

Youth-R-Coach: A peer-to-peer program for young people suffering with chronic disease

June 14 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.

"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 Baláková, 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. Direct links to each book can be found at <https://youth-r-well.com/youth-r-coach/>.

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