Poster Presentations

PARE0001 #DOESNTSHOWDOESNTEXIST/#SYNSINTEFINNSINTE – AN AWARENESS CAMPAIGN FOR PUBLIC TRANSPORT BY SWEDISH NATIONAL ORGANIZATION FOR YOUNG RHEUMATICS

K. Nordlund, M. Beermann. Swedish National Organization for Young Rheumatics, Stockholm, Sweden

Background: "Rheumatism amongst young people, is that really a thing?" "Isn't rheumatism something that only old people have?" "You seem so happy and so active, surely you can't be in pain?" These are all questions that young people with rheumatism have to listen to, and answer every day. Yes, it's possible to have rheumatism even as a young person, and to be in pain, even though we're not letting it show. We know adjustment is possible, and that we can live our life to the fullest and follow our dreams, despite rheumatism. But sometimes it demands some extra understanding from the people around us. That's what we wanted to recognize, for the second year in a row, but with another approach, and created a campaign together with AbbVie.

Objectives: It can be hard to understand and fully grasp something you can't see, something that is invisible. But as young people with rheumatism, we have to live and deal with our swollen joints, with the pain and the fatigue, and with the side effects of our medication. None of which should be questioned. We recognized that this was an issue for most people with rheumatism, especially young people, and especially in the public transport. Therefore, we wanted to start a conversation about that we, young people with rheumatism that doesn't show, can also need to sit down at the priority seats. The main purpose with our campaign was to acknowledge the fact that you can't always tell whether or not a person has a diagnosis, or is in pain. We also wanted to show young people with rheumatism that they are not alone in their situation.

Methods: We wanted to make a quiz. Each pair of person with and without rheumatism in the campaign is presented in a photo taken on a bus next to each other with a quiz question. For example: "Who of us needs to sit on the bus so we can hang out in the skate park this afternoon?" The whole idea of the quiz is to make people realize that it is impossible to see if a person needs to sit on the bus or not, that you have to trust us when we asks for a seat. Every answer is put together with the person's story about their passion in life and what it's like to live and deal with an invisible disability in public transport. The quiz was released on October 9th 2017, together with a new decal for public transport that all of our members helped us put on buses and trains all over Sweden, pins to wear all week for all our members, debate articles in local and national papers, interviews in radio and television, letters and decals to all public transport companies, and a social media campaign with photo and personal story each day. People were also told to share their own stories under the hashtag #synsintefinnsinte

Results: The campaign ended up being our organization's most successful campaign to this date, we reached over 4.5 million people – more than we could ever dream of. The campaign had more likes and shares on both Facebook and Instagram than any of our other campaigns has had so far. The debate articles in local and national papers were really important for the campaign and started a lot of discussions, debate and awareness. The photos combined with the personal stories make a powerful statement. We managed to show that young people with rheumatism some days also need access to the priority seats and we look forward to the conversation continuing on at #synsintefinnsinte.

Disclosure of Interest: None declared

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PARE0002 ADHERENCE TO THERAPY AND PATIENTS ENGAGEMENT IN ITALY: A CLOSE LINK

U.G. Viora, R. Brogini, G. Campolieti, F. Leonardi, F. Padovani, S. Tonolo, on behalf of ANMAR Italia. ANMAR Italia, Rome, Italy

Background: In the last years ANMAR Italia and the federated Regional Association worked hard to educate people with Rheumatic diseases (RMDs) to an appropriate adherence to the therapy prescribed, as the Mosaico project confirmed that even patients in bio-technological therapies reveal unwillingness to assume their drugs within the schedule prescribed by the rheumatologist (timing and doses).

"ANMAR we care", study by the Italian Association of patients with Rheumatic diseases (ANMAR) in 2017 thanks to an unrestricted grant from ABBVIE and the precious collaboration of the Engage Minds Hub Research Center of Università Cattolica del Sacro Cuore di Milano directed by prof. Guendalina Graffigna, intended to analyze the problem again after the campaigns acted in the last two years and to link adherence to therapies with the degree of patient engagement.

Objectives: to verify the percentage of adherent patients and their degree of adhesion to the therapy.

To appraise the relationship among adherence and engagement of people with rheumatic diseases.

Methods: in the study we administered to patients a specifically pursued questionnaire containing a fair number of questions on adherence to therapies.

This sub-analysis was made using the answers to those questions and data have been interpolated with those related to the level of engagement of the patients.

Results: overall data confirm that in Italy also in 2017 the percentage of people with RMDs adherent to therapies settles in dissatisfying degrees (54%) and that such includes patients partially adherent.

Looking at the relationship within adherence and engagement, if divided in the four groups anticipated by the PHE Model the percentage are: Blackout (cognitive blindness, deny, freezing) 47%, Arousal (superficial knowledge, alert, behavioral disorganization) 46%, Adhesion (cognitive adhesion, acceptance, formal adherence) 61%, Eudaimonic Project (sense making, elaboration, situated practices) 78%.

Notice that patients with Psoriatic Arthritis are the most adherent, followed by those with Fibromyalgia, Spondylitis and finally with Rheumatoid Arthritis.

Conclusions: this analysis highlights that the information and awareness campaigns made in the last years were useful, but results are still far away from the optimum.

As we expected, the engagement degree hardly affects the adherence process, but totally unexpected is that patients in "Arousal" are more confused and less adherent than those in "Blackout".

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PARE0003 PROVIDING PATIENT AND FAMILY EDUCATION AND SUPPORT FOR CHILDREN WITH RHEUMATIC DISEASES AND THEIR FAMILIES: CASSIE AND FRIENDS ANNUAL FAMILY DAY IN BC

J. Wilson¹, L. Tucker², on behalf of Tucker, Petty, Setton, Houghton, Morishita, Guzman, Brown, Green, Tekano, Davidson, Best, Eccles, Cabral. ¹Executive Director, Cassie and Friends Society for Children with Juvenile Arthritis and other rheumatic diseases; ²Pediatric Rheumatology, BC Children's Hospital, Vancouver, Canada

Background: Family Day, an annual patient education event starting in 2009, is organized and funded by Cassie and Friends, a registered BC charity dedicated to transforming the lives of children with rheumatic diseases and their families. It is a full day, multi-track conference held outside the hospital environment, organized collaboratively by the pediatric rheumatology team members at BC Children's Hospital and the Cassie and Friends' volunteer conference committee.

Objectives: To describe the growth and impact of an annual Family Day event on children with rheumatic diseases and their families in BC.

Methods: The program includes lectures, round table discussions, and patient panels for parents and caregivers, with both age-related recreational and educational activities for children and youth (i.e. peer to peer support). Content and format of the program is informed annually by feedback from previous Family Days and advice from pediatric rheumatology team members. Formal feedback from attendees (parents) is provided by a post-event survey.

Results: Registration has increased annually from just a handful of families in 2009 to 141 attendees in 2015, and 372 attendees in 2017 (with a waitlist). In 2017, attendees were 81 children and youth with rheumatic diseases, 68 siblings, and 150 parents and caregivers. A total of 72 speakers and volunteers

participated. 186 participants had attended Family Day the previous year; 148 participants were first time attendees. Families came from 29 communities throughout British Columbia. 59% of attendees completed the post-event survey. The event was rated as very good or excellent by 98% of respondents, with most stating they would recommend Family Day to other families, and planned to attend the event next year. Parents enjoyed opportunities to meet other parents and health professionals in small interactive groups, and asked for more actionable strategies to help them with their children. The post-meeting questionnaire identified what families perceived as their greatest challenges in dealing with their child's rheumatic disease: day-to-day family life, pain, well-being, school, medications and treatments, and fear.

Please also see our Family Day video with kids and teens sharing what the day means to them: <https://vimeo.com/234426339>

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.

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PARE0004 LET'S MOVE WITH ARTHRITIS! – NORDIC WALKING FOR PEOPLE WITH RMDs

P. Balazova, J. Dobsovicova Cernakova. *Slovak League Against Rheumatism, Piestany, Slovakia*

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 through 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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PARE0005 DEVELOPMENT & DISSEMINATION OF A RESOURCE ABOUT METHOTREXATE USE FOR AND BY PATIENTS WITH INFLAMMATORY ARTHRITIS

D. Richards¹, N. Robertson², L. Wilhelm³, L. Proulx², A. McKinnon¹, J. Gunderson⁴, C. Reece², A. Sirois⁵. ¹Canadian Arthritis Patient Alliance, Toronto; ²Canadian Arthritis Patient Alliance, Ottawa; ³Canadian Arthritis Patient Alliance, King County; ⁴Canadian Arthritis Patient Alliance, Glaslyn; ⁵Canadian Arthritis Patient Alliance, Montreal, Canada

Background: In managing inflammatory arthritis, methotrexate is often one of the first therapies prescribed.^{1,2} Methotrexate is a therapy used long-term and often in combination with other medications.^{3,4} 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 taking 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 web-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.

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