



## IYC 2001 is over - but the power in us are developing

*by Dorte Rønslér, chair of IOYR*

The International Youth Congress is the most important activity of IOYR. It's where members and future-members meet – all young people with rheumatism. This summer the 5<sup>th</sup> IYC took place at Haraldvangen close to Oslo in Norway....

The Norwegian project-group had made a great platform for the participants to gain information, experiences and power for themselves – but also, very importantly, for their national youth-work at home, and for future co-operation with other countries.

Lectures, discussions, group-work, physical activities and parties during the nights gave the theme of the congress “The Power in you” more than 100% credit and we all broke a lot of barriers.

Articles in this newsletter, mails send to the project-group and messages in the new guest-book at our website [www.ioyr.org](http://www.ioyr.org) show that we more than reached our goals with the IYC 2001. For many participants the IYC changed their life. It was simply a fantastic week....

On the first day I talked with one of the participants. She felt unmotivated in her youth-work back home, it was so difficult for her to reach and get other young people with rheumatism motivated. I talked with her some times during the week and I could see that she changed step by step. On the last day she came to me and said

“oh, I don't want to go home in a way, I want to stay”. But also – with a big smile – she said “but I also have got so much power and ideas what to do when I come home” and she continued “I also know that if I get unmotivated again and want to get ideas I have a lot of friends and contacts all over Europe”.

I know that many others feel like this. The Norwegian project-group had made the platform and the participants showed that they could use it. Thanks to everybody supporting, working for and participating at the IYC 2001. You all made the week very special!!

### **4 New members**

During the IYC we got 4 new members of IOYR. And we are very happy to welcome Latvia, Italy, Slovakia and Slovenia. Now IOYR has 18 members and we hope that we can soon welcome more. At least 3 have shown a lot of interest during and after the congress.

You can see a list of all members on our website at [www.ioyr.org](http://www.ioyr.org).

### **New board**

At the IYC the General Assembly also took place. Here the participants discussed the future of IOYR and gave the board a lot of ideas to work with. We will soon send out the minutes from the General Assembly.

During the General Assembly of course the election for the board took place. New members on the board are Laura Margulies from Swit-

zerland and Kirsten Russ from Germany. Very welcome to you! Lucinda Blauw, Catherine Gibb, Vilma Bandzeviciute and Georg Hodnefjell from the old board got elected again. Montse Sánchez-Oro Perez from Spain and Karolina Piotrowska from Poland left the board and I want to thank the two of you for your work in IOYR.

After the General Assembly the board had a small meeting and here Lucinda was elected at the treasurer.

For me personally the IYC 2001 also meant a lot. Not only as a participant and a part of the project-group, but also because I got elected as chair of IOYR. I'm very happy, but also humble about this. I will work very hard to fulfil your wishes and support to me and I'm looking forward very much to the work with all our members, the board and of course our co-operation-partners.

You can also see a list of the board at [www.ioyr.org](http://www.ioyr.org).

One of my goals is to spread information about IOYR, but also to develop the exchange of information and experiences, not only between IOYR and the members but also between the members. The IOYR-board can't do this alone and it is my hope that you will all help us with this. I hope that in spreading the information we can gain more members and also give people power – like we got at IYC - to start and develop not only national but also international work.

Now we can all start looking forward to the next IYC. It will take place in 2004. Thanks to Switzerland for taking the challenge with hosting this congress. Be sure that you have a lot of friends who wants to help you...



## **Once upon a time...**

*by Gábor Kürtösi, Hungary*

Once upon a time there was a place called Haraldvangen where many young arthritic peo-

ple gathered together from all over Europe. Haraldvangen was in the middle of a great forest by a clear watered lake.

I started my story like that because the whole week was as exciting as if we had been in a fairy tale. Our bungalows were set in a fabulous environment, as was the auditorium where there were many interesting presentations connected to our different kinds of rheumatic diseases.

The first presentation had the title "The Power in You" which was also the slogan of the congress. The presentation, by Kåre Dreyer, showed us how we can make our hidden power come to the surface and how to use it more efficiently. This power is often blocked by our subconscious.

"Breaking Barriers" was the title of the presentation the next day. Rolf Husebø talked about psychological barriers, which stop us doing what we are able to do - maybe because of our own stereotypes about ourselves.

Before you should think we sat in a lecture room all the time, I will write about our outside activities, too. On the afternoon of the second day we could test whether we had been good students after the first two presentations. We could try breaking barriers through different programmes like horseriding, fishing, sailing, and water skiing.

Water skiing was my barrier to break since I had never thought before that I could speed on the water like that. You should also try it! Break your barriers and use the power in you! You will enjoy it!

The third day was a bit more relaxing with one presentation in the morning and two optional ones in the afternoon. I would like to highlight the presentation in the morning. "Owning Your Health" was the most interesting one for me since it was again a kind of continuation of the above presentations. The title also suggested that we should not just break our barriers but we should also know our limits. In my translation: you should not go on an 11-kilometre-long

tour if you know you will end up in a wheelchair next day.

In the evening, after the presentations, everybody joined the "international evening" where all the 17 nations showed their national drinks, food, music, dresses etc....

Day 4 was an exciting day on a Viking ship. Sailing in a Norwegian fjord was really amazing while we could try the widest range of delicious seafood. Although we did not have too much time for Oslo, we could see most of the sights.

On the last two days we took part in some more presentations. The one about new medical treatments was interesting because we got some information about very expensive medicines which could help a lot of arthritic people in the future if their cost decreases.

There was a kind of strange feeling in the air on the very last afternoon in Haraldvangen. It was the mixture of happiness and sadness. We were happy to go home and to see our families and friends again but we were sad because we all knew we would have to say "goodbye" to our European friends for another three years.

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## **The week was too short**

*by Signe Bicule, Latvia*

I am sure that everybody spent a wonderful time in Haraldvangen. But that week was too short...

I am very glad that I took a part in this Youth Congress. I got so many experiences, as never before in my life. I saw the way other organisations are working, I met so many different, nice people.

I am sure the experience that I got in this congress, will help me to work better with my organisation. Now I know what I want to do and what can I do for my organisation in the future. So, I can work with that, with the help of IOYR.

Thanks for giving me this wonderful week and the chance to work better!

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## **Breaking barriers**

*by Camilla Ladestam, Sweden*

When I was asked to go to Norway to an International Congress for youth with rheumatism I almost immediately said yes. What worried me most about the week was the language. I was afraid that I wouldn't be able to understand what was said in the lectures and that I wouldn't be able to speak properly with the other congress participants. But it turned out that my English was better than I thought and that it wasn't that difficult to understand each other.

I remember the first evening and the opening ceremony when we were sitting with a rose in our hand. I was a little bit tired and I worried about how I should be able to switch into English but somehow it went smoother than I thought. (And it was fun to hear Lars-Espen play a Swedish song).

The first night I went to bed early so I can't tell anything about what happened after the ceremony and the dinner. But I'm going to tell you a little bit about the "lavvo" instead.

We were sitting there in the "lavvo", baking our "pinnbröd" over the open fire and talked a little bit, and I think we got something magical to drink in our "kosor" because after that drink songs came from everywhere. One song that everyone seemed to know was "Father Jacob". I myself thought it was kind of cool that we could sing it in so many different languages. Another song that seemed to follow us was aaaaa.....aaaa....., this was a song that gave us many laughs. I don't know when I got to bed that night but I know that I was very tired the next morning.

I, and I think I share this opinion with many others, thought that the lecture about "Breaking Barriers" was very good, because if we don't dare to break barriers we won't get anywhere in

our lives.

During the week I broke many barriers. One thanks to my Danish friends, who sang karaoke with me, something that I never thought I would dare to do. Another barrier was to speak English in front of so many people. And then of course there was the water skiing. I think there were many who broke barriers this week and I hope to continue breaking others in the future.

Whether to become a mother or not when you have a rheumatic disease can be a hard decision. There are probably millions of questions that are spinning in your head. The lecture about pregnancy and motherhood gave me many answers. I think that many agree with me when I say that the time in hand was too short. I also want to say that there probably were just as many questions in the heads of those who wish to become fathers and I think that it was a pity that they ended up a little bit in the shadow.

I think it was a good idea to have a one-day break and I really enjoyed the boat trip on the Norwegian “fjord”. It was a splendid day for a trip on a Viking ship. For me it was extra funny because only a week before I saw a ship like the one we went on and said to my boyfriend that I would like to go on a big boat like that someday. And it happened quicker than I expected.

This week gave me a lot of energy and I made a lot of new friends, who I hope to see soon again. Before I finish these lines I would like to mention a little about the last day and the unbelievable funny night. The last day we were all sitting in a circle, all very quiet, and anyone who felt like saying anything to the others could do so. Many tears fell and many words were said during this hour. I never thought that it was possible to make so many contacts in one week; I really didn't want to go home.

In the afternoon we had some spare time, and we in our house were tired and laid down in our beds to rest for a while. We weren't supposed to sleep so we didn't set any alarm clock. Lucky enough everyone didn't sleep too deeply. Half an hour before dinner Linda came into our room

and asked if we were ready to go. But we weren't, we were still sleeping. And now we all got up in a hurry.

When we finally came to the dining room the tables were set and we had to take our places and wait for the delicious food (fish). During the dinner there were several good speeches, for instance one from Richard (Great Britain) who also had noticed the fish that constantly seemed to appear on the table. After the dessert there was time to get one more memory to bring back home. We got a book with a picture of each of the participants in. Under the photos were a few short descriptive lines, our names, addresses and so on. I think it was good to get everyone's e-mail addresses so you can easily mail all your new friends.

Later on I had a marvellous evening with many stupidities to laugh about. I would like to thank everyone who was there and made this night so funny. I really hope that I will get to experience another IOYR Congress. I wish all of you plenty of luck with your work at home and I hope that you all are just fine.



## **You are accepted**

*by Ingrid Kóšová, Slovakia*

The IYC 2001 was a great opportunity for young people with rheumatism to get involved in discussions about the possibilities of how to be active, and how to make partnerships on both national and international level. For me personally, it was an instructive week spent with those young people, who are already aware of the difficulties that people with rheumatism have to overcome and who have become “thanks to” their experiences as patients, almost experts on their own rheumatic disease.

I was glad to find out that these people are able to struggle and live a happy and meaningful life. The crutches and wheelchairs are perceived in a totally new way - they are no more considered to indicate problems or barriers – they serve as means of transport that gets you closer

to your goals, they save time, shorten distances and you no longer have the dilemma whether to join the others, or not.

We, the rheumatics, are well informed about our diseases and individual treatments and prognoses. After accepting rheumatism as a lifelong companion, we learn to live with ourselves and we are, step-by-step, day-by-day, more aware of our possibilities and the whole know-how of living with pain and with certain limitations.

Sometimes it happens that even “non-rheumatics” come to us to ask for advice. For them, we are often the experienced ones, who know how to cope with different tasks that arise every day. Here something like “reversed integration” may happen, when people with good health are integrated into our “community” and not vice versa. In fact, in what other way if not through “reversed integration” could we teach them to accept us as equals? Call them to see how we are doing things, so they could understand our joys and sorrows, our aches and pains, our specific humour. Show them in what way we are unique! Invite your friends to take part in our activities, share your points of view, show them the sources of our happiness!

Because there is one thing I am sure about: in spite of all the difficulties, we are all able to be happy - we are able to shine!

One thing is of special importance for me. During the week I realized, I wasn't trying to be perfect. I felt safe with you and with my body and thoughts, because everybody was so tolerant and eager to express his/her own feelings of solidarity that you could feel safe and protected from each side. A pleasant atmosphere had started immediately after our arrival: the friendly greetings, hugs and words unlocked the hearts as if by magic. I just said to myself: “Hey, there is no need to be perfect with these people. Nobody wants you hide your hands or do anything special to fit in - YOU ARE ACCEPTED!” The week proved that the most important thing was you were there, willing to do something, to get involved, ready to give a

bit of yourself to others. This attitude made the communication easy, gave flow to our emotions, unlocked our hidden thoughts and feelings so that we could express and develop our creativity freely, without limitation. The mere fact that all those countries came to be co-creators of a birthing power is a power itself. Even if we are from different parts of Europe and we suffer from various kinds of rheumatic diseases, our WILL made us all equal and close to each other, helped us to lessen the existing barriers and helped us to accept all our specific, unique differences of individuals with rheumatism.

The congress has opened a multicultural dialogue, improved mutual understanding and respect and will serve as a stimulus for further activities.

Finally, I would like to thank all the participants for their willingness to work, to be active, to speak out, and to be helpful, open and positive, for willingness is the key, the motivating power of every good cooperation. It was a pleasure for Slovakia to take part in such a fabulous event.

Both Daniela and I were happy to meet you and we wish you all the best and lots of inspiration and energy to work. Hope to see you in the future!



## **A sense of belonging**

*by Richard Jeffery, United Kingdom*

Well here we are – can you believe that it has been a week since we all said our goodbyes from Haraldvangen?

I have been interested in the IOYR since I heard all about it from Catherine Gibb, Marianne Scobie & Sandra Beeston.

It was a hard struggle to gain funding to attend the IYC, and then when I did I was worried that there would not be any places left. After a few tense days with lots of phone calls from London to Norway, I finally realised that the dream had become a reality and I was going to the IYC.

As soon as the coach pulled up at Haraldvangen I felt a sense of belonging. At the “get together” in the evening, it was a wonderful icebreaker exchanging roses with the other participants and getting to meet so many wonderful people from 22 different countries. I should not be biased but one person who I met who will always have a place in my heart is Jacqueline Mäder from Switzerland.

On the Sunday morning it was down to business and the start of IYC 2001. The guest speakers were fascinating to listen to and very interesting. Over the week I have learned so much about other people and have learned about THE POWER IN ME.

On Wednesday we had a wonderful day in Oslo and the biggest surprise was the beautiful cruise on a Viking ship. It was so great that throughout the whole week everyone on the congress was so friendly and talkative. I have come away from Norway with so much knowledge and with so many good friends. I just wish that I could travel to all the countries to see everyone. It is going to be a long 3 years until the next IYC.

I would like to congratulate all the old and new members of the board and send a special good luck wish to Dorte Rønslér.

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## Heavy, cosy and relaxing

*by Lucinda Blauw, Sylvia Langbroek and Juul van der Veen, the Netherlands*

This congress is the fifth IYC. This time the title is “The Power in You – How to make international co-operation a platform for growth”.

From all over Europe 75 youngsters from 22 countries are gathered, representing different arthritis organisations. The congress takes place in the holiday resort ‘Haraldvangen’ owned by the Norwegian Red Cross. This resort is situated north of Oslo in ‘the middle of nowhere’ with a beautiful view over the lake ‘Hurdalsjøen’.

On Saturday 21 July we - Juul, Sylvia, Lucinda and Sietske (3 members of the youth committee and an assistant) - arrived. At the end of the afternoon the congress was officially opened.

Sunday was the first day of the programme. From that day on every day had been given a theme. Within these themes there were presentations, discussions and other activities.

The first theme ‘Motivation through presentation’ started with a presentation titled ‘The power in you’. This was supported by practical exercises in groups of two persons. These exercises were pretty intensive because we had to talk about our inner feelings and thoughts. During the second part of the day we made a wall exhibition about the youth committee of the Netherlands Rheumatism League, which we explained, to the group afterwards.

On Monday the theme was ‘Breaking Barriers’. This day was introduced with a personal story from one of the Norwegian project group. In the afternoon everybody got a chance to break his or her own barrier. This could be done through several sporting, and even spectacular, activities. The most spectacular was the water-skiing. Juul did this and still has painful shoulders because of it, but she says it was a great kick and super cool. Sailing was another activity you could choose, Sylvia chose this one. With the activity horse-riding you could choose from riding on a horse or in a cart behind it. The latter meant crossing through a small part of the wood, which resulted in a lot of screaming girls.

Tuesday covered the theme ‘Owning your own health’. We talked about being boss of your own life with rheumatism from a medical and social perspective. In the morning we used statements to discuss this. This resulted in very interesting and recognisable points. In the afternoon we started with an introduction to the Norwegian centre for mothers with rheumatism. After that you could choose between a workshop about heredity, pregnancy and taking care of children and a workshop about setting priorities and finding a balance in life.

On Wednesday we enjoyed a day out in Oslo!

All the presentations and discussions together are pretty intensive. Fortunately this 'heavy' part of the programme is varied by cosy and relaxing activities. We ate a typical Norwegian lunch in an open-air-museum with folkdance as desert; we partied in a big wigwam with a campfire in the middle. Over this fire we baked bread on a stick, whilst listening to a Norwegian sage. There was also an international evening where every country could present itself. We brought 'Beerenburg', candies, liquorice and syrupwaffles from the Netherlands. We were dressed in tulipblouses with a windmill-hat on our heads and the Netherlands' flag on our cheek. Dressed like this we sang the song 'Vlieg met me mee naar de regenboog' ('Fly with me to the rainbow' - it's a parody on the international songfestival) by Paul de Leeuw. Everybody tried hard to copy the moves as we did them and to fly (sing) with us.

Up to now (half way through) we think the congress is a big success. There is a really relaxed atmosphere and everybody is highly motivated to participate in the activities.



## **The whole wide world at one place**

*by Tina M.-L. Mortensen, Denmark*

...or maybe not quite. But it felt like that, with all the different languages around me, at the dinner table the first few days.

But that was only until we all felt more at ease. Then English flooded out of every mouth.

Now The International Youth Congress 2001 is over. It was a totally fantastic week at Haraldvangen near Oslo in Norway. More than 70 participants from 22 countries found "The Power in you" and crossed a lot of barriers.

The first day was just about getting to know each other. We were welcomed with a red rose, that we were expected to give to someone from another country. This was a good way to make us talk to a stranger – to make strangers friends. A kind of volunteer force. ☺

The facilitator for the whole week was Kate Nash from the UK. She had a very strong personality and a natural way of getting our attention. This made us all listen to her and we all marked her words. As the very first thing she reminded us, that most of us didn't have English as our mother tongue, so we were not expected to talk like those from the UK. We were all in the same boat. It meant a great deal to us, that she said that.

She also told us that she and her husband Peter met each other at IYC 1992. So we should think of this like a "Dating Agency". The most important thing was to make relations with others. And so we did....

The second day the theme was "Motivations through presentations". We had to find our own power through lectures and discussions. The whole week we had this perfect mix of listening and sharing our thoughts.

On this day I also remember the trip to the Norwegian Sæter where we went for lunch and to see folkdances. The weather wasn't with us that day, but our spirit was, as we were talking and dining with each other.

In the afternoon the room looked like a big Kindergarten. We sat on the table and on the floor creating our "Country wallpaper". It was a lot of fun but also stressful, as these things always are in the last minutes. We all worried about bringing the best things to the exhibition.

In the evening we all gathered together in the Lavvo to hear Norwegian folktales and to bake bread on a stick over the fire. A Lavvo is an enormous tent with a hole in the top for the smoke. And here we sat around the fire and sang together: "Uhhhh, Aramsasa...".

The third day Rolf Husebø from Norway began with a very good and personal presentation about him, his life and experiences. In the afternoon we all broke some physical barriers with riding, water skiing, fishing or sailing. "I'm sailing, I'm sailing on stormy waters...". No stormy waters, but just sun, sun and sun. So I enjoyed my trip on the water and the water skiing. I was feeling *so* proud of myself. And that is indeed a very good feeling. Yeah?

The fourth day was about "Owning your own health". We had a lot of different cases/situations where we discussed what to do and why – a great way to understand the different participants.

In the afternoon we heard about the "Centre for mothers with rheumatic disease".

After dinner each country presented themselves by singing, showing pictures, sharing food or something like that. We chose to show four different ages by letting each say something about their age. Dorte was dressed like a small girl, Connie explained about being a student with the (small?) student support, Jette told about being busy as a career woman and a wife, and I was dressed as an old woman. We ended our little session with a song that we sing when we get drunk, because Denmark is known for the beer. .... And hopefully for something more??

We all went on a trip to Oslo on the fifth day. First we had a great time on a Viking ship with lunch, followed by some time in the centre of Oslo. The planning group had arranged two different departure times from Oslo back to Haraldvangen, just in case someone wanted to go back early. But of course no one wanted that. ☺

The sixth day some chose to sleep a little longer and some went for a trip to a small town nearby. Just before lunch one of Norway's leading rheumatologists came and told us interesting things about the newest medicine. In the afternoon we all had the IYOR General Assembly. The Danish delegate Dorte Rønsler was elected as new chair. And I must say that the Danish

delegates felt very happy and proud of her! We ended the day with a barbeque on the porch looking over the water with the characteristic rocks.

The seventh day went by creating national activities through our (new) international contacts. We heard about the EU's Youth Program, the European Manifesto from our good friend Michael Bernardy, the different countries' special projects, co-operation between countries and gained more ideas. Connie Andersen made an informative presentation of the Danish project "Patient Partners".

A Goodbye Party ended that day and the whole brilliant week. Here there were speeches and presents for the new board and the skilful project group.

Even though everybody felt sad because of the very last day of this magnificent week, all the participants still enjoyed being together and the opportunity for a last conversation with new friends.

This week has been so great. I can't even explain it. Between these lines you should fill out a lot of positivism, warmth, confidence and F.U.N...!

**Thanks to everybody  
supporting, working for and  
participating at the IYC!**

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### More Information

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