



News from the board

by Lucinda Blauw, chair of IOYR

World Wide Conference in Madrid

During 15 en 16 October 1999 the second World Wide Conference of Arthritis & Rheumatism Patient Organisations took place in Madrid. It was organised by the Social Leagues of EULAR in collaboration with MSD.

The participants represented 26 countries.

The purpose of the conference as described by the Social Leagues was as follows: 'This meeting provides an excellent opportunity for EULAR Social Leagues and other patient organisations from around the world to come together to exchange ideas and discuss individual country perspectives on a range of issues facing Arthritis and Rheumatism patient groups'.

The program contained speeches and discussions about:

- communication & awareness raising
- international co-operation
- new trends in treatment
- information-education, support & self-management
- making the most of your patient organisation

The chair of IOYR was given the opportunity to speak about the international youth organisation.

IOYR meetings

Since the last newsletter IOYR had two meetings. A board-meeting in January and a manifesto meeting in March. During the board-meeting we talked about the IYC 2001 in Norway, the next Newsletter, the Members Open Day, the elections in 2001, etc.

The manifesto meeting was planned to discuss the manifesto and to come up with projects we could base on the manifesto.

Both meetings were very productive and we succeeded in having a meeting with the full board at the last meeting. So we finally could start to get to know each other a little bit better.

Searle/Pfizer Manifesto meetings

In January and in March two manifesto meetings were planned. The first was only for the steering group. In that meeting we talked about the purpose of the manifesto and what should be in it. By signing the manifesto, all organisations will mean the same when they talk about arthritis or rheumatism. The manifesto can be used for political or social purposes, for example to draw attention to the position of people with arthritis. National organisations can use the manifesto as a basis to set up projects.

We spoke also about the format of the manifesto. It should contain 10 statements which fit on one piece of A4 paper.

The statements will be about: capacity and recognition of organisations, education and training, employment, equal opportunities and access, healthcare, health professional awareness, medical research, policy involvement, self management and personal development and social research. In a small book the 10 statements will be explained.

In March the standing committee of EULAR Social Leagues organised a meeting with the steering group. During a very long but successful day we talked about the manifesto. A lot of good remarks came out of it.

Welcome to IYC in Norway

by Georg Hodnefjell, Norway

It is with great pleasure the Norwegian organisation of young people with rheumatism BURG invites you to attend the IYC - International Youth Congress - 2001 in Norway. BURG was founded in 1980, organising young people with rheumatism from all over Norway, and their parents. BURG has 1500 members in 19 regional branches.

Since 1995 BURG has been member of the international organisation of youth with rheumatism, IOYR. IOYR considers the youth congress, which is arranged every 3rd year, to be one of its most important activities. BURG are therefore proud to be chosen to host the congress in 2001.

Congress venue

IYC 2001 will take place at «Haraldvangen», a modern and beautiful holiday and activity centre, located just one hours drive outside the capital of Norway, Oslo.

Haraldvangen is often used as a camp school, and as a course centre for various humanitarian and social organisations. During the IYC 2001, Haraldvangen is exclusively reserved for congress participants.

The accessibility and the conditions at

Haraldvangen are the best. All paths have hard surfaces and all buildings and surrounding areas are especially suitable for disabled people. In addition to the congress facilities, Haraldvangen offers a wide range of outdoor activities like horse riding, sailing, canoeing, elk safari, rafting and more. There might be room for some of these activities through the congress program. Our intention is for Haraldvangen to be a frame; for learning and exchanging information and experiences, in a friendly relaxed and enjoyable atmosphere which hopefully will make the participants break barriers.

*How to make international co-operation
a platform for growth*

THE POWER IN YOU

IYC NORWAY 2001
International Youth Congress for young
people with rheumatism.

Participants

Young people with rheumatism, aged 18–35 from all over the world can participate.

Our invitation goes to youth organisations in countries where we know such organisations exist. In addition to this we are working to reach and invite, young people with rheumatism in other countries, who are concerned and interested in doing organised work for young people with rheumatism. Ref. the goals for all our international work, which is to improve the conditions for young people with rheumatism; by developing and strengthening existing self-help organisations, and to inspire and help build organisations where such not yet exist.

About the Congress

- The congress is arranged in co-operation with the International Organisation of Youth with Rheumatism IOYR
- A maximum of 70 persons will participate, including congress staff and personal helpers
- The language used will be English
- Congress fee is not yet set. We are still working on possible sponsors, and will present the price in our next announcement (Will be distributed in December 2000)

Registration/ questions about IYC2001? Please contact:

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Program

Though various lecturers and knowledge exchange we will set the individual in focus as force and a catalyst to build powerful organisations and self-help groups. We want to show how we, within a national and international network, can make a difference in improving the conditions for young people with rheumatism. «We will help you to find The Power in You».

Themes that will be included in the program:

- Owning your own health
- We have knowledge about our self
- Independence and development
- Breaking barriers
- Development of organisations/democracy
- How can I make a difference
- National and international work and co-operation

The themes will be enlightened and debated through classes, seminars, discussion groups,

work shops and physical activities. We will also put in the program news from science and the development of new treatments for rheumatic related disabilities.

IOYR-memberorganisation:

Finland

by Tiina Kriikkula

The Finnish youth council was set up in summer 1993 to plan and organise events and projects for children and young people with rheumatism. The youth council is dependent on the mother organisation (The Finnish Rheumatism Association) because it does not have its own budget. We have an employed worker for children and young people – a youth secretary. She is, for example, the secretary of the youth council.

Magazine

The youth council has published a magazine called Vaappu since 1993. The last Vaappu comes out at the beginning of year 2000, because it has been distributed inefficiently. After that we will have youth pages in the magazine of the mother organisation. The magazine “Reuma” reaches all the members of the Finnish Rheumatism Association. So, in the future many more people (more than 50 000) around Finland will hear our voice and hopefully we’ll get more active young people along.

Activities and theme year 2000

Our mother organisation arranges different kinds of courses for young people such as rehabilitation and adaptation training courses. Members of the youth council plan smaller events, for example, weekend events with themes such as self-esteem. Year 2000 has the theme of ‘children and youth’ in the Finnish Rheumatism Association. Therefore, we are having more events and courses for children and young people than in a normal year.

Local youth groups

Some local associations around bigger towns have an active youth group like Tampere, Turku and Jyväskylä. All in all there are young members in about 40 local associations. We are starting a youth group in the Helsinki area in 2000. Then new youth groups can get financial support from the mother organisation, because year 2000 is our theme year.

Support friends

In Finland we have a support friend network which means that twelve young people with different kinds of rheumatic diseases are trained to help young people who have problems or difficult situations with their disease. Support friends meet once a year to share their experiences. In the year 2000 new support friends will be trained.

Co-operation

Young people in the Finnish Rheumatism Association have co-operation with other organisations of disabled people and with schools and universities. Young people with rheumatism go and tell medical students and student nurses and social workers what it like to live with a chronic disease. The Finnish Rheumatism Association is one of twelve national health organisations in this project called Polku (= the Path).

Finland has also international co-operation naturally with IOYR but also with other Nordic countries.

IOYR-memberorganisation:

Poland

by Anna Talaska

The Young Arthritis Association is a Polish Organisation situated in Poznan. Members of this organisation are mostly young people aged between 16-35 years old, who have a rheumatic disease. Some are pupils and students but the majority of them are people working in different professions. As ordinary

members they are the main part of the organisation. Those who are above 35 years old and still intend to stay within the organisation become supportive members. There are also people who are not suffering from any rheumatic disease in the association. They help us in our association's activities freely as honorary members.

The main aim of our association is to help young people who have rheumatoid arthritis. We try to meet this aim in many different ways.

The most important activities of our organisation are the meetings, which take place every month. We have an opportunity to meet and talk together on different previously planned subjects. Each member has an opportunity to propose his own subject for future meetings. We also organise telephone duties once a week if any member would like to discuss an important problem. Thanks to those meetings mutually supportive groups were created. Meeting and talking together develops strong bonds between people, giving an opportunity to know each other better, solve problems together and make friends. Apart from the formal meetings we meet together in other interesting places in the city or outside the city, taking part in different excursions. They are our favourite way of spending time and are very popular.

The other field of our activity is treatment and improvement of the physical condition of arthritis by organising:

- a course of rehabilitation and going to a spa resort
- financial support for those who need rehabilitation devices and joint replacements
- medical consultation with a rheumatologist

Also we publish a local leaflet once a month called "CREAKER" (the word comes from a joint creaking). We include there current

information concerning the activities of the association, for example, subjects for discussions and the date of the next meeting. Also “CREAKER” contains information from other disciplines, such as medicine, psychology and law.

Many people who have a severe physical disability and have problems coming to the meetings really appreciate this form of contact with our association.

In our plans we would like our organisation and its multidisciplinary activities to be known on a wider scale, by informing people how we help people who have arthritis.

We do hope that it will enable better communication between us and all the people who are interested in our organisation and us.

Find addresses for Finland and Poland at www.ioyr.org

The Partnership Project:

Going into Co-operation – Germany visits Switzerland

by Michael Bernardy, Germany

As part of the Partnership project within IOYR, members of the Youth Section within Deutsche Rheuma Liga (BAK/DRL) accepted the invitation of the Swiss League against Rheumatism (SRL) last summer to meet with young people with rheumatism in Zurich and surroundings.

Ute Kohl (speaker of youth with rheumatism in DRL) and me (Michael Bernardy, Vice Speaker) had been curious about the situation of young people with rheumatism in Switzerland. One year before, the Swiss IOYR contact, Jacqueline Mäder had already participated in a German weekend, so she already knew about the “German way” to run youth work.

A large variety of different help remedies and brochures made the office of the Swiss organisation look a bit like a mail-order house. We learned that SRL is an umbrella organisation which serves the three regions of Switzerland: publications have to be published in three (!) different languages (French, German and Italian) – indeed a unique situation.

With regard to public relations, SRL has started some interesting initiatives: there is a spot on TV which shows the problems of people with arthritis; for a programme about aching backs called “Backademy” they found a sponsor, who produces waterbeds.

During a meeting with a group of young people we introduced our work in BAK in Germany:

- Three years ago we established the so-called “Rheumafoon” – a telephone helpline run by young people with rheumatism for young people with rheumatism. The six contact persons in the different regions in Germany had been educated in special seminars to answer questions that are connected to the illness.
- Another successful project is the planning of the national youth weekend, which takes place every second year. It was last held in summer 1999, with participation from Switzerland and Denmark.
- Publication of our own magazine “Rheum-Na und?”
- Co-operation with our national office and the parents of children with rheumatism within a working committee.
- International engagement within IOYR for five years.

The exchange of information between countries like Switzerland within the Partnership Project in IOYR in the meantime has become an important part of our international work in BAK. It’s very useful for every country to participate in the Partnership Project, because all members gain ideas for their national work.

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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Next newsletter:

Read about Open Day and EULAR Congress.

You are more than welcome to write an article for the newsletter. Please mail it to Lucinda Blauw.