

This is a repository copy of EULAR Young PARE: The voice of young people with rheumatic diseases across Europe.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/106649/

Version: Accepted Version

# **Proceedings Paper:**

Andersen, J, Stones, SR orcid.org/0000-0002-5943-1310, Balážová, P et al. (4 more authors) (2016) EULAR Young PARE: The voice of young people with rheumatic diseases across Europe. In: Annals of the Rheumatic Diseases. 17th EULAR Annual European Congress of Rheumatology, 08-11 Jun 2016, London, United Kingdom. BMJ Publishing Group, pp. 1325-1326.

https://doi.org/10.1136/annrheumdis-2016-eular.4979

This is an author produced version of a paper published in Annals of the Rheumatic Diseases. Uploaded in accordance with the publisher's self-archiving policy.

### Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

## **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



# PARE Member (People with Arthritis and Rheumatism in Europe)/Patient

Topic area: PARE abstracts

Topic: Patient information and education

#### **EULAR16-4979**

EULAR YOUNG PARE: THE VOICE OF YOUNG PEOPLE WITH RHEUMATIC DISEASES ACROSS EUROPE
J. Andersen\* 1, 2, 3, S. Stones 1, 4, 5, P. Balazova 1, 6, L. Van Nieuwkoop 1, 7, T. Papastavrou 1, 8, N. Caeyers 9, F. Klett 10
1 Young PARE, EULAR, Zurich, Switzerland, 2 Lupus Europe, Essex, United Kingdom, 3 SLE/LUPUS UNG DK,
Figtforeningen, Gentofte, Denmark, 4 Paediatric Rheumatology CSG, NIHR CRN: Children/Arthritis Research, Liverpool, 5
Faculty of Life Sciences, University of Manchester, Manchester, United Kingdom, 6 Slovak League Against Rheumatism,
Piestany, Slovakia, 7 Youth-R-Well.com, Rotterdam, Netherlands, 8 ELEANA Hellenic League Against Rheumatism,
Athens, Greece, 9 ReumaNet Jong&Reuma, Bresserdijk, Belgium, 10 EULAR, Zurich, Switzerland

My abstract has been or will be presented at a scientific meeting during a 12 months period prior to EULAR 2016:

Is the first author applying for a travel bursary and/or an award for undergraduate medical students?: Yes Is the first author of this abstract an undergraduate medical student?: No

Please confirm that you will apply for the travel bursary on the EULAR website www.congress.eular.org: Yes Background: The group of Young Patients with Arthritis/Rheumatism in Europe (PARE) in EULAR, the European League Against Rheumatism, is a network of young people, from across Europe, living with a rheumatic or musculoskeletal disease (RMD) and working with a patient organisation in their country. They volunteer their time to represent young people with RMDs within EULAR PARE, advocating for better care, communication and quality of life for individuals, under 35, across Europe.

**Objectives:** When the group was established, objectives were designed to:

(1) establish and strengthen national RMD youth groups across Europe; (2) create and support the European network of RMD youth groups to exchange best practices; (3) empower youth leaders; and (4) ensure that the voice of young people with RMDs is heard on all levels in society.

**Methods:** EULAR Young PARE are actively involved in local, national and international activities to support young people with RMDs. Members of EULAR Young PARE developed an action plan to communicate and promote their work, embedding the youth perspective into and supporting all EULAR PARE activities.

**Results:** A strong voice of young people, especially at the Annual European Conference of PARE, has been established, with topics delivered and dedicated to the needs of young people. All PARE activities and projects now entail a young person living with an RMD, feeding back into the Young PARE working group. Furthermore, strengthening collaboration with the EMEUNET network is a leading example of how we learn together.

**Conclusions:** Young PARE have moved forward considerably over the last twelve months, gathering and sharing information about the ways that young people with RMDs are supported in European countries. Now, EULAR Young PARE is continuing to unite patient organisations across Europe, helping to raise awareness and make a difference to young people living with RMDs while challenges remain. It is important to keep the network sustainable, and EULAR Young PARE committed to working on this over the coming years.

**References:** EULAR Young PARE. Available from: http://www.youngpare.org [Accessed 13 December 2015]. **Acknowledgement:** Special thanks to EULAR and EULAR PARE for supporting the vision of EULAR Young PARE. EULAR Young PARE would also like to acknowledge all of the patient organisations that they continue to work with.

Disclosure of Interest: None declared