

IOYR



International Organisation of Youth with Rheumatism

www.ioyr.org

Newsletter no. 15

October 2004

World Arthritis Day Special Edition

Hello and Welcome!

by Marianne Cunningham, Board Member

Greetings from the new board of IOYR! As you will read in this newsletter, there was a General Assembly this year, which took place at the International Youth Congress (IYC) in Switzerland. We hope that this brings back many happy memories for those of you who were able to take part in the IYC and if you were not able to attend, then we hope it inspires you to join us in 2007 in Sweden!

There are many important things about this newsletter. One is that it is sent to you in time to mark "World Arthritis Day", a day when all over the world, people with arthritis are able to speak up for their rights and make their voices heard. There should be extra debates and publicity for organisations that support people with arthritis / rheumatism. Why don't you write something for our next newsletter to tell IOYR what you did to mark World Arthritis Day?

One very important thing is that this newsletter contains many "thank – you" messages. From the members of the new board of IOYR, there is a big thank you to the members who, at the General Assembly, elected us all and helped to set our priorities for the next three years. From the last board, there are thanks for your

support over their time as the board, and thanks to Dorte Ronsler for being such a fantastic chair.

From everyone involved in IOYR there is a massive thank you to everyone involved in organising the IYC in Switzerland. A tremendous amount of work went into planning, funding, organising and delivering the IYC. The Swiss organisation deserves a huge round of applause and pat on the back from all of us.

Lastly there is a thank you to our members, without you there would be no IOYR, no board, no IYC's, no international co-operation no plans for the future. So, whether you have been a member for many years, a few years or even just a few days, WELCOME AND THANK YOU! We look forward to hearing from you.

The new board members introduce themselves to you later in the newsletter. Also in this edition:

- A report about the Swedish organisation
- A report about IYC 2004 from the Dutch delegation
- A thank you to Dorte Ronsler
- Very sad news regarding a dear friend
- How to write something for the newsletter

Find contact-details to the members of IOYR at www.ioyr.org

Riksorganisationen Unga Reumatiker

by Anna Ageberg

The Swedish organisation of Youth with Rheumatism, Riksorganisationen Unga Reumatiker, became an independent organisation 1994. However, we are still in close cooperation with the Swedish Rheumatic Association. We have more than 1500 members and our organisation is concerned with children and young-people aged 7-35 with rheumatic diseases, and is built up like this;

National Office

National convention
National Board
Regional Board

Local working groups

At the **national convention** which happens every second year, we vote for ten people to sit on the **national board**. The national board get together for meetings at four occasions per year at our **national office** in Stockholm. One of the board's most important tasks is to support **regional boards**. There are regional boards already working or starting up in most places in Sweden. If a region is not yet ready to become a regional board, it is possible to start a **local working group** to arrange activities for members living in the same area.

The aims of our organisation are;

- To spread knowledge and information about children's and young people's rheumatism.
- To stimulate increasing research
- To look after the interest of children and young people within The Rheumatism Association
- To cooperate internationally on issues concerning children and young people with rheumatism
- To arrange courses and camps

- To support local management and working groups

As a member in Riksorganisationen Unga Reumatiker we will give you information about different rheumatic diseases, the opportunity to participate in courses and camps as well as in activities that are arranged by a region or a local working group. You also get automatic membership in the Swedish Rheumatism Association and their magazine (6 issues/year), and a chance to apply for contributions to rehabilitation and aids.

The camps, courses and conferences that we arrange on a national level are for example winter camps, summer camps, and youth weekends. We arrange lectures at these camps that contain information about living with rheumatic diseases, being a parent with rheumatism, and how you can affect society. Examples on local activities are physiotherapy in hot pools, visits to cinemas, and excursions.

IYC 2004 Switzerland

By Nicole des Bouvrie

It all started with the same thing it ended with: train ride of ten hours. But what happened during the time in between is hard to write about. The nearest village Thun was very pretty, the location next to the Thunersee was beautiful and the rooms were perfect. But those are not the things I will have on my mind when I think of the week in the Swiss mountains I spent with forty other youths in which I changed the life we live and the world around us. Because, when you just think about it, spending a week with young adults with life flowing through their veins, who want to spend some time of their holidays on putting up, proceeding and getting the finishing touch to an organization of people and/or youth with rheumatism, that is not something that is easily forgotten.

IYC 2004 continued...

Of course it can be difficult to get in the right mood, in which clear ideas and arguments have the ability to get on the surface and find other minds to inspire. Thank God the organising committee decided to get Mark Doughty from Great Britain to get people together with his Icebreaker. Everyone was able to share whatever they wanted to share and he got everyone to think about the things we wanted to be accomplished after this IYC.

After a great night with karaoke and games (and of course some sleep) we were expected to have breakfast at half past seven. At least, that was the general idea among the Dutch delegation of the Reumatistenbond. I won't say we were the only ones, but still – most people came to the place we had breakfast (perfect food by the way) a lot later. From nine in the morning until six in the evening – with of course lunch and some little breaks in between – we listened and participated in Mark Doughty's class about "Overcoming barriers to Success or 'I know what I should be doing but I just can't seem to do it.'" We heard his story, how he found out he had arthritis and the way he handled it. He talked about the moments he became aware of which possibilities he had in his life. He showed us a simple model of which processes you are going through when you get a confrontation of any kind. We discussed this in groups and everyone could find out how their own life-approach worked. It is not easy to be asked how you handle your disease, but it was good to get a certain structure to really focus on some essential points.

The second day there were several presentations planned that were all about medicine. Doctors told us the latest news on experimental medicine. I thought some were very medical orientated and hard to follow, others I felt were not that interesting and others provoked a lot of questions among the participants. We heard about a Swiss

institute in which Chinese medicine is being combined with Western medicine. We heard about cannabis and the way new anti – TNF medicines worked – a lot of the IYC participants were using these themselves. And last but not least the way rheumatism / arthritis influences your "Sex life, family planning and pregnancy" was discussed. And as a lot of the people there were female, this was really a good topic to be informed about.

The two days following were filled with things about the organization itself. In "the General Assembly" the old members told what had been going on the last four years and new board members were elected. But, above all, we all talked about the future of IOYR. It was very important that everyone participated, and everyone did. After the relaxing Tai Chi exercises it was about time to focus our energy to make sure IOYR stays the energetic organization it is now.

And besides all these concentrating things it is also possible to make a whole list of things we did. Like that boat trip at the lake of Thun, playing Set – a game of cards which everyone joined in together – the trip to a nearby mountain, the Red Sofa – a small plastic red couch on which every organisation presented themselves. This was recorded on video, so we got to see everyone's strange hats and beautiful clothes. And then the letting go of so many balloons with all a little burning fire beneath it, which was a very pretty thing to see, I can assure you. Too bad if you didn't see it, but you have another chance, in three years there will be another IYC organised for you in Sweden.

We hope to see you all there,

Nicole,

On behalf of the Dutch Delegation

Our good friend and pretty girl from Denmark

Dear Dorte,

Professionally we have experienced you as a fighter for quality and control, this we got to learn and enjoy especially under the IYC2001. You have been an idealist and the world's best organiser. To be allowed to be together and work with a person who gives you this feeling is the very important thing in a team.

Dorte, you have contributed strongly to IOYR's existence and you have made sure IOYR is still going on. Now you have passed the baton on. We weren't able to take part in IYC2004, but we should have been there just to say goodbye to you. We regret we couldn't be present.

We hope you are really proud of yourself and all the experience you have got and all the good memories that will follow the new you without FNUG and IOYR.

Thank you for your enormous effort for young people with rheumatism through many, many years!

Love to our hero, from Georg and Rolf (Norway)

Ask the Board...

Name: *Linda Vøllestad Wesbye*

Organisation: BURG, the Norwegian organisation for children and youth with rheumatism

Age: 25

Where do you live: Bergen, Norway

What type of arthritis do you have? Athralgia and myalgia

For how long? Since age 13

Occupation: student, I am doing a master degree in anthropology (hopefully finished June 2005).

Home life: I live with my husband Hans Jacob

3 things I love: Hans Jacob, being with my friends and live a meaningful life doing voluntary work and study!!!!

3 things I hate: judgemental people, discrimination and bad weather

My dream: to become an excellent anthropologist with a good job and being healthy and happy living with my lovely husband☺

Where do you live: Freiburg i. Br., in the sunny south-west of Germany

What type of arthritis do you have? RA

For how long? Since age 14

Occupation: PhD-student in history

Home life: I'm still single living on my own

3 things I love: meeting friends, riding my bike, relaxing with good music and a cup of coffee

3 things I hate: lack of access for disabled people, arrogance, buying shoes

My dream:

- living without medication and pain

- Arthritis is well known and accepted by society

- to have always someone to rely on

Read about the other two board members in the next newsletter. See pictures of all four board members on www.ioyr.org

Name: *Astrid Küntzel* **Age:** 28

Organisation: Deutsche Rheuma-Liga Bundesverband e. V.

A sad message to you all...

It is with much regret that we have to report the death of Barbara Kupferschmid, from the Swiss rheumatism organisation. Participants at the IYC 2004 got to know her so well during that week and we're sure they were all very shocked and sad to hear the news. The IOYR board sent flowers to her funeral on behalf of IYC participants and IOYR members and a joint notice was printed in the Swiss newspapers from IOYR and the Swiss organisation. On behalf of IOYR we'd like to say how much we appreciated Barbara's spirit, energy, enthusiasm and commitment to making the IYC a huge success and the world a better place for young people with rheumatism.

Liisi from Estonia was kind enough to send this message:

For me, she was a friend, a mother, a teacher during the short week I knew her. That only was possible to happen due to her empathy towards others, the way she cared. She was a cheerful person, with weird but sweet jokes and always uplifting you. Making you feel good. I hope, although I am quite sure, that she knew how loved she was for who she was. An extraordinary *chica*! It is difficult to put in words what I think of her and how she was, but I have no doubt that you all know what I mean.

With my deepest love to You, Barbara!

In memoriam to Barbara

Barbara worked at the Swiss League for nearly 20 years. During the last 10 years, she was supporting our Youth Group in every way. She has been our Contact Person, our organiser and our Friend. With her open mind and her big heart she always made us feel very comfortable in our Groups. Barbara was so much more than only an Employee at the Swiss League. She did her work with all the power of her heart, and she was always there for every one of us. Barbara did her work with passion, always thinking of the minorities in our society.

During the last 3 years she was a very important part of the IYC 2004. Barbara was supporting this event in every way, she was fighting against all barriers, and she always believed in our power to realise this IYC. She was so happy when the IYC started this summer, and we are glad to know that she could experience this great Congress.

On behalf of the Swiss Youth Group we want to say thanks to her, for the Power, the Energy and for her big heart, filled in with love. She was really a special Person with very special relationships with everybody. We also want to say thanks for her company during all this years, and we hope with all our heart, that she is happy now at her new home.

Barbara, we will never forget you! We will keep our reminders of you deep in our hearts !

Jacqueline Mäder

How to write an article for the IOYR newsletter!

One of the interesting discussions at the General Assembly (GA) was when we asked members present to answer the question "What are the barriers to being involved in IOYR?" The board was interested to learn how they could support members to be more involved and also wanted to ask why people don't write articles for the newsletter.

Many people told us at the General Assembly that they thought the newsletter was great and looked very professional but they felt their English was not good enough to send an article, or they felt unable to write something in English. Now that we know this information we can say to all our members and supporters that we welcome articles from everyone, no matter how "good" or "bad" their English is. A lot of work and time goes into editing the newsletter and many of the articles we receive require a lot of corrections to be made to the English. So when you see the articles in print, remember that often they have been corrected and edited. If you feel it would be easier to write an article in your own language, then we can have it translated into English for you if necessary. You could also send us an audio tape if you can speak well in English better than you can write in English. Contact us for the best post address to send your audiotape to. If you can write well in English and would like to offer to translate articles for us, then please let the board know.

Contact the board at ioyr@ioyr.org

Next newsletter:

You will receive the next newsletter in Spring 2005. You are more than welcome to write an article for the newsletter. Please mail it to ioyr@ioyr.org. **Deadline is 15. January 2005.**

The Aims of the IOYR

The main aims of IOYR are to:

- exchange information and experiences and to learn from 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.
- stimulate intensive research of the experiences of young people with rheumatism.
- co-operate with other organisations with similar interests, as appropriate