

## Poster Presentations

THURSDAY, 15 JUNE TO SATURDAY, 17 JUNE 2017

### Building patient led organisations

#### PARE0001 GROWING STRONGER TOGETHER: IMPLEMENTING EULAR YOUNG PARE'S STRATEGY

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**Background:** In a recent European youth survey, 53% reported that rheumatic and musculoskeletal diseases (RMDs) affected their ability to work, while 75% reported that RMDs interrupted their education. Therefore, in 2017 and 2018, while continuing to achieve the objectives reached in 2015 and 2016, EULAR Young PARE will focus on two key points from EULAR Young PARE's strategic objectives: work and education.

**Objectives:** In 2017, in line with EULAR's efforts to raise awareness of the needs of people with RMDs among employers and other stakeholders, the specific and still unmet needs of young people with RMDs will be highlighted, so that employers and other stakeholders will be more aware of the needs of young people with RMDs and young people will receive better support to find a suitable job. In 2018, education for young people with RMDs will be in focus, so that educational institutions across Europe will be more flexible and assistive in supporting high quality education for young people with RMDs.

**Methods:** In 2017, we will support EULAR's lobbying activities by raising awareness among employers and other stakeholders about the needs of young people with RMDs. We will also provide information to support young people in finding suitable jobs and to be aware of their rights in the workplace. Best practices concerning ergonomics, support programmes, career counselling and suitable jobs will be collected and shared. In 2018, we will support educational institutions across Europe to be more flexible and assistive in providing high quality education for young people with RMDs by offering training and support to national youth leaders.

**Results:** Thanks to the results achieved in 2015 and 2016, it is anticipated that structures will be in place to continuously raise awareness among employers, medical staff in schools, teachers and unions about the competencies and limitations of young people with RMDs. These activities enable EULAR Young PARE to expand and strengthen the active network of youth groups across Europe. Every PARE organisation will have a PARE youth liaison person, who will be encouraged and supported to take active roles in their national organisations and in the EULAR community.

**Conclusions:** The objectives reached by EULAR Young PARE in 2015 and 2016 are closely related to its future aims and achievements, allowing EULAR Young PARE to grow stronger and continue its work by the side of young people with RMDs, in order to improve their quality of life.

#### References:

[1] EULAR Young PARE. Available from: <http://www.youngpare.org> [accessed on 30 January 2017].

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### Arthritis research

#### PARE0002 CELEBRATING TEN YEARS OF SUCCESSFUL PATIENT INVOLVEMENT IN RESEARCH OF INFLAMMATORY CONDITIONS

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**Background:** In 2016, the Research Institute (RI), Primary Care and Health Sciences, Keele University, UK, celebrated 10 years of Patient and Public Involvement and Engagement (PPIE) in research of musculoskeletal and other long term conditions. Our Research User Group (RUG) with over 90 members with a range of long-term conditions, actively work with research teams on studies. Many of whom have been involved in ten studies of different inflammatory conditions. We provide two case studies: 1) CONTACT: a trial comparing the effectiveness and side-effects of two commonly-used drugs (Naproxen and low-dose Colchicine) to treat acute gout in primary care; 2) A qualitative interview study with people with rheumatoid arthritis (RA) who had attended a nurse-led review clinic, which included identifying people at risk of anxiety and depression.

**Objectives:** To describe how PPIE helped shape the design and delivery of the CONTACT and qualitative interview studies.

**Methods:** 1) For the CONTACT trial, two RUG members with experience of gout joined the Trial Steering Committee. Another seven RUG members formed an advisory group to provide the patient perspective on trial procedures.

2) For the qualitative interview study, a group of eight people with RA from a local rheumatology centre (*Haywood User Group*) commented on the documents for the ethics application and met to discuss data analysis and dissemination.

**Results:** 1) In the CONTACT trial, RUG members made a difference by:

- Commenting on the trial design and acceptability of the drug intervention
  - Helping to produce clear and user-friendly information sheets for participants in the trial.
  - Provide practical advice regarding how participants were recruited
- Future RUG involvement will include helping to interpret the trial findings planning further dissemination and discussing future research studies.

2) In the qualitative interview study, the PPIE group:

- Contributed to the development of readable patient questionnaires for use in the clinic
- Offered their perspectives on the interpretation of the qualitative data
- Helped develop a leaflet to inform patients about mood problems related to rheumatoid arthritis and where help could be sought
- Contributed to the establishment of an RA annual review clinic at the local hospital
- Advised on the dissemination of results to a lay audience
- Generated ideas for a study about the delivery of RA annual review clinics in primary care, supporting a related grant application

**Conclusions:** Both studies demonstrated the wide-ranging benefits of PPIE input throughout the research cycle of identification, designing, managing and disseminating research. The RI will continue to involve patients with long-term conditions in studies for the benefit of the wider patient community.

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### Work and rehabilitation

#### PARE0003 ASSESSMENT OF PAIN AND IMPORTANCE OF EXERCISE IN HIP OSTEOARTHRITIS

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**Background:** Osteoarthritis (OA) of the hip is a common condition which affects men and women of all ages. The cartilage becomes damaged. Stiffness and reduced range of movement are common. The pain experienced from OA of the hip may be felt in your lower back, buttocks and groin. You may also feel pain from your hip in your leg and down into your knee. This is called referred pain. The goals of OA treatment include alleviation of pain and improvement of functional status. Optimally, patients should receive a combination of nonpharmacologic and pharmacologic treatment. A physiatrist may help in formulating a nonpharmacologic management plan for the patient with OA.