



A huge Thank You to our amazing sponsor Vifor who generously provided us with an unrestricted grant for the purpose of running this conference.



Thank you to all of our Speakers, our Organizing Committee and all of the Patients and attendees.

Agenda for 2019 All Ireland Vasculitis Conference

<p>Friday 4th October</p> <p>4pm Arrival at Clare Lodge</p> <p>6pm Supper</p> <p>7.30 pm AGM</p>	<p>Medium Vessel vasculitis – Dr Mike Clarkson</p> <p>Large Vessel Vasculitis – Dr Lorraine O'Neill</p> <p>12. 15 Consultant Panel (all above) VINE and ERNs why are these important to us and how can we help.</p> <p>12.45 Roundup of morning's subjects, observations – Patricia Ryan</p> <p>1pm Lunch</p> <p>2pm Drugs and treatments – Hospital Pharmacist (Dawn Davitt, Tallaght Hospital) Interactive session</p> <p>– UKIVAS updates on drug treatments of Vasculitis, Dr Eleana Ntatsaki, Consultant Rheumatologist, remote presentation from Ipswich Hospital.</p>	<p>4pm NI Vasculitis Survey – Dr AJ McKnight QUB,</p> <p>AVERT study update – Dr Jennifer Scott</p> <p>5pm Close</p> <p>6pm Dinner</p>
<p>Saturday 5th October</p> <p>10am Welcome by Chairperson</p> <p>10.15am Opening Address - Baroness Margaret Ritchie</p> <p>10.30am What is Vasculitis – The lived experience by people living with different types of Vasculitis</p>		<p>Sunday 6th October</p> <p>10am Laughter Yoga</p> <p>11.15 Break</p> <p>11.30 Mindfulness</p> <p>12.30 Close</p> <p>1pm Light Lunch</p>
<p>11.15am Break</p> <p>11.30am Breakout Sessions – Small Vessel Vasculitis – Prof Mark Little</p>	<p>3pm What we can do for ourselves Diet - Rachel Lynch,</p> <p>Reaching out to other agencies – Tim Whymark</p> <p>3.45 Break</p>	<p>2pm Home</p>

2019 Conference Speakers



Baroness Margaret Ritchie has always been a staunch supporter of Vasculitis Ireland Awareness, helping us in the early days make links with the various Minister's of Health in NI. She became a SDLP councillor in 1985 and was elected to the Stormont Assembly as minister for Social Development in 2003. She led the SDLP party from 2010-2011 and was MP for the South Down area in Westminster from 2010-2017. Since then she has continued working and lobbying for small local groups and indeed was involved in planning the NI Vasculitis Survey with the NI Behcet's UK group. Margaret's work has been recently recognised by being given a peerage in Theresa May's resignation honours list and she is due to take up her seat in the House of Lords later this month.



Ronan Brennan.

I have Wegener's Granulomatosis - Granulomatosis with Polyangiitis Vasculitis, - that's a mouthful!

I was diagnosed in 2016 by Professor Mark Little

I am 48 years old I come from an I.T and software background.

I currently work part time for myself and mix it with being a full time carer for my two children who have autism.

I enjoy traveling and reading.



Fionnuala Mc Kinney is 60 years old, and lives in the Seaside town of Warrenpoint. Fionnuala has been ill since childhood with bowel, skin and mucus membrane problems. Throughout childhood she had problems with oral ulceration that made eating painful, and lots of problems with bleeding that left her tired and anaemic. Fionnuala is also dyslexic.

Despite these problems, she trained to be a Nurse in the RVH in Belfast in the 70's and then went on to become a Midwife and Health Visitor, working in Ireland and England.

In her forties she studied to be a Family Therapist, but at 48 years of age she had to stop work due to illness. However, in recent years she has been able to do some work for a charity working 5 hours a week, which although sounds very little is enjoyable and challenging.

Fionnuala and Ann Gough facilitate the Northern Ireland Bechet' group. Fionnuala also enjoys spinning, weaving, painting and making lace as well as playing the flute and walking her dog.



Prof. Mark Little. After graduating from medicine in Trinity College Dublin 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 has published over 100 peer-reviewed manuscripts and was awarded the President of Ireland Young Researcher Award in 2012, when he returned to Ireland to become the Fottrell Professor of Nephrology in TCD, and consultant Nephrologist in Tallaght and Beaumont Hospitals. He is a co-founder and coordinator of ERN-RITA, the rare immune disorders European Reference Network, lead of the European Vasculitis Society Registry initiative, chair of the Vasculitis Ireland Network and co-founder/co-chair of UKIVAS, the vasculitis society of UK and Ireland.



Dr Mike Clarkson (MB, BAO BCh, University of Dublin, Trinity College 1994) undertook postgraduate training in Internal Medicine and Nephrology in Dublin 1994-2001 and was awarded an MD by thesis in 2002. He completed a clinical and research fellowship at The Brigham and Women's Hospital and the Massachusetts General Hospital, Harvard Medical School, Boston (2001-2004). He was appointed to the staff of the Brigham and Women's Hospital before taking up his current position in Cork University in 2005. His clinical interests include small vessel vasculitis and renal transplantation. His research interest include Phase II / Phase III clinical trials in vasculitis.



Dr. Lorraine O'Neill is a graduate of the National University of Ireland Galway. Having completed higher speciality training in both Rheumatology and General Internal Medicine she undertook an MD with University College Dublin on the pathogenesis of vascular inflammation and remodelling in giant cell arteritis. She then completed a vasculitis fellowship in the University of Oxford and thereafter took up a consultants post in Oxford where she practiced for 5 years before returning to St Vincent's University Hospital as a Consultant Rheumatologist earlier this year. Her interests include giant cell arteritis and connective tissue disorders.



Dawn Davin is a Senior Clinical Pharmacist in Tallaght University Hospital (TUH) and Clinical Lecturer with the School of Pharmacy and Pharmaceutical Sciences, Trinity College, Dublin. She has been specialising in renal pharmacy for over ten years. She is a graduate of Trinity College Dublin where she completed a BSc in Pharmacy and an MSc in Hospital Pharmacy. She has also completed an Independent Prescribers course for Pharmacists at Queen's University, Belfast and Project Management in Quality Improvement Methodology at TUH. She is chairperson of the Hospital Pharmacists Association of Ireland's Special Interest Group in Renal Pharmacy and a member of the UK Renal Pharmacy Group. Currently, she works as a member of the multidisciplinary renal team at TUH providing patient care to renal patients. Aside from her renal interest, she has a keen interest in prescribing practice, education and quality improvement.



Dr. Eleana Ntatsaki, I am a Consultant Rheumatologist at Ipswich hospital NHS Trust and an Honorary Senior Lecturer at University College London. I first joined Ipswich hospital in 2006 and after completing my training in the East of England and London re-joined the Rheumatology team as a permanent NHS Consultant in 2016.

I am a general rheumatologist with a specialist interest in ultrasound for early arthritis, Connective Tissue Disease (systemic lupus erythematosus, vasculitis) and Integrated Medicine. I run a dedicated ultrasound and CTD clinic and I am the East Anglia Rare Autoimmune Disease lead for Ipswich hospital.

I am a very keen educator, awarded with the "Educator of the Year" distinction by Health Education East of England and I am a Fellow of the Higher Education authority. I have a Master's degree in Medical Education, and I am the Educational supervisor for Rheumatology trainees in Ipswich Hospital.



Rachel Lynch is a support group facilitator with Fibrolreland She has a degree in Visual Communication and Psychotherapy. She worked as a graphic designer for 12 years before being diagnosed with Fibromyalgia, Scheuermann's Disease and Hypermobility. In later years she discovered she also had Lyme disease. Having retrained as an Adult Educator and Psychotherapist, her current role involves working in various community settings helping people with mental health and educational issues. She is a EUPATI Fellow and has given the patient perspective at the international Conference on Pharmacodepidemiology, NCPE conference on Pharmacoeconomics in the Irish Healthcare Setting and the IPPOSI 10 year anniversary conference. She is a member of the teaching Council of Ireland and the Irish Association of Counsellors and Psychotherapists



Tim Whymark is our Website Officer. He was diagnosed in 2017 with Granulomatosis Polyangiitis Vasculitis and has seen significant life changes since his diagnosis, including having to medically retire from work. He is 50 years old and lives in Co. Roscommon



Dr Amy Jayne (AJ) McKnight has a keen interest developing excellent research and improving resources for individuals living and working with rare diseases. AJ has worked for rare disease communities for ~40 years, more recently extending this interest into formal research at QUB where we are building an enthusiastic and productive rare disease research team. AJ also runs busy NI molecular research laboratories for inherited diseases using a range of approaches. She has participated, led, or helped lead the robust discovery of hundreds of loci for rare diseases and complex polygenic traits, including identifying novel risk factors and biological networks. Together with colleagues, she has helped develop powerful approaches to data analysis and data integration, which led to the identification of novel biological pathways for disease.



Dr. Jennifer Scott is a Nephrology Specialist Registrar, and a Wellcome-HRB Irish Clinical Academic Training (ICAT) fellow, from Galway (Ireland). She has just commenced her PhD at the ADAPT-SFI centre (Trinity College Dublin), under the supervision of Professor Mark Little. She is very excited to explore the environmental factors that trigger ANCA Vasculitis relapse, using novel data analytic approaches.



Michelle A. Major, founder of The Sunshine Project is a leading expert in laughter & happiness habits. Michelle was the first Certified Laughter Yoga Teacher in Northern Ireland. Michelle is also an NLP Practitioner/Coach, Reiki Master/Teacher, and Corporate Coach/Trainer. Michelle is a popular inspirational and motivational speaker at events and conferences.

"It is my vision to spread joy, happiness and laughter habits to every corner of Ireland. I have dedicated over 14-years of my life to discovering what makes people happy. It is my mission to empower others with the positive tools that have transformed my life so that they too can lead a happier, more joyful life."

With over 14 years experience coaching & leading teams in the corporate world, Michelle has a strong understanding and knowledge of people, their learning styles, and how to unlock pure potential to create results.



Veronica Ellis is a qualified teacher with over 25 years' teaching experience. She has taught a variety of ages and groups of children and young adults both within mainstream and special education, including children with severe learning difficulties and with emotional and behavioural difficulties.

Her motivation in teaching mindfulness is to create a space where people feel safe and valued and where they can mindfulness practices in a relaxed and comfortable setting. She is committed to teaching children and adults how to integrate mindfulness into everyday life.

She is motivated to teach people how to still their minds and enrich their lives by developing a curiosity and deep appreciation of life.

Through the practice of mindfulness, she helps create working environments where people can flourish and where workers, teachers, parents, young people and children can develop more harmonious, meaningful and connected relationships

2019 Organizing Committee



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