

# IOYR



---

International Organisation of Youth with Rheumatism

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

Newsletter no. 14

July 2004

---

## Do something

### - do not wait for somebody else to take action...

*by Dorte Rønsler, chair of IOYR,  
dorte@ronsler.dk*

During the last 9 years - since I was elected to the first board in IOYR in 1995 - I have told people many times about IOYR and answered questions about the organisation.

Try to explain to yourself what IOYR is. Or even better, try to explain it to somebody that doesn't even know about it.

If you look behind all the fine words with international, organisation, structure, meetings, congresses, learning, being inspired, getting motivation, sharing experiences etc. then you find the members. - They are very important for IOYR - since without members there is no IOYR...

The members of IOYR are organisations – and the organisations are people. There has to be people who want to work to make a difference - and don't forget that they must be supported by their organisation to do so.

Without people like that, organisations and groups on local, regional, national and even international levels can't work.

You don't have to be in the front of an organisation or group to make it work and develop. Writing an article for the newsletter or magazine, responding when you are asked for information or the fee, participating in the events and meetings of the organisation, tell-

ing other people in the organisation that they are doing a great job – these and many more are all things that are important for an organisation to run.

Don't wait to get involved. If you want to be where things are happening you can join different kind of working groups and boards. Many organisations are hungry for young people to get involved.

I don't want to miss this opportunity to remind the "older" people in the organisation that the youth are not only people that can work, their work and ideas also have to be supported.

No matter what kind of work you are doing or want to do, when you first step in to this kind of work you must remember that people count on you.

Not much destroys your own work more than not being able to trust the promises people give you. So it is important that you don't promise more to yourself and to other people that you can give. Be honest if you cannot keep deadlines, as that can happen for everybody, but it is very useful to let the people you work with know. That also shows that you have respect for and like their work.

When you start to work in an organisation, then go step by step, find yourself in the work. Then you will still enjoy it, and the work will not overwhelm you.

### **Thanks a lot from me...**

This is my last article as chair of IOYR. In a few days the General Assembly will take place and I will "retire" from the board of IOYR.

I want to use this opportunity to thank everybody I have been working with and been in contact with since I began in the international work of young people with rheumatism.

Also from me come thanks to the board members who won't stay in the board after the General Assembly. And a very warm welcome and very good luck to the new IOYR board. You as board members are lucky: You have a great chance to change the world - maybe just a bit, but an important bit - for many young people with rheumatism.

But you cannot do it without the members of IOYR. So dear board and dear members - organisations and the members of the organisations - do not forget to support each other. Remember that somebody is doing hard work that you can support in many ways. Stay in contact with each other, in that way it is much easier to support each other - both ways.

And everybody, remember: *Do something - don't wait for somebody else to take action...*

---

### **In Memory**

It was with great sorrow that at the end of May we received the message that Mattias Svensson from Sweden had died, aged 29 years old.

Even though we knew Mattias was seriously ill, everything seemed unreal when we got the message to say he had died.

Mattias was the international youth contact person from Sweden and he has played an active and key part in IOYR activities over many years. He was involved in the Web Project group and the planning group for IYC2007, which is planned to be held in Sweden.

His energy, enthusiasm and sense of fun mean we all have many happy memories of Mattias and he will be sadly missed by us all.

We honour his memory and will never forget him.

*Dorte Rønslær*  
Chair of IOYR

*In the obituary about Mattias there was a very beautiful poem. We have found the English version and this is copied here:*

### **What is Death?**

*by Henry Scott Holland 1847-1918, Canon of St. Paul's Cathedral*

Death is nothing at all.  
I have only slipped away into the next room.  
I am I and you are you.  
Whatever we were to each other,  
that we still are.

Call me by my old familiar name.  
Speak to me in the easy way  
which you always used.  
Put no difference in your tone.  
Wear no forced air of solemnity or sorrow.

Laugh as we always laughed  
at the little jokes we enjoyed together.  
Play, smile, think of me, pray for me.  
Let my name be ever the household word  
that it always was.  
Let it be spoken without affect,  
without the trace of a shadow on it.

Life means all that it ever meant.  
It is the same that it ever was.  
There is absolutely unbroken continuity.  
Why should I be out of mind  
because I am out of sight?

I am waiting for you,  
for an interval,  
somewhere very near,  
just around the corner.

All is well.

---

## What is happening in Portugal?

by Sandra Canadelo, ANDAI, Portugal,  
andai@net.sapo.pt

Dear friends from IOYR, First of all, we would like to express our happiness for having been accepted in your organisation and our eagerness to participate in your activities. We can start by introducing our association to you, by letting you know of some facts about us and about the situation of young people with arthritis in Portugal.

The National Association of Patients with Arthritis and other Childhood and Juvenile Rheumatism (ANDAI) was founded on 31 December 1997 and has now a similar statute to that of an NGO. It is the only association in Portugal which concerns children and young people with this type of diseases. Our objectives are to:

- create awareness in the general public to the fact that these diseases also exist in children and young people;
- facilitate the exchange of ideas, and to encourage solidarity between members;
- give information to patients and parents, and to the public in general;
- create awareness about the disease in teachers and in other people working in the education sector;
- create awareness in GPs about the existence of these diseases;
- obtain greater help from the government as to access to medication, prostheses, physiotherapy, etc.
- write and hand out materials about the disease and existent treatments

What we would like would be to share our experience, difficulties and small victories with you and to learn from you. We believe that only commitment and a good amount of training can lead us in the correct path. We hope we can start sharing experiences soon!

Warm regards ANDAI

## EYRA - New Beginning

by Ingrid Põldmaa, EYRA, Estonia,  
inxpolda@hotmail.com

It all started three years ago in Norway...

One day my doctor asked me how my English was. It seemed a very strange question to me - why? The next thing that I remember is the youth congress in Norway and a new friend Triin.

But one more big surprise - another youth organisation from Estonia - awaited us in Norway. Who were they? Why had we not heard about them? Soon we learned that the other organisation was mostly for children and their families and they came from Tartu, the second biggest city in Estonia. We were representing our mother organisation Estonian Rheumatism Association in Norway.

"Breaking barriers" - the theme for the International Youth Congress 2001, it is hard to find better words to describe my feelings. It was the first time for me to meet young people with the same fears, problems and hopes. I broke my barriers and I have to thank all who were there. Even after three years the feelings have remained the same.

I could say that without the IYC2001 we would not have the EYRA today. At the IYC2001, we all wanted to join the IOYR, but we could not do it. So we decided to establish a new organisation for youth with rheumatism in Estonia. In the same year, we started slowly, step by step.

It was good to have our small team, but how could we find a way to reach other young people who have rheumatism? We produced booklets and gave them to our doctors, we talked with our friends and so the word started to spread.

It was the right time for me to get active. During the first year after I was diagnosed, I stayed at home and started to build a wall, separating me from the world. I just wanted to be left alone. My schoolmates helped me a lot

and instead of retreating to solitude, I became more open. At the IYC, I met other people and realized that they had similar problems.

I was very happy when I got a call from my doctor: she had given my telephone number to a girl, who had been recently diagnosed and was desperate. I think that we helped each other a lot and we are still friends.

One by one, so we started. Our organization is not big, but we are friends and have good contacts with other organisations. The best way to bring together new people is by training, through the Internet, and personal contacts.

For almost a year we met unofficially. We finally started preparations for the official registration of our organisation in June 2002. It took almost a year, until July 2003, before we acquired a legal status. The year was not easy for us and we had to face difficulties - health problems, shortage of money, limited right of say...

We do not have paid staff, only volunteers, and this makes things somewhat complicated.

Since July 2003 we have done a lot. We have organised different training sessions, participated in international youth exchange programmes, we serve as the Pare Manifesto national representative and Eurodesk support centre in Estonia. I am also a link to our umbrella organisation and we have often given each other a friendly hand.

We have many plans for the future and we hope that cooperation with the IOYR will be mutually beneficial.

**Find contact-details to the members of IOYR at [www.ioyr.org](http://www.ioyr.org).**

## **26 record breaking Danes**

*by James Rickmann, FNUG, [james@fnug.dk](mailto:james@fnug.dk)*

The splendid Danish competitive spirit has once more proven itself when 26 teenagers with arthritis in the beginning of November

2003 spend a brief moment simultaneously in one single car.

The determination was not to be fooled with when they broke the record from 2001 when 23 teenagers tried the same stunt with success.

The Danish teenagers dare others throughout Europe or the rest of the world to try to break this last record. The car is a Chrysler Grand Voyager so it should be possible to break this current standing record.

The Danish organizer of the record can be located by e-mail [james@fnug.dk](mailto:james@fnug.dk) for further details - or if you want to challenge the Danes.

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

## **The importance of being motivated as a volunteer**

- ideas and practice from the Netherlands Youth Group (2002)

*by Juul van der Veen, The Netherlands Rheumatism League*

The "Arthritis patients on the move (APOM)" congress is a yearly world wide conference of Arthritis and Rheumatism Patients Societies. For 6 years it has been organised by the Social Leagues of EULAR in collaboration with the pharmaceutical company MSD. In 2002 it took place in Lisbon, Portugal, and "Motivating your volunteers" was the theme of one session. I prepared a presentation for that session together with Lucinda Blauw, entitled: "The Importance of being motivated as a volunteer: Ideas and practice from a youth group".

Lucinda asked me to write a summary of the results for the IOYR-newsletter, since finding and keeping volunteers in rheumatism organisations is a current problem, also at international levels. These results are from the year 2002.

## **The Netherlands Rheumatism League**

The Netherlands Rheumatism League (NRL) is an umbrella organisation of 106 local rheu-

matism organisations and 14 youth groups. Major tasks of both NRL and local organisations are providing information and support and promoting common interest. The NRL operates mainly on a national level and it works with several committees including the youth committee.

### Reasons - being involved in voluntary work

What we see is that a small group of people do voluntary work for a long period of time. It is difficult to get new young volunteers. So, if a few persons decide to stop doing voluntary work, it will be a serious threat for the continuity of the youth committee.

To get new volunteers we put advertisements in newsletters and the monthly magazine of the NRL. We composed information packages

for potential volunteers and provided this during our activities. We mentioned during meetings that we were looking for new volunteers and we also asked people directly.

To be honest, we were not very successful.

Therefore, we investigated the reasons for starting with, staying involved in, and stopping with voluntary work among 10 current volunteers and 5 former volunteers of the youth committee of the NRL.

The reasons to start with and stay involved in voluntary work are almost the same. We divided them in individual goals, goals that can be reached within the organisation and goals outside the organisation (Table).

*Reasons for being involved in voluntary work*

Individual	Within organisation	Outside organisation
<ul style="list-style-type: none"> <li>• social contacts</li> <li>• being understood</li> <li>• learning</li> <li>• development of skills</li> <li>• self esteem</li> <li>• satisfaction</li> <li>• working experience</li> </ul>	<ul style="list-style-type: none"> <li>• asked by others</li> <li>• work within a nice team</li> <li>• motivate each other</li> <li>• attention for young people within the organisation</li> </ul>	<ul style="list-style-type: none"> <li>• no one else does it</li> <li>• mean something for others</li> <li>• young people with rheumatism exist!</li> </ul>

“Social contact” was an important individual goal; getting to know new people, have a nice time together and feel understood. “Learning” can be in several ways; keep informed of new development in the land of rheumatism or development of skills like organising and communicating. “Asked by others” was an often mentioned reason for participating in voluntary work.

### Reasons to stop with voluntary work

Below you find the most important reasons to stop with voluntary work.

- getting too old (>35-40 years old)
- It is too much:
  - worsening of health condition
  - change of family situation
  - accepting a paid job

- loss of joy, challenge or support
- can't go along with the changes in the organisation
- not feeling appreciated anymore

### Recommendations - motivating volunteers

We concluded that for keeping young volunteers with rheumatism in the organisation, it is important to make it possible that the volunteers can easily, temporary (partly) withdraw from the work considering the change in health situation. With regard to the meetings it is important that flexible meeting hours are possible (for example during the weekend) and that time for socialising is included and that enough support is provided. With regard to the learning goals of individuals it would be nice if organisations could meet this goal, for

example to provide courses. Both parties involved, volunteers and NRL, have to work on a good relationship. In this, the volunteer needs to feel appreciated in their work.

In getting new volunteers, we advise rheumatism leagues to emphasise the goals that can be reached that were result of this study.

### **Discussion**

In the discussion after the presentation it was remarkable to notice that many organisations did not use the name “volunteers”, because of the idea that if you are able to do voluntary work, you can also have a paid job. Those countries speak about “active members” instead of volunteers. But in every country it seemed that getting and keeping volunteers is an actual problem.

---

## **Next newsletter:**

You will receive the next newsletter in autumn 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 20. August.**

---

## **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

---

## **More information about IOYR**

c/o FNUG • P.P. Ørums Gade 11, bygn. 10 • 8000 Århus C • Denmark  
Phone + 45 86 11 85 21 • Fax + 45 86 11 73 88 • [www.ioyr.org](http://www.ioyr.org) • [ioyr@ioyr.org](mailto:ioyr@ioyr.org)

---