Planning for the future

New EULAR President, Professor Gerd Burmester, starts his term of office at the end of the EULAR Congress in Rome on Saturday 13 June 2015

Currently Professor of Medicine in the Department of Rheumatology and Clinical Immunology at the Charité University Hospital, Free University and Humboldt University of Berlin, Germany, Gerd was President of the German Society of Rheumatology from 2001-2002. He was Chair of the EULAR Standing Committee of Investigative Rheumatology 2003-2006 and Chairman of the Scientific Programme Committee of the EULAR Congress in Berlin, Germany in 2004. He became EULAR Treasurer in 2011 and was chosen as President Elect in 2013. He shares his presidency priorities with Breakthrough.

It will be important to further develop and enhance the strong relationship within EULAR between the scientific part, patient care and PARE by intensely addressing these still unmet needs.

- Identifying rheumatologic conditions early (including new instruments such as the internet).
- Immediate referral to the specialist (helping to find algorithms to identify early symptoms, the initiation of early arthritis clinics).
- Continuous care by the rheumatologist (help raise awareness of the importance of the rheumatologic specialty to attract medical students into this discipline, such as the patient partner programme).
- Patient education and continuous information.
- Research efforts both on the national and the European level.
- Recognition of rheumatologic conditions as important diseases compared, for instance, to cardiology and oncology with appropriate resource allocation to rheumatology.
- Participation of patients in the development of recommendations and guidelines.
- Continuous co-operation with PARE to identify upcoming issues of research, diagnosis and treatment in rheumatology.

To reach this goal I will focus on four priorities.

**Time is Joint campaign**

There has been tremendous progress in diagnosing and treating rheumatic diseases over the recent decades, especially with regard to inflammatory disorders. Here, we have many excellent conventional drugs and the newly developed biologics. More agents are on the horizon, and the advent of biosimilars will certainly lower the burden of the economic challenges connected to these agents. We also have much better tools now to diagnose the diseases earlier with regard to careful clinical examinations, imaging and laboratory procedures.

However, in most countries it is quite difficult to use all of these tools as early as possible for our patients. We should regard early manifestations of rheumatic diseases as medical emergencies which need immediate attention in order to ideally prevent any damage.

The Time is Joint campaign will require close interaction between PARE and physicians to especially alert the general public of the sometimes subtle symptoms of early disease. Moreover, PARE organisations will be instrumental in helping those affected to immediately find the appropriate specialist and to build up pressure that people affected with early rheumatic diseases will get immediate attention and care. Together, we will be able to prevent severe disease courses in many individuals.

The next focus will be “precision medicine”.

This does not necessarily mean the detection of new fancy biomarkers but the implementation of tools that are already available in order to tailor the best possible medicine to the patient. Here, careful clinical examination, laboratory data and imaging will help to find the best possible approach to treatment. PARE will be made aware of these tools so that they can interact with physicians to use these for the best possible treatment.

A major effort will be the founding of the EULAR School of Rheumatology.

EULAR is offering a tremendous variety of educational tools, most notably the online courses and educational events including the annual congress. However, thanks to the internet, the advent of new media, such as smart phone applications, means completely new and interactive tools will be available.

The EULAR School of Rheumatology will combine all these tools in one “big house”, where we will have different “classes” of certain levels of knowledge and will also educate not only a physician but, of course, PARE and the health professionals.

A school is a living environment that constantly needs new input; new students will be educated, but of course the quality also needs to be excellent. This will be a particular strength of EULAR since so many cultures are involved bringing in completely new ideas. The close interaction between the three pillars of EULAR will provide the best preconditions to build up our new school.

**Reach Out campaign**

Finally, many international societies approach EULAR to learn from European experience. In turn, we as Europeans can learn from the efforts of people with arthritis in other non-European countries. It will be important to find a forum in which members of various societies can interact and learn from each other.
DEAR COLLEAGUES

By Diana Skingle

It is time for me to say farewell as Chair of the Standing Committee of PARE. The past year has been an exciting time. I have been thoroughly impressed by the dedication of the volunteers I have met from the PARE member organisations who freely give their time and expertise to participate in so many PARE activities.

The EULAR Annual European Conference of PARE continues to transfer an increasing range of skills to participants through its workshop format. The Stene Prize competition is attracting increasing numbers of participants, and the Knowledge Transfer Programme is fully subscribed. The network of Patient Research Partners is highly respected and valued by researchers. The youth and dissemination projects are moving ahead. The 2014 World Arthritis Day (WAD) competition received wide support, and we are hoping for even stronger participation in the 2015 WAD High 5 campaign.

So PARE has a full agenda, and much has been achieved. However, it sometimes seems that trying to improve the lives of those living with rheumatic and musculoskeletal diseases (RMDs) across Europe is a huge, never-ending task. There is so much still to do: lobbying for better access to healthcare; providing services to help people with RMDs manage their condition; awareness-raising about the burden of RMDs on individuals and on society. But every effort, large or small, is always worthwhile. As the ancient Chinese philosopher Lao-Tzu said: “A journey of a thousand miles must begin with a single step.” Everyone can make a difference and achieve amazing things. Just take that first step.

In farewell, I should like to thank the members of the PARE Board and the EULAR Secretariat who have all been so supportive. It has been an honour to work with you. As I now hand over to my successor, Dieter Wiek, I should like warmly to wish him every success for his period of office.

Diana Skingle is the outgoing Chair of the Standing Committee of PARE

Making a difference

Dieter Wiek introduces himself as the new Chair of the EULAR Standing Committee of PARE

I am a retired grammar school teacher. At the age of 17 the first symptoms of a rheumatic disease developed, but the diagnosis of ankylosing spondylitis, however, followed several years later. Despite being seriously affected, with many ups and downs over the past 40 years, I am very grateful that I was able to work with high contentment up to pension age.

Realising that information, therapy and talks with others could help me, I joined a self-help group at the beginning of the ’80s, founded a group in my town. Since then I have also been active as a volunteer of Deutsche Rheuma-Liga in different positions. The support of family, friends, the exchange with those who are also affected by a life-long illness and the adequate medical treatment enabled my self-management strategy.

I am a Patient Research Partner and I joined the PARE Board two years ago.

During my time as Chair Elect I have tried to understand EULAR’s complexity and the varied structures of our PARE organisations. In spite of their diversity, all PARE organisations strive to achieve the optimal care for patients with a rheumatic or musculoskeletal disease.

Supported by the EULAR Secretariat, my predecessors have achieved a lot. A very special thanks goes to Diana Skingle who took over as Chairperson without having any preparation time and has done a great job.

The Standing Committee of PARE offers numerous activities and programmes so that representatives from national organisations can share and learn from each other. After a few years of gaining experience I feel that we can now build on what we have and even improve the current offer.

For my term of office I will look into the development of online tools, but also forums at our face-to-face meetings where we can share our projects, show best practice, and explain the details of our organisational framework. We should provide support so that participants have the opportunity to adopt and adapt materials or projects to their specific needs. All our national member organisations should give and share, but they must also be made aware how they can benefit from the different platforms offered.

Co-operation with the other two EULAR pillars – the Scientific Societies and Health Professionals – remains an essential and crucial part for all our work. The educational activities and the advocacy engagement – two of PARE’s key Strategic Objectives – benefit highly if they are done in close collaboration.

I look forward to a busy and exciting term of office and, together with my colleagues from the PARE Board, I will do my best to making a difference for people with RMDs in Europe.
News from the EULAR Standing Committee on Education and Training (ESCET)

By Ingrid Lundberg, Chair, and Annamaria Iagnocco, Chair Elect

EULAR’s commitment to training and education in rheumatology has always been strong. Educational offers are one of the key strategic areas of EULAR. We seek to design an up-to-date high-quality educational programme for rheumatologists and health professionals catering to their immediate and changing needs. EULAR strives to offer courses and educational materials that cover niches or complement already existing training opportunities and products. The EULAR Standing Committee on Education and Training (ESCET) is the forum within EULAR to develop and support training and education in rheumatology.

The commitment to education and training was reiterated in the current EULAR strategic objectives which include providing educational resources for health professionals and patients, as well as innovative learning methods based on e-learning. EULAR has spelled out for the first time a vision towards a EULAR certification process for specific knowledge, expertise and skills for physicians, health professionals and patient representatives.

Broad educational programme

Over time, EULAR has developed a broad educational programme, including face-to-face and electronic courses, textbooks, DVDs with diagnostic and treatment practices, as well as workshops and young rheumatologist sessions at the annual EULAR congress. In addition, various forms of education and training grants are provided.

EULAR postgraduate courses are very popular. The 15th EULAR postgraduate course was held in Prague in October 2014 with nearly 100 attendees from Europe, Africa and the Near East. This yearly course is designed for clinical residents and fellows with solid knowledge and basic skills in rheumatology and focuses on in-depth learning about mechanisms leading to rheumatic diseases, and on updating in diagnosis and treatment. The teachers are all influential scientists in their fields of rheumatology and immunology and their pedagogics are highly recognised.

A substantial period of the course is dedicated to interactive sessions. These sessions focus on clinical case discussions, presented by the participants and approached in small groups with the professors. There are also workshops on how to design a clinical trial or on how to write or review a paper. The course’s overall evaluation in 2014 was excellent. The next one is being prepared by the Chair Elect of ESCET, Professor Annamaria Iagnocco, to take place again in Prague from 18-21 October 2015.

The EULAR online courses are a growing activity within the EULAR educational programme. Eric Hachulla, as scientific online courses coordinator, is doing a fantastic job in getting these to run at a high scientific content level, with excellent pedagogics and updated clinical recommendations. The original Full Online Course on Rheumatic Diseases, with 50 teaching modules runs for two years. Each module corresponds to 5-8 hours of work, which participants spend two weeks to cover. This EULAR online course reached an all-time number of registrations in 2014 with 952 enrolments.

In addition to the Full Online Course on Rheumatic Diseases there are four growing courses with more focused topics: the Connective Tissue Diseases (CTD) Online Course, the Scleroderma Online Course, the Online Introductory Ultrasound Course, and, the newest release, the Online Course in Paediatric Rheumatology. This year we will launch another course, the Online Course for Health Professionals. Courses start in September every year.

Patients are important educators

Patients are important educators in EULAR activities and their participation in courses for physicians, scientists and health professionals is very important. In the annual EULAR ultrasound courses many patients have participated over the years making these courses feasible for teaching “live” and highly appreciated.

EULAR also offers educational activities for patient organisations: the EULAR Knowledge Transfer Programme. This is designed for patient organisations wishing to improve their skills in a particular topic (“learning organisation”), learning from the experience of another organisation in the EULAR network (“teaching organisation”). Usually 2-3 grants per year are available for knowledge transfer. More information is available on the EULAR website.

For updated information on EULAR educational activities and for registration to courses please visit the EULAR website (www.eular.org).

Exciting news this year is the launch of the 2nd edition of the EULAR Textbook on Rheumatic Diseases to be launched at the Rome Congress in June 2015. There we welcome Professor Annamaria Iagnocco, from Rome, as the new Chair of ESCET.

Ultrasound in rheumatology practice

Annamaria has been a pioneer in introducing ultrasound in rheumatology practice and is one of the teachers leading the EULAR Ultrasound Courses and the US online course, as well as being the scientific organiser of this year’s Ultrasound Course and US Teachers Course in Rome.
Another year has passed and it is time for our annual Congress at which the Chair of the Standing Committee of Health Professionals (HP) Susan Oliver will step down. Our new HP Standing Committee Chair is Professor Anthony Redmond who is a podiatrist from the University of Leeds.

Tony is head of Clinical Biomechanics and Physical Medicine, leads his own team of researchers and is well known for his work in biomechanical conditions, particularly in foot and ankle problems in musculoskeletal diseases. He has contributed to a variety of foot related policies, guidelines and standards and is past chair of the UK’s Arthritis and Musculoskeletal Alliance, an umbrella organisation representing a range of professional and patient organisations to government. As Chair Elect of the HP Standing Committee he might already have got an idea of what lies ahead, but now it is time for him to step up and we will all support him the best we can.

Improve standards of care

The past year of the EULAR HP has included new initiatives as well as the delivery of results from previous ones – all aiming at improved standards of care and better health and functioning of people with rheumatic and musculoskeletal diseases (RMDs). Below is a selection.

The HP membership campaign has resulted in eight new HP member countries during the past two years. This is mainly thanks to Sue Oliver’s travelling across Europe to meet local HPs and assist them in sorting out the bits and pieces necessary for their membership applications. This in itself is a fantastic outcome, but thanks to her efforts there is more to come with several additional countries currently preparing membership applications.

Last year’s Congress in Paris was the start of a new and exciting collaboration with our American peers, the Association of Rheumatology Health Professionals. We have since agreed on a common project that has been approved by the EULAR Executive Committee. “The Health Professionals’ approach to pain management in Inflammatory Arthritis and Osteoarthritis” project chaired by Prof Rinie Geenen from the Netherlands will, hopefully, result in HPs providing evidence-based support for management of pain more promptly and thus benefit people with RMDs.

The work on EULAR recommendations for patient education for people with inflammatory arthritis led by Mwidimi Ndosi and Astrid von Tubbergen was recently published in the EULAR journal ARD. Eight evidence-based and expert opinion-based recommendations for patient education for people with inflammatory arthritis are suggested and intended to provide a core framework for the delivery of patient education and training for HPs in delivering patient education across Europe.

Identify barriers

It is also with great pleasure that we can announce the launch of the EULAR HP online course that will start in September. The course includes eight modules on rheumatoid arthritis, osteoarthritis, fibromyalgia, regional musculoskeletal pain, assessment and evaluation, interventions, psychosocial approaches and evidence-based practice.

This year the EULAR HP research grant was awarded to a group of researchers from Belgium, Denmark, Ireland and Sweden led by Dr Nina Brodin. Their aim is to survey the awareness and use of objective and subjective measures of physical activity and aerobic capacity and identify barriers for implementation of such methods in HPs in rheumatology. A further aim is to describe the awareness and use of these measures in patients with inflammatory rheumatic disease. This is an important first step towards better promotion of health-enhancing physical activity among people with rheumatic and musculoskeletal diseases in Europe.

The following are evidence-based and expert opinion-based recommendations suggested for patient education for people with inflammatory arthritis (Zangi et al, Ann Rheum Dis 2015).

1. Patient education should be provided for people with inflammatory arthritis as an integral part of standard care in order to increase patient involvement in disease management and health promotion.

2. All people with inflammatory arthritis should have access to and be offered patient education throughout the course of their disease including, as a minimum, at diagnosis, at pharmacological treatment change and when required by the patient’s physical or psychological condition.

3. The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis.

4. Patient education in inflammatory arthritis should include individual and/or group sessions, which can be provided through face-to-face or online interactions, and supplemented by phone calls, written or multimedia material.

5. Patient education programmes in inflammatory arthritis should have a theoretical framework and be evidence-based, such as self-management, cognitive behavioural therapy or stress management.

6. The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme.

7. Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team.

8. Providers of patient education in inflammatory arthritis should have access to and undertake specific training in order to obtain and maintain knowledge and skills.
Benvenuti a Roma!
The Eternal City hosts EULAR Congress 10–13 June 2015

After a successful Congress in 2010, this is the second time that Rome welcomes the Annual European Congress of Rheumatology from 10–13 June 2015. The “capital of the world” is ready to receive around 13,000 expected participants to this unique arena from all over the world for the exchange of scientific and clinical information.

Marios Kouloumas, EULAR Vice President representing PARE, and his team have prepared a PARE programme which specifically focuses on the point of view of people with rheumatic and musculoskeletal diseases (RMDs). Said Marios: “With the input of the Standing Committee of PARE and the expertise of the members of the EULAR Scientific Committee I am confident that we have managed, once more, to put together a stimulating and diverse programme which will also be attractive for health professionals to attend.”

He further informed: “Our topics this year cover daily life issues around family and work, show successful examples of political campaigning and how to measure success, demonstrate how innovative care can bring health services back to the patient, and also focus on providing the latest information around the use of glucocorticoids, the treatment of systemic lupus erythematosus and the hot topic of biosimilars.”

Dieter Wiek, incoming Chair of the Standing Committee of PARE, added: “We are delighted that PARE has received even more abstracts than in 2014 – here we can clearly say that our PARE Conference workshop in Zagreb, which gave concrete advice on how to write and submit abstracts for the congress, has shown some effect. We would like to thank all the submitters and the organisations very warmly. For the second time EULAR will award the best PARE abstract during the Opening Plenary Session on Wednesday between 18.45–20.00 and we invite you all to join us.”

For an overall session timetable, please see the overview below. It includes the Joint Sessions organised with the Health Professionals in Rheumatology and the Scientific branch of EULAR. Joint Sessions always provide a useful platform for health professionals, people with RMDs, researchers and clinicians to discuss shared interests and find ways to work more closely together.

To get started we recommend that you attend the Pre-conference Outlook session, on Wednesday 13.30-14.30, which will provide you with all logistic details needed for finding your way around the congress venue, as well as offer information about the programme.

As in previous years, the PARE Booth will be waiting for your visit and is meant to be the central meeting point for PARE delegates to receive the latest information on PARE activities and to meet their European colleagues to exchange the latest news. Come and visit and get your own copy of the 2015 EULAR Stene Prize booklet, as well as many other recent publications.

Just next to the PARE Booth, the PARE Posters will be displayed from Thursday to Saturday. After the great success in 2014, PARE will again offer two official PARE Poster Tours – one on Thursday and one on Friday at lunchtime. If you would like to join in for one of the tours, please don’t forget to register officially on the day – places are limited!

If, at the end of the congress, you find you were not able to cover all you had wished to, you can always attend the PARE Highlight Session. Here you will be given an overview of the learning taken from the congress and its outcomes from the perspective of health professionals and rheumatologists, as well as the first feedback from PARE delegates.

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<td>Lost in the system – how to use innovative care to bring health services back to the patient</td>
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EU Public Affairs: the journey continues

By Neil Betteridge, Liaison Officer, Public Affairs, EULAR

As someone who has been privileged to act as an advocate for people with rheumatic and musculoskeletal diseases (RMDs) for most of my life, I am delighted to have an opportunity here to set out EULAR’s current plans and priorities in the area of EU Public Affairs for the coming period.

Before looking ahead in more detail however, it is worth reflecting on how far we have come in a relatively short period of time. Until 2004, only a few member organisations of EULAR, mainly the patient organisation (then known as the Social Leagues), were actively campaigning on quality of life issues for people with RMDs at the European level. It was during the Presidency of Professor Josef Smolen however, just over a decade ago, that this activity became prioritised by EULAR as a whole.

In the ensuing years, Prof Smolen, supported by myself (as Vice President representing PARE) and several others including successive Presidents, led on a number of policy related initiatives which greatly raised the profile of RMDs and of EULAR. Our plan was, and is, to improve the societal position of all 120 million people with RMDs in the EU – no easy task!

We established a Brussels office for expert advice and continuous relationship building with the EU community; and a Public Affairs Group consisting of EULAR leaders from all three pillars of the organisation, which still meets regularly to support the activity. The current PARE representative on this Group is Marios Kouloumas, from Cyprus.

Crucial here was the development of the Brussels Declaration

These initiatives included securing a Written Declaration from the European Parliament explicitly prioritising RMDs as an EU health priority, achieved by attracting signatures from more than 50% of all Members of the European Parliament (MEPs). This advance was followed a few years later by persuading the Belgian Presidency of the European Union to host the first ever officially EU endorsed conference on RMDs, which EULAR principally organised and whose findings were presented to a meeting of Health Ministers from member states the following day. Crucial here was the development of the Brussels Declaration, a consensus statement outlining the needs, wishes and rights of the RMD community. This is still a “live” document, which has been endorsed by the health ministries of several countries thanks to the work of EULAR members (PARE, health professional and scientific societies).

In 2013 when I was appointed as Professor Smolen’s successor as EULAR’s Liaison Officer, Public Affairs, it was both a great honour and a great challenge to build further on a decade of success!

As EULAR was at that time developing its new strategy for this period, I felt it was important to embed public affairs goals within that plan to ensure alignment with the organisation’s overall objectives. The result is that one of the seven sections of the strategy is completely given over to this area. Moreover, to show how our advocacy work would contribute to this, we developed EULAR’s first ever Public Affairs strategy, which you can find on the main EULAR website.

The future prospects for EULAR are exciting and your support, in ways which I hope benefit your organisation at the national level, are crucial to our success.

Becoming visible in Horizon 2020 was the number one priority at the EU level

For example, over the last few years a major success for EULAR has been to have the EU explicitly include RMDs as a major chronic disease in important work streams such as the latest research framework programme, Horizon 2020. Some years ago PARE members, as well as scientific and health professional members, told the Standing Committee of PARE that becoming visible in Horizon 2020 was the number one priority at the EU level. We were thrilled and proud to achieve this recognition when the text of the programme was finally agreed at the end of 2013 – but that marks the beginning, not the end, of our ambitions.
We now need a EULAR-wide strategy in research, which includes the patient as well as the health professional and clinical perspective, to support efforts to get the maximum return on the research funds available, in a period where overarching topics rather than specific disease areas are being given priority by the European Commission (the budget holder for the programme).

"We will seek your views and support in taking it forward"

To this end, we are lucky to have Professor Iain McInnes leading EULAR’s new Research Roadmap project. Working with stakeholders internally and externally to set out a clear long term vision for research in this area, and staying focused on the quality of life of people living with RMDs both now and in the future, we will be able to share the outputs of this work over the coming months and seek your views and support in taking it forward with policymakers in your country as well as in Brussels.

Our public affairs activity will also include the improvement of the legislative framework regulating medical research practices, in particular the new Data Protection Regulation. EULAR is concerned about the possible outcomes of the ongoing negotiations between the main EU institutions. The proposed legislation will establish new conditions for the storage and use of personal data by third parties in commercial and non-commercial activities (including research).

"Medical research would be severely hindered in Europe"

Should the European Parliament position prevail, medical research would be severely hindered in Europe, as it would impose very strict conditions for the use of patients’ data in scientific activities. Together with a number of scientific organisations EULAR has signed a position statement calling on the EU to ensure the introduction of specific provisions for the use of personal data in scientific activities.

In addition, EULAR has invited its member organisations to join a campaign aiming to express their support to these specific provisions. Please contact me if you require further details.

Taken together, this work has given EULAR a higher profile at the heart of the EU. We are now expected (and even requested) to get more involved in, and develop positions on, policy areas that were so far not a priority in EULAR EU affairs (such as medicines / biosimilars, eHealth, etc.). Our annual Brussels conference in October, close to World Arthritis Day, is now embedded as a key date in the EULAR calendar and I hope that your organisation will continue to inform and support these events via your ideas and your active participation. This year we will be holding it on 13 October: please note it in your calendar and try to ensure you can join us!

"Your support is essential"

Your support in securing the continued backing of the European Parliament is also essential in this next period. One of the key priorities for EULAR currently is to re-establish the EP Interest Group on RMDs. In the last months, EULAR has met a number of newly elected MEPs and will continue doing so in the months to come to get their support on specific policy initiatives related to our strategic priorities.

EULAR’s actions will, therefore, continue to focus on three main policy areas: research, public health, and employment & social affairs. Specific issues on our agenda include EU policies on chronic diseases; access to health care, following our successful conference on this topic last October where we are now drafting a policy paper to take the issues forward; standards of care; cross-border health care; and health professionals’ mobility, to ensure consistent quality of care across the whole EU.

So the support of all our members – but on several issues PARE members in particular – is going to be critical. We carry out this work so that it helps people with RMDs to enjoy a better quality of life. This is something where PARE members are the real experts.

"Help us to help you"

If we are not representing your priorities then please tell us! If we are, please get involved and help us to help you to change things for the better of people with RMDs, in your country and across Europe as a whole. It’s what people with RMDs, whose position has for too long been neglected by policymakers, want and deserve – which means carrying out this work is not so much an option as a responsibility that we owe.

Marios Kouloumas, EULAR, Vice President representing PARE, supports the use of personal data to enable medical research in Europe

MEP Edite Estrela, former chair of the EU Interest Group on Rheumatic and Musculoskeletal Diseases (2009 – 2014), with Neil Betteridge, International Liaison Officer, Public Affairs, EULAR
This year people with rheumatic and musculoskeletal diseases (RMDs) were invited to write about their personal experiences and the role that health professionals have played in supporting them to live as independently as possible, achieve important personal goals, and to take control of their lives.

“It was very meaningful to read the contributions to this year’s competition as they clearly showed what a central role doctors, nurses or physiotherapists play in the life’s of people with RMDs. Mutual respect, trust and understanding can open the door to a successful collaboration and make all the difference for people with RMDs and the challenges they are facing. These essays are wonderful testimonies that living life to the full can be reality with the right support at the right time. I am sure they are an inspirational read for many patients and health care professionals,” said Diana Skingle, Chair of the Standing Committee of PARE and ex officio jury member.

The winner of the 2015 Edgar Stene Prize competition is Charlotte Secher Jensen from Denmark. Her essay “Living in the moment” impressed all five jury members. It was a difficult choice to make, as this year 24 entries competed for the Prize – the highest number ever received. Charlotte will present her essay during the PARE Session “Taking control – success through empowerment and self-management” at the EULAR Congress on Saturday 13 June between 12.00-13.30 in SC2 – Room A.

A 2015 Stene Prize booklet containing an anthology of contributions on the exciting 2015 theme has been produced and will be available at the PARE Booth in the EULAR Village. It can also be downloaded from the EULAR website (www.eular.org) after the congress.

EULAR develops many recommendations to help health professionals make evidence-based treatment decisions. These recommendations are published in the Annals of the Rheumatic Diseases, a scientific journal for health professionals. For most people with a rheumatic or musculoskeletal disease (RMD) these publications are not accessible or easy to understand. This lack of clear information is a barrier for patients in making well-informed decisions.

For this reason, the EULAR Standing Committee of PARE commissioned the development of a dissemination guide for national patient organisations. The purpose of the guide is to provide practical suggestions for improving the understanding and dissemination of EULAR recommendations among patients in each European country.

Guide for dissemination
The guide has been developed by a EULAR task force with patient representatives and health professionals. Based on a systematic literature review, the task force formulated a set of key principles for a successful dissemination strategy.

First, a dissemination plan should be written right at the start of projects, including the identification of the target audience and potential tools and events for dissemination. Second, patients should not only be involved in the development of the recommendations but also in developing a lay version. This lay version should be translated and adjusted to the cultural context of each individual country. The guide provides a checklist with rules and tips for the translation process.

Finally, a combination of traditional and innovative dissemination tools should be used to reach a wide range of patients. A paper leaflet in lay language is not enough. Patient organisations should also use social media such as Facebook and Twitter. Also national and regional events provide ideal opportunities for dissemination.

Making EULAR recommendations easier to understand
By Maarten de Wit, Project Convener

Workshop on how to use recommendations and guidelines to make a difference at national level at the EULAR Annual European Conference of PARE 2014 in Zagreb

Piloting the dissemination guide
The guide was discussed in a workshop at the PARE Conference in Dublin in April 2015 and will be presented in the PARE abstract session at the EULAR congress in Rome. We hope that the guide will also be used by the members of the EULAR network of patient research partners who review lay summaries of scientific articles, published by the Annals of the Rheumatic Diseases. See page 10 for further information.
The 2015–2016 theme for World Arthritis Day is “It’s in your hands, take action”. Our aim is to encourage the active involvement of patients and their families in the design of new care models and in decision-making about individual options for treatment, along with raising wider awareness about rheumatic and musculoskeletal diseases (RMDs).

In 2015, we are asking people to take action by spreading a uniting gesture: the WAD High 5.

Let’s take social media by storm by owning High 5 across social media channels with the hashtag #WADHigh5. We need your help to achieve this!

Whether you are a large organisation or an individual you can get involved in WAD in a variety of ways.

1. **Share a #WADHigh5**. Take to social media to share a virtual High 5 photo or video using #WADHigh5. Write the name of the person you are High5ing on your hand along with a message of encouragement to stir them and others into action.

2. **Plan or take part in an event**. Flashmobs, discussion groups or even leaflet distribution – get involved in or organise RMD awareness-raising activities. Make sure you share your photos on social media using #WADHigh5.

3. **Use the global WAD Toolkit**. In the Toolkit you will find template materials and branding. By keeping all activities, messaging and branding consistent, we stand a greater chance of being heard.

4. **Interact with www.worldarthritisday.org**. We have just launched a new website – take a look and don’t forget to share the link with your networks.

5. **Get High-5ing!**

   The High 5 is central to our campaign so try and use it in everything you do and share, share, share your photos! Thank you for your support and get ready to High 5!

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**High 5 for World Arthritis Day 2015**

Take action and share High 5 photos and videos on social media using the hashtag #WADHigh5

The 18th EULAR Annual European Conference of PARE

**IT’S IN YOUR HANDS TAKE ACTION**

High 5 for World Arthritis Day 2015

Take action and share High 5 photos and videos on social media using the hashtag #WADHigh5

**EULAR Annual European Conference of PARE**

Dublin, Ireland 24–26 April 2015

Arthritis Ireland recently hosted the 18th EULAR Annual European Conference of PARE in Malahide, a beautiful seaside resort close to the city of Dublin. 140 delegates from all over Europe came together to discuss the overall Conference topic of “Patient centred care – taking control”.

Arthritis Ireland used the opportunity of hosting the Conference in Dublin to raise awareness of rheumatic and musculoskeletal diseases (RMDs) with key Irish stakeholders, and hoped to inspire the many volunteers who give their energy and free time to support Arthritis Ireland’s various activities. More than 20 Irish volunteers from different parts of the country joined the event and were excited to exchange experiences and best practice with their European colleagues.

“It was a great honour that the Irish Minister for Health, Dr Leo Varadkar, accepted our invitation to open the 18th EULAR Annual European Conference of PARE,” said John Church, CEO of Arthritis Ireland. “This year’s topic fits extremely well with some of the core activities run by our organisation, such as our self-management courses. We hope that by sharing our knowledge and best practice widely, many delegates were inspired and motivated to implement these in their own country as we understand that self-management courses are not yet available everywhere.”

As in previous years, the Dublin Conference offered a variety of workshops from campaigning to e-health, plus plenty of time for networking and exchanging experiences. For the first time all plenary sessions and some of the workshops were live streamed to enable many more interested participants to join in! If you have missed the event you can still watch it – just follow the link [http://www.eular.org/social_media.cfm](http://www.eular.org/social_media.cfm)

The High 5 is...

- Recognised all over the world, making it perfect for a global campaign like WAD
- Attention-grabbing, helping us take RMD awareness to all audiences
- Highly visual, you can’t ignore it!
- Action-driven, calling for people to take action over RMDs
- Accessible to all, you can High 5 when standing, sitting and in a range of different ways (e.g. Low 5 / Side 5)
- A uniting, positive expression, used to show support and encouragement – which is exactly what we are aiming to achieve for people with RMDs
Integrating the youth perspective into PARE  By Petra Bednarova and Linda van Nieuwkoop

After a successful meeting in Tallinn, the PARE youth task force developed a youth strategy and wrote a plan of action for 2015 and 2016. The first step to enhance the integration of young people in PARE is the establishment of a permanent PARE youth working group. This working group will expand the Young PARE website by gathering best practices of national youth groups to organise appealing activities for their members. Young PARE will, in particular, promote the use of social media.

Another challenge for the working group is the establishment of new youth groups in countries without activities for young people with rheumatic and musculoskeletal diseases (RMDs).

Finally, the group will create opportunities for sharing knowledge and experiences between national youth leaders. To this end the new working group will organise the first Young PARE networking event, scheduled for August 2016.

Petra Bednarova (Slovakia) will be the first chair of the Young PARE working group and is full of ideas for the future. She hopes that the working group will bring young people with RMDs across Europe together. Petra said: “We hope to establish a working network that will contribute to better quality of life of young people and their voice will be taken into account on national and European level.”

Linda van Nieuwkoop (Netherlands) has energetically contributed to the strategy document as chair of the PARE task force. She will stay active as member of the working group with a special interest in developing an online knowledge centre on the website of Young PARE. She hopes to inspire countries which do not have any youth group yet to start one and will invite already existing youth groups to exchange their knowledge and experience to learn from each other and improve services for young people with RMDs in Europe.

Lay summaries of scientific publications bring research to patients  by Nele Caeyers, Patient Research Partner

Since 2010, Patient Research Partners have been involved in many different scientific projects. In this way, EULAR and the Standing Committee of PARE guarantee that the patient’s expertise is embedded in ongoing research.

The Annals of Rheumatic Diseases, the official journal of EULAR, and the publisher company BMJ, have started a new initiative to bring the latest high-quality scientific publications to patients. The journal produces lay summaries of key scientific articles, which makes the publications understandable for people without a scientific background.

Through the lay summaries, a wider audience can benefit from the latest developments in rheumatology. The lay versions are always reviewed by several members from the EULAR Network of Patient Research Partners, to ensure the message is clear for everyone. These lay versions are available on EULAR’s website under the heading of PARE, Patient Research Partners.

National organisations are welcome to spread the lay summaries among their community. To maximise dissemination of the information among patients, the translation of the lay versions into national languages is recommended to reach an even wider public.

Meeting of Patient Research Partners in Amsterdam

Two groups of 15 people with rheumatic conditions have been trained by EULAR so far. All of these enthusiastic volunteers have been involved in international research some way or another. In October 2015, the patient research partners will get the chance to exchange experiences and learn new skills during a two-day course in Amsterdam, led by Maarten de Wit (Project Convener). It will make them ready for the future, in which patient involvement in research will be a “must”.

Interested in the EULAR Network of Patient Research Partners? Do you have questions about this project or want to collaborate with patients? Please contact Florian Klett at the EULAR Secretariat at florian.klett@eular.org
Knowledge Transfer Programme 2014 – Poland / Switzerland

By Jolanta Grygielska, Polish Rheuma Federation

In March 2014 representatives of the Polish Rheuma Federation (REF) familiarised themselves with examples of good practice at Rheumaliga Schweiz (RLS) in Zurich.

Self-organisation, collaboration and volunteer activities provide real benefits and it can be demonstrated through the many achievements of RLS. To ensure successful management, RLS has prepared a development strategy, plans and financial forecasts for the next 10 years.

Courses. For many years the RLS has been involved in the education of coaches, instructors and physiotherapists. The Polish representatives were introduced to a range of courses, and they visited an aqua exercise group in Biel and a balance exercise group in Lucerne.

Internet. Since 2012 significant financial investments have been made to make the RLS website more professional. Two specialists are employed for tasks related to the website and it corresponds to 1.5 full-time positions.

Publications. Two to three publications belonging to colour-coded series are published each year: blue – for patients, green – about prevention, yellow – with more general content. As an outcome of the Knowledge Transfer exchange, the book “Alimentation” from the yellow series has been translated into Polish.

As a result of the Knowledge Transfer exchange, REF decided to change their co-operation with medical consultants in a more specific way, for example through the new Committee for Exchange with the Polish Rheumatology Society Support Groups. A project of constant information sharing about local support groups via family doctors educated by rheumatologists resulted from this agreement.

The gap between the Swiss and Polish economies is enormous, so having similar logistic solutions in Poland will probably occur in 15-20 years. To change our “volunteer” image to a more “market” image we require stable wide economic processes, more financial resources, education on how to use market tools for new projects, more people who want to risk a “business play” on a NGO.

We have learnt that the best way to achieve more successful projects is the professionalisation of activities on every level with autonomy of member organisations. Our knowledge will be used to reach an appropriate position for rheumatology in Poland’s healthcare system and to organise our activities more effectively in raising public awareness.

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Finnish Rheumatism Association welcomes a new direction

By Maria Ekroth, CEO of Suomen Reumaliitto

People with rheumatic or musculoskeletal diseases (RMDs) are generally in a better condition today than only 10 years ago thanks to modern medical treatments. At the same time the scope of activities and needs of the members of the Finnish Rheumatism Association have also changed. A fresh approach was needed.

In the association, the brand image had become dusty – our highly recognised and valuable activities had outgrown the brand. Our well-established and respected organisation was in urgent need of a more suitable pledge and a stronger identity. At the same time, it was necessary to start updating the activities and to make them even more attractive to appeal to a wider age group.

Network creator

It was deemed important to change from an umbrella organisation into a companion and a network creator. The core tasks of the association were thus specified: the association is 1) a network providing those who are affected by RMDs with important information, assistance and peer support; 2) an expert gathering with the ability to offer up-to-date and reliable information to those affected with an illness and to health care professionals; 3) a major player defending the position and everyday life of people affected by RMDs, and promoting good medical treatments and rehabilitation.

We developed our operations in the above-mentioned fields. We achieved an even closer co-operation between decision makers within social welfare and health care, rheumatologists, rheumatology nurses and people with RMDs.

We provided a wealth of new information, and we managed to clearly increase the number of visitors to our website (www.reumaliitto.fi). We created, in cooperation with an advertising agency, a new, fresh and modern visual identity and logo. Instead of the previous graphics, the identity now features people, and there is an even warmer person-to-person dialogue present.

The association’s new logo consists of a heart and a clover, the latter having been traditionally used in the logo. The result is a logo which symbolises modernity, compassion and dialogue, and which is airy in order to make room for creativity.

The goal of the overhaul is to inspire and encourage even wider age groups – from children to retirees – to participate in our activities.

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Brand renewal
Together for better health

By Mary Vella, President of Arthritis and Rheumatism Association Malta (ARAM)

2014 was a great year for ARAM. We won the poster award for the Most Successful/Innovative Campaign for our “Living better – Ageing Well” activities at the EULAR Annual European Conference of PARE held in Zagreb on 7–9 November. Education is the tool to master one’s condition and ARAM makes sure that its focus on education is carried out professionally.

The association makes it a point that ongoing monthly seminars are organised by professionals for members on various topics aimed at empowering people to gain knowledge and understanding for better control and self-care. These seminars ensure that members understand exactly how to recognise and deal with symptoms and are able to recognise when to seek advice quickly.

A pain management specialist, an osteopath and an acupuncture specialist have been invited to explain pain management to our members. They have been shown how to carry out stretching exercises and eat a healthy balanced diet. Apart from education seminars, we organise weekly specialised pool therapy programmes with a qualified instructor. Interactive cooking sessions are also held during the year by the Ministry of Health’s Health Promotion and Disease Prevention Directorate.

Train the Trainer course

We first heard about self-management courses during one of the EULAR PARE Conferences by Arthritis Ireland. These courses are designed especially for small groups of 10–12 participants, taught by two lay trainers who are qualified and subject to quality assurance. From our own experience, we realised that self-management courses are a must for people with rheumatic and musculoskeletal diseases (RMDs). As a member of Agora, the platform of organisations of people with RMDs in Southern Europe, ARAM was offered a “Train the Trainer” course in Amsterdam in February 2014. This three-day training course was used to teach us how self-management programmes could be modified and implemented in each country to fulfil our particular needs.

In Malta, with the collaboration of a consultant from the Health Promotion and Disease Prevention Directorate with whom we had worked on other projects, ARAM came together and adapted the course materials to Maltese culture. Various meetings were held to plan each session including the translations of handouts about food and exercise plans.

Positive experience

The name of the course was “Kors Hajja Ahjar-kif niehu hsieb tieghi nnifsi” meaning “A course for a better life – how to deal with my condition” because we wanted to make sure that it was a positive experience. The course involved six 2.5 hour group sessions held weekly. The interventions were conducted according to a written manual: in our case we used Kate Loring’s handbook from the Stanford programme.

We held our first course last year from 29 April to 3 June, led by two qualified trainers, myself and Marie-Therese Camenzuli. The course was well received by the 11 participants who described it as a very positive experience, and it was another great achievement for ARAM.

The work of our association is ongoing. A smile on a member’s face is enough to motivate the association to be more creative and innovative about new endeavours for the common good of its members.

ARAM won the poster prize for the Most Successful/Innovative Campaign at the EULAR Annual European Conference held in Zagreb on 7–9 November in 2014.