Social & Medical Services
Initiated by Patient Organisations

Paula Brito e Costa
Casa dos Marcos – Resources Centre - Portugal

EURORDIS Membership Meeting 2013
1st June, Dubrovnik
“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)
**Name of Service:** Resources Centre

**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/](http://casadosmarcos.rarissimas.pt/)
Total Budget/Year: Not defined yet

Total Nr. of Beneficiaries/Year: Not defined yet (depending on the Service Tipology, 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.
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 2nd 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.
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.
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.
A child’s dream… a mother’s fight…
## CASA DOS MARCOS
### IN THE NATIONAL FRAMEWORK

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

Public/State Contracting – **SC**  
Private Services – **PS**

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EURORDIS Membership Meeting 2013 Dubrovnik  
Workshop 10 – Social & Medical Services initiated by patient organisations
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

<table>
<thead>
<tr>
<th>Service</th>
<th>Patients</th>
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</tr>
<tr>
<td>Autonomous Residential Unit</td>
<td>5 patients</td>
</tr>
<tr>
<td><strong>Occupational Activities Centre</strong></td>
<td>45 (30+15) patients</td>
</tr>
<tr>
<td>Respite Centre</td>
<td>9 patients</td>
</tr>
<tr>
<td><strong>Clínical Unit (ambulatory care)</strong></td>
<td>Opened to the Community</td>
</tr>
<tr>
<td>Rehabilitation Centre (ambulatory care)</td>
<td>Opened to the Community</td>
</tr>
<tr>
<td>Continuity Care Unit</td>
<td>39 patients</td>
</tr>
<tr>
<td>Research Unit</td>
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</tbody>
</table>
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.
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.
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.
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.
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.
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.
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

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Thank you!

ObrigadÍSSIMA!

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