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.

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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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