2013 EULAR Autumn Conference objectives

1. To inspire, educate and empower delegates and their national organisations to develop and execute campaigns around the topic of healthy ageing through:
   - providing expert key note speakers;
   - sharing best practices;
   - developing practical materials that can be adapted for national activities and meet national needs.

2. To make delegates and their national organisations aware and receptive to the benefits of regional, European and international collaboration by:
   - clarifying and promoting the activities and relevance of EULAR;
   - demonstrating how EULAR can support the interests of its member organisations on a national and local level;
   - giving insight to the “Nordic welfare model” and achievement of Nordic cooperation, The Nordic Reuma Council.

3. To inform and inspire participants from Gigtarfélag Iceland about EULAR activities and empower them by participating at the conference and organising a short meeting after the conference with all the Icelandic delegates.

4. To increase the awareness and understanding of rheumatic and musculoskeletal diseases as a major health issue in Iceland as well as in Europe by conducting media outreach activities and inviting key stakeholders to attend the opening, including inviting the Minister of Welfare to give the opening speech.
Thursday, 14th November:

Delegates arriving on Thursday afternoon were invited to participate in a quick-fire ‘speed networking’ ice breaker, similar in format to speed dating. Delegates were asked to provide some key facts about themselves prior to the conference. Sitting opposite each other, delegates had three minutes to find out as much as possible about each other and which facts matched which person, before moving on to a new partner. The networking provided a lively atmosphere to the conference and was much liked and highly rated by the delegates.

“I think it was a good idea as I got to know people whom I never talked to before. It makes you feel that you belong to the group and are welcomed.”

Friday, 15th November:

Marios Kouloumas, Vice-President, EULAR, representing PARE, opened the proceedings and moderated the Friday plenary session. Prof. Maurizio Cutolo, President of EULAR, presented the opening remarks on behalf of EULAR.

Dóra Ingvadóttir, President of Gigtarfélag Iceland, welcomed the delegates on behalf of the Icelandic League Against Rheumatism. Madame Vigdis Finnbogadóttir, Former President of Iceland, addressed the delegates and provided a brief history of Iceland and Icelandic culture, including sagas where rheumatic diseases are mentioned. Vigdis was Europe’s first female president and the world’s first democratically elected female head of state.

Anna Lilja Gunnarsdóttir, Permanent Secretary, Icelandic Ministry of Welfare addressed the delegates on behalf of the Ministry of Welfare. Stefán Ólafsson, Professor of Sociology, University of Iceland, gave a presentation on the Nordic welfare model and healthy ageing in Iceland.
Marios Kouloumas conducted an informal and very informative interview with Maurizio Cutolo on the topic of healthy ageing. Additionally, Professor Cutolo provided a short handout with Six Hot Topics in Rheumatology.

Dr Frane Grubišić, President, Croatian League Against Rheumatism presented a clinician’s perspective of healthy ageing with an RMD, which was followed by an interactive session.

“\textit{I especially liked the lecture by the Professor of the University of Iceland. Very informative.}”

Neil Betteridge, EULAR Liaison Officer, Public Affairs, and Sören Haar, leader, EULAR Brussels Office facilitated a workshop on politics and healthy ageing in Europe which commenced with a UK case study with examples of what is being done at a national level to accommodate healthy ageing. The aim of the workshop was to develop outlines of manageable projects that would benefit people with RMDs. Delegates were divided into sub-groups to develop different projects, which included self-management, changing social attitudes, and increasing access to social care.

The self-management project decided that everyone with an RMD at any age should have access to a self-management pathway, with suggested slogans, “Achieve quality of life through self-management” or “Start early, start now”. Information could be disseminated in public areas such as waiting rooms and also via social media. People could be trained to become “ambassadors” and create testimonials or success stories and run self-management workshops. Delegates agreed that it is particularly important to set up mobile teams who can access remote areas.

Education, starting at an early age, and raising awareness of the impact of RMDs was the focus for the changing social attitudes project, with positive communications and fun awareness raising activities, including celebrity ambassadors, street activities on awareness days, short films and media outreach. To overcome public perceptions that people with RMDs are expensive and don’t contribute, a press event highlighting that, “We’re all ageing”, could be held with academic, political, patient and celebrity speakers. This would highlight that, with support, people with RMDs can contribute actively to society and the economy. It was noted that medical and social data is needed to understand what problems we are trying to solve and to measure success.

The project on increasing access to social care and services would target the public, politicians and regulators with the overarching message “it could happen to you”. Media stunts would be used to raise awareness such as “A day in the life of a care home resident”. One of the barriers to healthy ageing is a lack of esteem. To overcome a lack of self-belief people could be educated through websites and leaflets on alternative ways of exercising and overcoming the limitations. When you have the right data and engagement, you get empowerment – “When you win, we all win”.

Evidence
Engagement
Empowerment

John O’Flynn, President of Arthritis Ireland, facilitated a workshop to identify how organisations can motivate people with RMDs to adopt healthier lifestyles. Delegates were provided with an overview of Arthritis Ireland activities including group walking and ballroom dancing, as well as how it maintains its well-supported website. Lea Salminen and Emmi Myöhänen presented on the musculoskeletal service pop-up stations in Finland, where simple but revealing tests are used to determine a person’s mobility status. This workshop benefitted from the input of delegates from a good spread of countries and cultures with
different ideas on what comprises a healthy lifestyle, for example good time management, pain- and self-management techniques and the importance of taking up hobbies and being sociable.

In order to overcome psychological barriers to leading a healthy lifestyle delegates decided the most important solution is education. This encompasses all forms of education, including medical education of rheumatologists and other healthcare professionals, patients, families, society and social services. It was agreed that to ensure the right services are being offered, it is very important that everyone has a clear understanding of what it is like to have an RMD. Education can take the form of classes and events, starting at a young age in schools, and could include self-management. Delegates also highlighted the importance of setting goals for an improved quality of life, whilst being able to accept things that can’t be changed. People with RMDs take value from peer support groups and it is important to reassure them that they are not alone. People with RMDs need to focus on what they can do and set themselves realistic achievable targets, taking small steps. People with RMDs also need to be smart and could be encouraged by a campaign entitled, “Use your brain to kill the pain”.

It was suggested that professional help is required to run and fund projects, rather than amateurs who are not experienced or knowledgeable. To overcome funding barriers organisations can self-fund by selling home-made products, partner with companies and institutions and use technology to ask for donations or advertise on websites. It is also important to increase support from the government by lobbying and collaborating with other leagues.

**Education**

**Self-awareness**

**Motivation - Positive thinking**

The workshop on working with volunteers, facilitated by Anne Refsgaard, manager and trainer of volunteers at the Danish Rheumatism Association, began with some ice breakers. Delegates were asked to stand up and make a line according to their height and as a second more complex task they were asked to build a row according to the warmness of their hands – this was great fun and mingling got everybody engaged quickly. This warm up was followed by a short role play consisting of a volunteer and an organisation’s board member. Anne then presented a Danish best practice case study. The aim of the workshop was for delegates to discuss and outline potential challenges and solutions relating to volunteering.

Delegates noted that some organisations find it hard to recruit volunteers. To overcome this barrier it was suggested that these organisations should recruit using the internet, social media and advertising. Prior to recruitment, organisations should agree on the specific tasks for each volunteer and develop a strategic plan which includes enough time to train volunteers and set a probation period for new volunteers. Organisations find that one of the main barriers to volunteering is funding. If organisations are struggling financially and can’t afford to pay volunteers’ expenses, they should run fundraising activities. Another barrier to volunteering is a lack of education. Volunteers should be educated in order to develop the necessary skills for the work they will be carrying out. Speakers and coaches should teach volunteers the different skills required to become a successful volunteer. Experienced volunteers can then teach new volunteers and also become part of the recruitment process to help attract new members. One of the advantages of bringing new volunteers to an organisation is that they bring new ideas.

In order to keep hold of their volunteers, organisations should appreciate, acknowledge and thank their volunteers. Ultimately delegates agreed that volunteering is driven by a big heart.
and therefore organisations could thank volunteers by holding volunteer days and reward volunteers by providing them with small presents. It is also important to keep the projects interesting to keep volunteers motivated. Delegates noted that volunteers who are suffering from pain and fatigue should be allowed to work reduced hours or part time. Organisations should hold discussions with volunteers regarding their hours during the recruitment process.

**Appreciation**

**Education**

**A big heart**

“The interaction in the workshop ‘Working with volunteers’ was great.”

Linda van Nieuwkoop, Chair of Youth-R-Well.com, facilitated the first youth workshop, where delegates were presented with an overview of the outcomes of the PARE youth project. The aim of the workshop was for delegates to discuss and prioritise the main themes relevant to young people with RMDs in Europe. Daniel Sundstein and Marco Greco, who are both youth leaders of the European Federation of Colitis and Crohn’s Associations (EFCCA), presented a case study on youth activities in their organisation.

Factors which are most important to young people with RMDs are support and education. They would like to be educated and provided with information on their disease and how it will progress. They also need to be educated on healthcare, medication, physical therapy, assistive technology and financial support. As part of their education they want to be shown how to cope with their disease and also to find out what jobs would be suitable for them. Young people will start to think about relationships and therefore they would like to have advice on managing relationships, sexual relations, starting families and parenting. In particular delegates mentioned that it would be useful to receive information on how to have children whilst receiving drug therapy. Young people want peer-to-peer support by speaking to others with the same problems. They also want to receive mental and psychological support from schools, friends, families and employers. They would like face-to-face discussion groups with people of the same age to find out how other people cope with their disease and also to boost confidence and self-esteem. Young people also want to be able to have fun and travel.

“I very much liked the network opportunities, they are very valuable. Workshops are an extremely useful method for exchange of experiences.”

Theodora Seitanidou next to the Lupus Europe poster, presented by Andromachi Salamatiki, which won the prize for the most beautiful poster.
Following the workshops Diana Skingle, PARE Board Member, moderated the interactive feedback session which was presented in a more informal and interactive format than last year.

“I thought the short informal feedback worked well, with presenting three key words. It was difficult to cut it to only 3 words but this lead to good discussions.”

In the poster exhibition 16 creative posters were displayed. The posters receiving the most votes in the three categories were from the United Kingdom for the most successful / innovative campaign around the theme of healthy ageing presented by Donna Saunders; from Hungary for the most successful / innovative campaign (open theme) presented by Judit Ortutay, and from Lupus Europe for the most beautiful poster, presented by Andromachi Salamaliki.

To help encourage delegates to fully understand the campaigns depicted in the posters an optional poster rally was introduced this year. Delegates were provided with a list of facts relating to the posters and were asked to match the facts to the related poster. Delegates enjoyed the fun, competitive element of the rally and those presenting a poster reported it increased interest and enquiries. Sija de Jong from The Netherlands finished the rally first, with the correct answers and won the prize.

Saturday, 16th November:

In his workshop on supporting older people with RMDs, Tom Gentry, policy adviser for health services at Age UK, provided insights into the work of Age UK and some key research findings. Dieter Wiek gave a short presentation on work being conducted by the Deutsche Rheuma-Liga (the German Rheumatism League) and provided delegates with a handout showing six German case studies, with their thoughts on getting older with an RMD. At the beginning of the workshop delegates identified their fears about getting older with an RMD. Their main fear was a lack of independence and reliance on others, followed by no longer being able to cope with daily living. Delegates were also worried about loneliness and isolation, becoming institutionalised and not having enough money.

The main aim of the workshop was for delegates to discuss and identify how organisations can better support older people with RMDs. It was agreed that organisations have an important role in helping people access information and in providing a platform where they can socialise and become less isolated. To do this organisations need to find out where older people are, especially those in remote areas and encourage volunteers to...
carry out home visits. Mobile clinics could visit older people to give medical aid and information. Technology could also play a role in supporting older people with access to the internet, including internet courses, online hobbies, social media and Skype.

Prejudice against older people and societal preconceptions were identified as a challenge and it was suggested that a campaign with the slogan, “It could happen to you”, could be developed to engage the general public. Older people should also be provided with information to ensure they are aware of their rights. Older people should be able to connect with each other through local groups such as day centres and churches. Psychological support, including group therapy and a support helpline could also be useful for older people who are struggling to cope.

Connections
Enabling
Open mindedness

The workshop on self-management courses, facilitated by Sigrún Baldursdóttir, operator of a physical therapy clinic and fibromyalgia clinic in Iceland, aimed to determine why organisations should offer self-management courses to people with RMDs and what steps organisations could take to set up self-management courses. The workshop began with an Icelandic case study on self-management courses, which was presented by Sigrún and Arnór Vikingsson, Chief of Rheumatology, Landspitali University Hospital in Reykjavik. Delegates agreed that one of the main reasons organisations should set up self-management courses is to provide knowledge and education. It was suggested that self-management courses should be run by professionals, who are educated, and led by people with RMDs, who have the experience. It was suggested that courses should provide a basic level of education for all people with RMDs with additional disease-specific modules. It was suggested that EULAR/PARE could develop some basic course elements for organisations to adapt and translate for local implementation.

Setting up self-management courses enables people with RMDs to become empowered and improve their quality of life. It is important to monitor the outcome of self-management courses, for example following up with individuals after a year. Organisations would need to determine how to measure improvements to quality of life, as this can be difficult to evaluate. Funding can be provided by the government, organisations, sponsorship and from the participants.

Knowledge/education
Empowerment
Quality of Life

Following on from the first Youth workshop which prioritised the outcomes of the Youth Group survey, the second workshop focused on steps that could be taken to formalise a PARE Youth Group. Ingrid Pöldema, PARE Board Member and leader of the youth activities within the PARE Board led the workshop together with Walter Atzori, Senior Programme Officer, European Patients’ Forum (EPF). Walter presented an EPF case study on developing and implementing the four goals of the EPF youth strategy. Linda van Nieuwkoop also gave a presentation on mobilizing platforms. The workshop divided into two groups; one group discussed the benefits of building an international youth network and how EULAR PARE can support the interests of youth organisations. The second group focused on mobilising online platforms and how national youth groups could use internet and social media to inform, support and empower young people with RMDs.

Workshop discussions focused on national and PARE organisational levels. The first group of delegates agreed that it is important to use the appropriate tools and approach when interacting with young people. Language barriers and different age groups also need to be taken into consideration when developing plans. Also,
delegates suggested that youth group topics need to be interesting and inspiring.

The second group agreed that social media is a useful tool for targeting and attracting a youth audience. Social media activities should be interactive and reach users on a personal level. It is important to ensure that messages communicated on social media platforms are simple and easy to understand. Social media should also provide useful information which can be shared easily with others.

Moving forward, the youth group agreed that all motivated young people are welcome to become involved in and supported by the group. Young people with RMDs should be recognised and, as such, it was thought to be beneficial to have a youth representative on the PARE board, who participates in all PARE activities. It was also discussed that ideally there should also be a youth representative within EULAR and all EULAR stakeholders should be aware of the youth group. Additionally, a youth workshop should always be considered at the EULAR Autumn Conference in order to make sure young people’s voices are heard.

Involvement
Recognition
Ownership

Following the workshops, Diana Skingle moderated the interactive feedback session.

“The content and moderation of the workshops that I attended were excellent and very useful and I’m sure that my organization will use the information and the knowledge that I’ve gathered.”

Marios Kouloumas presented the closing remarks for the end of the conference.

The gala dinner was held at The Blue Lagoon, which was a unique and magical location. Delegates were given the opportunity to swim in the lagoon itself or be shown round the clinic and its facilities. The gala dinner included a speech by Marios Kouloumas who thanked all contributors and in particular the Iceland host organisation for a most successful event. The evening was thoroughly enjoyed by all.

“The next EULAR Autumn Conference for PARE will be hosted from 7 – 9 November 2014 by the Croatian League Against Rheumatism in Zagreb, Croatia.”

16th EULAR Autumn Conference for PARE, Reykjavik, Iceland, 15th – 17th November 2013  REPORT