

IOYR



International Organisation of Youth With Rheumatism

www.ioyr.org

Newsletter Number 22

August 2008

Dear friends!

The last newsletter has recently been posted on the website. No reason to relax, especially because Germany has to say goodbye. We are glad to welcome Sweden, which will take over the creative work at the newsletter for the following year.

Beside this we would like to start a discussion with you all. Therefore please read carefully the article "EULAR, PARE, AAA – some explanations" which begins below.

And last, but not least, in the last newsletter we asked for articles, which fit the topic "rheumatism here and everywhere". Don't miss the article at the end of this newsletter.

And now....enjoy!

Germany

EULAR, PARE, AAA ... some explanations.

EULAR = European League Against Rheumatism

The European League Against Rheumatism (EULAR) is an organisation which represents patients, health professionals and scientific societies of rheumatology of all the European nations. EULAR organises activities in areas of research, patient care and education and is built-on a structure of committees and managerial bodies.

IOYR



The committees and managerial bodies are: The *General Assembly*, the *Executive Committee*, the *8 Standing Committees* (including: Standing Committee for **PARE**, People with Arthritis/Rheumatism in Europe, read more about the individual committees on www.eular.com) and the *3 Programme Committees*.

The General Assembly is the highest authority of EULAR and is composed of the delegates of the member organisations and the members of the EULAR Executive Committee. The Executive Committee has to reflect the development of EULAR and its activities. The Standing Committees define, manage and perform the various activities of EULAR. The Programme Committees are responsible for the scientific, allied health professionals' and social leagues' programmes at the Annual European Congress.

EULAR Congress

The Annual European Congress of Rheumatology takes place once a year – mostly around June – in one of the big European cities. Four days long patients, health professionals and scientists meet to exchange experiences, opinions and data. It is divided into a Scientific Programme, PARE Programme and Programme of the Allied Health Professionals.

PARE = People with Arthritis/Rheumatism in Europe

Till 2007 PARE was known as "the campaigning arm of the EULAR Social leagues". Since 2008 it is fully integrated into EULAR and is one of the Standing Committees. PARE is composed of delegates of national organisations of people with arthritis/rheumatism across Europe and meets twice a year on the occasion of the EULAR congress and the EULAR Autumn Conference. The aim of PARE is to improve the quality of life for the more than 100 million people in Europe living with arthritis and other musculoskeletal conditions and empower them to lead full and independent lives. To make this possible PARE organises a lot of different activities and programmes: *EULAR educational visit programme*, *programme at the EULAR Congress* and the annual *Autumn Conference* of people with arthritis/rheumatism.

I O Y R



APOM = Arthritis People on the Move: Autumn Conference of EULAR

APOM is originally called "Arthritis People on the Move (APOM)" and is well known as the Worldwide Conference of Arthritis and Rheumatism Patient Societies. From 2008 on it will be the official **Autumn Conference of EULAR**. As it was before it will also in the future take place once every year and is organised by the EULAR Standing Committee of PARE. So you can conclude that APOM is the annual meeting of people with arthritis/rheumatism in Europe and its aim is to educate and to offer specialised training and networking.

In 2008 the conference will be held from the 7th – 9th of November in Budapest, Hungary. The working theme for the conference in 2008 is around *Work and Rehabilitation* but will also include sessions about epidemiology/standards of care and family life.

AAA = Alliance Against Arthritis

The Alliance Against Arthritis is the political arm of EULAR and brings together the Scientific Committee of EULAR, the Standing Committee for PARE and the Allied Health Professionals, in order to improve the prospects for people with rheumatic diseases and reducing the burden of these conditions. Therefore AAA meets every year and fights for stronger disability legislation, greater funding for research into arthritis/rheumatism and improved access to treatments.

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IOYR



World Arthritis Day 2008 – Think Positive!

World Arthritis Day has been celebrated since 1996. Each year a specific theme is featured to highlight relevant topics for people with arthritis e.g. *Exercise and arthritis 2006, Small things matter 2007*. The activities have been receiving support from industry in order to develop material (e.g. agency support, brochures, posters, press release template, online survey) for the national organisations to be translated and adapted for their national use.

Since 2003 there has been a website featuring national events organised by the national member organisations as well as activities organised on European level. The EULAR Standing Committee of Standing Committee of PARE leads the activities officially. Read more about World Arthritis Day on the website (www.worldarthritisday.org)

World Arthritis Day Project 2008

This year the theme is 'Think Positive'. This theme has been chosen to show that the challenges associated with arthritis/rheumatism can also be emotional, but that there are a number of positive things everyone can do to feel better and get more from life. Projects for 2008 include:

World Arthritis Day Online Survey It only takes a few minutes to answer the questions. The outcome will be highlighted on 12 October.

World Arthritis Day Leaflet It is a leaflet featuring people with arthritis, their story and tips and hints to overcome difficult periods in their life (according to the theme Think Positive).

World Arthritis Day Video Diaries This project was successfully launched in 2007 and carried forward in 2008. This year Diarists from a number of countries across Europe are creating short films using special camcorders to 'show and tell' their physical and emotional challenges, how they overcome these and what helps them to maintain a positive attitude.

IOYR



IOYR = International Organisation of Youth with Rheumatism

After ten years of planning IOYR was founded in 1995. The idea that young people with arthritis should work together on an international level was originally born in the Dutch League of Associations of Patients with Rheumatic Disorders. The aim of IOYR was and still is to exchange experiences and information between young people with rheumatism across Europe.

More about the history and relationships of IOYR will follow in one of the next newsletters!

IYC = International Youth Congress

The IYC is the meeting point of young people with arthritis/rheumatism and takes place every 3 or 4 years in one European country. One week long young people with arthritis/rheumatism, whose mother organisations are members of IOYR, can join these event. The congresses are organised with different topics all around the disease and its consequences.

1992 – England, UK; 1996 – Kalundborg, Denmark; 1998 - Berlin, Germany; 2001 – Haraldvangen, Norway; 2004 – Gwatt-Zentrum, Switzerland; 2007 - Ängelholm, Sweden and..... 2011 – Belgium (planned!)

Germany

Crossing borders with arthritis

“Without borders – Being young with rheumatism in Germany and in neighbouring countries” was the motto of our meeting of young people with arthritis in Cologne, Germany in October 2007. Every second year we - young people with arthritis from different Regions in Germany - meet for an exchange of experiences and joint work. In 2007 we invited our neighbouring countries to this event and guests from the Netherlands and Switzerland were able to follow this invitation.

The meeting focused on three aspects of living with arthritis as a young person: One subject was which state support is given to people with arthritis who continue to work in the different countries. A second theme was

IOYR



information about support for young people with arthritis in education and studies. Our aim was to figure out the differences and the similarities in these countries. Furthermore Dr. Frauke Förger showed for the third subject which issues regarding medication should be taken into consideration by young people with arthritis who are planning to have children. After lectures on the three topics, talks and workshops were the basis for a lively exchange of experiences and then we had a lot of room to give our fancy full scope and to develop new ideas for working together across the borders.

During one of the workshops, which was called “vision”-workshop, we outlined again and again that there is a common wish to work against the common opinion that arthritis is a condition of older people. Another discussion point was how to get other young people to join the organisations. It was interesting to find out, that every country has problems to motivate young people with arthritis to engage themselves.

By the end of our meeting we were not able to solve these problems, but the meeting was a full success, because we were able to create ideas, make contacts and have visions for the future.

We are looking forward to further cooperation between young people with arthritis across our borders.

Time to say goodbye!

One year is over and we hand over our creative work on the newsletter. When the decision was taken that we would be responsible for the newsletter from 2007 to 2008 we were highly motivated and full of ideas. Reality showed us that with our daily work, private live and work for our mother organisation we were not able to make all the ideas come true. However we managed to publish two newsletters and we hope that they included interesting topics for everyone. It was a pleasure to create the articles and from time to time it was really hard work to motivate editors (especially ourselves) to write articles.

To make a long story short: Thanks for your attention and feedback and **WELCOME with us together, Sweden**, which will take over the newsletter from 2008 to 2009.

Many greetings from Germany and goodbye, yours

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