

IOYR - International Organisation of Youth with Rheumatism

2001 - 2004



IOYR - 2001-2004

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IOYR - International Organisation of Youth with Rheumatism

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June, 2004

It seems like yesterday...

It seems like yesterday when we said goodbye in green and beautiful Norway after a wonderful IYC 2001.

For those that didn't participate it must also seem like yesterday when you had your representatives coming home, talking about all the things that happened at IYC 2001, all the new ideas they got and all the new energy they have gained.

Now, here we are with a lot of pages filled with text about what happened at the IYC 2001 and since we left Norway. And it is clear that it wasn't yesterday - it is almost three years ago. And we no longer have a long election period ahead of us - there is less than two months left before a new election will take place.

There is no doubt that more could have happened during the last three years and that IOYR has had its problems. But despite the problems we have had, IOYR has moved forward since 2001.

I wish the board members that will be elected at the General Assembly in July lots of luck and hope that they will move IOYR even further forward in the direction where IOYR shall go. "And where is that" you can ask? That, I am looking forward very much to discussing with your representatives at the General Assembly that will take place during the IYC 2004 in July in Switzerland.

For the members of IOYR I encourage you to support IOYR, the board of IOYR and the young people in your organisation who are interested in local, national or in international work. You will not regret any of it...

Thanks to everybody who has been a part of the work of IOYR during the last three years and also to all of you, that has supported us in different ways. Without you, IOYR would have not moved at all.

I am looking forward to seeing you in Switzerland.

Many greetings from the board


Dorte Rønslér
Chair

This report includes information about IOYR and the organisation's work from July 2001 - June 2004.

Members

Before the IYC 2001 in Norway IOYR had 13 Members. The organisations were from Czech Republic, Denmark, Finland, France, Germany, Hungary, Lithuania, The Netherlands, Norway, Poland, Sweden, Switzerland and United Kingdom. During the IYC 2001 four new members signed up and were welcomed – the organisations were from Italy, Latvia, Slovakia and Slovenia.

After the IYC, the IOYR Board tried to stay in contact with the member organisations to get new information about what's happening in their countries, about projects and work in the member organisation. With some countries this was not easy because there was no young contact person named and active, so some IOYR mails received no answers and the board found it difficult to offer their support.

The board always tried to include news from members into the newsletters - to inform other members about news and projects and to give them new ideas for their work.

Cyprus heard about IOYR and signed up in November 2003. The same with Estonia, Portugal and Iceland, they became member in the spring 2004. Just before we finished this report also Belgium signed up to be member of IOYR.

Many new members are good. But unfortunately we also lost Spain as a member. We lost contact since the end of 2001, but we hope that we will soon be in contact with the youth from Spain again.

We also lost Hungary as a member, because their organisation closed. But the contact is still there and we are, as this is being written trying to find a solution as to how IOYR best can support Hungarian youths with rheumatism.

Having 21 member organisations is fantastic and it means we must work even harder now to ensure we meet our aims of members being more included in IOYR work between meetings and IYC's and helping them be more active in working together. However, this is what IOYR and the IOYR board is here for! We very much enjoy seeing IOYR develop and grow.

Then we also have all the future members. Now and then we get new contacts – from all over the world. People and organisations that want to hear more about IOYR and show an interest in becoming member. We hope that we soon have even more members.

Newsletters

In order to inform the members and interested persons about news and the international and national activities of IOYR, we make a newsletter.

The board writes and collects articles for newsletters. The aim was to give out three to four newsletters per year, an aim that unfortunately could not be fulfilled for a number of reasons.

After the IYC 2001 a special edition about IYC 2001 was given out. It shows how great this congress was and how much power such a meeting can release.

After that there was one more newsletter in 2001, one in 2002 and three in 2003. Every newsletter includes news from the board and the activities of IOYR as an example in external meetings, planning steps for the next IYC and news.

Besides that there were reports about national activities and special themes like being a student with rheumatism, being father or mother with rheumatism and much more, written by different persons from different countries.

All newsletters have been sent with letters and information about IOYR work to the member organisations and were included on the IOYR website www.ioyr.org. with the possibility to load it down as PDF-file. The newsletter was also sent to friends and supporters of IOYR, including people who sign up for information on the website.

Looking into the future we hope that many more organisations and persons will use the chance to tell us about interesting themes in the newsletters, that more people will download them from our homepage and that the IOYR board will get more reactions back from member organisations.

www.ioyr.org

The website of IOYR - www.ioyr.org - is the most important place between meetings and face to face communication to make contact with the IOYR board and other young people with rheumatism and their supporters. Here you can:

- get information about news and the work of IOYR or IOYR board
- download the newsletter and other information
- join the mailing list to get informed by email about latest news and chat-days
- communicate at the debate or guestbook with persons from other countries
- to meet other young people in the chat - there is an organised chat once a month

General assembly 2001

One important part of the International Youth Congress is the general assembly. At a general assembly important questions are discussed about the future of the organisation. There is also the election of a new board.

At the general assembly in Norway 2001 chair Lucinda Blauw opened the meeting and welcomed everybody. Italy, Latvia, Slovenia and Slovakia were especially welcomed as they were new members in IOYR.

Per Åge Bjørke, the president of the Norwegian Rheumatic Association led us through the general assembly. He expressed how essential and necessary the group discussions are for the future of IOYR. It is important both for the organisation as a unity and as a working tool for the board. Lucinda Blauw then told us the history of the IOYR and IYC.

We then had group discussion and the themes discussed in the six groups were:

- Homepage
- Members fee
- Constitution
- Projects
- Newsletters
- New members
- Aims (in the constitution)
- Membership
- Open day
- Sponsorship

All the groups came with inspiring and important suggestions for IOYR. Group discussions like this are a great help for the new board. It shows what the members think is essential, a guideline.

We then moved on to the election. Dorte Rønslér from Denmark was standing for chair. There were no other candidates and she was unanimously elected.

There were several candidates for the board and they all presented themselves before the voting took place. The candidates were:

1. BURG, Norway - Georg Hodnefjell *
2. Rheuma-Liga, Germany - Kirsten Ruß *
3. Kaunas klubas "ARTRITAS", Lithuania - Vilma Bandzeviciute *
4. LIRE / AJER, Spain - Vanessa Spitzer Rubio (represented by Julio Aguado Cañamares)
5. Rheumatism Patients League, The Netherlands - Lucinda Blauw *
6. Rheumaliga, Switzerland - Laura Margulies *
7. SMCNPZS, Poland - Karolina Piotrowska
8. Young Arthritis Care, United Kingdom - Catherine Gibb *

The ones marked with a star were elected for the board for 2001 - 2004.

There was an equal amount of votes between Lithuania and Poland. There was a second voting to find out which country got the board place.

Welcoming new members into the board, also means saying good bye to old ones. The current board expresses here its thanks and appreciation to Anna Talaska from Poland and Montse Sanchez-Oro Perez from Spain.

There was also a discussion about the member fee and there was an agreement that the fee should change from pounds to euros, but continuing with the same amount of fee a year (100 UK Pounds - 160 Euro).

Lucinda Blauw congratulated the new board members and thanked Per Åge Bjørke. Then the new chair Dorte Rønslær thanked everyone for their support and requested everybody to be an active member of the IOYR the next period!

Board and board meetings

As written above, the board is elected at the General Assembly that takes place every third year. It is important to note that it is the organisation that is the member of the board and not the actual person who represents the organisation. However, all of the representatives must be young people who have rheumatism and are no older than 36 years old.

Board Meetings

The board meets twice a year for board meetings in different countries, usually where the board members live. Since the last IYC 2001, IOYR has had five board meetings. During these meetings the board were talking about the contact to members, Members Meeting, the PARE Manifesto, the IYC 2004 in Switzerland, Newsletters, the elections in 2004 and the website and chat, among other things.

After the general assembly the board had a small meeting at which Lucinda Blauw was elected as the treasurer. In September 2001 the board met in Copenhagen, Denmark at our first board meeting. A lot of plans were discussed during the first long and hard weekend meeting and we were already working hard developing the work of IOYR and the projects where we are involved.

In 2002 the board had their first meeting in Amsterdam in February. In October 2002 the board used the opportunity to have a small meeting during the PARE Manifesto Representatives Meeting in Königswinter, Germany.

The board had our second normal board meeting in 2002 in London at the beginning of December. Here we said welcome to Linda Vøllestad Westby from Norway who was BURG's new representative on the board. Linda replaced Georg Hodnefjell who in the spring 2002 decided not to go for election for the national board in Norway. Linda was elected as BURG's vice chair and now she was also on the board of IOYR. We welcomed Linda and at the same time we said thanks to Georg for his work in IOYR. Georg had been a board member since the launch of IOYR in 1995, and there is no doubt that we most of all can thank Georg for his enormous work as project manager for the IYC 2001 in Norway.

The first board meeting in 2003 took place in Lithuania at the beginning of May. Here we welcomed Marianne Scobie, from Scotland as new board member from United Kingdom instead of Catherine Gibb who decided to resign from the board. Marianne is on the board of Arthritis Care, her mother organisation and was co-chair of the youth organisation. The board welcomed also Marianne and thanked also Catherine Gibb, board member since 1995, for all of her hard work for IOYR and wished her well for her future work and health.

After the meeting in Lithuania we had our next board meeting in November in Switzerland at the place where IYC 2004 will take place. Here we also met the planning group for IYC 2004 to talk about the difficulties and the problems connected with IYC 2004.

The meeting planned for April 2004 in Glasgow did not take place. There were a number of reasons including not being enough money to justify a meeting as some work was not completed and so needed to be finished first. Instead the board worked via e-mail to complete all the outstanding tasks.

The constitution

A major piece of work for the board has been the re-writing of the constitution. This was a mammoth task involving gathering suggestions from members, collating them and re-drafting the constitution in time to be sent out with the General Assembly paperwork for ratification by members at the General Assembly. This also included putting together a paper explaining why / why not each suggestion was included.

Members Meeting

Originally the Members Meeting was known as Open Day. At the meeting at the beginning of February 2002 the board of IOYR decided to change the name of this event.

The 'Members Meeting' is a mini-congress for the members of IOYR. This event takes place every third year - between the IYC's - International Youth Congress.

The goal of the meeting is to learn from each other about our work for and as young people with rheumatism. We want the meeting to be a forum where we all get new ideas and inspiration for our work back home.

Because the first Open Day / Members Meeting was a big success, the board decided to organise one in this period as well.

The second Members Meeting /Open Day was planned to take place in May 2003 in Vilnius, the capital of Lithuania. It was decided that each IOYR member organisation could participate with two delegates together with one delegate from their 'mother-organisation'. The themes of the meeting were activities and work of and for young people with rheumatism and ideas about how to use the PARE Manifesto in this work. The organiser "Kaunas Club Artritas" was looking for everything best possible to arrange the Members Meeting, but unfortunately, the Members Meeting had to be cancelled because not enough people/organisations signed up.

The Board thinks it could have been a great opportunity to meet between IYC 2001 and IYC 2004 and is very sad that the Members Meeting had to be can-

celled. The board also wishes to thank "Kaunas Club Artritas" for all their hard work in organising the event.

Hopefully the third Members Meeting will work without problems!

IYC 2001

In the summer of 2001 was the International Youth Congress, IYC, held in Norway, at Haraldvangen, hosted by BURG, The Norwegian organisation for children and youth with rheumatism. For a whole week in July, 75 participants from 22 nations got the opportunity for self-development, inspiration, new insight, breaking barriers, co-operation, new friendship and finding the "Power in You". The common denominator was rheumatic diseases. We will here give some highlights from the IYC 2001 which is IOYR largest arrangement every third year. It will also be a reminder for us who participated in Norway and an inspiration for new participants in the next IYC in 2004.

The theme for the congress was *the power in you - how to make international co-operation a platform for growth*. The Norwegian project group had been working hard for three years to create the best IYC ever. And then they had the day come where the planning was complete and the participants start arriving. Both the project group and the IOYR board were nervous and eager to see if the congress would be a success.

Each day of the week had its own theme and name. And the theme was completed with speeches, lectures and group work. The first day "*motivation through presentation*" begun with a presentation of what we wanted the participants to achieve through the week. We also needed to know more about each other, so everybody made a presentation of their country. The presentations decorated the meeting room the whole week.

Every night there was a social gathering. One night we had a party in a lavvo with singing, playing guitar and a special drink from Norway served in wooden tree-cups. We also had an old lady who told us traditional Norwegian folktales.

"Breaking barriers" was a very special day for many of the participants. The aim of the day was to challenge our personal barriers both mentally and physically. We had a fantastic personal speech from Rolf Husebø and how he has learned to live a life where the rheumatism is no barrier for what he can do. It is rather our minds and thoughts that are stopping us than the rheumatism. That afternoon we had different physical challenges outside like horse riding, water-skiing, canoeing, fishing and making speeches.

Many of the participants had never thought that they could manage water-skiing, but they did! Here the participants definitely challenged many personal barriers and it was a special afternoon we shared with each other.

The following day, "*owning your own health*", was also a remarkable day. The great Kate Nash, our motivator, challenged us to take control of our health and life.

Her good group discussions made a deep impression. That afternoon we had a lecture about rheumatism and pregnancy. Hege Kroksvik from the “Centre for mothers with rheumatic disease” told us some important things. When having a child the rheumatic disease is only one of many factors to consider. After the lecture we had a parallel section, one with Hege continuing her theme and Kate’s group talked about balancing priorities in life.

That evening we had an international party. Every participant had brought something special from their country. And we had a presentation with national costumes, singing, dancing and tasting unusual food and drinks. It was a spectacular night.

On Wednesday we had an *excursion to Oslo*, the capital of Norway. We went on a Viking ship and were cruising in a nice sunny weather. We also had some spare time to do some shopping and explore Oslo on our own. This evening we had karaoke and some new pop stars were born.

“*Into the future*” was the day where we could hear news from science about rheumatic diseases and new treatments. This was also the day for the IOYR general assembly. Dr. Øystein Førre told us that there was going to be revolutionary news in the field of research on rheumatism medicine in the near future. This was the morning section, the afternoon was IOYR’s general assembly led by the President of Norwegian Rheumatism Association, Per Åge Bjørke. You can read more about the general assembly elsewhere in the report.

Friday the last day before departure was called “*from international knowledge to national activity*”. We wanted to give the participants tools to manage all the feelings and experience we have when we are coming home. A powerful day with many strong speeches, the new IOYR chair Dorte Rønsløer held one of them “me after IYC”. She shared with us what the participants can expect when you come home. A great moment was when we all stood in a ring holding hands and shared memories, feelings and impressions from the week that had gone. It was a very powerful impression and the goal was achieved. The participants had experienced the strength, the “Power in You”. Friday evening we had a goodbye party, with a live orchestra - ensemble. We had a nice dinner, live music, dancing and good bye speeches. Saturday was departure day with lots of goodbyes and tears.

The week was over, just when it had begun. Three years of planning to make the best IYC ever had clearly been worth it. It was definitely a success. To know that there are young people all over the world who also have rheumatism is in a way good to know. We got the opportunity to meet some of you and share the fantastic atmosphere and develop the strength, the power in our self.

IYC 2004

At IYC 2001 Switzerland offered to be the next holder of IYC 2004. Up to then they had started to work for that great event with a working group.

In the middle of 2002 the first announcement was given out and the working group has given much power to make the organisation of IYC 2004 and the finances

clear. But in some ways there were many problems with getting support from IOYR because of communicational problems and of sponsors because all countries and organisations have problems with their money.

In November 2003 at their joint meeting the IOYR board and the Swiss Rheumaleague decided to have a shorter IYC because of communication and organisational problems and to make the financial difference smaller. IYC 2004 will take place in GWATT-Centrum - a very nice place with accessible rooms and many possibilities to have a great congress.

The final announcement was given out in April 2004. We hope that many organisations and persons will participate and that we will have a good meeting there, with everyone gaining new power for IOYR work and to discuss ideas for IOYR and its future.

At the IYC the General Assembly will take place over one and a half days. This will be planned by the IOYR-Board.

World Arthritis Day

Every year on October 12 the World Arthritis Day takes place. It is a great opportunity for people with rheumatism around the world to raise awareness of rheumatism and how it is to live with.

In 2003 IOYR decided - for the first time - to really mark the day. We choose the headline "MOVING!" and had two special events with this headline. First of all we made an issue of our newsletter. Only with articles about MOVING! - unfortunately we only got two(!) articles for this issue. But nevertheless it was a good newsletter, since the articles showed moving with power and engagement.

In the evening we had a chat on www.ioyr.org - also with the headline "MOVING!"

IOYR plans to mark the World Arthritis Day every year.

Web Project

The IOYR initiated a web project in order to create a virtual network for youth with rheumatism. A place in "hyperspace" where people and organisations could meet and exchange information from anywhere in the world provided they had access to the Internet.

In technical terms to succeed the web project would need to:

- Hire space on an internet server (or buy a server and connect it)

- Create web programs that run on the server, providing people with the means to send, receive and store information e.g. chat rooms, forums, email, homepages etc, across the internet.
- Enable organisations to create their own presence on the web regardless of computer skills.

A team of IOYR members with the correct computer skills would carry out the necessary work involved in such an operation, while the IOYR board members sought funding for the project. The project group members were Jette N. Agerbo (Denmark), Cesare Patara (Italy), Andreas Gunleikskås and Helge Elvik (Norway), Mattias Svensson (Sweden), Con Cunningham (United Kingdom) and Dorte Rønslér and Georg Hodnefjell from the board.

Project group members had one weekend meeting in June 2002, at the FNUG (The Danish Youth Organisation) offices in Aarhus, Denmark. At this meeting, the work load was divided into certain technical areas for example, finding a suitable location or host, designing the look and feel of the site, creating a message forum, creating a database to store information etc.

To this end the various members of the web team have been working on their own, occasionally meeting at the IOYR.org chat room to check progress and relay information to the board.

At present the project is on hold while funding is arranged, but much of the work has been carried out. The project is high on the IOYR agenda and we hope it will be achieved in the short-term rather than the long-term.

People with Arthritis / Rheumatism Manifesto

Together with ARI and EULAR Social Leagues IOYR has been a part of developing the PARE Manifesto and has been a part the PARE Manifesto Steering Group since the beginning of the work.

Since the presentation about the PARE Manifesto at the IYC 2001 in Norway, there have been many exciting developments, including a great deal of visibility for the Manifesto. After becoming the new chair of IOYR, Dorte Rønslér took over the place in the PARE Manifesto Steering Group from Lucinda Blauw, the former chair of IOYR.

During the ARI / ILAR congress in August 2001 in Edmonton, Canada, several members of the PARE Manifesto Steering Group were present. As a former member of the Steering Group Lucinda Blauw was also there. One of the tasks for Lucinda was to help to staff the PARE Manifesto exhibition stand, which attracted most interest from doctors, representing countries in Africa, Asia, Europe and South America. Especially delegates from outside Europe, who applauded this patient initiative and welcomed the opportunity for better collaboration between doctors and patients were very interested to learn about the Manifesto. More than 75 people endorsed the Manifesto and received information from the stand.

At the stand Lucinda also had the opportunity to inform people about IOYR and our work.

The chair of the PARE Steering Group, Michael Bernardy from Germany, gave a presentation on the Manifesto. The presentation was part of a joint session with the Canadian Arthritis Foundation, which voted to develop a global Manifesto, based on the European Manifesto.

On Saturday 12 October 2002, World Arthritis Day, PARE National Representatives had their first dedicated meeting. The meeting included a full day of presentations and plenary discussions covering areas of European and national interest. The plenary session offered delegates an opportunity to discuss the presentations with the speakers and members of the Steering Group and to share their experiences and needs. Members of the IOYR board also participated in this event and there was a presentation about IOYR.

Securing access to the best treatments for people with rheumatism is a problem shared by most European countries. On Saturday and Sunday, 29/30 March 2003, 26 PARE National Representatives from 21 countries attended an 'Access to Treatment' workshop in Brussels, Belgium. During the two days guest speakers presented case studies from their organisation, which provided practical steps to lobbying and examples of successful national campaign. Ten representatives from European patient groups gave impressive presentations on the situation in their countries and all shared common concerns.

A key aim of the workshop was to create a consensus document that consolidated these common concerns and which can be used to lobby at a national and European level. A copy of the Consensus Document can be found on the PARE Manifesto website, www.paremanifesto.org. IOYR was also represented at this workshop and later on we have also signed the document as well.

In the beginning of 2003, Catherine Gibb, board member of IOYR, left the PARE Manifesto Steering Group due to her commitments to the IOYR Board. At the end of 2003 IOYR decided that they would not continue taking part in the Steering Group. Of course IOYR will still support the Manifesto and stay in contact with the members of the PARE Steering Group.

Also Michael Bernardy from Germany decided to step back from the work for the PARE Manifesto, due to him becoming a father. In 2004, Neil Betteridge from the UK took over from Michael by being the new chair of the PARE Manifesto Steering Group. Together the old steering group members and with three other new members, elected from the EULAR Social Leagues, they will continue the work in spreading the news about the PARE Manifesto and help people and organisations working with it.

If you want to read more about the PARE Manifesto please visit www.paremanifesto.org.

Congresses, meetings and projects

Representatives from IOYR have participated in external international meetings and congresses. At all meetings the representing persons gave information in different ways about IOYR and IOYR work, and received many interested questions and thoughts back.

EULAR Congresses

EULAR stands for the European League Against Rheumatism. Every year a EULAR congress takes place in one of the capitals or big cities in Europe. In 2002 it took place in Stockholm, Sweden, in 2003 in Lisbon, Portugal and in 2004 in Berlin, Germany. The congress is the moment for everybody who has anything to do with rheumatism to meet and learn. The congress programme is divided in three interest groups: Scientific, Social Leagues and Allied Health Professionals. During the congress different lectures are simultaneously held for the different interest groups.

The Social Leagues programme is especially for representatives from patient organisations or for individual people with rheumatism. A good development is that during the last three years more and more combined sessions take place, so that people with rheumatism, doctors and researchers (learn to) listen to and learn from each other!

Each EULAR congress IOYR tries to participate with a couple of board members to meet people and organisations to inform them about IOYR, but also to meet members and find new members.

ARI Conference and ILAR Congress , 27 - 30 August 2001

IOYR participated in the Arthritis and Rheumatism International (ARI) Conference and International League Against Rheumatism (ILAR) Congress in Edmonton, Canada, via Lucinda Blauw, in her role as member of the Manifesto Steering Group.

The ILAR Congress is set up in a same way as the EULAR Congresses, with the big difference that there are no social leagues in ILAR. In this ILAR Congress there was a co-operation between ILAR and ARI, so ARI could have a programme for their members during the congress with lectures and discussions about advocacy, research, partnerships, consumer education, sharing best practices and media relations.

During one of the meetings, the members of ARI elected a new board. They also voted to develop a global Manifesto.

Endorsement of the Bone and Joint Decade

IOYR endorsed the BJD - The Bone and Joint Decade - in February 2004. The BJD is an initiative involving everyone concerned with the care of people with bone and joint disorders.

The goal for the Bone and Joint Decade is to improve the health related quality of life for people with musculoskeletal disorders throughout the world. The BJD will do this through the following aims, to:

- reduce the social and financial cost of musculo-skeletal disorders to society
- improve prevention, diagnosis and treatment for all patients
- advance research on prevention and treatment
- empower patients to make decisions about their care

IOYR previously endorsed the BJD, via the PARE Manifesto, but in February 2004 we also did this as IOYR.

Market of Possibilities and PARE Manifesto National Representatives

On Friday 11 October 2002 IOYR participated in the Market of Possibilities in Königswinter, Germany, organised by the Deutsche Rheuma-Liga. During this day organisations presented projects and there were workshops to participate in. Also a big poster exhibition, where countries presented the work of their organisations, was placed in the hallway. Of course IOYR also took this opportunity to show some of the work IOYR does.

During the next day a meeting of PARE Manifesto National Representatives took place where Dorte Rønslér, chair of IOYR, outlined the activities of IOYR in a plenary session.

APOM - Arthritis Patients On the Move

The 'Arthritis Patients On the Move' Conference is a conference which has the goal to bring all Social Leagues together. During two day's representatives from social leagues all over the world, but especially Europe, meet each other and hear from each other what is going on in all the different countries and organisations. In 2001 the APOM took place in Warsaw, Poland, where Dorte Rønslér was involved in planning the conference.

In 2002 the APOM was held in Lisbon, Portugal. Presentations took place in a plenary session and workshops in small groups. Lucinda Blauw was one of the hosts of a workshop about motivating volunteers.

Board Members 2001-2004

Denmark	FNUG - ForeningeN af Unge med Gigt Representative: Dorte Rønsler (chair of IOYR)
Germany	Deutsche Rheuma Liga Bundesverband e.V. Representative: Kirsten Russ
Lithuania	Club "Artritas" Representative: Vilma Bandzeviciute
The Netherlands	Reumapatiëntenbond Representative: Lucinda Blauw
Norway	Barne- og ungdomsrevmatikergruppen, BURG Representatives: Georg Hodnefjell - 2001 - 2002 Linda Vøllestad Westby - 2002 - 2004
Switzerland	Rheumaliga Schweiz Representative: Laura Maria Margulies
United Kingdom	Arthritis Care Representatives: Catherine Gibb - 2001 - 2003 Marianne Scobie - 2003 - 2004

Find contact-details for the board at www.ioyr.org

What does it stand for?

ARI	Arthritis and Rheumatism International
BJD	Bone and Joint Decade
EULAR	European League Against Rheumatism
ILAR	International League of Associations for Rheumatology
IYC	International Youth Congress
PARE Manifesto	People with Arthritis/Rheumatism Europe Manifesto

Find links or/and information at www.ioyr.org

Members of IOYR as at 28. June

Belgium	Vlaamse Reumaliga vzw
Cyprus	Cyprus League against Rheumatism
Czech Republic	Revma Liga V České Republice (Revma Liga v ČR)
Denmark	FNUG - ForeningeN af Unge med Gigt
Estonia	Eesti Noorte Reumaliit
Finland	Finnish Rheumatism Association
France	Association Francaise de Lutte Anti-Rhumatismale (AFLAR)
Germany	Deutsche Rheuma Liga Bundesverband e.V.
Iceland	The Icelandic League against Rheumatism - Youth Group
Italy	ANMAR - Associazione Nazionale Malati Reumatici
Latvia	Latvian Rheumatic Association
Lithuania	Club "Artritas"
The Netherlands	Reumapatiëntenbond
Norway	Barne- og ungdomsrevmatikergruppen, BURG
Poland	Stowazy Szenie Mlodych Chorych
Portugal	ANDAI - Associação Nacional de Doentes com Artrites e outros Reumatismos da Infância
Slovakia	Youth section of the league against rheumatism
Slovenia	Rheuma Association of Slovenia
Sweden	Riksorganisationen Unga Reumatiker
Switzerland	Rheumaliga Schweiz
United Kingdom	Arthritis Care

Find more information about the members at www.ioyr.org