



Lots of activities

- let's meet face to face and online

by Dorte Rønslér, chair of IOYR

Every young person with rheumatism that - maybe only once - has met another young person with rheumatism knows how valuable that is. Meeting another person who knows how it is to live with pain, knows about the change from a good day to a bad day and knows how it is to meet the ignorance of other people. Meeting another young person with the same problems, realising that you are not the only one, makes it easier to be you.

It might also give you the power and ideas to make forums where you and others can meet to exchange experiences, thoughts and hopes about being a young person with rheumatism.

This is why IOYR finds it very important to arrange meetings and forums to meet. In this newsletter you can read about events where you can meet other young people face to face, but also online at www.ioyr.org and in the future in our web-project.

Open Day → Members Meeting

Maybe you have already heard about the Open Day - this is one of the activities for members in IOYR. This event takes place every third year - between the IYC's (International Youth Congress). The first Open Day - and so far only one - took place in Denmark in 2000. At our meeting at the beginning of February 2002 the board of IOYR decided to change the name of this event. In the future the 'Open Day' will be the 'Members Meeting'.

Members Meeting is a mini-congress. The goal of the meeting is to learn from each other about our work for and as young people with rheumatism. We want the meeting to be a forum where we all get new ideas and inspiration for our work back home. You can read more about the meeting in 2000 on our web-site www.ioyr.org and in this newsletter you can read about the next Members Meeting that will take place in May 2003 in Lithuania.

Other Meetings

IOYR is a partner in the work of the European Manifesto. This manifesto will be the focus in October this year when the 'German Association of People with Arthritis' (Deutsche Rheuma Liga, DRL) in collaboration with the European Manifesto Secretariat and Steering Group hosts the 'Market of Possibilities'. IOYR really hopes that it will be possible for our members to participate.

In Switzerland the planning for IYC (International Youth Congress) 2004 is progressing. As you can read later on in this newsletter they have a really enthusiastic working-group and I think we can all look forward to hearing more from this group.

Let's chat...

We all know that October 2002, May 2003 and summer 2004 seem so far away. But don't worry, we will meet before that. We will meet online! The chat at www.ioyr.org is open 24

hours a day and it is also possible for you to tell others when you will be in the chat. Learn more about the chat by reading Helge's article in this newsletter.

Sometimes we invite you to official chat-meetings. The next time will be Wednesday 3. April. Twice on this day we will chat about 'Activities for Young People with Rheumatism'. We hope that everyone interested in the subject will visit the chat. You are very welcome at 14.00 and 19.30 (UK-times).

Let's chat nationally...

Very often we hear the question 'Do you know any young people with rheumatism from my country?'. Sometimes we can answer 'yes' and help with the contact. Other times the answer from us is 'no'. But now IOYR is working to give you the possibility to make a forum for national contact.

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 website. The forum will consist of templates that give you the possibility, without any knowledge about web-design, to very easily make a site with information, forum, chat etc. where you can get in contact at a national level.

The members of the group for the web-project are: Jette N. Pedersen (Denmark), Cesare Patara (Italy), Andreas Gunleikskås and Helge Elvik (Norway), Mattias Svensson (Sweden) and Con Cunningham (United Kingdom) and Dorte Rønsløer and Georg Hodnefjell from the board.

If you want more information about the web-project or anything else about IOYR you are more than welcome to contact us. You can find the contact-details on the last page of this newsletter.

Members Meeting 2003 - Welcome to Lithuania

by Vilma Bandzeviciūtė, Lithuania

The first Open Day of the International Organisation of Youth with Rheumatism (IOYR) took place in May 2000 in Copenhagen, Denmark.

It is with great pleasure that the Lithuanian organisation club 'Artritas' is planning the second Members Meeting (Open Day) in May 2003 in Vilnius, the capital of Lithuania. The meeting will take place from Friday to Sunday afternoon. The dates will be confirmed very soon at www.ioyr.org and in the next newsletter.

The theme of the meeting will be activities and work of and for young people with rheumatism - and ideas about how to use the European Manifesto in this work. We would really like to hear from you if you have any ideas, wishes or suggestions for the meeting. Please send us a mail at ioyr@ioyr.org.

Each IOYR-member-organisation can participate with 2 delegates together with one delegate from your 'mother-organisation'. The participants will have to pay travel and accommodation including food. IOYR will work to find funds for the meeting to make it easier for you to participate.

The organiser, Kaunas club 'ARTRITAS', is an independent organisation founded in 1994 and reorganised in 2000. Club 'ARTRITAS' has been a member of IOYR since the start of IOYR in 1995. 'ARTRITAS' are proud to welcome you to Lithuania and together with IOYR we hope that you will go home with good memories and ideas for your work.

The Market of Possibilities - Plans for a Pan-European Manifesto event

by Michael Bernardy, chair, Manifesto Steering Group

As the members of IOYR already know, the European Manifesto for people with arthritis (PARE) represents the voice of more than 103 million people across Europe who live with chronic arthritis conditions. It was created by the three big associations in Europe, which are the EULAR Social Leagues, Arthritis Rheumatism International (ARI) and IOYR!

In autumn 2002 the European Manifesto will have existed for 2 1/2 years - a good date to look back, but also to think about future activi-

ties within the world of the European Manifesto.

Therefore the German Association of People with Arthritis (Deutsche Rheuma Liga, DRL) is organising an international weekend that will take place from 10th to 13th October in Bonn, the former capital of Germany. The meeting is being organised in collaboration with the European Manifesto Secretariat and in co-operation with the European Manifesto Steering Group. The main goal of this Meeting will be strengthening the PARE Network.

Who can participate and what is it about?

The meeting will provide a forum for national representatives from social organisations and national PARE representatives. Participants will meet and survey how the implementation of the Manifesto has been realised so far in their countries. The programme therefore comprises elements such as introducing projects that show best practice, exchange of experiences and topics which help to improve networking amongst each other.

The Market of Possibilities will be a full two-day programme.

The 'Market' will take place on the first day. The second day will have the headline 'Reflecting the work with the Manifesto'. PARE representatives who have supported the efforts of the Manifesto in the past will have the opportunity to exchange their experiences. To be mostly voluntarily responsible for such an important task might sometimes be difficult. The participants will learn from presentations about the progress, the difficulties and the status of implementation in each country.

On behalf of the organisers I hope that the Market of Possibilities will work as a colourful mix of lots of creative ideas. A large variety of opportunities, activities and projects will be offered to the participants - all under the motto 'Giving & Gaining'.

More than ten countries have already confirmed their participation - and we are glad that IOYR will also be actively involved. Altogether we

expect to welcome 150 people from all over Europe. If you are interested in getting more detailed information about the meeting, please contact the German Secretariat for the European Manifesto in Bonn. You can also visit our homepage: www.paremanifesto.org and will also find further information under www.ioyr.org

More info about the manifesto?

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IYC 2004

- Becoming a group

by Laura Margulies, Switzerland

The organisation group for the IYC 2004 in Switzerland met on the 2nd of February to discuss the first topics of the congress. To start organising such a congress means a lot of administration. Mountains of papers, thousands of questions and a lot of interesting discussions started in the coffee-room of our mother organisation in Zürich.

Creating, preparing and holding an IYC is a work that needs responsibility and creativity and it's very stressful as well. Shortly after the meeting I asked myself: 'What makes one become a part of this task? Why does a person want to give that much support to an IYC?'

I think you are all wondering who the people are that want to face this three year long adventure.

As we are a group of not less than eight members, I asked all of them to tell us their idea for becoming a part of IYC 2004.

For example Lucie, a 32 year old young woman, wants to make people dream of the IYC 2004 as much as of the congress in Norway, because she already had the feeling of participating through thousands of pictures and stories about the last congress.

And Fäbe, 18 years old and the only man in our

group, caught the spirit through his mother Jacqueline (Switzerland's delegate for five years).

Jacqueline is, of course, a part of the organising group as well: She's the one to share with us all her knowledge from the other congresses and through her long work for IOYR.

For Xenia (22 years old) it is very important to help people communicate, to make them share their experience and accept one another as well as themselves.

Last but not least there is Barbara: She's our link to the mother organisation, she holds all of us together through her unique support. When asked how she feels about organising the congress, she answered nothing less than 'YIPPIEHHHHHHHHH'!

As you can see, all of us have hopes and dreams for the congress 2004 in Switzerland. And we all share one thing: We are all eager to face the work, to share the emotions, to create, prepare and hold a wonderful satisfying congress!

Switzerland is looking forward very much to seeing you all in 2004!

More information about IYC 2004?
Please contact
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IOYR-member-organisation:

Young in Czech Republic

by Jana Korandová, Czech Republic

My name is Jana Korandová. I work at the Institute of Rheumatology in the post of Chief Nurse. In addition to that I am one of the Czech Rheuma League members and at present I am one of the people responsible for our Rheuma League Bulletin. I also try to help our Social League with their activities.

I first learned about your organisation a few years ago, but it is only since the EULAR Annual Congress in Prague (June 2001) that I can say, 'I personally know a few IOYR members.' That's great, as we have started to co-operate more.

What has happened actually since June 2001?

- One of our young members (Romana Lukáčková from Southern Bohemia) was given the opportunity to attend the IOYR Congress in Oslo. When she came back she was so enthusiastic we could hardly believe it. Well, when we heard Romana's story, saw pictures of IOYR participants who were dancing, riding horses, water skiing, etc, Romana didn't have to explain any more.

Once more we would like to thank the whole IOYR Board for giving us the chance to send one of our members to your Congress. Thank you very much also to all those people who enabled IOYR Congress participants to do all that they did!

- We also have received the address of your home page. Now, we can all read and/or use it if we want to do so. This is the most fantastic opportunity for all our young people with rheumatism, and for all those young people who are afraid to attend our meetings, who don't want to communicate with us because they don't understand why they should do so.

Believe me, I know what I am speaking about as I am one of those who tries to keep our Rheuma League on the move.

Though our Rheuma League was established in the year 1991, from the very beginning we had not only plenty of plans and ideas on how our Social league should work, but also plenty of problems when things didn't go so well and we had to overcome lack of understanding, lack of active members, etc.

One of our aims was to establish a Group/ Organisation of Youth with Rheumatism in our country (OYR). Unfortunately we failed and our plan remained unrealised. Thus, at present, our young and elderly have to work together. That is possible, but not the very best solution for many reasons.

Of course the fact that there was no response to all our efforts is not encouraging. Where did we

fail? Aren't young people the same all over the World? Why do your young people respond and ours don't?

Perhaps one of the reasons is that we did not find the right way of communication. Planning activities should have been done more according to their needs - the content of the whole programme should be better 'tailored' to the needs of our younger friends.

There may be other reasons:

1. Our young people with arthritis are afraid to admit their problems, because they were not properly informed by us, the health professionals.
2. Some young people with arthritis may not want to accept their present health condition ('If I joined such groups of similarly affected people, I will constantly be reminded of my present state'). These people do not realise that a better understanding of their disease might make it easier to live with it.

Of course I am not speaking of all young people. Also in our Rheuma League we have fantastic, active young individuals who are interested in all that we are doing and these people are doing a lot themselves (Romana is one of them). Unfortunately, these people are in the minority and what's more, they live in different regions of our country, which makes the situation even more difficult.

Find contact-details for Czech Republic at
www.ioyr.org
Here you can also find information about
other member-organisations

It may be clear to you why we are happy to be able to surf over your Web sites. Maybe somebody from your OYR could tell us what more we should do and how we should do it.

For your information

For our February Bulletin we have prepared the Czech version of the text - 'History of IOYR' (not everybody in the Czech Republic knows English). Our Bulletin gives information on IOYR's website-address and explains the con-

tent of your pages to readers (a brief description of 'what is what, who is who').

Hopefully, those young people who don't want to communicate with us will find it interesting to read IOYR's pages. Maybe they will come and join us later, and will establish their own organisation.

From IYC 2001:

Do you kick your child?

by Jette N. Pedersen, Denmark

Is it possible for me to take my medicine if I get pregnant? What will the impact on my body be during and after pregnancy? Does the medicine I have been taking through the years have any influence on my ability to get pregnant? Are there any aids (help remedies) for childcare? Am I able to become a good parent?

Pregnancy and children was one of the themes at the IYC congress in Norway. The theme made people talk and think.

Nurse Hege Koksvik works at the 'The Centre for Mothers with a Rheumatic Disease'. She was in charge of a workshop at IYC. And there we were, 25 women of childbearing age and one guy, listening to Hege talking about what it will be like to become a parent.

Hege told us that rheumatism is more than just one condition and that the disease differs from person to person. She told us that in spite of this there is a pattern when women with rheumatoid arthritis have children. During pregnancy the disease will improve for 75% of women. This improvement might occur within the first 3 months of pregnancy or later and will usually last until the baby is born. Some women will have no change in their disease and about 10% of women might feel worse during their pregnancy. Nobody knows what causes the differences and how you will feel during your pregnancy.

Rheumatoid arthritis has no negative influence on the pregnancy or the embryo. Women with rheumatism usually have a normal length of pregnancy and a normal delivery. Women with rheumatism usually have healthy children. Two or three months after the birth, the rheumatism

usually gets worse. Women often fear this, as the flare up of the rheumatism usually coincides with their homecoming and the need to take care of the child. Very often the disease will ease within a year and returns to the level it was at before the pregnancy. In the long term pregnancy should have no influence on the development of the disease.

Concerning Lupus and pregnancy, it used to be customary for doctors to advise women with lupus to have an abortion. That doesn't happen today. Approximately 50% of pregnancies will go on completely normally. However 25% of women with Lupus will give birth prematurely and 25% of pregnancies will end in a spontaneous abortion. Even though many women with Lupus have normal pregnancies and give birth to normal children, some problems might occur during pregnancy, which you ought to be prepared for. It is highly recommended that the pregnancy is very well planned.

According to women with psoriatic arthritis being pregnant will mostly affect the arthritis in a positive way. Most women will have fewer problems with their joints during pregnancy and the skin problems may even go away. Psoriatic arthritis has no impact on the pregnancy itself, the embryo or the child. However women must be prepared for the fact that their disease will return within a few months.

What kind of medicine?

It was very obvious that Hege knew what she was talking about and was able to answer all the questions from the audience. It was also very clear that all the participants had had many thoughts about the subject. There was a very fundamental worry about the impact of drugs on the ability to get pregnant and the impact on the pregnancy itself. It is a well-known fact that many women fear the medicine-free period they have to go through because of their baby. Concerns about the effects on the embryo played a very important part in many questions.

But we were reassured by the fact that you do not necessarily have to stop taking all your drugs before you start thinking about having a

baby. There are several drugs you can take during pregnancy without harming the embryo or the newborn baby. In the treatment of rheumatoid arthritis Methotrexate is the only drug you have to stop taking before you get pregnant.

There was a lot of discussion about the messages we had received from our doctors and it turned out that they were very different. The explanation for this was that the drug companies do not want to take any chances with marketing products that might later harm the embryo. The starting point is always to use a label saying that it is not recommended for pregnant women to use the drug. This does not necessarily mean that the medicine will harm the baby. But it is still a good idea to talk to your doctor 'in time'. With a sparkle in her eye, Hege added that we were very welcome to request our rheumatologists to ask for information from the Centre, if they have any questions.

Remember!!!

Next chat-meeting at www.iovr.org:

Wednesday 3. April at

14.00 and 19.30 (UK-time)

Everybody is welcome to join!

The headline of the chat will be

'Activities for Young People with Rheumatism'

Read more at www.iovr.org

A choice with a dilemma

Making a decision to have children was very obviously a subject that interested the participants at the congress in Norway. It was a very natural thing for some while others explained that they felt it would be hard to have little children, but that having arthritis prepares you for the obstacles you will face. In that way you can use your 'experiences' with arthritis positively when you become a parent.

Others were not so convinced. One participant said 'I'm afraid that having a baby will mean that my husband will have not one but two children to take care of, if I need help too...' It was especially the flare-up of rheumatism that is very common after a pregnancy that seemed to be a big deterrent – coming home with a completely helpless new-born baby and in addition

having to hand it over to other helping hands.

The most important message was that the thoughts across the countries were the same but the solutions have to be different and adapted to each different person. This led us to a specific part of the subject: tips and tricks for handling the baby in spite of stiff knees and crooked fingers. For instance, a leash might solve the problem of your child running away from you, even though your neighbours might think this is terrible. And if you have a problem carrying the baby around at home, it might be an idea to buy a laundry basket with wheels. And you ought to have a decent pillow to breastfeed your baby.

Unless you want others to take over the baby you have to forget what other people think about your alternative solutions – as long as it works. If it is easier for you to turn your baby with your foot instead of lifting the baby when changing diapers, you should do it, even though your mother (in law) might find it terrible that you 'kick' your baby. What others do is their way of doing it. Trust your own judgement and find your own way of doing things. Like the main theme of the Congress said: 'Find the power in you'.

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, both from people with rheumatism and from those who treat them.
More information at www.revma.org.

Using the IOYR chat

by Helge Elvik, Norway

These are the simple steps you need to do to enter the IOYR chat. First you should have a web browser ready. Point your mouse at the icon for the web-browser. Start it, and enter this address in the address-field www.ioyr.org.

When you press the enter key, after a moment you should be presented with the web-site. Choose 'chat' from the menu.

This is the front page for the chat. Here you can either log in to the chat, or look at the schedule. The schedule is reached by clicking 'When to meet at the chat'. For more on that, read about it below. Now you're ready to enter your name, and enter the chat. In the text field 'Username' enter the name you want to be known by in chat.

After you have entered a name, you can enter the chat room by clicking 'login' with your mouse. The chat pops up in a new window.

The chat

When you are inside the chat, you type messages by typing in the white text field near the bottom of the window. The message is sent when you press 'enter', or click on the 'send' button. It is also possible to send private messages to other people in the chat. If you click on the arrow that is pointing down, to the left of the text field, you will get the names of everyone in the chat. Select the one you want to send private messages to. You can select a funny face to go with your message by clicking one of the circles beside one of the images. Also you can type with another colour by clicking on 'Textcolour', and selecting your preferred colour from the list.

The schedule

When you click on 'When to meet at the chat' on the main page, you will be presented with a window. From here you can click 'next' and 'back' to scroll back and forth in the calendar. If there are chats scheduled, the date will be marked with red. You can click on a date to get details about that particular date. When you're in the details, you can also schedule for a chat on that particular date yourself. Enter your name, and the approximate time you will be there.

That should be all you need to know to be able to sit down and start chatting. Hope to see you soon at www.ioyr.org.

Next newsletter:

- More about Open Day and IYC 2004
- Articles about being a parent with rheumatism
- Your article???

You will receive the next newsletter in June. You are more than welcome to write an article for the newsletter. Please mail it to ioyr@ioyr.org. Deadline is 15. May.

The Aims of the IOYR

The main aims of IOYR are:

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

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