Rhoda Walker
Rhoda is the current chair of the Northern Ireland Rare Disease Partnership and has worked with them for the last four years.

She is passionate about NIRDP's vision that "no one is disadvantaged because of the rarity of their condition" and of course sees first-hand the day to day difficulties faced with her own family's 10-year journey with Ehlers Danlos Syndrome.

Rhoda has over twenty years' experience in community development, working across a wide range of statutory and voluntary organisations. She is keen to use her experience to continue to develop collaborative working to ensure that all available resources are best used to meet community needs.

Vicky McGrath
Vicky is Chief Executive at Rare Diseases Ireland, the national alliance for rare disease patient organisations across Ireland. In her role she is responsible for representing the views and opinions of some 300,000 individuals with rare diseases and their families to ensure that their voice is heard and is central to the development of healthcare services in Ireland.

Vicky's son has an as yet undiagnosed rare disease and her own personal experience managing the challenges that this presents gives her some insight into the individual challenges facing the wider community.

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 practical hands-on experience in both small and large organisations.

Her key experiences include building, integrating and managing teams with diverse backgrounds; developing and executing strategic and operational plans; establishing and building relationships with a variety of stakeholders; and, negotiating agreements and securing funding.

Vicky has a BE, an MSc in Biomedical Engineering, an MBA and is a fellow of BioInnovate Ireland.

Michaela Hollywood
Michaela is 29 and lives in Crossgar. She was born without ears and has spinal muscular atrophy type 2.

Michaela has an academic background in Public Relations, holding both her undergraduate and master's degree from Ulster University. She now works for Muscular Dystrophy UK's Trailblazers on ensuring that young disabled people are not disadvantaged by societal barriers.

Michaela has received a number of accolades for her work to remove societal barriers for disabled people including a Point of Light Award in 2015 from then Prime Minister David Cameron, listed as one of BBC's 100 Women in 2015 and a Spirit of Northern Ireland award.

Most recently, Michaela visited the United States on the Professional Fellows On-Demand 2019 Emerging Leaders Exchange for Northern Ireland and Ireland. This was sponsored by the US Department of State and the International Fund for Ireland and focused on working with marginalised youth.

Dr Naresh Chada
Dr Chada has been the Deputy Chief Medical Officer for Northern Ireland with responsibility for Public Health since April 2019. He had previously been a Senior Medical Officer in the Department of Health since 2001.

His particular areas of interest include health emergency planning, policy for diabetes and development of the public health workforce. Dr Chada qualified as a Doctor from the University of Manchester in 1988 and did his specialist training in Public Health in the West Midlands.

Philip Watt
Since his appointment as Chief Executive Officer in 2009, Philip has been instrumental in improving Cystic Fibrosis Care in Ireland; lobbying for access to new therapies such as Kalydeco & Orkambi and campaigning for better CF facilities in hospitals.

Philip was Chairperson of the Medical Research Charities Group (now HRCI) for 6 years and is currently Chairperson of the Rare Disease Taskforce & Irish Donor Network. A graduate of Trinity College Dublin and postgraduate of the University of Ulster, Philip is currently undertaking a part-time PhD in the Centre for Public Health in Queen's University Belfast.

Dr Amy Jane McKnight
AJ has a keen interest in improving the lives of those living with rare diseases, in particular improving diagnosis, communication, and care pathways.
She is a Reader at the Centre for Public Health, QUB with inherited disease research laboratories embedded within NI's Regional Genetics Centre.

AJ participates on the board of directors for the NI Rare Disease Partnership, helped develop the NI rare disease implementation plan, is part of the Northern Ireland Rare Disease Stakeholder Group, and is rare disease research lead for the recently funded NI Genomic Medicine Centre.

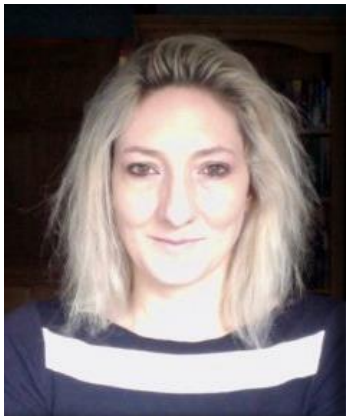
AJ's research team primarily use state-of-the-art tools to identify genomic risk factors for human diseases, plus investigate how each person's genes interact with their environment.

Whole genome sequencing of >1,000 individuals for rare diseases is underway as part of the NI Genomic Medicine Centre, with complementary 'multi-omic' analyses helping to improve the speed and accuracy of diagnosis for local individuals with rare diseases. Moving beyond standard genetic tests provides extra information that increases the opportunity for us to discover the cause of an individual's disease, alongside learning more about the underlying biology and treatment options for each disease. We hold several registries and are actively engaged in making maximal use of complex genomic information.

Dr Suja Somanadhan
Dr Somanadhan is a Programme Director and Assistant professor in Children's Nursing at the UCD School of Nursing, Midwifery & Health Systems.

Dr Somanadhan's clinical background is children's nursing, and she has over 18 years of clinical experience in paediatric health care settings in Ireland mainly focused on metabolic and endocrine disorders, neonatology, and general paediatrics.

Dr Somanadhan is a recipient of a Fulbright Scholar health impact award 2019-2020, On her Fulbright Scholar award, she will examine the integrated care and services of patients and their families with Rare Diseases in the US Health system and use this analysis to learn and improve the provision of expert care for the person and their families living with Rare Diseases in Ireland. She will also explore the programme of work used to engage the Rare Disease patient community throughout the translational science process at the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health (NIH).



Stephanie Duguez
The first time Stephanie heard about rare disease was as a teenager, watching the French Telethon. The Telethon introduced her to neuromuscular conditions, and how genetics could help to understand these diseases and identify therapeutic targets. Ever since then, she has wanted to study neuromuscular disorders, and now work as a scientist in this field.

During her career, she worked in different institutes (LPEH Saint Etienne, France, Genethon France, CNMC Washington DC, Institute of Myology France) on muscle cellular physiology, Duchenne Muscular Dystrophy and Motor Neuron Diseases. She recently joined the University of Ulster's Northern Ireland Centre for Stratified Medicine, where she leads the research group in neuromuscular health.

Their group focuses on how the muscle communicates with other cells in the body, and its role in motor neuron disorders such as Amyotrophic Lateral Sclerosis (ALS), Spinobulbar Muscular Atrophy (SBMA or Kennedy disease) and SMA-IV.

Having worked for the associations created by the French Telethon, Stephanie is very much aware that rare diseases collectively are frequent, and that solidarity is a key point to fight rare diseases. She also understands the necessity to make people aware of rare conditions. Stephanie was introduced to NIRDP through fellow researchers in the area and is now a member of the board of directors. She is convinced that the work done by this group is crucial to improving patient care in Northern Ireland.

Derick Mitchell, PhD
Derick is the Chief Executive Officer of IPPOSI. Derick has a strong background in research, strategy and advocacy from over 12 years' experience spanning a number of leadership roles in research and multi-stakeholder engagement in Ireland and at the EU-level.

Derick has a strong track record in collaborating to influence healthcare policy with the goals of enhancing research infrastructure, increasing patient involvement and improving access to treatments. He believes in the power of a united voice when it comes to patient advocacy and the central role of patients and their representative organisations in healthcare and research.

Derick leads IPPOSI's involvement in the European Patients Academy (EUPATI), an initiative which is training patients to become involved in the medicines R&D process, and has spread the IPPOSI public-private partnership model to over 20 countries. He was instrumental in the development of the IPPOSI (EUPATI-based) patient education programme in Ireland.

Derick serves on the advisory boards and steering committees of a number of health-related initiatives including Health Innovation Hub Ireland, DataSavesLives.eu, EHealth Ireland, HIQA, UCD Research Ethics Committee, as well as the Medical & Life Sciences Committee of the Royal Irish Academy. He is also chairperson of the Scientific Advisory Board of the HRB-Trials Methodology Research Network (HRB-TMRN).

Derick holds a Bachelor of Science degree in Biotechnology from NUI Galway and a PhD in Molecular Medicine from University College Dublin. Outside of IPPOSI, Derick spends his free time attempting to influence his two young daughters.

Dr Julie McMullan
Julie is a post-doctoral research fellow in the Centre for Public Health at Queen's University.
She is carrying out research around communication and education of rare diseases.

Julie enjoys meeting the people 'on the ground' and hearing their stories and experiences. Julie is keen that the work she does raises awareness of rare diseases as well as contributing to improving care in Northern Ireland and further afield.

Martha Killilea
Martha completed an undergraduate degree in Public and Social Policy at NUI Galway in 2016, she continued her studies in NUI Galway and graduated with a master's in health economics in 2017.

Martha is currently working with the HRB Primary Care Clinical Trials Network Ireland and PPI Ignite @ NUI Galway where she coordinates and supports screenings of 'The Patient Effect'. Martha also supports other activities including PPI, conference and education events, website management, and contributes to meetings/conferences and network promotion.

Dr Kerry Moore
Kerry is a research scientist, working with university-based members as a PhD student, research associate and now as a post-doctoral research fellow at Queens University Belfast.
She has extensive experience of working with patients, overseeing research projects and teaching. She has also worked in diagnostic genetics and was a research associate at the Northern Ireland Cancer Registry.

Kerry aims to help build an informative research resource on the NIRDP website while developing a library of practical information for patients, carers, scientists and healthcare professionals alike.
She is determined to enable those in Northern Ireland with a rare or hard to diagnose condition to tell their story through the 'Share Your Rare' project and is collaborating with the Patient and Client Council and the Public Health Agency to create

training courses to improve patient and public involvement in transforming health and social care. Kerry is also representing the NIRDP in the current review of Neurology services and has a seat on the Neurology Review Team and on both the Neurology Care Coordination Workstream and the Neurology Coproduction workstream.

Kerry has three young children to keep her busy in her spare time.

Gillian Cassidy, BTh Gillian is a director of NIRDP, Chairperson of 22q11 Northern Ireland, and works in the City Hospital 22q Transition Clinic as the Patient Advocate Coordinator. She runs a 22q Facebook page and support group.

Gillian is a mum of 4 young children — her eldest daughter Lucia lives with 22q11.2 deletion Syndrome. She also lives with a neurological condition and a chronic skin disease. Gillian is an advocate for rare diseases, believes that knowledge empowers, and people are stronger together!

Professor Ian Young
Professor Young is currently Chief Scientific Advisor to the Department of Health and Director of Research and Development for Health and Social Care.

In addition, he is Professor of Medicine at Queen's University Belfast, where he was also Director of the Centre for Public Health from 2008-2014, and Deputy Medical Director and Consultant Chemical Pathologist at Belfast Health and Social Care Trust.

Professor Young's main clinical and research interests are in biochemical aspects of nutrition, particularly in relation to the disease prevention. He is an author of over 350 published research papers and has obtained over £30 million in research income. He is Chair of the Scientific Division of the International Federation for Clinical Chemistry and Laboratory Medicine, the world's leading laboratory medicine organization, and Associate Editor of Clinical Chemistry, the journal of the American Association for Clinical Chemistry.

He is a member of the UK Scientific Advisory Committee on Nutrition, and the Scientific Advisory Board of the National Institute of Biological Standards and Controls

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Debby Lambert
Debby Lambert, MSc, CCGC, Information Scientist and Orphanet Ireland Project Manager, National Rare Disease Office, Mater Misercordiae University Hospital, Ireland.
Debby is an MSc trained genetic counsellor, registered in Europe and Canada, and has an MSc in Epidemiology and Biostatistics.

After 20 years of clinical practice as a genetic counsellor, she is now an information scientist in the National Rare Diseases Office. When she is not at the office, Debby is also the chair of the professional registration board for genetic counsellors in Europe, the EBMG.

In her spare time, she is a co-investigator on the University of British Columbia's GENCOUNSEL genetic counselling research project, funded by Genome Canada. Her research interests are rare and genetic diseases in populations, and genetic counselling practice.