



NEWSLETTER OF

**THE EUROPEAN NETWORK FOR
CHILDREN WITH ARTHRITIS AND
ASSOCIATED DISEASES**
www.enca.org

2008, September



Dear friends,

It is a long time ago that an ENCA newsletter was published.

But now we would like to give you a report of what has happened during the last months.

All over that you will find some reports from different member associations of ENCA.

In 2007 the ENCA group met at the PReS congress in Istanbul where we elected a new board.

Chairman:	Carla Hoekstra. (Netherlands)
Vice-chairman:	Sunil Ramdewor (France)
Treasurer:	Hanny Weustenraad (Netherlands)
Secretary:	Caroline Cox (UK)

Claudia Grave (Germany) was selected to the PReS representative in order to cover the needs of the families with rheumatic children and juveniles within the council of PReS.

Since Istanbul we have had very intensive and successful contact with PreS so that now much more awareness is taken to the parents, including the possibility of a presentation within the scientific programme.

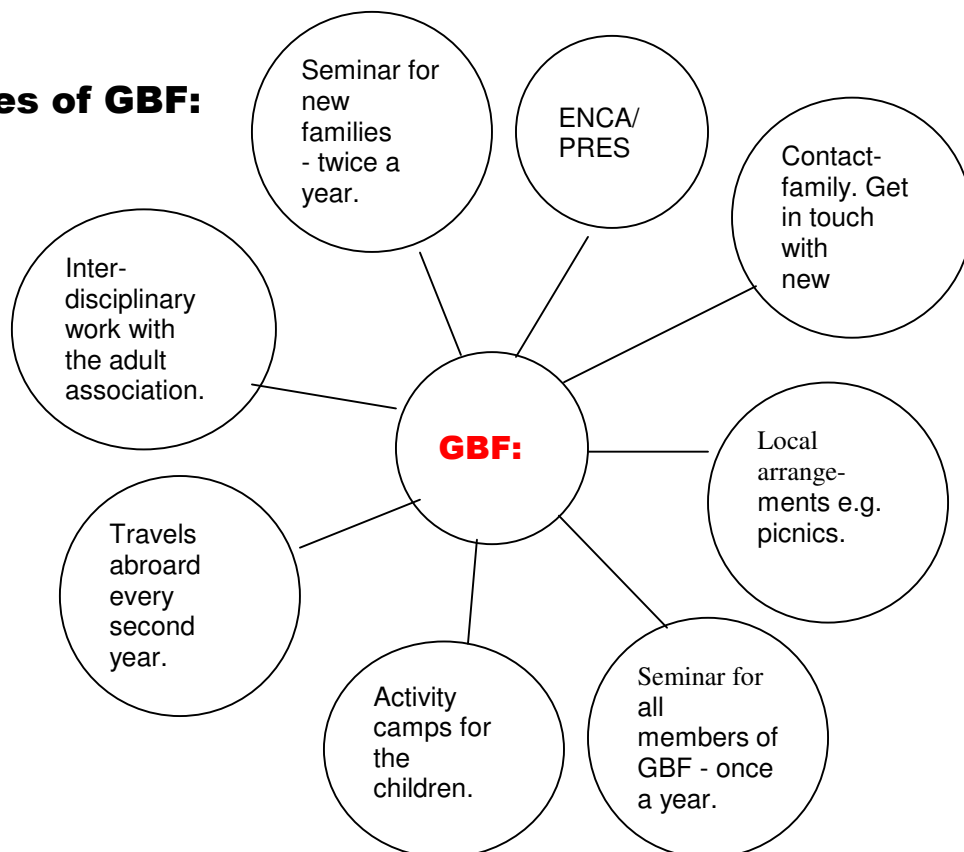
We would like to say thank you to the congress team from London.

Claudia Grave



The Danish parents' association of children with juvenile arthritis - short in Danish - GBF

Activities of GBF:



Special activities in 2007:

- Camp for girls, horseriding.
- Travel to Egypt in October.
 - Booklet about arthritis involving jawjoint.



On a boat at the Red Sea

Activities coming up in 2008:

- May: Activity camp - climbing, canoe paddling, evening bonfires, etc.
- Nov: Weekend trip to Germany to an aquapark.
- 12 March: One-day seminar in Aarhus. Topic: Juvenil arthritis. Admission free!



GBF seminar

Children in the kitchen at s GBF seminar



Links: www.gbf.dk

Youngsters with JIA

Children with JIA are going to the paediatric rheumatologist. But when children get older they have to change over to the rheumatologist for adults. For JIA-youngsters this is a big step. To ease this changeover there are nowadays a 'transitionpoly' established in the great hospitals. For example in the north of the Netherlands, in Groningen, there is a special adolescence consulting hour. Because having a chronic disease in this stage in life can be experienced as a serious obstruction. Beside all the changes in their bodies the adolescent has to cope with, there is the expectation that he/she take responsibility for their disease.

The adolescence consulting hour in Groningen is meant to be for adolescences of

16 – 18 year. This special consulting hour is set up for the following purposes:

1. A pliable transition from the children ward to the rheumatologist for adults for JIA-youngsters and their parents.
2. To achieve independence/autonomy in coping the disease and to get insight in the disease itself, medication and agreements/appointments.
3. Special care for this age group with relation to school, choice of career, living accommodation etc.
4. Attention for psychical aspects of having a chronic disease.
5. Attention for condition and level of activities.

During the adolescence consulting hour the youngster is visiting the own paediatric rheumatologist but visits also the rheumatologist for adults. Questions that come up for discussion are for example:

1. How active is the disease?
2. How are you doing psychically?
3. How are you doing socially?
4. How is it at school, with the study or teaching practice?
5. How independent are you?
6. How is the state of condition?
7. What is the level of activities?

In this way patient and the future rheumatologist get accustomed to each other and in the future the changeover will probably be smooth. And the future rheumatologist gets sight in his future patient. In Groningen are also a physiotherapist and a social worker attached to this special consulting hour.

During the adolescence there are changing's on several fields: bodily, socially and psychically. Often there is a change in study, work, teaching practice, new living accommodation (for the first time living alone), new friends, lovers, sex, etc. For the most youngsters this is a very radical period. And certainly when you have a chronicle disease likes JIA. How JIA does fit in in your live as a nearly adult?

The JIA Vereniging Nederland (the Dutch association for parents of children with JIA) has attention for the youngsters and their problems. In our association activities are organized for children of 0 – 18 years. When you are older than 18 you have to changeover to other (adult)associations for fellow-sufferers.

Last year the committee 'Reuma Together' is established. This is a working party that is representing eight national/regional groups of young adults with rheuma. A board member of the JIA Vereniging Nederland is represented also in the committee 'Reuma Together' to further the transition of JIA-youngsters of 18 year to groups of fellow-sufferers on 'adult rheuma level'.

The goals of the committee 'Reuma Together' are:

- To reach as many youngsters and adults (until 35-40 year) with rheuma and make them connected to national digital networks (youth-R-well.com) and regional/local rheumagroups.
- To further transition of 18-years to other adultgroups of fellow-sufferers.
- To achieve coordination of several initiatives for rheumapatientes of 18 – 40 years.
- To make use of each others assessment, connections and contacts.

On Saturday June 16 2007 the committee 'Reuma Together' organised a big meeting. During this day there was an information market with stands about live/dwell, work, study, live in lodgings, benefits, pregnancy, heredity, upbringing and education, sports and medicines. There were two workshop rounds and the visitors of this meeting could chose from the following workshops: move with rheuma, theatre, how to cope with pain and tiredness, Tai Chi, reintegration, percussion, self-defence and cosmetic & rheuma.

Besides all these activities a happening this day was the start of the new website: www.reumatogether.nl This is a website with a summary of all rheuma-activities for youngsters and young adults in

the Netherlands. It is a homepage with links to all the several groups/associations for youngsters and young adults with rheuma/JIA and the website has a general agenda and activitycalender.

About 200 youngsters and young adults did visit this large event. It was a big success!

Netherlands

Growing up with juvenile idiopathic arthritis (JIA) - Transition from the paediatric rheumatology team to adult services –

Transitional care for adolescents with childhood-onset of arthritis has become of topical interest. We know that juvenile idiopathic arthritis (JIA) persists into adulthood in about 50 per cent of patients. Some of them result with impairments of body functions, individual activities and participation in society. In spite of that a lot of teenagers don't take essential drugs regularly and 15 per cent even discontinue the whole therapy. What are the reasons and which are possibilities to prevent this breakage?

Adolescence can be a difficult time for teenagers with arthritis. They may have to struggle with delayed puberty, their continuing dependence on their parents, and the knowledge that their condition makes them different from their friends. Rheumatology services for teenagers are under-developed so that the change from paediatric rheumatology - to adult services is a difficult phase. Many teenagers found it a shock to leave behind their paediatric health care team with whom they have had a long relationship built up over many years. By handing out documents

only, the rheumatologist can neither get an overview about the course of the disease, nor he can recognize the individuals burden. Therefore Paediatric and adult rheumatologists must establish a close cooperation and must implement specific transition programmes to assemble together all the necessary components of a good transition. In order to know the special needs of the adolescents the German Rheumatology Research Centre (Deutsches Rheumaforschungszentrum) will start a prospective research project which is supported by a research grant from the German League Against Rheumatism. We are hopeful to raise awareness of the need for better transitional care for teenagers with JIA to the health care policy leading to the formation of national initiatives and to create a scientific basis for the longstanding claim of these young patients. We act from the assumption that those who are taken up to a transition programme should be able to cope better with the disease, and less complications could be expected. We hope that one day, adolescent services will become the norm in rheumatology. I think, it is feasible, it just needs organising and some imagination.

Germany (EULAR congress 2007)

RELEVANCE OF PHYSICAL FITNESS TO CHILDREN AND JUVENILES WITH JUVENILE IDIOPATHIC ARTHRITIS (JIA) FROM THE PARENTS VIEW

Abstract: Juvenile idiopathic arthritis (JIA) has a great impact on daily life functioning of children, juveniles and their families. Disease symptoms, functional impairments and treatment modalities may interfere with the normal psychological and social development and quality of life. In chronic diseases quality of life has been increasingly recognised as one of the most important parts in patient outcomes and in therapeutic interventions - Quality of life in children and juveniles means a multidimensional subjective concept that includes social, emotional, and physical functioning of the child and family. Very often children and juveniles with chronic JIA are confronted with an ideal to be sportsmanlike and dynamic. A lack of facilities, low physical fitness, the perception that the child has "a disease", a low self-esteem and over-protection by parents are the causes for hypoactivity. Depending on the disease activity, the limit of motion leads to social exclusion! and mental problems. Children and juveniles with JIA have particularly to deal with fitness ideals and their own physical situation. All over that they are very much at risk to develop an early osteoporosis running by osteoporotic fractures. The inflammatory process itself, a decreased physical activity as well as a concomitant use of corticosteroids enhances the decrease in bone mineral density (BMD). May be it is time to focus studies in order to show the importance of physical fitness for children with JIA and how physical fitness affects psychological distress

Parents are very much interested in developing special attractive and funny fitness exercises programmes, which slow down the loss of BMD and the risk of falling and fractures and could improve coordination and balance. Furthermore parents hope that movement and fitness exercises could make a contribution to cope with pain and stiffness, support and improve the mobility in order to increase quality of life and to raise self esteem.

Germany (EULAR congress 2006)