

News Rheum



Edition 9:
Primary Care in Ireland
Summer 2021

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

Welcome to the summer edition of News Rheum Newsletter. The theme of this edition is Primary Care in Ireland

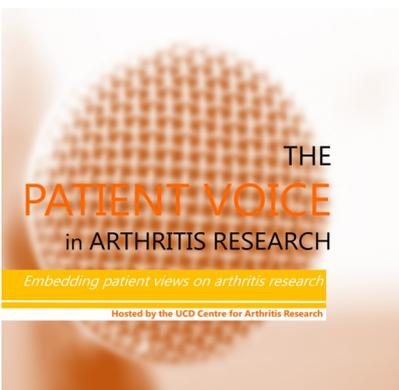
IN THIS ISSUE

In our last edition of News Rheum, we hosted a hugely successful annual conference in collaboration with Arthritis Ireland and the Patient Voice in Arthritis Research. Since then, we have had a very successful 2021 research seminar series. The UCD Centre for Arthritis Research Steering Committee for 2021 consists of 10 committee members including three are patient representatives. The 2021 representatives are Wendy Costello (Paediatric and Rare Disease), John Sherwin (Degenerative Arthritis) and Stacey Grealis

(Inflammatory Arthritis).

We hope you are staying positive while living through the continuing Covid-19 pandemic and enjoy this issue of News Rheum.

- A MEDiterranean diet in Rheumatoid Arthritis: The MEDRA trial, by Tala Raad, PhD candidate, University of Limerick
- Our Journey with Childhood Arthritis by Oana Serb
- Improving the ManagemENT of OsteoArthritis in PrimaRy Care in Ireland (ENACT)
- Physiotherapy Research: Childhood Hypermobility Study
- UCD Centre for Arthritis News



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patientvoicearthritis@ucd.ie

MEDiterranean diet in Rheumatoid Arthritis: The MEDRA trial

Tala Raad, PhD candidate, University of Limerick

Two years ago, I started my PhD journey in the School of Allied Health at the University of Limerick.

My doctoral research investigates the effect of diet in the management of Rheumatoid Arthritis (RA). RA is one of the most prevalent forms of inflammatory polyarthritis affecting 0.5-1% of the adult population worldwide. Apart from medication, diet has always been a topic of interest to people living with RA and many people with RA find that their symptoms may improve as a result of changing their diet. Despite this, no specific diet has been identified as superior to another and dietary

guidelines for this population are lacking.

The Mediterranean diet (MedDiet) has been gaining popularity not only in the scientific literature but also in clinical settings due to its many health benefits and anti-inflammatory properties. The increasingly popular eating pattern emphasises fruits, vegetables, nuts, whole grains and extra virgin olive oil while limiting red meat and sweets. While there is evidence to suggest that the MedDiet is beneficial for inflammatory conditions, the evidence to recommend this dietary pattern for people with RA is scant.



it is a collaboration between the University of Limerick and University Hospitals Limerick (UHL) Rheumatology department.

The programme involves a 12-week dietary intervention delivered through telehealth by a Registered Dietitian (RD). The overall aim of the study is to explore via telehealth the effects of adhering to a MedDiet or adhering to the Irish Healthy Eating Guidelines on health status and quality of life in adults living with RA in Ireland. Forty participants aged ≥ 18 years with a definite diagnosis of RA are recruited through Arthritis Ireland's social media platforms and UHL rheumatology clinics.



As part of my PhD programme, we are conducting a dietary intervention study in adults living with RA in Ireland. The title of the study is 'MEDiterranean diet in Rheumatoid Arthritis: MEDRA' and

Participants are randomly allocated to either the MedDiet group or a healthy diet (low-fat) group. Both groups receive a dietetic consultation with the study RD who is able to tailor the diet to individual preferences. During each follow-up teleconsultation, the RD assists participants in setting individual goals that will help them stay motivated towards changing their diet. All participants are provided with meal plans and recipes specifically designed to explain the principles of the assigned diet. Questionnaires are used to measure the effects of the intervention diets on participants' health status, pain, physical activity levels and quality of life.

Towards the end of the intervention, all participants will be invited to take part in small focus groups which will be conducted in order to better understand participants' perceived beliefs,

barriers and benefits towards adhering to the intervention diet.

Data collection for the MEDRA study commenced in January 2021 and is expected to continue until August 2021. The telehealth approach offers a safe and convenient way to collect data while preventing face-to-face contact with participants which is an essential consideration given the COVID-19 public health pandemic.

With its specific design, the MEDRA study will also demonstrate whether a web-based or telehealth type dietary intervention can be a feasible method to implement in a RA cohort.

Diet is a modifiable risk factor that can potentially be targeted in the management of RA. To our knowledge, the MEDRA study is one of the first randomised controlled trials assessing the Med-



Diet in a non-Mediterranean country and the first in Ireland.

Thus, it will provide insight into implementation of this dietary pattern in the Irish population. We anticipate that the information obtained may contribute to a better understanding of the effect of a MedDiet on RA and may inform current practice and impact on dietary guideline development.

Although the COVID-19 pandemic has imposed several challenges during the last year, it has also presented several learning opportunities and I'm extremely grateful to my supervisors, Dr. Audrey Tierney, Professor Norelee Kennedy, Dr. Anne Griffin and Dr. Louise Larkin and to all the study participants for their continuous commitment and engagement in the study.

Public and patient involvement (PPI) adds value and improves the quality of research as it provides insight that can help to make health research more relevant to the needs of patients and service users. Arthritis Research Limerick (ARL) is a partnership between researchers at the University of Limerick and clinicians at University Hospitals Limerick. ARL is now creating a formal PPI panel to inform ongoing and future research.

If you have a rheumatic condition and are interested in joining our panel please contact: louise.larkin@ul.ie or tala.raad@ul.ie

Our Journey with Childhood Arthritis

By Oana Serb

Our story begins when our daughter was around one year old. She is almost eight now.

She started waking up during the night complaining that her knees hurt. I would rub her legs and put her back to sleep. As a parent, you ask yourself what is happening; why such a small child complains of pain. Obviously, you push the worry away and think that, maybe, because she is an energetic child that's why she's in pain.

I lived with pain my whole life. I have rheumatism and since I was just a baby, my parents would take turns during the night in massaging my feet, legs and arms. Even now, as an adult, I have so much pain sometime that I need anti-inflammatory medication.

I always asked myself if my daughter would have it too. But I dismissed the idea; even when the signs were clear, so to say.

She was and still is a very active child. She likes to run, to cycle and skate. Talking to my family and friends and expressing my worries, they all tried to comfort



me saying that, most probably,

because of her endless energy she's tired and that's why she's in pain.

For a couple of years, she just complained of knee pain. I never felt the need to consult a doctor and never knew exactly how rheumatism (this was the only thing that I could think about) can be diagnosed.

In 2018 we moved to Ireland. Our daughter adjusted very well here. She made friends and the weather did not bother us too much.

A couple of months after we moved here, she was playing when I noticed that her fingers from her right hand were not straight. I thought maybe I didn't see right, so I asked her to straighten her fingers. They looked, to me, a bit bent. So I asked my husband if he can see it as well, which he didn't. But the thought stayed with me and I continued observing her. I was not happy at all about it so we decided to visit our GP. He, obviously, didn't know Ayana since she was a baby, but he listened to my concerns. So he took some blood tests. The results came back but there was nothing significant to show.

I am so grateful that our GP listened to my concerns! After hearing that I have rheumatism he sent a referral to a paediatric rheumatologist and told us that it would be better if we consulted a professional.

That's how we met our rheumatologist, Dr Emma MacDermott. She's a brilliant doctor and the moment she saw our daughter, she told us that she has arthritis.



To be honest, I was not sure what that meant. I knew, of course, that it affects the joints, but how much and how exactly, that is what I didn't know. The doctor sent our daughter for more blood tests and for X-rays. These showed that she had polyarthritis, meaning that more than one joint in her body was affected.

After she was diagnosed—Juvenile Idiopathic Arthritis (polyarthritis)—her doctor decided what course of treatment she should follow. She would have to see the doctor every 3-4 months; she would also have to have blood tests every two weeks for the first two months and then every month, and she would have to visit the ophthalmologist (arthritis can affect the sight). She started Methotrexate (injections) when she was six years old. Humira was added to her treatment after a couple of months. Unfortunately, Humira did not work the way her doctor was expecting, so she replaced Humira with Enbrel. We are hoping that this one will work much better.

How do you go to your daughter knowing that, in those moments, you are the bad guy? How do you give her the injection when she shouts and cries so hard that you get goose bumps?

What do you do and what do you say when she constantly asks you why is she the only child in her class with bent fingers? How do you react when so many evenings before going to sleep she starts crying and saying that she is sick of all the pain and prays that she won't have to take the injections anymore?

Our daughter has panic attacks when injection time comes. She becomes a different child. And her sole goal is to get away from me. She would do anything just to get away from the injection. It breaks our hearts when we see her like this and we continuously tell her that this will help with the pain.

It's been more than two years since she started the treatment. We are positive that she will overcome this condition. We

know that it is an autoimmune disease and she will have to live with it for her whole life, but we are hopeful that, at least, she will be pain free.

She is still in pain; she still wakes up during the night crying that her legs hurt. Sometimes, she doesn't want to go outside because of the pain.

I became a mother who worries a lot. Even though I want her to live knowing that she is not sick and she can live a normal life, I always have in the back of my mind the idea that whenever she falls or she hurts herself, it'll take longer for her to recover. I tend to tell her to stop running because her knees will hurt; to stop climbing trees because she might fall down and hurt herself; I always make sure she is well dressed or she wears gloves and she is not cold. And now, with this pandemic, she needs to wear a mask all the time. At school, when she plays with other children...

This condition changed her life, but as parents we do our best to

make sure that she lives a normal life and she knows that there is nothing wrong with her as a person. She is beautiful, intelligent, creative, funny and a lot of fun and she is our awesome child!

How do you feel knowing that you have arthritis?

Ayana: Disappointed, maybe. And sad. I feel like a different kid.

Do the children in your class treat you differently because of your arthritis?

Ayana: They don't know that I have arthritis.

How does Dr MacDermott make you feel every time you see her?

Ayana: Happy, because I know she helps me. I gave her a card once that said "Best doctor in the world".

Oana Serb is the parent of a child with arthritis. For more information about juvenile idiopathic arthritis (JIA), please see [Arthritis Ireland](#).



Improving the Management of Osteoarthritis in Primary Care in Ireland (ENACT)

What is the aim of the ENACT project?

The Management of Osteoarthritis in Primary Care (ENACT) project is a 4-year project funded by the Health Research Board (HRB) that aims to improve the care of people with osteoarthritis who attend their general practitioner (GP) in Ireland by developing a “model of care”. This model will map out the range of services and supports a person who visits their GP might need and will include treatments that are proven to be beneficial, including self-management, education, exercise and advice on weight-management. By developing this model, we aim to support people with osteoarthritis in the primary care setting and avoid unnecessary use of hospital-based services. In this way, the new model will ensure that directed and quality care will be provided and will also help the health system manage resources better. This work will be carried out by a multidisciplinary team of researchers from a range of disciplines including medicine, physiotherapy, psychology and pharmacy primarily based in RCSI. Firstly, we will find out which models are being used around the world and how effective they are both for the patient and for the health service. We will then ask people with osteoarthritis, GPs and other primary care team members their opinions on how osteoarthritis is currently managed and how it should ideally be managed in primary care in Ireland. This will be done through semi-

structured interviews. We will use that information to develop a model of care which we will test in three GP practices with patients who attend mainly because of osteoarthritis. Afterwards, we will interview the GPs and patients to seek their thoughts on the model in order to fine-tune it to ensure it is appropriate and mainstreamed towards day to day osteoarthritis primary care in Ireland.

How did ENACT come about?

Osteoarthritis is the most common joint disease in Ireland, affecting approximately 400,000 people. It is one of the leading causes of pain and physical disability. The number of people with osteoarthritis in Ireland and internationally is growing, with an estimated half of those aged over 65 years old diagnosed with osteoarthritis. This makes it one of the most prevalent chronic diseases alongside other conditions such as high blood pressure. OA affects women more often than men, especially after menopausal age.

The impact of the burden of pain associated with osteoarthritis also affects many other aspects of life. People with osteoarthritis often experience poor sleep and depression. It can impact work and reduce social participation, resulting in overall poorer quality of life. Despite this enormous burden that osteoarthritis places on individuals, families, healthcare systems and societies,

there is growing evidence that the care that people with osteoarthritis receive, both in Ireland and internationally, varies and is often below par. Even though evidence shows that progression of the disease can be slowed, pain can be relieved, disability can be minimised and the need for surgery may even be postponed or avoided with appropriate multi-disciplinary treatment including exercise, weight management and other chronic care interventions that address the needs of people with OA holistically.

The GP is generally the first port of call for people seeking care for osteoarthritis in Ireland. Yet, it does not feature alongside other chronic diseases such as asthma and diabetes in chronic disease management programmes or strategies <https://www.hse.ie/eng/health/hl/selfmanagement/hse-self-management-support-final-document1.pdf>. Therefore, osteoarthritis is currently not a priority in chronic disease management programmes, compared with other chronic conditions such as diabetes, cardiovascular disease and asthma. The NICE guidelines for osteoarthritis care and management <https://www.nice.org.uk/guidance/cg177> were developed in the UK in 2008 and updated in 2014. This is an international guideline which sets out the treatment that people with osteoarthritis should receive to enhance their function and overall quality of life highlights the

importance of a holistic approach. This means that emphasis should be placed on assessing the effect of osteoarthritis on a person's physical, mental and emotional health and wellbeing. Patient education, self-management, pain management, exercise and weight loss interventions (where the person is overweight) are key in the early stages. Physiotherapy assessment is also recommended for providing guidance on exercises that will help. The guidelines also specify that a person with osteoarthritis should be reviewed on an annual basis and referral for joint surgery should only be considered if the patient has been offered the above treatments, yet is still experiencing ongoing symptoms, such as pain, stiffness and reduced function, that have a substantial impact on their quality of life. For most people osteoarthritis does not progress to this late stage.

Other countries such as the UK, Norway, Sweden and Australia have developed what are called "models of care" to tackle the growing burden of osteoarthritis and the underuse of certain recommended treatments. These models have been shown to be successful in improving care for people with osteo-

arthritis. The ENACT project will learn from these models and adapt them to suit the management of osteoarthritis in the Irish healthcare system, with the overall aim of improving the care of people with osteoarthritis in Ireland through proactive and evidence-based management. This means that people attending their GPs with osteoarthritis would receive standardised care and regular annual review, similar to other chronic diseases such as diabetes. If the model of care was rolled out in the future, it would be important to measure the cost-effectiveness of the model compared to usual care.

The ENACT team includes principal investigator Dr. Helen French, Senior Lecturer, School of Physiotherapy, RCSI, Dr. Joice Cunningham, Postdoctoral Research Fellow, School of Physiotherapy, RCSI, Professor Susan Smith, Primary Care Medicine, RCSI, Dr. Jennifer Ryan, Lecturer in Public Health and Epidemiology, RCSI, Dr. Frank Doyle, Senior Lecturer Health Psychology, RCSI, Dr. Cathal Cadogan, Senior Lecturer, School of Pharmacy and Pharmaceutical Sciences, TCD and Dr. Barbara Clyne, Research Lecturer, Department of General Practice, RCSI. The model of care will be de-

veloped through a collaborative process. We will work with key stakeholders including people with osteoarthritis, Arthritis Ireland and healthcare professionals such as doctors, physiotherapists and nurses. We will be setting up a Public and Patient Involvement (PPI) panel, which will provide the patient perspective throughout the different stages of the research in relation to development of the different phases of the research. They will also help develop dissemination strategies for lay audiences at the different stages.



If you would like to learn more about ENACT, please email the principal investigator Dr Helen French (hfrench@rcsi.ie) or the post-doctoral researcher Dr. Joice Cunningham (joicecunningham@rcsi.ie)

Physiotherapy Research Childhood Hypermobility Study

PhD candidate Susan Ward is researching symptomatic hypermobility in children. Susan graduated from Trinity College Dublin with an honours degree in Physiotherapy in 2001 and started working with Dr Orla Killeen in the Paediatric Rheumatology team in Children's Health Ireland at Crumlin (formerly Our Lady's Children's Hospital, Crumlin) in 2007. Her clinical experiences led her to embark on a research project in 2020, to develop a physiotherapy decision-making tool for paediatric joint hypermobility. We spoke to Susan about her PhD and how she sees her work impacting clinical practice.

toms and hypermobility isn't clear. The medical terms used to describe hypermobility related conditions has changed over time which can be confusing to children, to their families, as well as to clinicians. Our research team use the term 'symptomatic hypermobility'. The varied pattern of symptoms can present a challenge in terms of diagnosis and treatment. Physiotherapists often play a key role in their management. Exploring this range of symptoms in children and young people is an important part of our research and will lead to the development of a physiotherapy decision-making tool to help direct care.

ical Research Fellowship from the National Children's Research Centre (NCRC). The National Children's Research Centre (NCRC) has been in existence for over 50 years and has been funded since its inception by the Children's Health Foundation Crumlin (formerly the Children's Medical and Research Foundation (CMRF) Crumlin). Our research team hope to develop a decision-making tool which can help to guide clinicians in the treatment of children with this challenging condition.

Future impact

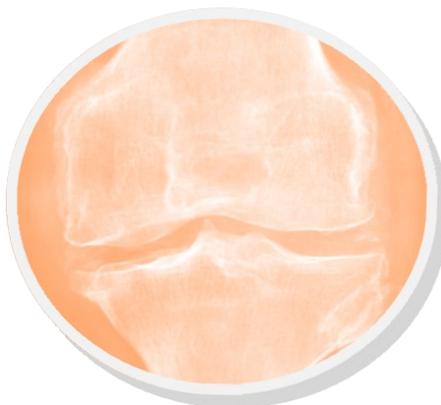
We hope that our research will contribute towards a better healthcare pathway/patient journey from diagnosis to treatment for children and young people with symptomatic hypermobility.

Currently, there is no agreement about how to effectively manage children and young people with symptomatic hypermobility. We hope that our research will further the knowledge and understanding of this condition and by developing a decision-making tool, help to target treatment more effectively in the future.

What is hypermobility?

Joint hypermobility is the term used to describe the ability that a joint or group of joints has, to move beyond its normal range and is common in the general population. Children are more hypermobile than adults, and for most, this causes no problem. Some children and young people with hypermobility might perceive having extra range of movement as a help, especially in certain sports like gymnastics, dance, or swimming. However, others, report pain in their joints and muscles, which tends to be worse towards the end of the day following activity. They can report fatigue, or difficulties with functional tasks like hand-writing, which can limit their ability to participate in daily activities.

Symptoms in other systems of the body including the gastrointestinal, cardiovascular, urogenital, and psychological can be more common in individuals with joint hypermobility. But the link between these symp-



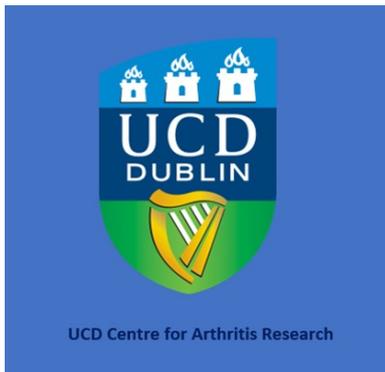
Research Team

Our research team includes Dr Emma MacDermott (Consultant Paediatric Rheumatologist, Children's Health Ireland at Crumlin) and Dr Sara Dockrell (Discipline of Physiotherapy, Trinity College Dublin). We are also working with Dr Janet Deane (NIHR Clinical Lecturer and AHP Research and Innovation Lead) from the University of Manchester and Manchester University NHS Foundation Trust and Dr Jane Simmonds, Associate Professor from Great Ormond Street Institute of Child Health, University College London. This project is funded by a Clin-



UCD Centre for Arthritis Research News

2021 has been a year so far for the UCD Centre for Arthritis Research with a successful research seminar series, research collaborations and new publications. We hope to continue this activity throughout the rest of 2021.



Research Seminar Series

The Centre for Arthritis Research—Rheumatology Research Seminar Series started again this semester for 2021. The seminar series has hosted a number of world class academics during the first semester of 2021.

The keynote speakers to date have included Professor Christian Hedrich, from University of Liverpool's Institute of Translational Medicine, who presented research on the topic of 'Juvenile-onset SLE – Are Children Young Adults?'. This was followed in March by Professor Christopher Buckley, Kennedy Institute of Rheumatology, University of Oxford and the University of Birmingham. Professor Buckley presented research on 'Targeting Fibroblast Subsets in Inflammatory

Arthritis'. The seminar was followed by a lengthy question and answer session.

The April seminar featured a presentation titled "Exercise combined with Acceptance and Commitment Therapy (ExACT) compared to a standalone supervised exercise programme for adults with chronic pain: a randomised controlled trial", by Dr Máire-Bríd Casey, Senior Physiotherapist, Mater Misericordiae University Hospital.

Most recently, Dr Andreas Goebel, from the University of Liverpool's Institute of Translational Medicine presented research on the subject of "Autoantibody contribution to chronic primary pains - mystery unravelled?". The June seminar, taking place on Friday 18th via Zoom, will feature guest speaker Dr Jose Scher, from the New York University School of Medicine.

The Rheumatology Research Seminar Series will take a short break during the summer but it will resume next semester. If you would like to attend our seminars, please keep check on our [twitter page](#) for updates about future seminars. We remain very grateful to our guest speakers and audience members. We look forward to welcoming you to future seminars.



The Patient Voice in Arthritis Research

The Patient Voice in Arthritis Research is a public and patient involvement (PPI) initiative, coordinated by the UCD Centre for Arthritis Research. It aims to ensure that the real-life experiences of patients and their families are considered in research decision-making. If you would like to become involved, please contact patientvoicearthritis@ucd.ie

iCAN: Irish Children's Arthritis Network

The [iCAN Network](#) is a national support network for children with arthritis and their families. If you would like to become involved, please contact iCAN at icanireland@gmail.com

Arthritis Ireland

[Arthritis Ireland](#) works to support people with arthritis by providing access to healthcare, treatments and minimising the effects of arthritis on their quality of life. If you would like to become involved, please [contact](#) Arthritis Ireland.



Questions? Ideas?

Would you like to write for
News Rheum?

We are always happy to hear from you. If you have an idea to share, a question to ask please do not hesitate to get in touch. We are always happy to hear from people who would like to contribute to News Rheum and what we cover. Get in touch at patientvoicearthritis@ucd.ie

If you would like a printed version of News Rheum, please contact us ((0)1 716 6728 or patientvoicearthritis@ucd.ie





Centre for Arthritis Research Rheumatology Research Seminar Series 2021

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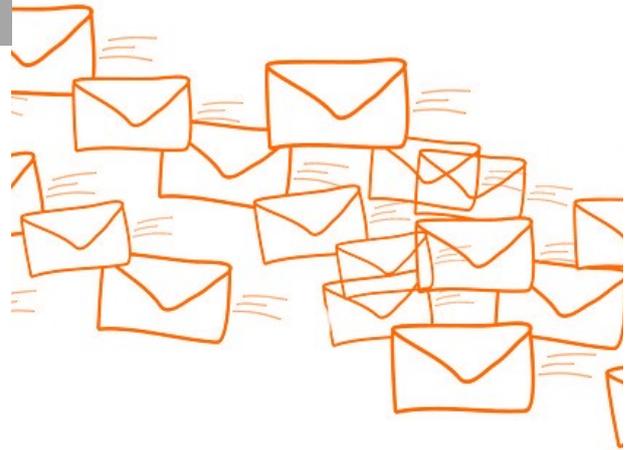
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