

# IOYR



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International Organisation of Youth with Rheumatism

[www.ioyr.org](http://www.ioyr.org)

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## Take action

### - take one of the big chances in your life!

*by Dorte Rønslér, chair of IOYR, [dorte@fnug.dk](mailto:dorte@fnug.dk)*

IOYR is also about making contact. We do it as individual young people with rheumatism, we do it between national organisations and we do it as the umbrella organisation.

IOYR is in contact with representatives from many organisations - organisations that are already members and organisations that we hope will be future members.

Making contact gives a lot of result for everybody involved. During these last months we have welcomed to 3 new members: Portugal, Estonia and Iceland. We are very happy to have more members from the south, east and north of Europe.

Right now IOYR has only European organisations as members. But we are in contact with young people with rheumatism and other interested people from all over the World. We are very much looking forward to welcoming our first non-European member. Will that be you? Will you come and make contact as well?

#### **Take Action...**

...take one of the big chances in your life. You will never regret it. Earlier IYCs – International Youth Congresses - have changed so many people's lives in ways that are unbelievable. You might not believe this unless you try it or see it yourself. Will this summer's IYC change your life?

In less than 4 months some of us will meet in Switzerland. I hope that you will join us. The final announcement for IYC has just been sent out and now you can sign up for the congress.

IYC is also about making contact. It is about getting inspiration for your national work. It is about having fun. It is about meeting old friends and making new ones. It is about sharing ideas and information with other organisations. It's about developing confidence and life skills. Again, join us! You won't regret it!

You can find interesting articles about earlier IYC's at [www.ioyr.org](http://www.ioyr.org). Here you can also download the final announcement for IYC 2004 if you haven't got it already.

**More information about IYC 2004?**  
Please contact [icy2004@ioyr.org](mailto:icy2004@ioyr.org)

Even though it seems far away we can tell you already that the host country for the next IYC in 2007 has been identified. The IOYR member organisation Unga Reumatiker in Sweden has offered to host this event. Of course the IOYR board has gratefully accepted this.

#### **Take another chance**

At the IYC 2004 in Switzerland the general assembly will take place and there will be election for the IOYR board.

Personally I will "retire" after 9 years in the IOYR board. With so many great years in the

bag I think I can truly say that you should go for election.

Of course it is hard work, but it is also a fun experience. Personally you gain a lot from being involved in an organisation like IOYR and the experiences you get will be of great benefit for your national work. Please contact your national organisation and talk with them about the nomination for the IOYR board.

You are very welcome to contact the other board members or myself, if you want to hear more about our work in IOYR. Find contact-details at [www.ioyr.org](http://www.ioyr.org).

### **The PARE Manifesto**

As you probably know IOYR has been involved in the work with the PARE Manifesto (People with Arthritis / Rheumatism in Europe Manifesto). At the end of 2003 the working-period of the PARE Manifesto Steering Group ended and new election had to take place. At that time IOYR decided to stop as a member of the Steering Group.

We are still supporting PARE Manifesto more than 100% and are involved in different projects with the PARE Manifesto. You can read more about the PARE Manifesto at [www.paremanifesto.org](http://www.paremanifesto.org).

### **Endorse Bone and Joint Decade**

In February 2004 IOYR endorsed the BJD - The Bone and Joint Decade. The BJD is an initiative involving everyone concerned with the care of 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 musculoskeletal 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

We earlier endorsed the BJD through the PARE Manifesto, but now we have also done this independently as IOYR.

You can find more information about BJD at [www.boneandjointdecade.org](http://www.boneandjointdecade.org).

If your organisation also wants to endorse the BJD you can contact The Bone and Joint Decade Secretariat at [bjd@ort.lu.se](mailto:bjd@ort.lu.se).

### **EULAR**

EULAR stands for the European League Against Rheumatism. As you might know every year a EULAR congress takes place in one of the capitals or big cities in Europe. The congress is the opportunity for everybody who has anything to do with rheumatism to meet and learn. During the congress you can go to lectures in the scientific, social leagues or allied health professionals programme.

The social leagues programme is especially for representatives from organisations of people with rheumatism. Luckily there is a tendency to have combined sessions, so people with arthritis and doctors listen to and learn from each other.

The last congress was in Lisbon, Portugal in June 2003. One of the 'new' issues there was that people with arthritis are more and more involved in the scientific research and that the researchers have learned that pain and also fatigue play a far bigger role in a patient's life than they thought. Already measurement techniques concerning pain have been developed, so when new medicines are tested, the research will also tell us if it actually works in reducing the pain.

### **Are you going to Berlin?**

Members of IOYR will also go to EULAR 2004 that is taking place in Berlin the 10. – 13. June. Are you going? Wanna meet other members of IOYR there? Then send a mail to [ioyr@ioyr.org](mailto:ioyr@ioyr.org). At the 1. June we will send a list with email-addresses to everybody we heard from.

## Fighting alone

by *Elpidas Pitta, Cyprus*  
*cyplar@cytanet.com.cy,*

I was only 13 years old when I fell ill. It was very hard for me to believe that. My life had changed all of a sudden I was a normal girl and I had many friends.

From that moment on, I visited many doctors. I took many medicines, I stayed a few days in the hospital but I was still having symptoms of many illnesses and syndromes.

I lost all my friends and I don't know why!!! Everyone looked at me in a strange way and I hated that. Their behaviour was very odd. For four years my life was boring. I had difficulty in walking. I was shy about that and for myself.

I was alone. I was jealous of everybody of my age. Every weekend I stayed home and I avoided going out with my friend. I was afraid. I knew that everybody saw me as an ill girl not as a normal one.

It was very difficult to accept the fact that everybody was looking me in curiosity. I had to live this torture for five years until my doctor diagnosed that, I had "Antiphospholipid Syndrome".

**Remember to sign up for the  
IOYR news-mail at [www.ioyr.org](http://www.ioyr.org)**

I must say I was shocked, I talked to myself honestly and I took some important decisions for my life.

I accept my illness and I discover more positive ways to live my life. Now I am a student at the University of Cyprus and I am proud of myself.

Above all I feel active and I have strongly learned to live with the pain and to organise my daily life.

I must say my illness makes my moral resources stronger!!

## International youth exchange - a medium to empower yourself

by *Liisi Toom, Estonia, liisitoom@hotmail.com*

There are many ways to make oneself feel good, to get adrenalin, to learn new things, to get to know new people. It's all about choice. One way is to organize/participate in an international youth exchange, under the European YOUTH programme, action 1.

This programme has been in action for almost a decade and given a possibility for many youngsters around Europe to travel, to learn and to have fun with people similar to them and yet so different.

### So what is it really about?

International youth exchange is a 6-21 days-long gathering of youngsters from 2 or more countries in order to discuss debate and share thoughts about some specific issue. At the same time you can learn about the ways of different cultures and traditions, the way they think, act and express themselves. Cultural dimension is a big part of every exchange, in fact, this is one of the reasons these kind of events take place – to find out that there are different, which does not mean "bad", ways to see one thing.

YOUTH programme also supports people with any kind of disability and encourages them to take action.

### This is where we come in...

Knowing all that I mentioned above, a newly established **Estonian Youth Rheumatism Association** has come up with an idea to organize their first **international youth exchange**.

Therefore we are looking for partners who would like to take part in the exciting experience of a youth exchange. First, bit information about our organisation and our ideas for the exchange.

Estonian Youth Rheumatism Association (EYRA) was established in the beginning of 2003 by group of very active young people aged 17-35. Not all the members of the organisation have rheumatism; there are also

people who support us, morally and with their knowledge. The reason we come together is to enjoy ourselves and do something fun but more importantly to find all sorts of ways to cope with our illness and share experience and knowledge on medication, physiotherapy, alternative medicine, etc, etc, etc. We also intend to work more tightly with same type of organisations around the world to learn from them. We already have taken part of International Youth Congresses for Youth with Rheumatism and that is where we got the idea to have our own special organisation.

### **What do we do?**

We get together both officially and non-officially. We started with one-day-seminar to find out if there is a base for establishing the organisation. Since the outcome of that seminar was so positive, we met again for a winter camp, where we talked about the aims and practical things in organisational work and we had a lecture about nature and how it can strengthen our health. On top of seminars we meet as friends to share our worries and joys. All our meetings are based on an open environment, meaning we come together to relax, knowing that others accept you and your disabilities.

**Chat at [www.ioyr.org](http://www.ioyr.org):  
22. April 19.00  
6. May 19.30  
17. June 18.00  
11. July 19.00  
All times are UK-times**

### The reason behind the youth exchange:

Some of the members of the organisation have taken part in youth exchanges and seen the effect it leaves in participants. Therefore we thought it might be a good starting project for us, too. Since we are interested in making contacts while promoting healthier life, tolerance towards differences and intercultural learning, so we could do all that in a youth exchange!

### **Now more facts about the exchange:**

*Target group:* Age - 18-35. Mixed groups (F/M, people with and without physical disability)

*Countries:* Basically anyone who would be interested.

*Number of participants:* Depends on the number of countries.

*Duration:* 8 days + 2 days for travelling

*Place:* To be decided

### **Our aims:**

- Integration between socially labelled as “normal” and “un-normal”
- To raise awareness about the disease (rheumatism)
- To find out what people consider as “disability”, to explore the meaning behind it.
- To compare how different countries see disability
- We all are different in some way and sometimes it is really difficult to see that different is GOOD!
- No matter the differences we all want to have FUN and enjoy ourselves and be welcomed by others
- To stimulate awareness of other cultures and introduce new perspectives

### **What we could do, some ideas for activities:**

- Interview people on the streets about disability issue and on differences in general
- Sport activities as a mean for healthier life
- Workshops on youth taking action (why they do it, how they do it and do they think it is worthwhile- does it make a difference)
- Discussions, interactive exhibitions, confrontation games

As you may have noticed, there are many things yet to be decided and that’s where we need YOU! We want to organize this with partners so it would be even more interesting and fulfilling! And I know that there are so many other aspects to add, to discuss!

We are looking forward to your suggestions and reflection on the idea. As we all saw in the IYC 2001 in Norway, we have the POWER in ourselves to make a difference, not by changing others but by changing ourselves and the way we see ourselves! This kind of exchange would be a good possibility to empower ourselves again and again.

## **A normal student life - study with rheumatism**

*by Linda V. Westby, Norway*

My name is Linda and I am 24 years old. I have just started on my master degree in social anthropology and I am moving to Spain for 6 months this spring to do reach for my thesis. In this article I am going to tell some of the challenge I have experienced as a student with rheumatism. But I will try to show you how the rheumatism has made me stronger and tougher in my everyday life.

I got rheumatism when I was 13 years old. It turned my life up side down, from being an active football player to being a sick little girl who spent 14 months in hospital within the next 2 and a half years. An experience like this turns your life into a different direction. Suddenly I couldn't play football anymore, I could barely walk. I was nearly 14 years old and suppose to be a rebellious teenager, but instead I was growing up too fast, taking responsibility for myself. I found myself in a new world with a body that didn't work. I couldn't do the things I used to do. I managed to finish secondary school somehow and I was going to continue onto high school. I was determined to study at the same school that my friends were. Even though it meant getting up at 5 o'clock every morning. Then taking the bus for 20 minutes, then the train for 35 minutes and then a walk of 2 kilometres. This was my great big plan but to my big surprise the doctors at the hospital didn't allow me to do this. I was furious and desperate. Then the doctors decided with my parents that a boarding school would be the best thing for me. I of course didn't agree. And as none of my friends were going there I did get very upset. But now I can see that this was the best solution and that I never ever could manage my own school choice.

Even though I didn't want to go to the boarding school in the first place it turned out very well. And I met the love of my life and now my husband, Hans Jacob.

When I now look back it was three great years but also three difficult years. I was very inse-

cure of myself and the disease. I wanted to be like everybody else. I wanted to walk normally without limping. I wanted to be able to do what all my friends did. But I couldn't. It was here I really learnt how to be more stubborn and strong and to do things my own way and in my own time.

The second slap in my face was when I was going to university. My childhood dream was to become a nurse. But then there were people telling me that this was not an alternative for me. I would never manage this profession. Again there were people telling and deciding what I couldn't do. But luckily I did listen to the career adviser and I took her advice to find another profession. Their advice was to become a teacher and I agreed that this would be a more sensible solution.

Then it was off to University and I was going to study several subjects at the University before I became a teacher. Life at University was quite hard in the beginning and I found out quickly that I couldn't manage to study at the same speed as my fellow students did. I needed more time both to study and to look after my health. I needed to be a student who could take classes and subject in my own speed and time. It has been perfect! I have used more time than my fellow students but this has also been an advantage. I have had the opportunity to study longer before our exams. And it sometimes has led to a deeper understanding of the subject than normal students can get, because they have a time limit. It has also giving me the opportunity to do activities after a day at University!

After a few years at university I found out that I didn't want to become a teacher, it wouldn't suit me. I had found my subject and my profession and it is social anthropology. So that's why I am now doing a master degree in social anthropology.

I would say that my road as a student has been "bumpy". There have been some ups and some downs. It isn't always easy to live with a rheumatic disease that sometimes decides what you can do and what you can not do.

One way I have found that helps me deal with the rheumatism is to help other people who are in the same situation that I was / am in. I find great pleasure and strength to do voluntary work for the child and youth rheumatic organisation in Norway, BURG.

To have the opportunity to meet other people who know what you are going through. To be able to share and to get advice from someone who is in the same situation has been fantastic. To know there are people who have the same difficulties and have found ways of coping and sharing them has been amazing. I have got great advice that has helped me a lot through University, like what kind of rights I have as a disabled person. I would like to take this opportunity and invite you all to do voluntary

work for your local or national or even international organisations of rheumatism.

So in what way do I think that the rheumatism has effected me? If I look back on the last 10 years of my life I can see that the disease has affected me in a positive way. Yes there has been a lot of aching and tears. But I also think there has been a lot of joy and happiness. I am a much stronger and tougher girl now. I have learned that I could do nearly anything if I do it in my own way and time. I have learned to be less prejudiced about people. Every human being deserves to be as they are, whatever they look like, whatever affects them. I think it is very important that we focus also on the positive aspects that rheumatism can give us.

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## Next newsletter:

You will receive the next newsletter in summer 2004. You are more than welcome to write an article for the newsletter. Please mail it to [ioyr@ioyr.org](mailto:ioyr@ioyr.org). **Deadline is 1. June.**

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## The Aims of the IOYR

The main aims of IOYR are to:

- exchange information and experiences and to learn from each other.
  - encourage the development of self-help in each of the countries.
  - empower young people with rheumatism and enable us to get our voices heard.
  - raise public and professional awareness of the situation of young people with rheumatism and change attitudes.
  - exert policy influence, both internationally and nationally.
  - develop links between medical professionals and young people with rheumatism and increase understanding.
  - stimulate intensive research of the experiences of young people with rheumatism.
  - co-operate with other organisations with similar interests, as appropriate
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## More information about IOYR

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