Rare Disease Day 2019
Bridging health & social care

Agenda

9.15am **Registration - Tea/Coffee**

10am **Session 1: Setting the Scene**

- Welcome address: Vicky McGrath, CEO, Rare Diseases Ireland

10.05am **A parent's story:** Alan Finglas, Founder, MSD Action Foundation

10.15am **Update on the Rare Disease Plans**

- Vicky McGrath, CEO, Rare Diseases Ireland
- Dr Miriam McCarthy, Director of Commissioning, Health & Social Care Board, Northern Ireland

10.45am **Q&A**

11am *Tea/Coffee break*

11.20am **Session 2: Patient Experience of Health & Social Services**

- Clare Hudson, Project Manager, HSE: Your Voice Matters
- Linda Craig, Regional Lead, 10,000 More Voices, Health & Social Care, Northern Ireland
- Fiona Aherne, Advocacy & Policy Officer, DEBRA Ireland & Emma Fogarty, Patient Ambassador, DEBRA Ireland

12.05pm **Q&A**

12.20pm **Session 3: Panel Discussion - Co-ordinated Health & Social Services**

- Avril Daly, Chair, Rare Diseases Ireland; Vice President EURORDIS; CEO of Retina International (panel discussion Chair)
- Anne Lawlor, Chair, 22Q11 Ireland Support Group
- Orla O'Brien, CEO, LauraLynn
- Tanya Boggs, Project Officer, Stronger Together, Northern Ireland Rare Disease Partnership

1.00pm **Closing remarks**

- Vicky McGrath, CEO, Rare Diseases Ireland

1.10pm **Meeting close**

Session 1: Setting the Scene

The 12th annual Rare Disease Day focuses on bridging the gaps in the coordination between medical, social and support services in order to tackle the challenges that people living with a rare disease and their families face every day. Rare Disease Day 2019 is an opportunity to be part of a global call on policy makers, healthcare professionals, and care services to better coordinate all aspects of care for people living with a rare disease.

Vicky McGrath 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 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 leadership roles in both small and large organisations and her key experiences include: building, integrating and managing teams with diverse backgrounds; developing and executing strategic and operational plans; establishing and building relationships with all stakeholders; negotiating agreements and securing funding.

Alan Finglas, Founder & Research Manager, MSD Action Foundation/ SavingDylan.com (Est. 2015). Alan's son Dylan (6) was diagnosed with Multiple Sulfatase Deficiency in late 2014 at which point all meaningful research had ground to a halt. Alan represents MSD Action Foundation (MSDAF) on the Rare Disease Task Force and on the board of the Medical Research Charites Group. Alan was a recipient of a 'Champion of Hope Award' from Genetic Disorders UK in 2017 in conjunction with Global Genes. He has recently been invited to become a patient board member of MetabERN and he is part of a working group of MetabERN on lysosomal storage disorders. There are now potential therapies on the horizon for children suffering from MSD as a result of research initiated by MSDAF.

Miriam McCarthy is the Director of Commissioning at the Health and Social Care Board, having taken up post in December 2017. Miriam is a medical doctor trained in both general practice and public health. Miriam has extensive experience in policy and strategy development. As a senior civil servant during the period 1998-2011 she led many high profile service reviews which have shaped the direction of acute and specialist hospital services in Northern Ireland. In her role as Director of Commissioning Miriam provides leadership to improve patient care, ensure sustainable services and transform the delivery of care. Miriam has also been closely involved with the work of the National Institute for Health and Care Excellence (NICE) and was a member of a Technology Appraisal Committee between 2013 and 2017.

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Session 2: The Patient Experience

The patient perspective in Northern Ireland will be provided by the 10,000 Voices Campaign, while the HSE's Your Voice Matters Campaign will shed light on patient experiences of health and social services in the Republic. This session will also include a patient case study that describes one organisation's efforts to identify how best to access co-ordinated services on behalf of its members.

Linda Craig, Regional Lead for Patient Client Experience, Public Health Agency, Northern Ireland. Linda is responsible for exploring the service user experience and support trusts in service improvement strategies to enhance the patient client experience. A key part of this work is an initiative called 10,000 More Voices which adopts a robust methodology to gather and analyse qualitative data through the patient narrative. Patient client experience has been central to Linda's career as a nurse. Following a primary degree in Anatomy, Linda pursued a post graduate diploma in Adult Nursing in 2001 and commenced nursing in Emergency Departments in 2003. Emergency Departments have been the focus of her clinical experience for over 15 years where she has worked as a nurse practitioner, clinical nurse educator and lead nurse.

Clare Hudson, Project Manager, Patient Narrative Project, Clinical Strategy and Programmes Division, HSE. Clare has been the Project Manager for the Patient Narrative Project since October 2016. She is a Speech and Language Therapist with a BSc in Clinical Speech and Language Studies from Trinity College Dublin and an MSc in Language and Communication Impairment in Children from the University of Sheffield. During her 20 years in clinical practice and management in the UK and Ireland Clare has worked to enable people to have their voices heard. The patient Narrative Project provides opportunity for Clare to enable the voices of many patients, health service users and their families across Ireland to be heard to influence the design and delivery of models of integrated care.

Fiona Aherne, Advocacy and Policy Manager, DEBRA Ireland. DEBRA Ireland is the national charity, set up over 30 years ago, to support patients and families affected by Epidermolysis Bullosa (EB). Fiona has a degree in Social Care and over 10 years experience working in homeless services. In 2013 she moved to DEBRA Ireland as a Family support worker. After a number of years in that role she moved to Advocacy where she has since lobbied for access and services for families living with EB. Fiona represents DEBRA Ireland on the national Rare Disease task force .

Emma Fogarty is the Patient Ambassador of DEBRA Ireland and lives with the recessive dystrophic form of Epidermolysis Bullosa (EB). She has headed up numerous awareness campaigns since taking up her role as ambassador 10 years ago and has recently campaigned for awareness of EB amongst policy makers and politicians. She played an integral role in securing HSE funding for Irelands first EB Outreach Nurse in 2016. Emma continues to campaign for more adequate services for patients and families living with EB. Emma lives in Abbeyleix in Co Laois with her family.

Session 3: Panel Discussion

'Co-ordinated Health and Social Services'

Avril Daly is CEO of the patient-led global NGO, Retina International and is responsible for the implementation of the organisation's strategic plan. This includes working with all stakeholders to build consensus on the development of policy initiatives focused on generating support for retinal research to promote innovation for unmet medical need and the provision of training and educational tools that enable patients to advocate with confidence for the needs of the Retina community at large. Avril was CEO of the Irish NGO, Fighting Blindness for eight years and is the current Chairperson of Rare Disease Ireland. In 2009 she was elected to the Board of Directors of Rare Disease Europe - EURORDIS, and has been the organisations Vice-President since 2012.

Anne Lawlor is a founding member and chairperson of the 22q11 Ireland Support Group. The organisation, set up in 2007 supports Irish families affected by 22q11.2 deletion syndrome, the most common genetic condition after Down Syndrome. Dedicated to raising awareness of 22qDS as a poorly understood and under-recognised condition, Anne completed a Masters in Management of Community and Voluntary Groups and actively works for integrated care for those affected by 22q and other rare conditions. A recipient of a 2017 Global Genes Rare Champion of Hope Award Anne has also accepted two Charity Impact Awards on behalf of 22q11 Ireland. She lives in Dublin with her daughter Áine aged 35 who was diagnosed with 22qDS aged 15.

Orla O'Brien, CEO, LauraLynn. Orla joined LauraLynn Children's Hospice in April 2018, having spent almost 30 years working in children's healthcare. Orla qualified as a Registered Children's and General Nurse in 1989 and subsequently as a paediatric intensive care nurse before taking on management and leadership roles. Orla was also previously Chief Operations Officer in the Children's Hospital Group, Deputy Director of Nursing in Our Lady's Children's Hospital and Project Manager in the Department of Health. Orla holds both a BSc in Nursing Management (Hons) and a Higher Diploma in Healthcare Risk Management (Hons) from UCD; a Diploma in Human Resource Management from the NCI; a Diploma in Physics and Chemistry from the RCSI; and most recently an MSc in Leadership and Management (Hons) from the RCSI Institute of Leadership.

Tanya Boggs was appointed as project officer for the "Stronger Together" pilot project with Northern Ireland Rare Disease Partnership in November 2017, returning to NI to take up this part time position. She has found the challenges of supporting people with rare conditions hugely varied and challenging. Fortunately her previous 25 years' experience as a nurse has been immensely helpful in traversing the health care system while advocating for those with rare disease. Returning to NI after a long absence to undertake this job with NIRDP has been lifechanging, and she looks forward to continuing to champion healthcare for all, but especially those most vulnerable.

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