

**Annual European Congress of Rheumatology  
(EULAR 2018)**

Amsterdam, The Netherlands, 13-16 June 2018

**YOUTH-R-COACH: A PEER-TO-PEER PROGRAM FOR YOUNG PEOPLE SUFFERING  
WITH CHRONIC DISEASE**

Young people empowered to be 'experts-by-experience' share their personal experiences to help other young people cope with chronic disease

**Amsterdam, The Netherlands, 14 June 2018:** The details of a youth project presented today at the Annual European Congress of Rheumatology (EULAR 2018) demonstrate how, by empowering patients to become 'experts-by-experience', young people can give support to peers as well as provide insights into living with a chronic illness as a young person.<sup>1</sup>

"Youth-R-Coach is a fantastic program supporting young people living with rheumatic or musculoskeletal disease by empowering select individuals to share their experiences. The initiative supports Young PARE in our mission to ensure that society is aware of the millions of young people living with rheumatic and musculoskeletal disease throughout Europe and how best to support them," said Petra Balážová, Chair, Young PARE. "We hope that this will inspire other similar projects in other parts of the world."

Youth-R-Coach is a Dutch project that works with individuals aged between 18-27 who have a rheumatic or musculoskeletal disease (RMD), supporting them to recognise their "expertise-by-experience" and to act as a coach to their peers. The focus of the project is the development of self-written books, with support of a writing coach, which are based on personal experiences of living with an RMD. Each book is very different with some writing short columns, and others producing an entire novel. What all the books have in common is that they aim to make their experiences available for peers, to act as a source of support in dealing with their disease. The books are also intended for a wider audience, such as family members, teachers and healthcare professionals, as they provide valuable insights into living with a chronic illness as a young person.

"Our Youth-R-Coach program has been a great success," said Linda van Nieuwkoop, program advisor and mentor for the Youth-R-Coach program of Centrum Chronisch Ziek en Werk. "We have been amazed by the energy and enthusiasm of all the participants to share their experiences and act as a coach to their peers. We are delighted with the diverse range of books that we hope will support other young people coping with a rheumatic or musculoskeletal disease as well as other chronic conditions."

The Youth-R-Coach program works with groups of seven individuals and involves a portfolio of assignments. Even though the process is an individual one, the program includes a group kick-off meeting, a weekend training and a final group meeting in which workshops are provided to teach new skills such as 'online coaching' and 'presenting'. All participants shared a mentor, who also has an RMD, and the group stay in contact during the program and help each other with the portfolio and writing of their book.

The aim is to provide participants with useful tools for coping with, and teaching others about their disease. How the participants use their new-found skills following the program is down to personal interests and competencies.

Youth-R-Coach is a Dutch project of Centrum Chronic Illness and Work in collaboration with Youth-R-Well.com, made possible by the FNO Foundation. The books are available at [www.bol.com](http://www.bol.com). Direct links to each book can be found at <https://youth-r-well.com/youth-r-coach/>.

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### **NOTES TO EDITORS**

**For further information on this study, or to request an interview with the study lead, please do not hesitate to contact the EULAR Press Office:**

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### **About Rheumatic and Musculoskeletal Diseases**

Rheumatic and musculoskeletal diseases (RMDs) are a diverse group of diseases that commonly affect the joints but can affect any organ of the body. There are more than 200 different RMDs, affecting both children and adults. They are usually caused by problems of the immune system, inflammation, infections or gradual deterioration of joints, muscle and bones. Many of these diseases are long term and worsen over time. They are typically painful and limit function. In severe cases, RMDs can result in significant disability, having a major impact on both quality of life and life expectancy.<sup>2</sup>

### **About 'Don't Delay, Connect Today!'**

'Don't Delay, Connect Today!' is a EULAR initiative that unites the voices of its three pillars, patient (PARE) organisations, scientific member societies and health professional associations - as well as its international network - with the goal of highlighting the importance of early diagnosis and access to treatment. In the European Union alone, over 120 million people are currently living with a rheumatic disease (RMD), with many cases undetected.<sup>3</sup> The 'Don't Delay, Connect Today!' campaign aims to highlight that early diagnosis of RMDs and access to treatment can prevent further damage, and also reduce the burden on individual life and society as a whole.

### **About EULAR**

The European League against Rheumatism (EULAR) is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with RMDs. EULAR aims to reduce the burden of RMDs on individuals and society and to

improve the treatment, prevention and rehabilitation of RMDs. To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action.

To find out more about the activities of EULAR, visit: [www.eular.org](http://www.eular.org).

## References

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<sup>1</sup> Van Nieuwkoop L, van Geene L, Janssen R. Youth-R-Coach, a program for youth with a chronic disease. EULAR 2018; Amsterdam: Abstract OP0173-PARE.

<sup>2</sup> van der Heijde D, *et al.* Common language description of the term rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR). *Annals of the Rheumatic Diseases*. 2018;doi:10.1136/annrheumdis-2017-212565. [Epub ahead of print].

<sup>3</sup> EULAR. 10 things you should know about rheumatic diseases fact sheet. Available at: <https://www.eular.org/myUploadData/files/10%20things%20on%20RD.pdf> [Last accessed April 2018].