Breaking down barriers,
Improving Public Involvement in Research

UCD Centre for Arthritis Research
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UCD Centre for Arthritis Research
Seventh Annual Public and Patient Involvement
Free online Conference

Rare Rheumatology

Niche Conditions and Future Directions

6th November 2024

10am – 2pm

Programme

Time	Speaker	Title
10.00	Introduction	
10.00	Prof. Rachel Crowley	Rare Bone Stories from an Endocrinologist
10.15	Prof. Mark Little	Rare Immune Disorders In Ireland – Role Of The European Reference Networks
10.30	Ms. Vicky McGrath	The Future is Brighter for Rare Diseases
10.45	Break	
11.00	Dr. Elizabeth Price	Rarer Autoimmune Rheumatic Diseases - The Challenge!
11.40	Patient Videos:	
	Rebecca Beesley	Juvenile Idiopathic Arthritis
	Seth Durrant	Neonatal-Onset Multisystem Inflammatory Disease
	Christine Rainey	Cryopyrin Associated Periodic Syndrome
	Paula King	Vasculitis
12.00	Ms. Julie Power	The World of Vasculitis from a Patient’s Perspective
12.15	Lunch	
1.00	Dr. Emma Dorris	Rare Disease: The Importance Of Lab Based Research
1.15	Ms. Grainne O'Leary	Arthritis Ireland: Supports And Services For People With All Rheumatic And Musculoskeletal Diseases
1.30	Dr. Eve Smith	Patient Centred Target Drive: Working To Improve Outcome For Childhood Systemic Lupus Erythematosus Patients
1.45	Submitted Abstracts	
2.00	Close	

Speakers

Professor Rachel Crowley

Consultant Endocrinologist

St. Vincents University

Prof. Crowley is an endocrinology consultant at SVUH and a clinical professor at UCD. She is co-lead of the HRB-funded Rare Disease Clinical Trial Network and lead of the Rare Disease Research Catalyst Consortium, information about these projects is available at www.rarediseaseresearch.ie. She is the adult lead for the European Reference Network for rare bone diseases Irish centre at SVUH (ERN BOND) and sees patients there in a monthly clinic who also participate in research and trials. She works with national and international partners on research projects, guidelines, reimbursement of rare disease drugs, patient support resources and research methodology.

Professor Mark Little

Consultant Nephrologist

Tallaght and Beaumont Hospitals

Mark is Professor of Nephrology in Trinity College Dublin and consultant nephrologist in Tallaght and Beaumont Hospitals.

After graduating from medicine in Trinity he completed his Nephrology training in North London in 2006. During this time, he obtained a PhD from Imperial College London, and post-doctoral time spent at Hammersmith Hospital, University of Birmingham and University College London consolidated a translational research programme focused on autoimmunity and systemic vasculitis.

His research interests include novel model systems for investigating the pathogenesis of ANCA vasculitis, biomarker development and application of data science techniques to study autoimmunity. He leads the HELICAL, PARADISE and FAIRVASC EU consortia, which seek to apply novel data science and linkage techniques to health data. He has published over 200 peer-reviewed manuscripts and was awarded the President of Ireland Young Researcher Award in 2012. He is a co-founder and autoimmune lead of ERN-RITA, the rare immune disorders European Reference Network, lead of the European Vasculitis Society Registry initiative, chair of the RITA-Ireland Vasculitis Network and co-founder of UKIVAS, the vasculitis society of UK and Ireland.

Ms. Vicky McGrath

Chief Executive

Rare Diseases Ireland

Vicky McGrath is Chief Executive at Rare Diseases Ireland (RDI), the national alliance for rare disease patient organisations in Ireland. Vicky joined RDI as CEO in 2018 and has overseen development of the organisation into a strong and stable voice for people living with rare diseases in Ireland and their representative organisations, ensuring that rare voices are heard in the drive for equity - equitable access to diagnosis, treatment, health, social care and opportunity.

Over the course of Vicky's tenure at RDI awareness of rare diseases has grown. This is true in particular at government/policy level as acknowledged in the 2020 Programme for Government, 2021 adoption of a UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families." and 2022 support for development of an EU Action Plan on Rare Diseases. In 2024 rare diseases were highlighted for investment in the Government's budget.

Vicky is a member of Ireland's National Rare Disease Strategy and Implementation Plan Steering Group, established by the Department of Health in 2023, and co-chairs the Rare Disease Patient Forum at the Department. She is a member of the Clinical Trials Oversight Group, established July 2024 by the Department of Health, and HIQA's Health Technology Assessment Scientific Advisory Group. Vicky also represents the rare disease community on implementation of the HSE's National Strategy for Accelerating Genetic and Genomic Medicine in Ireland.

Vicky came to Rare Diseases Ireland from industry where she spent 20 years in various leadership roles within the life-sciences sector between the US and Ireland. She has a BE (Mechanical Engineering), an MSc (Biomedical Engineering), an MBA and is a fellow of BioInnovate Ireland.

Dr. Elizabeth Price

Consultant Rheumatologist

Great Western Hospital

Dr Elizabeth Price is a Consultant Rheumatologist at Great Western Hospital in Swindon. In addition to General Rheumatology she has a specialist interest in Sjogren Disease. She currently focuses on clinical research into Sjogren's and was the lead author and driving force behind the British Society of Rheumatology Guidelines for the management of Sjogren Disease. The updated guideline was published in April 2024.

She is a Past President of the British Society of Rheumatology (2018 – 2020) and current national Clinical Lead for the HQIP mandated New Early Inflammatory Arthritis Audit (NEIAA) running across England and Wales.

Ms. Julie Power

Patient Contact and Policy Officer

Vasculitis Ireland Awareness

Since 2005, Julie has been living with Granulomatosis with Polyangiitis Vasculitis and in 2010, she founded an all island of Ireland Vasculitis support group. The aims of Vasculitis Ireland Awareness (VIA) are to provide support, raise awareness, improve services, and have meaningful patient participation in research into these rare diseases. She works with Vasculitis UK, the Vasculitis Foundation and Vasculitis International, to provide support and share current information about diagnosis, management and treatments and has recently appointed Vasculitis Patient lead in ERN RITA.

Julie sits on the Rare Kidney disease Registry and Biobank Steering Group and is the VIA representative in RITA Ireland. She is also involved in several research projects, (RAINDROP, HELICAL, FAIRVASC, DeCOmPRESS, AVERT, PARADISE, ERN RITA Vasculitis patient Journeys) facilitating PPI involvement and ensuring the patient perspective is included.

She is a former Board member of the Northern Ireland Rare Disease partnership (NIRDP)and the board of the Irish Platform for Patient Organisations, Science, and Industry (IPPOSI) contributing to improving care and services for Rare Disease Patients in both jurisdictions.

Julie is a fellow of European Patient Academy of Therapeutic Intervention (EUPATI), having participated in expert-level training in medicines research and development. This European training has been invaluable for networking and support, and to ensure that her advocacy work is effective and sustainable. She continues to contribute to empowering other patients to get actively involved in decisions that affect them at every level, from individual to local, national, and international level.

Dr. Emma Dorris

Engaged Research Manager

UCD Research

Dr Emma Dorris is the Engaged Research Manager at UCD Research. She has a PhD in molecular medicine and a Master of Public Policy. She also acts as programme manager for the PPI Ignite Network @ UCD. She has a background in biomedical research and is an internationally recognized specialist in the involvement of public stakeholders in research that is not public-facing. Emma was a member of the UCD CAR and established the Patient Voice in Arthritis Research. Emma has authored a number of articles in the area of public involvement and has a passion for improving research culture across all disciplines. She has a particular interest in policy and practices related to public involvement in research and in developing ways to build capacity at systems level towards more relevant and impactful research. She is a long-term advocate of open science practices and improved research culture.

Ms. Grainne O’Leary

Chief Executive

Arthritis Ireland

Gráinne O’Leary is chief executive of Arthritis Ireland, where she is leading the strategy of the charity to be one of the leading patient centric health charities in Ireland. Prior to her appointment as chief executive in 2018, she was head of services with the organisation since 2004 and has worked as a senior manager in the non-profit and healthcare sector for over 20 years.

Gráinne developed and implemented Arthritis Ireland’s suite of patient support services, including the innovative Stanford University self-management programme, a national helpline and a national physical activity programme in partnership with the Irish Society for Chartered Physiotherapists. She serves as a board member of the Disability Federation of Ireland.

Dr. Eve Smith

Paediatric Rheumatologist

University of Liverpool

Dr Eve Smith, is a Clinical Academic at the University of Liverpool/Alder Hey Children's NHS Foundation Trust. She is Chair of the PreS SLE Working Party and co-lead of the International cSLE Treat-to-Target (T2T) Task Force. Her work is central to advancing cSLE T2T Analysis across Global Registries, for which she, along with CARRA collaborators has received the 2023 FOREUM/Rheumatology Research Foundation Collaborative Partnership Award. In 2022, Eve's commitment to excellence in lupus research was honoured with the Medical Research Foundation Emerging Lupus Leaders Prize. As a founding member of World Young Rheumatic Diseases Day (WORD Day) Committee, Eve contributes to raising global awareness of PRD's.

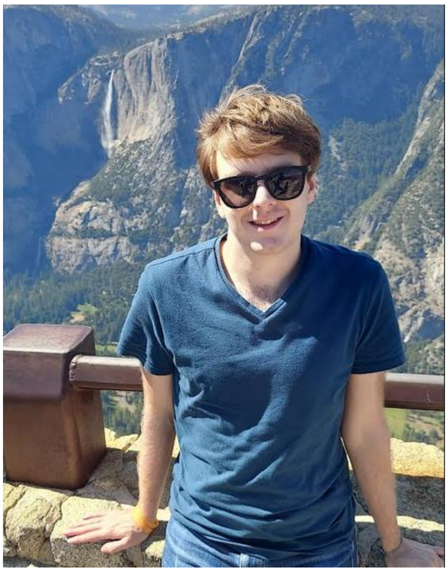
Patient Videos

Rebecca Beesley

Richard and Rebecca Beesley founded the UK charity Juvenile Arthritis Research in 2018 to help fill some of the gaps in the field of JIA in terms of research, awareness and family support. The charity has grown to support hundreds of families all across the UK and their work is also recognised and respected internationally.

Rebecca is an adult who has Juvenile Idiopathic Arthritis herself as well as having a daughter with JIA. Her volunteering with Juvenile Arthritis Research involves supporting many families affected by the condition. Working closely with parents, schools, and researchers she brings insights into life with JIA, has spoken at conferences and has helped to develop many resources for patients, parents and schools.

Seth Durrant



Seth is a Biochemistry Ph.D. student at the University of California, Merced, and has Neonatal Onset Multisystem Inflammatory Disease (NOMID). He got his degree in biochemistry at Brigham Young University where he also worked in a microbiology lab during three years of his program. From there he participated in a summer internship at Dr. Goldbach-Mansky's lab at the NIH before starting his Ph.D. program. Due to his disease, he has a deep interest in the functions of the innate immune system, and his research focuses on the biochemical properties of innate immune proteins. He wants to continue researching these proteins and contribute to a deeper understanding of these systems. In doing so, more people like himself can get treatments and support.

Christine Rainey

Christine Rainey is a registered psychiatric nurse and a proud mother of 5 children.

She has lived with Cryopyrin Associated Periodic syndrome also known as (CAPs) all of her life that was diagnosed in 2018 with the perseverance of her daughter.

After taking early retirement due to cancer she has returned to agency work as a nurse looking after a young man with complex needs which she enjoys each day getting up and supporting him in his care needs.

She believes in the volunteer movement and supports people going through cancer by empowering people with the visual side effects of cancer through the Look Good Feel Better Ireland programme. An International cancer support charity in over 25

Paula King

Paula was born in Trinidad and Tobago, her father was an R&D Chemical Engineer and the family came back to live in Cheshire, England when she was 8. She was educated at Loreto Convent, Altrincham and completed her secondary education in Paisley, Scotland. She subsequently studied Zoology at St. Andrews University, specialising in Marine Biology. She was married in 1978 and with her husband, who is from Dublin, established a salmon hatchery on the River Lickey, a tributary to the Blackwater.

After selling the fish farm in 1989, Paula qualified as a secondary teacher in Biology and Chemistry. In 1998 she completed her HDip. in Guidance and Counselling and worked as Guidance Counsellor at Blackwater School,

Abstracts

Lifestyle management in Rheumatic and Musculoskeletal diseases (RMDs) – results of a Research Priority Setting Partnership World Café

Megan Curran[1], Kevin Durkan[2], Stacey Grealis[3], Sean McKenna, Clodagh Toomey[1], Kate McCann[4], Norelee Kennedy[1], Audrey Tierney[1]

1. University of Limerick
2. Atlantic Technological University
3. UCD Centre of Arthritis Research
4. Royal College of Surgeons Ireland

Introduction:
Rheumatic and Musculoskeletal diseases (RMDs) are diseases that affect various organs and impact an estimated 100 million people in Europe (1). While pharmacological treatments are the primary method for managing RMDs, the significance of lifestyle medicine approaches has also been emphasised (2). Understanding the relationship between lifestyle factors and RMDs is crucial, but it is equally important to explore the experiences of individuals living with these conditions through participatory research (3). This insight can help inform research priorities for future health and care needs.

Objectives:
To identify key research priorities for RMD lifestyle management with patients, clinicians, and other stakeholders involved in care, advocacy and research of RMD's. Methods: A qualitative study design using a world café methodology. The world café event was held on April 24th at the University of Limerick, followed by an online discussion on June 12th. Participants were adults, English speaking, and were a patient living with an RMD, a carer or family member or friend of someone with an RMD, or clinician or researcher working with RMD's. The tables addressed key questions about lifestyle factors, including enablers, barriers, and future research areas for lifestyle medicine in RMDs. Data was analysed using a thematic analysis framework (4).

Results:
Fourteen people took part in the study. Four main themes were identified: The role of the healthcare system; Role of patient and self; Role of social connection and Aspects impacting lifestyle management. Multiple subthemes emerged including limited healthcare resources, a group medical model approach to lifestyle management delivery, isolation of disease and patient empowerment.

Conclusion:
The world café data provides a rich understanding of the experiences of RMD patients, carers, clinicians and family members of lifestyle management of RMD's, which can be used to inform future RMD research studies and prioritisation of health and care service needs.

PPI in SYNERG-IE Sjögren's Research

Nikki Dunne, Gráinne Tynan, Joan Ní Gabhann-Dromgoole

Royal College of Surgeons Ireland

The RCSI SYNERG-IE programme, funded by the Health Research Board's Applied Programme Scheme (APRO-2023-028) is a five year multidisciplinary project aimed at improving care for people living with Sjögren's through research, education, policy and practice development. A key feature of this project is the integration of Patient and Public Involvement (PPI) at all stages, ensuring that the perspectives of those living with Sjögren's are central to the research process. This presentation will outline the process of PPI in the SYNERG-IE project, including learnings on the establishment of a diverse and inclusive PPI advisory panel.

RCSI and Sjögren's Ireland, a patient advocacy group representing people living with Sjögren's in Ireland, have been collaborating on research, education and awareness raising projects since 2021. Building on this work, the SYNERG-IE research programme was developed in close collaboration with Sjögren's Ireland, during the project's design and grant-writing stages. Sjögren's Ireland contributed to setting the programme's aims and objectives and participated in the panel interview with the funding body, ensuring patient representation from the outset.

To develop the PPI advisory panel, we launched a structured and transparent call for applications, aiming to recruit individuals with diverse experiences of Sjögren's. The selection criteria prioritised clinical variety (from mild to severe symptoms), demographic diversity and aimed to include those balancing their condition with paid work or caregiving responsibilities. Our goal was to ensure representation from groups often underrepresented in research. We will discuss the process of reviewing applications, selecting participants and the considerations taken to ensure a broad range of perspectives were included.

A unique element of the SYNERG-IE programme is the employment of a patient-researcher, who brings first-hand experience of living with Sjögren's into the research process. The involvement of this patient-researcher, combined with the PPI panel and Sjögren's Ireland, enriches the development and execution of the research, ensuring that the patient voice is consistently reflected in both the governance and the implementation of the research.

The presentation will reflect on the early years of PPI involvement and the anticipated role of the panel over the coming years. We will highlight the challenges and opportunities encountered so far and discuss the impact of this model on the future direction of Sjögren's research within the SYNERG-IE programme.