

News Rheum



Edition 7:
Self-Management
Summer 2020

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

Welcome to the seventh *News Rheum* Newsletter! This edition's theme is *Self-Management*

Facilitating self-management by patients is central to treating any chronic condition. This issue focuses on patients' experiences managing their condition and practical advice they can offer.



Lonely in a Crowd -
Photograph by Photovoice Project Participant Amanda Prather

We hope you enjoy *News Rheum*. If you would like to get involved, please contact us at:

patientvoicearthritis@ucd.ie

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Tools Before and After an Arthritis Diagnosis

by Tina Rooney

Diagnosis

A simple but interesting word, which can take many years to hear. My diagnosis story spans twenty-six years.

My back started to ache when I was twelve and I slowly, agonizingly deteriorated from there to Ankylosing Spondylitis and Osteoarthritis. Here are some tools I learned that I hope will save you some time and effort: .

Acceptance

This was the hardest for me; I was stuck on it for a long time. I cried when a pain consultant innocently asked me, “When was the last time you didn’t have pain?” – I couldn’t remember. That was so stark and so hard. Slowly, I knew I needed to grieve for the old me and accept that this would never end. Then, I put on my big girl pants and started to be completely honest and self-deprecating and do something positive.

I discovered another type of acceptance: the dawning awareness that my amazing pain consultant, my rheumatologist and the drug companies did not know how to “fix” me. They did not have all the answers; if they did, I would be “cured”. This turned into a kind of power for me. I started to read medical journals, to ask more questions, to keep abreast of treatments and I decided to look into research. It infuriated me that I was handed a diagnosis, then left abandoned. No team of people reviewing my case – nothing. In fact, as a private patient, I discovered public patients had more support and access to resources. I know it is a privilege to pick up the phone and make an appointment whenever suits me but otherwise it is not much use; what I really need is access to options like hydrotherapy.

Attitude

A good attitude is a half the battle. Sure, today sucks but tomorrow will probably be better; just focus on getting through today. On days when the pain is overwhelming, do not beat yourself up. So what if the washing is not done. Who cares? You are more important. Beating yourself up starts a negative cycle that make pain worse.

Aides

I am thirty-nine, for another few weeks anyway! I struggled with aides for years. My husband would lovingly and jokingly try to cajole me into them over the years, but I was having none of it! Seriously, a thirty-year-old with a walking stick? I do not think so. Or a raised toilet seat? No Way! A cervical spinal decompression and fusion later and I am the one stalking German supermarkets for special offers on aides. Do not be foolish or vain like me. Buy the blooming loo seat if you need it! They are practical and make life easier; roll with it.



Self-Help

This can be hard to hear. I heard it over and over and resisted until I was in the right headspace. It is so important to help yourself. If you cannot commit to that, how can others help you?

Meditation

I honestly thought this was hokum but I found it is a skill you must learn to make it an effective tool. There are tonnes of online videos to get you started; try five minutes a day and you might be surprised.

Massage/Physiotherapy

The arthritic person’s nirvana. If I could afford it, I would go twice every day. There are gadgets that help you massage yourself. Someone you live with might be willing to help. Even massaging one sensitive spot is so helpful. Physiotherapy is amazing too and, curiously, costs less than massage.

Interview with Photovoice Project Participant Amanda Prather

by Susie Donnelly

Q: What prompted you to get involved in research?

When I was first diagnosed with RA, I found that I lacked support. It was quite isolating and it's really a lot to deal with every day, so I wanted to find a way to share my experience. This study involved taking photographs of my daily life with RA – my lived experience. I've always been interested in photography and enjoy having a creative outlet so this appealed to me. I also liked the idea of being involved in a project that aimed to inform society and policy in this area.

Q: How did you find the experience?

I loved it! I really enjoyed it. As I was recently diagnosed, it gave me a chance to get used to speaking about what it's like to live with RA. The study involved a series of group workshops and it was encouraging to share my experience with others who completely understood what I was going through. It was also interesting to understand what others are going through and see how this illness can be experienced by different people.

I was part of a committee within the study who worked closely with Susie and a visual artist, Claire Dix, to organize a photo exhibition. I really enjoy doing this kind of work and being involved in these types of public events. I have experience in graphic design and used that to help create a booklet to accompany the exhibition.

I was happy to have several friends come to the exhibition. Although I had explained what it's like to live with and manage RA to them before, when they came along and saw the images, they really felt they understood more. RA is such a difficult thing to try and understand if you're not living it, but I think the exhibition had an impact on them and created more compassion for those living with it.



Lonely in a Crowd © Amanda Prather

Q: What advice would you give to people managing an invisible illness, such as arthritis and fibromyalgia?

I'd advise people to stay informed through their clinician who can provide up-to-date and accurate information. Social media can be great but be cautious as it is sometimes overwhelming. As a community, Arthritis

Ireland does a great job and has lots of great resources.

Find a network of good emotional support. Surround yourself with people that love you and don't judge you. If there are negative people in your life, try to do your best to limit your time with them.

Finally, stay hopeful! There are lots of invisible illnesses out there and this one is hard! Find little things that bring you joy and focus on the positive.

Interview with Photovoice Project Participant Amanda Prather

(continued)

Q: After reflecting on your life with RA through this process, what did you learn about self-management?

I've learned that self-management is difficult because your ability to manage changes when you have a flare-up. You get more pain and fatigue, and as much as you'd like to exercise and do all the things you are supposed to be doing, you can't. But worrying about a flare-up can become overwhelming. This is a chronic, life-long condition that I will be living with for another 30 or 40 years! It's a long road, and it's best to take it one day at a time. During the COVID-19 pandemic, it has become particularly important to take care of yourself. We put so much pressure on our bodies to perform. But sometimes we need to accept that we have to rest or take time out.

I've begun to speak out about living with RA and even contributed an essay for the book, *My RA Story* with Sinead Moriarty and Arthritis Ireland last year. I've learned it's important to use my voice and share my experiences. I find this creates connections with other people who can relate to life with invisible illness. For example, I have a relative with profound hearing loss who connected with me on social media after I shared my story and really related to it.

I think I'm learning to not worry so much about what other people think. Others may not understand what I'm going through, and often ask "Have you tried this or that?" but I'm learning what works and what does not.



Amanda's photographs, along with those of ten other participants, were featured in *I'm Here But I'm Not: A Photovoice Exhibition of Living with Rheumatoid Arthritis* at The Mater Hospital and The Chocolate Factory Arts Centre throughout the Autumn of 2019.

The exhibition is online at www.ucd.ie/car/t4media/Photovoice_Booklet.pdf

A Wonderful Journey and Working Experience in Dublin

by Ng Chun Ruh

I started my journey from Malaysia to Dublin on 1st March 2019 with the intent to spend a year working in Ireland as a Clinical Fellow in Rheumatology. I was based in the Mater Misericordiae University Hospital and UCD Conway Institute. It was a great challenge for me to be away from my family and of course a great culture shock in terms of weather, food, clothing and so on.

After settling into my accommodation in Dublin, I started travelling to and fro daily between UCD and the Mater Hospital following my scheduled timetable.

I had the opportunity to learn from Professor Gerry Wilson, Professor Geraldine McCarthy and Dr Suzanne Donnelly in their clinics for early arthritis, connective tissue diseases and crystal arthropathy. I had the chance to study rare rheumatological diseases, such as Behçet's Disease, which is relatively uncommon in Malaysia, and also learned how to use biological therapy in the treatment of rheumatic disease. At the same time, I had the opportunity to do ward rounds and run ultrasound clinics with my best colleague Dr Yousef. He is as a specialist registrar in the Mater Hospital and an International Fellow from Saudi Arabia. During the year, I mastered new communication skills, clinical skills, ultrasound technique and specialized techniques (called capillaroscopy and microscopy) for diagnosing crystal arthropathies. I had great interactions with Irish patients who were all very kind and polite. Our rheumatology team also included Advanced Nurse Specialist Patricia, a sweet and hardworking lady, and three staff nurses – Maria, Aileen and Susan. They were really lovely and always came to my aid when I needed help.



Prior to my work in the UCD Conway Institute, I had zero experience in laboratory research. I am grateful to have had the chance to work alongside Professor Wilson and my research supervisor Dr Kevin Sheridan. My research project investigated how methotrexate, a commonly used treatment for RA, effects primary synovial fibroblasts, a type of cell found in the joints of patients with rheumatoid arthritis (RA). Kevin and other researchers in the lab such as Dr Niamh Morgan and Dr Emma Dorris taught me skills in project management and important laboratory techniques such as those to examine vital components of human cells like DNA and proteins. I also gained some experience in statistical analysis and analysing results. Lab research requires patience, patience and more patience; you will meet lots of obstacles, for example cells getting infections or not growing well. Sometimes, you might need to spend your whole weekend in the laboratory! Even though it was tough in the beginning, I can now say confidently that I can conduct laboratory research with minimal assistance. ☺

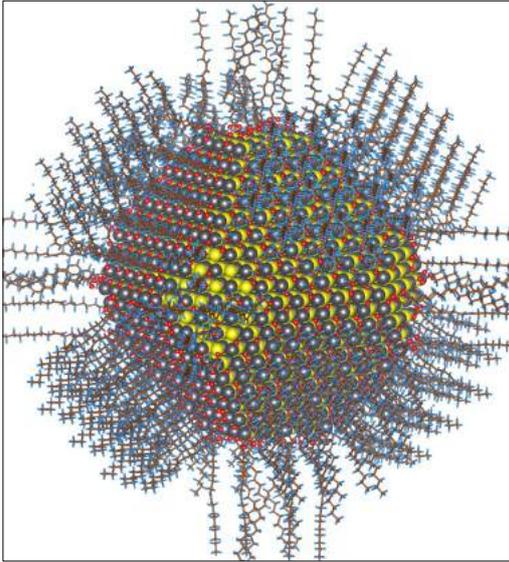
During my stay, I had the chance to attend international events such as the European League Against Rheumatism (EULAR) meeting, the Irish Society of Rheumatology (ISR) meeting and conferences on vasculitis and ultrasound which has helped me to build up a network and at the same time update my clinical knowledge. Besides this, I took part in multiple training programmes run by the Royal College of Physicians of Ireland (RCPI) for international clinical fellows.

In a nutshell, these 365 days were long for my family, who were waiting for my return, but all too short at the same time. I hope in the future I will have the opportunity to come again, perhaps for my PhD in the near future.

More Effective Medicine with Fewer Side-Effects: How UCD Veterinary School Researchers are Improving Osteoarthritis Treatment

by Rumi Khandelia, Daniel Crean, Emma Dorris & David Brayden

Osteoarthritis (OA) is a leading cause of chronic disability, typically affecting knees, finger joints, hips and lower spine. It mainly affects those aged over 60. More than 40 million people in Europe are affected by OA, which can be costly, with a total annual treatment cost per patient of around €10,000.



Nanoparticles like this are increasingly being used in medicine

Currently, five categories of OA medicine are available, of which non-steroidal anti-inflammatory drugs are prescribed most often. Non-steroidal anti-inflammatory drugs can be very helpful in managing pain and inflammation;

however, they may seriously harm other organs (such as heart, stomach and kidney) when taken orally as tablets. Though these drugs are available in a less harmful ointment form (applied on affected joints), these ointments have been shown to provide less relief than the tablets.

Our project is developing a method by which OA patients can use these non-steroidal anti-inflammatory drugs without damaging other organs. One way to do this is to inject the medicine directly into the affected joint. However, the big question is how to keep the drug in the joint? On its own, it is not retained in the joint for long. We are designing a carrier that will stop this from happening; we plan to attach the drug to a nanoparticle which will help keep it in the joint longer. This will not only reduce harm to other organs but also require fewer injections to achieve the same relief, thereby reducing overall treatment cost.

This project is funded by the EU's HORIZON 2020 Programme (Marie Skłodowska-Curie Actions Individual Fellowship) and Science Foundation Ireland's CURAM Centre for Medical Devices. It involves scientists from University College Dublin, The Royal College of Surgeons in Ireland, St. Vincent's University Hospital and Mater Misericordia University Hospital.

For more information, please contact:
rumi.khandelia@ucd.ie and david.brayden@ucd.ie



Amazing Erasmus+ Learning Experience

by Saša Samec

I came to Dublin at the beginning of November 2019 as a recent medical graduate. I graduated from the Faculty of Medicine in Ljubljana and was given an amazing opportunity to complete my Erasmus programme under the supervision of Professor Gerry Wilson. He kindly accepted my request and introduced me to his working environment. I am interested in internal medicine (the area of medicine that deals with preventing, diagnosing, and treating internal diseases) and I chose to broaden my knowledge of rheumatology, which is an important part of it.

Half of my time was spent in the Mater Misericordiae University Hospital and the other half in the Conway Institute at University College Dublin.

Finding appropriate accommodation in Dublin was incredibly challenging; it was almost impossible to find something reasonably close to the city centre within my student budget. It did not take long for me

to realize that Dublin is a very expensive and rainy city. But people were nice and they made my stay much easier and more pleasant. Even though I was there during winter-time, I was still able to catch some sunny days to explore the amazing nature in Ireland.

During my stay in the hospital, I worked with doctors in the outpatient clinics of Professor Gerry Wilson, Professor Geraldine McCarthy, Dr Suzanne Donnelly and Dr Shafeeq Alraqi. I saw different diseases, which will definitely stay in my head forever and will help me to make the right, careful diagnosis in my future career as a doctor. I was able to see different clinical presentations, diagnostics and treatment plans for many diseases.

I had a chance to speak with some younger specialist registrars and interns and to share our cultural and working differences. I was positively surprised with the work and responsibilities that the nurses have. I also met a lovely doctor from Malaysia and we spent a lot of time together as we had similar working schedules. It is always nice to meet people from all around the world and see how different and at the same time similar we are. Together, we conducted a survey about patient satisfaction with biosimilar switching and presented our results.



At first glance I did not like the idea of working in the biomedical laboratory, because I was always more interested in the clinical part of medicine. But as time passed, it was the exact opposite. I am very grateful for the chance to see scientific work in practice. Nowadays many very interesting research projects are going on and they guide the treatment options we use every day. I had the pleasure to learn from my mentor Dr

Niamh Morgan. She is interested in rare diseases and at that point she was researching a very rare genetic disorder. She taught me many laboratory techniques, such as growing human cells and extracting and analysing important components of those cells, like DNA, RNA and proteins. I also gained essential statistical knowledge, which is necessary for understanding the majority of scientific articles. During their team meetings I improved my critical thinking as I was part of discussions about many different auto-inflammatory conditions. It was also nice hearing others' points of view on the same chronic condition, for example the contribution of a social scientist to the management of rheumatoid arthritis.

Cellfies - Images of Research: Crystals in Osteoarthritis

by Hollie Canning

Osteoarthritis is a chronic, progressive joint disease characterized mainly by the degeneration of the cartilage that lubricates joints. Other structures present in the joint, (such as bone, tendons, ligaments and nerves) are also affected, resulting in painful, stiff, and swollen joints.

Basic Calcium Phosphate (BCP) crystals can be found in osteoarthritic joints. Historically, it was believed that these crystals were just a consequence of tissue damage. However, more recently it has been shown that BCP crystals are actually a cause of joint damage. My research aims to understand how BCP crystals do this damage.

Human joints are very complex structures, with many different types of cell. Some of the cells in joints are called Fibroblast-Like Synoviocytes. "Fibroblast-like" because there are similar to a different cell type called a fibroblast and "Synoviocyte" because they come from an area in the joint called the synovium. The synovium is a layer that reduces friction between two layers of cartilage in the joint.



Image 1: These fibre-like assemblies were grown in the lab from cells from the joint of an osteoarthritis patient.

In my research, I grew fibroblast-like synoviocyte cells donated by an osteoarthritis patient to investigate whether BCP crystals cause damage to these cells from the joint. This research is important because it could improve our understanding the role that BCP crystals play in osteoarthritis.

Image 1 shows a picture, taken with a microscope, of these cells growing in a lab. These cells were then treated with BCP crystals; Image 2 shows cells treated with the crystals.

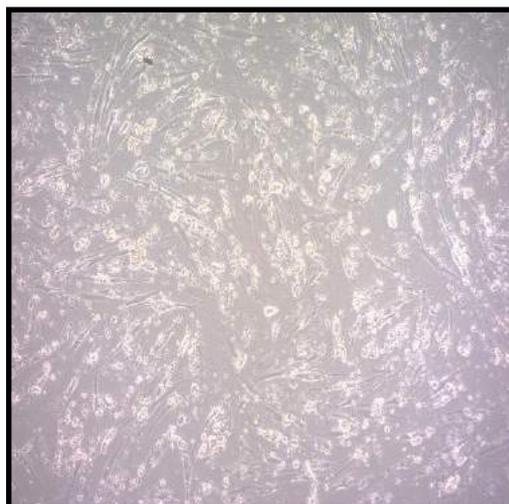


Image 2: These lab-grown patient cells have been treated with BCP crystals, which are the brightly visible structures.

Several lab experiments were carried out to investigate what effect, if any, the BCP crystals had on the cells. These experiments looked at whether, following treatment with the crystals, the cells experienced changes in growth or the release of important inflammatory signals that could cause tissue damage. Our results showed that the crystals did not change cell growth of these cells and there was no increase in tissue destruction signals from these cells.

However, when we did the same experiments on macrophages (blood cells also found in the joint), the BCP crystals did affect cell growth and also caused the cells to release signals that can lead to tissue destruction. It is important to look at different cell types in this way to investigate the mechanisms at play in a disease. Different cell types can be affected in different ways and investigating these different reactions gives researchers a better picture of how osteoarthritis progresses. By uncovering what is happening in osteoarthritis, this research ultimately aims to improve the treatment and lives of patients living with the condition.



CONTACT US

UCD Centre for Arthritis Research
Conway Institute
University College Dublin
Belfield, Dublin D04 C7X2

T: +353 (0)1 716 6728

E: patientvoicearthritis@ucd.ie

Tweet us @UCD_CAR

