# News Rheum

## Edition 5:
## *Transitions: Old & New Life*
## Autumn 2019

WORKING TOWARDS BETTER RHEUMATIC AND ARTHRITIS RESEARCH - **TOGETHER**

**Welcome to the fifth *News Rheum* Newsletter! The theme of this edition is TRANSITIONS: OLD & NEW LIFE**

It has been a packed few months of events and conferences. Below are two of our Research Fellows at the ISR Autumn '19 Conference.


Drs Kevin Sheridan & Niamh Morgan at the Autumn 2019 meeting of the Irish Society for Rheumatology.

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

patientvoicearthritis@ucd.ie

IN THIS ISSUE

# Highlights from the 20th Annual European Congress of Rheumatology

***by Stacey Gerealis***


Was held in Madrid, 12-15 June and for the first time it was jointly organized by the Paediatric Rheumatology European Society. Over 14,500 people attended the conference to share and learn the latest findings in rheumatic and musculoskeletal disease research. The opening ceremony was a special occasion with the awarding of the Stene Prizes.

As a first-time attendee at Congress, it was an amazing occasion to attend, with a great deal of information all in one place. Like other first-timers, I suffered from Fear of Missing Out on the first days – which session to go to? Thankfully, all sessions are recorded and all abstracts can be downloaded from the EULAR Congress App (www.eyeled.de/eular-congress-app-2019/).

For me, the EULAR Congress was a great opportunity to speak with professionals face-to-face. I was surprised how many academic, medical and healthcare professionals took the time simply to chat. It was great to share experiences and collaboratively come up with new ideas to address the challenges in our community.

It is exciting to see the work that has been done by researchers from Ireland with other EU members and across the world. I was encouraged by the level of interest from young professionals and by how they are tackling societal problems and coming up with innovative and cost-effective measures to help people with rheumatic and musculoskeletal diseases (RMDs). I was delighted to hear, at many different levels, the importance of the patient's voice and that better-informed patients make better decisions about managing their condition.

# Annual European Congress of Rheumatology (continued)

Ireland was well represented at Congress, from chairing sessions to presenting posters.

- Prof. Oliver Fitzgerald co-chaired a session on the multiple rheumatological faces of psoriatic arthritis (called *PsA is more than just Poly Arthritis*)
- Prof. Douglas Veale co-chaired the session on *Different Pathophysiological Pathways in Spondyloarthritis*
- Prof. Norelee Kennedy presented *Exercise: The Best Drug Ever*
- Prof. David Finn presented *The Science of Cannabinoids*
- Dr Emma Dorris presented *A Novel Relationship in a 3-Generation Family with Beçhet's Disease*
- Brian Lynch presented People *with Arthritis & Rheumatism's #SeeMe: Raising Awareness & Understanding of Juvenile Idiopathic Arthritis*

Posters were presented by:

- Sandra Kayes on *A Trial Shoulder Exercise Programme*,
- Dr Connor Mcgee on *Outcome measures and Biomarkers in RMDs*,
- Dr Kieran Murray on *Increasing Influenza and Pneumococcal vaccination rates in Patients*,
- Ann O'Riordan on *Breaking Bad: Vertebral Fragility Fractures & the Impact to Management of Bone Health* and
- Emma Dorris on *Genotype of the Rheumatoid Arthritis Severity Locus RS26232*

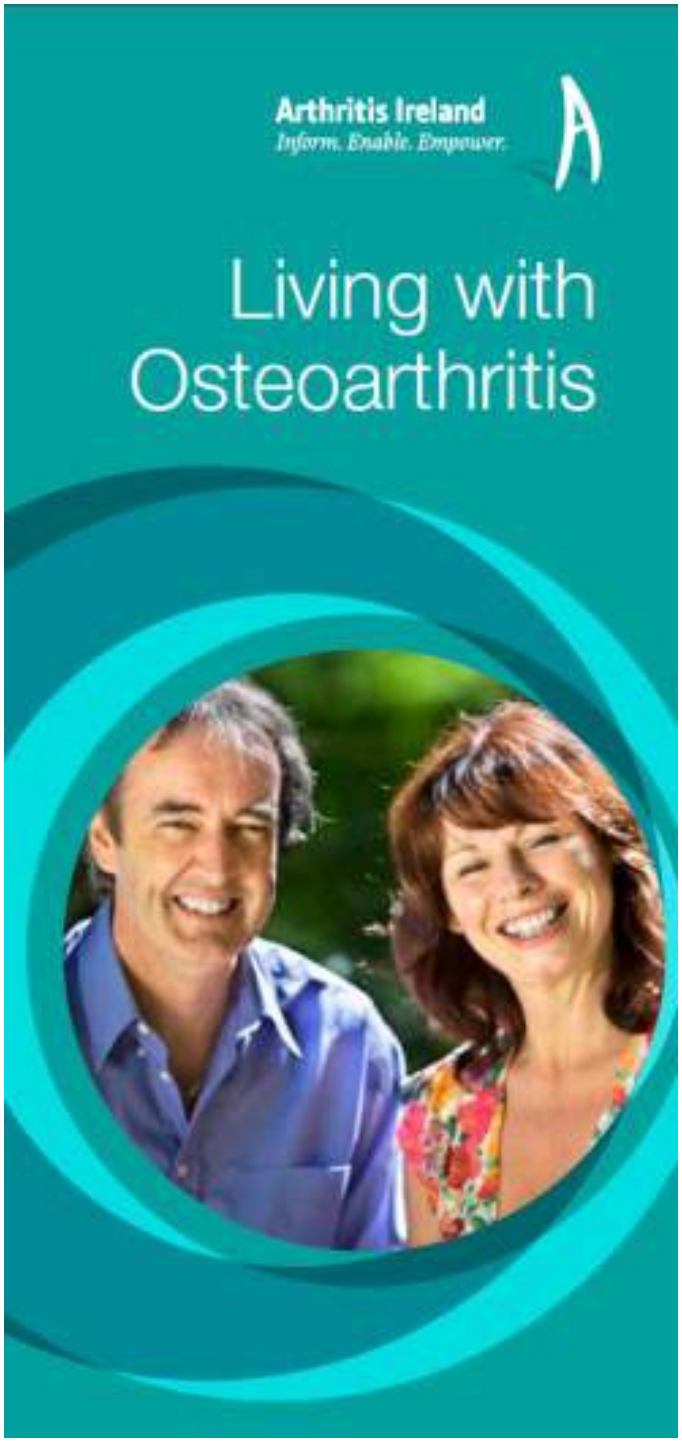
EULAR Congress 2019 was an informative, educational and enjoyable experience. The 21st EULAR Annual Congress of Rheumatology will take place in Frankfurt on June 3rd-6th 2020.

# Osteoarthritis: 'Wear & Tear' Arthritis

***by Breda Fay***

After many years of pain and reduced mobility, telling myself that wear and tear was to be expected after my life-long sporting involvement and a familial propensity to Arthritis, I recently worked up the courage to speak to my GP. Instead of minimizing my discomfort, I related the symptoms of my condition honestly for the first time, not only to him but to myself. He immediately referred me for X-Rays and a consultation with an orthopedic consultant who recommended knee replacement surgery. Within the next few weeks I will have TKR (Total Knee Replacement) surgery. All this "knee–talk" prompted me to explore my condition.

Arthritis Ireland runs 6-week courses all over the country. It was developed by Stanford University and provides a variety of techniques to manage this and similar conditions. Over six thousand people have completed the course since its introduction in 2006. To find out if there is a course in your area, go to **tinyurl.com/y6ms7y5x**. You can also find out whether there are other classes in your area, such as swimming, walking or chair exercises.




The following article is adapted from the American Arthritis Foundation website and the original is available at **tinyurl.com/yxo9xhxj**.

Further information on osteoarthritis is available from Arthritis Ireland at **tinyurl.com/yxjfay3l**

# Osteoarthritis: 'Wear & Tear' Arthritis

## Adapted from an original article by the Arthritis Foundation (tinyurl.com/yxo9xhxj)

**What is Osteoarthritis?**

Also called degenerative joint disease or "wear and tear" arthritis, osteoarthritis (OA) is the most common chronic joint condition.

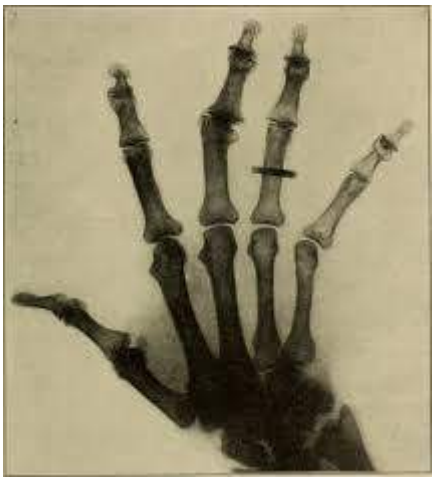
In normal joints, a firm, rubbery material called cartilage covers the end of each bone. This provides a smooth, gliding surface for joint motion and acts as a cushion between the bones. In OA, the cartilage breaks down, causing pain, swelling and problems moving the joint.

OA can affect any joint but is occurs most often in knees, hips, lower back and neck, small joints of the fingers and base of the thumb or big toe. As OA worsens over time, bones may break down and develop growths called spurs. Bits of bone or cartilage may chip off and float around in the joint. In the final stages of OA, so much cartilage wears away that bone rubs on bone, leading to joint damage and more pain.

**Who is Affected?**

OA occurs in people of all ages but is most common in those over 65. Other risk factors include obesity, previous joint injury, overuse of the joint, weak thigh muscles and genes.

- One adult in two will develop symptoms of knee OA during their lives.
- One adult in four will develop symptoms of hip OA by age 85.
- One in 12 of those 60 or older have hand OA.



**What are the symptoms?**

OA symptoms vary, depending on which joints are affected and how severely. However, the most common symptoms are pain and stiffness, particularly first thing in the morning or after resting. Affected joints may get swollen, especially after extended activity. These symptoms tend to build over time rather than show up suddenly. Some of the common symptoms include:

- Sore or stiff joints – particularly the hips, knees, and lower back – after inactivity or overuse.
- Limited range of motion or stiffness that goes away after movement
- Clicking or cracking sound when a joint bends
- Mild swelling around a joint
- Pain that is worse after activity or toward the end of the day.

Here are ways OA may affect different parts of the body:

- Hips: Pain is felt in the groin area or buttocks and sometimes on the inside of the knee or thigh.
- Knees: A "grating" or "scraping" sensation occurs when moving the knee.
- Fingers: Bony growths (spurs) at the edge of joints can cause fingers to become swollen, tender and red. There may be pain at the base of the thumb.
- Feet: Pain and tenderness is felt in the large joint at the base of the big toe. There may be swelling in ankles or toes.

# Osteoarthritis (continued)

**How is OA treated?**

Osteoarthritis is a chronic (long-term) disease. There is no cure, but treatments are available to manage symptoms. Long-term management of the disease will include several factors:

Physical Activity: One of the most beneficial ways to manage OA is to get moving. While it may be hard to think of exercise when the joints hurt, moving is considered an important part of the treatment plan. Studies show that simple activities like walking around the neighborhood or taking a fun, easy exercise class can reduce pain and help maintain (or attain) a healthy weight.

Strengthening exercises build muscles around OA-affected joints, easing the burden on those joints and reducing pain. Range-of-motion exercise helps maintain and improve joint flexibility and reduce stiffness. Aerobic exercise helps to improve stamina and energy levels and also helps to reduce excess weight. Talk to a doctor before starting an exercise program.

Weight Management: Excess weight adds additional stress to weight-bearing joints, such as the hips, knees, feet and back. Losing weight can help people with OA reduce pain and limit further joint damage. The basic rule for losing weight is to eat fewer calories and increase physical activity.

Stretching: Slow, gentle stretching of joints may improve flexibility, lessen stiffness and reduce pain. Exercises such as yoga and tai chi are great ways to manage stiffness.

Assistive devices: These include scooters, canes, walkers, splints, shoe orthotics or helpful tools, such as jar openers, long-handled shoe horns or steering wheel grips. Many devices can be found at pharmacies and medical supply stores.

Some items, such as custom knee braces and shoe wedges, are prescribed by a doctor and are typically fitted by a physical or occupational therapist.

Pain and Anti-inflammatory Medications: Medicines for OA are available as pills, syrups, creams or lotions and can be injected into a joint. They include:

- Analgesics: These are pain relievers and include acetaminophen, opioids (narcotics) and an atypical opioid called tramadol. They are available over the counter or by prescription.
- Nonsteroidal anti-inflammatory drugs (NSAIDs): These are the most commonly used drugs to ease inflammation and related pain. NSAIDs include aspirin and ibuprofen and are available over the counter or by prescription.
- Corticosteroids: Corticosteroids are powerful anti-inflammatory medicines. They are taken by mouth or injected directly into a joint at a doctor's surgery.
- Hyaluronic acid: Hyaluronic acid occurs naturally in joint fluid, acting as a shock absorber and lubricant. However, the acid appears to break down in people with OA. The injections are done in a doctor's surgery.

# Highlights from the Irish Rheumatology Society

***by Dr Kevin Sheridan***

The Autumn '19 meeting of the Irish Society for Rheumatology took place 26-27 September, in the Killashee Hotel in Naas. UCD CAR team members Prof. Gerry Wilson and Drs Niamh Morgan, Ng Chun Ruh and Kevin Sheridan attended.

The opening talk was delivered by Prof. Aisling Dunne from Trinity College Dublin. This talk, *Disease-Associated Particulates & Joint Inflammation*, detailed her group's findings on the role of calcium phosphate crystals in osteoarthritis.

This was followed the presentation of submitted oral abstracts, including Niamh's talk *The Genetic & Molecular Dissection of an Early-Onset Familial Mucocutaneous Ulcerative Condition*. Niamh outlined her investigation of five multi-case Irish families which have a Behçet's Disease-like illness and the discovery of a new gene mutation associated with this illness.

Winners of 2018 Rheumatology Patient Improvement funding gave 5-minute presentations on the aims of their research projects. Prof. Geraldine McCarthy presented on behalf of herself and the UCD CAR's Dr Emma Dorris, discussing their work to improve patient involvement in Fibromyalgia treatment.

Prof. Robert Moots of Liverpool University gave an engaging talk, *Clinical Update on the Management of Behçet's*. He detailed the difficulties in diagnosing Behçet's and the impact this can have on those living with it. This included a video interview with a patient who discussed his struggles with misdiagnoses and the resulting physical and mental impact.

I presented a poster entitled *Investigation Into rs26232 Genotype Association with Susceptibility & Severity of Rheumatoid Arthritis* during the lunchtime premier poster session, which featured the top 10 poster abstracts chosen by the review panel.


Dr Kevin Sheridan presenting at the Autumn 2019 ISR Meeting

# Irish Rheumatology Society (continued)

Prof. Gerry Wilson & Dr Suzanne Donnelly from UCD


Dr Niamh Morgan presenting

Dr Natasha Jordan, a doctor from Addenbrooke's Hospital in Cambridge, led an enlightening discussion on *Fatigue in Lupus*. This focussed on the benefits of exercise in reducing fatigue for those with Lupus Erythematosus and the difficulties patients experienced in setting and maintaining an exercise program.

The second oral abstract session featured four talks from Prof. Ursula Fearon's group from Trinity College Dublin. These detailed the biological processes that may contribute to a range of inflammatory diseases such as JIA, Down Syndrome-associated Arthritis, rheumatoid arthritis and psoriatic arthritis.

Dr Marwan Bukhari, a British NHS doctor from Morecambe Bay, opened the second day with his talk *Quality-of-Life Issues with Osteoporosis.*

Dr Mark Rowe's talk, *Live with Vitality*, was a change in direction; he focussed on the needs of practitioners, clinicians and researchers and the importance of looking after our own mental health. Dr Rowe emphasized that, while focussing on the patient's needs is of course important, we must not forget our own; he supported this with stories of burnout affecting those who concentrated on work to the neglect of their well-being.

The meeting finished with Prof. David Walsh's presentation *The Pain of Rheumatic Disease*. Prof. Walsh presented his groups findings on pain sensitization in rheumatoid arthritis and the distressing impact pain has on patients, including restricting ability and negative mental and social effects.


Drs Kevin Sheridan & Niamh Morgan from the UCD CAR

# Summer Project Yields New Tools for Public & Patient Involvement

**reprint from HRB *Research Spotlight* series**

**In a HRB-funded summer project, James MacCarthy developed new tools to help promote public and patient involvement in health research. He spoke to Dr Claire O'Connell about his motivation and the benefits of thinking beyond the lab.**

Summer projects can be surprisingly productive. For James Mac Carthy, signing up to a HRB-funded project was very productive indeed: he worked on new ways to help promote public and patient involvement in health research and helped to develop a tool to track how patients engage with a research project as it is happening.

As an undergraduate on the Biomedical Sciences programme in University College Dublin, James received an email outlining the summer project, and to him it looked different and interesting. 'It appealed to me, because the project wasn't based in a lab, and I knew I would be doing a lab-based project as part of my course, so this would give me experience of another type of research', he says.

He signed up for the eight-week project with supervisor Dr Emma Dorris, who is head of the UCD Arthritis Research Group. James's job was to help with the public and patient involvement, or PPI.

'PPI basically looks to carry out research with patients as opposed to for or about them', he explains. 'It looks to involve them in the research and lets their voice be heard to direct the path of research that is relevant to them'.

**Barriers to PPI**

The whole approach is undeniably good-natured, notes James, but there are barriers, and one of the starting points in his research was to identify what researchers saw as barriers to PPI. 'For many researchers, PPI is becoming a condition of funding, so they need to implement it', says James. 'We gathered researchers together and asked them how they felt about implementing PPI and the kinds of barriers that stood in their way'.

Many of the answers were about the time involved, and the lack of training and communication that researchers had for engaging with patients. 'Researchers have a lot on their plates, and we were hearing that implementing PPI was a struggle, in part because of time and in part because they didn't have much guidance on how to do it'.

In order to help researchers work through these barriers, the UCD team developed a tool that lets them work through potential problems, mapping them out almost in a flow-chart, explains James. 'It asks them to come up with solutions to those challenges, to identify in advance how they might overcome them', he says.

HRB Health Research Board

The Patient Voice in Arthritis Research

UCD DUBLIN

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James MacCarthy, 2018 summer placement student at UCD Centre for Arthritis Research

# Summer Project (continued)

**PPI for PPI**

While James was involved in that work, the meat of his research lay in developing another tool, one that meant patients could record their levels of satisfaction during a PPI project, so that researchers could get a real-time alert if there were problems brewing. 'The survey is deigned to facilitate the ongoing evaluation of PPI as a research initiative is taking place', he explains. 'After 3-6 months, this survey would be given to patients, they would be asked to assess the initiative by responding to a series of prompts or questions on an 11-point scale'.

James sought the advice of survey expert Dr Suzanne Guerin at UCD to develop the tool, and, very importantly, he sought he advice of patients. 'It was like doing PPI on my own project', he says. 'I sent the test surveys out to people who were taking part in the Patient Voice in Arthritis programme in UCD and they were able to tell me what they wanted to be asked about , and to point out where the language needed to change to be more readily understandable'.

James was a named author on a recent paper describing the PPI tools in the journal PLOS ONE. He presented his results at the Student Summer Research Awards in UCD and he also got the chance to talk about the findings at a conference in Newcastle in the UK. 'Lots of people were interested in it', he says. 'The idea of assessing PPI as it goes on, that went down well with people'.

**Different Perspectives on Science**

Following the successful summer project, James went on to his final year of the Biomedical Health & Life Sciences course in UCD, completing his lab project as part of it. 'I worked on a bacterium called Campylobacter that lives in chicken', he explains. 'It doesn't make the chickens sick, but if it is not cooked and killed and it gets into humans, it can make us sick with food poisoning'.

For his project with Dr Marguerite Clyne, James found that the bacterium behaves differently at varying levels of acidity, which is of interest as it survives the acidity of the stomach both in chickens and humans. 'It was an interesting question I wanted to look at', he says.

With the degree in the bag, James is looking forward to doing a Masters in Business and Biotechnology at Smurfit Business School in UCD, where he will learn about another aspect of health research: how medications are brought to the market.

**Spinning Success**

Throughout his scientific studies, James has kept busy with another side to his life: he is a fitness instructor. A life-long interest in sports – mainly rugby as a child and teen – led to him becoming qualified as a spin and gym instructor after he left school. It is a move that has stood to him during his student days.

'I found that the hours were long for studying biomed, and my rugby training often clashed with lectures or lab times, so reluctantly I had to give up the rugby, which was a bit frustrating', he says. 'But the upside is that I have been able to keep fit by instructing gym and spin classes, and that has also meant an income!'.

For another striking example of student research at the UCD CAR, go to tinyurl.com/y6zdoq8m for a video designed to raise clinicians' awareness of Inflammatory Arthritis of Down Syndrome

# Highlights from the Irish Society for Human Genetics

***by Dr Niamh Morgan***

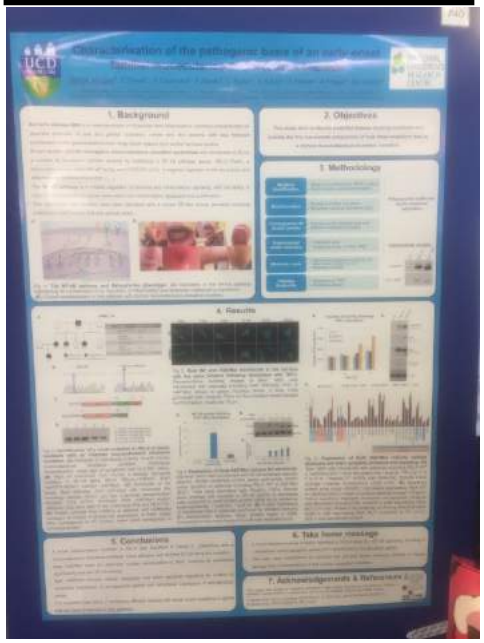
The Irish Society of Human Genetics (ISHG) 22nd annual meeting was held on 20 September in Stranmillis University College, Belfast. Every year, this meeting brings together Ireland's clinical and scientific human genetics communities, allowing human genetics researchers to present and to discuss challenges and opportunities. Several key industries were also in attendance to provide information about products or services involving genetic research.

It was a jam-packed day, starting with registration, coffee and a welcome address by ISHG Secretary Gianpiero Cavalleri before the talks kicked off. The first session comprised 10-minute presentations from five researchers based in different parts of the country, focussing on scientific (rather than clinical) research. They mostly discussed large-scale genetics studies now underway in Ireland.

In the morning session, the first talk was from Edmund Gilbert (Royal College of Surgeons), who spoke on studying the genetics of people from Scotland and the Isles. This is important for understanding our genetic makeup, our ancestry and the movement of Vikings and other ancient peoples; movement was a major factor in determining the genetics that make us who we are today. The third talk was from Joan Fitzgerald (NUI Galway), who is using genetics to understand cognitive resilience (the brain's ability to buffer against disease and recover from trauma) in healthy aging. She is investigating whether specific genes in the brain are associated with healthy aging. In future, these findings could be used to predict the development of brain diseases, such as dementia. Joan won the Young Investigator Award for Postgraduate Oral Presentation. Both of these talks were large-scale studies, the first examining DNA from 2,554 people and the second from >300,000. The final talk of the morning was by Daniel Maloney (TCD), who also won a Best Postdoctoral Oral Presentation prize. He spoke on the use of gene therapy to treat the inherited eye disease Dominant Optic Atrophy. Using gene therapy (an experimental technique that uses genes to treat or prevent disease) on diseased cells, his team could restore cells to a healthy state. Daniel demonstrated how this therapy might be used to treat Dominant Optic Atrophy.

After this interesting morning, we were invited for poster viewing and coffee. With a record number of posters this year (>40), it is a great opportunity for young researchers to display their work, discuss with experts and get helpful feedback. I presented a poster on some of the research being carried out at the UCD Centre for Arthritis Research. My poster showed how we are performing genetic analysis on patients with a rare auto-inflammatory condition in order to understand what causes their disease, which could help clinicians provide more effective treatments.

Dr Niamh Morgan's poster presentation at ISHG 2019



# Irish Society for Human Genetics (continued)

Prof. Jan Veldink of UMC Utrecht

After the poster presentations came Jan Veldink's keynote talk *Genetic Basis of ALS: The Past, Present & Future* – the highlight of the day for me. Jan is a professor and neurosurgeon at Utrecht University Hospital in the Netherlands. He has devoted much of his career to researching the genetic and environmental causes of diseases like ALS (Amyotrophic Lateral Sclerosis, also called Motor Neuron Disease). He aims to understand the causes of these diseases so that this knowledge can be used in the future to treat and diagnose patients. Jan is completely dedicated and passionate about his work and he showed impactful videos of patients speaking about their experiences with ALS; for laboratory researchers like myself, who spend most of our time not interacting with patients, it was a powerful reminder of why we do our research. Jan has accomplished some ground-breaking ALS research, so it was a great privilege to attend his talk.

At lunch, we viewed the posters and spoke with industry sponsors; the afternoon talks were five 10-minute talks on clinical genetics, particularly rare diseases. I will highlight two of these. Deborah Lambert from the National Rare Diseases Office spoke on *Who Needs Rare-Disease Services in Ireland? Constructing a List of High-Prevalence Rare Diseases for Ireland, to Inform Service Needs*. As the title explains, her work aims to identify rare diseases that are (despite their name) highly prevalent in Ireland; because Ireland has no Rare Disease Registry, there is a severe lack of data here. Deborah reported that a list of high-prevalence rare diseases (rare diseases that affect the highest amount of people) in Ireland has now been generated. This important piece of work will inform rare-disease policy and help us create care systems that address the needs of Irish people with rare diseases.

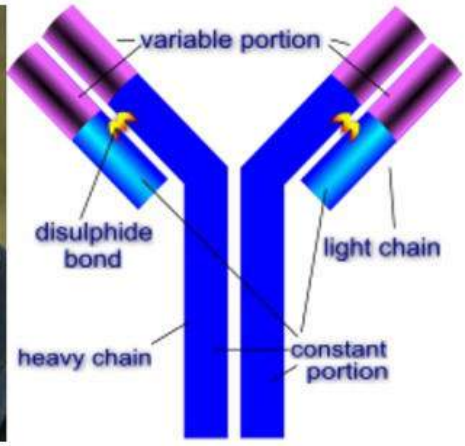
Daniel Murphy, also from the National Rare Diseases Office, gave a talk on *European Reference Networks: Potential for Rare-Disease Research & Patient Care in Ireland*. He explained that, despite the impact of rare diseases (which affect around 300,000 people in Ireland), diagnosis and treatment is extremely difficult because of the rarity of individual diseases, scattered patient populations and lack of specialist expertise. He introduced us to the European Reference Networks (ERNs), virtual networks of healthcare providers across Europe that concentrate knowledge and resources and facilitate discussion on diseases that are rare or complex or that require very specialized treatment. Daniel discussed how Orphanet Ireland has successfully assigned 331 out of 345 of the most high-prevalence diseases in Ireland to ERNs and 248 of them to Centres of Excellence (physical sites connecting patients to ERNs). This will enhance diagnosis, clinical research and treatment access for patients.

The second keynote speaker was Peter Robinson from the Jackson laboratory in the USA. His talk was entitled *The Human Phenotype Ontology: A Semantic Framework for Phenotype-Driven Translational Research & Genomic Diagnosis*. Peter spoke about his program, the Human Phenotype Ontology. This contains standardized vocabulary of phenotypic (physical) abnormalities found in genetic diseases. Clinicians can log their patients' symptoms in this program and it will be able to diagnose the most likely disease. This was a very interesting talk and the potential benefits of this tool for clinicians and patient are clear.

This was a very diverse meeting, with topics ranging from whole-population genetics to specific rare diseases. The next meeting, ISHG 2020, will be held in Dublin; for details, see http://irishsocietyofhumangenetics.blogspot.com.

# Research Seminar
# November 20th

## *Immune Privilege Collapse in Alopecia Areata: Hunt for the Auto-Antigens*




3 pm seminar

Prof. Desmond Tobin,
Director,
UCD Charles Institute of Dermatology

Desmond Tobin is Professor of Dermatology at UCD School of Medicine and Director of the Charles Institute of Dermatology, University College Dublin (since Sept 2018). Previously he was Professor of Cell Biology and Director of the Centre for Skin Sciences at University of Bradford, where is now holds an Honorary Visiting Research Professorship

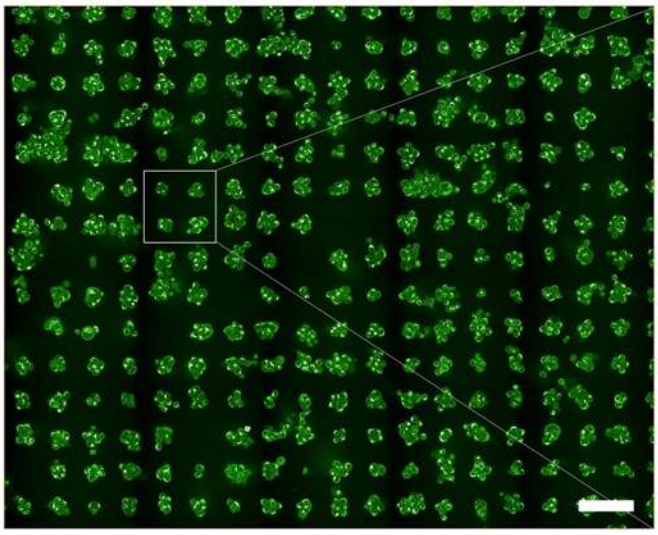
**All welcome; refreshments provided**

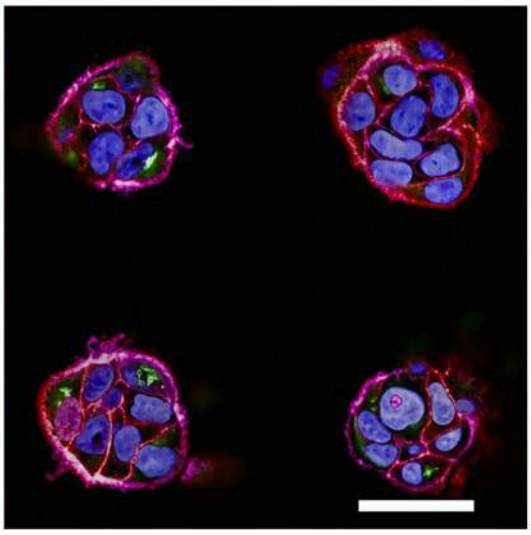
Friday Nov 20th | Conway iHub | No registration needed

# Cellfies: Images of Research

***by Margaritha Mysior***

The left image shows lab-grown mini-tumours. The right image shows a close-up of four of them, with the different components that make up the cancerous cells labelled with different colours. These images were taken using a microscope.





Our bodies are made up of microscopic cells; these cells have a limited lifespan, so they need to divide to replace themselves with new cells to keep the body going. Cancer is a major disease where this cell division goes of control. This leads to the formation of tumours that grow in size, eventually stopping the body's tissues and organs from working correctly.

Cells can communicate with each other by sending out messages known as 'signals', allowing them to coordinate and fine-tune their functions in the body. These signals are usually made within compartments in our cells, are transported through the cell and finally released outside the cell, where neighbouring cells will receive the signal. Many types of cancers are caused by cells sending the wrong signals to nearby cells. This can be caused by a breakdown in communication between our compartments of a cell, in signal transport or in signal release. Our lab is interested in studying these communication and transport pathways inside cells and, in particular, understanding what makes them work properly or go wrong.

To study them, we grow mini-tumours in the lab from cancer cells. They are grown on surfaces that force the tumours to line up in regular patterns. This ensures they are a similar size and shape to each other, making them easier to compare. We then make the various cell compartments different colours so that we can see them more clearly under a microscope. Using these tumour models in the lab we can study the compartments in the cells, and how the cells' transport and communication systems work.


UCD Centre for Arthritis Research and
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A research conference open to the public
The Patient Voice in Arthritis Research

# EU Open Science Fair

***by Dr Emma Dorris***

As many of you know, I am passionate about public involvement in research as I fundamentally believe it makes research better. Public involvement is one of the pillars of something called responsible research and innovation, which is part of a larger movement known as Open Science.

Open Science is a new approach to the scientific process based on cooperative and collaborative work and new ways of sharing knowledge. It acknowledges that knowledge produced by publicly funded research is a public good and should be available openly to maximize its impact.

Open Science is aimed at removing the barriers to sharing any kind of output, resource, method or tool, at any stage of the research process. The movement has been around for some time but is facing many challenges getting widespread acceptance. These challenges include simple resistance to change, disincentives in the current reward systems of universities and funders, a lack of tools and services and a lack of connection to non-academic communities.

The Open Science Fair is co-hosted by four European Research Council projects on Open Science and aims to showcase the elements required for the shift to Open Science, including digital infrastructures and services, policies and guidance for good practice and new types of open science activities.

I was there to present some of the voluntary work I do with the not-for-profit group, *eLife* Ambassadors for Good Practice in Science, highlighting some of the challenges that prevent life science researchers from involving the public in their research. I was also there to learn from some of the extraordinary and inspiring co-speakers and attendees.


Dr Emma Dorris speaking at the 2019 Open Science Fair

# EU Open Science Fair (continued)

I will highlight two presentations that were especially powerful for very different reasons. One was the keynote from Dr Paola Masuzza, a passionate advocate for open science. Paola is a data scientist for a corporation and an independent researcher for the Institute for Globally Distributed Open Research and Education and spends much of her free time advocating for free and fair access to knowledge. Paola co-founded Civic Lab Ghent and sits on the Steering Committee of the Open Science Massively Open Online Course. This 'MOOC' is a 10-module free course, created by hundreds of researchers and practitioners who have all volunteered their efforts to create a community to propel research forward (https://opensciencemooc.eu/). She passionately spoke about the responsibility of all stakeholders to ensure that research is rigorous, accountable and reproducible – core elements of open science.

From left to right: D. Paola Masuzza (IGDORE), Dr Eloy Rodrigues (Minho University), Liina Munari (European Commission)

In contrast, we all received a reality check from Dr Bregt Saenen, Policy & Project Officer at the Research & Innovation Unit of the European Universities Association (EUA). Bregt gave us a sneak-peak at the EUA's latest survey of research institutions and how they assess researchers. The full report is due out later this month. The take-home was that, when it comes to assessing individual researchers and research careers, research institutions still do not reward open science practices, including social outreach and public involvement. There is clearly much more work to do on this to ensure that open science best practice is valued by those making decisions on researchers' careers.

The wonderful thing about Open Science events is that all material is open, accessible and sharable. If you would like to see videos of any of the presentations, or access the presentation files, you can visit www.opensciencefair.eu/programme-2019 .

Event organizers from Minho University

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