Don’t Delay, Connect Today

Dear PARE friends,

In case you have not heard about EULAR’s important new campaign, don’t hesitate to find out more: Connect Today! The importance of early diagnosis of a rheumatic or musculoskeletal disease (RMD) cannot be overstated. To avoid permanent damage, it is so important to start treatment as soon as possible.

The three pillars of EULAR (organisations of people with RMDs, health professionals in rheumatology and scientific societies) will therefore focus on early diagnosis with the major campaign ‘Don’t Delay, Connect Today’. Bring the campaign to the notice of your organisation, and your country too, and help us to spread the message all over Europe.

On World Arthritis Day (WAD), 12 October, EULAR will launch a video to stress the importance of early diagnosis. Don’t forget to visit the WAD website and tell us how your organisation is planning to mark the day.

On 17 October 2017, the Annual EULAR Conference in Brussels will focus on health research and the challenge to overcome the very real impact of RMDs on individuals and on our societies.

The European Union’s support for research and innovation in the field of RMDs has increased over the last few years, which is, of course, important to reduce the burden of these diseases. We want to focus on increasing efforts to understand, prevent, diagnose and treat our conditions.

Within PARE, we will start our new internal arrangements this autumn. To make sure PARE remains a strong platform in the future, we will need your help and expertise. Volunteers from all over Europe are the heart of our organisation and indispensable to the work of PARE. If you think you can contribute to our task please contact your national organisation.

Enjoy the remainder of 2017.

All the best

Nele Caeyers
Chair, Standing Committee of PARE

EULAR Congress, Amsterdam
Abstract submission system ready to receive your contributions!

From 1 October 2017 to 31 January 2018 the EULAR abstract submission system for the EULAR Congress 2018 in Amsterdam is open and ready to receive your contributions! Your contributions are crucial in making the PARE programme relevant and interesting for your fellow delegates and to showcase the latest developments within the rheumatic and musculoskeletal diseases (RMD) community from all over Europe. We count on you to share your campaigns, projects and expertise! If you submit an abstract you can also apply for a bursary. Please note that this is a separate application process. Follow the instructions on the EULAR Congress website carefully. If you have any questions about abstracts or bursaries, please contact Birte Glüsing at the EULAR Secretariat: birte.gluesing@eular.org.

We look forward to receiving a great variety of PARE abstracts!
New EULAR Vice President representing PARE

It was a great honour for me to be elected the new EULAR Vice President representing PARE and to succeed Marios Kouloumas. I’ve worked with Marios very closely as Chair Elect and Chair of PARE in the past 3 years and he has done a tremendous and extraordinary job. I would like to thank him for his great work.

I regard it as a priority of my work to strengthen the ties with national EULAR PARE member organisations, and to support their activities for improving prevention, healthcare, rehabilitation, and research in their countries, and in Europe. In some countries there exist several patient organisations for rheumatic and musculoskeletal diseases (RMDs) that are not our member organisations. So it should be our aim to encourage organisational structures that enable the inclusion of these organisations, as it is essential to reach as many people with RMDs as possible.

The old slogan “Nothing about us without us” has not lost its validity. This means that people with RMDs, and our representatives, demand adequate representation in issues that affect us, and an influential role in the relevant decision-making processes. And this assumes that patient organisations are user-led, and that people with RMDs play a pivotal role. PARE’s Engagement Programme is an important instrument to achieve these goals.

As a member of the EU Public Affairs Group I will contribute and raise my voice at pan-European level to advocate for RMD research and the improvement of patients’ healthcare. I also look forward to developing the PARE classroom of the EULAR School of Rheumatology with a new team of volunteers.

Co-operation, transparency and team spirit characterise PARE’s and EULAR’s way of working. Collaboration between the PARE board members, the PARE leadership, the secretariat and the EULAR leadership have been excellent in the past and I’m looking forward to working with all members on our collective goals.

EULAR Secretariat

After 10 years and an outstanding commitment as a member of PARE’s support team, Florian Klett, PARE Programme Manager, has decided to move on to a new field in the rheumatology arena and to focus more on his work for FOREUM – the Foundation for Research in Rheumatology. However, we are delighted that Florian will continue to work with EULAR on many other activities, such as the EULAR Campaign ‘Don’t Delay, Connect Today’. PARE will therefore continue to be able to benefit from his enthusiasm, expertise and friendship in the future!

Some of you had the pleasure to meet a new addition to our PARE support team during the EULAR Congress in Madrid – Alzbeta Göhmann, who joined the secretariat in May 2017 taking over from Florian. Please join us in giving Betka a warm welcome to the PARE family!

“As PARE Project Co-ordinator I am now responsible for the EULAR Patient Research Partner project including coordinating the network and implementing the upcoming tasks, and connecting the researchers and patient research partners. I also support the Young PARE group and provide them with administrative help and background information. My third main task is the Knowledge Transfer Programme support. Prior to EULAR, I have always worked with people and built and coordinated networks, so the work for PARE comes naturally to me and I really enjoy it.” says Betka.
To mark the occasion, EULAR has developed a dedicated video for the ‘Don’t Delay, Connect Today’ campaign for World Arthritis Day. Three people, each living with a different RMD, share their personal story and information about their life, lifestyle and RMD management.

Emotive and personal, the stories are designed to not only educate the viewer, but also to inspire: For these three people, early diagnosis and access to excellent care has provided them with the chance to adapt to and learn to manage their health needs, while living a meaningful life – where no opportunity to participate in society and all that life offers is denied to them. Please share the video widely to ensure that we reach the general public with our important message.

The EULAR Campaign ‘Don’t Delay, Connect Today’ was developed by the league’s three membership pillars: people with RMDs in Europe (PARE), health professionals in rheumatology and the scientific communities. Addressing society at large, the campaign has been designed to raise awareness and understanding on RMDs and to motivate people to recognise possible health warning signs that their bodies may be experiencing and to take action immediately by contacting their healthcare provider.

“Early diagnosis is key to preventing further damage”

Promoting this rapid response activity is what EULAR Past President Prof. Gerd R. Burmester has labelled the ‘Window of Opportunity’ – the time-frame in which early diagnosis can prevent RMDs from progressing and causing irreversible damage to the body. Early diagnosis is key to preventing further damage, but RMDs often receive delayed or no diagnosis. This is often due to a lack of awareness, thereby reducing quality of life, affecting physical ability and ultimately placing devastating psychological burden on the individual – and on health care systems, which could otherwise be avoided.

World Arthritis Day continues to be a key event in the rheumatology calendar, with EULAR reaching out to millions across Europe and the world each year on 12 October. In a further and connected step, EULAR will hold a World Arthritis Day Conference in Brussels on 17 October, ‘The future of EU health research and innovation. Do we need a novel approach?’. EULAR President Prof. Hans Bijlsma (left) together with keynote speakers will lead the one-day event and create a platform for discussion, debate and future-thinking regarding the role of, and opportunity for, RMDs in EU policy-making beyond 2020.

Will you #ConnectToday?

For more information visit eular.org and worldarthritisday.org

Follow @eular_org and @ArthritisDay on Twitter

See the World Arthritis Day pages on Facebook and Instagram.
New targets for early interventions in rheumatoid arthritis

Promising findings of international collaboration in BeTheCure*

by Susanne Karlfeldt, Florian Klett and Maarten de Wit

This year the successful international collaboration BeTheCure (BTCure) came to an end. This European public-private research initiative started in 2011 and studied early phases of developing rheumatoid arthritis (RA). More than 90 researchers participated in the final closing meeting in Prague on 5-7 February 2017 and presented the latest findings of their work.

The researchers studied promising biomarkers that may predict the onset of RA in healthy subjects who are at risk of developing RA. A biomarker can be a cell or chemical substance in the body that is objectively measured and evaluated as an indicator of a normal or abnormal biological process. A biomarker can be found, for example, in blood, urine, bone or synovium and tells us something about the presence, severity or progress of a disease process. By looking at auto-antibodies, in particular at the function of ACPA (anti-citrullinated protein antibodies), RF (rheumatoid factor) and anti-CarP (anti-carbamylated protein antibodies), BTCure identified important new biomarkers for future research. New biomarkers that play a role in the autoimmune system are potential targets for new treatments or even for preventing the onset of disease.

Building collaborative research networks

Florian Klett and Maarten de Wit, both members of the Patient Advisory Board, attended the meeting and learned more about the results of the project. According to the investigators, the benefits of the BTCure project are twofold: Firstly, all involved researchers expanded their network and approached fellow researchers for advice and assistance, something they would not have done five years ago. Learning about other people’s specific research knowledge and competences made it possible to resolve difficult challenges. This led to unique collaborations, including the exchange of samples, tissues, and knowledge.

Better understanding of the onset of RA

Secondly, the results show progress in our understanding of the pathogenesis of RA. International collaboration showed a shift in research to earlier stages of the disease. We are now able to detect abnormalities in the immune system in people who have only minor or even no joint symptoms at all. Treatment of people with preclinical signs of disease is important in order to prevent the activation of the immune system and to ensure that any abnormalities in the cells are immediately suppressed. It means that the onset of RA may possibly be preventable at an early stage, with drug free remission, and without any damage to the joints, which has always been a characteristic of the disease.

Follow-up programme

Currently we are not there yet. There are still important gaps in our knowledge of the immune system. Therefore a follow up research application has been developed. This new project, called RTcure, aims to translate the research findings into interventions or tools that can be used in the clinic. This might result in the longer term in effective screening tools and interventions for the prevention or earlier treatment of RA.

Patient involvement in basic research

Patient involvement in basic research is challenging. During the past five years we have tried to identify moments where patient research partners (PRPs) can provide meaningful input to improve the research activities. PRPs participated in meetings; we developed the Patient Advisory Board; EULAR joined action for protecting health and scientific research in the EU Data Protection Regulation; we distributed the letter of Appeal on animal model work to PARE organisations and national government; and helped to disseminate research findings.

How should patients contribute to our future research projects?

At the end of the closing meeting, 82% of the participants confirmed that patients should be involved throughout the life-cycle of a research project. The most important value for them was the fact that “patients keep us aware for whom we are doing research”. They also noted that there is a role for patients in co-designing research questions and disseminating research findings.

(continued on page 5)
New targets for early interventions in rheumatoid arthritis (continued from page 4)

Lessons learned
In BTCure we learned more about the necessary conditions to enhance stakeholder involvement in the design and conduct of a large international research initiative. It is important to:

- Involve patient organisations and PRPs right from the start, preferably at the project design phase
- Adapt research and meeting protocols to allow for meaningful patient engagement
- Ensure a governance structure for implementing meaningful and sustainable patient involvement throughout the lifecycle of the project
- Provide sufficient resources, for instance, to appoint a designated patient engagement coordinator
- Provide guidance and education to both PRPs and researchers.

For patient organisations with an interest in research please visit www.eular.org
For more information about BeTheCure please see http://btcure.eu

Involving Patient Research Partners in Euro-TEAM*
(Towards Early diagnosis and biomarker validation in Arthritis Management) by Diana Skingle

EURO-TEAM was a four year (2012-2016) multidisciplinary project funded by the European Union, with 16 partners in collaboration across Europe, which aimed to develop approaches to predict the onset of rheumatoid arthritis (RA) in people who do not yet have the disease. The key research was to identify biomarkers and disease mechanisms leading to RA, and the translation of these findings into improved information for those at risk. 9 Patient Research Partners (PRPs) participated in the project. The final report of the project has now been published: http://cordis.europa.eu/result/rcn/194541_en.html Below is an extract from the final report summary that refers to the impact of the involvement of PRPs in Euro-TEAM:

Potential Impact: Integration, patient involvement and the development of new networks:
The patient focused legacy of Euro-TEAM has allowed closer integration and working between academic units, industrial partners (SMEs)* and Patient Research Partners, enhancing the deliverability, quality and relevance of the work carried out within the current project. Importantly, it has catalysed future collaborative work on other related projects (e.g. the IMI-PREFER consortium).

The integration of the patient perspective and Patient Research Partners throughout the project has been particularly valuable. For example, they have ensured that the development and use of commercially available kits takes place in an environment where issues of relevance to individuals who are having their “risk” determined are understood and addressed. This has been particularly valuable for our SME partners. Historically, Patient Research Partners have been most involved in clinical research, outcomes research and psychosocial research. The effective integration of Patient Research Partners into this translational research project was an important and positive outcome. Our experiences of PRP involvement in such a project at a European level have helped define best practice in this field.

Through PRP involvement we have:
- ensured that patients are involved in shaping the research agenda, and therefore that our research is of value to patients
- facilitated the production of efficient, patient centred research, thus speeding up the clinical translation of our research into new treatments and clinical services that are of direct benefit to patients
- involved patients in the development of the design of research procedures and patient facing materials, thus enhancing their experience of participating in clinical research
- promoted collaboration between researchers and patients that is mutually advantageous, where researchers learn from patients and vice versa. Many of our patient research partners are appreciative of opportunities to contribute to research. Feedback on our activities from PRPs has been very positive .... Furthermore, many of our researchers, both from clinical and non-clinical backgrounds have benefitted greatly from understanding the patient perspective and therefore adapting their future research to better fit genuine needs and priorities.

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CORDIS http://cordis.europa.eu/

Euro-TEAM Patient Research Partners:
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* Small-to-medium enterprises

*BeTheCure: IMI JU funded project 115142-2. The Innovative Medicines Initiative (IMI) is a public-private partnership and Joint Undertaking between the European Union and the pharmaceutical industry association, EFPIA.

*BeTheCure: IMI JU funded project 115142-2. The Innovative Medicines Initiative (IMI) is a public-private partnership and Joint Undertaking between the European Union and the pharmaceutical industry association, EFPIA.
Federation of European Scleroderma Associations (FESCA aisbl) is an umbrella group of national scleroderma associations from 19 EU countries, and this year FESCA is celebrating its 10th birthday!

It has been 10 exciting and fast growing years for FESCA’s members and collaborative partners, not only within Europe but in the Americas, Australia, and elsewhere. Our focus has been on sharing awareness-raising campaigns, information, supporting research and practical strategies.

Since 2009, almost all members of FESCA have celebrated World Scleroderma Day on 29 June. The date was chosen by FESCA at a meeting in 2008 to honour the gifted Swiss artist - Paul Klee - who died on 29 June 1940. He was strongly influenced by his illness, systemic sclerosis (scleroderma), which his paintings illustrate.

For the past few years, FESCA has chosen a campaign for World Scleroderma Day, in which all our members have been able to take part. This year the slogan was ‘Scleroderma will not take my smile’. A poster (see below) and leaflet were produced and translated into many languages so they could easily be adapted by our members. We also invited people with scleroderma from all over the world to take a photograph and post it on social media using the hashtag #ScleroSmile. That way, not only Europe participated, but we saw pictures from many countries around the world.

We have already started planning the next World Scleroderma Day and hopefully we will be able to show the campaign at the next Systemic Sclerosis World Congress, which will take place in Bordeaux, France on 15-17 February 2018.

Read more about FESCA and World Scleroderma Day on www.worldsclerodermaday.org www.fesca-scleroderma.eu

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 and Twitter

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

EULAR supports the BJD
www.boneandjointdecade.org

The Bone and Joint Decade Preserving musculoskeletal health
Keep people moving