421 A CF kit for kindergarten

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Introduction: Two years ago, we developed an educational kit for primary schools. While presenting this project, parents asked us about the same kind of material, but addressed to children and teachers of kindergarten. The goal of this kit is to give teachers and peers of CF kids a better understanding of CF, adapted to the cognitive level of toddlers.
Methods and Contents: Teachers and educational specialists with CF experience, together with CF kids and families, developed this kit. As in all our educational materials, the kit is built up around 2 imaginary figures, Robin (a boy with CF) and his friend, the parrot Peps. Several CF families tested it before being finalized. This project focuses on offering plain information about CF, to raise awareness of the disease, not to explain it in detail.
The kit (French and Dutch version) offers guidance to teachers, with many teaching tips and materials (stories, games etc.), which can be used in class. For the pupils there are a puppet play to introduce the subject and worksheets with simple games and drawings that can be colored, so they can learn in an enjoyable way about CF. In conjunction with this kit there is a backpack with concrete material and a set of large hand puppets. There are also several brochures available for the teachers, a brochure for the parents explaining, e.g., how they can choose a school or how to inform the school about CF and finally a letter for the parents of classmates.
All materials are provided for free by the CF association and can be used autonomously by the schools.
Results: Teachers and parents were informed via the BCFA newsletter and a national journal for teachers (Klasse). Within a month, over 60 schools have asked for this kit. Remarkably, most of the schools are kindergartens without a child with CF, who use it to inform children about illness and health.

422 Developing an educational package for CF children aged 6–12, in order to improve their compliance

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Introduction: During psychological consultation, 20 CF children aged 6–12 were observed. More than 25% have problems with compliance. Interviews with children, parents and caretakers are reporting that (1) children showed a lack of knowledge about their own medical condition due to overestimation of their comprehension by adults; (2) medical hospital approach tended to underestimate the influence of the psychosocial context.
Aims: Aim is to develop an integrated educational package for cf children introducing cognitive and psychosocial topics.
Methods: We explored existing material in the Flemish region, and employed some elements in the new package. With support of the Belgium Association for Cystic Fibrosis, we involved a professional author and illustrator of children storybooks.
Results: Result is a modular package referring to the cognitive and psychosocial elements of education. First module is a comprehensive encyclopedia about CF with a guideline for parents and caretakers. A lot of pictograms are used to visualize some complex information. These will be used to label medication and therapeutic tools involved in CF treatment. The second module is a storybook that issues the psychosocial aspects of living with CF in a real life context. The package will soon be implemented and tested in the actual hospital setting.
Conclusion: CF children in the hospital are in need for a better education in order to improve compliance. An integrated and structured approach attending cognitive and psychosocial elements need to be developed and tested.

423 "School starts: let's go on" – Preliminary results of a study on the need of follow-up neonatal screening psychological support program

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Aims: Cystic Fibrosis (CF) emotionally affects not only the personal growth of children but also their parents'. Indeed, parents who have chronically ill children tend to have the ability to control their day to day mood, as they must be able to control the negative consequences of the illness. To evaluate the frame of mind of screening-diagnosed CF children's mothers who are going through their first experience of letting go of their children (first day of school) and to verify if the level of anxiety and neuroticism is stronger in mothers who have CF children as opposed to mothers who have healthy children.
Methods: To evaluate the anxiety dimension and neuroticism index, the M.H.Q. (Middlesex Hospital Questionnaire) and Luscher Tests were administred to mothers of screening-diagnosed CF children who are attending the first year of the nursery school or of primary school, followed by the CF Center of Tuscany in Florence or by the CF Unit in Leghorn (experimental group). The same tests were administered to mothers of healthy children at their first school experience too.
Results: So far we administered 28 tests. Mean neuroticism index was 35.7 (SD 14.6) in 14 CF children's mothers and 27.4 (SD 15.1) in 14 non-CF children's mothers ($p = ns$).
Conclusions: Preliminary results, although not statistically significant, evidence that CF children's mothers show higher levels of anxiety in relation to letting go their kids to school. This confirms the importance of a psychological support in CF screening programs not only at diagnosis but also during children growth.

424 Education of parents with young Cystic Fibrosis children less than 5 years old

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Introduction: We report our experience of meetings with parents of recently diagnosed CF children either after neonatal screening or after initial symptoms. The aim of these meetings was to answer to their questions, to organize meetings with experts and to allow exchange between families.
Materials: Following the first gathering, requested by the families, we continued to organize regular meetings with topics chosen by them. Appropriate experts to the chosen fields of discussion were invited. The whole health team involved in the care of the CF children also participates. These meetings take place during 1 whole day, allowing the possibility to lunch together.
Results: The following topics have been discussed: physiotherapy, home hygiene, dietary care, school, dealing with healthy brothers and sisters, psychological aspects, considering a pregnancy after having had a CF child, living with 2 CF children, meeting with an adult patient. The participation of the families increased regularly.
Conclusion: These meetings allow an exchange at a different level among families and with the nursing staff. This helps the parents to break their feeling of isolation at the announcement of their child's diagnosis as well as the difficulties in coping with daily care. The interaction with the expert allows families to better understand the issues and thereafter get more deeply involved in the daily care. For the health team, it allows better relationships with the child environment and better therapeutic management. These meetings have allowed us to sense the intensity of the problems – often underestimated – that these families encounter in their daily life.