

# IOYR



International Organisation of Youth With Rheumatism

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

**Newsletter Number 21**

**May 2008**

Dear friends, it is exactly one year ago that the last newsletter was published. It is high time to report what has happened during this year in the work of IOYR.

In March 2007 the board of IOYR asked us all in an article, if this is the beginning or the end of IOYR (“Beginning or end of IOYR?”). The article said that the current board were not able to continue with their work in the board. Lack of cooperation and support from members caused this decision. “Beginning or end of IOYR?” - The answer was given at the General Assembly during the IYC, which took place from the 18<sup>th</sup> – 24<sup>th</sup> July in Sweden. We will try to give a short description of the decisions of the General Assembly in this newsletter.

But before this conclusion we – all young people with rheumatism in Europe - would like to say **THANK YOU** to the old board. We know that you have done a difficult job, which was and still is of great value for all young people with rheumatism in Europe. It is regrettable that we were not able to give you the support that you have asked for. Much more we have great respect to your work. Thanks a lot to ***Marianne Scobie (UK), Astrid Küntzel (Germany), Linda Vollestad-Westby (Norway), Ingrid Poldemaa (Estonia) and all the other board members in the past, who kept the IOYR alive.***

Hopefully we will be able to build a new board in the future, which will be as engaged as you have been.

**Thank you very much to all of you!**

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Germany

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## **Decisions of the General Assembly 2007 Trial of a short conclusion**

Before and during the IYC no member country of the IOYR declared they were willing to be on the board. The old board members didn't want to participate again which they declared prior to the IYC. Therefore the main questions were: is this the end of IOYR and can we imagine closing IOYR as an organisation. The participants decided almost unanimously that ending the IOYR because of missing candidates for the board cannot be the solution. The following solutions have been found during the meeting:

- 1) A new board has been elected for the following three years. The board consists of "empty chairs".
- 2) The work of IOYR will be reduced to a minimum. Newsletter and homepage will be kept alive.
- 3) Each of the following three years one member country will be responsible for the newsletter and homepage (Germany 08/2007 till 08/2008, Sweden 08/2008 till 08/2009, Denmark 08/2009 till 08/2010). The technical part of the homepage will kindly be under the support of Marianne Scobie, UK.
- 4) At the next IYC in 2010 a General Assembly will take place again and the trial will be started to elect a new board.
- 5) The next IYC will take place in 2010 in Belgium.

So the answer if the IYC and the included General Assembly 2007 will be the "beginning or the end" of the IOYR has been given: It is the end of the known structure and a beginning of hope for the future and a complete new idea.

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Germany

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## **My impressions of IYC 2007**

My main impression when I arrived back home was, that I was awfully tired (I had an unbelievable deficit of sleep) and that I wanted to go back to Sweden as soon as possible (no questions, everyone's thoughts are free ☺).

This IYC was the first that I joined. I have to say that I was not really well prepared – although I visited Astrid Küntzel (one of our old IOYR-board-members) only a few weeks before to get all the important information. But everything was very well organized by the Swedish organisation (and if there has been something not as it should have been, I didn't realise it). It started with the welcome at the airport Copenhagen, the General Assembly and ended with the goodbye present - a file with pictures and statements of all participants.

The days were filled with activities. It was a good combination of theoretical lectures and practical stuff. So I remember very well the lecture of Marie Bengtsson "Irresistible Attraction". It opened my eyes to think consciously about energy boosters and drainers in my life. I also will never forget the picnic at the beach after the boat tour and especially the "Ball-Fight" – no one would have believed that we have rheumatism. The "Forum Theatre" on Sunday morning has born great talents among us and shown that there are no pressuring situations that we are not able to fight against. And as a wonderful ending: the cultural evening and party. I should not have tried that much schnapps, but it tasted great – which country was it from?

The General Assembly on Saturday and Sunday was in some points difficult and especially on Sunday (after the party) exhausting for all of us. But in the end we were effective and I really think that we have found a solution with which we all can live for the next few years.

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Before the IYC I was really afraid that my English would not be good enough and that no one would understand me. Well, I should not have worried. It was interesting how we all improved our communication from day to day and how we improvised if we realised misunderstandings.

At the end all I can say is: **Thanks a lot to the Swedish organisation, which made this congress possible. And thanks a lot especially to Anna Ageberg, Linda Johnsson and Peter Wallin – no question, you three organised a wonderful, well-prepared and unforgettable congress, THANK YOU!!!**

Gudrun Baseler, Germany

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## **My take away message from the IOYR-Congress in Ängelholm**

First I have to thank a lot Anna, Linda and Peter, who did most of the organisation – the blond Swedish did a great job! It was a good idea to place the participants in a sort of camp. The fact that we did not have single rooms was surely the main reason why we came closer relatively fast. In that case we were forced to tattle and chat also in our leisure time. I will never forget the amazing relaxing picnic at the beach and the funny karaoke evenings, and in truth those evenings emerged as nights even not ending by the sunrise. I also have to think very often of the entertaining wild Viking Cher NINA singing her **Red Bull ger dig vingar** aria. When time was boring she always brought in some fresh air with her singing never afraid of an embarrassment. Nina was and still is the proof for me, that your quality of life must not be reduced, although you have to live with a rheumatic disease. Gudrun showed me that chronic Polyarthritis is no roadblock for studying medicine and becoming a doctor. In a matter of career she could be a sort of a role model for every one of us.

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**To cut a long story short**, my final take away message is:

When I talked with people **before** Ängelholm, then I always thought by myself "Maybe I can cope easier with Rheuma. At least I got it with 3 years and my memories before 1985 are not so intensive. When I have a discussion **now** with people who ask me for help, I can tell them with a clear conscience that I am not the only one who had learned to cope with the disease and master life. The examples I give them are you great people from Ängelholm! You all assured me that it's not nonsense what I am telling those people.

post script: Let me also mention, that Poneh and I went to Belgium at the end of October 2007. We stayed at Thanny's place and had a gorgeous time spending days in Brussels, Antwerpe and Brugge. Ohhhhhhhh, that Belgium beer! Thank you Thanny !

Greetings to everybody,

Patrick Hanakamp ... Mampfimampfi,  
Austrian Rheumatism League

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## **Preview of the next newsletter**

Our idea for the next newsletter: **Without borders – rheumatism here and everywhere!** Have you contact with neighbouring countries and organise exchange visits? How is life as a young person with rheumatism in the other European countries?

Every article to these and similar topics are welcome and we are grateful getting feedback about this newsletter and ideas for the next. **Contact us:**

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