

IOYR



International Organisation of Youth with Rheumatism
Newsletter no. 8

www.ioyr.org
November 2001

Ideas to exchange - read and get inspired

by Dorte Rønslér, chair of IOYR

IOYR was launched in 1995 after years of hard work by the working party set up at the IYC 1992. Since 1995 a lot of things have happened. We have got more members, 3 IYC's (International Youth Congress) have taken place, one Open Day, presentations by the IOYR-board during different international conferences, IOYR-newsletters, a homepage – to mention some of the things.

In September 2001 the 'new' board – elected at the General Assembly July 2001 – met in Copenhagen, Denmark at our first board meeting. And dear members, don't be afraid that we won't continue the work for and with you during the next three years. A lot of plans were discussed during the long and hard weekend meeting and we are all ready - and already hard at work - developing the work in IOYR and the projects where we are involved.

We hope that you can feel this; one of the examples is that you already have a new issue of the newsletter – the last was published in August 2001. And we also hope that you want to be a part of this work, an example: The board can't write the newsletter by our self, you also need to send us articles to the newsletters - and also give us ideas and comments on our work by mails etc.

When members meet and develop

Many of us still think back and tell a lot about IYC 2001. Especially after getting the fantastic

packet with the cd-rom, the newsletter no. 7 and the IYC-report the thoughts came back. Reading the papers and looking at all the pictures made everybody of course remember the fantastic week in Norway and at the same time look very much forward to the IYC 2004 in Switzerland, which you can read more about in this newsletter.

But there is also a possibility to meet face to face, talk and exchange ideas before the IYC 2004. The board is working to have an 'Open Day' in the spring of 2003 where 2 delegates from each member-organisation can participate together with one delegate from the "mother-organisation". In next newsletter we will tell you more about the 'Open Day'. At www.ioyr.org you can read more about the first 'Open Day' that took place in May 2000. The board welcomes very much ideas to discuss at the 'Open Day' in 2003.

But remember it is not only when we meet face to face we can talk and exchange ideas. The www.ioyr.org gives a lot of different possibilities to do that all the time.

Projects and Co-operation

In this newsletter you can read about one of the projects IOYR is involved in - the "PARE – Manifesto". The Manifesto is a very good tool for every person with rheumatism because everybody can identify him/herself with it. The manifesto is the voice of people with Rheumatism and it tells that we should not be seen at as

suffering victims, but as people with power, experiences and possibilities. The IOYR-board hopes that we can help our members to use the Manifesto. As Michael Bernardy writes in his article, please also feel free to contact the manifesto-coordinator Birte Glüsing for help and ideas.

In August 2001 the ARI Conference (Arthritis/Rheumatism International) and ILAR Congress (International League of Associations for Rheumatology) took place in Edmonton, Canada. Lucinda Blauw from the IOYR-board participated and in her article you can read more about the congress. You can read that ARI elected a new board. IOYR welcomes the new board and hopes that we can start working more together in the future years.

In the newsletter you can also read more about different national projects. Kirsten Russ tells about the Rheumafoon in Germany and Connie Andersen tells about Patient/Partner in Denmark. Maybe you will get ideas for your own work reading those articles. One of the goals in IOYR is to “exchange information and experiences and to learn from each other”. That is why we want to have more of these kinds of articles in the IOYR-newsletter in the future. So please send us articles about projects you and/or your organisation is involved in.

Also, exchanging ideas about running an organisation is very important. I am sure that you will get that by reading the articles from Tina M.-L. Mortensen and Cesare Patara. The two articles show two very different organisations, but working with the some of the same goals as all of us.

More members in the future

In the last newsletter you could read about 4 new members in IOYR. The board hope of course to welcome more in the future and one of the ways to do that is to let people know that IOYR exists. During the winter we will send out information-packs to a lot of rheumatism/arthritis associations/organisations all over the world, telling them about IOYR and the work we are doing.

By getting more members IOYR is getting stronger, but actually that is not the most important part. The most important part is that by getting member of IOYR the national organisations will get stronger by the ideas and support they get from all the other members of IOYR. So hopefully we can soon welcome new members.

International Internet

In June 2001 IOYR’s homepage changed a lot and has been visited a lot during the last months. We can see that it has also given us a lot of contact far outside Europe and that is very interesting and something that we are very much looking forward to follow up.

But an international web-site is not good enough – or at least not enough. National web-sites are also very important and IOYR is working with some plans to give our members the possibility of building up their own homepage. As soon as we have more news about this big and very interesting project you can read more about it at www.ioyr.org and of course in the next newsletters.

As always we are looking forward to hearing from you and working with you. See you at www.ioyr.org and in the next newsletters.

☺ **NOTICE!!!**

Next chat-meeting at www.ioyr.org:
Monday 26. November at 19.30 (UK-time)
Everybody is welcome to join!
Read more at www.ioyr.org

The new board

Who are the members of the board elected at the General Assembly in July 2001? After reading the next couple of pages – and maybe visiting www.ioyr.org for seeing pictures of us – you hopefully have some answers to that question.

Dorte Rønslér, 30 years old from Denmark, has Juvenile Rheumatoid Arthritis.

Member of the IOYR-board since: 1995.

Represent: FNUG – Foreningen af Unge med Gigt (Danish Organisation of Youth with Rheumatism)

Task in National organisation: Member of the board 1988 - 2000. National chair 1994 - 2000. Editor of the members-magazine and our homepage (www.fnug.dk).

When I'm not doing work for the organisation I work as a secretary/web-editor.

If I was an animal I would be a Bear - strong, but also teddy-nice at times.

Favourite word or phrase: If you don't have grass on your knees when the day is done, you ought to reconsider your life. (From Calvin and Hobbes).

Most annoying thing: Indifference.

The CD in my player right now is: Sound-track - Bridget Jones Diary.

This single store I would choose to empty my credit card: Electronic World.

Lucinda Blauw, 30 years old from The Netherlands, has JCA.

Member of the IOYR-board since: 1995.

Represent: Jongerencommissie Reumapatiëntenbond (Youth Committee Rheumatism League Netherlands)

Task in National organisation: I am a member of the Advisory committee on youth policy. The task of this committee is to advise the board of the motherorganisation about what should be done for young people with rheumatism. We also try to 'promote' the fact that young people can have rheumatism and that they can have a good life. And I am the coordinator of the Workgroup Youth Contact. The task of this group is to organise national youth weekends twice a year.

When I'm not doing work for the organisation I just started working as a court secretary for 32 hours per week, 3 days at the courthouse and 1 day at home. Beside this I am involved in local voluntary work; I am the treasurer of an organisation that lends toys and learning materials to people who have difficulties with playing and learning. I also work in this 'toy-library'. And I am a member of a steering group about voluntary work and volunteers. The local government started this group because of the

international year of volunteers. In my leisure-time I like to spend time with my family and friends, go to the movies, read books, be creative, play games, travel, listen to music and lots more.

If I was an animal I would be an eagle, to be able to fly far and high and also to float on the wind.

Favourite word or phrase: Leven is meervoud van lef. But when you translate it into English it doesn't look as good as in Dutch ('Living is the plural of courage'). So in English I choose 'Be yourself – there are already enough others'.

Most annoying thing: Traffic jams – when I go to work it takes 1 to 1,5 hours to get there. When there are no traffic jams I can do it in half an hour.

The CD in my player right now is: Ladies & Gentlemen – The best of George Michael + Music from the motion picture Edtv + Music from and inspired by the City of Angels motion picture + Shania Twain – Come on over. (I have a 5-CD player and I play them in 'shuffle' mode)

This single store I would choose to empty my credit card: Does a department store count? If it does I would choose 'Vroom & Dreesman' because they have everything I like: books, CD's, toys, clothes, chocolates, creative materials, games, home decorating things, etc. Otherwise I would go for a specific bookstore in my place, because they don't only have books but also some games and lots of creative materials.

Kirsten Ruß, 26 years old from Germany, has Chronic Polyarthritis (RA).

Member of the IOYR-board since: IYC 2001.

Represent: German-Rheuma-League.

Task in National organisation: Member of the working group for young people with rheumatism in the mother organisation, international contact person.

When I'm not doing work for the organisation I am a teacher for disabled children, a mother of two happy girls, a wife, a trainer for little children in the age of 3-6 for gymnastics, an aerobic-trainer for woman.

If I was an animal I would like to be a deer – because they always looks pleased or a fish - swimming in the ocean.

Favourite word or phrase: “Be happy – don’t worry!” and “Carpe diem”

Most annoying thing: At this time: the situation in the world - living without peace! Generally - moments without any happiness; missing family and friends!

The CD in my player right now is: John Denver – best off...

This single store I would choose to empty my credit card: Two weeks alone on beauty-farm – just relaxing.

Vilma Bandzeviciuté, 25 years old from Lithuania, has Spondyloarthritis.

Member of the IOYR-board since 1998.

Represent: Kaunas klubas “Artritas” (Kaunas club “Arthritis”)

Task in National organisation: I’m international contact person, and also organizer of meetings.

When I’m not doing work for the organisation I am a student of agriculture and a party girl☺☺...!!!!...

If I was an animal I would be a Panther, because she is clever, careful and nice!!!!

Favourite word or phrase: Life is short and you have use all chances!!!!

Most annoying thing: Lies and cold!!!

The CD in my player right now is: Now is silence!!!! Only computer is playing on my nerves ☺☺☺

This single store I would choose to empty my credit card: I’m so lucky, I invest all my money in a cheese company!!!

Georg Hodnefjell, 29 years old from Norway, has JRA and Bechterew.

Member of the IOYR-board since 1995.

Represent: BURG, The Norwegian Rheumatism Youth and Children Organisation.

Task in National organisation: Member of the national BURG board. Member of the IOYR board and responsible for international co-operation. Project-manager for IYC 2001. Represent BURG in NRF, The Norwegian Rheumatism Association (Mother Organisation). Engage and supporting local activities.

When I’m not doing work for the organisation I work half time as organisation secretary in a trade union for employees in public related

jobs. Spend time with my family, wife and a 3-year-old daughter and friends. Do sports/exercise 3 times a week. Support and follow my local soccer-team Viking once a week.

If I was an animal I would be a Parrot – I like to talk with people.

Favourite word or phrase: Enjoy yourself and collect great moments.

Most annoying thing: Voracity, prejudiced, intolerance, people complaining all the time and alarm-clocks.

The CD in my player right now is: The best of The Doors.

This single store I would choose to empty my credit card: The local travelling agency.

Laura Maria Margulies, 21 years old from Switzerland, has Systemic Lupus Erythematoses

Member of the IOYR-board since July 2001.

Represent: Schweizerische Rheumaliga (Swiss Rheumaligue)

Task in National organisation: I’m a member of the group of young people with rheumatism, a dependent group of our motherorganisation.

When I’m not doing work for the organisation I work as a barkeeper, will start studies in German and psychology at the end of October 2001, do photography and poems as a hobby, love soccer, sailing and snooker.

If I was an animal I would be a cat, because they’re amazing in hunting, they know how to relax, are their own boss and they’re smart.

Favourite word or phrase: Odi et amo. Quare id faciam, fortasse requiris. Nescio, sed fieri sentio et excrucior. C. Valerius Catullus, (ca. 84 – 54 ante domine). (I hate and I love. Why I do this, you may ask. I don’t know, but this is how I feel and I’ll perish (because of it).)

Most annoying thing: Violence.

The CD in my player right now is: Buckshot lefongue.

This single store I would choose to empty my credit card: Honda motorbike shop.

Catherine Gibb, 34 years old from UK, has Ankylosing Spondylitis

Member of the IOYR-board since 1995.

Represent: Young Arthritis Care (YAC)

Task in National organisation: Vice Chair of

the UK Committee of Young Arthritis Care; Local Contact for YAC.

When I'm not doing work for the organisation I work as a Research Associate in the Nursing Research & Development Unit at Northumbria University. In my free time I like to go horse riding and to spend time with friends. I am also very involved with my Church and sing in the Worship Band there.

If I was an animal I would be a cat – because I could sleep by the fire in the winter!

Favourite word or phrase: Melancholy (or it was when I was 3 years old!)

Most annoying thing: Windy weather.

The CD in my player right now is: The Messiah by Händel.

This single store I would choose to empty my credit card: Laura Ashley.

IYC 2004

by Laura Margulies, Switzerland

After the IYC 2001, the Swiss delegates went home with an enormous enthusiasm in their mind. They became part of the IOYR-board and the honour of organising the next IYC 2004 was theirs.

As soon as we arrived back home, the brainstorming started. The first meeting was nearly one month after the congress had finished, but the ideas were already flowing before we knew that we would get chosen for the board. Jacqueline Mäder, the Swiss delegate for five years, Barbara Kupferschmid, the responsible and person-to-talk-to of the youngster group of Switzerland and Laura Margulies, the new Swiss delegate, were corresponding heavily through email, sending each other ideas, news and pictures. We met Friday, the 17th of August, the first time in a restaurant at the lake-side of Zürich to have lunch together and to start the three years preparation for our congress. We nearly had no time to eat while talking: our minds were running away and all three of us wrote down plans about the motto of the congress, discussions, group-work and speeches that could be held, but as well about parties, fun, activities and excursions. After the meeting

we all went back home to start finding the right place, the best hotel, the funniest surrounding for IOYR-people. Until now we found six possible places that we are going to visit during wintertime, to have a close look at them (and to find out if the management would mind about loud and never-ending parties).

On the 22nd of September, our youngster group met for the first time after the congress. Jacqueline and I told them about the congress, explaining the idea, describing the spirit and showing all our pictures. Everybody seemed to have a light in their eyes and a smile on their face when listening carefully to our stories. At the end, we asked who would be interested in becoming part of the project-group and four persons raised their hands in one second.

We're going to meet again as soon as possible to create the organisation team and to start working with the power in all of us to lead IOYR to hopefully another great and always remembered congress!

More information about IYC 2004?

Please contact

Laura Margulies, Switzerland,

lauramaria@bluewin.ch

ARI Conference and ILAR Congress

by Lucinda Blauw, The Netherlands

Lucinda Blauw, former chair of IOYR and at that time member of the Manifesto Steering Group, participated in the ARI Conference (Arthritis/Rheumatism International) and ILAR Congress (International League of Associations for Rheumatology) from the 27–30 August 2001 in Edmonton, Canada. The program of the ARI Conference was set up under the theme 'Action Against Arthritis - Taking charge in the 21st Century'. The Conference started with the General Assembly of ARI. One of the main discussion points was the making of an International Manifesto. Everybody was very positive about that.

Another point was the election of the new board. As Per Aage Bjørke (Norway) resigned as chair, a new chair had to be chosen. Robert Johnstone (United Kingdom), the former vice-president, has become the new chair of ARI and Kaarina Laine-Haikio (Finland) the new vice-president.

On the rest of the days, lectures and discussions were planned about advocacy, research, partnerships, consumer education, sharing best practices and media relations.

Most of the time Lucinda helped to host a stand for the Manifesto. When she was at the stand she answered questions from persons from all over the world about the Manifesto. At the same time she told about IOYR. Hopefully (youth) organisations from parts of the world other than Europe will become members of IOYR soon.

Latest news about the Manifesto

by Michael Bernardy, chair of the Manifesto Steering Group

The European Manifesto stands for the first time ever for the common voice of more than 103 million people in Europe who live with chronic arthritis conditions.

The European Manifesto lists the ten most important needs to ensure/improve quality of life for people with arthritis. This is because it was created **by** people with arthritis **for** people with arthritis. It must be understood as a tool that both individuals but also national and international organisations can focus on regarding social, political, and medical aspects.

The European Manifesto has successfully been launched on the occasion of the EULAR Congress 2000 in Nice.

In the meanwhile it has been presented at the following forums:

- European Parliament in January 2001 in Brussels
- EULAR Congress in June 2001 in Prague
- IYC in July 2001 in Haraldvangen/Norway
- ARI / ILAR congress in august 2001 in Edmonton.

The European Manifesto always raised a lot of attention.

Since the beginning of this year an International Steering Group has co-operated together to develop the Manifesto on an international level. It consists of Michael Bernardy (Germany) as chair, Robert Johnstone (UK) as representative from ARI, Dorte Rønsler (Denmark) and Catherine Gibb (UK) as representatives from IOYR, Gisela Dalvit (Switzerland), Marjan Hudomalj (Slovenia), Lena Öhrsvik (Sweden) and Neil Betteridge (UK) as representatives for the EULAR Social Leagues.

With the board elections of the IOYR assembly during the IYC in Norway, Dorte Rønsler became chair of the IOYR board. As Lucinda Blauw (Netherlands) retired to be representative for IOYR in the Steering Group, Dorte took over from her to be a member in our group. The Steering Group wishes Lucinda all the best for her future plans and thank her for all her support and excellent co-operation during the last years. We cordially welcome our new member Dorte and look forward to having a successful and long co-operation!

The Manifesto Steering Group is meeting three times a year to discuss future activities and the next steps of the implementation. The first meeting 2001 was held in Bonn (Germany), the second one in Prague during the EULAR congress and the last one for this year will be in December in Spain. The Steering Group has invited the Spanish PARE Representative, Francisca Carrion and the manager of LIRE, Julio Aguado Cañamares, to report about the situation of people with arthritis in Spain and about their experiences with the Manifesto implementation.

To be able to implement the Manifesto in all European countries this initiative needs the support of national organisations and individuals.

Since January 2001 a network of PARE Representatives has been established in 24 countries in Europe so far.

We invite everybody who would like to support

the Manifesto in his/her own country to get in contact with the co-ordinator of the European Manifesto, Birte Glüsing, who is working at our secretariat in Bonn.

Contact Birte Glüsing
c/o Deutsche Rheuma-Liga Bundesverband e.V.
Maximilianstrasse 14
53111 Bonn
Germany
Phone: +49 228 766 0615
Fax: +49 228 766 0620
bv.gluesing@rheuma-liga.de

She would be happy to put you in contact with the PARE Representative of your country to ensure that the work is co-ordinated and there are no double efforts.

On the occasion of the celebrations around the International Arthritis Day on 12th of October 2001, Birte has been invited by the Latvia Rheumatics Association to join their interesting programme and to give a presentation about the Manifesto. The Latvia Rheumatics Association is presenting the translation of the Manifesto into Latvian on this day.

Regarding the translations that are now existing, there has been a considerable progress during the last months. The Manifesto Steering Group is very pleased that at least the single page is now available in the following languages: French, English, German, Dutch, Danish, Polish, Hungarian, Portuguese, Spanish, Slovenian, Latvian, Lithuanian, Greek, Czech and Icelandic. Translations into Swedish, Norwegian, Arabic and Italian are on the way. If you don't find your language above, please don't hesitate to contact Birte and she will try her best to help by arranging a translation.

The Steering Group appreciates that the Manifesto is a main issue on the International Arthritis Day in so many countries, e.g. Iceland, Austria, Yugoslavia, Norway, Sweden, Finland, Latvia, Denmark etc.

If you are interested in more information about

us, or the Manifesto itself, we invite you to have a look at our new PARE Website.

www.PAREmanifesto.org

There you can find a lot of information, translations of the Manifesto single page, the newsletters (issue 3, the latest one, has been published in late August) and the possibility to endorse the initiative and to send us your comments. At the moment not everything is ready yet but it is under construction. If you miss something we hope that we can provide you with the complete information as soon as possible.

The Rheumafoon Project in Germany

by Kirsten Ruß, Germany

“Rheumafoon” is a project for young people with rheumatism and parents of children with rheumatism, by young people with rheumatism

The upholder of the project is the mother organisation (the German-Rheuma-League) for people with rheumatism. The Rheumafoon fulfils the overall aim of our organisation: to give help for self-help.

Eight young people have lent their ears by phone to give their knowledge for other people with questions about “Living with rheumatism”.

The Rheumafoon project started in 1996 and we proudly look back on 5 years of successful work. The project for parent consultation started last year.

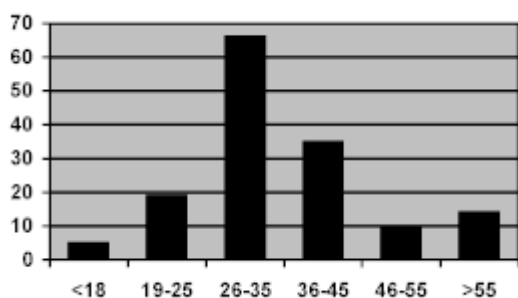
We are proud because every year the number of callers increases. By December 2000 it was 1524 phone consultations – averaging nearly one call a day.

The Rheumafoon advisors have the chance to learn all they need at workshops, where they discuss their questions two times a year with professionals and with supervision, to allow for an exchange of ideas, problems and stay in discussions with the other advisors. These work-

shops are an important part of the project, especially to give the advisors the power and knowledge they need.

One engaged woman, who is a member of the working group for young people with rheumatism (BAK), stays in contact with all advisors and supervises their work, adding information for the further development for the project. Every half year she makes a report about the work of the project and puts them in numbers and graphics. (Thank you Kathrin!)

Below you will find some of her work with some facts of the projects. This data allows an insight into the great work of the eight young people. The numbers are from the July 2000 – December 2000 evaluation, with 209 Rheumafoon-consultations. As a means of comparison, the work was started in 1996, when the advisors had together 279 telephone consultations in that year– and only four years later (in the year 2000) already 387.



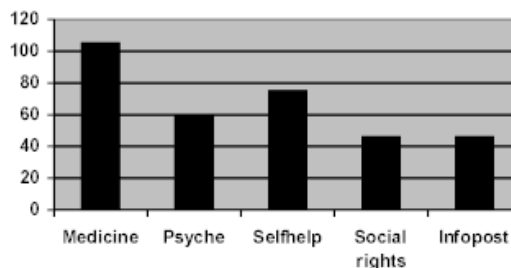
The age-distribution

The age-structure of the callers shows that most people with questions seem to be in the age of 26-35 and 36-45. Together this group represents nearly 50 % of the people calling.

It is interesting that only 9% of those calling are male, the rest (91%) female.

More than 60% are not a member of the German-Rheuma-League and have used Rheumafoon as their first contact and chance to use the service of the organisation.

Interesting, as well are the most frequently asked questions.



The topics of the telephone conversations

In summary, this concludes that all advisors need a good qualification – being young people with rheumatism themselves, is that qualification. They have done and are still doing very important and valuable work. I think they will do also in future. So let's say: Many thanks!

Health professionals and patients working together - The patient /partner program

by Connie Andersen, board-member in Danish Organisation of Youth with Rheumatism and project-manager in The Danish Rheumatism Association

The patient/partners are a group of patients with arthritis, who are educated to teach health professionals a correct and systematic joint-examination by using themselves and their own joints with arthritis as an example.

In the late 1980's Professor Peter Lipsky of University of Texas got the idea of the patient/partner program. In 1995 the project came to Denmark as well as other countries in Europe. In Denmark the project was started in close co-operation with a Danish rheumatologist. Today there are 15 patient/partners in Denmark – spread all over the country. The diagnoses of the patients involved are rheumatoid arthritis and/or osteoarthritis.

The education of the patient/partners consists of training in the anatomy and the medical terms of the joints. The patients have to be open and talkative and furthermore have accepted living with a long-lasting disease. This is necessary because the partners have to talk to students

about themselves, let the students touch their joints and be willing to go into details about what is difficult for them to do in daily living.

Better educated health professionals

The goal of patient/partners is to improve the education of health professionals who treat arthritis patients. The group of health professionals is various, for example, doctors, nurses, physiotherapists, occupational therapists and others. In Denmark we have made some evaluation of the program and without exceptions they all show, that the health professionals all find the visit of the patient/partners extremely relevant, think highly of and enjoy very much the way the patient/partners teach joint-examination. Furthermore the health professionals also get a chance to ask all kind of questions about living with arthritis, medicine, artificial joints, assistive devices and so on.

Gigtforeningen (The Danish Rheumatism Association) has the goal for the future that all health professionals are offered the opportunity to meet the patient/partners during their education and we are working on reaching that goal in the next 5 years.

Patient and project-manager

I started as a patient/partner in 1998 and as Gigtforeningen this year decided to develop the program at many levels, I was employed as a project-manager 25 hours a week. My job is to take care of everything concerning the program. I have educated 5 more patient/partners, and I am the one who has contact with all the schools using patient/partners. Furthermore I am working on making the program more visible and making sure that the quality of the program is high and stays high. I still go out to teach joint-examination together with other patient/partners - that is a part of my job I would be sad to miss.

The project is financed by the medical company Pharmacia, which covers the patient/partners travelling expenses when they teach the health professionals the joint-examination. The project is administrated by Gigtforeningen, through the project-manager.

Deformed fingers as advantage

Not only does the group of health professionals benefit from the program by meeting educated patients – the patients involved get something in return. They get of course a lot of new knowledge related to their arthritis and also learn “the language of the doctors”. Arthritis is for most patients connected with pain and negativity, but the program is a way to use arthritis in a positive way. Many patients feel, that if they know more about their disease it can give them the possibility to take charge of their own lives and that makes it easier to live with arthritis. A patient cannot change having arthritis, but being a patient/partner make the patients look at their situation in a positive way. One of the patient/partners in Denmark expressed it like this: “I knew that my deformed fingers could be useful someday!”.

**For further information please contact:
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candersen@gigtforeningen.dk
phone: +45 39 77 80 38**

IOYR-memberorganisation:

Youth with rheumatism in the Italian Association of Rheumatic Patients

by Cesare Patara

In Italy we don't have a youth organisation. Our regional associations, which together constitute our national mother organisation (ANMAR), have many young members but only a few work actively. In spite of this, our role is very important both at a national level and regionally and we have the full trust of the national board.

We are often sent to represent our national organisation to international congresses of social leagues and we have participated with different delegates to all the IYC congresses since the first congress in 1989.

Two young people with rheumatism are the national organisation representatives into a special commission established two years ago by the

Italian Ministry of Health to evaluate the diffusion of rheumatic diseases and to issue guidelines concerning disease prevention, patient rehabilitation and the creation of a satisfactory system for the assistance of those suffering from a rheumatic disease.

We also work at a regional level by helping our association to organize informative meetings with physicians and rehabilitation professionals and maintaining the contacts with the young members. We regularly write on the regional newsletters and sometimes also on the magazine of our national organisation.

This year our national association has taken part in a great information campaign in many Italian towns. During this campaign we have actively participated in talk shows and press conferences.

In conclusion, our increasing presence in the activities of our national organisation is very promising and gives us a great opportunity to better represent the situation and the needs of young Italian people with rheumatism.

**Find addresses for Italy and
Denmark at www.ioyr.org
Here you can also find information
about other member-organisations**

IOYR-memberorganisation:

Who in the world is FNUG???

*by Tina M.-L. Mortensen, Chair of FNUG,
Denmark*

FNUG stands for ForeningeN af Unge med Gigt – in English “Danish Organisation of Youth with Rheumatism”. We are an independent national organisation, working closely together with the Danish Rheumatism Association (Gigtforeningen) - both on local and national levels.

FNUG was set up in 1983 and works to make everyday life easier for youth with rheumatism both at work, in education and in their ordinary lives. We also work to increase everyone's

knowledge, that young people also can get rheumatism.

If you have rheumatism, and are between the ages of 12 to 36 you can become a member. FNUG has approx. 280 members. Everyone who doesn't fulfil our membership-criteria (age and rheumatism) has the possibility to be a support-member, and the organisation has approx. 120 supportive members. It costs 75 DKr (around 10 \$) a year to be a member/support-member of FNUG.

We receive financial support from the profits generated by the State football pools and lottery foundation, from the Danish Rheumatism Association, from private funds and from our members.

Activities – local and national

We have local activities and meetings where our members meet to discuss issues that to some degree, whether great or small, have to do with rheumatism. The topics for discussion can be for example ”Rheumatism and Medicine” or ”Alternative Treatments”, but during meetings many other issues are covered, from discussions about diet to driving a go-cart-race or doing rappelling (abseiling).

Furthermore, we have different groups who meet and plan various national weekend-courses. Such as “Rheumatism and Active life”, ”Rheumatism, Sex and Family-life”, “Rheumatism and Work” or ”Rheumatism and Education”. Each year we also have a Teenage-Weekend.

The planning-groups are set up during our annual general assembly between members who have some ideas and like to join.

All together we have approximately twenty different member-activities per year.

Structure

FNUG consists of a board with 9 people: Chair, treasurer, secretary, 4 ordinary board members and 2 deputy members. The board is selected at the annual general assembly and meets 6-7 times a year.

FNUG employs a part-time secretary in our office in Århus. The main duties of the secretary are bookkeeping and postal activities. Everyone else in FNUG are volunteers and not paid, but all costs like phone, travelling costs ect. are covered by FNUG.

FNUG also has a number of local contact-persons, who are connected to three areas we have divided Denmark into. It is the contact-persons who arrange the local activities. The contact-persons also give advice and guidance to young people with rheumatism and to people who encounter young people with rheumatism in their everyday lives. Once in a while the contact-persons also hold lectures for people from the health-section, among others.

Information, PR and signing up

We have our own magazine called "FNUG-magazine". The magazine is made by young people with rheumatism for young people with rheumatism. It is circulated every second month to members, support-members, hospitals, co-operations-partners etc. Each issue has a subject, but the magazine of course also includes information about the activities of FNUG.

FNUG also has a leaflet about the organisation, a video-movie and a pamphlet called "You and Rheumatism".

At www.fnug.dk you find our homepage. It is very useful for our members and for anyone else who wants information about FNUG, our work and what it means to be a young person with rheumatism.

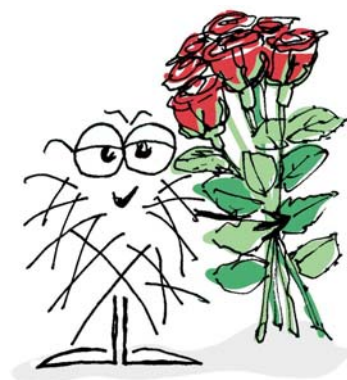
People can sign for more information or for our weekend-courses at the homepage. We have a debate, a chat and also a mailing list. A lot of the information is translated into English so you are very welcome to visit the site.

Both in the magazine and at our homepage you find the little 'Fnug'. (Fnug = flake like in the word snowflake). The Fnug is almost as old as the organisation. The first time the drawing saw the light of day was in the first issue of our FNUG-Magazine, February 1985 - and has since been a festive part of the magazine. The Fnug, always in good form, has given the arti-

cles a deep, serious, fun or bittersweet comment along the way.

The Fnug is more than a drawing or a doodle, which experiences a lot of funny things. The Fnug is also a symbol of what the organisation stands for. The meaning is that one Fnug is easy to knock down, but if we can stand together in the organisation FNUG we can support each other and help each other to keep on track with our goals in our lives.

The Fnug has as many expressions as there are people and options, because there is no situation in which the Fnug can't find itself. There has been over a 1.000 drawings made of the little Fnug.



And the winner is...

FNUG has instituted the award "The Golden Bone". The award is presented to one or more persons, who have done something for young people with rheumatism and/or FNUG. The presentation can take place once a year. We have as an example given the award to the big music Festival "Roskilde Festival" because of their initiative regarding "handicap service". This service makes it possible for disabled people to have the same possibilities as others to participate in the music festival, which lasts 4 days every year.

Co-operate? Yeah!...

As mentioned, we co-operate with the Danish Rheumatism Association and of course also IOYR. But also with The Danish Parents Association of Children with Arthritis, Ankylosing Spondylitis Society Denmark, The Danish Council Of Youth Organisations of Disabled People, BURG-Norway and Unga Reumatiker, Sweden. Co-operation is a very important thing for us. We do believe that together we stand stronger and that we can learn a lot from each other...

Next newsletter:

- More about Open Day and IYC 2004
- Article about Center for Mothers with Rheumatic Disease
- Your article???

You are more than welcome to write an article for the newsletter. Please mail it to ioyr@ioyr.org.



The Aims of the IOYR

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.

More information about IOYR

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