Dear friends,

Time keeps moving on, and World Arthritis Day (WAD) is just around the corner!

October 12 has become one of the most anticipated dates in our community. Organisations prepare their advocacy and lobbying activities giving voice to the 120 million people we represent all over Europe. Each individual living with a rheumatic and musculoskeletal disease (RMD) feels connected to a wider community that really understands what it means to live with such conditions.

Time2Work is the current theme for the EULAR campaign Don't Delay, Connect Today (see below), and will provide a full year of activities to promote WAD's main objectives: raising awareness of RMDs and how they profoundly affect lives and livelihoods; bringing together people with RMDs, health professionals and scientific societies to work for change; and encouraging decision-makers to take action to reduce the overall burden of these diseases.

In 2019/20, we will focus on the importance of work for people with RMDs, and its impact on their economic and social integration. This is the theme of the forthcoming EULAR Brussels Conference (see page 3). Of course voluntary work is as equally important and rewarding as paid work, so we have featured it in this year’s Edgar Stene Prize competition (see page 3).

I cannot overstate the importance of these EULAR PARE initiatives. Both in my personal life, and in my journey as patient advocate, they have certainly inspired me and had a positive impact on my life, leading me to leadership roles.

I hope this issue will inspire you too. #ConnectToday and have a very special World Arthritis Day!

Elsa Mateus, Chair, Standing Committee of PARE

The EULAR Don’t Delay, Connect Today – Time2Work campaign celebrates World Arthritis Day

"Employers can support the well-being of people with RMDs; work is a critical part of building self-esteem and it's a tragedy that so much talent is lost from the workforce" says Professor Iain McInnes, President of EULAR on World Arthritis Day (WAD) 2019.

For 2019/2020, Time2Work is the focus of EULAR’s Don’t Delay, Connect Today campaign which is committed to raising awareness of the importance of early diagnosis of RMDs. Early diagnosis, early referral to a rheumatologist and early access to effective treatments are known to improve outcomes, quality of life and the ability to work.

EULAR marks World Arthritis Day on 12 October by promoting campaign related activities and material on social media and the web, and by issuing a press release. The launch of a dedicated campaign toolkit, as well as a series of ‘Day in a Life’ videos (which portray the daily life of a person living and working with an RMD), are powerful campaigning tools.

Many organisations already take action – read more on the EULAR website to find out how EULAR member organisations across Europe are using the campaign to best effect. Share your 2019 WAD activities with the hashtags #ConnectToday and #Time2Work and follow the World Arthritis Day social media accounts at @ArthritisDay and @worldarthritisday! Thank you for taking action this WAD!
This year the PARE Board meeting took place in Berlin on 6-8 July. It was the first PARE Board meeting chaired by Elsa Mateus, newly elected Chair of the EULAR Standing Committee of PARE. A range of issues were covered during the meeting – Young PARE challenges, review of the functioning and roles of the Standing Committee and PARE Board, PARE activities outside the Working Groups, updates on on-going PARE projects and future activities.

To open the meeting Elsa Mateus gave her vision and objectives for the next two years. The main focus will be on PARE volunteers by developing a volunteering framework, and proposing a volunteering policy within EULAR. Education and empowerment will be implemented through the EULAR School of Rheumatology PARE Classroom, and by maintaining the high quality of the PARE conference and the PARE programme at the EULAR Congress. Research, and the involvement of patients in it, will be developed further by optimising the EULAR patient research partner network. Advocacy and awareness of rheumatic and musculoskeletal diseases (RMDs) will be achieved by raising the visibility of the PARE community and its needs, and by enhancing collaboration among the three EULAR pillars: PARE, health professionals in rheumatology, and scientific societies.

In order to support these objectives the PARE Board decided to create two new Working Groups. The first - “PARE member organisations liaison, and internal and external affairs” - led by Polina Pchelnikova, is dedicated to reviewing the PARE Board Terms of Engagement, flagging up membership issues, updating the database of PARE organisations, exploring possible new members and conducting surveys among national organisations. The second Working Group - “Volunteers Task Force” - led by Elsa Mateus, will maintain and develop the EULAR volunteer network by developing the EULAR volunteers database, promoting voluntary opportunities, motivating volunteers to get and stay involved, and acknowledging voluntary work through a certificate. New PARE Board member Jeanette Andersen has replaced Polina as leader of the PARE Editorial Board.

The question of upcoming vacancies in various Working Groups was also discussed. The next call for volunteers will be launched on 15 November 2019. So if you would like to contribute to PARE activities and be involved in some exciting projects, keep in touch with your national EULAR member organisation of PARE for news of how to apply.

Abstracts for EULAR 2020, Frankfurt!

The EULAR abstract submission process will be open from 1 November – 31 January 2020. It is your chance to share your organisation’s success with the worldwide rheumatic and musculoskeletal disease (RMD) community. For Frankfurt 2020, the PARE programme will have an exciting range of sessions: patient participation in research; family planning and relationships; management of members and volunteers; how to cope with an RMD and managing treatment outcomes and work. The Scientific Committee eagerly awaits your submissions and hopes to receive an exciting range of abstracts showcasing best practice and activities from the PARE community!

Knowledge Transfer Programme

The Knowledge Transfer Programme is a grant programme for EULAR PARE member organisations designed to improve and apply skills by learning from the experience of other organisations in the EULAR network.

Calls for proposals launched: 12 September 2019
Webinar on how to fill in applications: 3 October 2019
Deadline for submissions: 10 November 2019

Please upload your completed application to: https://esor.eular.org/course/view.php?id=126

Dates for your diary

- 12 October: World Arthritis Day
- 29 October: World Psoriasis Day
- 1 November - 31 January 2020: Abstract submissions for EULAR 2020
- 10 November: Deadline Knowledge Transfer Programme
- 20 January 2020: Deadline for Edgar Stene Prize essays
EULAR Public Affairs Update: What does “the new EU” mean for people with RMDs?
by Neil Betteridge, Strategic Affairs Adviser, Public Affairs EULAR

EULAR’s Public Affairs activities take place at different levels geographically:
1) national, 2) EU, 3) the whole of Europe, and 4) also sometimes globally. However, recent European Parliament elections, and the establishment of a new Commission this year, mean that the EU is our current focus.

With the new Parliament, we will continue the collaboration we had during recent parliamentary terms, when more than 20 MEPs supported the Interest Group on rheumatic and musculoskeletal diseases (RMDs), and met in the Parliament regularly. But we now need to win the respect of new policymakers, and to gain their support going forward. This is why EULAR’s 2019 World Arthritis Day Conference in Brussels is entitled “A sustainable and effective EU health policy for citizens: Focusing on chronic diseases and inclusion in social and economic life”.

The aim of these annual conferences is to develop policy recommendations to support our advocacy actions. Led by Gerd Burmester as Liaison Officer, we aim to ensure EULAR makes a highly visible contribution to the dialogue with policymakers on shaping upcoming EU health policies. The conference also addresses the economic and social integration of people with RMDs and other chronic conditions, on which we can build further advocacy activities on our priority topic of ‘work’.

EULAR is also launching our ‘vision paper’ on the future of European health policies, stressing the need for concrete action from the EU on tackling chronic diseases such as RMDs. Health and employment/social affairs policies must be coordinated to meet the challenge of long-term conditions in particular. We call on policymakers to ensure that citizens and patients are at the centre of policy decision making. This means an even stronger role for PARE members, whose voice must be heard at national and EU levels to ensure policymakers ‘get it right’ for people with RMDs.

Edgar Stene Prize Competition 2020
by Ovidiu Constantinescu, Editorial Board member

“Being a person with a rheumatic or musculoskeletal disease (RMD) - How my voluntary work benefits me”

This is the thought-provoking theme put forward for the 2020 Edgar Stene Prize Competition. People living with RMDs across Europe are invited to write about their experiences in helping others, and about their work for the community. We all know that voluntary activities are as challenging and rewarding as any paid work. Sharing with others the reasons that made you get involved in the first place, what drives you in such endeavour, the rewards and moral benefits that you enjoy at the end of the day, may be an inspiration to others to become a volunteer. Helping others to cope with the difficult moments in their life can have beneficial effects both for the individuals and for the community. Therefore it is important that such experiences are shared and acknowledged by all.

The Edgar Stene Prize competition offers a good platform for a wide geographical spread of people living with RMDs to share their experiences of coping/taking advantage of their local circumstances (cultural, legal, health facilities, health financing etc.) in carrying out volunteer activities. Entries will be first judged by their respective EULAR member organisation of PARE in a national competition. Essays, not exceeding 2 pages (A4), may be submitted in the writer’s own language. Each national jury will select the best entry from their country (only one entry) and send it to the EULAR Secretariat by 20 January 2020 for consideration by the EULAR Edgar Stene Prize Jury. The winner will be announced by 15 March 2020.

The Edgar Stene Prize winner will be invited to attend the Opening Plenary Session of the 2020 EULAR Congress in Frankfurt and will receive €1,000 prize money.

Please see the EULAR website for more information.
EULAR recommendations for the management of antiphospholipid syndrome in adults
by Prof. Maria Tektonidou, University of Athens, Athens, Greece

Due to the rarity of antiphospholipid syndrome (APS), its wide clinical spectrum and the lack of high-quality randomized clinical trials, the formulation of guidelines for the management of APS has been both a dire necessity and a difficult task. “EULAR recommendations for the management of APS in adults” were therefore developed to address this issue, aiming to provide evidence-based recommendations for APS stemming from a combination of expert opinion and a systematic review of the relevant literature. A task force of specialists (including patient research partners) from 11 European countries tackled four pivotal questions regarding the prevention and treatment of different forms of APS:

- risk stratification and modification in asymptomatic individuals with positive antiphospholipid antibodies (aPL);
- primary and secondary prevention of thrombosis in APS;
- management of obstetric APS; and
- catastrophic APS (CAPS) treatment.  

BACKGROUND

Antiphospholipid syndrome (APS) is a systemic autoimmune disorder manifesting as venous and/or arterial thrombosis or obstetric complications, secondary to elevated production of antiphospholipid antibodies (aPL). APS can occur in a primary form (primary APS, PAPS), in combination with other autoimmune diseases such as systemic lupus erythematosus (SLE) or in the rare, severe and sudden onset, form of catastrophic APS (CAPS) leading to multorgan failure. There are three types of aPL including anticardiolipin (aCL) and anti-beta2 glycoprotein (anti-β2GPI) antibodies, as well as lupus anticoagulant (LA).  

The qualitative and quantitative characterization of aPL such as their type, single-, double- or triple-positivity, titer, and persistence of positivity in repeat measurements, formulate the “aPL profile”. Stratification of patients into those having low- and high-risk aPL profiles is considered as one of the main pillars on which the varying recommendations are based. Proposed risk attenuation measures are comprised of lifestyle modifications, emphasizing the importance of treatment adherence and eliminating cardiovascular and venous thrombosis risk factors. 

RECOMMENDATIONS

As far as pharmacological treatment of APS is concerned, different substances including low-dose aspirin (LDA), vitamin K antagonists (VKA), heparin, hydroxychloroquine (HCQ) or immunosuppressive agents can be used variably in accordance to each different clinical scenario.

- Administration of LDA is recommended for asymptomatic aPL carriers, patients with SLE without history of thrombotic or obstetric APS, and non-pregnant women with prior obstetric APS, if high-risk aPL profiles are present.
- Patients with first unprovoked venous thrombosis should receive VKA with a target international normalized ratio (INR) of 2-3, while in those with first arterial thrombosis VKA treatment of a target INR of 2-3 or 3-4 can be considered, according to each individual bleeding/thrombosis risk.
- In patients with recurrent thrombotic events despite an appropriate treatment, either adding LDA to the treatment regimen, increasing the target INR to 3-4 or using low molecular weight heparin are effective alternatives. Use of direct oral anticoagulants (DOACs) is not recommended in patients with a history of vascular thrombosis and triple aPL positivity.
- In pregnant women with prior obstetric APS, prophylactic dose of heparin should be used in conjunction with LDA. In women with recurring pregnancy complications despite a combination treatment with prophylactic dose heparin and low dose aspirin, therapeutic dose of heparin plus LDA, or add-on therapy with either HCQ or low-dose prednisone during the first trimester, are appropriate treatment options.
- First line treatment of CAPS includes a combination therapy with glucocorticoids, heparin and plasma exchange or intravenous immunoglobulins.

Following the formulation of the current recommendations for APS in adults, an emerging need for more high-quality studies is evident. To this end, a plan in the form of a research agenda has been drafted by the task force, underlining the main points on which future studies should be focused. Further clarification of the pathogenetic mechanisms of APS along with studies focusing on how the different phenotypes of the syndrome may respond to various treatment types are necessary in order to facilitate the expansion and improvement of the current recommendations so as to achieve better quality of care for individuals with APS. 

The full recommendations can be viewed on the EULAR website. A lay version will be available soon.

Juvenile arthritis has a great impact on the lives of young people. They face problems with the invisibility of the disease, and can have issues with explaining their symptoms and showing how they feel. To visualise the invisibility of juvenile arthritis, Youth-R-Well.com published around 30 cartoons on their website. They were developed by Rens van Vliet (27) who lives with juvenile arthritis himself. The cartoons tell stories about his life with juvenile arthritis. They are funny and very recognisable to those who live with arthritis.

The cartoons are so successful that Youth-R-Well.com decided to publish the cartoons in a comic book. Besides the cartoons, we also wanted to provide more information about the various topics that are covered in the cartoons. As a result, the comic book also contains information for young people with juvenile arthritis, such as how to deal with employers. By combining the fun cartoons with relevant information, the comic book is very popular among young people. Youth-R-Well.com has published 500 copies of the book which can also be viewed online. They are also distributed to hospitals, so that young people can read them while they are waiting to see their specialist.

We hope other organisations are inspired by our comic books and will start similar projects, so that we can support more young people with arthritis around Europe.

You can find the comic books (in Dutch) on the Youth-R-Well.com website.

For many years, the Cyprus Ministry of Health has declined the Cyprus League Against Rheumatism’s (CYPLAR) request to hire rheumatology nurses for governmental hospitals because there were no trained nurse specialists, or even any nurses interested in being trained in rheumatology. Challenge accepted!

After many discussions with the Education Department of the Government Nursing Services, we persuaded them to organise an educational programme for nurses, and to agree to have CYPLAR as an associate in the structure, development and presentation of the programme.

27 Nurses have now been trained on the three-month course “Patient Care with Rheumatic Diseases”. The programme included lectures on rheumatology, physiotherapy, paediatric rheumatology, podiatry, diet, psychology, the role of nurses, patients, etc. There was also a three-day clinical exercise and a visit to a day-care department to learn about the preparation and delivery of biological and biosimilar treatments. Lectures on patient perception, disease awareness, treatment and management were given by CYPLAR’s psychology staff and volunteer patient experts.

Following completion of the programme, CYPLAR surveyed the participant nurses. The results were very encouraging. The importance of CYPLAR’s contribution to the programme scored very highly (62% absolutely important; 19% very important; 19% important). Asked about their interest in working as a rheumatology nurse, or having further training, 100% responded positively.

In conclusion, CYPLAR has proved the importance of the contribution of patients to better understanding and treatment of rheumatic and musculoskeletal diseases (RMDs). It has also demonstrated to the Cyprus health services that there is a need for rheumatology nurses, and that there is a clear interest by nurses in that role.

The next challenge: A second education programme, and the placement of rheumatology nurses in the outpatient rheumatology clinics!
“Me and my dilemma”
by Connie Ziegler, Gigtforeningen - Danish Rheumatism Association

“Can I go to my sister’s wedding in my really ugly shoes?”
“My rheumatic and musculoskeletal disease (RMD) is not visible. Often I am yelled at when I park my car with the blue badge visible”

“Should I reveal at a job interview that I have arthritis?”

During the EULAR Congress 2019 in Madrid, Gigtforeningen was honoured to present a Danish campaign called “Me and my dilemma”.

In 2018, Gigtforeningen had decided to raise awareness of the range of challenges people living with RMDs face on a daily basis. Many find that those around them – relatives as well as others – have difficulty understanding the struggles and dilemmas faced by those living with a chronic disease. Gigtforeningen involved its supporters by asking them for examples of dilemmas from their daily life. We had about 100 responses and we established 4 ‘dilemma shows’ in malls around Denmark. We had a known-from-tv journalist to moderate the shows where a panel of 4 famous Danes discussed the dilemmas in an entertaining, yet respectful way.

At each show we had 100-300 people in the audience who also participated in the discussions. The ‘dilemma shows’ had a broad appeal. They were entertaining and serious at the same time. The shows were an eye-opener both for the panel and the audience. We recorded all the shows and afterwards we produced 5 great podcasts, made up of extracts from each show. The podcasts are: Social life, Love & Friendship, Work life, Everyday life, and Children & Teens. These podcasts have now been downloaded more than 5,100 times.

Gigtforeningen has also produced other podcasts (all in Danish), and you can find them at https://www.gigtforeningen.dk/podcast/

Overall our podcasts have been hugely successful and have been downloaded more than 61,000 times.

Would you like to read about your national organisation’s activities in one of the next issues? Please send your article (300 words max and photographs) to birte.gluesing@eular.org

The European League Against Rheumatism (EULAR) is the organisation which represents people with rheumatic and musculoskeletal diseases (RMDs), health professionals and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. Within EULAR, the national organisations of People with Arthritis/Rheumatism in Europe (PARE) work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

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The Standing Committee of PARE would like to thank all those who have contributed to this newsletter.

EULAR supports the Global Alliance for Musculoskeletal Health
http://bjdonline.org