

IOYR



Open Day for IOYR-members

by Lucinda Blauw, chair of IOYR

The first Open Day of the International Organisation of Youth with Rheumatism (IOYR) took place on Saturday 6 May in Copenhagen, Denmark. The invitation for this Open Day was addressed to the 14 member youth organisations and their mother organisations. Every youth organisation could appoint two young people with rheumatism and ask one member of their mother organisation to participate in the Open Day.

The goal of the Open Day was to learn from each other about each other's work for and as young people with rheumatism. This day had to be a kind of open discussion day, where everybody could get new ideas and inspiration to go back home with.

The mother organisations were invited because in some countries the communication between both organisations was not as they would like it to be, especially concerning the international work. Through this day the mother organisations were given the opportunity to learn about the international work and what it means for young people and can mean for themselves. They also would be able to talk with the other mother organisations about the youth work.

The participants of this day were

Vilma Bandzeviciūtė (Lithuania), Georg Hodnefjell + Lars Espen Rath Vestad (Norway), Marianne Scobie (United Kingdom),

Angel Moral Mate (Spain), Sara Hjalmarsson + Mattias Svensson (Sweden), Jacqueline Mäder (Switzerland), Lucinda Blauw + Juul van der Veen + Maarten de Wit (mother-organisation) (The Netherlands), Dorte Rønsler + Connie Andersen + Anders Madsen + Anne Lessél (mother-organisation) (Denmark).

Activities

During the day different participants told about activities for young people with rheumatism in their countries. Vilma told about the support group in Lithuania. The group comes together to talk about rheumatism, but also to do nice things together. To reach new young people with rheumatism they are in contact with the doctors.

Marianne told about the Positive Future Workshop for teenagers aged 11-17, organised by the English youth group. The goal of this workshop for the children is to gain more self-confidence and become more assertive. The workshops are highly appreciated by the children as well as their parents. It's easy to find sponsorship for this kind of activity, the problem is to reach the children who can attend it.

Organisation-work

Mattias explained the structure of the Swedish youth organisation, which is completely independent from the mother organi-

sation. They organise lots of different activities, such as summer and wintercamps (skiing for everybody).

Jacqueline told about the Swiss youth group and the partnership they have with the German youth organisation. Because they speak the same language the Swiss and the German youth group have been able to join each other in their meetings a few times.

Georg and Lars told about the co-operation with the mother organisation as an independent youth organisation. The difficulty is that they are not fully independent, they need their mother organisation for financial support and for staff members and office facilities. One of the good things is that the youth organisation can offer their members more. And the mother organisation assists the volunteers in the youth organisation.

Connie told about the magazine of the Danish youth organisation, which is published six times a year. They use the magazine to inform their members about local and national activities, and the members can exchange experiences and tell about how it is to be young and have rheumatism.

Juul told about a small research project from the Dutch youth group, in which needs and problems of youth with rheumatism were investigated.

The main conclusion was the young people with rheumatism do have a need for contact with other young people with rheumatism, but they also think that that is scary and confronting. And they don't have a clear picture of the activities of the Dutch organisation. One thing that has come out of it is that the Dutch youth group is working on a 'starters information package' for young people that are just diagnosed with rheumatism.

Bone & Joint Decade

Maarten told about the Bone and Joint Decade and how youth organisations can participate. This decade is a world-wide, long term initia-

tive to work together internationally with a national focus, in projects concerning joint diseases, low back pain, osteoporosis and trauma to the extremities. There will be given special attention to 'crippling' diseases in children and youth.

Read more about the Bone and Joint Decade at

www.bonejointdecade.org

Maybe you can find out what is happening in your country concerning this....

Discussions

In the second part of the afternoon the group was split in two and both groups discussed about the future of IOYR. What will happen on a national and an international level? What can we as members do in and for IOYR? What can IOYR do and what can we expect from IOYR?

One of the main things that came out of this discussion was that the members need more information from IOYR. They need to know what is going on. This is also true the other way. The board of IOYR needs information from the members to write about in the newsletter.

One of the biggest goals of IOYR is to set focus on the fact that young people with rheumatism exist. The other goals could use some explaining and more discussion, something for the next international youth conference.

There was also a social programme included. On Saturday evening the Danish mother-organisation gave us tickets for the amusement park Tivoli. And for those who were still present on Sunday there was a sight seeing tour through Copenhagen, partly in a boat.

News from the IOYR-board

by Lucinda Blauw, chair of IOYR

Since the last newsletter IOYR has had two board meetings. During these meetings we talked about the Members Open Day, the Manifesto, the IYC 2001 in Norway, the next Newsletter, the elections in 2001, etc.

In this newsletter you can read about the Members Open Day and the IYC 2001 in separate articles.

Manifesto

The People with Arthritis/Rheumatism in Europe (PARE) Manifesto has been launched in Nice, France in June 2000, during the EULAR Congress, where it was presented to officials and the media. The steering group has completed its work, and a Working Group will begin on 1 January 2001 to ensure that the work of the Manifesto and the Action Plans continue. The members of the working group will come from the three co-operating organisations – IOYR, ARI and EULAR Social Leagues – with Michael Bernardy from Germany as Chair.

The next three tasks of the working group will be:

- Spread the Manifesto across Europe and help organisations to get the Manifesto translated into their own language. Pharmacia are funding this and giving help where necessary to ensure the Manifesto looks the same in each country and language.
- Organise a reception for members of the European Parliament in January 2001 in Brussels, Belgium.
- Set up a secretariat to work for ARI, IOYR and EULAR Social Leagues

So it will be continued.....

3rd World Wide Conference, Slovenia

During 13 to 14 October 2000 the third World Wide Conference of Arthritis & Rheumatism Patient Organisations took place in Ljubljana.

It was organised by the Social Leagues of EULAR in collaboration with MSD.

The theme this year was a double one: Developing your organisation & Disability politics and arthritis.

The program contained speeches and discussions about:

- Patient organisations and social leagues at different stages of development: internal and external challenges
- New patient organisations and social leagues under development
- Challenges faced by established patient organisations and social leagues
- Disability politics – an international overview
- Accessibility for disabled people to ensure equal opportunities – a focus on built environments and transport facilities

Three board members of IOYR were present at this conference. They were able to talk to delegates from different countries about IOYR and the next IYC.

*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.

IYC 2001 in Norway

by Georg Hodnefjell

As you know the IYC 2001 will be organised in Norway by IOYR and BURG, the Norwegian Arthritis Youth Organisation.

IYC 2001 will take place at the holiday and activity centre Haraldvangen during week 30, from 21. - 28. July 2001. Haraldvangen is located 1-hour's drive from the Norwegian Capital Oslo.

At this moment the IYC 2001 project-group is working with the final announcement, finance and to develop the programme. It is very exciting and so far every thing is on schedule. During December 2000 we plan to send out the final Announcement, which includes information about the congress fee, accommodation, programme/agenda and the final registration process. It also includes a form about personal information/needs and a form with information about arrival and departure times.

Time limit for registration and payment for IYC 2001 will be:

28. February 2000: Kr 3.000,-

30. April 2000 Kr 3.500,-

The fee includes accommodation with all meals, participation in the programme and the excursion. We expect participants to raise funds individually in their home country for travel and the congress fee.

So far 32 people and 8 IOYR member-organisations have answered and confirmed their interest. We are delighted to be in contact with so many people and we still wait for others.

Registration/questions about IYC2001? Please contact:

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A detailed programme and timetable will be distributed next year to those who sign up for the congress. If you have further questions, or maybe some ideas that you want to share with us, don't hesitate to contact us again. We welcome all ideas with gratitude. You will receive the final announcement soon.

Launch of Manifesto

by Cathy Debenham, Arthritis Care, UK

Raising public awareness about the scale and impact of arthritis, empowering people with arthritis and involving them in policy development are just three of the ten key principles outlined in the Manifesto for the Third Millennium.

Launched at the EULAR Congress 2000, the manifesto was prepared by three international organisations: Arthritis and Rheumatism International, the standing committee of the European League Against Rheumatism (EULAR) Social Leagues and the International Organisation of Youth with Rheumatism.

"People with arthritis make up the largest population of individuals living with a long-term medical condition", said the chairman of the manifesto steering committee, Richard Gutch (chief executive of Arthritis Care, UK). "It is critical that our government leaders and the public recognise that current levels of support and services for people with arthritis must be improved, enabling them to live as independently as possible. Our new manifesto gives a strong, unified voice to these needs."

The manifesto brings together the concerns of people with arthritis across Europe and their vision for the future. It will be used to lobby individual governments and be used to lobby the European Union. The aim is for arthritis to be featured as a priority in the

European health agenda and by national governments.

EULAR congress president Professor Hubert Roux welcomed the manifesto as an important document. It is important to remind all people concerned that as we live in a democracy in Europe this represents over 100 million voters and this is something that politicians are likely to be attentive to.

IOYR-memberorganisation:

Switzerland

by Jacqueline Mäder, Member of the Swiss Group and Representative for IOYR

It was on Saturday, 23rd March 1996 when the Swiss League against Rheumatism started up a national Youth Group.

Since May 1996 we have had 3-4 meetings a year. Normally we meet in a restaurant, where we discuss several themes concerning Rheumatism. To get the best information as possible, sometimes we invite speakers from different medical professions, to hear about new projects and treatments.

There are about 35 members in our Group, but only 10 – 12 of them participate at the “normal” Meetings. In the case of a special event, it looks a little bit different. The interest is more if we have an invited speaker, or something like an exhibition.

If we are looking to other countries, our Group seems to be very small. There are several reasons, why we don't have more members. Switzerland is a small country, we do not have that many people. Another reason is the barriers between the 4 different languages. There's no way to get them all together in one Group. So if we speak about a national Group, we speak about members from the German part of Switzerland. In general, participation is open for everybody, but the language is German only.

Another part of our interests is the international work in IOYR. On December 1995 a Swiss Delegation participated at the IOYR – Launch in Berlin, to see how IOYR works. Our Delegation returned back home with a lot of news and interesting information and we decided to participate at the IYC 96 in Kalundborg, Denmark.

The Group elected me as the representative at this event, and so I was very excited when I started my travel to Denmark.

It was a great week in Kalundborg with many young people. I felt very well there and because of the great programme, there was a lot for me to learn.

I went back home with so many ideas and hopes, and I never felt such a motivation before to go on. After this Congress we decided to become a member of IOYR.

As a young person with Rheumatism I'm very happy to have an exchange with other young people. It's a help to know that I'm not alone with all the problems around my disease, and to hear how others are coping with their pain. It's very interesting to hear about different strategies for coping with the pain, and to find out the best one for yourself.

IOYR-memberorganisation:

Norway

by Georg Hodnefjell

BURG, The Norwegian Arthritis Youth Organisation, is an independent organisation for children and young people with rheumatism, which is a part of NRF (the Norwegian Rheumatism Association). BURG's purpose is to work for young people with rheumatism-related disabilities, and, in co-operation with NRF's elected board and administration, to seek to improve these young people's situation. BURG has organised groups

all over the country and in almost every county, and when we entered the new millennium we counted 1300 members.

BURG was founded on 25th November 1980 and has ever since worked hard to increase the comfort in young people with rheumatism's situation. BURG has a national board, 17 county groups, 1300 members, an employed secretary and its own constitution, economy and action-plan. BURG has many and varied tasks both on a national and local level.

Nationally we make programmes for courses and information brochures, arrange conferences and gatherings for members. We also take care of social-political issues, and co-operation with other organisations and institutions. BURG has its own children and youthpages in NRF's member magazine "Revmatikerer". BURG is also an active partner in Nordic and international co-operation.

BURG is internationally active through its membership in IOYR where BURG is represented on the board. During the summer of 2001 BURG, in co-operation with IOYR, is arranging an international congress for young people with rheumatism-related disabilities. It is with great pleasure and pride that BURG is inviting young people from all over Europe to stay in Norway for one week with a lot of new experiences.

The county groups organise social activities, training in hot swimmingpools, treatment and leasuretrips, courses with relevant themes, member to member counselling, advisorwork for the individual member, external information and other activities.

Today BURG is an independent organisation and at the same time a part of the mother organisation NRF. It is important to BURG to be independent both in aspects of control of the organisation's work, and the economic support from the government. This economic support has a strict set of rules regarding in-

dependence and constitution. Despite this, it is very important for BURG also to be a part of NRF, so we can offer the best support to our members. There are also economical and organisational reasons for BURG to be a part of NRF.

Our members have many different needs that require huge and compound resources to meet them.

It can be everything from a barbecue night to political influence and the making of information material.

As a part of NRF, BURG can give their members a more complete service.

NRF offers representatives and volunteers in BURG many different activities, like training courses, conferences, workshops and activities at all levels of the organisation. Active participation provides our representatives and volunteers with a lot of experience and expertise.

NRF - as a large and strong organisation with 47.000 member - gives BURG support in many important cases, such as medical treatment and insurance rights for our members.

NRF is ready to include children and youth in their plans and strategies and NRF's administration and staff are also there for us. NRF gives BURG money every year as support to run the organisation, and pay a full-time secretary to work for BURG. NRF also offers free office rent, free telephone, fax, postage, and other office facilities and free accounting.

**Find addresses for Switzerland
and Norway at**

www.ioyr.org

**Here you can also find information
about other member-organisations.**

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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*Merry Christmas and
Happy New Year*

