



eular

EULAR standing committee of PARE youth working group

PARE youth strategy 2015-2020

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## Executive summary

This document outlines the PARE youth strategy, which is in line with the objectives chosen by the EULAR Standing Committee of PARE (SC PARE) in the overall EULAR strategic plan “Vision 2020”. Over the last five years, the SC PARE has deliberately sought to incorporate the perspective of young people with Rheumatic and Musculoskeletal Diseases (RMDs) in all activities and projects. By organizing youth workshops, EULAR congress sessions on youth with RMD aspects, appointing youth representatives in PARE task forces and inviting additional representatives to the EULAR Annual European Conference of PARE, it has emphasized the importance of the involvement of young people. Arthritis is not a disease of people of older age but can affect every individual at every age. Apart from the specifics of young people compared to the older target group, qualitative interviews also revealed the challenge of seeing young adults as people learning to be autonomous persons, building up their own lives, integrity and careers separated from their parents and childhood home. Finally, active young people with RMDs are the future leadership of the national patient organizations and deserve special attention.

For these reasons, in 2012 the SC PARE initiated a youth project with the aims to conduct research into the needs, preferences and barriers of young people with RMDs and to develop a youth strategy for 2015-2020.

This project has now come to an end. The findings of the research project were published in 2013 and provided the basis for extensive discussions among an international group of active youth leaders about the PARE youth strategy.

This document outlines eight strategic objectives with several suggested actions that will be helpful in the future to inspire and guide all stakeholders to implement this youth strategy. Implementation cannot be done by one party only. It requires collaboration of all individuals and organizations that commit themselves to improve the quality of life of young people with RMDs. The joint efforts of EULAR, national organizations of patients, health professionals and scientific societies is needed to ensure that young people can live independently and receive support tailored to their specific circumstances. This can be done by raising awareness of the needs of young people, promoting support programs developed for young people, establishing and strengthening national youth groups, and building a European network of youth leaders (Young PARE).

## Purpose of the PARE youth strategy

The SC PARE currently has delegates from 39 organizations, consisting of representatives of 35 national EULAR member patient organizations and 4 European disease specific umbrella organizations, known as PARE organizations, plus the PARE Board as management body.

The youth task force has started its own network of young people with RMDs aged 18-35 years in Europe. This network is called Young PARE, the same name as the website that has been used for the youth project. According to the PARE youth research report; half of the PARE organisations do not have a youth group<sup>1</sup> or do not organize activities for younger people.

The impact of RMDs on young people is often neglected. Therefore, all stakeholders, including EULAR, national patient organizations, disease specific umbrella organizations, health providers and policy makers should give more attention to this specific target group. We believe that the youth perspective will make a difference in EULAR.

PARE organizations often try to organize activities for younger people with RMDs. Empowering youth groups all over Europe is important to improve health care for young people, but also in the context of capacity building to guarantee sustainability now and in the future.

However, to be truly effective, it is important that young people with RMDs develop their own groups, strategies and activities and that they are fully integrated into the existing structures.

All previous actions by the SC PARE to become more inclusive in terms of young people with RMDs have been done on an ad hoc basis, without official recognition, strategy or plan of action. With this youth strategy, it is aimed for EULAR to fully recognize the importance of the youth perspective.

Based on research carried out over the past two years, it is now possible to set concrete goals for the future, embedded in EULAR's strategy and the implementation work carried out in PARE. This strategy document addresses the needs of youth groups and PARE organisations to improve the services to young people with RMDs by enhancing international collaboration and integrating the perspective of young people with RMDs in EULAR.

Therefore, this document presents strategic objectives in prioritized areas. A more detailed plan of action for 2015-2016 is available as an official project proposal for the implementation of the objectives.

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<sup>1</sup> In this strategy document, the words 'youth group' and 'youth organization' are used interchangeable. Youth groups can be independent legal entities, informal networks of young people, virtual communities or part of an adult organization such as the PARE member organizations.

## Methodology

The PARE youth strategy is based on the PARE youth research project, which has been carried out over the past two years. In 2012 the PARE youth task force started an explorative study, using mixed methods. The challenge was to incorporate elements of participative and action research and to collaborate as much as possible with representatives from the target group. The aims of the task force were to gather information on the needs, preferences and barriers of young people with RMDs between 18 and 35 years and to get an overview of youth activities in European countries.

For the first phase, a questionnaire was sent out to 39 PARE organizations in order to map youth activities throughout the countries. During the second phase, national researchers were involved in a qualitative study in five countries. Interviews and focus group meetings were organised in Cyprus, Estonia, Germany, the Netherlands and Sweden. The findings of this qualitative research were analysed and discussed during a two-days extended youth task force meeting in Tallinn (March 2013). This meeting, gathering 11 youth representatives, resulted in a detailed overview of six main areas that have an important impact on the lives of young people with RMDs.

In the third phase, based on the previous qualitative research, the Task Force developed a 31 item electronic survey. After being translated into 18 languages, the survey was launched all over Europe on the 1<sup>st</sup> of July and closed on the 19<sup>th</sup> of September 2013. To support the outreach and dissemination of the survey, the Task Force built the [Young PARE](#) website. 3501 people responded in total. After excluding those without RMDs or not belonging to the target age group, the data of 2329 respondents, coming from 41 European countries, were analysed, presented and discussed during the youth workshop at the PARE conference in Reykjavik, and published in the “Final Report - PARE youth research project” (January 2014).

In 2014 the youth Task Force was renewed and started the fourth phase of the youth project. Based on the data of the pan-European survey, the task force developed 8 country fact sheets (see Annex) and organized a two-days international youth strategy meeting in October 2014 (Tallinn). 27 youth representatives discussed the outcomes of the entire youth research project and gathered input for the development of the PARE youth strategy. During and after the youth workshop at the PARE Conference in Zagreb (November 2014), the task force formulated 8 strategic objectives, including sets of suggested actions and a more detailed proposal for implementation.

## **Vision and Mission of Young PARE**

**Young PARE is a European network of national youth leaders led by the PARE youth working group.**

### **Vision**

**Young PARE aims to improve the quality of life of young people with rheumatic and musculoskeletal diseases (RMDs).**

### **Mission**

**Young PARE aims to establish and strengthen national youth groups all over Europe, create and support the European network of youth groups to exchange best practices, empower youth leaders and ensure that the voice of young people with RMDs is heard on all levels of society.**

## Young PARE strategic objectives

1. By 2020, national youth leaders are integrated into EULAR, especially the EULAR Standing Committee of PARE.
2. By 2020, there is more awareness in society of the specific needs of young people with RMDs.
3. By 2020, health care services are interdisciplinary, more holistic and focused on the need of tailor-made information, including social and psychological support for young people with RMDs.
4. By 2020, educational institutions across Europe are more flexible and assistive in supporting high quality education of young people with RMDs.
5. By 2020, employers and other stakeholders are more aware of the needs of young people with RMDs and young people receive more support to find a suitable job.
6. By 2020, Young PARE campaigns for societal changes that make the world more inclusive for young people with RMDs.
7. By 2020, every European country has an active national youth group\* for young people with RMDs.
8. By 2020, PARE has established an active European network of national youth groups called Young PARE.

## **1. By 2020, national youth leaders are integrated into EULAR (the Standing Committee of PARE).**

### **Suggested actions**

- Incorporating the perspective of young people with RMDs in all activities, task forces and programs of the EULAR SC of PARE.
- Establish a permanent youth working group within the structure of the EULAR SC of PARE
- Providing secretarial support and assistance to the youth working group, in particular by supporting the development of project proposals.
- Encouraging youth representatives, youth leaders to participate in all activities of PARE and educate them to become future PARE leaders.
- Providing special sessions, workshops and projects for the European network of national youth groups (Young PARE)

Over the last 5 years, the SC PARE has started to integrate young people in all activities. Until now, there is no official international youth group and we recommend that the current PARE youth task force will be transformed into an ongoing working group within the PARE structure. The current youth leaders want to take ownership over the PARE youth strategy and take responsibility and concrete tasks to put the strategy in practice. Over the last year, the youth task force has received support from the EULAR secretariat, which was very beneficial for capacity building. Young people want to be involved and this is also expected by the national organisations and groups. In order to establish a sustainable youth working group and European youth network (Young PARE) it needs ongoing secretarial support to develop and implement the annual plans of action, to support national youth liaison persons and national EULAR member PARE organizations.

The youth working group should be integrated by having a youth representative in every PARE working group and the PARE board to make sure the voice of young people is heard.

To achieve all of the suggested actions, Young PARE should be facilitated to educate and empower youth leaders through the support of leadership training programs, theme development of a virtual knowledge centre on [www.youngpare.org](http://www.youngpare.org) and the establishment of an international network of national youth groups in cooperation and agreement with national PARE (mother) organisations.

## **2. By 2020, there is more awareness in society of the specific needs of young people with RMDs.**

### **Suggested actions**

- Developing campaign materials and programs for national youth groups and PARE organizations to approach different stakeholders.
- Organizing empowerment and educational activities for youth leaders.
- Providing regularly consistent updates on the Young PARE website and social media pages.
- Feeding tailor made messages and activities to SC PARE in campaigning for changing the public image of RMDs as a disease of older people.

The impact of RMDs on young people is often neglected. Therefore, all stakeholders, including EULAR, national patient organizations, health care providers and policy makers should give more attention to the specific needs of this target group. Young people need to raise awareness in society about the fragility of their wellbeing and the issues that need to be addressed, often in another way than for other age groups. Young PARE could help EULAR disseminating information; improve public knowledge and understanding, to improve conditions for young people suffering from RMDs.

There is a need to focus more on the transition from child care into adult care. In some countries young people are not allowed to separate and grow up as individuals. They are often kept in the role and mindset of a child for a very long time which hinders their development towards independent citizens. From our qualitative interviews we learned that for some young people this transfer is poorly managed with examples of young people not having a doctor at all anymore, because they have no information how to find a rheumatologist for adults.

The society should be aware of the fact that an RMD can be an invisible disease. People affected by it do need specific care and consideration. The needs of young people with RMDs ought to be recognized and understood through empowerment and support.

Another important issue is the fear of disclosure. Young people experience barriers to express their feelings or fear to speak about their disease, not only to their peers but also to teachers or employers or even to family members. A safe place for young people should be created outside the doctor's office. National youth groups are the perfect solution to this particular issue. Young people meet their peers with the same problems and they can share their feelings along with their worries. National groups could also provide necessary support in terms of educational materials, workshops and presentations (mostly with health professionals, such as a psychologist, a physiotherapist, a rheumatologist, along with a life



coach). When young people learn to talk about their disease in a “safe group”, then at a later stage they might be willing to start talking publicly and in the end lobby on national level for recognition of RMDs on younger age. PARE organizations are encouraged to develop and support the activities of such youth groups to ensure activities are in agreement with overall national action plans on tackling RMDs.

### **3. By 2020, health care services are interdisciplinary, more holistic and focused on the need of tailor-made information, including social and psychological support for young people with RMDs.**

#### **Suggested actions**

- Gathering best practices of health care, in particular around psychosocial support programs, tailored to young people with RMDs and based on a holistic approach.
- Providing templates for educating young people with RMDs such as materials, websites and social media campaigns.
- Stimulating the international exchange of self-management programs and other (peer-) support programs.
- Providing the groundwork for EULAR to develop international standards of care for young people with RMDs.
- Stimulating further interdisciplinary activities in and outside EULAR, such as e.g. inviting health professionals specialized in transition and youth health care to contribute to PARE events and activities.

There are three main challenges of young people with RMDs to access health care.

The first challenge is the lack of access to rheumatologists and the care for social and psychological factors such as coping with the diagnosis and fear of chronicity. Health professionals should pay more attention to the overall impact of the disease. Young people ask for a more holistic approach, time to discuss issues like fatigue, depression and dealing with misunderstanding in society and want access to psychological support if needed.

The second challenge is the lack of information. Most information like the health care system is medically driven, focused on the signs and symptoms of the disease and on drugs and side effects. Young people are not well informed about their disease, available support programs and patient rights or the regulations that exist in their country.

Patient education can take place in the hospital, carried out by health professionals providing access to information, e.g. where they can find special health care to physiotherapists or occupational therapists, what their rights are and what kind of patient organizations exist.

Our research has shown that members of a patient organization have better quality of life and have better access to rheumatologist and information. Patient organizations are a good source for information, peer education and mental support. Education should be focused on the opportunities of young people rather than the limitations, for instance an extra year to finish studies if you have a chronic condition.

Patient organizations play an important role in supporting communication between young people: By, i.e. using social media and organizing activities young people will start talking to each other and information will flow automatically.

The third challenge is the long time between first symptoms, diagnosis and start of treatment, sometimes up to 10 years. Young PARE should be instrumental in pointing to the need for EULAR to promote the education of general practitioners, to learn recognising the key signs and symptoms of RMDs in young people early. Collaboration with other Standing committees in EULAR is envisaged to identify gaps in current education, such as the EULAR Health Professionals or paediatrics. Rheumatologists could benefit from the views of Young people with RMDs in identifying the best possible moment when to refer young people to other specialists such as a psychologist or a physiotherapist. In countries where specialized nurses in rheumatology exist, can play an important role in empowering young people.

Young people should learn to be more assertive, ask questions and become their own specialist, able to self-manage their disease, once diagnosed. For some diseases the development of national care pathways, following the disease journey of a young person could help to make the health system more tailored to the need for a holistic approach, better patient education and improved communication between health professionals.

Young people should therefore also be actively supported to self-organize but with strong links to the national patient organization, if not already embedded in the overall national patient organization to ensure a good flow of communication.

## **4. By 2020, educational institutions across Europe are more flexible and assistive in supporting high quality education of young people with RMDs.**

### **Suggested actions**

- Establishing a virtual knowledge center with best practices on supporting young people with RMDs during their studies.
- Providing support and education to national youth leaders by gathering best practices and developing materials.
- Educating, training and empowering youth leaders about patient rights and practical skills to advocate.
- Raising awareness of the public in general, medical staff at schools, teachers and unions about the competences and limitations of young people with RMDs.

Education plays a vital role in every young person's life. The PARE youth research report showed that many young people cannot finish their studies with nominal time. Respondents gave several reasons for this, demonstrating that often small things matter. Firstly, we have to focus on empowering and guiding young people to be able to share their limitations with teaching staff.

Personal challenges: lack of understanding from teachers and other staff at school, fear of disclosure and lack of availability or know-how of individual solutions. Educational law, local rules and inflexibility create huge challenges. Small changes can have positive effects, for example flexible deadlines, a study coach who has personal experience of living with an RMD, a resting room, an adjusted table or chair, accessible transport and personal assistance. Support from the family, friends and teaching staff is important.

Young people do not have a lot of life experience. Lack of skills, assertiveness to manage various problems or fight for legal rights is very common. They don't have the skills to, ask for help' and they need additional support. Young people need to obtain skills to be empowered, self-management skills. A future World Arthritis Day theme around education could be a good way to highlight the problems and solutions.

## **5. By 2020, employers and other stakeholders are more aware of the needs of young people with RMDs and provide more support to young people to find a suitable job.**

### **Suggested actions**

- Empowering young people with RMDs to accept their disease and become more self-confident and aware of their own abilities.
- Creating a virtual knowledge center to exchange best practices
- The virtual knowledge center will also hold information and advice for young people about the rights at the workplace and adaptation, ergonomics, support programs, legal rights and available tools and measures, career counselling, suitable jobs etc.
- Supporting youth leaders to become role models or ambassadors for their peers.

Young people with RMDs face many challenges in their work life. Most of them have a job and want to work, despite the negative impact of a RMD on their work ability.

Some young people have difficulties to find a suitable job or experience limitations in the job they would like to perform. These young people need a kind of career counselling or a life coach or a person, who is able to support their choices and knows about the opportunities and limitations of RMDs. Disclosure is also an issue. Many young people are afraid to talk about their disease during job interviews or at the workplace, partly due to insecurity and lack of knowledge about their own rights and partly due to the fear of being rejected because of their condition. They are afraid of the disabled label (stigma), which might affect their whole career.

To change this situation young people should be prepared and supported before they enter the labor market. They need to learn to be assertive, open to new ideas and adapt to new situations. Ask for a life coach and career counselling to know what they can do. PARE organizations can play an important role to educate employers, decision makers and society about the impact of RMDs on the working place and what potential solutions are for overcoming the barriers. In this regard, they can organise educational events, be visible and lobby for better facilities. The youth working group can help by developing guiding materials, gathering good examples and making them available online and sharing them with PARE organisations and their European network of youth leaders , Young PARE.

## **6. By 2020, Young PARE campaigns for societal changes that make the world more inclusive for young people with RMDs.**

### **Suggested actions**

- Building a virtual knowledge center of best practices of national and local campaigns to improve the life of young people with RMDs.
- Developing educational materials.
- Organizing network events and trainings and workshops on communication and self-management for youth leaders.

One's own mind set is often the biggest barrier to actively participate in society. Not valuing yourself and lack of self-confidence prevent many young people from speaking out loud and with confidence about their condition. The invisibility of illness often creates confusion among others and makes it hard to explain what it means to live with a chronic disease. Fatigue and pain are the main obstacles that limit social life according to the PARE youth research report. Disclosure can help people to better cope with their disease but bears also risks of misunderstanding and losing friends.

Change needs to be initiated by young people with RMDs. To overcome these barriers, young people must be positive about themselves, their own abilities and rights, and dare to take action. In fact, they have to become ambassadors. But they cannot break down the barriers and create opportunities for societal change without the support of others. Society needs to understand and accept the normality of one's unique set of adaptation needs and provide support where needed.

Youth groups can be helpful in supporting self-management and enhancing self-confidence of young people with RMDs. Many young people belong to a youth organisation that acts as a main source of information and patient education. Together and embedded in PARE organisations, trainings and workshops on communication, lobby and presentation skills should be developed. They can also share best practices of empowerment and self-management programs and lobby for inclusion in society on national level.

EULAR may provide the platform and exchange centre for all youth activities aimed at lobbying and awareness raising.

## **7. By 2020, every European country has an active national youth group for young people with RMDs.**

### **Suggested actions**

- Stimulating PARE organizations to establish youth groups by providing guidance and support.
- Strengthening of new and existing national youth groups by promoting international networking and exchange programs.
- Educating and empowering youth leaders across Europe.

The PARE youth research project mapping exercise showed that 22 PARE organizations have some form of activities for young people with RMDs. In 16 countries, no activities were reported. The form, in which the activities are organized, varies.

As mentioned before the words 'youth group' and 'youth organization' are used interchangeable. Youth groups can be independent legal entities, informal networks of young people, virtual communities or part of an adult organization such as the PARE member organizations.

Many PARE organizations experience difficulties in attracting young people to their organization. One of the barriers is the image of the existing patient organization and the average age of their members. Young people do not want to associate themselves with the activities of these organizations and prefer to meet people of their own age and undertake challenging, active activities. This is why it is recommended that young people are encouraged to organize their own activities with support and wherever possible embedded in the overall organizational structure of the PARE organization but with a clear "young" face. Best practices, published on [www.youngpare.org](http://www.youngpare.org) contain implementation ideas.

Another barrier is the fact that young people often think they are the only one with a chronic disease in a world full of healthy people. In fact, many young people suffer from a chronic illness, but are afraid to talk about it with their peers. The invisibility of RMDs in particular and the fear not to be taken seriously makes it even more difficult to disclose the disease or to become active as a youth leader. PARE organizations should acknowledge that young people deserve special attention and therefore actively support young people to set up meetings for their peers. They should also provide funding or support to acquire funding to set up their own activities. It is the responsibility of young people affected by RMDs to help with this initiative, to take action and establish a national youth group in their own country. They should contact PARE organizations and seek help and support in doing so.

From our qualitative interviews, we learned that many respondents were more informed and had better access to the rheumatology care because they belonged to a patient organization. The youth working group will support initiatives aims to organize trainings and workshops to educate and empower youth leaders who are willing and able to establish such a group. Young PARE will develop a guide for establishing a national youth group that

will contain information for youth leaders as well as PARE organizations, published on [youngpare.org](http://youngpare.org). In those countries, where youth organizations are established outside of the PARE member organization, close co-operation with the PARE member organization is required.



## **8. By 2020, PARE has established an active European network of national youth groups called Young PARE.**

### **Suggested actions:**

- Establishing a network of active national youth liaison persons representing all national youth groups in Europe.
- Empowering and educating the national youth liaison persons and other active youth leaders.
- Promoting the development of youth applications under the heading of EU youth programs to foster cooperation between youth organizations, Young PARE and EULAR.

As a result of the feedback of the Tallinn youth strategy meeting, a need of establishing a European network of national youth groups was recognized. Such a network, Young PARE, should facilitate the education, empowerment and support of national youth leaders. It is therefore the aim of Young PARE to help youth leaders to establish a youth group and then to create a platform where all the youth leaders can find information, share experiences, be supported and educated. This platform will come in the form of a virtual knowledge center that will contain information toolkits, educational materials as well as best practices of established youth groups.

Youth leaders with RMDs should become role models for their peers. This can be supported by providing education and empowerment in different areas, such as awareness campaigns, communication skills or self-management. The youth working group, in cooperation with EULAR, will organize networking and educational events that will focus on the needs of youth leaders. Once they are more empowered, they can spread awareness about the activities of Young PARE as well as other youth organizations on national level and thus strengthen the European network.

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### Advisory Board

- Epp Adler (Estonia), youth worker, trainer
- Judy Ammerlaan (Netherlands), health professional representative
- Nele Caeyers (Belgium), patient representative
- Pedro Marchado (Portugal), EMEUNET, rheumatologist

### Secretarial support

Florian Klett, EULAR PARE Programme manager

### Volunteers

Diana Skingle (UK)

## Appendix - Glossary

EULAR	European League Against Rheumatism ( <a href="#">link</a> )
EULAR member PARE organisations	<a href="http://www.eular.org/member_pare.cfm">http://www.eular.org/member_pare.cfm</a>
EULAR PARE Board	The management team of the EULAR Standing Committee of PARE. The SC of PARE is chaired by a nominated chairperson and supported by a board of up to eight members (including ex –officio), the EULAR PARE Board. The PARE Board includes delegates from national PARE organisations that are member of EULAR, including one youth representative. All members are volunteers.
PARE	People with Arthritis /Rheumatism in Europe
PARE Conference	EULAR Annual European Conference of PARE
PARE organisations	Organisations with delegates in the EULAR Standing Committee of PARE
PARE representatives in EULAR Executive Committee	EULAR Vice president representing PARE Chairperson EULAR Standing Committee of PARE Please see <a href="#">EULAR Executive Committee</a> <a href="http://www.eular.org/executive_committee.cfm">http://www.eular.org/executive_committee.cfm</a>
PARE youth research report	PARE youth research project report available online: <a href="http://www.youngpare.org/wp-content/uploads/2014/04/Final_report_PARE_Youth.pdf">http://www.youngpare.org/wp-content/uploads/2014/04/Final_report_PARE_Youth.pdf</a>
PARE Youth task force	Project task force 2012-2014 led by young people with RMDs
PARE Youth working group (from 2015)	Working group in the EULAR Standing Committee of PARE for and by young people with RMDs
SC PARE	EULAR Standing Committee of PARE, a subcommittee of EULAR's Executive Committee
RMDs	Rheumatic and Musculoskeletal Diseases
Virtual knowledge center	Online information and best practices for youth organisations and youth groups which will be available on <a href="http://www.youngpare.org">www.youngpare.org</a> .
Young PARE	The European network of national youth leaders and PARE youth liaison persons