

# News Rheum



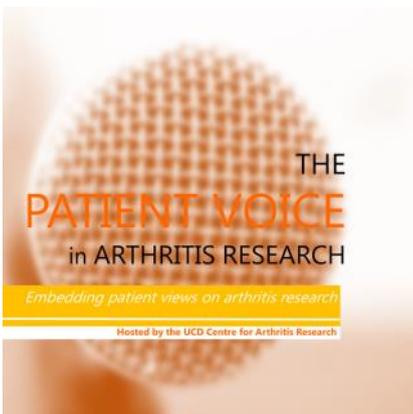
Edition 3:  
Back to Basics  
Winter 2018

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - TOGETHER

**Welcome to the third News Rheum Newsletter! The theme of this edition is BACK TO BASICS**

It's been a year since the first meeting of The Patient Voice in Arthritis Research. Since then, your input into our research has resulted in real and lasting change. The UCD Centre for Arthritis Research has restructured and will have a new Steering Committee from 2019. Of the 10 committee members, three are patient representatives. The 2019 representatives are Wendy Costello (Paediatric and Rare Disease), John Sherwin (Degenerative Arthritis) and Peter Boyd (Inflammatory Arthritis).

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



[patientvoicearthritis@ucd.ie](mailto:patientvoicearthritis@ucd.ie)

## IN THIS ISSUE

- Under 50 and Living with Arthritis National Conference  
*by Anna Pang*
- Value of Research to Irish Patients  
*by Peter Boyd*
- PPI in Basic and Preclinical Research  
*by James Maccarthy*
- Highlights from the Arthritis and Rheumatic Disease Research Conference in UCD  
*by Stephanie Skeffington*
- Lending an Ear  
*By Siobhán O'Higgins*
- Involvement Update  
*by Emma Dorris*
- A Guide to Basic Blood Tests  
*by Dr. Sharon Crowley*
- Cellfies: Images of Research  
*by Stephanie Merrigan*

## Under 50 and Living with Arthritis National Conference

by Anna Pang

### Hosted by the Young Arthritis Network (Arthritis Ireland).

The event was well planned, with beautiful scones and tea on arrival. We were introduced to the team members of the Young Arthritis Network and also the local Kildare Arthritis Ireland branch, who together hosted and planned this event. There was a variety of speakers throughout the day, all very informative. One speaker, who came from Employ Ability, spoke about rights to work and shared information on services available to people with a health condition who wish to work part time. The talk was very insightful and it is great to know that such a service exists.

Another guest speaker was an occupational therapist from Talaght Hospital, who demonstrated cooking roast vegetables, while using various joint protection kitchen aids and gadgets. I found this excellent, as she gave simple, but very useful and practical, tips. This was followed by a talk from Citizens Information, who gave lots of useful advice, including information on medical cards.

We broke into small groups, where we discussed personal issues around our health condition. My group was led by a trained counselor, who used to work on the Arthritis Ireland helpline. This was a great way to share feelings that we do not often get to discuss; it was a safe place, with people who could relate and understand. Everyone showed support towards each other and tears and laughter were shared.

After a beautiful lunch there were a few more speakers. One was a psychotherapist; he was very informative and easy to listen to. He shared issues that parents often face while living with arthritis or related conditions. Following this were two parents, sharing their story about living with arthritis and being a parent. I was one of them. I got to share my pregnancy story, about the

struggles to get pregnant, miscarrying, flare-up, agony, getting better, getting pregnant, having my son, breast-feeding, flare-up, not being able to hold my son, feeling like a failure of a mammy, shoulder replacement and recovery. Following my talk, we finished the day with spot prizes, kindly donated by Power City, and then chair yoga. This was a great experience, as I got some good stretches, all from my chair. It also really helps to relax the mind – a great way to wind down the day.

Overall, this was a great event. Many at the conference, had only recently been diagnosed or were still on the waiting list for diagnosis. They found the event very helpful and, for some, it was their first time meeting other under-50s living with arthritis.



## Value of Research to Irish Patients An interview with Prof. Gerry Wilson by Peter Boyd



Professor Gerry Wilson took up his position as Chair of Rheumatology in UCD in 2013. A well-known and highly respected researcher, opportunities and offers came up all the time to move and establish a new base.

Dublin, and the potential offered by Arthritis Ireland, presented itself at just the right time to entice Professor Wilson out of Sheffield and continue his career in Ireland.

“There were a number of reasons that Dublin was the right move, at the right time for me,” explains Wilson.

“Dublin has a critical mass in rheumatology, as does Ireland, with some great expertise in most of the major rheumatic conditions. There are internationally renowned experts, which is great clinically for patient-based research.

“There’s also great expertise in immunology in Dublin which is vital. The funding from Arthritis Ireland and Atlantic Philanthropies made a lot of things possible and finally, it was a good time and stage for me personally.”

Professor Wilson leads research in Dublin from the ground up, with a combination of undergraduates on attachments, and PhD students with medical or scientific degrees doing a minimum of three years’ of research.

The Post-Doctoral Researchers have completed their PhDs and are really “the bread and butter of research, having done the training and have the expertise.”

There are then one or two Fellows who will have completed a PhD and generally have two three-year post-doctoral projects.

“The big thing now is that we generate so much data,” says Wilson. “So, people who are good at data analytics are vital to us, there are 20 researchers outside simply crashing numbers.

“Whether that data is generated here or taken from the huge amount of data online, you can examine and interrogate. That’s the big thing and what I’m looking to develop is people who are good at DNA analysis from data.”

“When I did my PhD it took me about a year and a half to get about a thousand bases of sequencing in ten individuals. Now I can generate that overnight. The data is so much easier to generate.”

This is a huge benefit not problem as Professor Wilson explains.



**Interview Cont. . .**

“I don’t think you can have too much data as long as it’s accurate. You may not know how to use it immediately, so we store it electronically. It may be the basis for future research projects.

“Throwing away the data would be unethical as someone has paid for it. You’re mining a haystack of data for a needle of information but there may be multiple needles within that haystack, so you must store the data.”

As patients, we are always seeking stratified, personalised and targeted treatment plans and this is something that data analysis is being used for, although it is a painstaking process.

“We’ve been using the new genetics to look at families and how a rheumatological condition runs through the generations to find the gene mutations. You can find a gene that hasn’t been implicated in the common form of the disease.

“If everyone in the family has that same gene, then they all have exactly the same condition, the same underlying cause of the condition.

“So, if the grandfather, for example, responds very well to an Anti-TNF agent, then you know the exact drug that will work when the grandchild presents with that condition because you know the exact gene and the single biological cause.”

For one family, this was the scenario that presented itself through the efforts of the research team. “We found the mutation in the key inflammatory gene of the 21,000, the one that controls three or four hundred genes,” explained Wilson. “Only one other family is reported to have anything closely similar to this in the world.

“To measure that as an academic success is quite simple and straightforward. Then there is the family and the child themselves.

“For the child, they don’t have to live with this nasty condition, they are able to go to school, they don’t have to go to hospital, don’t miss out on much socially in the really big early teenage years.”

That is one way to measure success; however, for academia, presenting at big conferences, having papers published and obtaining grants are “the real bread and butter”.

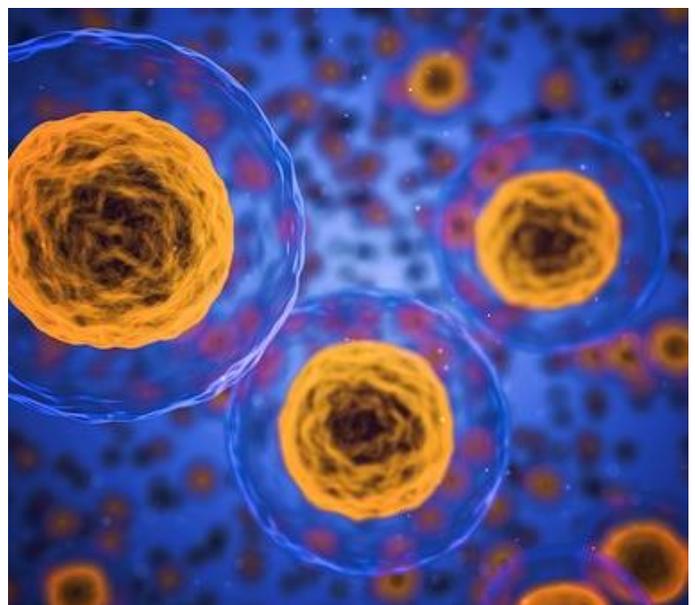
“When I’m issuing grants,” says Wilson, “the first thing I do is look for their published papers, see if they’re published well.”

The benefits to the patient, the academic success, the health service gains of “not cycling through ineffective treatment or invasive surgeries” and the harder to quantify health economics savings all make research and investment in research vital, sustainable and a crucial element in securing:

*A better world for people living with arthritis today and a world without arthritis tomorrow.*

**Arthritis Ireland’s Vision**

*Prof. Gerry Wilson is the Arthritis Ireland Chair of Rheumatology at UCD, Director of the UCD Centre for Arthritis Research and is a Principal Investigator in the UCD School of Medicine based at UCD Conway Institute*



## Facilitating Patient and Public Involvement in Basic and Preclinical Research

by James Maccarthy

My name is James and I am in my final year of studying biomedical science in UCD. During the summer, I spent 8 weeks in the UCD Conway Institute under the guidance of Dr Emma Dorris and the Centre for Arthritis Research. Our project focused on the development of ways to help researchers carry out patient and public involvement (PPI) in basic and pre-clinical research

to the best of their ability. Before undertaking this project, I spoke with Dr Dorris and was surprised to learn that PPI is not routinely used across research in Ireland. I was keen to understand why and equally determined to find a solution.

As I learned, PPI can add significant value to a research project as it ensures that the real-life experiences of patients are considered when it comes to the important decision-making processes regarding the direction of research and it ensures that research is carried out ‘with’ or ‘by’ patients as opposed to ‘for’ or ‘about’ them. However, there are significant barriers holding back PPI.

We invited researchers to speak about what stopped them from involving the public and patients in

their research. Including researchers from various fields of health research and experience proved to be very beneficial to the discussions. Following our discussions with researchers, we were able to identify the key barriers of PPI from their point of view and develop the planning canvas in response to these barriers. In order to address these barriers, we developed a two-step Open Source tool to be used by both researchers and patients. The first tool we developed

constructive feedback we received on our survey was incredible. Based on our PIP feedback, we adjusted our questionnaire to make it as patient friendly as possible. We decreased the number of questions and changed the language, phrasing and structure as advised. It was a pleasure to work with our PIP’s. Their level of enthusiasm and detailed feedback surpassed my expectations and their contribution undoubtedly added benefit to our research.



The only challenge I faced during this project was caused by confusion in understanding of PPI. Before starting the project, I was required to get an ethics exemption from the Human Research Ethics Committee. My initial ethics exemption was de-

was the “PPI Ready: Researcher Planning Canvas”. The planning canvas aims to encourage researchers to critically think about potential problems/challenges that they might face when involving patients or the public in their research, so that they can avoid them, or plan solutions to these problems before they arise.

We also developed a PPI assessment survey to allow for the ongoing evaluation of a PPI research cycle from a patient’s perspective. This survey was designed to assess the quality of PPI and to be filled out by patients. In order to develop this survey, we collaborated with our patient insight partners (PIP’s). We developed an initial draft questionnaire which we sent to our PIP’s for feedback. Working with patients proved to be very useful. The level of insight and con-

nied by the board. They stated that it was unethical to be in contact with a vulnerable group (which they consider patients to be). I was engaging patients as research collaborators and not as research subjects and this is where the confusion occurred. Fortunately, a more detailed summary of the project was submitted by Dr Dorris and my ethics was approved. However, this lack of understanding occurs throughout Irish ethics committees, as highlighted by researchers, and needs to be addressed to help researchers include patients and public and make their research as relevant as possible.

*James (far right, above) presented this work at the UCD summer student research awards, and won the bronze medal from a field of 122 students. His work is currently under scientific peer review & we hope it will be published soon.*

## Highlights from “A Collaborative Approach to Arthritis and Rheumatic Disease Research Conference” in UCD



UCD kicked off its inaugural Collaborative Approach to Arthritis and Rheumatic Diseases Research conference on November 2<sup>nd</sup> with an opening address by Gráinne O’Leary (Arthritis Ireland) who noted that one Irish person in four has arthritis. This statistic reinforces the need for more research on all rheumatology diseases in Ireland and for this conference’s approach: creating a collaborative approach among all stakeholders. These stakeholders were fully represented at the conference and integrated well with each other.

The first session focussed on bedside research. Professor Oliver Fitzgerald (Consultant Rheumatologist (retired) and UCD) spoke about the importance of remembering to ensure you have **C.L.E.A.M.U.R.S.** during research. **C**linical / **T**ransitional (clinical intervention and non –interventional), **L**istening (to the patient), **E**valuating, **M**easuring, **U**nderstanding it all, **R**ecording and **S**toring.

The unique aspect of the conference was not only that they al-

lowed patients to attend but that abstracts were solely completed by patients. Each poster shared a patient’s own experience and how it affected their everyday life, from education to social life how they felt in terms of interacting with healthcare professionals and how they felt the system could change for the better. The age range and types of



L-R: Dr. Emma Dorris (Organiser), Prof. Orla Feely (UCD VP Research & Innovation), Prof. Michael Keane (Dean of Medicine), Stephanie Skeffington (Representing the Patient Voice), Minister Finian McGrath.

rheumatological diseases covered gave a wide representation of what it is like to live with arthritis and rheumatic diseases in Ireland. I was honoured to submit posters giving my experience of juvenile idiopathic arthritis (JIA) and granulomatosis with polyangiitis (GPA). This type of patient involvement even encouraged my mother to see the value of sharing her experience of rheumatoid arthritis. Thanks to Emma Dorris’s inventiveness, she could finally see how she could make a difference. The patient posters

were well received and were a highlight of the conference for most attendees and created some very interesting discussions.

Minister Finian McGrath (Minister of State for Disability Issues) spoke about the current environment for those with rheumatological conditions in Ireland and noted the newly launched *Model of Care for Rheumatology* ([www.hse.ie/eng/about/who/cspd/neps/rheumatology/achievements/model-of-care-for-rheumatology-in-ireland.pdf](http://www.hse.ie/eng/about/who/cspd/neps/rheumatology/achievements/model-of-care-for-rheumatology-in-ireland.pdf)). He also noted the ICRIN (Irish Clinical Research Network) and the importance of this network for Irish research ([www.crdi.ie/research/icrin](http://www.crdi.ie/research/icrin)).

I was not the only participant who was a little surprised to see a speaker in veterinary medicine listed on the programme but I can guarantee I was not the only person in the auditorium completely absorbed to hear Hugh Giffney talk about how their research



Simon Stones (Patient Advocate & Researcher)

continued overleaf.....

hopes to result in methotrexate being tested as a slow release implant. One of the benefits would be reduce the side effects, which for those who have ever taken methotrexate know is a big problem for patients and the number one reason for non-adherence by patients.

After lunch, there were a number of workshops and I attended *Introduction to the Research Cycle*, run by Dr. Emma Dorris. This



Assoc. Prof. Deirdre Hurley

was designed to help the public to see how and why they should engage with research. Despite only being 2 hours long, we covered so much, in an interesting interactive format.

We went through the research cycle and discovered how UCD research is funded and how funding applications are made, including key points to make in an application for both patients and researchers. We discovered the role of ethics committees and discussed how literature and consent forms should be laid before being given to patients/trial participants. At the end of the workshop, each participant was able to see how they could contribute to research.

The evening was wrapped up by Stephen Simpson of Versus Arthritis who spoke about *Cloudy*

*with a Chance of Pain*. This research has the of participants in the world and will be released soon. The topic of whether the weather actually affects your arthritis is widely debated both inside and outside of the patient community and this hotly anticipated research will surely be a huge talking point once released.

The key quote of the event for me came from Suzanne Guerin (UCD Psychology) who noted “It’s so important to explain to the participants what the research is for and how their contribution will affect it”. This was a fantastic event to attend, not just as a patient advocate but as a patient with JIA for over twenty years. I could not have dreamed in 1997



Some of the speakers and conference chairs:

L-R Back: Prof. Oliver Fitzgerald, Denis O’Sullivan, Dr. Susie Donnelly, Gráinne O’Leary, Prof. Gerry Wilson, Dr. Stephen Simpson, Prof. Denis Shields, John Sherwin Front: Dr. Stephanie Merrigan, Wendy Costello, Dr. Daire O’Leary, Dr. Emma Dorris, Hugh Giffney, Prof. Orla Feely

## 'Lending an Ear'

By Siobhán O'Higgins



Although childhood arthritis is common, with 1,200 under 18's living with Juvenile idiopathic arthritis (JIA) in Ireland, but our Paediatric Rheumatologist to patient ratio for Irish children is the second lowest in Europe. JIA makes everyday activities difficult. JIA can cause pain, fatigue and emotional upset and makes it more difficult for children to see friends and do the activities they enjoy.

We know that when children become teenagers they start making more choices about their health care, but many teens do not get all the help they need to be able to manage JIA themselves. This is where online programmes and peer mentoring can help. Sick Kids hospital in Toronto developed and tested 2 such programmes. An online 12 module programme to help teens take on managing their own condition, with 2 modules for parents, and "iPeer2Peer" to help teens learn to make decisions about their health, meet and be inspired by older young people living with arthritis. iPeer2Peer uses Skype conversations between young adults with JIA and adolescents with JIA as they transition to adult services. Teens who have gone through the programmes separately in Canada were better able to take care of their health, understand arthritis

and, amazingly, they had less pain.

The Centre for Pain Research team in 2016 talked with Irish teenagers with JIA, their parents and health care providers; all expressed interest in both programmes. The 'Lending an Ear' study is now testing whether us-



ing iPeer2Peer with an Irish version of the on-line programme is something Irish teens will use and be helpful (i.e., is it effective and feasible?). We are hoping the 2 programmes working together will improve the quality of life for Irish adolescents with JIA. This project is a partnership with Professor Jen Stinson's team in Sick-Kids Hospital Toronto and all the key stakeholders, so it will continue even after the research part is finished - both the on-line programme and the Peer 2Peer support will be free to everyone with

JIA.

So far:

- ◆ We have recruited and trained a Young Person Advisory Panel (YPAP) of 5 teens with JIA who are working with us to make sure that young people with JIA continue to have a voice that is listening to in the research.
- ◆ We have embedded Irish videos in the on-line programme and changed the information to fit with Ireland e.g. in terms of the medications and services we have here.
- ◆ We invited young adults (18-25 year olds) who lived with JIA through their adolescence to work with us as Peer mentors and they shared in a 2 day training.

**We are now recruiting 60 families, with 12-18 year olds with JIA, to work with us in a pilot Randomised Control Trail.** If you are interested in becoming involved in any aspect of our project please contact:

[Judith.burke@nuigalway.ie](mailto:Judith.burke@nuigalway.ie)

[Siobhan.ohiggins@nuigalway.ie](mailto:Siobhan.ohiggins@nuigalway.ie)

*Dr. Siobhán O'Higgins is a research Fellow at the Centre for Pain Research at NUI Galway*



We are looking for 12-18 year olds with JIA for the **'Lending an Ear'** research project.

Without leaving your phone or laptop, you could help us check out an Irish online support programme with lots of info and great tips for you and your family.

Please contact Judith  
[Judith.burke@nuigalway.ie](mailto:Judith.burke@nuigalway.ie)  
to find out what being part of Lending an Ear will mean for you



**On behalf of the News Rheum Team, we wish you all a peaceful and happy Christmas.**

**Nollaig Shona Dhaoibh**



## The Patient Voice in Arthritis Research: Involvement Update

by Emma Dorris

### Research Conference

We had our conference in November, the first research conference in Ireland open to the public, medical professionals and researchers. Stephanie Skeffington has written about her view on the conference earlier in this edition. Our speakers had the opportunity to have their presentations reviewed beforehand by some of our patient insight partners. A huge thank you to John and Karmen for taking the time to educate our researchers and helping to improve their presentations. Your input was immensely valuable to our speakers. Our patient involvement on the day included co-chairs (Wendy and John), Patient Experience posters (Anne and Áine, Patrick and Elaine, Stephanie, Mary, Luisa, and Jacqui), Speakers (Simon and Denis), and a workshop developed and delivered by patients for our researchers (Rachel and Sarah). A sincerest thanks to all involved, it was a genuine pleasure working with you on this.



### Methotrexate Research

Many of you responded to my call for input on your view on research into Methotrexate. I'm delighted to announce that that funding was successful. The UCD-Wellcome Trust Institutional Strategic Support Fund (ISSF) Clinical Primer Scheme awarded Dr. Sharon Crowley funding to carry out this research with us here at UCD Centre for Arthritis Research. We look forward to have Dr. Crowley join us in 2019. We will be looking for a patient insight partner to act as a patient mentor for Dr. Crowley. If interested, please email [patientvoicearthrit@ucd.ie](mailto:patientvoicearthrit@ucd.ie)

### Rare Paediatric Disease Research (Behcet's Disease)

The National Children's Research Centre, who is funded by the Children's Medical Research Fund Crumlin, awarded us a project grant to investigate

a rare rheumatic disease called Behcet's Disease. Specifically, we are investigating Behcet's Disease that is inherited in families and can affect children. During the recruitment of the researcher to work on this project, we had a patient insight partner on the interview panel. This was the first time we had done this and it found it very beneficial. We plan to do this for all future research positions. We're delighted to welcome Dr. Niamh Morgan to the team to work on this project. Niamh has a patient mentor for this project and they will be giving us joint updates on the project as it progresses.

### Fibromyalgia Research

If you recall from previous issues, we have started research into fibromyalgia specifically because you, our patient partners, called for it.

I am delighted to announce our first funding success. The Irish Society for Rheumatology (ISR) Rheumatology Patient Improvement Fund (RPIF) awarded us funding for a 2-year research Master's project "A co-design approach to improving the pathway to diagnosis for fibromyalgia patients". This project is currently recruiting the Masters Student. It will suit someone with a Degree in Psychology, Sociology, Nursing, other Allied Health Professionals, or a related discipline. For more information contact [emma.dorris@ucd.ie](mailto:emma.dorris@ucd.ie). We will have a high degree of patient involvement during this project. If you would like to act as a patient insight partner for this project please contact [patientvoicearthrit@ucd.ie](mailto:patientvoicearthrit@ucd.ie).

At our fibromyalgia focus group a number of you discussed the sensory issues associated with chronic pain and fibromyalgia and the impact it can have on social isolation. This really resonated with me and I had been looking for an opportunity to try to address it. I am delighted to announce that I am working with the UCD School of Computer Science, Access Earth (an Irish company that provides a free platform that allows you to find and rate places by



your accessibility needs), and hopefully you, on a project to try to address the social isolation caused by sensory discomfort. Our goal is to develop a sensory feature to the Access Earth App, such that meeting spaces (coffee shops, restaurants, hotels etc.) can be rated by sensory accessibility. I will be holding two workshops in January (date & location TBC) with people living with chronic pain, including fibromyalgia, who experience sensory issues. The workshop is aimed at (1) identifying and (2) ranking/prioritizing the key sensory triggers that cause the greatest discomfort (sound, glare, echo, cramped space etc.). We will also be asking for your input on the design on the app screen, to make sure it's suitable for your needs. Once the test version is built, we will be asking for you to test it and give us feedback such that we can tailor it directly to your needs. This project will only be successful with the input of those living with sensory discomfort. If you would like to be part of this project please contact [patientvoicearthrit@ucd.ie](mailto:patientvoicearthrit@ucd.ie)



The Fibromyalgia Research Strategy has been progressing. We had a very interesting workshop with researchers and professionals with backgrounds in sociology, psychology, biomedical science, nursing, physiotherapy, pain specialists, consultant rheumatologists, Arthritis Ireland and Versus Arthritis UK to discuss the patient-designed research strate-

gy. The Patient Registry (see Summer edition of News Rheum 2018) was deemed the priority, as it would enable better, more relevant research into the future. The next step? I am applying for funding to host a meeting of international experts (including people living with fibromyalgia) in Dublin in 2019 to brainstorm and devise the best way (and funding source) to get this going. Please note, in order to devise a patient registry correctly, we need to do some research into the best, most rigorous, and robust way to do so. This may seem slow, but I believe it is better to do it right rather than fast. Registries are only as useful as the information collected.

### Patient Mentors in Plain English

UCD Centre for Arthritis Research is based at the Conway Institute. The UCD Conway Institute is an interdisciplinary research centre exploring the central causes that underlie major chronic diseases such as arthritis, diabetes, obesity, cancer, vascular diseases, and neurodegeneration. Every year the Institute hosts a research conference, *The Conway Festival of Research*. This year, the festival opened with a session on involving the public in research. As part of this, researchers were paired with a "Patient Mentor in Plain English". We had an excellent workshop whereby the patients taught the researchers what was important from the patient perspective, and how important language use is. We did a major jargon-busting exercise and the patients and researchers worked together to improve the researchers plain English research summary. The "before" and "after" research summaries were displayed at the conference. Some of the patient-researcher teams also spoke about the experience at the conference. Well done to Patient Voice in Arthritis Research participants Stephanie and Theresa who were teamed up with Conway PhD students. The researchers found it really beneficial. Thank you.



## A Guide to Basic Blood Tests

**Blood tests are commonly performed in Rheumatology clinics. They are important measurements of rheumatological disease activity and also important for monitoring side effects of drugs used to treat these conditions.**

**These are the most common blood tests used that may be performed on patients in our clinics.**

### Haemoglobin (Hb)

Haemoglobin measurement is one of the most common blood tests performed on patients as part of a full blood count. It is a measure of the iron containing protein found in red blood cells. It gives blood its characteristic red colour. Haemoglobin carries oxygen throughout the body to all the organs and tissues. Age, gender and race are taken into consideration when interpreting the results as these can change the expected normal range for that individual. A low haemoglobin indicates anaemia. This can have many causes. It can occur because of blood loss due to either digestive tract bleeding or excessive menstrual bleeding. It can also occur due to nutritional deficiencies such as B12, folate or iron. It can be related to chronic diseases including rheumatological diseases, bone marrow disorders or inherited problems with haemoglobin structure. A high haemoglobin count can be seen in smokers, lung diseases, congenital heart defects, dehydration or genetic causes.

### White Cell Count (WCC)

White cells are an important part of the body's defence system. They are also measured in the full blood count. There are different types of white cells which are produced in response to different triggers. Many rheumatology drugs including methotrexate, salazopyrin and the anti-TNF drugs that are prescribed to treat rheumatological conditions can have the side effect of lowering the white cell count. This needs to be monitored as a very low white cell count can be a risk factor for serious infections. A low white cell count can also be caused by many other reasons including bone marrow conditions, autoimmune conditions or in certain cancers. A high white cell count may occur in conditions such as infection, inflammation, ingestion of steroids, certain blood cell cancers or allergic conditions.



### Platelets (Plt)

Platelets are cells essential for normal blood clotting in order to prevent bleeding. In rheumatology, certain medications used to treat rheumatological conditions can reduce the platelet count. Aspirin, colchicine, ibuprofen and all other non-steroidal anti-inflammatories can also be asso-

ciated with reduced platelet count. Signs include bleeding or bruising more easily than usual, small red spots on the skin, dark stool colour or excessive menstrual bleeding. A low platelet count can also be seen in bone marrow disorders where not enough platelets are produced or in conditions where platelets are consumed too quickly. High platelet counts can be seen in inflammatory conditions, certain infections, cancers and certain types of anaemia.

### Creatinine (Cr)

The creatinine blood test is used to assess kidney function. Creatinine is a waste product of muscle breakdown which is almost all filtered from the blood by the kidneys. Therefore, blood levels of creatinine are usually a good indicator of how well the kidneys are filtering both this and other substances. This result is used in conjunction with information on gender, weight, age and race to calculate how well the kidneys are working. Increased creatinine levels suggest kidney disease from any cause. This may include dehydration, complications of diabetes, damage from infections to the kidney, autoimmune diseases that affect the kidney, medications that can cause kidney damage or sepsis. Low creatinine are not as clinically relevant but may be associated with reduced muscle mass.

### Liver Function Tests (LFT)

Liver function tests are important in rheumatology as many drugs need to be monitored for their effect on the liver. While they are useful to pick up liver damage these tests are not diagnostic of any specific cause of liver damage. In the early stages, most of this damage can be reversed by re-

## Your Blood Test Questions Answered cont...

moving the offending agent. Causes of elevated liver enzymes include certain rheumatological diseases, autoimmune diseases, drugs, alcohol, gallstones and infections to name a few.

### Erythrocyte Sedimentation Rate (ESR)

ESR is a test that indirectly measures the level of inflammation in the body. ESR is not a diagnostic test as it can be elevated in a large number of conditions. It is not possible to tell which condition has given the abnormal result. It must be interpreted in conjunction with the patient's history and the physical exam findings. It is generally elevated in most rheumatological conditions and it used as a measure of disease activity.

### C- Reactive Peptide (CRP)

CRP is another commonly used marker of inflammation. Like ESR, it is very non-specific and can be elevated in a range of conditions. Generally a reducing CRP means a good response to treatment and declining levels of inflammation in the body, while an increasing result means increased inflammation due to autoimmune disease or infection.

### Rheumatoid Factor (RF)

This is a

common test sent by Rheumatologists when a diagnosis of rheumatoid arthritis is suspected. It is a substance that is produced by the body that targets and damages the body's own tissues. However its presence doesn't confirm a diagnosis of rheumatoid arthritis as it can be present in normal individuals who do not have rheumatoid arthritis. It is not present in every patient with rheumatoid arthritis therefore a negative test does not out rule rheumatoid arthritis. Higher levels of rheumatoid factor generally correlates with more severe disease and a worse prognosis.



### Anti- CCP

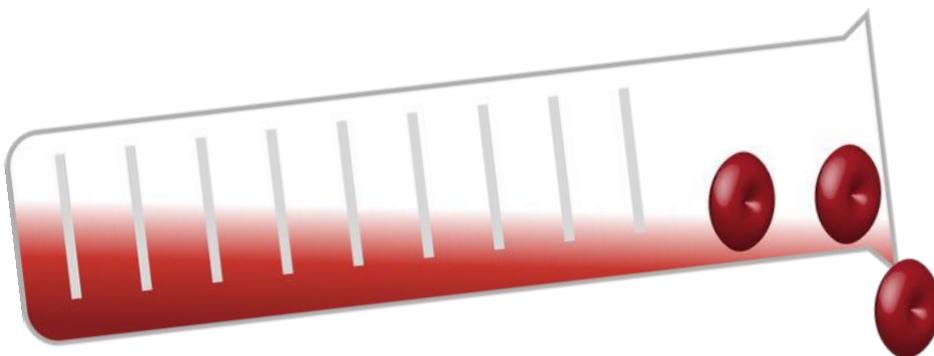
This is another common test performed when a diagnosis of rheumatoid arthritis is suspected. This test is more specific for rheumatoid arthritis than rheumatoid factor. This means normal patients are less likely to test positive for this blood test when the disease is not there. A positive result can say with 90% certainty that the diagnosis is rheumatoid arthritis. It is also a useful tool to estimate prognosis as testing positive generally means the arthritis can be more ag-

gressive and will need early intervention with medication. It must be emphasized, however, that RA is a clinical diagnosis and may be made in the absence of positive tests for these proteins.

### Uric acid

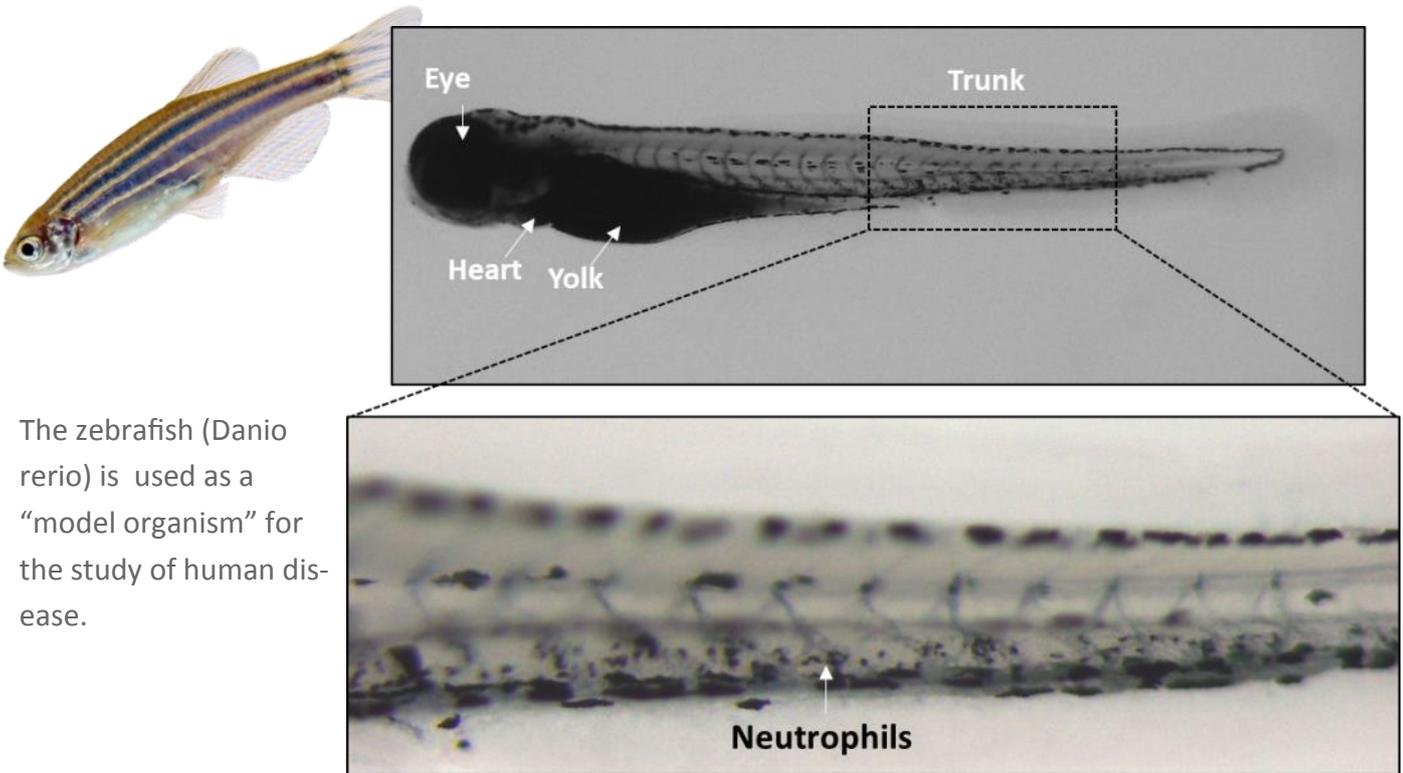
Uric acid may be tested for in the blood when a diagnosis of gout is suspected. It is a breakdown product of the body. Increased levels of uric acid can cause crystals to form in the joints and lead to inflammation known as gout. This may be caused by either producing too much uric acid or not being able to eliminate it from the body as efficiently as required. Excess alcohol and red meat can cause increased production of uric acid while conditions like kidney disease and genetic causes can result in it not being eliminated from the body efficiently enough and building up in the joints. A high uric acid alone however is not diagnostic of gout. Patients must exhibit the clinical features of the disease. Also levels of uric acid may be low during an acute gout flare so it must be interpreted with caution.

*Dr. Sharon Crowley is a Rheumatology Specialist Registrar at Our Lady of Lourdes Hospital in Co. Meath.*



# Cellfies: images of research

by Stephanie Merrigan



The zebrafish (*Danio rerio*) is used as a “model organism” for the study of human disease.

## Zebrafish and the Immune System

We use a variety of laboratory techniques to study the genetic cause of arthritis and related diseases. Most frequently, we use patients’ cells or tissue samples. However, cells in a test tube do not reflect the full complexity of a body. Therefore, in order for us to determine if a difference in DNA (or a specific gene) is the cause of a patient’s symptoms, we often need to use experimental animal models.

You may wonder why we would use zebrafish, when humans seem to be extremely different than zebrafish,. However, we are actually much more similar to them than you might think. In fact, 70% of human genes are found in zebrafish.

The zebrafish is an important research model which can be used to help us understand both development and disease.

Like humans, the zebrafish has a backbone and surprisingly similar with structural (anatomy and organ) and genetic similarity to humans.

The zebrafish is frequently used as a model organism due to its rapid development,. At 3 days post fertilisation the average larva is just 3.5 mm in size. Within the UCD Centre for Arthritis Research we are employing the zebrafish to investigate neutrophil behaviour in response to drug treatment and genetic differences. Neutrophils are a cell of the immune system, important for the body’s response to infection and danger. Neutrophils have a destructive role in diseases such as rheumatoid arthritis.

Our overall aim is to investigate neutrophil behaviour in zebrafish in response to the removal of genes which have been link to rheumatoid arthritis. This research will give us an important insight into which genes promote or protect against rheumatoid arthritis.

The first image (colour) shows an adult

zebrafish. The upper black & white image shows a whole zebrafish larva at 3 days post fertilisation. The lower image shows high magnification (zoomed in image) of the larval trunk. At this age, the zebrafish is transparent. We have used a special staining that allows us to see and track immune cells called neutrophils.

Please note that all experiment models undergo the strictest training and ethics review prior to being conducted. All research is overseen by the UCD Animal Research Ethics Committee (AREC) and is in compliance with the Health Products Regulatory Authority (HPRA) and EU Directive to protect animals used for scientific purposes .

*Dr. Stephanie Merrigan is a former researcher at the UCD Centre for Arthritis Research.*



The Patient Voice in Arthritis Research is 1 year old!

Thank you for working with us this year— let's do even more next year!

## Questions? Ideas?

Would you like to write for News Rheum?

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



*“Two sides of the same coin: patients and researchers have varying perspectives but all are working for the same cause.”*

Simon Stones, Speaking at “A Collaborative Approach to Arthritis and RMD Research, UCD Dublin 2018

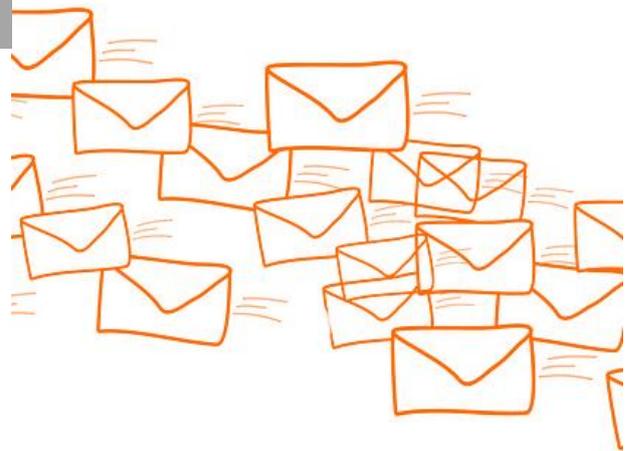
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