



# Social & Medical Services Initiated by Patient Organisations

*Paula Brito e Costa*

*Casa dos Marcos – Resources Centre - Portugal*



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***“Placing one foot in front of the other, I've climbed to higher lengths. Reaching beyond my own limitations, to show my inner strength. No obstacle too hard, for this warrior to overcome. I'm just a man on a mission, to prove my disability hasn't won.”***

**Robert Michael Hensel, Born with Spina Bifida  
Guinness World Records holder for the longest non-stop wheelie in a wheelchair (6.178 miles)**

# GENERAL INFORMATION ON THE SERVICE

**Name of Service:**



**Resources Centre**

*casa dos marcos*



**Rarissimas**

**Country:** Portugal

**Type of Service:** Resources Centre

**Origins of funding:** Public and Private Funds

**Cost for beneficiaries:** For services under state contracting – free or with a co-payment up to 20% of the total price established by the State (Solidarity and Social Security Ministry and Health Ministry)

**Dates/Times of the Year:** All year long

**Target Population:** Patients, families, professionals - All diseases

**Age-Groups:** All ages

**Countries of Origin:** For services under State contracting – Residents in Portugal; Private services – all countries

**Webpage:** [www.rarissimas.pt](http://www.rarissimas.pt) ; <http://casadosmarcos.rarissimas.pt/>



# MAIN FIGURES



**Total Budget/Year: Not defined yet**

**Total Nr. of Beneficiaries/Year: Not defined yet** (depending on the Service Typology, which determines the average length of stay, to be defined in the terms of the State contracts, yet to be signed and on the afflux of people to the private services)



**Total Nr. of Permanent Staff: ~ 85**

**Total Nr. of Intermittent Staff: n.a.**

**Nr. of Volunteers/year: n.a.**



# BRIEF HISTORY

**Date of Start:** Opening foreseen by the end of 2013

**Created by patient group with support of/ in partnership with:** the construction site was made available by the Municipality. 30% of the construction works were financed by public funds (European structural funds programs with a national contribution). 70% of the 5,5 million € investment have been Raríssimas responsibility (values obtained mainly by fundraising and bank loans)

**Short History:** Raríssimas was founded in 2002 by a group of mothers of children suffering from a rare disease. It was registered as an NGO in 2003. Its headquarters are in Lisbon, but there are two other Delegations (Oporto and Azores). Raríssimas has 3 Rehabilitation Centres and a Helpline - *Linha Rara*, distinguished for the 2<sup>nd</sup> year at a European level.

Raríssimas is a founding member of FEDRA – Portuguese Federation of Rare Diseases Associations, a member of Eurordis and Cornelia de Lange Syndrom Foundation.



# GOVERNANCE AND MANAGEMENT



**Funded by: Public funds, EU funds** - Public Financing Programs promoted by the Ministry of Solidarity and Social Security as well as the Ministry of Health; **Private funds** – companies, individual donors and revenue from its rehabilitation activities

**Governance structure:** Raríssimas has 3 formal bodies – the General Assembly, the Audit Committee and the Board of Administration. The Board has 5 elements, all of them either patients themselves or patients relatives (mothers, mainly). Raríssimas also has 2 other formal structures: the Scientific Council and the Advisory and Strategic Council.

Casa dos Marcos will have a Board of Administration as well, but dependent on the Association Board, General Assembly and Audit Committee. The First Lady has joined the project – formal high level institutional sponsorship.

**Are medical experts involved in the governance process?**

Yes.

**How many?** Directly involved – 3

**What is their role and their scope of action?**

- 1 - Clinical Director – Global Supervision; Member of the Board;
- 1 – Rehabilitation Director – Service organization and supervision
- 1 – Scientific Director – Advisory, strategic planning and institutional representation in Scientific Committees and events.

Responsible for the Research Unit.

# QUALITY ASSESSEMENT

## **Are patients evaluating the service after attending?**

The team is finishing the design of all necessary documents and an evaluation questionnaire model for the patients' or/and patient's families is under revision.

## **Is the service accredited by any authority performing quality control?**

It will be. The licensing process is quite demanding and it involves several institutions: The funding Ministries services; the Town Hall services; Civil Protection; Energy suppliers certified companies and official regulating agencies.

**Is the service connected to a Centre of Expertise/Hospital?** Not formally yet. There are only 3 Centres of Expertise nominated by the Health Ministry, all in Central Hospitals from the National Health Service, exclusively dedicated to Lissosomal Diseases.

Raríssimas has always worked close with the national health service institutions and professionals and this relation tends to be strengthened .





# CASA DOS MARCOS –THE PROJECT



*A child 's dream...  
a mothers' fight...*





# CASA DOS MARCOS IN THE NATIONAL FRAMEWORK

Governmental Body	Solidarity and Social Security Ministry	Health Ministry
Target Population	(Deficiency/Impairment)	(In need for medical/nursing care)
Typified Services	Domiciliary Support	•Acute Care – Hospitals
	Occupational Activities Centre	•Primary Care Services
	Family Foster	•Continuity Care (after Hospital discharge)
	Residential Units	✓Convalescence;
	Transports	✓Rehabilitation;
	Vacation Centres	✓Long-term and maintenance;
	Ambulatory Support	✓Paliative
Users'/Patients' Referral Process	Waiting list defined by Social Security and service institution criteria (as defined in internal regulation)	Local Coordinating Groups, gathering professionals from hospitals, primary care and social services
	Raríssimas is negotiating an atypical model in which the referral would be autonomous	
Casa dos Marcos Services and Business Model	Residential Unit - 24 users - SC	Continuity Care - 39 patients - SC
	Autonomous Residential unit - 5 users - SC	Ambulatory Care - PS
	Occupational Activities Centre - 45 users (30 -SC; 15 - PS)	Rehabilitation Unit - PS
	Respite Centre /Health Tourism - 9 users - PS	

Public/State Contracting – SC

Private Services – PS

# ASSISTANCE MODEL

- Raríssimas has tested Casa dos Marcos' conceptual model through Centros RarÍSSIMOS' activity and has heard the patients' and families needs through Linha Rara Helpline.
- Casa dos Marcos is an integrated response, gathering social, clinical and educational services.
- Casa dos Marcos will have highly specialized intervention programs both on a resident and ambulatory regimens.



# ASSISTANCE MODEL - II



Residential Unit	24 patients
Autonomous Residential Unit	5 patients
<b>Occupational Activities Centre</b>	<b>45 (30+15)patients</b>
<b>Respite Centre</b>	<b>9 patients</b>
<b>Clínical Unit (ambulatory care)</b>	<b>Opened to the Community</b>
<b>Rehabilitation Centre (ambulatory care)</b>	<b>Opened to the Community</b>
Continuity Care Unit	39 patients
Research Unit	



# RESIDENTIAL UNIT



This is a social response aimed at people over 16 years old, under the tutelage of Social Security.

Casa dos Marcos' Residential Unit has a capacity for 24 people.

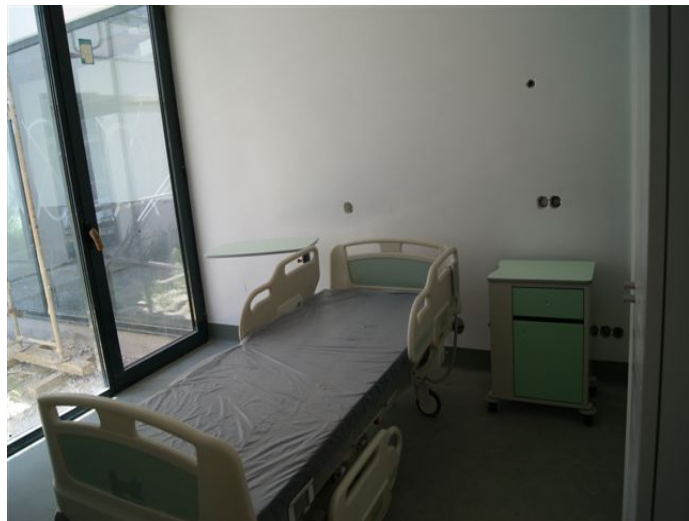


# OCCUPATIONAL ACTIVITIES CENTRE



This is a social response under the tutelage of Social Security Services, thought for patients who have completed their mandatory attendance at public school, but who need to keep being stimulated and exposed to activities adapted to their specific condition. This is a school inside Casa dos Marcos for patients over 16. We have place for 45 people, 30 under protocol with the Social Solidarity Ministry and 15 for private profiteering, thus helping us assuring our financial sustainability.

# RESPIRE CENTRE



The Respite Centre Service has no formal frame in Portugal, although Raríssimas has been struggling for the governmental institutions' recognition of its imperative need.

Casa dos Marcos has a capacity to receive 9 patients, offering the social/educational activities as well as medical, nursing and rehabilitation care during a patients' stay.

# CLINICAL UNIT (AMBULATORY CARE)

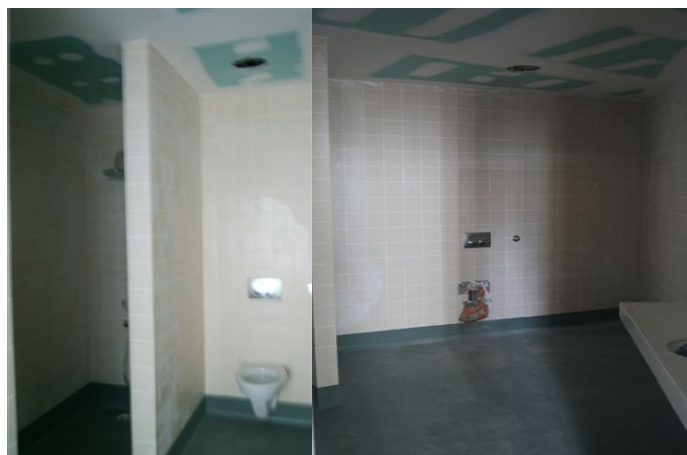


This unit will receive patients for a first evaluation or follow-up in consultation environment, making available a wide range of medical specialities and therapeutic professionals.

This service will also respond to community needs.



# REHABILITATION UNIT (AMBULATORY CARE)



This unit works with patients on their rehabilitation and capacity building processes through a personalized approach. There will be an Early Intervention Unit, specially focused on children's problems from their birth until 6 years old

Physiotherapy gym will be opened to the community.



# CONTINUITY CARE UNIT



Under the tutelage of the Health Ministry, this Unit is prepared to receive patients after hospitalization, as well as patients whose clinical condition does not allow them to stay at home when special care conditions are in demand.

Casa dos Marcos has an installed capacity for 30 patients.

# RESEARCH UNIT



Having collaborated with several Universities and Research Centres of excellence, from which IMM and CEMBE must be pointed out as remarkable *Friends*, Raríssimas decided it's time to focus on the systematization of the data produced by its services and professionals and formally constitute a multidisciplinary research team to produce scientific knowledge in the social and clinical areas.



# PRIVILEGED LOCATION FOR HEALTH TOURISM DEVELOPMENT

Offices of Economics, Employment and Health Ministers – Despacho nº  
15689/2012 (December)

## Casa dos Marcos' Strategic Location

Setúbal

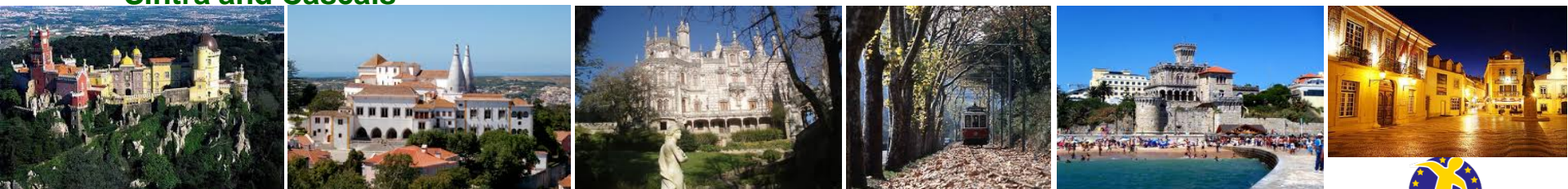


Casa dos Marcos is strategically located in the Setubal's peninsula, only 30 minutes away from Lisbon (and Lisbon's airport).

Lisbon



Sintra and Cascais



# PUBLIC MAECENAS



Ministério da Solidariedade  
e da Segurança Social



Ministério da Saúde



Programa de Alargamento  
da Rede de Equipamentos Sociais



PROGRAMA OPERACIONAL **POTENCIAL HUMANO**



UNIÃO EUROPEIA  
Fundo Social Europeu





# PRIVATE MAECENAS



SANTA  
CASA

Misericórdia de Lisboa. Por boas causas.



# RESEARCH UNIT

## Headquarters

Address: R. das Açucenas, Lote 1, Loja Dta. 1300-003 Lisboa

Telephone: 21 778 61 00 / 96 965 74 45

Fax: 21 778 61 99

Email: [info@rarissimas.pt](mailto:info@rarissimas.pt)

## North Delegation

Address: Pta. Arqº Mário Bonito, 75/77 4475-358 Milheirós - Maia

Telephones: 22 960 84 63 / 9613 25 628

Fax: 22 960 84 63

Email: [porto@rarissimas.pt](mailto:porto@rarissimas.pt)

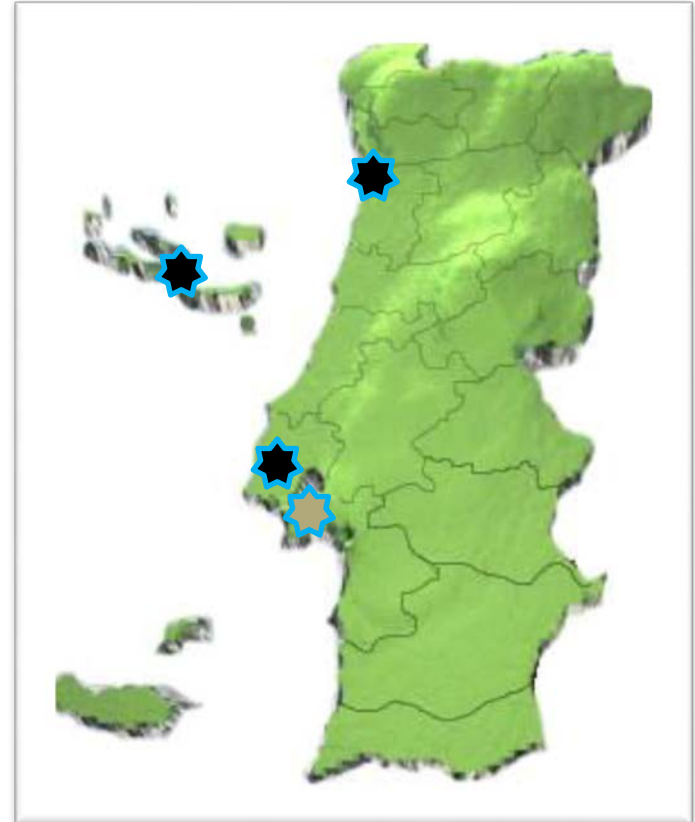
## Azores Delegation

Address: R. do Cais, 25 Apartado 42 9940-355 São Roque do Pico

Telephones: 292 642 711

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***Thank you!***  
**ObrigadÍSSIMA!**

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