

Speakers



Per Kristian Haugen

Clinical Psychologist, Norwegian Centre for Dementia Research, Oslo

Per Kristian Haugen is a Clinical Psychologist and a Senior Researcher at the Norwegian Centre for Dementia Research in Oslo. His main field of interest is in researching improvements in the diagnostic assessment and in the care and treatment of people with dementia. His on-going projects include his contribution to the implementation of "The Norwegian Dementia Plan 2015" as set out in 2008 by the Norwegian Ministry of Health and Care Services. Per Kristian is the leader of two programs in this plan namely (i) a plan for diagnostics in primary care (designed to ensure that all Norwegian municipalities will have dementia teams by 2015) and (ii) a plan for people with early onset dementia (diagnostic evaluation, services, families with dementia).



Dr Siobhan Hutchinson

Consultant Neurologist, St James's Hospital

Siobhan Hutchinson is a Consultant Neurologist in St James's Hospital where she co-manages the Cognitive Clinic with her colleague Colin Doherty. They established the Cognitive Clinic in 2006 to provide a specialised service to neurological patients with cognitive and behavioural problems. A large portion of the patients seen at this clinic are people with young onset dementia. Siobhan is a graduate of UCD medical school, her neurological training was in Dublin and Boston. She did her sub-speciality training and later worked in a Cognitive Neurology Unit in Beth Israel Deaconess Medical Center, Boston - a unit originally established by Norman Geschwind and currently under directorship by Albert Galaburda.



Professor Brian Lawlor

Consultant Psychiatrist for the Elderly,
St James's Hospital and Trinity College Dublin

Professor Lawlor's interests are in the early detection, diagnosis and treatment of Alzheimer's disease, the neurobiology and treatment of behavioural and psychological symptoms in dementia and mental disorders in the community dwelling elderly. The overarching aims of Professor Lawlor's research programmes are to develop clinical, neuropsychological and biological markers of Alzheimer's disease at the earliest possible stage and to test promising new interventions in clinical populations. His most recent research involvement is as Project Co-ordinator for the NILVAD trial, an FP7 investigator driven Phase 111 clinical trial of Nilvadipine in mild to moderate Alzheimer's disease. He has published over 180 papers in his research fields and has edited three books on Old Age Psychiatry.



Matthew Gibb

The Dementia Services Information and Development Centre/MISA,
St James's Hospital

Matthew Gibb has a professional background in Social Work practice and a Masters degree in Social Policy and Social Work Studies, from the London School of Economics. Matthew has extensive experience working with older people, carers and people with sensory and physical disabilities. His role is both that of Senior Medical Social Worker to patients attending the Memory Clinic (Mercers Institute for Successful Ageing) and Social Researcher at the DSIDC. Matthew is currently involved in a number of projects including the Dementia Friendly Communities initiative with the Alzheimer Society of Ireland and the Dempth project at St James's Hospital.

Speakers



Professor Simon Mead

Consultant Neurologist, UK National Prion Clinic

After medical training at Cambridge and Oxford Universities and a PhD in the genetics of prion diseases at Imperial College London, Simon Mead is now a consultant neurologist and Clinical Lead of the UK National Prion Clinic based at the National Hospital for Neurology and Neurosurgery. Also working at the UK Medical Research Council's Prion Unit, his research interests include clinical trial studies enrolling CJD or prion disease patients, the discovery of genetic factors that cause or influence prion disease and the development of treatments for prion disease based on antibodies.



Professor Mary McCarron

Dean of the Faculty of Health Sciences, School of Nursing and Midwifery,
Trinity College Dublin

Mary McCarron, PhD RNID, RGN, BNS. F.T.C.D is Dean of the Faculty of Health Sciences, and Professor of Ageing and Intellectual Disabilities, in the School of Nursing and Midwifery Studies at Trinity College Dublin. Mary is a leader in multidisciplinary health sciences and an international expert in the fields of intellectual disability, ageing, dementia, and palliative care. Her primary research interest is in Ageing and Intellectual Disability (ID) a topic well aligned to Trinity College's research agenda on Ageing. Mary is the Principal Investigator of the first ever Longitudinal Comparative Study on Ageing in Persons with Intellectual Disability (IDS-TILDA) to be conducted in Ireland or internationally. A consultant and spokesperson on ageing related issues for key organizations and 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.



Gerry Martin

CEO - Alzheimer Society of Ireland

Gerry Martin joined The Alzheimer Society of Ireland as Chief Executive Officer in May 2013. Prior to this, Gerry held leadership roles in the Permanent TSB for 15 years including General Manager for the bank's branch network. Gerry holds an MSc (Management Practice) from The Smurfit Graduate School of Business (UCD).



Dr Declan Byrne

Consultant Physician in Geriatric and General Medicine, St James's Hospital

Declan Byrne is Chair of the DSIDC Steering Committee and Consultant Physician in St James's Hospital specializing in Geriatric and General Medicine. Declan also trained in clinical nutrition and pharmaceutical medicine and is a member of the management committee of the Irish Society for Parenteral and Enteral Nutrition and a Fellow of the Royal College of Physicians of Ireland. His research and clinical interests span acute medicine, stroke medicine, malnutrition, frailty and pharmacoeconomics. He is the Chairman of the Board of Directors of the Irish Nutrition and Dietetics Institute and the Chairman of the co-ordinating committee for the BSc in Human Nutrition and Dietetics at Trinity College Dublin and the Dublin Institute of Technology.

Dementia Services Information and Development Centre

Promoting excellence in dementia care

Top Floor, Hospital 4, St. James's Hospital,
James's Street, Dublin 8, Ireland

Tel: +353 1 4162035 Fax: +353 1 4103482
Email: dsidc@stjames.ie www: dementia.ie



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The DSIDC
2014 Annual Conference
Thursday 20th November

Young Onset Dementia



DEMENTIA SERVICES
INFORMATION AND
DEVELOPMENT CENTRE

promoting excellence
in dementia care

Welcome

Dear Friends and Colleagues

Welcome to the Dementia Services Information and Development Centre's annual national conference. Our conference theme this year is Young Onset Dementia which is an illness affecting about 4000 people under the age of 65 years in Ireland. Representing only about one in ten of all people with dementia in Ireland, this small but very significant group have distinctive medical, social, emotional, psychological and financial needs that straddle the boundaries of various service sectors including, older peoples health and social care services and mental health and disability services. In Ireland to date, this group of people have been hugely overlooked and their dilemmas and difficulties have by and large remained hidden except to themselves and close family members directly affected.

Our conference papers today have been carefully selected to address a broad range of topics directly relevant to both individuals diagnosed with this rarer form of dementia and the needs of their formal and informal caregivers.

We are especially delighted to welcome Helen Rochford Brennan who will open our conference this morning by talking about her own lived experience of this more unusual form of dementia. Helen is a member of the Alzheimer Society of Ireland's Working Group on dementia and is also a member of the European working group on dementia. She was first diagnosed with dementia at the age of 62 and since then has been an active campaigner advocating for the human rights of people with dementia.

From across the water, we are particularly pleased to welcome Professor John Keady and Mr Per Kristian Haugen both of whom as practitioners and researchers have been actively involved in researching and campaigning to expand and improve specialist age appropriate services for this very vulnerable group of people in their respective countries – the UK and Norway.

Closer to home we are delighted that Professor Brian Lawlor (Old Age Psychiatrist), Dr Siobhan Hutchinson (Consultant Neurologist) and Professor Mary McCarron (Dean of Health Sciences, Trinity College) have agreed to share with us their many years of knowledge and expertise in this area. Each of these health service professionals have had much experience researching and providing clinical/professional services to this group of people for whom there is a distinct absence of public policy in Ireland.

It is very important to remember the distinctive nature of young onset dementia and the difference in the profile and prognosis of those people compared with those diagnosed with late onset dementia. Only one in 1000 people with Alzheimer's disease has a known genetic cause but young onset Alzheimer's disease is much more likely to run in families, than late onset, and heritability, including genetic counselling is a further key consideration here. An expert on this topic is Dr Simon Mead from the UK National Prion Clinic, at the National Hospital for Neurology and Neurosurgery, and he will speak about this during the afternoon's proceedings.

The conference will also be used to learn more from Gerry Martin CEO of the Alzheimer Society of Ireland, about what is happening nationally and at a political level in relation to the implementation of the Irish National Dementia Strategy.

I along with my colleagues at the Dementia Services Information and Development Centre, welcome each of you very warmly to this year's conference which we are confident will provide ample opportunity to engage with speakers, network amongst yourselves and learn more about best practice both locally and further afield.

With best wishes



Director DSIDC

Programme

From	To	Time	Title	Speaker	Chair
9.00	9.30	30	Registration		
9.30	9.35	5	Welcome & Introduction	Professor J B Walsh	Associate Professor Suzanne Cahill
9.35	9.55	20	From Roses to Rights: My Journey with Early Onset Dementia	Helen Rochford Brennan	
9.55	10.35	40	Younger People with Dementia: Planning, Practice and Development	Professor John Keady	
10.35	11.15	40	People with Early Onset Dementia "A Special Group with Special Needs?"	Per Kristian Haugen	
11.15	11.30	15	Tea / Coffee		
11.30	12.10	40	Young Onset Dementia: Different Disorders? Different Experiences? Perspectives from a Young Onset Dementia Clinic	Dr Siobhan Hutchinson	Matthew Gibb
12.10	12.50	40	Early-onset Dementia: The Case for Early Diagnosis	Professor Brian Lawlor	
12.50	13.00	10	Questions and Answers		
13.00	14.00	60	Lunch		
14.00	14.40	40	Next Generation Sequencing: Approaches to Diagnosis of Genetic Causes of Dementia	Professor Simon Mead	Dr Declan Byrne
14.40	15.20	40	'Responding to Early Onset Dementia in Persons with Down syndrome: Award Winning Approaches to Assessment and Care'	Professor Mary McCarron	
15.20	15.50	30	Younger-Onset Dementia and the National Dementia Strategy	Gerry Martin	
15.50	16.00	10	Questions and Answers		
16.00	16.15	15	Conference Closing Remarks	Associate Professor Suzanne Cahill	

Speakers



Professor J Bernard Walsh

Clinical Professor Department of Medical Gerontology Trinity College Dublin

Professor Walsh graduated from UCC and subsequently trained in Cork and in the Mater Hospital Dublin, Kings College Hospital in London and in the Royal Liverpool Hospital. He was a Visiting Professor to the University of California in San Francisco where he looked at services for the Elderly in the City of San Francisco. He is currently the Director of the Mercer's Institute for Research on Ageing in St James's Hospital. He is the Director of the Osteoporosis and Bone Health Unit in St James's Hospital and a member of the American Society for Bone and Mineral Research and the European Calcified Tissue Association. He is the author of over a hundred peer review papers in the areas of Vitamin D, Bone Health, Memory, Cardiovascular and general medical problems in the elderly. He was previously the Clinical Director of St James's Hospital and is the immediate Past President of the Irish Gerontological Society.



Associate Professor Suzanne Cahill

Director of The Dementia Services Information and Development Centre and Research Associate Professor, Trinity College Dublin

Suzanne Cahill holds degrees from University College Dublin, the University of Stockholm and the University of Queensland in Australia. She has worked as a Social Worker, Researcher and College Lecturer and was first appointed as Director of the Dementia Services Information and Development Centre at St James' s hospital in 1999. She has served on many different committees both in Ireland and in Australia, campaigning for the rights of older people particularly those with a dementia. Since 2000, she has taught under-graduate courses on Ageing and Dementia to Social Work and Social Policy students at Trinity College Dublin and has supervised many post-graduate students to doctoral and masters level. In 2012, she along with her colleagues from Trinity College and NUI Galway, co-authored the research report titled "Creating Excellence in Dementia Care", an evidence based report, which has been used to underpin Ireland's forthcoming National Dementia Strategy. Suzanne has published widely on ageing and dementia related topics both nationally and internationally.



Helen Rochford-Brennan

Chair of the Irish Dementia Working Group

Helen Rochford-Brennan is from Tubbercurry in County Sligo and spent many years working in the tourism and disability sectors. Helen has also devoted tireless years to community activism, working at board level in several organisations. In July 2012, Helen was diagnosed with early onset Alzheimer's disease. She is chair of the Irish Dementia Working Group, which is resourced by The Alzheimer Society of Ireland.



Professor John Keady

University of Manchester and NHS Foundation Trust

John Keady is a registered mental health nurse and completed his part-time PhD in 1999 using a grounded theory methodology. Prior to this, he practiced for several years as a community psychiatric nurse in dementia care, a position he held in North Wales. Since 2006 John has worked at The University of Manchester where he holds a joint position between the University and the Greater Manchester West Mental Health NHS Foundation Trust. John currently leads the inter-disciplinary Dementia and Ageing Research Team at the School of Nursing, Midwifery and Social Work. His research is mainly concerned with the biographical and subjective experience of dementia and he is founding and co-editor of the bi-monthly Sage journal: Dementia: the international journal of social research and practice, now in its thirteenth year.