

IHRF Agenda

Advancing Genomics in Ireland

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improve
health

November 12th, 2020 Webinar via Zoom
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11.00am	Welcome from event Chair Eibhlin Mulroe ; CEO, Cancer Trials Ireland
11.05am	Key themes from discussion paper on genomics in Ireland Dr Avril Kennan ; CEO, Health Research Charities Ireland
11:10am	Investing in an Irish public genome project Prof John Greally ; Director, The Center for Epigenomics, Albert Einstein College of Medicine, New York City
11.40am	Panel discussion followed by audience Q&A Panellists: Eileen O'Sullivan ; Patient Representative Prof Walter Kolch ; Director, Systems Biology Ireland and Precision Oncology Ireland Dr David Kavanagh ; Director of Clinical Partnerships, Genuity Science Dr James O'Byrne ; Consultant in Biochemical/Clinical Genetics, The Mater Hospital
12.30pm	Meeting close



Ms Eibhlín Mulroe, MBA, Chief Executive, Cancer Trials Ireland

In June 2015, Eibhlín was appointed CEO of the Cancer Trials Ireland (formerly ICORG) in June 2015 and manages a cross functional team including clinical operations, Data & Statistics, Quality and Pharmacovigilance.

She has a BSocSc Hons from Queens University Belfast and is an MBA graduate from the Smurfit Business School, University College Dublin.

In her early career Eibhlín worked in Irish Politics and then the NGO sector. In July 2007, she became the first CEO of the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI) and Chair of a Task Force in the European Patient Academy for Therapeutic Innovation (EUPATI). Eibhlín was appointed by the Irish Minister for Health to the Department of Health Steering Group on Rare Disease Policy in 2010, she represented patients on the Health Information and Quality Authority (HIQA) Research Ethics Advisory Board, HIQA, HTA Advisory Board and was a member of the HSE Patient's Forum. She served as the patient representative on the Legal Consultative Panel of the Irish Medicines Board (now HPRA). Eibhlín led IPPOSI to partake in 2 EC Research Consortiums, BBMRI and EUPATI, the latter is a unique initiative to develop an EU Patient Academy.

Eibhlín is a member of the following Boards/Committees.

- Governance Committee of Blood Cancer Network Ireland (BCNI).
- Steering Group of the Irish Health Research Forum
- Advisory Board of the Cork Clinical Research Centre
- Mindful Nation

Eibhlín recently stepped down from the HSE's Ehealth Board which she served on since it's inception.



Dr Avril Kennan is CEO of Health Research Charities Ireland (HRCI)

Dr Avril Kennan is CEO of Health Research Charities Ireland (HRCI), an organisation that supports a community of 40 charities to engage in all aspects of health research. She oversees a partnership with the Health Research Board to run a funding scheme for patient-focused research projects, the management of the Irish Health Research Forum and the support of a patient and public involvement (PPI) 'Shared Learning Group' for research charities.

Avril's PhD and subsequent lab experience are in the field of molecular genetics. In previous roles in DEBRA Ireland and DEBRA International, she drove a range of international initiatives, including the management of a network of over 200 clinicians and patients to develop evidence-based clinical guidelines and the establishment of an international patient registry.



Professor John Greally; Director of the Center for Epigenomics, Albert Einstein College of Medicine, New York City.

Dr John Greally is a Professor in the Departments of Genetics (Division of Computational Genetics), Paediatrics (Division of Genetics) and Medicine (Division of Haematology) at the Albert Einstein College of Medicine, where he has been on faculty since 2001.

Dr Greally received his honours degree in Medicine from the National University of Ireland in Galway (NUIG) in 1988, subsequently moving to the Children's Hospital of Pittsburgh for Paediatrics residency and Yale University in 1993 for subspecialty training in Clinical Genetics. Since his clinical training, he focused on basic science research, receiving his PhD degree in 1999 from NUIG.

Dr Greally's research is in the area of epigenomic regulation of the genome, and its dysregulation in disease. Dr Greally is the founding director of the Einstein Center for Epigenomics, where the development of computational resources to manage and analyse complex data sets from massively-parallel sequencing has been a priority from the establishment of the Center in 2008. He serves on the editorial boards of the journals PLOS Genetics, Genomics and Epigenetics and Chromatin, and is involved with the New York Genome Center.

His research includes studies of the epigenetic regulation of cell differentiation and transcription-targeted cytosine methylation, and epigenetic abnormalities in human diseases such as autism spectrum disorder, osteosarcoma, type II diabetes mellitus, hepatitis C virus and toxoplasma infections. He also performs clinical duties at the Children's Hospital at Montefiore as a Clinical Genomicist, seeing patients who have been tested with new genome-wide technologies.



Eileen O'Sullivan, Patient Representative.

Eileen is a breast cancer patient/survivor (BRCA1 carrier) and patient advocate with a specific interest in supporting and contributing to patient involvement in cancer research across the wider cancer ecosystem. Eileen is also a strong proponent of the benefits of effective communication of evidenced based nutritional and exercise information to cancer patients throughout their individual cancer journey and regularly publicly challenges misinformation and pseudoscience that may result in harm for patients. Eileen sits on the Irish Cancer Society Research Advisory Committee and the HIQA Patient Data Advisory Committee.



Walter Kolch is Director of Systems Biology Ireland and Precision Oncology Ireland

Trained as an MD he worked in experimental clinical research, pharmaceutical industry, and basic biological research. Before moving to Dublin in 2009 he held a Chair for Molecular Cell Biology at the University of Glasgow, and was a Senior Group Leader at the Beatson Institute for Cancer Research in Glasgow, Scotland. He is best known for his work in oncogene signal transduction, proteomics and systems biology. His current research interest focuses on understanding how biochemical signal transduction networks specify biological decisions, and how systems biology approaches can advance precision medicine. He serves on several editorial boards and advisory boards, and is a Fellow of the Royal Society of Edinburgh and a Member of the Royal Irish Academy.



David Kavanagh, PhD, Director of Clinical Partnerships, Genuity Science

David leads the clinical partnerships group at Genuity Science. The partnerships function is a key external-facing group with responsibility for establishing large-scale collaborations with clinical and academic institutions throughout the world. David provides leadership, strategic direction and day-to-day coordination of activities for strategic partnership relationships with external entities across a myriad of disease cohort populations.

Within the function, the partnerships team is principally responsible for establishing and managing Genuity's clinical and academic partnerships at an institutional level while the program team supports the cross-functional development, delivery and co-ordination of Genuity's cohort research programs and works with our collaborating clinicians, biobanks and researchers to ensure successful delivery of each program.

David has extensive experience in life sciences and has held leadership roles in several high-growth academic and commercial life science organizations including Systems Biology Ireland, located at University College Dublin and CompareNetworks, a San Francisco-based life science marketing company. David's areas of specialty include life science innovation and commercialization, operational & high performing team development in life science start-up environments, genomics, systems biology, connected health, life science marketing, life science text mining and healthcare consulting.

David holds a PhD in Biochemistry from University College Dublin.



Dr James O'Byrne MB BCH BAO, BA mod (Biochem), PhD, MRCPI, Cert Med Gen (UK Path), Consultant in Clinical/Biochemical Genetics

Dr James O'Byrne is a Consultant Clinical/Biochemical Geneticist at the Mater Misericordiae University Hospital (MMUH).

Primarily based in the The National Centre for Inherited Metabolic Disorders-Adult Unit, he is also involved in supporting the development of a number of genetic initiatives in ophthalmology, cardiology, neurology and GI cancer.

Dr O'Byrne's special interests include the organelle diseases, Lysosomal Storage and Peroxisomal Disorders and he holds a PhD from the Karolinska Institute in Peroxisomal Disorders and Fatty Acid/ Bile Acid Metabolism. His research interests include treatable genetic conditions and is the Principal Investigator in Ireland on a phase 3 clinical trial for a novel therapy for Fabry Disease.

Dr O'Byrne graduated from Medical School in Trinity College Dublin (TCD). He attained Certificate of Satisfactory Completion of Specialist Training in Clinical/Biochemical Genetics from the Royal College of Physicians of Ireland (RCPI). Dr O'Byrne also holds a membership examination in paediatrics from RCPI and a basic science degree in Biochemistry from TCD. Supported by the Richard Steevens scholarship fund, he completed a fellowship at British Columbia Children's Hospital and Vancouver General Hospital, on treatable genetic disorders that result in intellectual disability.

Dr O'Byrne lectures in the fields of Clinical Genetics/Genomics, Rare Diseases and Metabolic Medicine on a number of teaching modules in RCPI, TCD and University College Dublin and was recently invited to speak at the St Lukes Symposium 2020: Advanced Masterclass on "Genomic Medicine: a Game Changer".

About the Forum

The Irish Health Research Forum (IHRF) was established by Health Research Charities Ireland (formerly the Medical Research Charities Group) on foot of their major report 'The Health Research Landscape in Ireland: What Researchers Say' in 2014. It continues to be led and managed by the HRCI and is nationally recognised for the quality and value of its events.

The Forum considers key health research issues, identifies constructive solutions and seeks consensus at twice annual Forum meetings of Health Research stakeholders with the goal of working towards the realisation of positive effects for health research, health care and ultimately the patients and public.

The IHRF Steering Group comprises of stakeholders with significant profile in health research and facilitates a coordinated approach positively influencing the health research environment in Ireland.



The IHRF is a partnership of organisations and stakeholders that aims to influence health research in Ireland.

Steering Group

The role of the Steering Group is to execute the work of the forum, to identify topics and issues for consideration and prepare for the Forum meetings.

Prof Brendan Buckley, Chairperson IHRF Steering Group. Honorary Clinical/Adjunct Professor -UCC &UCD

Prof Eilish McAuliffe, Professor of Health Systems, School of Nursing, Midwifery and Health Systems, UCD

Dr Jacinta Kelly, Chief Executive, National Children's Research Centre

Dr Avril Kennan CEO, Health Research Charities Group

Dr Catherine Gill, Programme Manager in Post Award and Evaluation, Health Research Board (HRB)*

Prof Kevin P Balanda, Director of Research and Information, The Institute of Public Health Ireland

Dr Conor O'Carroll, Independent Consultant on Research and Higher Education policy and funding

Dr Fionnuala Keane, Chief Operating Officer, Health Research Board - Clinical Research Coordination Ireland

Philip Watt, CEO, CF Ireland

Julie Naughton, Irish Research Staff Association

Peter Brown, Interim Director, Irish Research Council

Caitriona Dunne, Head of Advocacy, Fighting Blindness

Hazel Ann Smith, Chair, Irish Research Nurses Network

Eibhlin Mulroe, Chief Executive, Cancer Trials Ireland

Dr Geraldine Canny, Head of the Irish Marie Skłodowska-Curie Office

Suzanne McCormack, CEO, Irish Thoracic Society and Chair, Health Research Charities Group

Dr Ana Terres, Head of Research and Development, HSE

Dr Mark White, Vice-President for Research, Innovation & Graduate Studies, Waterford IT

Finian Hanrahan, Scientific Programme Manager, Science Foundation Ireland (SFI)

*HRB have Observer status on the Steering Group.



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