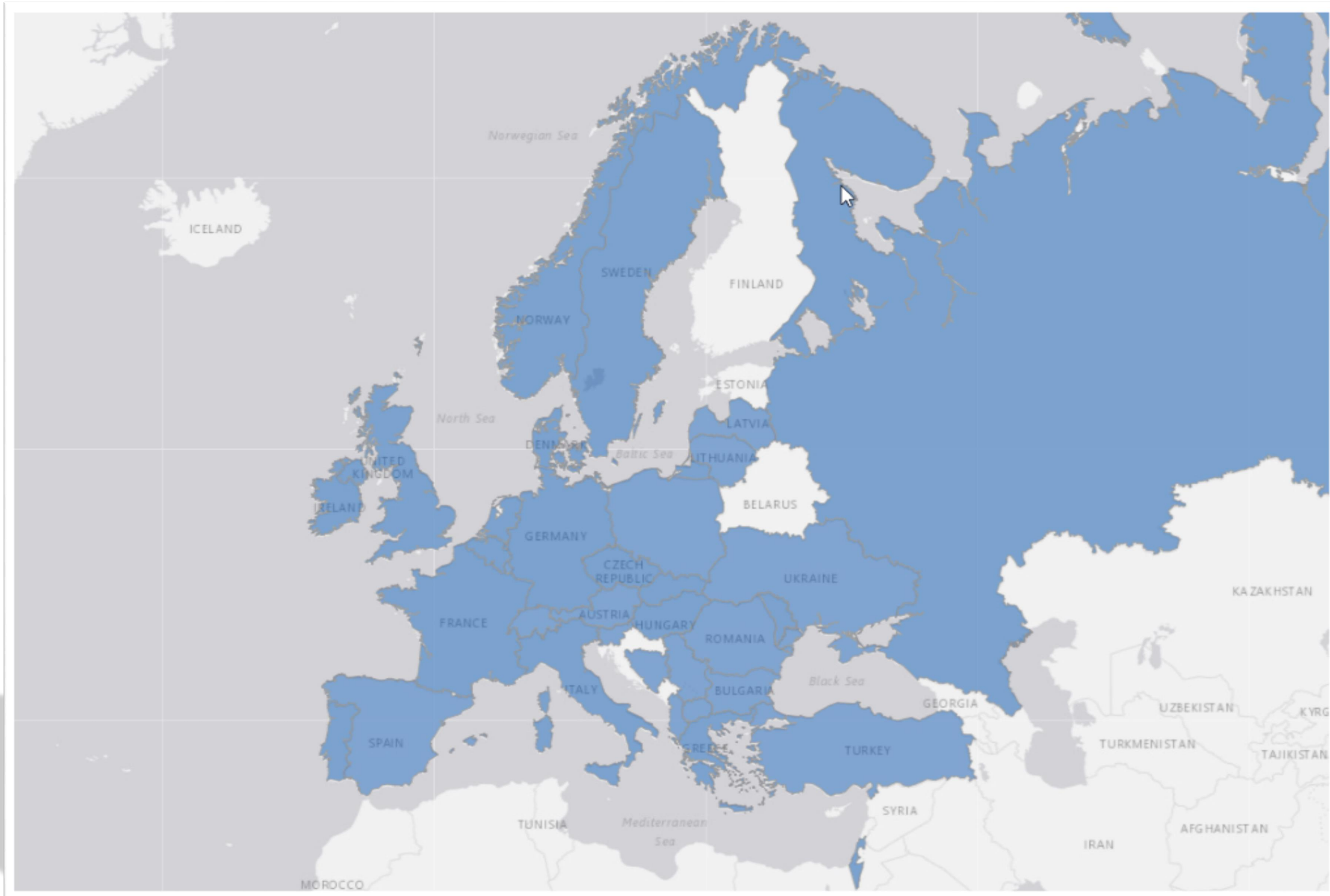
88 patients (25%) under the age of 18 are colonized by Pseudomonas. 82 patients (44%) of 18 have similar conditions. The average BMI of patients over the age of 18 is 17.82. Diabetes mellitus is found in 25 patients (7%) under the age of 18 and 29 patients (16%) of 18. By 01 Jan 2009 there were 27 patients who underwent lung transplantation (since then more patients were transplanted).  
Following the trends in Europe our aim is to decrease the number of individual settings treated patients and move towards a more centralized direction. To achieve this goal it is necessary to take into account the demographic and geographic distribution of CF patients within Hungary. The present data collection may serve this need necessarily.

Our first CF patient cycled around Europe's largest lake



# ECFS Patients Registry project

More than 42,000 people with CF  
33 participating countries



# History

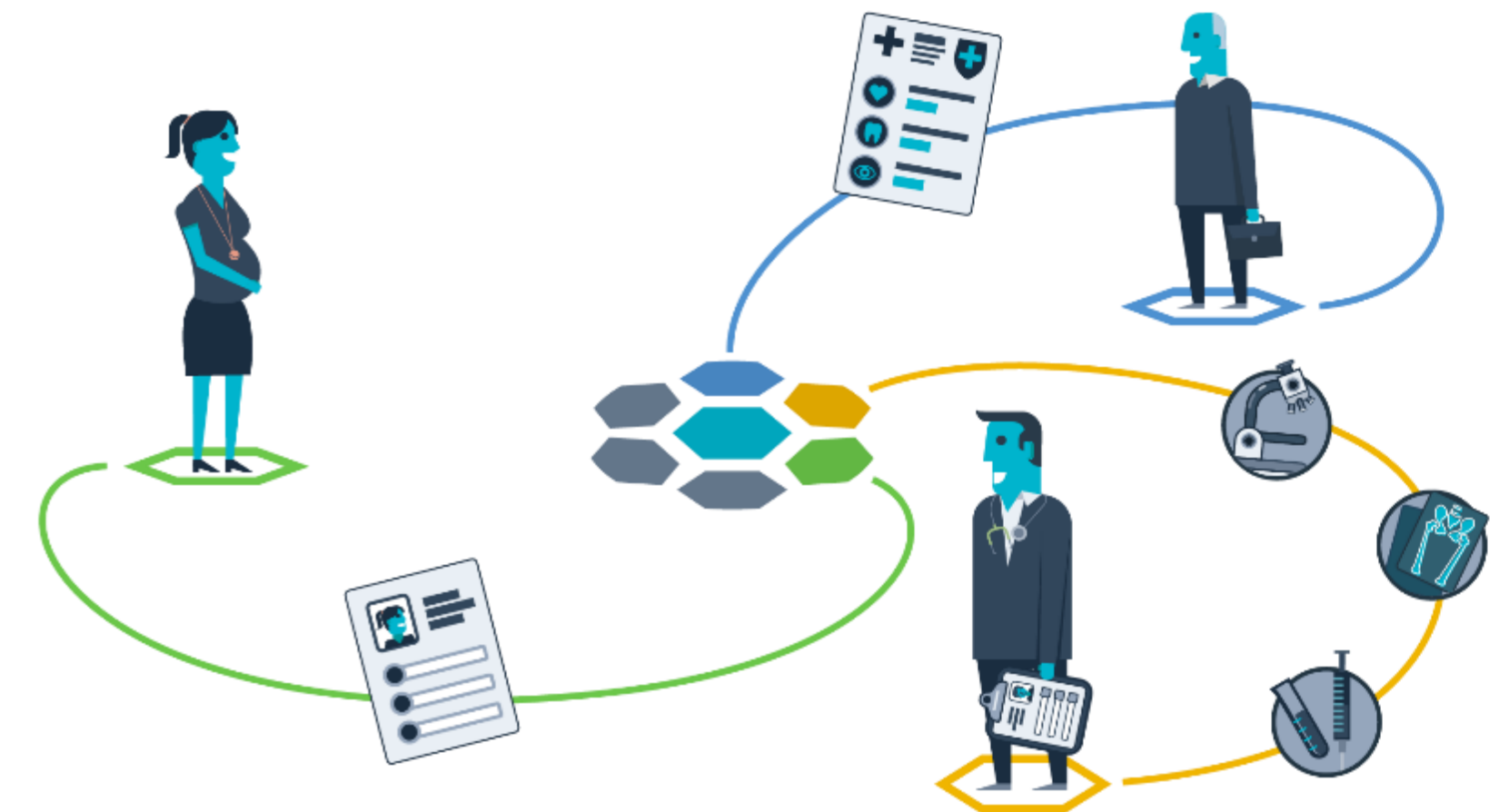
- Hungarian Registry was established in 2007
- It was the classical story, the greatest center wanted to know how many patients were treated and what were the actual status with them
- We went through the standard evolution:
  - 1, summarize documents on paper
  - 2, create excel sheets
  - 3, MS Access (desktop) database
  - 4, centralized SQL server with reporting capabilities





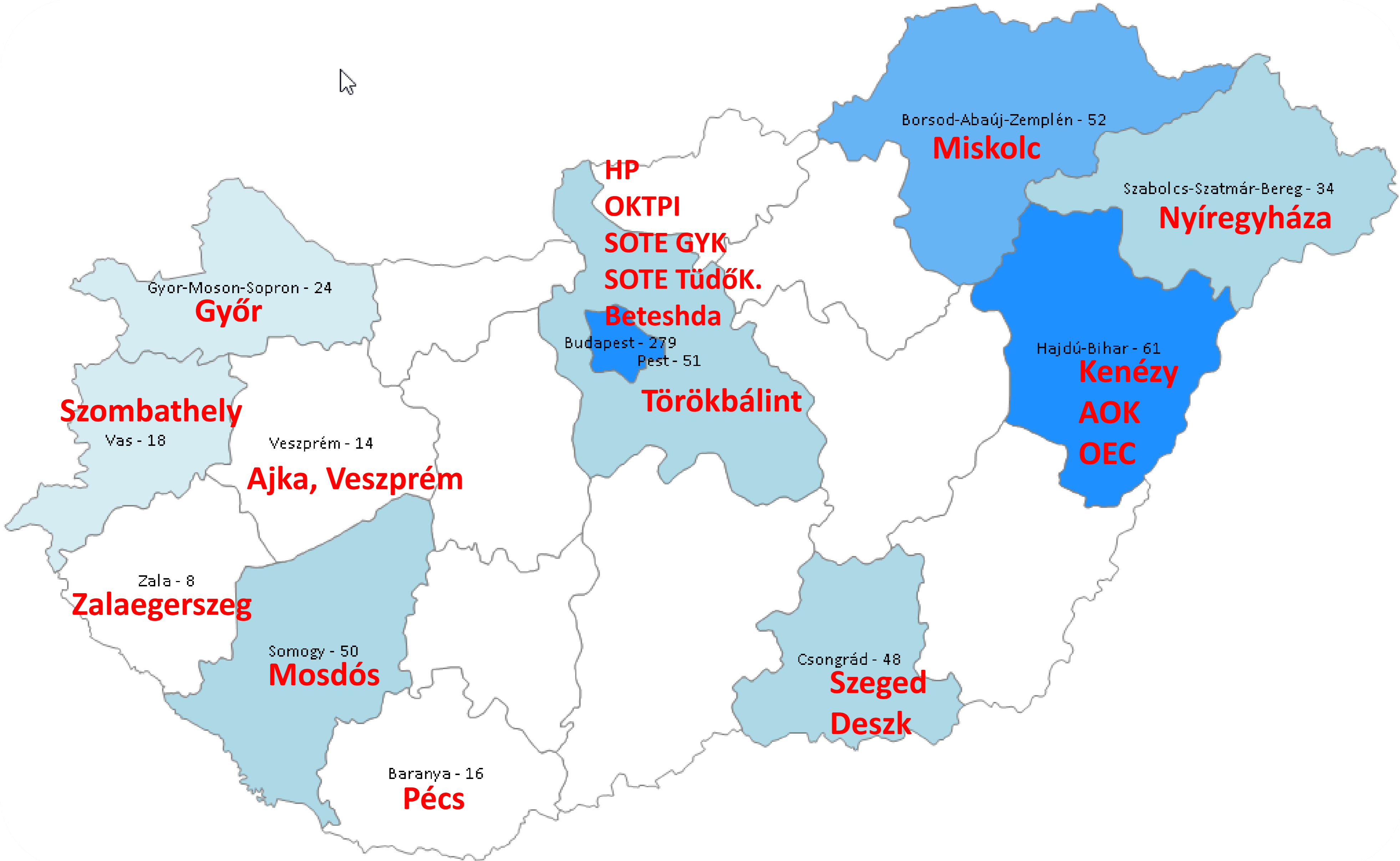
# National Registry

- 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

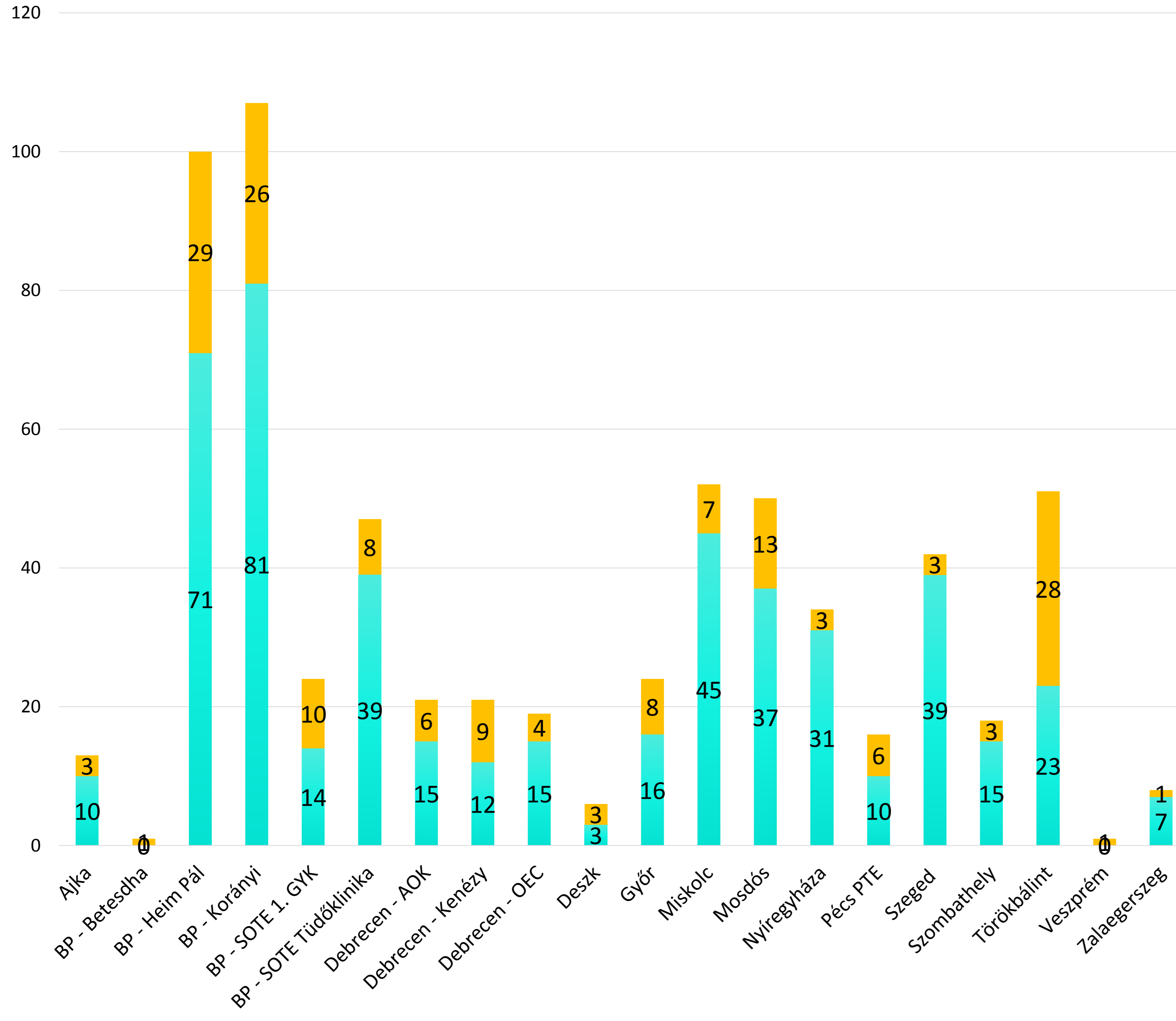


# NUMBER OF PATIENTS BY CENTERS

Center names are in red



# NUMBER OF PATIENTS BY CENTERS



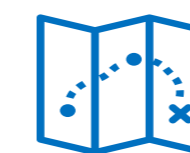
## CF CARE

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

Center1



Data sent via web



Data sent via excel



Center 2



**Fixing errors, creating unique IDs**



Central SQL Database



Reporting services,  
Custom reports, publications

# Challenges

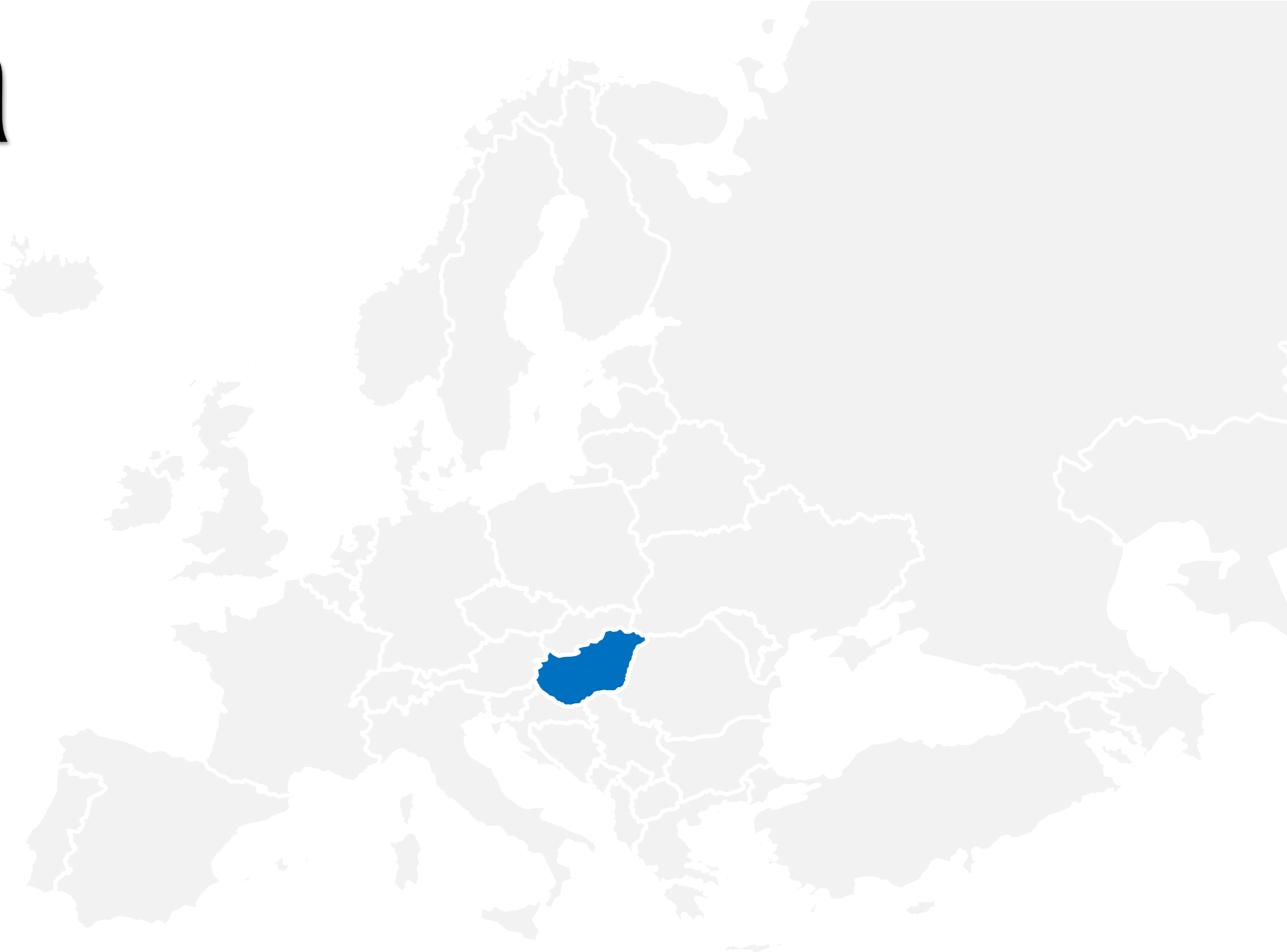
- It was very hard to proof the usefulness or its meaning **without result**  
In the first time it looked like the work what the centers invested in the data reporting it was not worth it -> resistance
- We tried to show as much as we can from the actual years data in order to show the potential of 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



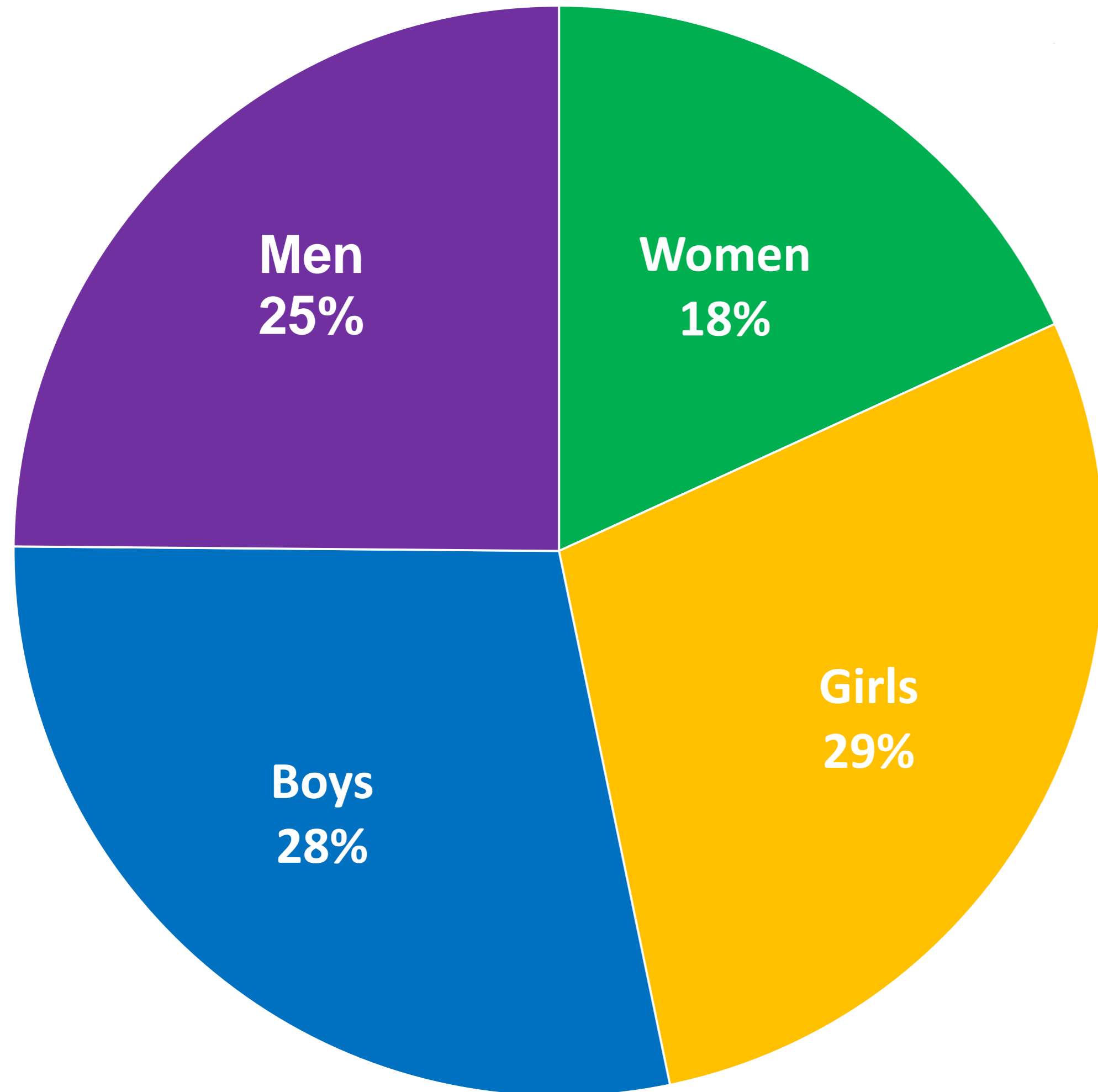


# Registry data

HU - 2015



# DISTRIBUTION BY GENDER



## TOTAL NUMBER OF PATIENTS: 567

Men: 302

Women: 265



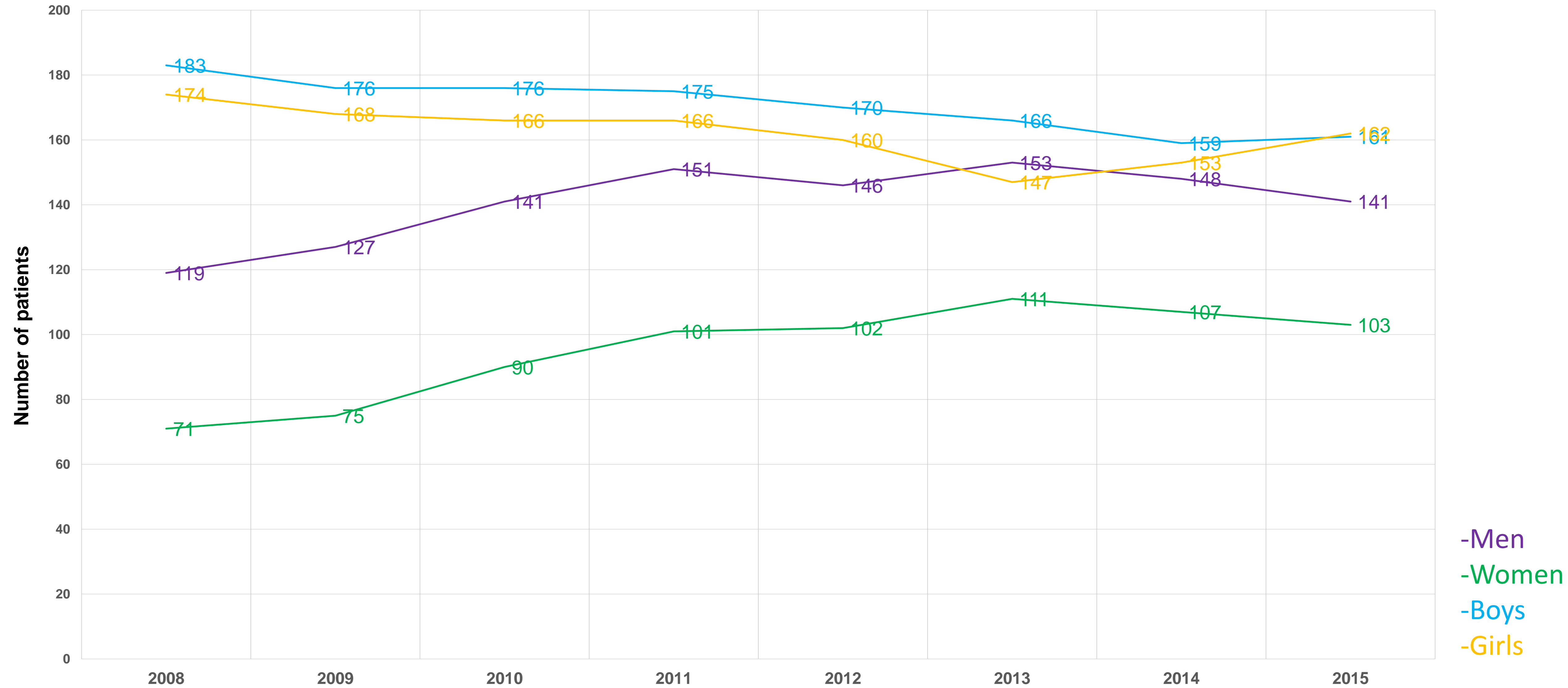
## AVERAGE AGE

Men: 17,8 years

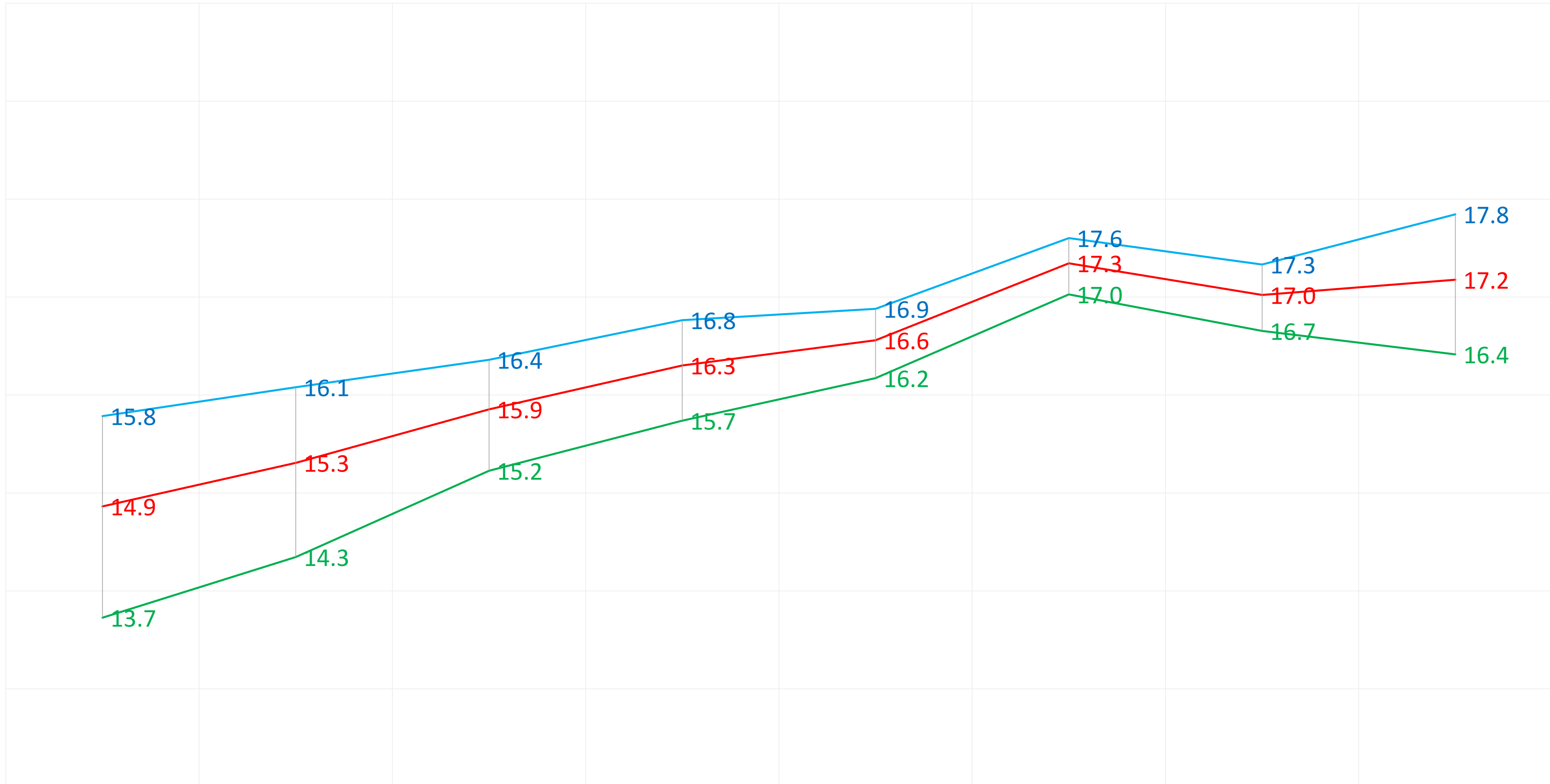
Women: 16,4 years



# NUMBER OF PATIENTS BY GENDER



# AVERAGE AGE BY GENDER



-Men  
-Women  
-All patients



# NUMBER OF PATIENTS APPROACHING AGE 18



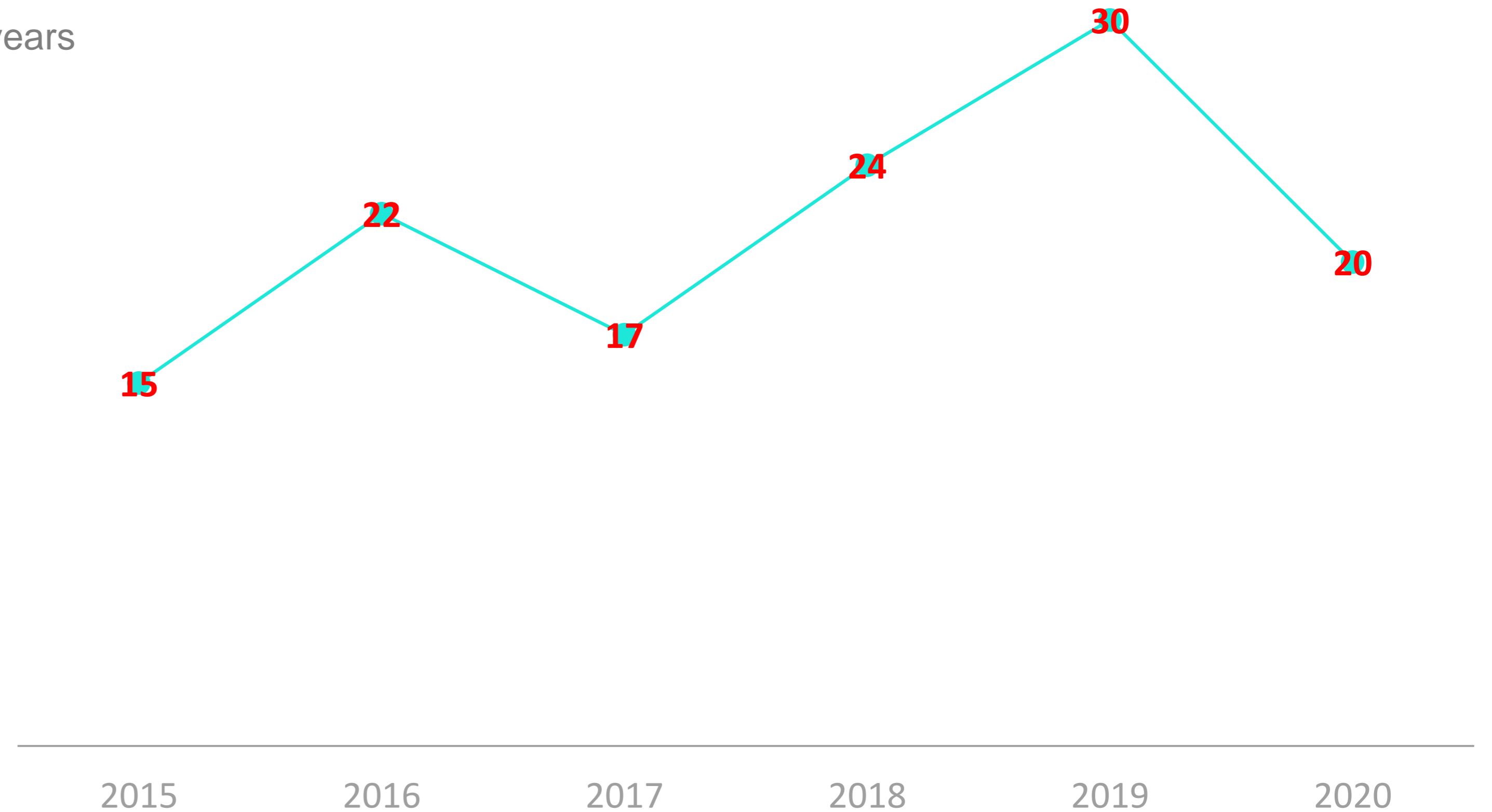
## PATIENTS TO ADULT CARE

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



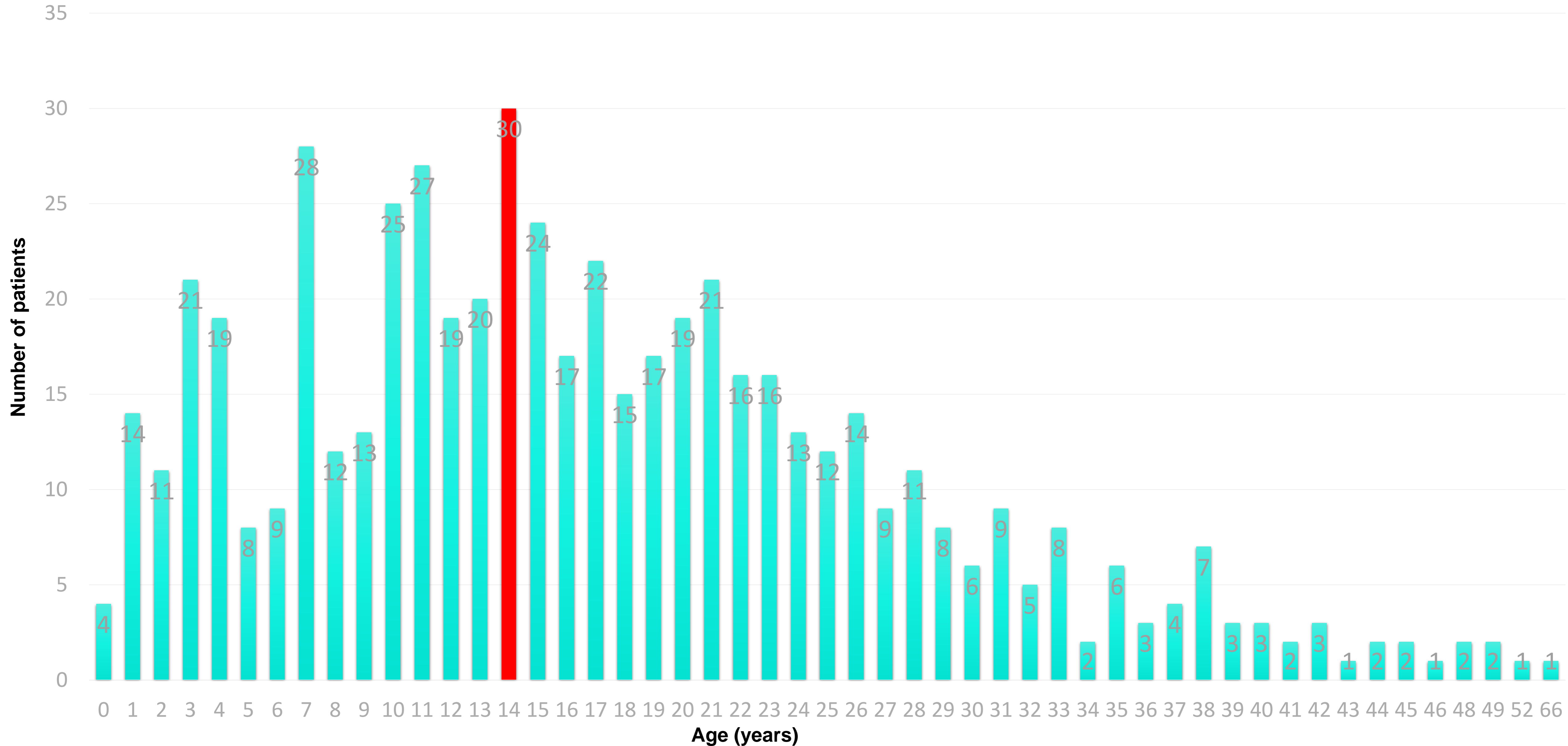
## BY CENTERS

BP - Heim Pál	4
BP - Korányi	3
Debrecen	1
Győr	1
Miskolc	2
Mosdós	1
Szeged	4
Szombathely	2
Törökbálint	1
Zalaegerszeg	1



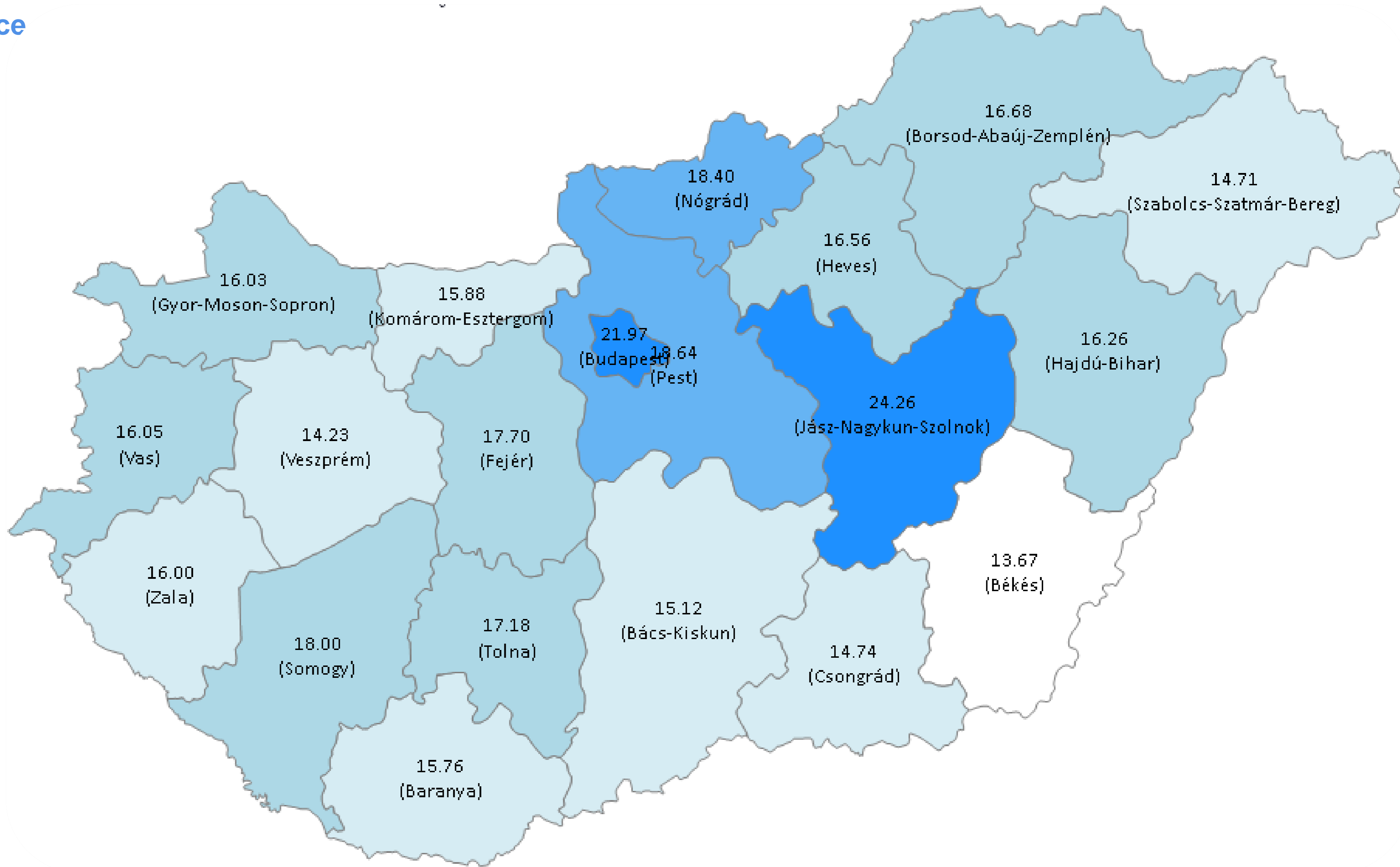
# AGE STRUCTURE

16



# AVERAGE AGE BY COUNTIES

Average age by residence



Most / least populated counties in Hungary:

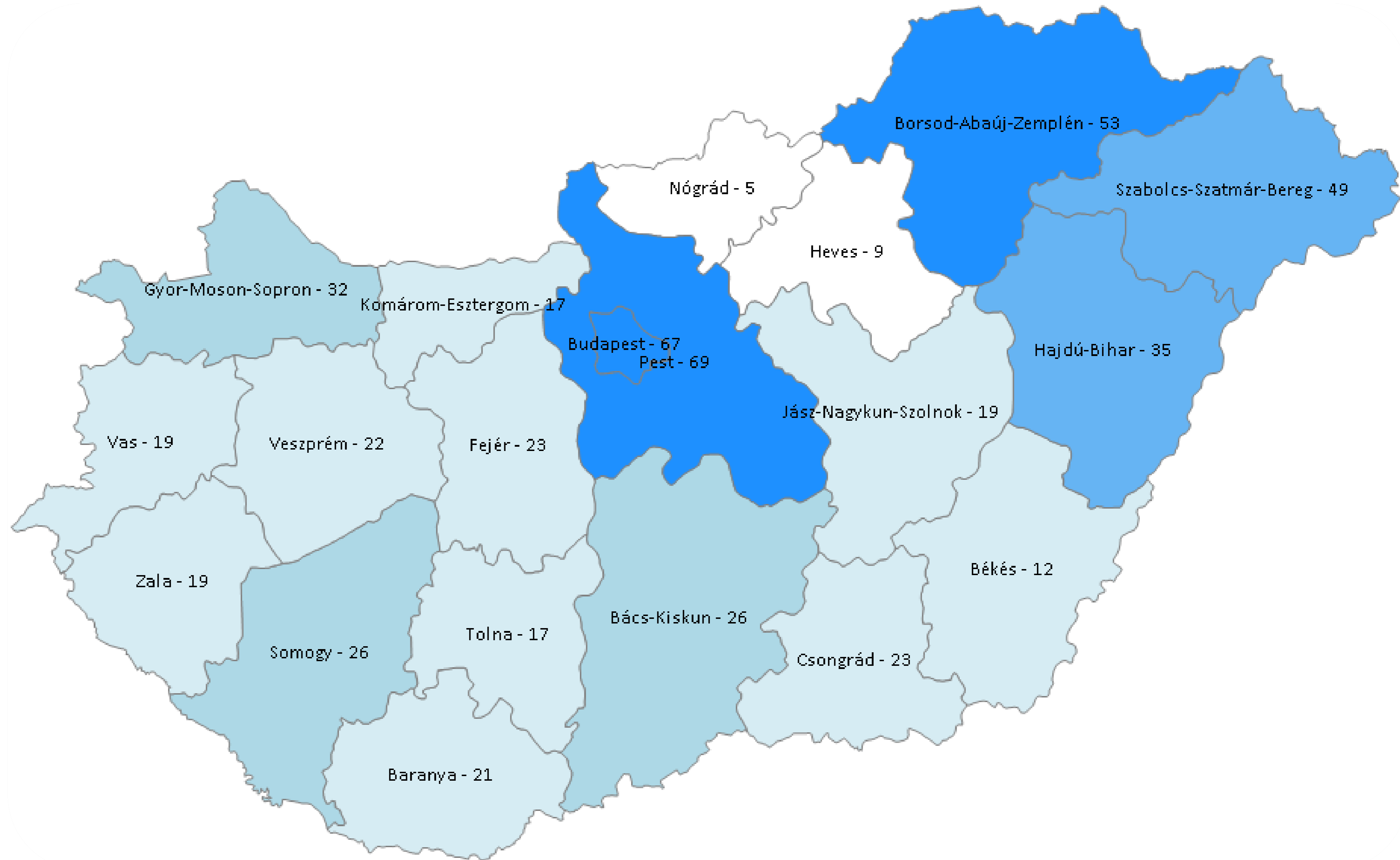
- Pest: 69
- Jász-Nagykun-Szolnok: 19
- Nógrád: 5



# NUMBER OF PATIENTS BY COUNTIES

18

Numbers by residence



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

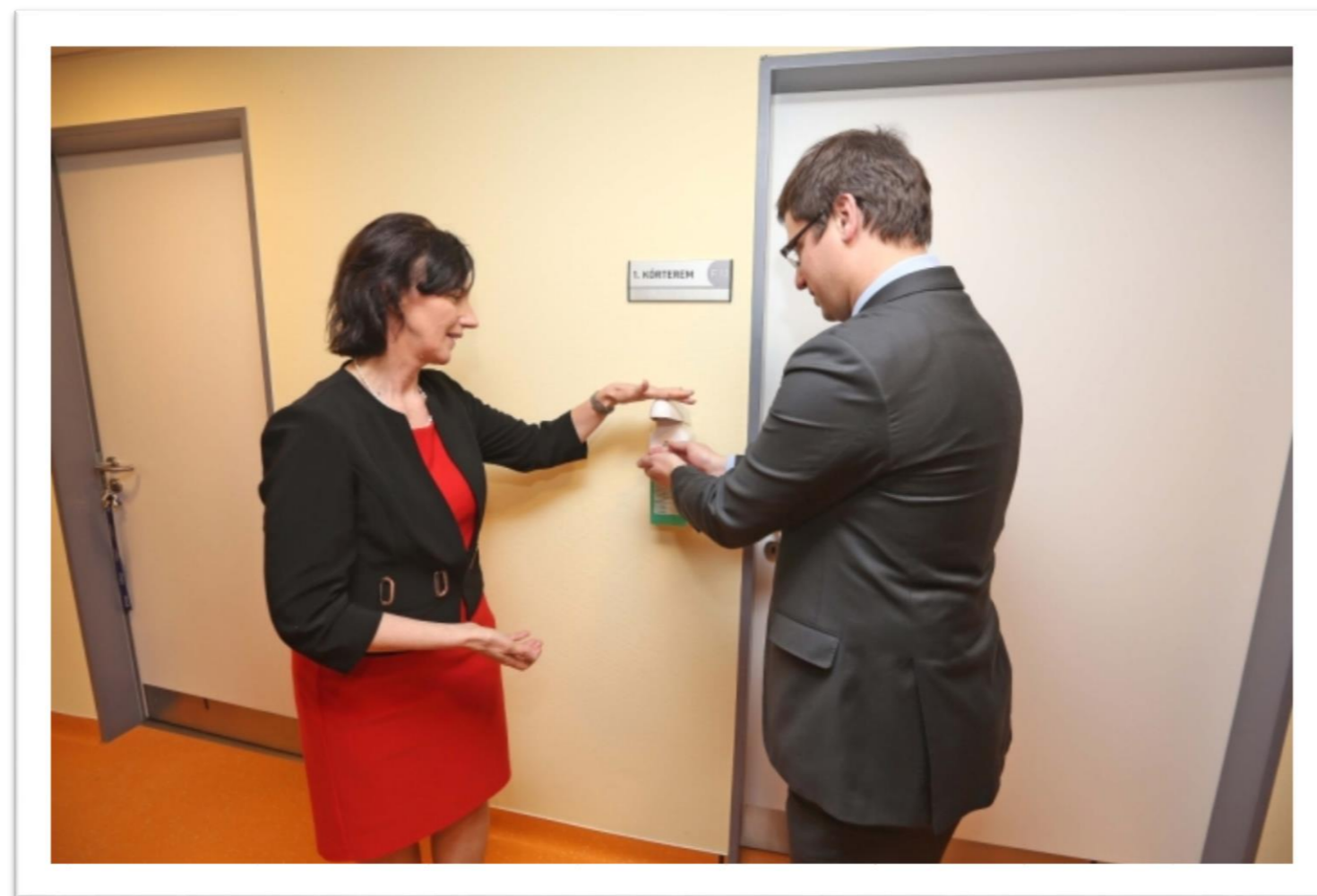
- The data reporting is based on the **consensus of the 18 care center**, there are no regulations or instructions by the law makers or by the healthcare system / government
- Hungary is still working on the implementation of the neonatal screening (we have been informed about the beginning of the pilot 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





**COLLABORATION WITH OUR NEIGHBORS**

[CONFERENCE IN HUNGARY 2017  
<http://www.bettertogether.hu> | FIRST ANNOUNCEMENT]

**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.bettertogether.hu> 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 lung 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, Tópart street 17. Hungary

**LANGUAGE:** English Scientific topics: Care of cystic fibrosis patients, Lung transplantation cystic fibrosis, meeting with patients association 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-1041 Budapest Szigeti József u. 19.  
<http://www.bettertogether.hu>  
<http://www.cisztasfibrozis.hu>

**CONTACT PERSONS**  
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Adrien Halász MD, PhD - [halaszadr@gmail.com](mailto:halaszadr@gmail.com)  
Zsuzsa S. Nagy - [zsuzsasnagy@gmail.com](mailto:zsuzsasnagy@gmail.com)  
Géza Marsal - [geza.marsal@gmail.com](mailto:geza.marsal@gmail.com)



Felnőtt Cisztás Fibrózisos  
Betegek Egyesülete



EMBERI ERŐFORRÁSOK  
MINISZTERIUMA





# 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](mailto:geza.marsal@gmail.com)  
<http://www.cysticfibrosis.hu>

