

CF centre - Croatia

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Cystic fibrosis

- most common autosomal recessive disease
- lifeshortening
- 1 in 30 Caucasians are carriers
- 1 in 3300 live births in Caucasians
- incidence of disease ranges from 1: 2000 to 1: 4000 in Northwestern Europe

CROATIA

- 150 patients

Adult CF patients

- 1/5 of all CF patients (2008.)
- men 53.9%
- women 46.1%

Adult CF centre Jordanovac 2018

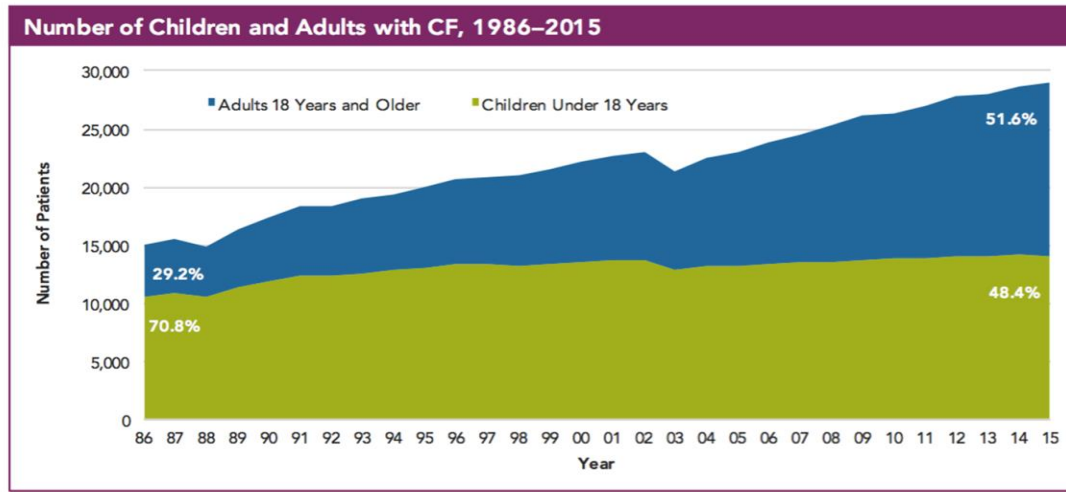
29

56% female

44% male



CF Survival Is Improving



The decrease in the number of individuals in 2003 is due to a delay in obtaining informed consent forms before the close of the calendar year at some CF care centers.

Adult CF centre Jordanovac 2018

- 24.85 y
(18 – 33 y)
- Transition from pediatric to adult CF health care occurs at a median age of 22 years.

- 2015. median survival: 41,6 y
- 49,7% > 18 years
- Newborn today may live to 5th or 6th decade

CF Center vs Primary Care: Specialized Centers

Large body of literature shows:

- Improved outcomes
- Improved survival

MULTIDISCIPLINARY TEAM

Croatia CF center

Who is included?

CF center should have close links with consultants within the hospital

specialist CF nurse
specialist doctor – a pediatrician
specialist doctor - a pulmonologist
dietitians
physiotherapists
social workers
psychologists
pharmacists
microbiologists



Gastroenterology
Hepatology
Endocrinology
Ear, nose and throat (ENT)
General surgery
Hepatobiliary surgery
Pediatric surgery
Radiology
Obstetrics and gynecology
Infectious disease
Infection control
Rheumatology
Ophthalmology
nephrology
National transplant center

Routines of CF care

OUTPATIENT CARE

- Control each 1-3 months (some every month?)

Every visit include :

- routine physical examination
- measurement of weight,height –**BMI!!!**
- oximetry
- pulmonary function tests
- **sputum**
- laboratory test - 6months, in some cases 3 months

- Chronic PA infection – separate day, at the end of the day, different location from the other patients
- NTM infection – 1patients
- Home intravenous treatment – NOT YET
- **24-h access to the CF center**

I should
contact the
CF Center



Routines of CF care

INPATIENT CARE

- Single / double rooms
- Clear infection control policy
- Physiotherapy treatment, including sputum mobilization techniques
- Psychologist
- Clear protocols for the dosing and administration of antibiotics, feeding by NGT

I should
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Image 1: Routine measurement of height, weight - BMI



Image 2: Inhalation

Physiotherapy

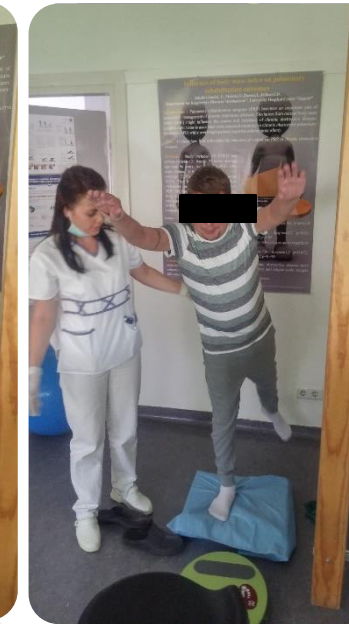
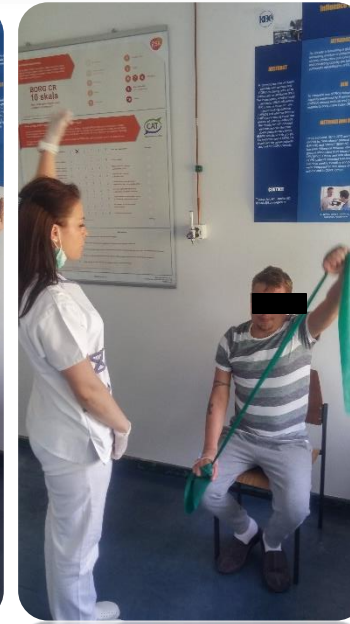




Image 3: physiotherapy -bicycle



Image 4: Nordic Walking



Image 5,6 :VEST -A respiratory system that produces high-frequency oscillations of the chest wall

Highlights of our centre

Lung transplantation program

- in collaboration with AKH University Clinic in Vienna
- Pre-transplantation diagnostic and follow-up and postoperative follow-up – Department for respiratory diseases Jordanovac, UHC Zagreb
- 68 lung transplants and 2 heart and lung transplants
- 7 CF patients – 2 died



CHALLENGES

- Segregation: LuTx / CF
- Adherence

Patient understands and agrees with therapy but has difficulty consistently maintaining regimen

Clinician-report – Questionnaires

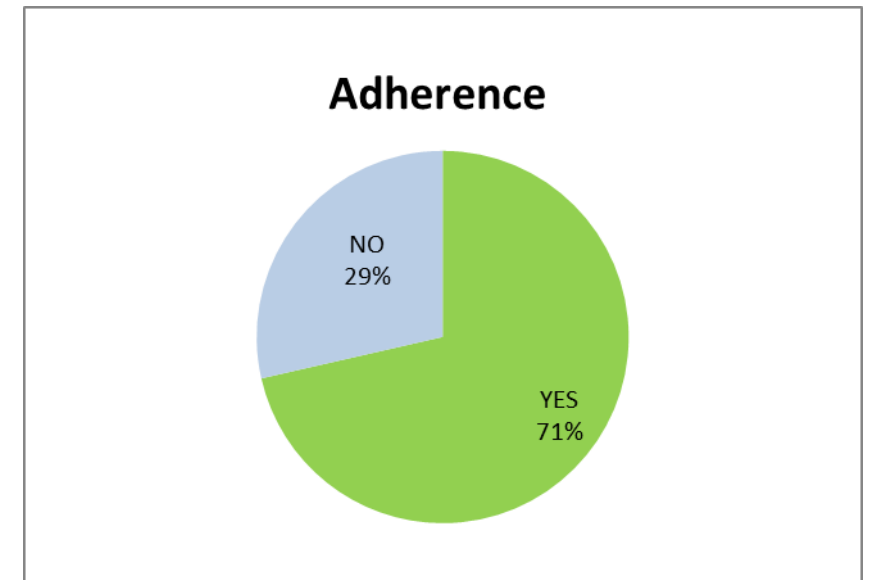
Adherence of CF patients to drugs

YES 71%

NO 29% - Reasons:

I simply forgot

I was not home



Transition care

- cooperation between CF pediatrician and CF adult pulmonologist in CF centre is the cornerstone of successful transition
- Annual Review
 - ✓ A history of all medical reports
 - ✓ A full clinical examination review by a CF specialist physiotherapist
 - ✓ Spirometry in patients over 5 years of age
 - ✓ Nutritional review
 - ✓ Blood sampling....
- CF centre meeting 1x months

People with CF age
18 years or older



Working together for you

„The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment and ensuring access to high-quality, specialized care.”

.....CF Center Croatia, is led by this mission in work

