Annual General Meeting 2018

Saturday, September 22\textsuperscript{nd}, The Killeshin Hotel, Portlaoise

PROGRAMME

\textit{Morning Presentations for Parents/Carers}

9.00 – 9.30 am: Sign in and refreshments
9:30 - 9:45 am: Welcome and Introductions

\textbf{OPTION 1}

\textbf{Early Intervention/Children/Teenager information}

9.45 – 11.15 am
Speaker and session details to be confirmed.
11.15 – 11.30 Break and Refreshments.

11.30pm-1.00pm

‘Supporting families during their child’s early years’

Presentation by:

Eimear Collins,

Early Development Officer, Down Syndrome Ireland.

This session will explore how families can support the development of young children with Down syndrome. It will discuss how Down Syndrome Ireland and local branches can best support families, and Eimear will facilitate a discussion on family’s experiences of early intervention services.
OPTION 2

Teenagers/Adult information

9:45 – 11.15 am

Presentation by:

Professor. Mary McCarron,

Dean of the Faculty of Health Sciences,
Professor of Ageing and Intellectual Disability,
Director of the Trinity Centre for Excellence in Ageing and Intellectual Disability,
Trinity College, Dublin 2.

‘Latest insights on Ageing in People with Down syndrome’

Tremendous gains in the life expectancy of adults with Down syndrome mean it’s not uncommon now for people with Down syndrome to live into their 50’s, 60’s and 70’s. An incredible success story and one that we should celebrate as more and more people with Down syndrome experience the many exciting milestones that accompany growing older. That said old age can also bring unexpected challenges including some conditions of ageing that are well known in the general population appearing at a younger age. While we can’t stop ageing, there are opportunities to modify the number and impact of age related conditions and maximize the chances of people with Down syndrome living well in old age. It is important that people with Down syndrome their families and caregivers are adequately prepared and learn about the opportunities and challenges that may lie ahead. There may be no fountain of youth but for many years we can all enjoy a happy and healthy older age.

11.15 - 11:30am Break and Refreshments
11.30am – 1.00pm

Presentation by:

**Christy Lynch,**

Chairperson, Taskforce on Personalised Budgets.

Christy Lynch was the Chairperson of the Government’s Task Force on Personalised Budgets, which was established in September 2016 by Minister of State for Disability Issues Finian McGrath to look at how personalised budgets could work as a funding mechanism for people with a disability, providing them with greater choice and control over the services and supports they receive. The Taskforce’s report “Towards Personalised Budgets for People with a Disability in Ireland” was published in July 2018. The report recommends the Government establish two-year pilot projects to inform a wider roll out of personalised budgets in Ireland. Christy will speak first-hand about the Taskforce and its recommendations and is on hand to answer all your questions about the rolling out of Personal Budgets in Ireland.
Mary McCarron, PhD RNID, RGN, BNS. F.T.C.D

Mary McCarron is Dean of the Faculty of Health Sciences, and Chair of Ageing and Intellectual Disability at Trinity College Dublin.

Since joining Trinity College in 2002 Professor McCarron has held many senior leadership roles including, Director of Research and Head of the School of Nursing and Midwifery which is now one of the largest Schools in the University and ranked 31st in the World 2016. With excess of 1400 students and over 100 staff this school and has a strong research programme with 18 undergraduate and postgraduate programmes. In 2011 Professor McCarron was elected Dean of the Faculty of Health Sciences, with responsibility for the School of Nursing and Midwifery, School of Pharmacy and Pharmaceutical Sciences, School of Dental Sciences, Medicine, with a student body in excess of 4,000 and a staff of 650. She is a member of the Senior Executive Management team of the University.

A leader in multidisciplinary health sciences, Professor McCarron is a committed ageing research leader at Trinity College and an international expert in the fields of intellectual disability, ageing, dementia, and palliative care. Professor McCarron is the founder and Principal Investigator for the first ever Longitudinal Comparative Study on Ageing in Persons with Intellectual Disability (IDS-TILDA) to be conducted in Ireland or internationally. This study is a supplement to The Irish Longitudinal Study on Ageing (TILDA). With its nationally representative sample, huge support from people with ID, their families and providers, and opportunities for comparisons with the general population, IDS-TILDA increases understanding how lives and chronic conditions change over time and provides insights on key issues at end of life. Professor McCarron's innovative and inclusive approaches are internationally recognized as an exemplar for ensuring meaningful involvement of persons with disability in the research process.

With extensive experience in working in the area of dementia in people with Down syndrome Professor McCarron has led large longitudinal cohort studies spanning over 25 years. Her special interest is on the early detection and presentation of dementia, and in the development of humane approaches to care and support. Her award winning approaches on environmental design and technology innovations are sustaining and improving quality of life for people across the continuum of dementia. She has been a key advisor of ageing and policy issues to various governmental and other groups at a National and International level. The emerging IDS-TILDA data is already informing needed policy responses to develop human and appropriate services for this increasingly at risk group. She has been successful in obtaining over €10,000,000 in research funding, as PI or collaborator, and holds/has held grants from a variety of National International sources such as the Department of Health,
Health Research Board, National Disability Authority, All Ireland Institute of Hospice and Palliative Care, Atlantic Philanthropies and Horizon 2020.

Professor McCarron is an active member of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), she plays a critical leadership role in EngAGE, the Trinity College Dublin consortium of over 140 multi-disciplinary researchers on ageing issues. In 2010 in conjunction with Professor Heleen Evenhuis, Professor McCarron led the Development of a PhD Exchange Programme between the School of Nursing and Midwifery at Trinity College and the Department of Intellectual Disability Medicine, Erasmus Medical Centre, Rotterdam, Netherlands.

She holds a research Professorship at the Centre for Excellence in Ageing & Community Wellness at the University at Albany NY. Her work is widely published.

Christy Lynch

Christy Lynch was the Chairperson of the Government’s Task Force on Personalised Budgets. The Task Force was established in September 2016 by Minister of State for Disability Issues Finian McGrath to look at how personalised budgets could work as a funding mechanism for people with a disability, providing them with greater choice and control over the services and supports they receive. The Taskforce’s report “Towards Personalised Budgets for People with a Disability in Ireland” was published in July 2018 and can be found here: https://health.gov.ie/disabilities/task-force-on-personalised-budgets/. The report recommends the Government establish two-year pilot projects to inform a wider roll out of personalised budgets in Ireland. Christy will speak first-hand about the Taskforce and its recommendations and is on hand to answer your questions about the roll out of Personal Budgets in Ireland.

Tom Murray

Tom is a past President of Down Syndrome Ireland. He is also a former Government appointed Chairman of the National Council for Special Education and served for ten years on the Board of the National Institute for Intellectual Disability based at Trinity College, Dublin.

A life-long activist on disability rights and issues, Tom, his wife Liz and daughter Eleanor are long standing members of the Louth/Meath Branch of DSI. Eleanor is an elite athlete with DS and has represented Ireland in swimming at six World Swimming Championships and the four European Swimming Championships held to date. Eleanor is Ireland’s only female athlete to ever medal at Open World Championship level and is the reigning Open European.
Champion at the 1,500m Freestyle as well as being a nine times European Championship medalist in Open European finals in a variety of swimming strokes and distances.

Tom is passionate about the benefits to young people with DS from participation in elite sport and is a committed enthusiast for the Sports Union for Athletes with Down Syndrome (SU-DS) motto that elite DS sport is all about “Ability and not Disability”. He is a strong believer that Ireland, as a sports mad country, can, given the right circumstances, be a significant player in the future of International DS Sport.

Tessa Heinlein Van Heerden

Tessa is a native of South Africa currently resident with her family in Dundalk, Co. Louth. Tessa is a former Special Needs Teacher and Equine Therapist. She has long years of experience of involvement in DS and Disability Sports in her native country.

Tessa set up her own company, Tsenya, which is currently contracted to the Sports Union for athletes with DS (SU-DS) to help promote, market and develop DS sport worldwide using social media and other vehicles to achieve those aims.

Tessa has a particular mission to spread the message about the benefits of participation in elite sport for those with DS and of the need to develop quality sporting opportunity for those with DS in close cooperation and partnership with the recognised international and national governing bodies for the sports involved. Tessa is a strong international expert and advocate for opening up opportunity for those with DS to participate in elite sport on a widespread, worldwide basis. Currently, her focus is on spreading the mission, vision and values of SU-DS here in Ireland and on raising awareness here of the SU-DS agenda for DS Sport.

Eimear Collins

Eimear is the New Parent Liaison/Early Development Officer with DSI. Eimear works with families to support them and their children throughout the early years, up to and including the transition to primary school. She is available to provide advice and support to parents and early years services in relation to early development, early intervention services and early childhood care and education. She is also involved in the development and delivery of conferences, workshops and training at regional and national level.