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PARE0011

AFSL’S (FRENCH LEAGUE AGAINST RHEUMATISM) NEW ACTIONS TO HELP PEOPLE WITH RHEUMATIC DISEASES TO GET AND STAY EMPLOYED.

L. Carton1,2, L. Grange3, F. Altou Launois3, G. Chales4, B. Liesse2, C. Jandard2, Paris, Paris, France; 3AFSL, Paris, France

Background: Accessing jobs and being able to stay in a paid work position are a personal issue for people with rheumatic diseases, as well as for society. AFSL, French league against rheumatism, has been acting towards patients and employers since 2014 in this field.

Objectives: After a preparatory work with a panel of all types of professionals and institutions working on the subject, key messages on means to improve the professional situation of people with rheumatic diseases have been published. These messages were used as a basis for an awareness training designed for human resources training and employers’ managers, and in a guidance booklet designed for patients and published in 2016: «At work, even if affected by rheumatic diseases ». This booklet, rather than gathering administrative and social resources in favour of patients, was based on patients’ and experts’ expression, written with them and proposed gradual guidance along their path from their professional choices to the disabled worker certification when needed.

Two new actions have been seen as necessary in 2019 in order to go on with our actions: updating our booklet after 2 new laws had been issued in the field of labour law, and additions seemed necessary because of new work methods are developing (distant work from home, independent work); and the need of a new widely spreadable tool to accompany patients from the diagnosis stage, especially on the diagnosis disclosure to the work group issue.

The specific characteristics of rheumatic diseases: diversity, growing invisibility of diseases’ effects and aftereffects to new treatments such as biologics and early rehabilitation, variation in time and personal impact, make them hard to understand by employers and even untrained social workers. This is what we noted from our experience in patient education workshops. Patients have a tendency to hide their pathology, and thus cannot benefit from social advantages as disabled workers, with motivation based on keeping personal image and an idea of normality, and fear of negative reactions from the work group, such as depreciation, pity, idea of negative impact on team’s productivity).

Patients have to build a real strategy, taking into account these criteria and their personal choices, while preparing their job’s adaptation or social requests when needed. AFSLAR chose to create a new patient information tool: free short widely spreadable videos, available on line. These will also invite patients to get in touch with expert patients on the specialized hotline, participate to chats of patient education workshops.

Methods: Videos will show witness patients and experts, who will be asked about their experience and advice based on four questions:
- Should we speak about our disease (and when, how?), or not speak about our disease at work?
- What means « disablement », « being disabled » for you as a person affected by a rheumatic disease?
- What have you been able to do to get a paid position, or keep your job, that you could quote as an advice for other people in the same situation?
- If you had been given, or were given now a magic wand to make it easier to get or keep a job, or get/keep the job you dreamed of, what would you change?

At the end, videos will deliver further advice, tools and resources taken from the booklet, such as a model of decisional scale, or reference institutional website addresses.

**Results:** AFLAR wishes to contribute actively to rheumatic patients’ and especially young people’s information on the topic thanks to these more innovative and interactive tools.

**Conclusion:** Furthermore, wishes, solutions and ideas of witness patients and users will be gathered for advocacy towards employers, institutions and decision makers.

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**SATURDAY, 06 JUNE 2020**

**Campaigning**

**PARE0012 AWARENESS CAMPAIGN “LUPUS.GR 2020”**

K. Antonopoulou1, M. Konstantinidis1. 1ELEANA/HELLENIC LEAGUE AGAINST RHEUMATISM, ATHENS, Greece

**Background:** LUPUS GR 2020

**Objectives:** To sensitize and educate the wide public about lupus

To contribute to the process of de-stigmatization as the rigid problem of prejudice and stigma prevails.

**Methods:** The campaign “LUPUS GR 2020” consists of photographs, each of which has a different message for Lupus and 2 TV spots. The well know artists participated did not take any fee.

The campaign consists of

Press Announcements in digital and off digital media, in Social Media (Instagram - Twitter - Facebook), in Eleana Site and in YouTube

Post of the artists in their personal social media pages

Press Conference

Direct mail in international NGOs e.g. Lupus Europe, PAIN ALLIANCE EUROPE, AGORA PLATFORM, etc.

**Results:** We announced the campaign on January 24, 2020. Until end of January, we have 36 press clipping, 3 TV interviews, more than 35,000 views of the post in our fb and increase of telephone calls in our help line about lupus

**Conclusion:** The campaign has a high impact in the wide public as well as in all the stakeholders.

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**SATURDAY, 06 JUNE 2020**

**Patient information and education**

**PARE0013 ‘FIND A NUDGE’ AND OTHER TIPS TO MAINTAIN YOUR LEVEL OF PHYSICAL ACTIVITY FOR A LONGER TIME**

R. Geenen1. 1Utrecht University, Department of Psychology, Utrecht, Netherlands

**Background:** Pain, fatigue, physical disability, reduced well-being and sleep problems are common consequences of Rheumatic and Musculoskeletal Diseases (RMDs). Paradoxically, these consequences may all lead to a reduction of physical activity, while physical activity actually is an antidote against these consequences. This is acknowledged by experts that included physical activity and exercise into recommendations for management of RMDs [1-3]. Indeed, after programs aimed at a gradual build-up of exercise, many people with a RMD showed an increase of physical activity. However, it is hard to maintain a higher level of physical activity for years as part of daily routine [4-5].

**Objectives:** To identify and present tips, applications and illustrations that support people with an RMD to maintain their level of physical activity for a longer time.

**Methods:** Theoretical considerations and empirical findings guided the identification of tips. Care was taken that the tips and illustrations were translated into layman language and fitted in daily life of common people.

**Results:** Ten tips were found:

1) break the habit,
2) make sure you can do the exercise activity,
3) use aids if needed,
4) believe in a good outcome,
5) choose a physical activity that fulfils personal goals,
6) find a physical activity that you enjoy,
7) stop moving while it’s still fun,
8) find a buddy,
9) make an action plan, and
10) find a nudge.

A “nudge” is a little push in the right direction that makes a person unconsciously perform physical activities. Examples are an outdoor photography hobby, a dog that comes to you with a dog leash in his mouth, or grandchildren that persuade you to go with them to the playground nearby. If a person with a RMD manages to find a nudge that stimulates instinctive moving without feeling the effort, then physical activity may be maintained. People differ a lot and must discover for themselves which tips help them to maintain physical activity. They must be aware that it may take up to two months for changed habits to stick.

**Conclusion:** The presented tips will help to maintain your level of physical activity. Nevertheless, be aware that effort and perseverance are needed to keep on moving. A challenge for the future is to get more knowledge of natural and pleasurable physical activities. Peers with successful experiences and