the patients (52%) had a hope that the physical impact of RA will be better understood in the future.

Conclusion: Despite major advancements in the treatment of RA, the chronic disease continues to significantly affect many aspects of patients' lives, including relationships, career progression, daily activities, and ability to work. Both patients and HCPs felt that the physical and emotional impact of RA is not well understood by people without the disease. In line with a recently published study, pain, fatigue, and physical function remain primary barriers for patients to live a normal life and to participate fully.² In RA treatment decisions, patients' personal goals and patient-reported outcomes should be given greater consideration along with clinical targets.

REFERENCES

- [1] Wysocka-Skurska I, et al. Clin Interv Aging. 2016;11:1741-50.
- [2] Oude Voshaar MAH, et al. Arthritis Care Res (Hoboken). 2018 Oct 24. doi: 10.1002/acr.23799. [Epub ahead of print].

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PARE0010 INSIDE OUT – A PHOTO CAMPAIGN TO CREATE AWARENESS FOR YOUNG PEOPLE WITH RHEUMATIC AND MUSCULOSKELETAL DISEASES

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Background: Inside Out is a photo campaign of Youth-R-Well.com, the organisation for young people (16-30 years) with rheumatic and musculoskeletal diseases (RMDs) in the Netherlands. The project was inspired by Unga Reumatiker, the youth organisation in Sweden and their campaign #doesntshowdoesntexist. The campaign of Unga Reumatiker showed that young people can suffer from rheumatic diseases, even though these diseases are invisible. Youth-R-Well.com recognized that the invisibility of an RMD can have a major impact on the lives of young people and wanted to create a similar photo campaign to show the invisible side of RMDs.

Objectives: The main objective of this project was to create more awareness for rheumatic and musculoskeletal diseases affecting young people. One of the hardest parts of living with an RMD is the invisibility of the disease in daily life. We wanted to show that even though you cannot see it, many young people have to deal with the consequences of having an RMD on a daily basis. We also wanted to show other young people who are in a similar situation, that they are not the only one.

Methods: To make the invisible side of an RMD visible for others, Youth-R-Well.com created Inside Out, an eight part photo campaign. Eight young people with different types of RMDs, took part in this project. From each individual, two photos were taken: one photo in daylight and one photo in the dark with their rheumatic-spots highlighted by blacklight paint. Next to the photos, the participants introduced themselves in a few sentences and ended with a life quote with a focus on the positive side of life. They were all telling very different and very personal stories. The general quote of the photo campaign was "Although you cannot see it from the outside, it is still there". The photo campaign was posted on Facebook and Instagram. The photo campaign was released the week before World Arthritis Day, in which the photos of one person were shared on each day. The final photo, a group photo with all the young people and their black light photos, was shared on World Arthritis Day 12 October 2018.

Results: It was a successful campaign, in which we reached almost 30.000 people on Facebook and 5.000 people on Instagram. The success of the project and all the shares and great comments it received

were overwhelming. The power of two photos next to each other had a large impact on people who were not familiar with the fact that RMDs do exist among young people. As a result of the great comments, this photo campaign is going to be exhibited in Reade, the center for Rehabilitation and Rheumatology in Amsterdam, to reach more people and make them more aware of the invisibility of RMDs.

Conclusion: Based on inspiration from a youth organisation in Sweden, Youth-R-Well.com created the successful campaign Inside Out. We managed to create more awareness for young people with RMDs and the invisible side of having an RMD. We will continue to spread this campaign and show that young people with RMDs are not alone.

Acknowledgement: First of all, we want to thank all our brave participants who took part in this campaign. Secondly, we want to thank Unga Reumatiker, who inspired Youth-R-Well.com to launch this amazing photo campaign.

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Innovations in arthritis health care

PARE0011 PILOTING THE FIRST PATIENT PARTNERS PROGRAM FOR AXIAL SPONDYLOARTHRITIS: THE JOURNEY OF BELGIAN PATIENTS TO BECOME EXPERT TEACHERS IN RHEUMATOLOGY

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Background: Patients with axial spondyloarthritis (axSpA) were trained to deliver experience-based workshops to medical students, general practitioners, physiotherapists and other healthcare providers concerning axSpA. The most important aims of these workshops are to improve the early diagnosis and to increase awareness of axSpA in the medical sector. Taking an expert role as a patient however requires an extensive training.

Objectives: To describe the training program in detail and to illustrate both the less successful and the optimal implementation steps taken thus far.

Methods: In its first iteration, the training program was developed as a resource book including a curriculum, significant amounts of homework, without enough time for practical exercises. This resulted in a drop-out of a large portion of trainees. Thereafter, the training method has been adapted by copying successful parts of the approach of The Patient Partner[®] Program for Rheumatoid Arthritis (launched in 1999). Also, more concrete training opportunities via a DVD demonstrating the complete course and training materials, as well as offering hands-on trainings during a three day overnight stay were added. Besides creating opportunities for intensive practicing with each other, there was also more time for informal contacts and it allowed for proper group dynamics. So there is a lot of time for sharing among patients with a similar health background. A comfortable environment was created for the candidates, enabling them to go through a complete process and giving them sufficient time to train all the components of the program.

Results: On February 22nd 2018, five fresh SpA-patients started the training, all five of them successfully completed the training on June 2nd 2018. On a first evening of familiarization, trainers tried to know more about the motivation of the trainees, while in an individual interview a rheumatologist reassured that the candidates have the correct diagnosis, as their story should be consistent. The selected candidates received part 1 of the training manual by mail and they were invited to profoundly study the terminology and the anatomy, related to their disease.

During the first full day of the training, the trainers took time to explain this terminology and anatomy. Later on this constituted the building blocks of the course. The trainers closed this first day demonstrating the history taking and they asked the trainees to study at home their personal medical file.

On day 2, the homework of the previous day was first discussed, followed by related exercises. Day 2 finished with the demonstration of the clinical examination.

The training program was completed with three days with overnight stay. During these days a lot of practical exercises of the clinical examination were organized, followed by a discussion of the impact of the disease and the importance of active participation. The program ended with a general rehearsal and a written as well as an oral test to evaluate how each trainee had assimilated all this.

Conclusion: In the training program PPP SpA, the trainees learn to tell a uniform and academically correct story. This contains an accurate history taking and a correct clinical examination reinforced by the personal history of the Patient Partner. Moreover the whole process helps each Patient Partner to have a better insight in their own illness, a better capacity to cope and to develop more skills in the dialogue with medical practitioners. The experienced positive feedback of the trainees after every course is the best motivation to continue with this approach.

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Building patient led organisations

PARE0012 INVOLVEMENT OF PATIENTS IN ERN RECONNET: A SUCCESSFUL INITIATIVE RAISING PATIENTS' LEADERSHIP AT EUROPEAN LEVEL

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Background: European Reference Networks (ERNs) are virtual networks involving centres of expertise across EU Member States with the aim of tackling rare and complex diseases. The ERN ReCONNET involves currently 26 healthcare professionals (HCPs) from 8 countries and cover rare and complex connective tissue and musculoskeletal diseases (rCTDs). Patient participation and involvement, also through EURORDIS, is a key characteristic of ERNs.

Objectives: To demonstrate that patients' involvement and collaboration across disease and geographic borders via the ERN ReCONNET effectively brings better care for people living with rCTDs.

Methods: The European Patient Advocacy Groups (ePAGs) provide patients' opinion and input in all activities of the ERN. They relay the views of their wider communities, evaluate how the ERN acts on patients input, contribute to projects and research, develop and disseminate patients' information, ensure that patient rights and choices are taken into account in decision-making and identify national groups to work with the ERN's HCPs. To structure the patients' involvement, a Patients' Organizations Working Group led by a Senior and a Junior Coordinator, developed and approved its own Terms of Reference. Patients' Representative Disease Coordinator (PDR) have been identified for most diseases. They bring patient perspective, liaise with HCPs and their wider patient community. Three ePAGs are voting members of the Steering Committee.

Results: ePAGs have collaborated intensely in ERN activities, organising and participating to regular meetings, providing their input into projects. They co-designed and disseminated surveys on clinical practice guidelines and on patient education. In each disease area, they collected feedback from their community on topics such as unmet needs or therapeutic education, worked alongside HCPs on narrative reviews², abstracts, surveys and reviews of the literature². Lay language versions of documentation enable the wider community to understand the efforts of ERN ReCONNET, of which the ePAGs form an essential part. ePAG's involvement in the ERN has brought perspective for the future, identifying common surveys for next year, providing input on therapeutic educational programs or preparing patient journey documentation. A project to certify websites information quality on ReCONNET diseases and disorders was approved during the last meeting. From 10 ePAGs invited at the EMA symposium on clinical trials, 2 were from ReCONNET.

Conclusion: The ERN ReCONNET is a great opportunity for patients' leadership, bridging from EULAR and its PRP program to ERN and other EU initiatives. It will make a tremendous impact on the EU diagnostic and treatment landscape bringing a better quality of life to people with rCTDs.

REFERENCES

- [1] https://ec.europa.eu/health/ern_enTi
- [2] https://rmdopen.bmj.com/content/4/Suppl_1

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Patient information and education

PARE0013 EDUCATING PEOPLE WITH RMDs TO FOLLOW A CORRECT DIET: AN INNOVATIVE 3 STEPS PROJECT

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Background: Patients associations in Italy as in all the European countries have a strong role not only in empowering people with Rheumatic and Muscle-skeletal Diseases (RMDs), but also in educating them to new healthier lifestyles, comprehending physical activity and diet.

In Italy, the special relationship between people and food make our job more difficult than in other countries and it needs to try new ways driving people with RMDs to a correct diet without feeling different from the healthy population

Objectives:

1. to make patients, their families & care givers and the society aware of how much important is to follow a correct diet to prevent some of the damages that may be related to rheumatic diseases;
2. to make patients and their families aware of the importance to rely on experts in setting up correct dietary regimes;
3. to educate people with RMDs to a correct diet and healthy lifestyle, showing them it is possible to eat meals appetizing, tasty and also appearing beautiful even if following an appropriate and healthy regimen.

Methods: STEP 1 - ANMAR published "RMDs and diet". The booklet written by dr. Annalisa Olivotti, biologist and nutritionist, contains all topics concerning diet and RMDs; the Rheumatologist position and some suggestions by patients are present too. The booklet has been sent to all people receiving the ANMAR magazine "Sinergia" and was available for free in all ANMAR events and on its website.

STEP 2 - Since September 2018, through the regional associations, ANMAR organized a series of events to educate all the population and especially patients, their families and care givers, to follow a healthy diet, as a first aid to the pharmacological therapies.

STEP 3 - To complete the educational pathway of each meeting, all participants can experience how fun may be eating in a healthy way, having a dinner cooked by local chefs who have previously received a complete list of the most suitable foods for proper nutrition for people with RMDs.

Results: The project is still ongoing: nowadays we can refer these data:

- 15.000 copies of the booklet "RMDs and Diet" were published and distributed
- 5 meetings were organized, directly approaching a total of 450 people
- All participant highly appreciated the healthy menu cooked in the dinners
- 54 new recipes have been sent to the regional Association of Piemonte, leader of the project
- Using a "free - offer" request to enjoy the dinner, the project may also become a good fundraising way for the regional association organizer.

Conclusion: Data collected seem to confirm this one may be a suitable way to overcome the Italian cultural gap which leads to live diet as a bad and depressing lifestyle, as in Italy eating is not only a way to feed on, but an enjoyable moment.

We hope further data will enforce this first impressions and definitely confirm it.

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