CF school

Ten years experience in patient education of families with a child/adolescent suffering from cystic fibrosis (CF)

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Main purpose: to give the children/adolescents a good basis for making informed choices on how to live their lives with CF

- Knowledge about CF
- Good coping strategies
- Sense of responsibility

Groups of 4-8

5-year-olds

3 lessons of 3 hours in 3 successive months
Supplement to the parents’ preparation of the children for preschool.

Purposes:
- Let the children be together with other children with CF
- Let the children do physiotherapy together
- Let the children eat and take enzymes together

Teachers:
The nurses are the key persons. They teach together with:
- The physiotherapist
- The dietician
- The doctor
- The psychologist
- The social worker

10-year-olds

6 lessons of 3½ hours every second month for one year
- Teaching in CF e.g. the respiratory and digestive systems
- Practical things e.g. cooking, swimming, physical exercise
- Games and play e.g. quiz about CF
- Talking about responsibility

Topics:
- Siblings
- Sports

14-year-olds

6 lessons of 4 hours every second month for one year
- Teaching in CF
- Practical things e.g. shopping in the supermarket
- Psycho-social topics e.g. life stories, openness about CF, dreams about the future
- Talking about responsibility

Topics:
- Out of school and then what?
- Transition
- Growing up and having children

Have attended the CF school until now:

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-year-olds</td>
<td>21</td>
</tr>
<tr>
<td>10-year-olds</td>
<td>51</td>
</tr>
<tr>
<td>14-year-olds</td>
<td>36</td>
</tr>
</tbody>
</table>

Every child born in 1985 or later have been/ will be offered to attend CF school:

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Declined</th>
<th>Dropped out</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-year-olds</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>10-year-olds</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>14-year-olds</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

Annual meetings:
each established group meets 1 day per year
- in between attending CF school for the 10-year-olds and the 14-year-olds

Topics:
- Siblings
- Sports

- after finishing the school for the 14-year-olds

Topics:
- Out of school and then what?
- Transition
- Growing up and having children

CF Center, Aarhus, Denmark:
86 patients < 18 yrs.
Chron. Pseud. A.: 7
Burkhold. Cepacia: 2
Multires. Pseud. A.: 0
MRSA: 0

Infection control:
To attend the CF school the patients with Pseud. A. must be in treatment.
No patients with Burkhold. Cep., Multires. Pseud. A. or MRSA can attend CF school together with other CF patients.