

News Rheum



Edition 8:
Clarity in Research
Spring 2021

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

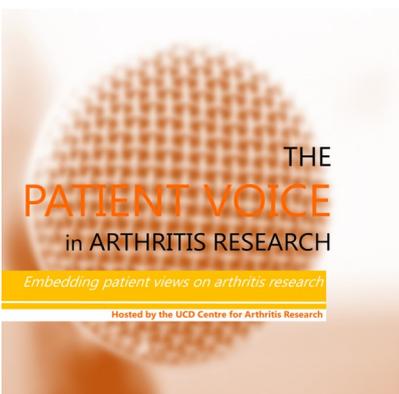
Welcome to the first 2021 News Rheum Newsletter. The theme of this edition is Clarity in Research

IN THIS ISSUE

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

- 2020 UCD CAR Annual Conference Report
- Conference Abstract: Adolescents with Juvenile Idiopathic Arthritis
- Conference Abstract: Keeping Time: Our Knees & Hips Need a Clock That Ticks
- Conference Abstract: How Satisfied are Children and Their Caregivers with Virtual Clinics? A Systematic Review of the Literature.
- Conference Abstract: Down's Arthritis
- Conference Abstract: The Role of the Gene PAM in Rheumatoid Arthritis
- Unravelling Science by Dr Megan Hanlon
- UCD Centre for Arthritis Research News

We hope you are staying positive while living through the continuing Covid-19 pandemic and enjoy this issue of News Rheum. If you would like to get involved, please



contact us at:

patientvoicearthritis@ucd.ie

UCD Centre for Arthritis Research Annual Conference 2020

Hosted by the UCD Centre for Arthritis Research in collaboration with Arthritis Ireland and the Patient Voice in Arthritis Research

The UCD Centre for Arthritis Research held its Annual Conference on Wednesday 18th November 2020.

The conference was coordinated in partnership with Arthritis Ireland and The Patient Voice for Arthritis Research group in UCD.

The organizing committee in collaboration with conference partners agreed upon the theme of “Self-Management for You and Your Family”, promoting the idea of a patient and family centered approach to managing long term health.

Due to the continuing public health emergency the conference was held online via a webinar format, which was very successful.

The conference, coordinated by Dr Dáire O’Leary on the day, featured an opening welcome from Gráinne O’Leary, Chief Executive

of Arthritis Ireland, highlighting that almost 90% of management for patients with arthritis is self management.

Dr Susie Donnelly outlined the complexity of self-management on a daily basis while dealing with constant pain. Dr Donnelly stressed the importance of good support networks. Mr Tim O’Sullivan, Arthritis Ireland Chairman, gave a detailed personal journey of living and managing a rheumatoid disease, drawing attention to the online learning courses provided by Arthritis Ireland.

Dr Jennifer Wilson-O’Raghallaigh, Clinical Psychologist at Beaumont Hospital, communicated the importance of maintaining mental health while managing a long term chronic condition through engaging with Living Well programmes and maintain social connectedness.

Professor Norlee Kennedy, University of Limerick, led a fascinating discussion on the importance of exercising in management of rheumatoid disease including arthritis. Professor Kennedy also outlined the im-

portance of seeking support and advice from your general practitioner.

St. Vincent’s University Hospital Dietitian, Ms Ellen Beirne’s superb presentation on ‘Diet and Rheumatic Disease’ outlined for conference participants the crucial importance of maintaining a well balanced healthy diet, including your 5 –a-day fruit and vegetables, when managing rheumatoid conditions.

Dr John Stack, Consultant Rheumatologist at the Mater Hospital, provided a comprehensive overview of the impact of the continuing Coronavirus pandemic on mental health on patients managing a rheumatoid condition. The importance of a positive outlook and healthy lifestyle was highlighted by Dr Stack.

Following the presentations there was a very lively, engaging and broad ranging question, answers and discussion between audience members and the conference speakers, providing positive feedback and potential themes for future conference events.



UCD Centre for
Arthritis Research



The Patient Voice in
Arthritis Research

A Collaborative Approach to Arthritis and Rheumatic Disease Research

A research conference open to the public

UCD Centre for Arthritis Research Annual Conference 2020 Abstracts

Manria Polus (1), Hannah Durand (1), Caroline Heary (1), Line Caes (2), Jennifer Stinson (3), Sara Ahola Kohut (3), and Brian McGuire (1)

1. Centre for Pain Research and School of Psychology; National University of Ireland, Galway; Galway, Ireland

2. Department of Psychology; University of Stirling; Scotland, UK

3. University of Toronto and Hospital for Sick Children (SickKids); Toronto, ON, Canada

What is the problem?

Adolescents with Juvenile Idiopathic Arthritis (JIA) face many physical, emotional, and social challenges during their teenage years. Having a peer mentor can help young people with JIA to cope with these challenges and learn to self-manage their health. We wanted to find out more about what kinds of topics young people with JIA discuss during peer mentoring sessions to guide future peer mentor training.

What did we do?

We recorded and analysed peer mentoring video calls between four adolescents living with JIA and their peer mentors as part of the Lending an Ear online JIA self-management intervention. The mentors were young adults who had learned to successfully manage their own JIA. During the peer mentoring, they provided the adolescents support based on their training and own experiences with JIA.

What did we find?

The adolescents and mentors completed overall 17 video calls. From those calls we identified three main topics: Illness Impact, Managing Illness, and Mentoring and Bonding. While mentees discussed challenges regarding illness management and illness impact on their lives, they also reported having developed supportive friendships and variety of coping skills. Mentors were able to bond with the mentees and provide them support individualised to each mentees support needs.



What does this mean?

The results of this study can improve our understanding of the support needs of adolescents with JIA, and how they might differ from adolescents with other chronic illnesses. The results can also help to develop and improve the way we train peer mentors.

UCD Centre for Arthritis Research Annual Conference 2020 Abstracts

Fagan, L.E. (1, 2, 3, 4, 5), Early, J.O. (1, 2, 3, 5), Kearney, C.J. (1, 4, 5), Kennedy, O.D.(1, 3, 5), Curtis A.M. (1, 2, 5).

1 Tissue Engineering Research Group (TERG), Dept. of Anatomy, Royal College of Surgeons in Ireland (RCSI), Dublin. 2 Curtis Clock Lab, School of Pharmacy & Biomolecular Science, RCSI, Dublin. 3 Kennedy Biomechanics Lab, TERG, Dept. of Anatomy, RCSI, Dublin. 4 Kearney Lab, TERG, Dept. of Anatomy, RCSI, Dublin. 5 Advanced Materials and Bioengineering Research Centre (AMBER), RCSI & TCD, Dublin, Ireland

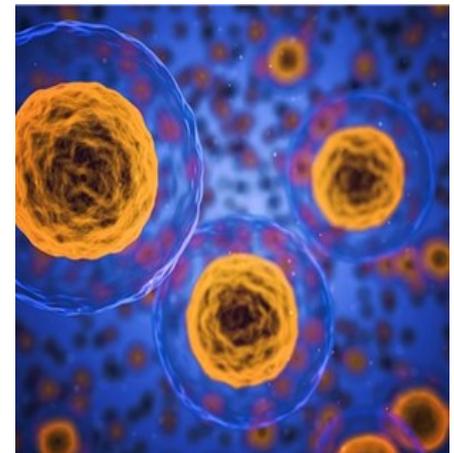
Keeping Time: Our Knees & Hips Need a Clock That Ticks

Arthritis is a disease that restricts our movement and causes pain by breaking down a tissue called cartilage, in joints like knees and hips. Cartilage is a wonderfully slippery substance that lines the end of our bones allowing frictionless movement between them. If cartilage wasn't there our bones would grind painfully off each other when we moved around! With arthritis the cartilage gets worn away or damaged which leads to joint pain.

In recent times, it was discovered that the human body has an internal clock system or body clock. This body clock ensures that certain system-wide things happen to the body at the right time of day. For example, it controls our sleepiness levels, which increase when it gets dark. The clock controls when we feel hungry, which increases in the morning, after exercise and throughout the day, but not during the night. From a timing point of view, it is also interesting that people often feel their arthritis pain is particularly bad at a certain time of day (morning/evening). This led us to discover that cartilage cells have their own, specific, local clock, separate from the whole-body system. Cartilage cells are called chondrocytes. When chondrocytes are healthy their clock ticks along to the correct time. We believe this allows them to essentially 'eat' (take up nutrients) during the day, which helps them to withstand all the daytime movement we do like walking, running and jumping. Then, during the night the chondrocytes 'sleep' (to rejuvenate themselves). Just like with our whole bodies, having these things occur at the correct time of day keeps our cartilage,

and joints, nice and healthy.

However, we have shown that when arthritis develops it essentially 'stops the clock' in chondrocytes.



We believe that without a functioning clock, our cartilage cells start to perform certain functions at really erratic times of the day. This is similar to how you feel when you are experiencing jetlag or work the night shift. We believe that this problem of 'clockless' chondrocytes causes cartilage to break down and the joints to become painful. The aim of our research is to understand why the clock stops working in arthritic joints, and whether we can develop new ways to cure or fix the clock in arthritis before it is too late.

UCD Centre for Arthritis Research Annual Conference 2020 Abstracts

Isabelle Mathew (School of Medicine, University College Dublin), Bronwyn Power (National Centre for Paediatric Rheumatology, Children’s Health Ireland), Orla Killeen (National Centre for Paediatric Rheumatology, Children’s Health Ireland), Daire O’Leary (School of Medicine, University College Dublin)

How Satisfied are Children and Their Caregivers with Virtual Clinics? A Systematic Review of the Literature.

Background

The Covid-19 pandemic has made it difficult for doctors and patients to meet. The main way patients and doctors have talked has been by phone or video conferencing platforms such as Zoom. This is called a virtual clinic or telemedicine and it allows for social distancing. This is a big change from usual face-to-face meetings. The technology to meet virtually has been around for a long time. However, before the pandemic, doctors and patients were slower to start using virtual clinics than expected.

Objective

We wanted to find out if children and their caregivers were satisfied or happy with virtual clinics compared to traditional face-to-face meetings by looking at the published research.

Methods

This was a systematic review which means that we looked for all the publications which might answer our question. We looked in databases including Pubmed, Medline, The Cochrane Library and Embase. We checked all the studies we found and carefully read any which looked at children’s clinic appointments. We made sure that the research was high quality by using a checklist called the McMaster Critical Review Forms for Quantitative/Qualitative Studies.

Results

Most of the studies only looked at adult patients. Most studies looked at how cost-effective virtual clinic is. Only 44 studies looked at how happy or satisfied children and caregivers were with the virtual clinic. Caregivers, and sometimes children, answered written questions in some stud-

ies. In other studies, caregivers were interviewed by the researcher. Overall, most studies showed that children and caregivers were happy with virtual clinic. The problem we found was that some studies didn’t really explain how they measured that happiness. Some studies told us that children and caregivers were very satisfied but didn’t explain what they meant by satisfied. This made some studies difficult to understand.



Conclusion

Most children and their caregivers seem to be happy or satisfied with the virtual clinic. Many think it just as good as face-to-face consultations. However, there are some problems with how the studies explain what they found. We need to do more research after the dramatic increase in virtual clinics during the Covid-19 pandemic. This research would help us make sure we were using virtual clinics in the best way to help children.

UCD Centre for Arthritis Research Annual Conference 2020 Abstracts

Kelly McDonagh, Dr. Hannah Durand, Prof. Brian McGuire

Centre for Pain Research and School of Psychology; National University of Ireland, Galway; Galway, Ireland

What is the problem?

Down's Arthritis (DA) is a particularly aggressive rheumatic disease, with many complications in its course and treatment. It is relatively common but poorly understood. There has been limited research in this area, however research on other conditions suggest having a child with DA may present unique challenges for parents.

What did we do?

We looked at the impact and experiences of parents caring for a child with DA. Ten mothers were interviewed over the phone to prevent the risk of COVID-19 transmission. Parents were encouraged to lead the conversation. Interviews were analyzed individually first and then together for common themes.

What did we find?

Parent's experiences varied, however common challenges included issues around child pain, communication, difficulty in getting a diagnosis for their child, and challenges in accessing relevant healthcare services. Parents discussed their many struggles, particularly parents of children that were nonverbal and living outside the catchment area for services in Dublin. Connecting with other parents of children with DA provided a vital source of emotional and informational support.



What is needed next?

Further research is needed to understand the impact of DA on the family, particularly fathers and siblings. As well as that, in order to reduce the parental burden of care, a greater level of awareness around DA is needed and more medical training and upskilling for medical professionals. Findings of this study can contribute to the development and providing of various means of support to children with DA and their families.

UCD Centre for Arthritis Research Annual Conference 2020 Abstracts

The Role of the Gene *PAM* in Rheumatoid Arthritis

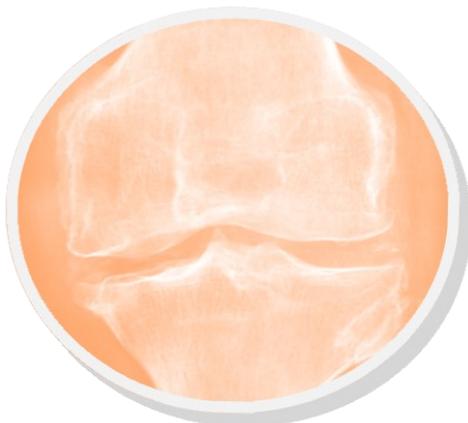
Kevin J Sheridan¹, Emma R Dorris¹, Eimear Linnehan¹, Michelle Trenkmann¹, Karen Creevey¹, Doug Veale¹, Ursula Fearon² and Anthony G Wilson¹

¹University College Dublin Centre for Arthritis Research, Conway Institute, University College Dublin

²Molecular Rheumatology, School of Medicine, Trinity Biomedical Sciences Institute, Trinity College Dublin

Rheumatoid arthritis is a disease in which the immune system of a patient attacks the patient itself. This results in swollen and painful joints, which can be severely debilitating. Rheumatoid arthritis affects approximately 1% of adults and in a portion of patients, medication may not work effectively. For this reason, an improved understanding of the biological factors which cause rheumatoid arthritis is desired in order to improve treatment.

The genetic site rs26232 has been found to be associated with rheumatoid arthritis, dependant on which pair of genetic bases are present (CC, CT or TT). Patients with the bases CC at the rs26232 site presented with a more



severe disease than those with CT, and more severe again than TT. Rheumatoid arthritis synovial fibroblasts (RASFs), cells found in the lining of joints in arthritic patients, were also more destructive when they had the CC genetic bases. This tells us that the genetic bases present at the rs26232 site can influence severity of the disease, but we did not know how.

To investigate how rs26232 may influence rheumatoid arthritis we looked at the genes beside it. We noticed that one of the genes, called *PAM*, was expressed in higher amounts in cells with the genetic marker TT compared to cells with CT, and higher again than cells with CC. This suggests that rs26232 may control the levels of *PAM*. It also suggests that low levels of *PAM* (as seen in the cells with CC) may be linked to more severe arthritis (as seen in patients with CC). We investigated this further by using siRNA technology. siRNAs allow us to artificially lower the levels of a gene in a cell so that we can observe the effects. When we used siRNA to reduce the levels of *PAM* in RASF cells, we observed three things: 1) RASFs with lower levels of *PAM* grew quicker. 2) RASFs with lower levels of *PAM* do not die as quickly. 3) RASFs with lower levels of *PAM* can grow through a membrane more efficiently. RASFs are an important factor in rheumatoid arthritis because they can move from the lining of the joint (where they are normally found) to the middle of the joint. This process is called invasion and leads to the destruction of the joint and contributes to pain and swelling. RASF cells which grow quicker, die less easily, and invade more efficiently, as observed, would therefore contribute to a more severe disease.

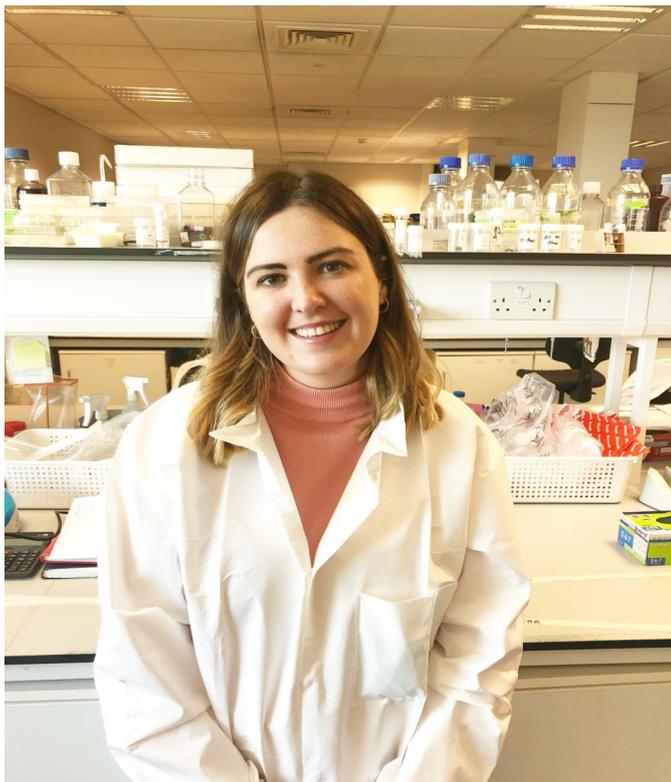


Unravelling Science

By Dr Megan Hanlon

Unravelling Science is a weekly scicomm podcast where I interview top Irish researchers and listen to the stories that shape the science but also the scientist. Each week I chat to a different scientist and get a sense of their journeys through academia, their passions and advice and their research with the aim of getting a glimpse the ‘people behind the publications’ so to speak.

In June 2020 the first episode of Unravelling Science went live. I was in lockdown in Westmeath, I had just finished my PhD and had been thinking about starting a podcast for a few months and thought well what better time? My first guest was Dr Mary Canavan a fellow Rheumatology researcher and good friend of mine, the interview was extremely conversational and casual which set the tone for the rest of the series. Now, two seasons and 24 episodes later it has become a top science podcast reaching No. 6 in the Apple Science Podcast charts in Ireland with listeners in over 40 countries worldwide and sponsored by Bio-sciences Ltd.



Each week features scientists from various career-stages and research areas such as immunology, bio-engineering, oncology, astronomy, food science with Prof Luke O’Neill, Prof Cormac Taylor, Prof Emma Teeling to name but a few. I have also been lucky enough to speak to some of the top Rheumatology researchers in the world including Prof Ursula Fearon, Prof Paul Peter Tak and Prof Ellen Gravallese (outgoing ACR president). It’s been a wonderful experience so far and such a privilege to chat to these experts in the field. I’ve had great feedback from both academic and lay audiences, there really is something in it for everyone from why we sleep, how studying bats could unlock the secrets of health to hearing from a former heroin addict turned neuroscientist and much more. I can’t wait to start Season 3 in the New Year, if anyone is interested in checking it out just search Unravelling Science on Spotify/Apple Podcasts/Google Podcast or wherever you get your podcasts!

<https://unravellingscience.podbean.com/>

<https://twitter.com/MeganHanlon4>

UCD Centre for Arthritis Research News



News Updates

2020 was a busy year for the UCD Centre for Arthritis Research with many researchers participating in outreach activities, grant applications, undertaking industry partnered research in addition to new publications. We hope to continue this activity in 2021.

Clarity in Research Awards at 2020 Conference

The UCD Centre for Arthritis Research conference which took place on Wednesday 18th November 2020 included the annual 'Clarity in Research' Awards. Similar to previous years, entrants were asked to submit an abstract aimed at a general, non-scientific audience. Following receipt of numerous very high-quality abstracts, the 2020 Clarity in Research Awards were presented to Kelly McDonagh, National University of Ireland, Galway, Isabelle Mathew, University College Dublin and Lauren Fagan, Royal

College of Surgeons Ireland.

Thank you to researchers who submitted excellent work for consideration and many congratulations to the 2020 Clarity in Research Awardees.

The Patient Voice in Arthritis Research

Continuing with our education and training sessions, we were delighted to have Bettina Ryll, founder of the Melanoma Patient Network Europe and board member of the EU Cancer Mission Board deliver a training seminar: "What patients can do for medical research." We will have access to this recording available soon.

Research Grants Applications

Professor Gerry Wilson, Centre for Arthritis Research Director, Professor Geraldine McCarthy, UCD School of Medicine/ Mater Misericordiae University Hospital and Dr Helen French, Royal College of Surgeons co-ordinated and led Collaborative Doctoral Award first stage submission to the Health Research Board in December 2020.

Research Seminar Series

The Centre for Arthritis Research was delighted to host a number of world class academics during the first semester of the year.

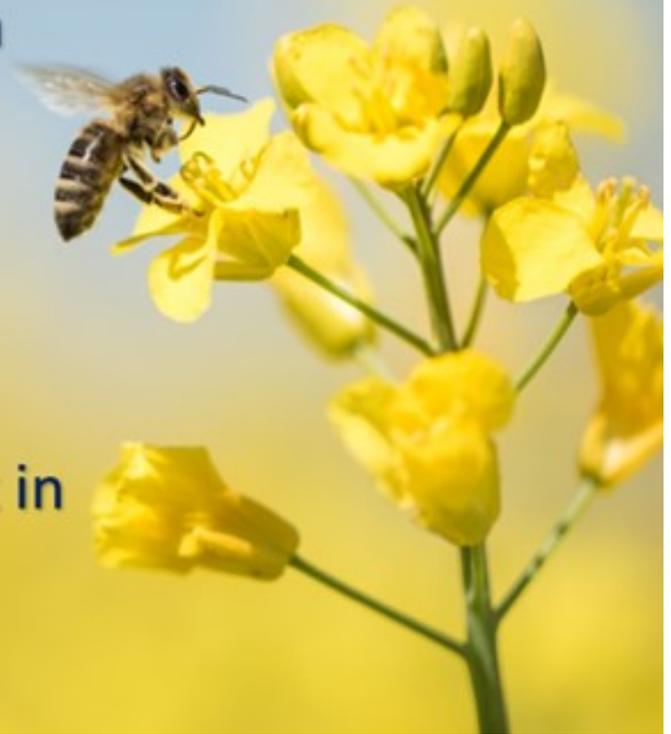
The seminar series featured fascinating presentations by Dr Helen French, Royal College of Surgeons Ireland, "*Exercise for Osteoarthritis: Moving Beyond Mobility & Strength Benefits*"; Dr Oran Kennedy, Royal College of Surgeons Ireland, "*Sub-Chondral Bone Damage, Post-Traumatic Osteoarthritis... & Skele-Tim*"; Professor Philip Conaghan, University of Leeds, "*OA: where are we now and where are we heading?*" and Professor Oliver Fitzgerald, Professor Steve Pennington, Dr Orla Coleman, Dr James Waddington, University College Dublin, "*Unmet clinical needs in diagnosis and management of Psoriatic Arthritis*".

We are incredibly grateful to our guest speakers and all colleagues who have attended and participated in the seminar series in 2020. The Rheumatology Research Seminar Series continues in 2021. Details can be found on the UCD Centre for Arthritis Research [website](#).



Thank you for working
with The Patient Voice in
Arthritis Research
throughout 2020!

Let's do even more work in
2021!



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

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“Exercise is Self-Management”

Professor Norlee Kennedy, University of Limerick, highlights the importance of exercise in managing rheumatoid arthritis.

Speaking at “Self-Management for You and Your Family”,
UCD Centre for Arthritis Annual Conference, November 2020

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