

NEWSLETTER OF



THE EUROPEAN NETWORK FOR CHILDREN  
WITH ARTHRITIS AND ASSOCIATED  
DISEASES

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about enca

### **What is Enca?**

Enca is a network of parents support groups, throughout Europe, who recognizes the need to support children with arthritis and their families.

Enca is affiliated to the Paediatric Rheumatology European Society (Pres)

### **Who joins Enca?**

At present the European countries, who make up ENCA are Denmark (president), England (secretary), Holland (treasurer and vice president), France, Belgium, Germany and Italy.

### **Our aims are:**

- To promote awareness of arthritis and associated diseases in children throughout Europe.
- An interchange of information about the diseases and their management.
- To help each organization who is joining the Enca.

### **How to join the Enca?**

Sent the form in this folder to the treasurer of the Enca

The joining fee is € 200,- with an annual subscription of € 50,-.

### **What do you get for your money?**

- You get the latest professional guidance from the world's leading professionals in the field of rheumatology
- You have the benefit and experience of established Support Groups from many European countries.
- You will have an input into the development of this new international organization.
- You can help to change the profile that childhood arthritis carries within Europe.
- To make a difference in the world of rheumatology.

**When do we meet?**

We meet each other every year during the PreS Conference which is held in different European cities each year or once every four years during the Eular conference.

**How to register**

You can register as a member by filling in the application form. You will receive written confirmation of your application once it has been received  
All details contained on the application form will remain confidential and will not be provided to any third parties without your prior consent

Sent the application form to  
Hanny Weustenraad  
Vesting 71  
3961 LN Wijk bij Duurstede  
Holland  
More information on [www.enca.org](http://www.enca.org)



.....  
Name contact person: .....  
Address: .....  
Town/City: .....  
Zipcode: .....  
Telephone no. : .....  
Email address: .....  
Website:  
.....

The annual membership fee for ENCA will be € 200,-, with an annual subscription of € 50,-.

Dear parents of children and juveniles with rheumatic diseases,

In order to exchange information about the activities of each association, to promote common projects at European level some parents from various European countries met again during the PreS (Paediatric Rheumatologie European Society) Cogress in Amsterdam.

With the first newsletter of 2007 we would like to give you an impression of European work and we very much hope to encourage you to join to ENCA.

Claudia R. Grave

Germany





# The Olympic Day run

It was for the first time that the Olympic Day Run was held in Amsterdam. It was a run for and by children with Juvenile Idiopathic Arthritis and their friends.

It was a long time ago when in Greece started the first Olympic Games with a run in honor of the Greece Gods. 3000 Years later there was a run again, but now in Amsterdam. In the Olympic Stadion, where in 1928 the Games took place, were children ready to run for Juvenile Idiopathic Arthritis (JIA).



During the big Arthritis Congress "The Euler" the run was organized on the Day of the Olympic Thoughts. A big sponsor run for children with Juvenile Idiopathic Arthritis.

The Olympic Thought, to join is much important than to win, is for children with arthritis a great opportunity. A lot of children with JIA can't join their friends who are joining a sports club. But that will be changed in the future!!!

The sponsor money will be used for a special sportprogramm for children with JIA. Together with the physiotherapist children will learn to join a sport. After a period of 6 month they can join a club in their own city or village. The sport clubs will be learn how they can coop with the child with JIA.



It was nice to see that a lot of children find it important that every child can join a sports club. A lot of children with arthritis came to the Olympic Stadion and took their friends with them. All these children wanted to run for the special sportprogramm.

At the end of the day the Dutch doctors also came to the stadion to run for the Children with Arthritis.

It was a very nice day with a lot of money for the special sportprogramm for children with JIA.

## The Treatment of Kids with JIA in Holland

When a child in Holland is diagnosed with **JIA** he/she will most likely be treated in one of the seven treatment-centres in the country. In these facilities there are **Rheuma**-teams consisting of children's rheumatologists, children's immunologists, children's physical therapists, children's psychologists and Social Workers. These teams work closely together.

The treatment of children who have **JIA** is usually an out-patient-treatment; a child is only admitted to the hospital when there are serious medical reasons to do so. This out-patient-treatment is relatively easy to sustain because the treatment centres are spread across the country, which reduces the time spend travelling to a minimum. Holland is only a small country after all.

The children's rheumatologists are the persons who the parents and children go to most of the time, and they also determine what kind of treatment these sick children are going to get. The treatments mostly consist of administering medication to fight arthritis, pain, and to control the progression of the disease. The rheumatologists do call in other specialists to help with the treatment; it's a collaboration of specialists in the best interest of the child.

The children's physiotherapist will also examine the child; this likewise happens in the out-patient-treatment consults. The physiotherapist tries to minimise the development of damage to the joints as much as possible. By letting the child do some exercises they will determine what the following-up treatment is going to be. Besides this, the physiotherapist will also let the child take a fitness test once a year to see how the physical fitness of the child is.

In case there is need of some social-psychological insights of the effects of the disease, other specialists will be called in. Some children with **JIA** have psychological problems as a result of their disease; it's not easy for children to cope with a life-changing disease, especially when they're young. These children can be helped by a psychologist but children are not the only ones who might need somebody to talk to, which is where a social worker comes in. They are there for the parents to talk to, and to give advise to help the parents along.

As soon as the treatment has started the specialist will try and find out if there is any possibility for the child to go back to a similar living style as the child had before he/she got ill. One of the things they will look at is whether or not the child can go back to school; adjusting school furniture or a computer can be one of the tools used to make it easier for a child to go back to school. Together with an occupational therapist will be determined what adjustments have to be made in order to make the child as comfortable as possible at school. Another possibility for the parents is to apply for a backpack with money to be used by the child; extra support can be bought with it but also specially adjusted educational material. The school is obligated to spend that money on the child who has **JIA**.

The possibility of increasing the mobility of the child is also looked into. Besides physiotherapy there are options to join in regular sports again; in several swimming pools in the country there are groups of children with **JIA** who follow a joint training schedule. On top of toning their muscles and increasing fitness, one of the paramount purposes of the program is the children bonding with each other, building friendships.

Currently, research is being done in exercise programs in which the children are trained during a certain period of time. As soon as the physical fitness of the children allows it, they will be introduced to several examples of the types of sports that will be suitable for them to do. After the child has made a choice of what sport he/she wants to do, contact will be made with the local sports club in the child's hometown. The sports club will then get advice on how best to proceed and how to handle a child who has **JIA**. With these kinds of programs the child will see that it is not impossible for him/her to play sports, despite their illness.

Naturally, the sick child will go on regular consults in the hospital; on average a child will be examined once every six weeks by a rheumatologist who will determine if the treatment is still going well. If necessary the child will also be examined by the other specialists.

## Rehabilitation – An important part in the management of rheumatic diseases in childhood

### A report from Germany



*"We are the winners!" – These optimistic young people are participants of the rehabilitation of the federal state Brandenburg.*

The outcome of children and juveniles with rheumatism considerably depends on an optimal therapy already by the disease onset.

Modern medical concepts of paediatric rheumatology are orientated on a successful therapy. Complex therapy strategies contain an early and – if necessary aggressive - drug treatment as well as physiotherapy, occupational therapy, psychological attendance and self-help.

However, there are borders for an optimal outpatient as well as inpatient treatment, and many children don't know the benefit of an effective therapy. Inpatient treatment in case of a flare up is not an alternative to a long-term rehabilitation.

The answer to this problem could be rehabilitation measures as an integrated component of a long-term complex antirheumatic treatment and lead.

Which are the possibilities?

It is no solution to care children in rehabilitation clinics for adults, but the situation in a lot of paediatric rehabilitation clinics is also not adapted to the needs of children with rheumatic diseases.

There are no paediatric rheumatologists and often the child with rheumatism is only one child between many other patients with different indications.

There are some paediatric rheumatology centres which offer rehabilitation for children with rheumatism for this reason.

The League against Rheumatism of the federal state Brandenburg and the Centre of Paediatric Rheumatology Cottbus have developed a complex solution for the named problems. The idea was to establish a special, yearly rehabilitation for children and adolescents during the summer holidays. This rehabilitation consists of a supervised continuation of the long-term drug therapy, intensive physical treatment as well as the transfer of extensive knowledge of coping with the disease.

The target group are school children at the age of 6 to 18 years in order to avoid an increase of school deficits because of their disease. Beside comprehensive medical care the rehabilitation shall include eventful and happy holidays.



**The specific characteristics of the project are:**

- Only children and adolescents with rheumatic diseases take part in this programme. There is no mixture with patients with other indications.
- Children and adolescents with inflammatory rheumatic diseases can participate **every** year instead of the normal interval of three years.
- The medical supervision by a paediatric rheumatologist or a paediatrician with experiences in paediatric rheumatology is assured.
- The participants get daily individual physiotherapy by special educated physiotherapists and respectively occupational therapists.
- Psychological care and patient education are specially adjusted to the needs of children and adolescents with rheumatic diseases.
- The participants are pre-selected, assessed and confirmed by the medical coordination centre, the Centre of Paediatric Rheumatology Cottbus, in order to achieve approval by the health insurance companies. These are the pension insurance of the federal state Brandenburg, all compulsory health insurance funds and the private health insurance companies.

Because of the low prevalence of rheumatic disorders in childhood these children are individual cases in their social environment. This fact makes the coping with the disease specific problems more difficult.

The rehabilitation is for a lot of them the only possibility of meeting other ones with the same problems and to profit from their experiences.

**The patient education** is an important component of the rehabilitation. The children and adolescents learn in small groups of the similar age at the basis of the Patient Education Program of the German Society of Rheumatology. They get knowledge about the disease and the methods of treatment, practise abilities and receive hints for the way, how to deal with themselves, the disease and the social environment.



Additional there are different offers like swimming, sauna, optional occupational therapy as well as adequate sports taking the criterions of joint protection into consideration. There are courses for different interests, for example healthy nutrition and lifestyle, coping with pain, creative working and much more. The kids enjoy the attendance at concerts and theatres, trips, riding as well as the beloved discotheque. They experience lucky, eventful holidays and found friendships. The majority has regular contact, especially the problematic group of the kids, who are going trough puberty. They come together again at teeny weekends or the group of young adults above 18.



3 weeks rehabilitation gives them the feeling – there are quality of life, understanding friends as well as a perspective with and in spite of the disease. Everybody can learn, to take the life in his own hands.

The rehabilitation started 1995 with support of the Ministry for Work, Social aspects, Health and Women of the federal state Brandenburg as a pilot project. Today this unique project is recognised by the health insurance companies, which bear the costs of the programme. Expertises of the Medical Service of Health Insurances in 1996 and 2004 certified the high quality of the rehabilitation.



100 girls or boys per year from Brandenburg and all other federal states have participated at this rehabilitation in the years from 1995 until 2006, many of them 4 to 5 times in yearly continuation.

Today we can speak about the “successful-concept” of Brandenburg. The number of severely handicapped children is very low. It has happened that young people of 18 years came to the rheumatologist and he said “You don’t have rheumatism”. After withdrawal of drug-therapy and the next flare up he said: “Yes, it is rheumatism, but you have got an effective therapy.”

The experiences show, that intensive rehabilitation in connection with medical long-term therapy and home therapies preserve the mobility and improve the outcome of children with rheumatism. Because it’s possible to avoid persisting illness and early invalidism, this rehabilitation programme seems to be economically efficient. They are worthwhile not only for the afflicted patients, but for the society and for the health insurance companies as well.

The League Against rheumatism of the federal state Brandenburg as well as Parent organisations of the German League against Rheumatism will fight for a continuance of this yearly rehabilitation in future, too.

**How does the Reha help you?**

*“The Reha is a great help, because here are alike people and the therapies are always helpful.” (Mandy, 16 years)*

*“It helps me to know, how I can act with rheumatism.” (Sabrina, 11 years)*

*“The Reha helps me, to cope with the disease and to understand it.” (Dajen, 17 years)*

*“I enjoy it totally, because I get to know real good people here, who have the same disease like me. I feel completely cool here! The therapies help me super, because I forget the pains here!” (Vanessa, 12 years)*

*“It helps me very well, because I see how the other people deal with their rheumatism. And I can learn here to cope with my disease too.” (Melanie, 16 years)*

*“The Reha helps me well. I enjoy it because I have many friends and we have fun.” (Jessica, 8 years)*

*“It helps me very well.” (Phillip, 12 years)*

For further information:

German League against Rheumatism, Section Brandenburg:

<http://www.rheuma-liga-brandenburg.de/position.html>

The medical coordination Centre, the Department of Paediatric Rheumatology of Carl-Thiem-Klinikum Cottbus, which is the Centre of Paediatric Rheumatology of the federal state Brandenburg:

<http://www.ctlk.de/Kinder-und-Jugendmedizin.0.61.1.html>

The Rehabilitation-Establishment, the Reha-Clinic “Hoher Fläming” Belzig, a long-term and committed partner of the League against Rheumatism of Brandenburg:

<http://www.rehaklinik.de/reha-klinikum-hoher-flaeming/indikationen/kinder-rheumatologie/kinder-rheumatologie.html>

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## Muscles – their function and importance in JIA

The body is made up of a skeleton of bones, which make us rigid and protect the soft organs (i.e. lungs, heart etc) within our bodies.

Ligaments hold the bones together, and the areas where the bones are joined are called **joints**. The joints are the areas where the body can move at, and these are also the sites that **arthritis** affects. Joints however cannot move by themselves and therefore **muscles** are there to move the joints.

This combination of structures allows us to be strong and sturdy but extremely flexible and mobile. There are several different types of muscles, some we do not control by thought, such as the muscles of the stomach and gut or the heart muscles. These muscles work despite any thought from us and keep working whether we are awake or asleep and we are unable to "relax them" and stop them working –(thank goodness!)

The other muscles are called **skeletal muscles** and these are controlled by our thoughts, these are the muscles that control your arms and legs etc and we decide how and when they should be used. However they fortunately do not require a great deal of thought to control them otherwise we would not be able to do anything else!

The importance of this is that the joints do not move without muscles and we have no control over our joints without these muscles. Muscles are vital to ensure that the joints are used properly and that they are held in the correct positions and used in the correct way, without this then the joints will get worn-out very quickly.

In order for muscles to do their job correctly they need to be both strong and fit. They need to be strong enough to hold the whole body up and to be able to carry objects too, and they need to be fit enough to last the whole day. Muscles stay strong by being used properly all day; however they become very weak very quickly if they are not used. Muscles only become stronger and fitter if they are exercised regularly, and gentle tasks such as walking around the house or sitting playing the play-station or watching the television do not make your muscles strong!

For children with arthritis there are many reasons why their muscles become weak, and once the muscles become weak they do not regain their strength unless they are exercised correctly and specifically.

### **Some Reasons for Muscle Weakness in JIA.**

1. Stiff joints stop muscles working.
  2. Painful joints stop muscles working.
  3. Less physical activity causes muscle weakness.
  4. Less participation in sport causes muscle weakness.
- Chemicals in the body that keep the inflammation active in the joints also cause the muscles to waste away and become weak.

For all these reasons the muscles in children with JIA become weak and unfit extremely quickly and once that this happens the joints are at more risk of wear-and-tear damage and often become more painful. Therefore strong, fit muscles are vital for children with JIA in order to protect the joints and to reduce pain and stiffness.

Unfortunately muscle weakness can start to develop as early as 2 –4 days after the joint swells. After several weeks of continuing joint swelling loss of muscle tissue occurs (**atrophy**) and this cannot be corrected without the appropriate exercises being completed.

There are many ways to exercise muscles, and while it is extremely healthy and good for children to perform tasks such as walking, bike riding, football etc these exercises and sports are great for general fitness but will not build up muscles specifically. This is further complicated by the fact that some muscles are naturally stronger than others and these muscles are used more during these activities. The strong muscles therefore continue to keep strong and the weaker muscles, which are not used properly, become weaker. A specific exercise programme is therefore extremely important to ensure that all the muscles are as strong as possible and that they then protect the joints allowing safe participation in other activities.

This principal is no different to the training regimes of professional sports people who not only train at their specific sport but they also train each muscle group specifically to ensure maximum efficiency and strength of their muscles, but to also prevent injury.

The exercise programme for children with joint problems should be seen in a similar light and that it is aimed at ensuring all muscles are strong and fit in order for the children to join in many activities safely and without pain while still protecting their joints.

There is considerable research into increasing the strength and fitness of muscles in children and the key points are that the number of times each exercise is performed (**repetitions**) is important and that the exercises should be done against resistance. The guidelines suggest that to improve strength and fitness of muscles in children a regime of increased number of repetitions and small amounts of resistance, between 0.5 - 2 kg (1 –5 lb) should be used. The number of repetitions should be between 15 –30 repetitions to ensure the most effective exercise regime. The other important factor for increasing strength is that the exercises should always be completed in a slow and controlled way and that the lowering of the limb is as important as the raising of it.

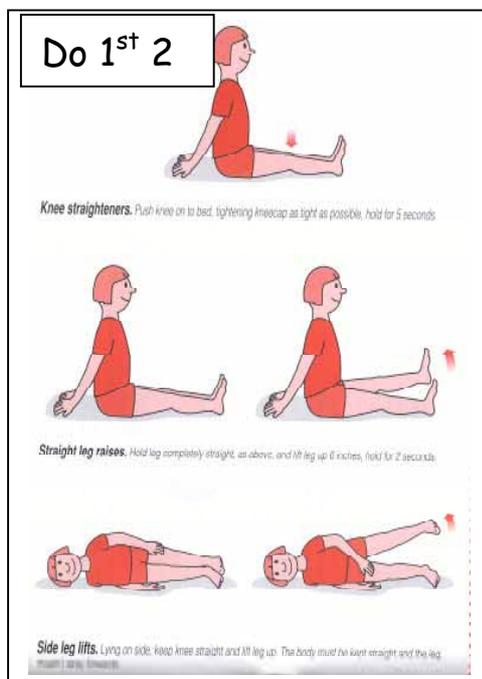
To be most effective the specific muscle strengthening exercise programme should be done at least 3 -4 times a week. However there may be times, for example at the initial onset of the arthritis or after a flare of the disease, that the programme may be started or increased to a 1x daily programme. This will be done to encourage the recovery of strength and endurance to be as efficient as possible and will also allow the exercise programme to be started with fewer repetitions and no weights and gradually increased (progressed) as appropriate. Weights will only be started or increased when the exercises can be performed correctly (i.e. the muscles are strong enough to be worked harder).

A common recommendation is that to minimise joint damage and muscle fatigue during physical activities such as football, hockey, ballet etc the individual exercise programme should be completed to 30 repetitions with a 3 lb. (1.5 kg) weight to ensure adequate endurance and strength of the muscles.

However at all times during the disease (active and inactive) the children should be encouraged to be as independent as possible. They should be encouraged to walk independently with out the use of aids such as wheel chairs or crutches etc and they can also be encouraged to participate in sports such as cycling and swimming. However when the disease is well controlled all sports can be tried.

Examples of specific muscle exercises are given below:

It is extremely important for your child to have a home exercise programme that has been designed by a Chartered Physiotherapist to ensure that their muscles are as strong as possible in order to protect their joints during all activities, including walking, and to minimise pain, stiffness and tiredness. This programme should be monitored and progressed appropriately by a therapist regularly.



These exercises are taken from the CHAT booklet, which was produced by the "CHAT ALLIANCE", and are also included in the "PHYSIO for KIDS" video produced by JOINTZ and these are both available from the CCAA.

NB: The first 2 exercises should be completed lying down.

"This article is written based on personal opinion and practice and the author acknowledges and respects the views and experience of other professionals"  
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