

EULAR

KNOWLEDGE TRANSFER PROGRAMME



The Netherlands – POLAND - ROMANIA

REPORT

May 2015

Background

The project is based on the need of Romanian League against Rheumatism (LRR) and Polish Rheuma Federation REF for a specialised tool which can respond to the needs of youth people with rheumatic and musculoskeletal diseases (RMDs), needs which are so different from those of adults with RMDs. This target group has been neglected in Romania and Poland and this needs urgently to be addressed as young people with RMDs will become the future leadership of our national patient organisations.

Building an online platform for youth (18-35) with RMDs seemed to be the best way to start attracting young people as members, especially that Youth-R-Well.com (YRW) has such great experience in the field, offering good insight tips and written materials (the guide).

The organisations involved in the project:

- The teaching organisation was Youth-R-Well.com, the national youth organization in The Netherlands
- The learning organisations were ROMANIAN LEAGUE AGAINST RHEUMATISM (LRR)
- Polish Rheuma Federation REF

Participants and Working group members

People from Romanian League - LRR involved in the project:

- Doru Stefan Cristian, AS, the coordinator - IT background;
- Silvia Sandulescu, scleroderma, - she is managing a website on scleroderma;
- Iuliana Prunila Negoita, RA, she has a blog on RA & disability and with her husband and personal assistant manages a website on disability;

Participants from Polish League:

- Magdalena Misuno
- Danuta Dąbrowska
- Michał Kowalski
- Ernest Łodyga

Working group from Youth-R-Well.com:

- Linda van Nieuwkoop, chair Youth-R-Well.com
- Wendy Olsder, board member Youth-R-Well.com
- Regina van Boerdonk, board member Youth-R-Well.com

The face-to-face teaching meeting took place in a town near Amsterdam, between the 1st – 4th of May and there were two participants from Romania and 4 from Poland. Experienced and dedicated young people from Youth-R-Well.com took part along with two invited speakers,

one young persons with and RMD who was involved in the fist steps of setting up Youth-R-Well.com ten years ago and one young person with RMD who was involved in setting up the website www.jong-en-reuma.nl



	ROMANIAN League	POLISH League	Evaluation and long-term measurement tools	LRR	Poland
AIM	Gain knowledge from Youth-R-Well.com regarding the ability to develop online peer-to-peer support for youth with RMDs (age 18-35)	gain from Youth-R-Well.com regarding the ability to develop online peer-to-peer support for youth with RMDs (age 18-35)	The face-to-face educational meeting	√	√
OBJECTIVE	build an online platform dedicated to young people with RMDs	build an online platform dedicated to young people with RMDs	The platform itself	On-going	On-going
ACTIVITIES	Train the trainers	Train the trainers	The face-to-face meeting	√	√
	Obtain a tool for implementing the platform	Obtain a tool for implementing the platform	The guide for implementing the Youth Platform	√	√
	Discuss the outcomes of the knowledge transfer visit and set the working group	Discuss the outcomes of the knowledge transfer visit and set the working group	The Working Plan	√	√

	Find funds to create & implement the Platform	Find funds to create & implement the Platform		√	On-going
	Talk to the specialised firm to decide Website design, content and front page	Talk to the specialised firm to decide Website design, content and front page	The Draft of the Platform	On-going	Partly done
	Create the Platform	Create the Platform		On-going	On-going
	Set the responsibilities of working group members	Set the responsibilities of working group members		Partially done	Partially done
	Launch the Platform	Launch the Platform	The Platform itself	Spring 2016	Autumn 2016
	Advertise / Raise awareness about the Platform		Different events On LRR's website	On-going	
	Monitor the Platform		Tools for monitoring the attractiveness and success of the Platform: Website Analytics	On-going after launching the Platform	On-going after launching the Platform

Future benefits for young people with RMDs

- ❖ The online platforms would allow youth with RMDs to connect with peers in a safe environment (not compelled to disclosure, if they don't want to disclose that they suffer from a chronic disease), to participate in a community, learn about the disease, how to cope with it and receive support;
- ❖ Allow youth with RMDs connect with peers to connect in a safe environment, receive support, access quality content on RMDs, learn about the disease, cope with it and participate confidently in the treatment;
- ❖ Young people better informed;
- ❖ Youth feeling less alone in fighting the disease, thinking more positive and feeling more in control over their future;
- ❖ Introducing young people with RMDs to the concept of Self-management, leading to a better quality of their lives;
- ❖ The possibility of using the platform for free and anonymously

Potential Challenges in implementing the project

- Not knowing the size of the target group
- Young people not being used to be a member of a support group or patient organization;
- People generally not being motivated to be volunteers
- Lack of experience on how to implement such a platform;
- Creating the bond and interaction between young people
- Stigma mentality (not wishing to be connected with the disease);
- Find moderators (most devoted and fit) for provoking interaction;
- Finding attractive topics (responding in the best way to young people's needs and interests);
- Writing and maintaining the internal rules (lack of specialists);
- Maintaining continuity (risk of dropping out, lose interest, health flares etc.);
- Lack of rheumatologists or other HPs interested in supporting;
- Delays in achieving the goals;
- Low funds available;
- No funds available for promoting the platform;
- No criteria of evaluating the success of such a platform.