

36th EUROPEAN CYSTIC FIBROSIS CONFERENCE LISBON, PORTUGAL Lídia Castro

12 – 15 JUNE 2013
LISBON, PORTUGAL

36th EUROPEAN
CYSTIC FIBROSIS
CONFERENCE



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INSG-CF Annual Meeting
12th June 2013 Lisbon, Portugal

- **30 Years of nurse experience**
- **Rehabilitation Nurse Specialist**
- **CF Experience 17 years**
- **Department of Paediatric Pulmonology
HSM Lisbon Portugal**



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CF Clinical Care Centres : Three

1. Lisbon (Açores / Madeira)
2. Coimbra
3. Oporto





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Total Numbers of CF Patients* – 298

- 176 < 18 years
- 122 > 18 years

- 140 male
- 158 female

Lisbon – HSM 44 (adults) 58 (paediatrics);
HD Estefânia 40 (paediatrics)

Açores – 14

Madeira – 7 (paediatrics) 2(Adult)

Coimbra – 24 (adults)HUC; (24 paediatrics)

Oporto – CHP(23 paediatrics)+(10 paediatrics);
52 H. S. João (adults)

*Portuguese Data Base



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Hospitals with Cf centers

CF Hospital's Lisbon



HSM 44 (adults) 58 (paediatrics) HD Estefânia 40 (paediatrics)



**Hospital de
Santa Maria
Adult/Paediatic**



**Hospital Dona
Estefânia
(Paediatic)**



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**7 (paediatrics);
2(adults**

Hospitals with Cf centers

14



**H. Funchal Dr. Hélio
Mendonça
Madeira**

**Ponta Delgada
Hospital do Divino
Espírito Santo
Açores**





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Hospitals with Cf centers **Coimbra**

24 (adults) HUC



Hospitais da
Universidade de
Coimbra

(24 paediatrics)
HPC



Hospital Pediátrico de
Coimbra





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Hospitals with CF centers



Hospital de S. João
Adult CF Patients
52 H. S. João (adults)

Oporto



Centro Hospitalar do Porto, EPE

Hospital de Santo António | Maternidade Júlio Dinis | Hospital Maria Pia

Paediatric CF Patients
CHP(23 paediatrics);(10 paediatrics)



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- **Screening for CF (neonatal screening) inclusion in PNDP (national programme early diagnosis)**
- **1st (2010) application**
- **2nd application (May 2011) Accepted December 2012**
- **Accepted in DGS (80%)**
- **June 2013 start of project (subscriptions/authorization)**
- **2014/2015-Approved in the national screening programme for other diseases**



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LUNG TRANSPLANT

- Lung transplantations – 2004 (CF Patients)
- 3/4 year – Sta Marta (1 paediatric)(Adult - 9 years)

First Transplant – 9 years (female 27 years; youngest 13 years)

National Total : 15 (Last 5 years)



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CF NURSES

- **CF nurses (no CF specialist nurses)**
 - **Paediatric nurse specialist**
 - **Community children's nurses**
- **Home care nurses(programme visits)**



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Useful organisations for families and Patients

**Associations : Association National de CF
(Lisbon)
Portuguese Association CF
(Vila Nova de Gaia, Oporto)**



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Useful organisations for Professional Nurses

Association:

- Paediatric nurse specialist
- Community children's nurses
 - Rehabilitation Nurse



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- # CF Meetings (2/3 last year)
- Spain - 1
 - Lisbon - 2



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New challengers

Transition consults : To improved

Annual meetings : to share information and
knowledge of nursing
practice in the treatment of
patients with Cystic Fibrosis



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**I AM
GRATEFUL
FOR YOUR
ATTENTION**

