Rare Disease Patient Solidarity

EC 2005120

Update on the Rapsody project

François Houyéz
On behalf of Terry Dignan

Barretstown
Rapsody work package 6

4th European Conference on Rare Diseases
Lisbon, November 27th-28h 2007
Participants
work package 6 of the Rare Disease Patient Solidarity Project
Rapsody

Shane Lynam
François Houÿez

May 1st 2006
April 30st 2008

DG SANCO

Georges Biheng

Terry Dignan

Gerlind Bode
Oliver Engel

Special support from the Baxter International Foundation

Francesca Magnomi
Sierra Porcari

Therapeutic Recreation Programmes ECRD 2007 Lisbon
Why therapeutic recreation programmes?
A quality of life issue

• “Camping” programmes afford children with chronic illnesses, and their siblings, the opportunity of spending time in supportive environments where they participate in a variety of recreational activities.

• In so doing, they seek to provide a positive experience for these children and this, in turn, may have a salutary impact on their physical, psychological and/or social well-being.
• In aggregate, the models convey that in assessments of the impact of therapeutic recreation services including camping programmes, important domains to measure are:
  ▪ (1) quality of life
  ▪ (2) physical functioning as it pertains to health status
  ▪ (3) psychological functioning, for example, cognitive and emotional well-being and self-esteem
  ▪ (4) social functioning, particularly social skills
  ▪ (5) leisure functioning
The main objective of a therapeutic recreation programme

• Entertainment! Fun! Leisure! Recreation!
In an environment that differs from day to day life

Fondazione Dynamo, Italy

Bator Tabor, Hungary

Barretstown, Ireland

Belušské Slatiny, Slovakia

WaldPiraten, Germany
Objectives

- American camping programmes have acted as a template for the development of European camping programmes.
- However, there is little information, especially within a European context, regarding the nature of these programmes, and a limited body of evidence regarding their effectiveness.
- Thus:
  - To create a European network of Therapeutic Recreation Programme for children and young adults living with a rare disease, with a database
  - To link this network to the European Camp Association
  - To identify rare diseases organisations running such programmes
  - To propose quality standards
  - To increase awareness on the existence of these programmes
  - To improve efficiency and training in order to ensure a solid basis to develop hosting capacities in the future
New programmes identified

- **France:**
  - ALPAS
  - Association Service Loisirs Vacances
  - ASRIM
  - AFDE
  - AFH
  - ASSYMCAL
  - VML
- **Norway:**
  - Frambu
- **Slovakia:**
  - Organizácia muskulárnych dystrofikov v Slovenskej republike
- **Belgium:**
  - International NF summer camps for teens
- **United Kingdom:**
  - The Calvert Trust Exmoor and Kielder
- **Italy**
  - Antonello Viti De Angelis
  - Associazione Sindrome di Crisponi e Malattie rare
  - Associazione Bambini Cri du Chat Onlus
  - Associazione Cornelia de Lange
- **Germany:**
  - Bundesverband Herzkranke Kinder e.V
  - Kindness for Kids
  - Kleine Helden e.V.
  - BVHK-Geschäftsstelle
- **Spain:**
  - Eusebio del Castillo Romay
A larger network

www.rapsodyonline.eu
Collection of information on the programmes

- **People served**
  - Season of the year, caregivers/siblings, countries ….

- **Camp programme staff**

- **Volunteers**
  - Total number, % return volunteers, age range…

- **Campers on waiting list**

- **Programmes**
  - Activities, hospital outreach programme, bereavement session…

- **Training**
  - Staff, volunteers, professional development staff receives…

- **Funding**
  - How are stays funded (direct fees, charities, private companies, public health budgets)
Collection of information on medical aspects

• Diseases groups
  • blended or single-disease sessions, unexpected challenges or rewards, most costly session to host...

• Medical staff
  • Average camper/medical staff ratio, medical volunteers’ training, psych/social person on staff, full time year round or seasonally employees...

• Supplies
  • Top medical supplies needed as a donation, items available for swapping with other camps

• Research
  • Research projects

• General
  • Instances when outside (off-camp) medical help was sought, How far away is the hospital to which you transport in an emergency
Some activities

- **Sport**
  - High Ropes Course, Tree Climbing, Mountain bike / Tandem, Canoeing, Archery, Diving, Rowing, Horse Riding
- **Handicraft**
  - Woodwork, Pottery, Mosaics, Crafting juggling material, Jewellery, Painting
- **Other**
  - Swimming, Visiting the city, Movie, Radio station, Disco, Casino, Theatre, Beach party, Photography
Some European Camp Association activities in 2007-2008

- Outreach programme at Barretstown to serve more children and children that are more seriously ill.
- Criteria: Any camp wishing to become a member of the Association will have to meet criteria in three areas – Programme, Medical and Facility (01/2008)
- European Standards: a set of minimum standards for camps and programmes working with children with serious illness in Europe
  - This summer two such camps (L’Envol France and OTW UK) were assessed against this template.
  - In 2008 two more camps (Bator Tabor Hungary and Limestre Italy will be assessed
- Int. Conf. on Therapeutic recreation for children with serious illness and other special needs
- New Camps: 2 new camps for children with serious illness
  - Villa Sans Souci– Germany and the Haven-Romania
- Research: Barretstown with the University of Nottingham to conduct a longitudinal research study into the benefits of Therapeutic camp programmes for children with serious illness (Study will be completed at the end of 2009)
- Bator Tabor (Hungary) with Barretstown to develop an international programme.
Rapsody WP6 deliverables

A brochure

An online cartography

A network

A survey

Joint US/EU collaboration on standards for Therapeutic Recreation Programmes

EXECUTIVE GENERAL

Note: All questions refer to 2005 figures unless otherwise specified.

<table>
<thead>
<tr>
<th>Question</th>
<th>2005</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pay scales for Program staff position / scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pay scales for Executive staff position / scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Include a copy of management organizational chart</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much time off are FTE staff given</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much time off are seasonal staff given</td>
<td></td>
<td></td>
</tr>
<tr>
<td>List any professional development opportunities provided</td>
<td></td>
<td></td>
</tr>
<tr>
<td>List your top 5 redesigns to the camp's physical structures/facilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>stray from the master architectural plans (both what has already</td>
<td></td>
<td></td>
</tr>
<tr>
<td>been completed and what is planned for future completion)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual cabin capacity (children / adults)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Where is your laundry facility located</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is your laundry facility's capacity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What type of sound system do you have in your dining hall</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What type of sound system do you have in your theatre</td>
<td></td>
<td></td>
</tr>
<tr>
<td># of staff living on site year round</td>
<td></td>
<td></td>
</tr>
<tr>
<td>List any charges levied for living on site year round</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Size of property</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Size of lake</td>
<td></td>
<td></td>
</tr>
<tr>
<td># of golf carts and other vehicles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is the longest distance a camper must walk during the day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>from one point to another distance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who manages Food Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food Services annual budget</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily per camper food budget</td>
<td></td>
<td></td>
</tr>
<tr>
<td>List any non-profit alliances</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Completed by: Date: ___________________________________________________

CEO approval: Date: ___________________________________________________

Therapeutic Recreation Programmes ECRD 2007 Lisbon
Campers’ statements

• I can trespass my borders.
• I can do something, even if I haven’t done it before.
• I can get along well with the others!
• First I have to get to know the other kids, before I judge them.
• I can count much more on others than I thought I could before.
• Now I know how it feels, to have real good friends.

• WaldPiraten Camp