New Year message from the EULAR President

Hogmanay is the traditional Scottish celebration at New Year time, usually spent with family, when thanks are given for the good times past, and thoughts turn to the opportunities and challenges of the year ahead. Plans are made and resolutions agreed with the utmost sincerity! Thus, for the ‘EULAR family’, what might be our Hogmanay resolutions?

Of course, we have our strategy set towards 2023 and across those ambitious targets we are moving apace with purpose and ambition. EULAR has a busy agenda and is making remarkable progress in so many areas encompassing political, clinical and educational life. To accommodate this, we have a renewed structure and remarkable secretariat to whom I must offer my profound gratitude for the work that they do for us all.

In this my first New Year as EULAR President, where do I see particular excitement? Well firstly, this wondrous age of molecular discovery, combined with unprecedented opportunities in artificial intelligence and e-Health, has led us to the cusp of a new era of medicine. In many respects, rheumatology has led the way recently with the advent of biologic medicines, and more recently small molecules, that have brought remarkable benefits for people with rheumatic and musculoskeletal diseases (RMDs). Similarly, the strategies whereby such medicines are used are becoming ever more complex as the health professional/patient partnership evolves. But many RMDs are underserved by current treatments and many unmet needs remain.

For this reason, EULAR is working towards a new approach to strengthen RMD research in Europe through the creation of a virtual research centre. Though early days, this promises to revolutionise the way in which research into RMDs will be delivered across the continent utilising the state-of-the-art technologies of this new age of discovery.

Second, and commensurate with this ambition to move ahead, I am especially encouraged to see our partnerships growing on a global basis – our friends in ACR, PANLAR, APLAR and AFLAR* are increasingly part of our community, as we are of theirs, and as we work together, I envisage continued development for all people with RMDs at the global level. Now that really is a resounding thought with which to start our New Year! And so a Gaelic toast to all as we start this new year, 2020: Slàinte mhath!

Time to wish and time to act

Dear Friends

Every new year brings along a review of past achievements and a chance to build new goals upon things we were not able to accomplish so far. The beginning of another cycle encourages you towards resolutions for a better year, strongly supported by hope. In our wish-list we usually include health, happiness, love, prosperity, success, and mostly, the fulfilment of our dreams.

How often do we dare to wish for a cure for RMDs? We learn to establish realistic goals and aim for achievable and measurable objectives.

Nevertheless, this is the time to wish, and we have 365+1 more opportunities to act, either in our daily and personal lives, or as a member of a wider community. Research, quality of care, education, and advocacy are being addressed within our EULAR community, as you can read in this issue of e-Breakthrough. Let us believe and follow the quote: “A dream you dream alone is only a dream. A dream you dream together is reality.” May we all be able to actively contribute so that 2020 brings us meaningful breakthroughs in every aspect of our daily lives.

Elsa Mateus, Chair, Standing Committee of PARE

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EULAR Study Group - Non-pharmacological treatment of autoimmune CTDs; Kussmaul Medal ............................................ 2
EULAR Public Affairs Update: The importance of collaboration in the new EU environment ................................................ 3
Lupus Europe exercise programme; Latest lay versions of EULAR recommendations ....................................................... 4
EULAR’s ‘Time2Work’ campaign and World Arthritis Day 2019 .......................................................... 5
Sjögren Europe .......................................................................................................................... 6

*ACR - American College of Rheumatology; PANLAR - Panamerican League of Associations for Rheumatology; APLAR - Asia Pacific League of Associations for Rheumatology; AFLAR - African League of Associations for Rheumatology
EULAR Study Group: Non-pharmacological treatment of autoimmune connective tissue diseases

by Carina Boström, Study group leader

People with autoimmune connective tissue diseases (CTDs) can live with several related impairments and experience limitations to their day-to-day activities. Many of these diseases are rare and complex, and clinical practice guidelines are missing. A systematic review showed that evidence for non-pharmacological care in systemic sclerosis (SSc), for example, is limited due to the wide variety in interventions and outcomes. Different referral, treatment targets and content of interventions mean that non-pharmacological care in SSc varies across Europe.

Health professionals in rheumatology (HPRs) expressed a wish to develop a wider network to explore the common features and treatment approaches for people with other CTDs – such as systemic lupus erythematosus, antiphospholipid syndrome, mixed connective tissue disease, Sjögren’s syndrome and myositis.

There is little research-based evidence available about patient education, lifestyle behaviour change programmes, psychosocial and self-management programmes, physical and occupational therapy etc for people with CTDs. However, there is some evidence of the positive effects of non-pharmacological interventions such as enhanced working life and exercise therapy. It was therefore thought that a EULAR study group focusing on the common areas across CTDs would facilitate research activities and help direct consensus.

The overarching aim of our newly-approved study group is to improve and standardise care, and to reduce the variation in care for people with CTDs. The group has several objectives including identifying areas where variation in care and rehabilitation exists; developing evidence-based guidelines for the care of people with CTDs through systematic reviews and EULAR recommendations for non-pharmacological treatment, and implementing better evidence and standardised care pathways across EULAR member countries.

Bringing together a multidisciplinary group of expertise in CTDs from a range of EULAR member countries will help to build critical mass to work systematically on evidence-based outcomes, treatments, recommendations and implementation of non-pharmacological treatment of these diseases. The group is open to all EULAR HPRs, medical doctors and patients with an interest in non-pharmacological treatment and related issues. People living with CTDs are important collaborators within this study group.

In order to increase knowledge about CTDs and non-pharmacological treatment, some study group members have started working on a new module about SSc for the HPRs online school within the EULAR School of Rheumatology. We have also decided to apply for a Task Force for a EULAR recommendation of non-pharmacological treatment in CTDs. We hope that the study group will contribute with increased knowledge about non-pharmacological treatment in CTDs and to the implementation of our research activities across Europe.

Kussmaul Medal awarded to Dieter Wiek

Dieter Wiek, EULAR Vice President, representing PARE, and Vice President of the Deutsche Rheuma-Liga, the German patient organisation in EULAR, has been awarded the Kussmaul Medal by the Deutsche Gesellschaft für Rheumatologie e.V. (DGRh), the German Society for Rheumatology.

The medal was presented to Dieter Wiek by the DGRh to mark his outstanding commitment in raising awareness of rheumatic and musculoskeletal diseases (RMDs), and in fighting for better care for those affected, as well as representing their voice at national and European level. The award ceremony took place at the opening of the 47th congress of the DGRh in Dresden, Germany, in September 2019.

Dieter Wiek said, “It is an honour to be awarded the Kussmaul Medal. I am delighted to be involved in the area of RMDs, to contribute to those who need better care, and it is a privilege to represent their voice at national and European level. I look forward to carrying this mission forward into the future.”

The Kussmaul Medal was first awarded in 2006, with the tradition continued on an annual basis by the DGRh. The medal is given to people who are recognised as being outstanding in their life’s work in rheumatology as well as to those who have demonstrated an exceptional contribution to rheumatology in Germany.
The importance of collaboration in the new EU environment: a Public Affairs update

by Neil Betteridge and Gerd Burmester, EULAR Public Affairs

2019 has been a very important year for the future of EU health and social affairs policies. The Parliamentary elections and the establishment of the new European Commission represent an opportunity to consider the role of the EU in improving the health of EU citizens, but also in promoting the socio-economic inclusion of people living with rheumatic and musculoskeletal diseases (RMDs) and other chronic conditions.

To facilitate discussion on the future of EU health policies, EULAR organised its annual World Arthritis Day Conference in Brussels in October 2019 on “A sustainable and effective EU health policy for citizens: Focusing on chronic diseases and inclusion in social and economic life”. The aim of the conference was to develop policy recommendations to EU and national policy makers on how to improve the effectiveness of health policies. In particular, their contribution to facilitating the participation of people with RMDs and other chronic conditions in the labour market (see the EULAR website for conference report, videos and presentations).

EULAR also launched its Vision Paper on the future of European Health Policies. The document presents EULAR’s recommendations to improve the effectiveness of EU health policies in the coming years, focusing on:

- The EU needs to be more ambitious and show its commitment in the area of public health. The new Commission also needs to strengthen support to Member States’ in fighting chronic diseases.
- It should finally deliver “health-in-all-policies”, ensuring good co-ordination between health and other policy areas (in particular, employment and social affairs, which play a central role in the participation of people with these conditions in the labour market).
- The Commission should strengthen the impact of its health policies. For instance, by defining concrete, actionable strategies on major chronic diseases such as RMDs.
- The EU should be more involved in improving access to quality health care. For instance, by promoting the development of integrated health care models and e-Health solutions.
- Finally, decision-making on European health policy should assign a central role to patients and patient representatives. ‘Nothing about us without us!’ as PARE would (rightly!) say.

EULAR believes that these measures would help the EU become closer to citizens and demonstrate in sceptical times the added value it can bring through progressive and effective policies.

Commenting, Ovidiu Constantinescu, Romanian League Against Rheumatism, said: “Keeping people with RMDs active is an investment, not a cost. Ensuring early access to diagnosis and optimum care enables them to be active and, ultimately, to work. Work done by RMD patients is also important for their well-being, when they see their efforts are recognised by the people around them.”
Rheumatology news

Lupus Europe exercise programme
by Jeanette Andersen, Chair, Lupus Europe

In collaboration with trained physical therapists, Lupus Europe has developed a five level exercise programme which has been endorsed by leading European lupologists. Not only can people with lupus benefit from the exercise programme, it can be safely used by all patients with rheumatic and musculoskeletal diseases (RMDs)!

My idea for the programme began, when I heard Prof. Frederic Houssiau at the 2016 EULAR Congress in London, explaining, how the only scientifically proven effective treatment for lupus fatigue is moderate exercise. When you tell this to any patient suffering from a chronic disease, however, you will get a very tired look back, saying "I am too exhausted to exercise!" (especially if it is said by a doctor). I felt the same way, but I think the key is not to think of ‘exercise’ as having to be like running a marathon or going to the gym for an hour. Of course, we would like people to do that, but even a little movement is better than nothing. When I was in a wheelchair for almost two years, I found it very frustrating not to be able to work out at all (before my diagnosis I used to be a fitness instructor and my daily life included at least one or two hours of strenuous workout) and asked my physical therapist, if she could find exercises that I could do lying down. Together, we developed a programme for me, which evolved as I got better, and continued after I had major back surgery and a new prosthetic knee, up until the point where I was actually able to go out for a run.

As a lupus patient myself, I know that levels of energy can change from day to day and that is why the programme is divided into five levels. From the first one - when you are lying down; level two - when you are sitting down; level three - standing up; level four – standing/walking; ending with level five - when you are able to run and jump. Normally, you would start at level one and then slowly progress through the different levels until level five, but that is not always possible. The goal is to do one of the levels fitting your energy level each day. All exercises can be done without training tools and in the individual videos you can see the various options for increased or reduced difficulties. Each programme takes 10-20 minutes.

Accompanying the videos are five pamphlets with explanations of the exercises at each level. The entire programme (videos and pamphlets) will be available for downloading from the Lupus Europe website shortly.

Latest lay versions of EULAR recommendations

Lay version of the EULAR recommendations for physical activity in people with inflammatory arthritis or osteoarthritis
Overall there are four overarching principles and ten recommendations. The overarching principles stress that physical activity is part of a healthy lifestyle and a general concept that can improve quality of life, and that physical activity has health benefits for people with inflammatory arthritis or osteoarthritis. Importantly, the recommendations for the level and frequency of physical activity that were developed for the general population, are effective, safe and feasible for people with these types of arthritis. Before beginning an exercise programme, each person’s physical activity plan should be worked out with their healthcare provider, and should take into account personal preferences, needs and abilities.

Lay version of the EULAR recommendations for the management of people with gout
Overall, there are three overarching principles and eleven recommendations. The overarching principles say that every person who has gout should be told about how the disease develops, what complications or other associated diseases they might get, and what treatments are available. People with gout should also be told how to manage individual attacks, and how to keep urate levels low. Every person with gout should receive lifestyle advice on how to manage their weight. People with gout should avoid alcohol, sugary drinks, and not eat too much meat or seafood. Regular exercise should be advised. Finally, if you have gout your doctor should check whether you have any other linked diseases, and whether you are at risk of developing a cardiovascular disease in the future.
EULAR’s ‘Time2Work’ campaign on World Arthritis Day 2019
by Peter Boyd, Young PARE Board Member

To mark EULAR’s ‘Time2Work’ campaign and World Arthritis Day 2019, many events took place across Europe, organised by EULAR’s national member organisations.

In Austria, national EULAR PARE member organisation ‘Rheumaliga’ marked its 25th anniversary in grand style, assisted by its growing cohort of young, active members. An interactive walk through Salzburg took place with members of the public spray-painting onto volunteers wearing black bodysuits, targeting where they thought a rheumatic or musculoskeletal disease (RMD) might hurt. The young members also asked the public if they thought people living with a RMD could work, play sport, study etc. The highlight of the day, at the end of the walk, was a giant ‘flash mob’ of old and young people dancing to “Uptown Funk”. The energy was tangible, and a bond created between everyone there: old and young, those with a RMD, and those without. Nobody felt alone any more.

That evening, a gala took place where the ‘Rheuma Prize’ was presented to employers, nominated by employees with RMDs, for the support they had offered in the workplace. Young Rheumaliga members recalled how their lives had been before diagnosis, how they had dealt with the diagnosis, fought back, learned more about their condition and arranged new lives for themselves and, at the same time, tried to study, find or retain work, enjoy a private life, stay active, cope with the condition and medication, and plan a family.

All in all, Rheumaliga organised a brilliant day to showcase the EULAR ‘Time2Work’ campaign and mark World Arthritis Day.

Meanwhile in Malta, national EULAR PARE member organisation, Arthritis and Rheumatism Association Malta (ARAM), held a half-day seminar on 21 October at the House of Representatives in Valletta. As well as presentations from the leaders of ARAM, EULAR President Prof. Iain McInnes (via video message) and Dieter Wiek, EULAR Vice-President representing PARE, were also invited to speak to the Maltese Parliament about EULAR and its ‘Time 2 Work’ campaign.

ARAM also raised awareness of the importance of entering and staying in employment, and discussed with policy makers the barriers to employment encountered by those living with RMDs and, more importantly, how they could be overcome. A patient representative, Roderick Agius, eloquently recalled how six years ago he had been diagnosed with psoriasis, which then developed into psoriatic arthritis. The pain in his hand joints, wrists, knees and shoulders is constant but he stressed that he should have better working conditions without having to beg. He said that all he wanted was that society understood without him having to explain, adding “I don’t want people to pity me”.

To conclude, The Speaker of the House of Representatives, Dr Anġlu Farrugia, thanked ARAM for its outstanding work in raising awareness about RMDs in Malta by sharing information between the general public and those living with RMDs in silence.

For further information about EULAR’s ‘Time2Work’ campaign, please see the EULAR website.
The idea of Sjögren Europe - a user-led federation of national patient organisations for Sjögren’s - emerged in Washington D.C. in April 2018 when several patient representatives met during the 14th International Sjögren’s Syndrome Symposium. We wanted to raise visibility and awareness, help researchers and clinicians to address the numerous unmet needs, and articulate patient voices throughout Europe.

During the EULAR Congress in Amsterdam in June 2018, we met with the representatives of various federations (e.g. Lupus Europe, FESCA*), and representatives of other organisations (e.g. EULAR, HarmonicSS*, FOREUM*, EUORDIS*, PARE) and doctors asking for advice on various aspects. Reactions to the project were enthusiastic, including on how it would merge the voices, perspectives and needs of patient communities from different European countries. Therefore the decision to create Sjögren Europe was made.

During summer and autumn of 2018, there was an important learning and networking process: we had the first contacts with the other patient associations; chose a name; drafted the by-laws, and designed a logo. Winter saw the creation of a website and the setting up of a Medical Board. Finally, on 23 February 2019, Sjögren Europe was officially launched with 10 countries as founder members.

The federation itself is now pioneering motivational ways of working. Patient representatives with extensive fatigue are encouraged to work flexibly, leading to lean and efficient methods, crucial in our new and innovative setting. Developing a good network and efficient collaboration will help us to establish an enthusiastic, supportive and meaningful community.

Meeting in person and working to create Sjögren Europe has made us realise how helpful it is to co-ordinate our forces. A better future for Sjögren’s patients is now not only a wish or a dream but a reality that we can build together.

For further information please see www.sjogreneurope.org

*FESCA - Federation of European Scleroderma Associations aisl
*HarmonicSS - a private-public funded research project entitled ‘HARMONIsation and integrative analysis of regional, national and international cohorts on Sjögren’s Syndrome (pSS) towards improved stratification, treatment and health policy-making’
*FOREUM - Foundation for Research in Rheumatology
*EUORDIS - Rare Diseases Europe

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

Follow EULAR and World Arthritis Day on Facebook, Twitter and Instagram

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