

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

Welcome to the first News Rheum Newsletter! The theme of the first edition is EXERCISE

Welcome to the first edition of News Rheum, our new quarterly newsletter. News Rheum has been created in response to feedback we received from our patient insight partners at our first Patient Voice in Arthritis Research discussion forum. News Rheum is co-produced by researchers and patients. Each edition will focus on a specific research theme. In this edition, we focus on Exercise. Patient insight partner Peter Boyd interviews Deirdre Hurley (UCD School of Public Health, Physiotherapy and Sports Science) about the SOLAS programme and Máire-Bríd Casey describes her work on the ExACT trial. We call for your questions about exercise and have a competition for our juvenile patients to design our logo. We hope you enjoy News Rheum. If you would like to get involved, please contact us at:

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EUPATI Patient Education Training Course by Wendy Costello

I am currently participating in the IP-POSI patient education course but how did I come to be involved? My daughter, Niamh, was diagnosed in 2003 with Juvenile Idiopathic Arthritis at the age of 4. This changed our family's life forever as we all struggled to come to terms with what the

future held for her. I knew I needed to talk to other families going through the same situation and I knew Niamh needed to meet other children living with JIA. I was always the annoying one in clinic talking to families asking them to connect with an online forum set up by my friend and me. Through this our numbers grew and grew and and with huge support from Niamh's rheumatology team in OLCHC, we formed a charity called iCAN (Irish Children's Arthritis Network).

I started to attend conferences to broaden my knowledge of this disease and also to support other fami-

lies with rare diseases. I became chair of **ENCA (European Network of Children** with Arthritis) two years ago and this opened up a whole new world to me. I was able to see internationally what was happening in research, advocacy and support in the area of JIA. I then connected with IPPOSI to keep an eye on what was happening in Ireland and

through their newsletter I spotted an advert for this course. I was very nervous applying as I really thought I would not get accepted. I was thrilled to receive the email to say I had made it onto the course.

after the module finished really brought it all together for me and I felt very pleased with myself on the train home: Me, my daughter's carer for the last 14 years, had completed Module 1.

Module 2 and Module 3 on health technology and regulatory affairs followed.

> Interaction with my fellow students at our face to face meetings really brought these modules alive for me. The speakers we had ranged from Dr Laura McCullagh to Peter Doran really inspired me with their valuable input to this course.



I have really lived in a JIA bubble for 14yrs so this course has also opened my eyes to different diseases and I have enjoyed meeting other patient advocates who are just as passionate about their cause as I am about mine. The information I have gathered on this

course has given me the confidence to put myself forward to participate in research, discussions on drug reimbursement and participation in workshops being held by the EMA on March 20th in London. I am really excited to see where the next part of my journey brings me but a huge thanks to IPPOSI for putting it all together.



Our first module was on clinical trials and I really felt out of my depth at face to face meetings to introduce the details. But as I downloaded the course work every Monday morning I quickly got a grasp of it and really enjoyed the lectures and information we were so lucky to be receiving. The face to face

SOLAS Programme shines light on exercise and osteoarthritis

by Peter Boyd

Self-management, patient centred care, and, 'Nothing for us, without us', have become very important in the treatment of osteoarthritis (OA) and all forms of rheumatic and musculo-skeletal diseases (RMDs).

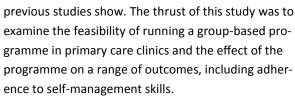
It is vital for the long term, effective management of symptoms that patients learn about their condition, understand what they can do to manage the symptoms and live better with their RMD.

Dr Deirdre Hurley-Osing, based at the UCD School of Public Health, Physiotherapy and Sports Science lays out the value and benefits to exercise explaining that "all the international guidelines endorse strengthening and aerobic exercises". There are general health benefits of exercise as we age, reducing cardiovascular risk factors, obesity, and blood pressure, which all hold fast for patients with OA. However, there is also evidence for reduced pain, increased muscle strength, physical function and quality of life from participation in exercise for patients with OA.

Exercise as medicine is a growing phrase but it is vital that OA patients know their recommended dose of exercise. The general guidelines of 150 minutes of aerobic exercise (30 minutes on five days per week of walking, swimming or cycling for example) and 2 sessions of strengthening exercises per week carries through.

The SOLAS (Self-management of Osteoarthritis and Low back pain through Activity and Skills) programme involved a 6-week group-based physiotherapist led education and exercise class being compared to individualised physiotherapy sessions in the SOLAS feasibility trial, funded by the Health Research Board.

There is no argument that both group-based and individualised physiotherapy are effective interventions for OA as the literature and



As Dr Osing explained, at the end of the 6-week programme "the effects on some of the behaviour change components and in the uptake of self-management skills were more positive in the SOLAS programme compared to individual physiotherapy."



Teaching people skills such as how to set goals, problem solving and how to monitor progress towards their goals were a big aspect of the SOLAS programme. One of the key areas of self-management behaviour change programmes must be supporting patients to set and review goals for themselves.

There were a series of exercises available for patients to take part in at the classes including treadmills, step -ups, cycling and bouncers for aerobic exercise, as well as strengthening and mobilising joint-specific exercises. After the initial introduction and self-management education session from the physio, the patients had the choice of what exercise to do during their 45 minutes. Within that they would spend no more than 5 minutes on the general exercises and no more than 2 minutes on the joint specific movements.

continued overleaf.....



interview continued...

As it was a self-management programme the physios sought to get patients to look at the intervention as a stepping stone to long-term change and to allow them to design their own exercise and activity programme based on their individual needs.

"This was one of the novel aspects of the programme, it wasn't a one size fits all approach and allowed for a tailored programme within a group setting. A lot of emphasis in the training of the physios was put on showing them how to allow individualisation within a group setting", said Dr Osing.

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The SOLAS programme is underpinned by self-determination theory, which supports patients' motivation to change their behaviour and which is what the physios were trained in. "We wanted to give patients autonomy within that, a choice in what they do and to understand the reasons why they are doing it and to feel confident in doing it," explained Dr Osing.

The research and evaluation continued after the patients completed the SOLAS programme. The physios were assessed on how well they implemented the behaviour change theory, in association with other disciplines, including psychology through Dr James Matthews. The success of the physios in encouraging behavioural change in participants was examined by audio-recording them running the classes. Their audio was then analysed as well as being transcribed to examine the communication skills of the physios and to "see if they are adherent to the underlying behaviour change theory" according to Dr Osing.

This has led to results around the feasibility of having physiotherapists deliver the intervention, what aspects they delivered well and what could be improved on. The reason being that, the more adherent to the behaviour change theory the physiotherapists are, the more likely the patients are to implement positive self-management and behaviour change once the intervention has concluded.

As patients we must meet the providers of self-management theory in the middle so that we implement behaviour change and learn how to live better with our RMDs.

There is no argument in the literature that either group-based or individualised physiotherapy sessions are beneficial to patients with OA. What the SOLAS programme, and the evaluation of its results, has shown is that group-based self-management interventions are feasible to deliver and may have a better and longer lasting influence on patients' self-management.



The Patient Voice In Health Research

Arthritis and Rheumatic Disease Research



Developing patient and researcher partnerships to help us expand our biomedical and clinical research into a more holistic model and improve our research relevance for patients.

To get involved or learn more contact: patientvoicearthritis@ucd.ie @UCD_CAR www.ucd.ie/car/about/patientvoice/

Hosted by the UCD Centre for Arthritis Research

Cancer Research



The Patient Voice in Cancer Research is an initiative to actively engage cancer patients, cancer researchers and other interested parties (patient advocates, families, carers, healthcare professionals, policy makers and those with an interest in cancer research) in discussions and decision making processes that positively

impact on cancer treatment and outcomes for patients.

CONTACT US BY EMAIL patientvoice@ucd.ie

Next Event on April 11 $^{\rm th}$, see details below

Diabetes Research



Our mission is to engage the researcher and patient communities to exchange knowledge and information to ensure that our core objectives are guided by patient experience and expectations. The patient's voice in diabetes research will ensure that future projects are shaped by and communicated effectively to patients and the wider community.

Contact: dcrc@ucd.ie www.ucd.ie/medicine/ourresearch/researchce nt res/diabetescomplicationsresearchcentre/

Inaugural event June 13th 5.30pm. dcrc@ucd.ie for details

Public and Patient Involvement (PPI)



The goal of PPI is to achieve a true partnership between public/patients and researchers, leading to improved research quality, relevance and outcomes.

The Patient Voice in Cancer Research is hosting their fourth event on April 11th. Register for free via Eventbrite. Search "Patient Voice"

Workshop 1: "Fund my Research" / Workshop 2: "Know my DNA"

www.eventbrite.ie/e/the-patient-voice-in-cancer-research-iv-tickets-43769764544?aff=eac2



Highlights from the PARE Conference 2018

by Stacey Grealis

Don't Delay, **Connect Today**

Johannes W.J. Bijlsma President of **EULAR** presented on Prevention and Early Diagnosis of RMDs.

Research Shows that early diagnosis of Rheumatic and Musculoskeletal Diseases (RMDs) and access to treatment is key to "preventing further damage and burden on the individual and society".

Bijlsma discussed the concept of 'Reduce, Prevent and Treat' before focusing on 3 levels of prevention:

- 1. Primary to prevent disease or injury before it occurs
- 2. Secondary to reduce the impact of disease that has already occurred
- 3. Tertiary to improve quality of life of people already affected by a disease, reducing disability, limiting or delaying complications and restoring function.

Using the window of opportunity of the early phase of the disease to ensure prevention of long-term comorbidities is extremely important.

The U-ACT -Early Strategy Study (Utrecht, Netherlands) aimed to bring early Rheumatoid Arthritis (RA) into sustained remission (SR).

Patients presenting a DAS 28 (Disease Activity Score) as low as <2.6 for ≥ 24 weeks in a row and the number of swollen joints ≤4 they, reduction of DMARDs commenced slowly. If the patient was without treatment for 12 weeks in a row they had then sustained drug free remission.



Three treatment strategies were then compared. The study results showed that standing RA with a mean disease RA is predominately diagnosed in females (67%). Three quarters of the patients were Rheumatoid positive with mean disease duration of 28 days.

The Netherlands has achieved the mean of 28 days by getting people into the system early by:

- 1. Training all medical students about **RMDs**
- 2. Early recognise of the disease by trained GPs and referral of patient to a rheumatology department.
- 3. Early arthritis clinics within all Rheumatology centres with patients seen within 2 weeks

Therefore, patients get early diagnoses and treatment, in which 80% attained sustained remission. Of these patients, 60% began entering remission at 12 weeks while taking tocilizumab, with or without methotrexate. This has made a significant difference in getting people back to work and partaking in normal daily life within 3 months.

New treatments in the last 20 years have reduced disease activity and been hugely important in preventing comorbidities. The COMORA study of over 4,500

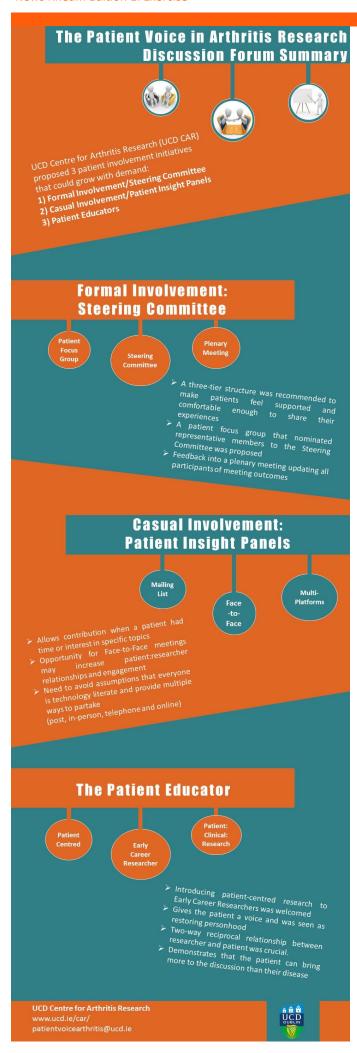
patients looking at comorbidities of long duration of 9.6 years in which only 1 in 3 people was employed.

This study identified other coexisting diseases GPs should be looking for; in particular depression which 15% of the patients reported. It is important to be able to recognise, admit, treat and prevent, at some level, depression. Physicians also play an important role in communicating the importance of good physical fitness to preserve physical function and help ease symptoms of depression.

It is importance that all the EULAR stakeholders connect together and communicate the campaign message through integrated campaigns at European and National level. This will enable the message to reach the public and build a platform for change across Europe towards early diagnosis and treatment of RMDs.

WATCH THIS SPACE The follow up data from the U-ACT Study will be presented at EULAR Conference 2018 in Amsterdam in June.

KEY DIARY DATE Next year's EULAR PARE 2019 will be in Prague from 5-7 April.



The Patient Voice in Arthritis Research

by Emma Dorris

The UCD Centre for Arthritis Research aims to incorporate public and patient involvement (PPI) into their standard research process.

Three PPI schemes were proposed for discussion at The Patient Voice in Arthritis Research inaugural discussion forum.

1) Formal Participation

The creation of a steering committee, with patient members, that would review outputs, grant proposals and develop longer term strategies for arthritis and rheumatic disease research.

2) Casual Participation

The formation of patient panels, who will give input into specific research plans, as and when required, in a manner that suits the patient.

3) Patient educators

Patients set challenges to our graduate students. The graduate student must consolidate the patient needs and clinical feasibility and develop a research strategy to address this challenge. The primary goal is not to achieve a solution to the problem (although it may), but rather to train the graduate to understand and account for the patient perspective within their research.



These three schemes have the capacity to grow with demand and offered a range of flexible ways that patients could be involved dependent upon their individual interest and availability.

Attendees were asked to discuss the interest, barriers and facilitators of the proposed schemes. The full report is available on our website www.ucd.ie/car and an audio version will be available from April.

If you would like to get involved please contact:

patientvoicearthritis@ucd.ie

Arthritis Ireland exercise resources

Here is a brief summary of what is happening countrywide:

The Arthritis Ireland Walking Groups (specially designed for people with arthritis and are run in communities across the country).

Most of our walking leaders have experience of living with arthritis themselves and this helps to foster a supportive and encouraging group spirit. Leaders are trained in techniques needed to facilitate walking groups. They will teach you how to get the most from your walking sessions by looking at things like posture, warm-up, stretching and clothing.

They are also a great source of encouragement for people striving to reach their walking goals!

You can access your local Walking on the Arthritis Ireland site.





Arthritis Ireland

Little Things make a Big Difference

Exercise groups are organised on a very regular basis and for a wide variety of abilities in almost every county. The activities range from Bocci to seated exercise classes, from Aqua fit to strolling groups and many more. Again access to the calendar of events is through the website.



Exercise at Home: You don't have to leave your own home to be involved in Arthritis Ireland's exercise programme.

The 'Take Control with Exercise' book and DVD has been developed specifically for people with arthritis by chartered physiotherapists working in the area of arthritis. This tried and tested programme has been devised in consultation with rheumatology departments throughout Ireland.

Price: DVD €12.99, Book €9.99, Set €20

<u>Click here</u> to order the 'Take Control with Exercise' book and DVD online or please call Arthritis Ireland on (01) 6618188 or email info@arthritisireland.ie.



For a really comprehensive list of activities organised by Arthritis Ireland log into http://www.arthritisireland.ie/go/exercise

Arthritis Ireland also runs Living Well with Arthritis and Related Conditions course. This award-winning course covers every area of self-management to assist you to reclaim your life from arthritis. The 6-week course was developed by Stanford University. In spring 2018 there will be courses in the following locations:

Location	Venue	Start date, time	Booking
North Dublin	Donnycarney Youth Community Centre	Tue 20th Mar, 7pm-9.30pm	<u>Book</u>
South Dublin	Deansgrange Parish Centre	Tue 10th Apr, 2pm-4.30pm	<u>Book</u>
West Dublin	Finnstown Castle Hotel, Lucan	Wed 28th Mar, 6.30pm-9pm	<u>Book</u>
Saggart/Rathcool	Rathcool Community Centre	Thu 12th Apr, 6pm-8.30pm	<u>Book</u>
Mullingar, Co. Westmeath	Bloomfield House Hotel	Tue 13th Mar, 7pm-9.30pm	<u>Book</u>
Newbridge, Co. Kildare	Keadeen Hotel	Wed 11th Apr, 10am-12.30pm	Book
Ballina, Co. Mayo	Newman Institute	Wed 18th Apr, 7pm-9.30pm	<u>Book</u>
Sligo Town	Sligo Park Hotel	Tue, 3rd Apr, 7pm-9.30pm	<u>Book</u>
Galway City	The Connacht Hotel	Thu 29th Mar, 7pm-9.30pm	<u>Book</u>
Roscommon Town	Roscommon Library	Tue 13th Feb, 5pm-7.30pm	Started
Cork City	Bru Columbanus	Mon, 12th Feb, 7pm-9.30pm	Started
Limerick City	IWA Limerick	Wed 21st Mar, 7pm-9.30pm	<u>Book</u>
Waterford City	Edmund Rice Heritage Centre	Tue 3th Apr, 7pm-9.30pm	<u>Book</u>
Clonmel, Co. Tipperary	Clommel Community Centre	Thu 12th Apr, 7pm-9.30pm	<u>Book</u>
Letterkenny	твс		

Email training@arthritisireland.ie with statement of interest in a particular location. A small fee of €32, (discounted price for medical card holders - €24) covers a small portion of the cost of providing the programme and provides you with Living a Healthy Life with Chronic Conditions book, an excellent resource written by arthritis specialists Dr. James Fries and Prof. Kate Lorig.

YOUR QUESTIONS ANSWERED



This News Rheum feature invites you to submit your questions which we will put to health professionals. Your questions on Exercise will be answered in the next edition. We now invite you to submit your general questions on Mental Health in Arthritis and Rheumatic Disease, which is the theme for our next issue. Questions and answers will be published (anonymously) in the summer edition of News Rheum. Please submit your questions by May 11th to:

patientvoicearthritis@ucd.ie

The ExACT trial by Maire-Brid Casey

The effectiveness of Exercise combined with Acceptance and Commitment Therapy for Chronic Pain. A Randomised Controlled Trial.

by Máire-Bríd Casey, Physiotherapist, HRB Clinical Research Fellow, PhD candidate, University College Dublin.

Having worked for the last number of years as a physiotherapist in the Mater Misericordiae University Hospital (MMUH), I was delighted to be awarded a research training fellowship grant by the Health Research Board in 2016. Over the course of this three-year fellowship I

am coordinating a clinical trial, which will assess the effectiveness of a multidisciplinary pain management programme for people with chronic pain.

The title of the study is the ExACT Trial and the idea devel-

oped from preliminary research undertaken by a multidisciplinary team, led by Dr Conor Hearty in the Mater Department of Pain Medicine, MMUH. The initial research showed a positive impact of a multidisciplinary Acceptance and Commitment Therapy (ACT) pain management programme on outcomes such as pain interference, mood, self-efficacy and physical activity. ACT is a form of cognitive behavioural therapy, which is showing promise for people with chronic pain. The approach aims to enhance quality of life and engagement in valued activity. While the theory behind ACT appears well suited for chronic pain, there are relatively few high-quality studies and further randomised controlled trials (RCTs) have been recommended, particularly comparing ACT to other active treatments. To our knowledge, the

ExACT trial will be the first RCT to examine the effectiveness of exercise combined with ACT for chronic pain.

The overall aim of the study is to assess the effectiveness of a combined Exercise and ACT programme, compared to a standalone supervised exercise intervention for chronic pain. One hundred and sixty people who attend the Mater hospital pain clinic will take part in the study and will be randomly allocated to a combined exercise and ACT treatment group or a standalone supervised exercise group. Both groups will receive treatment once a week for a period of eight weeks. The combined treatment will in-

these treatments for chronic pain. If a significant difference is found between the two treatments, the superior one could be introduced in similar clinical environments and has the potential to positively impact the lives of people with chronic pain.



Trial recruitment commenced in February 2017 and is expected to continue until November 2018. I am very grateful to the HRB for the opportunity to undertake this important research. I would also like to thank the trial participants, my supervisors, Dr Catherine Doody and

Dr Keith Smart, and all my colleagues in the Mater hospital, particularly Dr Damien Lowry and Dearbhail Flanagan for their ongoing commitment with delivery of the trial interventions. We anticipate that this research will help

research will help inform clinical practice in the management of chronic pain and we look forward to sharing the findings of the ExACT trial in the not too distant future!

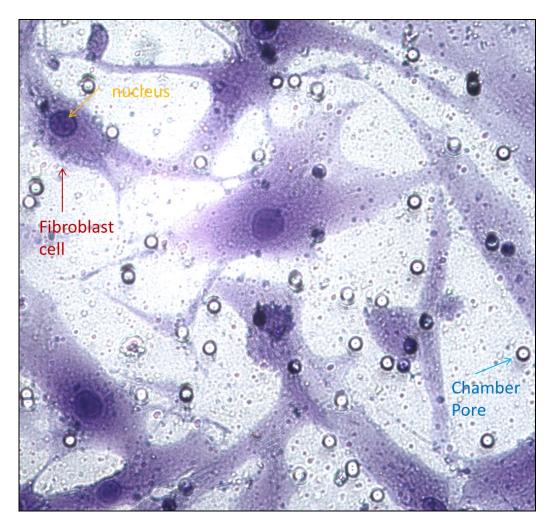


Exercise therapy is a well-established, effective treatment for people with chronic pain and Acceptance and Commitment Therapy (ACT) is a promising new approach in the management of chronic pain. ACT helps people with chronic pain to focus on awareness of personal values and promotes activity that will enhance their quality of life. The aim of this study is to compare the effectiveness of a combined exercise and ACT treatment with a standalone supervised exercise programme for people with chronic pain.



clude ACT based psychology sessions delivered by a psychologist and supervised exercise activities (gym and waterbased exercise) led by a physiotherapist. The standalone exercise group will undergo the same Physiotherapy led supervised exercise activities. Both groups will be assessed before and after treatment and again three months later. Questionnaires will be used to measure the effects of the treatment on peoples' ability to perform daily activities, pain acceptance, depression, anxiety and quality of life. Physical activity monitors will be worn to measure daily activity levels over the 8 weeks. Participants from both groups will be interviewed in order to improve understanding of how the treatments work from the patient's point of view. This study will provide important information about the effectiveness of

Cellfies: images of research



Invading Fibroblast Cells

Cells were isolated from a biopsy taken at arthroscopy and added to a special chamber called a Boyden chamber. This chamber has small pores and is coated with a solution that mimics the basement membrane. The basement membrane is a thin, fibrous, extracellular mix of tissue that separates the lining of an internal body surface from underlying connective tissue. In RA, fibroblasts (cells of the connective tissue) can invade into and attack the cartilage and bone. The Boyden chamber mimics this process: The fibroblasts must degrade the basement membrane, change their shape and squeeze through the pores. We can then stain the cells to detect if they have invaded.

We use this technique to see if certain drugs, compounds or genetic changes can make the fibroblasts more or less likely to invade.

#LoveIrishResearch

UPCOMING EVENTS

- ► Health Research Board (HRB) Primary Care Clinical Trials Network Ireland hosts their annual PPI Conference: Every Voice Matters, 25th April in NUI Galway: https://primarycaretrials.ie/2018/02/ppi-research-conference-wednesday-25th-april-2018/
- ► The 8th annual International Action
 Research Colloquium on 'Developing
 Leadership through Action Research'
 is being held at University College Dublin on June 28th
 and 29th 2018 http://www.argi.nmhs.ucd.ie/index.html
- ► 2018 Thinking Participatively Research Conference: http://www.icphr.org/pre-conference-2018.html
- ► 03-04 October 2018, UCD Conway Institute2018 & UCD Conway Festival of Research. Morning session focuses on PPI

NEW RESEARCH

➤ A new publication "Patient and public engagement in priority setting: A systematic rapid review of the literature" explains the current literature on how patients and the public engage with health research and set priorities:

http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0193579

► What are the mechanisms that enable the reciprocal involvement of seldom heard groups in health and social care research? A rapid realist review protocol: https://hrbopenresearch.org/articles/1-7/v1

COMPETITION: DESIGN OUR LOGO



Could your design be featured here?

News Rheum Needs Help

Calling all people under 18 living with arthritis or rheumatic disease: We need your help! News Rheum needs a logo.

We hope News Rheum will promote respect, conversation & partnership between all people working towards better quality of life for people living with arthritis: patients, carers, scientists and researchers of all kinds.

Can you design a logo that reflects this?

How to Enter

Design an original logo. Post it or email it to us and include your name, age and address.

The winner will receive a UCD hoody of their choice and have their design created into a digital logo for News Rheum. All entries will be displayed in our digital gallery and also displayed at our annual research day.



UCD CENTRE FOR ARTHRITIS RESEARCH UCD Conway Institute, Belfield, Dublin 4

patientvoicearthritis@ucd.ie | www.ucd.ie/car/ For Terms and Conditions see www.ucd.ie/car/

"the key point is that a patient can bring an awful lot more to the discussion than their disease"

Patient Insight Partner

The Patient Voice in Arthritis Research Discussion Forum 2017

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Tweet at us @UCD_CAR

If you are a researcher, patient, or someone with experience of arthritis or rheumatic disease, and you would like to contribute to *News Rheum*, please contact us.

Our next edition will focus on research in the areas of *mental health, sleep and mood* in people living with arthritis and rheumatic disease. It's due out on June 22nd.





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