

# IOYR



## The summer is almost over - Autumn is on its way...

*by Dorte Rønslær, chair*

...then the winter will come, it will be colder and for many of us it will snow. Then the spring will come back with green leaves on the trees and then suddenly the summer is here again. Just as it always happens...

Next summer we will meet in Switzerland for the IYC 2004. There we will have a new general assembly with election to the board. IOYR have sent a letter to our member-organisations and encouraged them to go for election for the board. If you are interested and want more information, please contact your national organisation or us at [ioyr@ioyr.org](mailto:ioyr@ioyr.org).

### **Members Meeting 2003**

Unfortunately, the Members Meeting had to be cancelled because not enough people/organizations signed up. The Board thinks it could have been a great opportunity to meet in between two International Youth Congresses (IYC) and is very sad that the Members Meeting had to be cancelled.

The Board thanks the Lithuanian youth group for their willingness to arrange the Members Meeting and hope to be able to enjoy their hospitality another time.

### **Welcome to Marianne**

The board had our first board meeting in 2003 in Lithuania at the beginning of May. Here we welcomed Marianne Scobie, from Scotland as new board member from United Kingdom instead of Catherine Gibb who decided to resign from the board.

Marianne is on the board of Arthritis Care, her mother organisation and was co-chair of the youth organisation. She joined Arthritis Care in 1994 as a volunteer telephone contact, giving other young people with arthritis support and information. She works full time as a manager for another large UK charity and travels all over the UK, which she really enjoys.

In her spare time Marianne likes going to the cinema and loves cooking, especially for lots of friends. She has had JCA/JIA since she was 8 years old. She lives in Glasgow with her partner, Con who has attended two IYC's (International Youth Congress) with her - in Berlin and Norway. Con is also involved in the IOYR web project.

See pictures and contact details of Marianne and the other members of the board at [www.ioyr.org](http://www.ioyr.org).

## IYC 2004

### - Where is the money?

by *Laura Maria Margulies, Switzerland*

Middle of July. I am sitting in the garden on a beautiful sunny day. I realize that it's exactly one year to go until IYC 2004 will take place in Switzerland. And I hope, it will be the same great weather we enjoy this year, so that you can see our country at its best.

In June, I have been running around at the EULAR 2003, still searching for sponsors for our Youth Congress. The time being, with all these economical inconveniences the whole world has to face, social groups like young people with rheumatism have to get used to the fact that there are not many investors anymore.

What to do? We just started a new campaign on national and international level. Together, the IOYR board and the Swiss Rheuma League are sending information packages, talking, phoning and staying in contact with industries, companies and especially pharmacies. We are persistent!

The program for the IYC is as good as finished and ready. Psychological aspects of young people with rheumatism as well as new or unknown medical ways, sexuality and partnership as well as musical highlights, dancing and sightseeing will lead the participants through an action-packed and powerful week. On the congress, we want to give you the possibility to **Take Action**: to learn and gain tools for a life with rheumatism, to make your voice heard, to find the power and will to get included in ordinary daily living and look forward to a better future.

But still it's very hard to find sponsors and sometimes really frustrating to be declined again and again. Next week, the Swiss Organisation Group of the IYC will have its next meeting. We'll talk about all these problems and hopefully we'll find new ideas and solutions for the coming campaigns.

If the searching for money carries on being that frustrating, we'll have to take new decisions about the program and maybe change our plans a little bit. But so far, we still believe

in our ability of persuasion and of course our luck. And with all the new contacts we made during EULAR 2003, there is a real chance to find a good investor for the IYC.

So, I still enjoy this beautiful sunny day and think of the unique time we'll all have together next year on IYC 2004 in Switzerland.

By the way: Do you maybe have a rich uncle in America? ;-)

**More information about IYC 2004?**  
Please contact  
**Laura Margulies, Switzerland,**  
[lauramaria@bluewin.ch](mailto:lauramaria@bluewin.ch)

## European Market of possibilities in Bonn/ Germany in October 2002

by *Kirsten Russ, Germany*

"Rheumatism has no borders" could be one headline of the market for international work with organisations that help people with rheumatism.

Nearly all countries of Europe have organisations for self help with the aim to make the life of people with rheumatism easier, to assist them manage their lives with rheumatism, to get medicine, therapy and financial support. 5 members of the board of IOYR was a part of this market – telling and showing what international networking means and giving inspiration to others.

The organisations are working with different dimensions, structure and social influence. But something makes them united – all work for and with people with rheumatism and all want to learn from each other. The market was a forum to do that. The organisations could talk about their work. Representatives could show something about their national work and projects with posters, presentations in working groups and with speeches in a big forum.

The market was organized by the German-Rheuma-League working together with the Manifesto Steering Group. More than 20

European countries participated to learn from other countries and to get new ideas about ways to organize self-help, to hear financial reports or about special projects. The congress shows how much competence, engagement and variety of ideas are on the move in self-help organisations.

In workshops the participants discussed about strategies and models of working, starting projects, getting financial support and gaining medical support. The aims to learn from each other and to give new perspectives were fulfilled. All countries came together in a congress with combined work in official parts and small talks between them. A boat trip, a dinner in a special building “Petersberg”, including a cultural programme with African dance and a visit to Bonn made the congress to a fascinating event.

Some participants made contacts and friends to work with in future. IOYR got new contacts as well. Some countries were interested in membership after the presentation of our chair Dorte Rønslér.

In the background of this market was the Manifesto for the third millennium “people with rheumatism in Europe”, that includes aims and perspectives to support people with rheumatism in their life. Last time it was translated into 20 languages and is used in 32 nations to make positions and be a motor for political and social work. If you want to know more about that, please look at [www.paremanifesto.org](http://www.paremanifesto.org).

The Market was one way to make the European network for Rheumatism self-help organisations a reality.

It was a very interesting congress with new ideas, contacts, much work and fun. IOYR got the chance to be actively involved with board members in that and were thankful for new perspectives and power!

## **The Danish Teenage-Weekend**

*by James Rickmann, Denmark*

FNUG arranges an annual event for teenagers with arthritis, which has become a major success for FNUG and its members. The idea behind the Teenage-Weekend is to create an informal, casual and relaxed atmosphere in which the teenagers with arthritis can have fun despite of their arthritis. The hidden agenda and goal behind it is making it possible for the teenagers to evolve together and let them discuss their experiences along with their hopes and fears.

The Teenage-Weekend takes place from Friday evening to Sunday lunch. All teenagers from every part of Denmark are invited including teenagers that are not members of FNUG. FNUG tries really hard to make the Teenage-Weekend a jumping pad for teenagers to get more involved with FNUG. Therefore the Teenage-Weekend also appeals to teenagers who hesitate for different reasons to become a FNUG member. There are normally between 20 and 30 teenagers who join the event each year.

Friday evening the teenagers settle into their accommodation and they quickly learn each other's names and all of them get well acquainted before long. The teenagers usually already have made friends during the journey to the weekend.

Saturday begins with a talk, relevant for teenagers with arthritis. It could be a doctor, a physiotherapist, a psychologist or even a nurse from an arthritis ward that comes to visit. This talk is the educational part of the weekend and is more or less followed up by the activities in the afternoon.

The afternoon starts with doing something physical, and we often choose swimming in warm water. The next activity is based on group work. The teenagers are carefully selected into groups with regard to their age differences, gender and a gut feeling on how they

would get along. The groups have to perform certain tasks or solve different assignments in a handful of workshops. The workshops are linked together by a topic which surprisingly is the same topic that the evening programme is sprung from.

After the workshops a long break is needed for everyone to relax, also it is necessary for them to build up energy for the evening event. Some of the topics have been “Harry Potter at Hogwarts School”, “Latin Fever“ and “English Glamour and casino”. The different topics have really been well thought through in regard to decorations, table settings, games and every small detail that makes the topic more realistic. The teenagers are allowed to have as much fun as they can, the scenery is staged for exactly this.

The last day of the weekend is reserved for a member of FNUG who speaks about him or herself. The theme is how they handled the problems that came as a teenager. Before everyone departs they exchange email addresses and take a group photograph.

In the planning committee there are about 4 FNUG members who are between 18 or 22 years old. They are supported and supervised by an older member who also is the responsible adult during the weekend. If something should go wrong the adult takes appropriate action. FNUG receives a lot of support from parents and very much enjoys the positive feedback that teenagers send us afterwards.

## **The past, present and future**

*Liisi Toom, member of YRA*

Going through the first documented papers and listening to my mother I realized that our organization started working far before it was officially acknowledged. The reasons were the parents' concern for their children's health and wish to take part actively in their treatment.

## **Past**

My mother, Regina Toom, as she was looking for the answers to the questions that came up because of my disease, ended up doing a lot of research. She made enquires among parents whose children were diagnosed with rheumatism/arthritis, and were in Tartu Children's hospital between the years 1986-1992. She found out that most of the parents had the same questions – Why does my child have this disease? How can I help with her/his treatment?

New studies at that time affirmed that rheumatism/arthritis is a bio psychosocial disease. Therefore the environment where the child grows and the involvement of her/his family is very important. But even parents need support, knowledge and help before they can help their child.

So, they first got together in 1993: all the parents who participated in the survey and some doctors. For almost 2 years, they were a section in an Estonian Rheumatism Association. Since that association was mainly for adults, the problems differed from children's problems. It was decided in 1995 that a new organisation will be made for children and youth with rheumatism/arthritis, as well as for their parents, doctors and people who want to help.

## **Present**

8 years later, in the year 2003, YRA exists as a growing organization (officially 80 members) for children (up to 18 years old) with rheumatism/arthritis and for their parents, friends and doctors from all over Estonia.

## **Activities**

Our organization has two main camps every year – summer and winter camp. Then most of the members have 2-4 days out in the countryside. Then we have playgroups for children and lectures for older members. We also discover Estonia and its wonderful secrets. Camps end with a night around the fire or around the Christmas tree.

In addition we have seminars once or twice a year where we study a bit of psychology, healthy-diets, managing in crisis and so on. These activities are free for the members of YRA.

### **Problems**

As in every organization we have our worries. The three main issues are:

- members are scattered all over Estonia, so it is difficult to come to 1-day-seminars;
- 18-year-old young people don't find the activities interesting enough to take part;
- and last but not least financial problems. We have a small annual member's fee and the municipal office supports us depending on the number of members. When we have camps or seminars we write applications to several companies. Companies have supported us with pastries, with lemonade, rarely with money. So far we have managed to do quite a lot with very little money.

But these problems don't intimidate us! They make us try harder to find new and better solutions.

### **Future**

As a result of young people (mainly 17-18-year-olds) with rheumatism/arthritis keeping distance from YRA there is a plan to establish a new organization for youth aged 18-35 from

all over Estonia. We found out the Estonian Rheumatism Association based in Tallinn, capital of Estonia, has the same problem (people around 20-30 do not take part in the activities) and now we are cooperating to get started.

IYC 2002 in Norway had a great influence in taking serious measures to create it. For now we have made 2 projects out of which 1 was accepted. Within this project we organised a one-day seminar and a 2-day camp for people interested in establishing a new organisation especially for people aged 18 and above. Both of the get-togethers were successful and urged us to continue. We are now at the point of deciding about all the basics of the organisation. Hopefully we can take part from the next IYC as representatives of a new organisation!!!

This was a short story of YRA's past, present and future. I believe that it has been a great help for all the mothers and fathers that have children with rheumatism/arthritis. They have had the chance to ask for help and support mentally as well as physically. It has given the children an opportunity to have fun with other kids just like they are. Being in an organization like this makes you realize that this disease is not a big ugly monster more like a little voice that demands our concern and care to keep the voice quiet and the body healthier.

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**Next newsletter – a special one...**

## **About MOVING!**

**Next newsletter will be published in October 2003**

**- but only with your help!**

The 12. October will be international rheumatism day.

This year IOYR wants to mark the day with the headline MOVING!

We will have a chat about it and also a newsletter with articles about this subject.

Please send us your article by 2. October at the latest to [ioyr@ioyr.org](mailto:ioyr@ioyr.org).

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## Next chat at [www.ioyr.org](http://www.ioyr.org)

### Next chat-meetings at [www.ioyr.org](http://www.ioyr.org):

Wednesday 24. September 19.30 (CET-time)

Everybody is welcome to join!

Remember also chat at 12. October about MOVING! Our headline for the International Rheumatism Day 2003.

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## The Aims of the IOYR

### The main aims of IOYR are to:

- exchange information and experiences and to learn from and help each other.
  - encourage the development of self-help in each of the countries.
  - empower young people with rheumatism and enable us to get our voices heard.
  - raise public and professional awareness of the situation of young people with rheumatism and change attitudes.
  - exert policy influence, both internationally and nationally.
  - develop links between medical professionals and young people with rheumatism and increase understanding.
  - encourage more research into the experiences of young people with rheumatism.
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## More information about IOYR

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