SATURDAY, 06 JUNE 2020

Patient information and education

PARE0001

DIET, NUTRITION AND ARTHRITIS – A WORKSHOP FOR YOUNG PEOPLE WITH RHEUMATIC AND MUSCULOSKELETAL DISEASES (RMDs).

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Background: The impact of diet and nutrition on RMDs is a growing topic with lots of ongoing research and remaining questions. Youth-R-Well.com, the organization for young people (18-30 years) with rheumatic and musculoskeletal diseases (RMDs) in the Netherlands, recognized that young people want to know more about this theme. Therefore, Youth-R-Well.com organized the workshop "Diet, Nutrition and Arthritis" to inform young people with RMDs about the facts and myths of the impact of diet and nutrition on RMDs.

Objectives: The main objective of this project was to inform young people with rheumatic and musculoskeletal diseases about the impact of diet and nutrition on RMDs. Youth-R-Well.com wanted to offer the knowledge of proven research and studies, and provide all the recent facts and fables about this topic. By becoming well-informed about the impact of healthy cooking, young people are able to improve the self-management of their disease. Besides providing information about the impact of diet and nutrition, the objective was to offer tips and tricks about ergonomic cooking. With the right tools for cooking, the participants might be inspired by a less painful and more suitable way of cooking, which also increases the self-management of their disease.

Methods: To make sure the event was consistent with the needs of young people, Youth-R-Well.com organized a cooking workshop, that consisted of two parts: informative presentations and a fun healthy cooking workshop. For the first part, we invited a professor and a dietitian specialized at this specific topic to provide the correct and up-to-date information. For the second part, we invited an occupational therapist to provide information about ergonomic cooking. The kick-off of the day was by two informative presentations: the professor, who focused on recent studies, and the dietitian, who focused on the practical side. Both the presentations ended up in a question and answer component, where the participants showed lots of interaction. After the first session, the practical side of the workshop could be started. Several nutrient full and healthy recipes were made in teams to interact with other participants. An occupational therapist facilitated the participants by presenting the less painful and correct technique for preparing food. The workshop is filmed and shared through YouTube, to make sure the information reaches more young people with RMDs.

Results: It was a successful workshop where over 40 participants were present. The educational and helpful presentations were well received and created more realization of the impact of an appropriate and altered diet. The survey, which was filled up by the participants, has shown that over 91% rated the event by the highest-ranking "good". Also, in the second part of the workshop, the practical cooking was very good and useful; it was rated as the most favorite part. The workshop was filmed and shared online, we reached over 1300 people with enthusiastic and lovely comments.

Conclusion: Based on the questions of young people around the impact of diet and nutrition on RMDs, Youth-R-Well.com organized the workshop: "Diet, Nutrition and Arthritis". Through the combination of informative presentations and a fun cooking workshop, Youth-R-Well.com managed to inform young people about this growing topic. We will continue to spread the information through our online video on our online channels to reach more young people with RMDs.

Disclosure of Interests: None declared

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PARE0002

IMPACT OF SERVICE DOGS ON THE BURDEN OF ARTHRITIS

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Background: Assistance dogs support humans with different physical disabilities: 1. Service dogs for people with diverse mobility impairments 2. signaling dogs for humans diagnosed with diabetes, hearing impairments, seizure, or posttraumatic stress disorder 3. guide dogs for people with visual impairments. Definitions and terms are not consistent over Europe; Austrian terminology is used in the following. These specially trained dogs support people in their everyday lives and make it possible that less help is required from personal assistants or caregivers. Diverse studies show this positive impact of assistance dogs on the quality of life of disabled people. There are just a few case reports from United States about service dogs for people diagnosed with any inflammatory rheumatic disorder. Dogs are trained individually for about 1.5 years before team training and the concluding team assessment through Austrian authorities take place. Since 2015, there has been an adapted legislation for service dogs in Austria which brings significant improvements in many areas. In comparison to

the model set by Austria, there is no corresponding legal basis at EU level or in other European countries.

Objectives: Case-report about my own situation diagnosed with juvenile idiopathic arthritis (JIA) in 2001 and my service dog May. May supports my every day live in private and business affairs since 2019

Methods: May was trained for less than two years before team assessment. May is able to pick up things I dropped. These include coins, my key, my mobile phone, clothes, towels and lots of other things I want her to pick it up for me. May opens and closes doors, empties the washing machine, pulls the laundry basket and even helps me put on and take off clothes. In general, she carries many things which I instruct her to carry. I am able to learn her more new things in a short time. Furthermore May acts safe on public transport and even airplanes. Due to special training May is allowed to move without dog leash or muzzle. A muzzle or leash would handicap the dog's work. As a result of May's help I need less personal assistance.

Results: May's physical and psychological support gives me greater independence and increases my self-confidence. She was trained to specifically meet the needs of my disability. Beside her skills, May helps to reduce pain and burden of arthritis.

Conclusion: My aim is to spotlight the great support of service dogs to severely affected arthritis patients. Austria had realized legislation for assistance dogs to guarantee certain permissions the owner's needs (e.g. access to working place, hospital). I would love to raise awareness about assistance dogs to improve the knowledge about those animals to implement European legislation.

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PARE0003

MY RA STORY - PERSONAL ACCOUNTS OF LIVING WITH RHEUMATOID ARTHRITIS

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Background: Over 2,000 people are diagnosed with rheumatoid arthritis (RA) in Ireland each year; three in four are of working age. In total, RA affects some 45,000 people in the country; 70 per cent of whom are women.

For someone newly diagnosed with RA, coming to terms with the news can seem overwhelming.

Such a dramatic shift in life circumstances can impact one's physical and mental well-being. While there is no shortage of information available about the condition, it can be overwhelming trying to filter this, assess what is trustworthy and reliable.

Objectives: •To provide information and hope to people newly diagnosed with RA, and to give a voice to those living with the condition;

•To increase awareness and understanding of RA – encourage engagement with HCPs, contributing to early diagnosis and better outcomes;

•To increase awareness of work of Arthritis Ireland as a patient organisation.

Methods: Arthritis Ireland approached best-selling author and RA patient, Sinead Moriarty, to front an RA awareness campaign, called My RA Story.

The purpose of the campaign was to increase awareness and understanding of rheumatoid arthritis, of what it is like to live with this chronic condition with its invisible pain and life-changing impact. In so doing, Arthritis Ireland wanted to give a platform to people to tell their own story, so that they could be heard. We then wanted to publish these experiences in book form.

In April 2019, we launched a video on social media featuring Sinead Moriarty speaking about her experience of living with RA. The video generated lots of engagement across social media and also helped garner national and regional media coverage in print and broadcast.

The call for RA stories received a fantastic response from the public and the reading panel had a tough job in selecting the contributions which would feature in the published volume. Once the successful contributions were chosen, Arthritis Ireland proceeded to design a book, which could be sold in the book trade and online.

Results: In September 2019, Arthritis Ireland published *My RA Story: Personal accounts of living with rheumatoid arthritis*. Launched in the National Library of Ireland by Sinead Moriarty, the 46 contributions touched upon themes of pain, fatigue, emotional impact, disability, surgery, education, career, family, goal-setting, self-management, connecting with others, hope, etc.

The contributors came from people who were living with RA for over 40 years, as well as from those who were more recently diagnosed.

The book is a hugely valuable contribution to health literature. Arthritis Ireland now plans to make the book available for sale internationally, through Amazon and other retail channels, as well as promoting it more extensively in rheumatology clinics.

In October, one of the contributors was interviewed on national television about her RA story, as part of a feature on World Arthritis Day.

Conclusion: This campaign gave people living with RA a platform to write about and share about their condition. Fronted by an RA champion with significant name recognition and an enormous audience in her own right, best-selling author, Sinéad Moriarty, the book, *My RA Story*. Crucially, the book is a valuable resource for people who are newly diagnosed with the disease and uncertain of what the future holds.

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PARE0004

PATIENT PERSPECTIVE ON THE EFFICACY AND RISKS OF GLUCOCORTICOID IN RHEUMATOID ARTHRITIS – AN INTERNATIONAL SURVEY OF 1344 PATIENTS

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Background: The Glucocorticoid Low-dose Outcome in Rheumatoid Arthritis Study (GLORIA) is an international investigator-initiated pragmatic randomized trial designed to study the effects of low-dose glucocorticoids (GCs) in elderly patients with Rheumatoid Arthritis (RA).

The research team is also committed to promote a better understanding of the risks and benefits of these drugs among health professionals and patients. In order to achieve these goals, it is important to assess the current ideas and concerns of patients regarding GCs.

Objectives: To evaluate the current patient perspective on the efficacy and risks of GCs in RA patients who are or have been treated with GCs.

Methods: Patients with RA completed an online survey (with 5 closed questions regarding efficacy and safety) presented in their native language. RA patients were recruited through a variety of patient organizations representing three continents. Patients were invited to participate through national patient organizations. In the USA, patients were also invited to participate through MediGuard.org. Participants were asked for their level of agreement on a 5-point Likert scale.

Results: 1344 RA patients with exposure to GCs, from Brazil, USA, UK, Portugal, Netherlands, Germany and 24 other countries** participated: 89% female, mean age (SD) 52 (14) years and mean disease duration 13 (11) years. The majority of participants (84%) had ≥10 years of education. The duration of GCs exposure was 1.6 (4.2) years. The majority of participants had read articles or pamphlets on the benefits or harms of GC therapy.

Regarding GCs efficacy (table 1), high levels of endorsement were found: about 2/3 of patients considered that GCs as very useful in their case, more than half considered that GCs were effective even at low doses, and agreed that GC improved RA symptoms within days.

Regarding safety (table 1), 1/3 of the participants reported having suffered some form of serious adverse events (AEs) due to GCs, and 9% perceived this as "life-threatening. Adverse events had a serious impact on quality of life, according to about 1/3 of the respondents.

Conclusion: Patients with RA exposed to GC report a strong conviction that GCs are very useful and effective for the treatment of their RA, even at low doses. This is accompanied by an important prevalence of serious AEs. Understanding the patient perspective can improve shared decision-making between patient and rheumatologist.

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Table 1 – Results of the surveys, across different countries, concerning patient perspective on the efficacy and risks of glucocorticoids in patients with RA.

	All	Brazil	USA	UK	Portugal	Germany	NL	Others**
GCs are or have been very useful to me								
Agree	58	64	56	62	42	51	66	54
Slightly agree	20	20	21	11	12	30	10	18
Neutral	6	4	8	7	5	6	6	10
Slightly disagree	3	4	5	1	4	0	3	3
Disagree	4	3	7	3	1	4	3	3
Missing	9	6	1	15	25	9	9	12
At a GC dose ≤7.5mg/day:								
Are very effective in the control of signs and symptoms of RA								
Agree	41	48	42	40	31	28	46	38
Slightly agree	25	20	15	20	28	45	20	12
Neutral	12	11	24	8	12	12	16	12
Slightly disagree	5	7	6	8	4	0	4	4
Disagree	6	4	7	6	1	4	5	7
Missing	12	6	3	19	25	9	9	15
Improve RA symptoms within days								
Agree	41	45	44	37	34	37	44	39
Slightly agree	23	23	19	19	20	33	23	24
Neutral	12	12	18	8	13	8	12	9
Slightly disagree	6	6	7	7	7	0	6	7
Disagree	8	8	8	10	1	3	5	7
Missing	11	6	3	19	25	9	9	15
I have suffered very SAEs due to GCs								
Agree	29	40	44	13	15	18	18	29
Slightly agree	3	9	9	0	0	0	3	18
Neutral	14	15	12	15	17	4	7	11
Slightly disagree	1	0	0	0	0	0	7	2
Disagree	44	40	43	56	43	58	27	41
Missing	9	6	1	15	25	9	9	12
How serious do you consider these SAEs								
Life threatening	36	NA	55	32	NA	NA	NA	23
Serious impact in my QoL	27	NA	28	52	NA	NA	NA	17
Minor impact in my QoL	29	NA	18	50	NA	NA	NA	32
Mid and well tolerated								

Numbers indicate %.

**Others (% of total): Italy 1.9%; Spain 1.7%; Romania and Canada, each one 1.4%; Belgium 0.6%; France, Australia and Venezuela, each one with 0.2%; Algeria, Angola, Argentina, Belize, Cyprus, India, Ireland, Japan, Mauritius, Mexico, Mozambique, Moldova, Nicaragua, Norway, Sweden and Switzerland each one with 0.1%.

*The Portuguese, Germany and Deutschland version as well as the English survey through MediGuard.org, didn't have this question due to legal constraints (% of answers per frequency category).

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PARE0005

INTEGRATED REFERRAL OF NEWLY DIAGNOSED RHEUMATOID ARTHRITIS PATIENT TO EDUCATION AND SUPPORT RESOURCES DELIVERED BY PATIENT LED ORGANISATION

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Background: NRAS follows best practice, evidence-based standards in all we do. Whilst huge strides have been made in the diagnosis and treatment of RA, the impact on quality of life can be significant and for many this disease remains hard to come to terms with. NRAS services and resources can improve the outcomes of people with RA/Adult JIA through a framework of supported self-management resources tailored to individual need. It is particularly important to provide the right support at the beginning of a person's journey with RA, when unhelpful health beliefs, anxiety and incorrect information can influence how someone responds to prescribed