



## EULAR in Prague

by *Lucinda Blauw, chair of IOYR*

After the Board meeting in Haraldvangen in March, five members of the board did meet during the EULAR Congress in Prague in June. There they talked about the last things concerning IYC and the general assembly.

### News about the Manifesto

The latest news about the 'People with Arthritis/Rheumatism in Europe Manifesto' has been presented for the press in Prague, Czech Republic in June 2001, during the EULAR Congress. In the months before an audit (research) was conducted to gain information about the different organisations for people with arthritis/rheumatism and the level of health service in Europe. This information is going to be used as a basis against which the Manifesto initiatives and efforts will be measured.

Right after the EULAR Congress the steering group met and discussed how to promote the Manifesto in the different countries in Europe. One of the ideas is to set up a mentoring system in which the members of the steering group will take responsibility for certain countries.

Another project will be the Manifesto website, which will be launched at the International Arthritis Day – 12 October 2001.

And presentations will be made during the International Youth Congress in Norway - July 2001, the meeting of Arthritis & Rheumatism International in Canada – August 2001, and hopefully also at a meeting of the Bone and Joint Decade.

The Manifesto is already available in a lot of languages; please check [www.ioyr.org](http://www.ioyr.org) for more information.

### EULAR

The board of IOYR was represented in big numbers at the EULAR-congress in Prague in May 2001 thanks to a generous sponsor gift from Pharmacia.

Vilma, Catherine, Lucinda, Georg and Dorte did all have the possibility to talk with people from organisations from all over Europe (and other parts of the world) to inform them about IOYR and tell them the latest news about IYC 2001. A lot of good contacts were established.

The members of the board also gave information about the Manifesto for and by people with arthritis/rheumatism in Europe. They helped at a stand at the congress where it was possible to get information and contacts about the Manifesto. Many people visited the stand and showed great interest. In the beginning of the congress there was a press-briefing about the Manifesto and besides that Catherine and Lucinda together with other members of the Manifesto-steering-group had speeches both at the Social Leagues Programme and at the Scientific Programme about the Manifesto. Very many and good possibilities to spread the information.

The Social Leagues Programme was set up around the ten themes from the Manifesto. During

the first day the themes were 'To develop and recognise national and international organisations of people with arthritis/rheumatism', 'Disability politics – Living without barriers' and 'Providing fully accessible education and work'. During this day Catherine had a speech about her personal experiences in education and work. She told about both negative and positive things, with the main point that it is often other peoples thinking and attitude that makes it easy or difficult to have a job or get an education if you have rheumatism. You can be positive yourself, but if your surrounding makes it difficult for you it might be impossible to get an education or a job. If your boss and colleagues on the other hand are interested in making things easier you will also be a better employee if you don't have problems concerning your rheumatism at work.

The program of the second day was a joint session with the health professionals and the last part also with medical / research colleagues. The themes of the day were 'To ensure doctor's and allied health professional's awareness of people with rheumatism/arthritis' and 'Communication & Partnership'. The lectures were about the importance of a good relationship with a rheumatologist and a therapist – from a person with arthritis point of view, the importance of a good relationship with a person with arthritis – from a doctor's and a health professional's point of view, the training of doctors by patients within the 'Patient Partners' project, the priorities of patients at their first consultation, the influence of patients on health care and social care, the partnership in a multidisciplinary programme, etc.

The last day was about the activities of the social leagues, now and in the future.

*IOYR-memberorganisation:*

## **Spain**

*by Montse Sánchez-Oro*

AJER (Asociación de Jóvenes con Enfermedades Reumáticas): Spanish Organisation of Youth with Rheumatism was set up in October 2000, during

our 4<sup>th</sup> National Congress.

Our organisation is made up of young people aged 18-35 years with all sorts of rheumatic diseases. We also have a medical committee made up of doctors, psychologists, lawyers, etc. We are trying hard at to socially integrate young people with rheumatic diseases in Spain.

Our structure is that each local branch of AJER chooses one representative, who attends nationwide meetings held twice a year. The decisions made are communicated to the local branches. There is one yearly meeting with all members.

AJER used to be financed by LIRE (Spanish Rheumatic League, our mother organisation) but since 2000 we have been independent, so we are now supported by the State (on a yearly basis), and through social welfare acts that we help LIRE to organise.

The president of AJER is on the Board of LIRE so we keep short lines of communication.

Our activities at the moment are:

- Promotion activities for young people
- Providing information by means of brochures, articles, the Internet, etc.
- Stimulating and participating in research in the field of rheumatism
- Publishing in our news broadsheet
- Holding meeting
- Preparing and holding a yearly congress
- Keeping in touch with other rheumatic organisations

### **Publications**

We publish articles aimed at young people in LIRE's bulletin. We also have a webpage. In addition, we've appeared on TV, and been interviewed on the radio. An article about us appeared in a medical magazine.

We've also made two videotapes: one presented by a famous basketball player and the other presented by the youth contact person of AJER, Montse.

*IOYR-memberorganisation:*

## **United Kingdom**

*by Catherine Gibb*

Young Arthritis Care is a self-help group run for all young people with arthritis / rheumatism – anyone up to the age of 45. We are not independent, and receive our funding from our mother-organisation – Arthritis Care. Arthritis Care is UK's largest voluntary organisation working with and for everyone with arthritis, from every section of the community.

The mission of Young Arthritis Care (YAC) and Arthritis Care (AC) is to empower people to take control of their arthritis, their lives and their organisation.

We provide information, training and support to help people take control of their health and their lives. At the same time we campaign for raised awareness about arthritis, and for better services for people affected by arthritis.

Young Arthritis Care was formed at the end of the 1970s, but was originally separate to Arthritis Care, although it was founded by young people who were members of AC at the time. In 1989 it became a part of Arthritis Care. YAC is a user-led organisation. It has a UK Committee with representatives from Scotland, Northern Ireland, Wales, and from North, South East, South West and Central England. The UK Committee meets three times a year. The UK Committee has two Chairs, one of whom is the YAC representative on the Board of Trustees of Arthritis Care.

Arthritis Care has 7 National/ regional committees (for Scotland, Northern Ireland, Wales, North England, South East England, South West England and Central England), each of which has two representatives from Young Arthritis Care.

Young Arthritis Care has a network of telephone Contacts throughout the UK, who can offer information and support, or signpost people to other

agencies and Arthritis Care's national support networks. The contacts are all volunteers with arthritis, who work from home. These Contacts are managed by development officers (paid employees) who also have arthritis. Some Contacts also produce a newsletter for the members in their area, and some organise a local group, where young people with arthritis can meet together socially. Sometimes, the group may have a speaker, for example about complementary therapies, or from a Rheumatologist. In some areas there are Contacts especially for men, or for parents of children with arthritis, or for teenagers.

Young Arthritis Care runs courses for young people with arthritis, throughout the UK. All courses are run by people with arthritis who have been trained to deliver the course, and include:

- Teenage Workshops: a week long residential course for teenagers with arthritis, which helps them to live independently, reduces their isolation and overcome the barriers that often face young people with arthritis.
- Person Development Courses: a residential course for young people with arthritis held over a weekend, which aims to build support networks, promote independent living, reduce isolation and barriers.

A magazine "Arthritis News" is published 5 times a year by Arthritis Care. "No Limits" is the magazine of Young Arthritis Care. It is published as an 8-page supplement of "Arthritis News" three times a year, and is aimed at young people with arthritis aged 18-25.

Young Arthritis Care is currently in the process of changing its structure and organisation in response to changes made within Arthritis Care over the past few years – watch this space!!

**Find addresses for Spain and United Kingdom at [www.ioyr.org](http://www.ioyr.org)  
Here you can also find information about other member-organisations.**

## News from [www.ioyr.org](http://www.ioyr.org)

During the last month we have been working a lot on our homepage. Maybe you have already visited the site and have seen all the changes and the news about IYC 2001...

### **Among the new things we are happy to mention**

- Debate-forum: We hope that you will find and give inspiration, questions/answers and get new contacts in the forum.
- Guestbook: Show us that you have visited our site - and tell us what you think about it and what you want on it.
- Mailing-list: If you want to receive mails from IOYR with news you should sign up on our new mailing-list.

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## The Aims of the IOYR

The overall aim of IOYR is to improve the situation of young people with rheumatism (aged 18-35) through information exchange, self-help and policy influence. Initially the IOYR will focus on countries in Europe but will work in the longer term on a truly world-wide basis.

*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.

The IOYR is a legally constituted organisation, registered in Germany. All activities are led by young people with rheumatism.

**More information about IOYR? Please contact:**

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