

# IOYR



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International Organisation of Youth with Rheumatism

[www.ioyr.org](http://www.ioyr.org)

Newsletter no. 10

February 2003

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## How is it?

### - Meeting you virtually and face to face

*by Dorte Rønslær, chair*

Let me start by wishing you all a Happy New Year even though it seems like ages since we jumped into 2003. Entering a new year means thinking. Back on things that have happened during the old year, but also thinking forward about all the things the new year will bring.

In IOYR 2003 will bring among other things a Members Meeting. You can read more about this in this newsletter and invitations have also been sent to IOYR's member-organisations.

The year will not bring an IYC (International Youth Congress), we have to be a bit patient and wait until 2004. But also this year will be busy for our members in Switzerland. They are working hard to make the IYC 2004 the best IYC ever.

#### **Let's think back...**

This is thinking forward, but more than one and half years after a new board has been elected it must also be time to think back. I cannot count the number of times I have been asked "How is it to be chair of IOYR?". Every time I hear this I think, "When will I stop being surprised about being asked this question?".

From 1994 to 2000 I was national chair of FNUG, the Danish Organisation of Youth with Rheumatism and I have been chair of IOYR since July 2001. There is a natural difference between the two positions. In FNUG I had

more or less daily contact to our members - in IOYR it can take days, yes, sometimes weeks without any sign of IOYR.

It is not possible for us to meet very often in IOYR - as board and/or as members. But when we meet, I realize a lot of the same things that I realized when I was chair of FNUG. You get feedback - positive and negative - on the work you do, you get a feeling about what the result of many many hours behind the computer and hours with travelling and meetings means to other people.

#### **Meeting members**

In June 2002 I had the opportunity to participate in the EULAR-congress (European League Against Rheumatism, a congress for rheumatologists, for allied health professionals and also for people with rheumatism) and in October I participated at "Market of Possibilities" in Bonn, Germany.

Both times I met a lot of you - the members of IOYR. Of course it was very positive to see you and also great to hear what IOYR and IYC 2001 in Norway meant to you. How you got ideas and power (in you...) to continue work back home, a work that you might sometime feel is aimless. How some of you came from "nothing", to after IYC 2001 to establish meetings and forums for young people with rheumatism.

Look, that was useful and now it might be possible for me to give a better answer to the question how it is to be chair of IOYR. And I can give a positive answer.

What I have got in my national organisation of help, support and solidarity, especially when I was very young, what I have got by meeting a lot of young people with rheumatism in Denmark and on international level, has given me the chance to give other young people with rheumatism the same opportunities for support and friendship. If that can help them just a bit compared to the help I have got, I am very honoured and happy.

Again it shows that meeting face to face is very important. Meeting you again gave me power to continue my voluntary work, working on my computer, arrange meetings and events, travelling and having meetings.

On national levels it is often easier to meet than on an international level. So it is very clear that it is easier to get feedback on national levels than on international levels. It is also cheaper to call or easier to write an e-mail in your own language, if you can't meet.

 **Remember!!!**  
Next chat-meetings at [www.ioyr.org](http://www.ioyr.org):  
Tuesday 18. March 19.30 (CET-time)  
Everybody is welcome to join!

The international work then depends perhaps much more than national work on those of us who have been chosen to do it. We must keep ourselves "by the fire" and keep on working to fulfil the tasks and goals of the organisation - even though we, in first instance, may not see the results or get the feedback from the people we are working for.

This is also a challenge to you. Please let us hear from you between our face to face meetings. How are you doing? How is your organisation? How can IOYR help you?

**It is not everything...**

Face to face is not everything, meeting by phone or by the internet is also very useful. The internet especially can make you meet people you wouldn't have reached. Getting a diagnosis like rheumatism can be very hard. Many people go directly to the internet and search for help, peers and answers.

You have earlier been able to read about our "Virtual Network for National Youth Organisation" and a lot of things have happened during 2002.

As you might remember a web-project-group has been set up to make a forum that gives IOYR's member-organisations the possibility to make their own national web-site. The forum will consist of templates that give you the possibility, without any knowledge about web-design, to very easily make a web-site with information, forum, chat etc. where you can get in contact at a national level.

It is a big project, but the project group, that has been set up is far reaching - Italy, Scotland, Norway, Sweden and Denmark are in the group - has the commitment and the competences.

The group works most of the time on virtual level, but in June 2002 they also had the possibility - over a weekend in Århus, Denmark - to meet face to face. Here they had day - long meetings and afterwards they all went home with a long list of things-to-do, before they can meet again.

We hope that it will be possible for all of you to start working on your national websites during 2003.

Some organisations already have a great website, but other organisations can now have the same experience with our help. That is what IOYR is all about, sharing and learning from each other, on many different levels, so lets do that - face to face and virtually.

Looking forward hearing from you.

*Read more news from the board later in the newsletter...*

## **Members Meeting 2003 - Welcome to Lithuania**

As you were informed in the last Newsletter, no 9. the second Members Meeting will take place in Vilnius, the capital of Lithuania. The organiser "Kaunas Club Artritas" was looking for the place where it would best to arrange our Members Meeting. Now the decision is that the Members Meeting 2003 will take place in hotel "BALTPARK" during the weekend from 9. – 11. May, 2003.

All the members of IOYR have together with this newsletter received the invitation to participate. Two persons from the youth-organisation and one person from the mother organisation of every member country can participate.

Participating in the Members Meeting will cost maximum 175 € pr. person + travel cost. We are working on finding funds that will support this meeting, but we also expect participants to raise funds individually in their home country for travel and fee.

The fee of maximum 175 € includes accommodation, participation in the programme and the excursion.

If you have further questions or maybe some ideas that you want to share with us, please don't hesitate to contact us. We welcome all ideas from you. Send a mail to [ioyr@ioyr.org](mailto:ioyr@ioyr.org).

## **IYC 2004 - about being in blossom**

*by Laura Maria Margulies, Switzerland*

Through meetings and a communication platform on the Internet, where all the members of young people with rheumatism from Switzerland can chat, discuss and work together, the IYC 2004 (International Youth Congress) starts to become real.

We found a wonderful location for the congress, settled next to a beautiful lake. The par-

ticipants will have their own guesthouses, a beach and a great forest to enjoy the breathtaking nature of Switzerland. It's the best concerning needs for disabled people and the dimension of IOYR.

Look it up at [www.gwatt-zentrum.ch](http://www.gwatt-zentrum.ch).

This led us to the possibility of settling the date. The IYC is going to be held from 17<sup>th</sup> to 24<sup>th</sup> of July 2004.

Thanks to Jacqueline Mäder, the former Swiss Delegate, our connections to Zurich Airport are going to be very helpful. Arrival, departure and transport to and from our location will surely work smoothly, as the airports assistance service will support us in every possible way.

We are very proud that we have finished our Preliminary Announcement of the IYC 2004. It shows our motto 'Take Action', explains the most important facts and presents the involved organisations. It has already been handed out at the EULAR-congress in Stockholm and also sent out to IOYR-members. You can read more about it at [www.ioyr.org](http://www.ioyr.org) or if you want to receive it send a mail to [iyc2004@ioyr.org](mailto:iyc2004@ioyr.org).

The flower of summer 2004 is already in blossom – let's enjoy its various colours and shapes together!

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

## **Short news from the board: New boardmember and working on the constitution**

*by Dorte Rønsløer*

The board had our second board meeting in 2002 in London at the beginning of December. Here we said welcome to Linda Vøllestad Westby from Norway who is BURG's new representant on the board. Linda is replacing Georg Hodnefjell who in the spring 2002 decided not

to go for election for the national board in Norway. Linda was elected as BURG's vice chair and now she is also on the board of IOYR.

We welcome Linda and at the same time we say thanks to Georg for his work in IOYR. Georg has been a board-member since the launch of IOYR in 1995, and there is no doubt that we most of all can thank Georg for his enormous work as project manager for the IYC 2001 in Norway.

In the spring 2002 all members of IOYR received a letter asking to give the board comments about the constitution. Thanks to all of you who during the summer sent us thoughts and ideas about our rules. The board is working hard trying to make all the ideas and suggestions come together to ONE suggestion. We plan to send it to you after our next board-meeting in May 2003.

## **Something about my life with rheumatism as a mother**

*by Kirsten Russ, Germany, mother to Jenny, 6 years old and Hanna, 4 years old*

I remember the day exactly. It was a Sunday. My knees were burning and really fat. I didn't know, what happened. Up to that day in 1998 – three weeks after the birth of my second daughter – my life was totally changed.

I was going to the doctor very often the next two weeks. She told me something about arthritis. I had no idea, what that meant. At first I had to choose between being a nursing mother or to take medicine to feel better.

I had to end nursing, because it was no longer possible for me to arrange my life – to prepare meals, to sit, stand up or go, to care for my children on my own.

So I had to go to the hospital – to get the diagnosis and to get better.

After 8 long long weeks I was going home again. My baby daughter was at my grandpar-

ents, and my husband and my girlfriend took care of my oldest daughter – the life had to go on – anyway!

When I was back my daughter started crying – she didn't know me. I couldn't be there for her in one of the most important times, her first months. Sometimes I saw her, but she was mostly sleeping.

I was crying and was sad that I was not the active and loving mother I always was, but then I was looking forward – to find the power and ways to manage the daily life with my children again.

The first year was very hard for all of us – for me, my friends, my family and sometime for our neighbours too.

I needed help to get up in the morning, to dress me and my children, to take them to the kindergarten, to wash or bath, to dress them again, to open the door or to prepare meals for us.

I was so thankful to have so many friends on my side. That helped me to be there for my children and to get more active and powerful again.

The medicine-therapy was very good. In the hospital it was really strong with 500 ml Cortisone per day and starting the Methotrexate (MTX) Therapy with 25 mg i.V. once a week. When I was going home, I still needed 50 mg of Cortisone. Now I'm happy to need only 10 mg of MTX as pills and Cortisone only on bad days.

I had to take all my time and energy to organise the daily life with my children and to take care of myself – to do gymnastics, go swimming, to find new power and to stay on my way and I had to go to the doctors very often. I was happy that my children were in the kindergarten 4 hours a day – so I could manage all my activities in that time.

My husband stands beside me, but in the time-structure of his work it was not possible to help me much in daily-life – for that I needed a social-system. That helped me in that hard time!

Now – nearly four years later – I’m really thankful, feel active and powerful again, have learned to live with the pain and to organise my daily life.

That’s why I look back a little bit proud, happy and I’m sure that I have accepted rheumatism as a good but sometimes hard part of my life. It opened up ways to other new things, wonderful people and another – more positive way to live my life!

My children learned to live with that too. For them it’s normal that more people take part of our family-life, that more than their mother is there for them and that their mother sometimes needs time to relax, that she cannot do all things other mothers can do.

I really enjoy the days and the time with my children. We are active together and that helps me.

Now I’m working again, I can manage daily life again and if I need time for me – I look or ask others for help.

I really love my children and I live every good day as intensive as possible.

We often go outside – to be in nature, reading stories, painting, baking, playing sport together.

I will never forget the change in my life, but I would never say that the experiences I got in life with rheumatism were negative for me or my children.

My life changed in a positive way – with children and with rheumatism.

**The Centre for Mothers  
with a Rheumatic Disease**

The centre is based in Trondheim, Norway and gives information and advice to women with rheumatism, who want to know more about pregnancy, giving birth and daily life with a small child. Another centre is on its way in Switzerland and both centres, as well as taking care of mothers with rheumatism from their own countries, will also accept requests from other countries.

**More information at [www.revma.org](http://www.revma.org).**

## **Being a father with rheumatism**

*by Georg Hodnefjell, father to Liselotte, 3 years old*

To be a father of a 3-year-old daughter is first of all a privilege and makes me proud. It is emotional, fantastic and powerful. It is a full time job, no vacations, hectic and chaotic - all independent from my rheumatism!

My name is Georg Hodnefjell and I am Norwegian. I got my rheumatism when I was 13 years old. At the age of 27 I got married and then became a father. My little baby was born on the 11<sup>th</sup> February 1999 and her name is Liselotte.

My rheumatism has changed from bad to very good and the other way during the time of being a father and the same with my wife who also has a rheumatic diseases.

I don’t think that my condition ever affects my daughter’s life in a bad way. Of course it has sometimes been hard on my life in practical way but a child doesn’t measure your health condition, they stand the way it is.

Each of us, and together, I think my wife and I give our daughter a rich life but it demands energy and courage.

I chose to live an active life and I didn’t change much after my daughter was born. I work almost full time in my job, I have my own house, I spend time with my friends, I spend time with my relatives and family and I work voluntarily for BURG and IOYR, and all these are my priorities in life.

Of course I realise that life has changed from when I was 18. I remember being very active, I was modern, and everything was perfect. My parents supported me and I felt everything was arranged for me. Suddenly I was 27 and father of a little daughter, a new element, changing my outlook on life. It was no longer possible to spend the time only on myself.

At the same time I had some periods where I really needed help from my wife or others to

deal with my daughter in a practical way because of my rheumatism and joint problems.

My rheumatism was of course a consideration when I thought about having a child but never a final reason. I did talk about my health condition and limit concerning having my own child but in my case there were many other considerations that were decisive, for example my relationship with my wife, our difference in age, our future time and other normal matters.

The way I see it, it's absolutely necessary to have two persons to raise a child, especially in our situation. I could not imagine being alone with my daughter, both for the matter of raising her and for difficulties with practical things.

I have to mention that my wife and I are very much lucky with our network; we have strong resources in family and friends. They have given us good help when we asked for and needed it.

It is definitely a fantastic experience to be a father of a 3-year-old daughter and I could never be without this experience. It gives me so much value every day and I am sure it also affects my rheumatism in a positive way.

Sometimes I reflect about how life would be without my daughter and I think my daily life would be more predictable. My daughter is a chaos generator! She makes every day different and I love it.

**Contact Kirsten and Georg**  
**Kirsten: [kirsten1975@aol.com](mailto:kirsten1975@aol.com)**  
**Georg: [ghodnejf@online.no](mailto:ghodnejf@online.no)**

## **“Starters information package” for youth with rheumatism**

*by Juul van der Veen, The Netherlands*

The “starters information package” will sound familiar to some of you, since we already mentioned it during the IYC in Haraldvangen last year. By then, it was about to be developed by the youth group of the Netherlands Rheumatism Patients' League. Besides me, Lucinda Blauw and Sylvia Langbroek are members of

this group who are known by most of you, since they also attended the congress (maybe better known as tulip girls?).

The idea for a package with information for youth with rheumatism was based on the outcomes of a qualitative study, in which the needs and problems of youth with rheumatism were investigated. With regard to the need for information, it appeared to be that this was mostly needed during the first years of disease. In general, information was gathered by the patients themselves. It was remarkable however, that topics on which more information was needed by the participants, had been already provided in several ways. Therefore, we concluded that the reach of information has to improve.

We decided to provide information about information sources concerning rheumatism, since too much information in the beginning of the disease could be overwhelming and scary. By knowing where to find which information, patients are able to look it up or ask for it when they are ready for it. Therefore, we composed a package of leaflets with information about the national rheumatism telephone line, interesting (internet) addresses, a list of brochures they could order, our youth leaflet etc. Further, we included a few reply cards to order an example of our monthly journal “In Movement”, to get information about local youth groups, and to have the opportunity to be put on a list for receiving information about activities on a regular basis. Everything is put in a nice, red stationary-case with no text on the outside.

At the moment, the starters information package is experimentally provided to patients who are just diagnosed with rheumatism. In November 2001 every Dutch “rheumaconsulent” (nurse specialised in rheumatism care) received five packages together with an evaluation questionnaire and a registration form. If all the five packages are provided to patients, they have to send back the questionnaire to order new packages. In this way, we are able to evaluate the providing and the appreciation of the starters package by rheumaconsulents.

In the meantime we also planned an in-between evaluation by telephone with a sample of rheu-

maconsulents. Further, we will start with the patient evaluation in November 2002. After having the results of the evaluation of both rheumaconsulents and patients we can draw conclusions about the project's success and if it will be continued in the future. Probably, you will read more about that in an IOYR newsletter later on.

**Find contact-details for The Netherlands at [www.ioyr.org](http://www.ioyr.org)  
Here you can also find information about other member-organisations**

## **The Record-breaking Danes: We dare you...**

*by James Rickmann, Denmark*

What is the highest number of young people with rheumatism that can be in a car at one time? The record in Denmark for the time being is 23. Be assured that no one has suffered injuries in result of participating in the record attempt...

The attempt to set a new record of the highest number of young people with rheumatism in a car at one time is set to be explored for the fourth time in the autumn 2003. This bone wrecking experiment has its place every year at the end of the annual Teenage-Weekend in FNUG (The Danish Organisation of Youth with Rheumatism). The participants are teenagers

with rheumatism and they are really true record-breakers!

The rules are simple: The participants can only join the record attempt if they have rheumatism of some kind. People without rheumatism are excluded. At the record attempt there are two impartial witnesses to confirm the results along with James Rickmann who is behind the record attempts in Denmark.

The record attempt takes approximately half an hour outdoors on a parking space. All the participating teenagers stand in a line and one at a time step into the car. They are counted while they stand in a line. When everyone is inside the car, all the doors are closed and immediately opened again, so everyone can jump (or easily walk...) out of the car.

The car used is a MPV (multi-purpose-vehicle) with 5 seats only. The luggage compartment is not allowed to be used at all because of safety reasons. For the Danish record attempts the Chrysler Grand Voyager has been used every year, though the Renault Espace or the Mercedes Vito easily can do. The larger vans are not allowed in the record attempts.

Any competition to the Danish record attempt is very much welcome and people interested can contact James Rickmann from FNUG on email: [james@fnug.dk](mailto:james@fnug.dk).

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### **Next newsletter:**

- Read about Market of Possibilities in October 2002
- More about Members Meeting 2003 and IYC 2004
- Your article???

You will receive the next newsletter in April 2003. You are more than welcome to write an article for the newsletter. Please mail it to [ioyr@ioyr.org](mailto:ioyr@ioyr.org). Deadline is 15. March.

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### **More information about IOYR:**

c/o FNUG - P.P. Ørums Gade 11, bygn. 10 - 8000 Århus C - Denmark  
Phone + 45 86 11 85 21 - Fax + 45 86 11 73 88 - [www.ioyr.org](http://www.ioyr.org) - [ioyr@ioyr.org](mailto:ioyr@ioyr.org)