Conclusions: A family-centered interactive educational and recreational day offers the opportunity for peer-to-peer connections, education and support for families of children, and youth with rheumatic diseases, and promotes the formation of a strong community addressing family and child needs.

Disclosure of Interest: None declared


PARE0004

LET’S MOVE WITH ARTHRITIS! – NORDIC WALKING FOR PEOPLE WITH RMDS

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Background: Slovak League against Rheumatism (SLAR) identified a need among its members to provide support when it comes to physical exercise and rheumatic diseases. Nordic Walking is fitness walking with specially designed poles. It uses 90% of the skeletal muscles. Nordic Walking is ideal for neck, shoulder and back problems while it also reduces pressure on knees and joints. Poles propel the walker along, making it easier to move faster than normal without feeling the effort. With the cooperation with the Slovak Nordic Walking Association, SLAR provides trainings in local branches and encourages individuals to do physical activities while monitoring their progress.

Objectives: The aim of the project Let’s Move with Arthritis is to improve treatment, prevention and rehabilitation of RMDs, to support healthy lifestyle and thus lower the impact of RMDs on individuals and society by a structured training on the correct Nordic Walking techniques.

Methods: The project Let’s Move with Arthritis started in September 2017 when SLAR obtained 5 pairs of Nordic Walking poles for each of our 17 local branches and clubs. SLAR provided trainings with the cooperation of the Slovak Nordic Walking Association. Individuals were tracking their progress using excel sheets. The goal was to achieve 1 000 000 steps for people with RMDs by 14 October when SLAR held its World Arthritis Day event. Steps of all individuals in local branches were summed up and the goal was not only achieved, it was overcome.

Results: A total of 506 individuals participated in the Nordic Walking trainings from September until 14 October 2017. They walked 1 144 km and made 3 386 517 steps. Each of the participating branches provided SLAR with a final report that showed that the cooperation with the instructors of the Slovak Nordic Walking Association was excellent. The activities showed that people with RMDs walked with enthusiasm. The local branch in Kosice made the most steps – over 800 000. Participants were keen on continuing Nordic Walking trainings also without instructors and beyond October 2017.

Conclusions: The project Let’s Move with Arthritis! proves that even people affected by RMDs are able to do physical exercise, in our case Nordic Walking. Importantly, the project provided simplified and step-by-step instructions to Nordic Walking with the aid of the Slovak Nordic Walking Association. The instructors provided individuals with warm-up techniques, correct Nordic Walking techniques and cool-down techniques after each session. The aim of the project was to reach at least 1 000 000 steps for people with RMDs but it also proved that people with RMDs benefit from physical activities like Nordic Walking when using correct techniques. It can improve their quality of life, increase mobility, improve coordination and strengthen the ligaments. Each participant expressed the will to continue with the project beyond October 2017.

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Disclosure of Interest: None declared

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PARE0005

DEVELOPMENT & DISSEMINATION OF A RESOURCE ABOUT METHOTREXATE USE FOR AND BY PATIENTS WITH INFLAMMATORY ARTHRITIS

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Background: In managing inflammatory arthritis, methotrexate is often one of the first therapies prescribed. Methotrexate is a therapy used long-term and often in combination with other medications. As people who live with arthritis, we know that for a variety reasons, people do not use methotrexate as prescribed by their healthcare provider and as a result, they may not experience its maximum benefits.

Objectives: We set out to build and disseminate a resource about methotrexate and its use from the patient perspective. It is our aim to help patients find ways to deal with their methotrexate by sharing other patients’ experiences and tips with them.

Methods: We surveyed people who live with arthritis about their attitudes and coping mechanisms related to taking methotrexate, seeking tips and tricks to share. A Board member/project manager created an online survey that was medically reviewed (English, French) and collected responses (circulated via newsletter, social media, patient organizations). Following the analysis of survey responses, a resource was developed and reviewed by 2 rheumatologists and a pharmacist. The resource was disseminated using similar methods to the survey.

Results: The survey response was global (363 responses, 77% with rheumatoid arthritis, 22% with psoriatic arthritis, 63% in Canada). Almost half of the survey respondents indicated they “do not like taking methotrexate, but it helps me manage my arthritis.” Along with 5 top adaptations made to better tolerate taking methotrexate, a major gap was that 80% of respondents indicated not talking to their physician or pharmacist about finding an appropriate solution with respect to taking methotrexate. A web-based resource was developed and its dissemination plan are currently being completed and will be presented.

Conclusions: CAPA created a we-based, medically reviewed resource about taking methotrexate informed by patients’ experiences who live with inflammatory arthritis. This resource aims to help people better manage taking methotrexate and is being disseminated.

REFERENCES:

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Disclosure of Interest: D. Richards Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its
A SUMMARY OF KEY FINDINGS FROM THE SJÖGREN’S SYNDROME FOUNDATION’S NATIONAL PATIENT SURVEY RELATED TO TREATMENTS AND MEDICATIONS USED

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Background: Sjögren’s is a systemic autoimmune disease that affects the entire body. The purpose of this major national patient survey was to gain an understanding from adults who have been diagnosed with Sjögren’s about the impact of the disease on their quality of life, including information on the treatments and medications used to treat the disease.

Methods: The SJögren’s Syndrome Foundation (SSF) conducted the Living with SJögren’s survey between May 11 and July 11, 2016. Participants were recruited by Harris Poll from a pool of 9,252 active SSF patient members. The survey was conducted among adults aged 18 years or older who had been clinically diagnosed with Sjögren’s by a physician or other medical professional. The survey asked closed-ended questions about patient experiences with Sjögren’s and the impact it has on their quality of life.

Results: There were 3,072 survey responses (33% response rate), 2,963 of which were included in the analyses. Survey respondents were 96% female and 4% male; 32% were aged 60 years or less. On average, respondents reported a diagnosis younger than 10 years. The survey showed that patients 60 years and over were significantly more likely than patients older than 60 years to have used over-the-counter or prescription fluoride (67%), and corticosteroids (62%). Notably, patients 60 years and older were more likely to use medications for fatigue (63%), brain fog/forgetfulness (53%), sleep problems (51%), joint pain or swelling (48%) and muscle pain (43%).

Conclusions: Patients reported relying on a large number and variety of treatments to manage their Sjögren’s as well as the need for new treatment options to treat the various manifestations of the disease. The findings from this survey will help to inform and support future SSF efforts to increase public and professional awareness of Sjögren’s and encourage research into new treatments and new resources.

Disclosure of Interest: None declared


SURVEY RESULTS FROM A NATIONWIDE ONLINE AWARENESS CAMPAIGN SUGGEST A CLEAR DISEASE-RELATED INFLUENCE ON PERCEPTION OF QUALITY OF HEALTHCARE FOR PATIENTS DIAGNOSED WITH PSORIASIS ARTHRITIS, PSA, VERSUS PATIENTS WITH SYMPTOMS SIMILAR TO PSORIASIS ARTHRITIS I.E. PSORIASIS AND JOINT PAIN


Background: Psoriasis arthritis (PsA) is a chronic inflammatory joint disease closely linked to psoriasis in the skin. The need for increased knowledge of PsA is extensive in both the public and in healthcare in Sweden. For that reason Swedish Rheumatism Association, Swedish Psoriasis Association and health portal company NetDoktor, with support from Novartis, initiated a web-based awareness campaign, which included a survey, in April 2017. On December 17, approximately 12,500 people, of which about 4,000 with the diagnosis PsA and 8,500 with psoriasis and joint pain, had taken part of the material. Of these, approximately 2,400 people participated fully and provided detailed information on how they view their disease and the care they are offered.

Objectives: Raise awareness and educate about to PsA aimed specifically to people with PsA or with symptoms consistent with the diagnosis – but also relatives, healthcare professionals and the interested public.

Methods: The awareness campaign consisted of five lessons that provided participants with increased knowledge about PsA, and a survey about their experience of healthcare. The survey gave us a foundation to address the deficiencies in healthcare, and in patient needs. The lessons highlighted the following issues: background, causes, symptoms, comorbidity, diagnostics, drug treatment and prognosis.

Results: The average waiting time for a diagnosis among the survey participants was 3.5 years. Every fourth person had waited 5 years or more, and over 10 percent waited more than 10 years for a diagnosis. The survey showed remarkable differences in treatment and perception of quality of healthcare for patients diagnosed with PsA versus patients with symptoms consistent with PsA.

Disclosure of Interest: None declared


FAMILY DAY BY THE SWISS LEAGUE AGAINST RHEUMATISM: A NETWORKING EVENT FOR CHILDREN AFFECTED BY JIA AND THEIR FAMILIES

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Background: In Switzerland 0.7 out of 1’000 children is affected by juvenile idiopathic arthritis (JIA). The incidence of JIA is 11:100’000 (1). The families affected by JIA are spread over three different language regions (the German, French and Italian regions). It is difficult for these families to get in touch with other affected families since there is no support group for JIA. A support group has never been established due to the uneven distribution in Switzerland.

Objectives: The aim is to offer continuing education for parents of affected children concerning their chronic disease, as well as their dealing with the illness as a family. Furthermore parents and children shall attain the opportunity to exchange information about their experiences and problems with peers in an informal setting.

Methods: The Swiss League Against Rheumatism has established the so-called “Family Day” (German: Familientag) which features a program for affected children and their siblings as well as a separate program for their parents on the same day. In order to enable families from all Swiss language regions to participate in the “Family Day”, it takes place separately in German and French in both language regions. Since most Italian speaking families in Switzerland either speak German or French, the “Family Day” is equally open to them. The Swiss League Against Rheumatism collaborates with the task group “Paediatric Rheumatology Switzerland” in order to develop relevant contents. The program for the parents aims at imparting medical therapeutic knowledge about their child’s disease. Several additional main topics (e.g. uveitis, developmental paediatrics) are chosen and presented by certified experts. All are made in layman language and explain medical terms thoroughly. The parents additionally get the opportunity for formal and informal exchange within their group. The children and youth program (0–16 yrs.), is dedicated to a specific non-medical topic (e.g. magic tricks). The children are divided into several age-specific subgroups and are assisted by staff from the Swiss League Against Rheumatism. Teenagers (11–16 yrs.) may attend a specialized program during half a day.

The “Family Days” are easily financed by foundation endowments.

Results: From 2011 to 2017 3298 families (1157 individuals) participated in the “Family Day”, of which 27% were in the French-speaking part of Switzerland. For participating parents this event became essential in order to educate themselves concerning their child’s disease and to exchange experiences with other affected families. For most families the “Family Day” has become a fixed event in their yearly calendar. Many families participate on a regular basis for several years.

Conclusions: The “Family Day” has been taking place for 7 years and remains an objective for the future. Demand from parents of affected children continues to be strong and continues to increase. Since support groups have not yet been possible to implement due to demographics, this one-day event remains a unique resource for affected families.

REFERENCE: