



Enable Ireland Cork Conference on Paediatric Spasticity, Orthopaedic, and Postural Management

Enable Ireland Children's Service Cork are hosting its 3rd International Paediatric Spasticity, Orthopaedic and Postural Management Conference to take place on **28th April in the Rochestown Park Hotel**. All our speakers are working in the area of Paediatric Physical and Neurodisability, particularly with Cerebral Palsy, Spina Bifida, and Neuromuscular conditions.

Every week, we will profile each of our expert speakers on [our website](#). Be sure to check in for weekly updates!

Conference Speakers Bios

Leeds Neurosurgery Team

Mr John Goodden has been in Leeds as Consultant Paediatric Neurosurgeon since February 2010. He is the Neurosurgery Lead for spasticity treatments. In October 2010 he travelled to St Louis (USA) and was trained by Dr Park in the techniques of SDR. Having then developed the necessary structures and team, he started the Leeds SDR programme in 2012. Since then he and the team have expanded the service and have now successfully treated more than 75 patients. Mr Goodden will be presenting an overview of the surgery and the patient outcome results obtained to date.

Mrs Kate McCune is Specialist Children's Physiotherapist in Leeds and currently leads the physiotherapy for patients post-SDR surgery. She is part of a skilled team that includes Katie Davis & Catherine Willsmore. The physiotherapy programme in Leeds is based upon the principles learned from training with Dr Park in October 2010 when one of the physiotherapy team also travelled to USA to learn from him. Kate will present 2 case studies of patients treated to provide some more in depth understanding of the benefits and outcomes of this surgery.

The Leeds Gait Team includes Shona Michael, Kit-Tzu Tang and Laura Milner. They run the Leeds 3D gait analysis lab. Since the start of the Leeds SDR programme, Standardised Gait Lab Data has been collected before SDR surgery as well as after (6, 12, 24-months initially). This has allowed a detailed objective assessment of the changes occurring after SDR which will be presented in this talk.

[Find out more about Leeds Neurosurgery](#)

F. Virginia Wright, PT, PhD.

Senior Scientist, Bloorview Research Institute

Holland Bloorview Kids Rehabilitation Hospital

Bloorview Children's Hospital Foundation Chair in Paediatric Rehabilitation

Associate Professor (status), Department of Physical Therapy, University of Toronto

Dr Wright is a physiotherapist and Clinician Scientist at Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada, and leads the SPARK (Supporting Physical Activity-based rehabilitation Research for Kids) Lab in the Bloorview Research Institute. Virginia holds the Bloorview Children's Hospital Foundation Chair in Paediatric Rehabilitation (2012- 2017). She is an Associate Professor in the Department of Physical Therapy at the University of Toronto and an Associate Member of CanChild, McMaster University, Hamilton, Canada. She has an MSc and PhD in Health Research Methodology from McMaster University, Hamilton, Canada.

Virginia's research is grounded in her experience as a physiotherapist and outcome measures co-ordinator, and guided by her close links with several pediatric rehabilitation teams at Holland Bloorview. She currently holds 3 research grants as co-principal investigator (1.5 million dollars in research funding), and is co-investigator on 5 other grants (\$800,000 in total). Her clinical research centres on development and validation of outcome measures for use in pediatric rehabilitation (cerebral palsy, prosthetics, and acquired brain injury in particular), and on evaluation of a variety of interventions in cerebral palsy. Her current program of gross motor outcomes research includes: validation of a new quality of movement measure (the Quality FM) that she created for children with cerebral palsy (CP) (as a companion to the Gross Motor Function Measure [GMFM]); refinement and validation of an advanced motor skills assessment (the Challenge Module) that she designed for children with CP; and a randomized trial that is evaluating treadmill-based robotic gait training in children with CP

For further information on Dr Virginia Wright please see following links:

<http://research.hollandbloorview.ca/scientists/Virginia-Wright>

<http://research.hollandbloorview.ca/Outcomemeasures/QualityFM>

<http://research.hollandbloorview.ca/Outcomemeasures/Challenge>

<http://research.hollandbloorview.ca/Outcomemeasures/ABICA>

Josse Du Cat and Dr. Petra Pauwels

Josse Du Cat graduated from the Faculty of Physiotherapy at the University of Leuven, in 1980 with a master's degree. In 1983, he started working at Sint Niklaas Center Belgium treating children with Cerebral Palsy and developmental disorders. In 1985 he started working at the University Hospital in Leuven, which is a center for very young children with development disorders. In 1986, he started working part-time at the Belgian Bobath Centre in Brussels involved with treatment of children with Cerebral Palsy. Since 1993, Josse has worked at the University Hospital in Leuven as part of the neuro-orthopaedic multidisciplinary team involved in the treatment of children with cerebral palsy. Part of Josse's role within the team is in the rehabilitation of children with cerebral palsy after orthopedic surgery, following botulinum toxin, baclofen pump implantation or selective dorsal rhizotomy. Josse is responsible for the study and planning of rehabilitation for 150 children a week within the hospital, as well as 24 residing in the ward. Children are assessed in the gait laboratory with Josse and the full team. Josse is a member of Belgian Bobath Instructors Association and the European Association of Bobath Instructors (EBTA). Josse is also a researcher and lecturer at the faculty of sciences of motion and physiotherapy (FABER) at the Catholic University of Leuven, specializing in neurology and paediatrics, he is also a lecturer at the University of Ghent, in the department of physiotherapy - specializing in issues related to neuropaediatrics.

Josse's talk at the Paediatric Spasticity, Orthopaedic and Postural Management conference will center around the effective use of Botulinum Toxin in children with Cerebral palsy to improve functional goals. The use of botox to predict outcomes for Selective Dorsal Rhizotomy (SDR) is a new area of research and we look forward to hearing about it on the day

Dr. Petra Pauwels is a Physical Medicine and Rehabilitation Consultant who also works at the University Hospital in Leuven. She is also head of the rehabilitation department in the Hospital of Zottegen. Since 1998, Petra is responsible for Baclofen pumps and SDR rehabilitation in children and adults with Cerebral Palsy. She is also involved with the orthopedic surgeon for the post-surgery rehab. In recent years, Dr Pauwels, Josse de Cat and the full team in Leuven have also concentrated their research efforts on the use of BTX-a in assessing suitability for Selective Dorsal Rhizotomy & predictive outcomes in children with Cerebral Palsy. Dr.Petra Pauwels will speak about this research during the conference. There will be a questions and answers chaired discussion at the end of the session 1 where you will have an opportunity to engage with the speakers.

Following the conference, we will ensure that all attendees receive relevant references and research papers.

Belfast Health and Social Care Trust

Reaching Out – A regional service and network approach for upper limb treatment in cerebral palsy

The trust developed a regional service to optimize management of upper limb spasticity in children with cerebral palsy. It used International Classification Framework and National Institute for Health and Care Excellence guidelines. This service is led by Dr. Claire Lundy, Consultant in Neurology/Neurodisability. The service aims to assist consultant paediatricians and community therapy teams in the practical management of the upper limb in children with movement disorders. The talk will focus on an MDT approach to upper limb management and also botulinum upper limb pathway, postural control, lycra clinic and joint medical/therapy clinics.

In 2016, the trust won a HSJ award for the most effective adoption and diffusion of best practice Judges commented that communication between different parties improved, and parents reported functional gains such as improvements in children's independence in dressing and eating. Judges were impressed by the "passion, clinical leadership, family involvement and impact on quality of life for patients".

Tina Weston – lead Clinical Specialist Physiotherapist/Physio injector, Julia Maskery – lead Clinical Specialist Occupational Therapist and Dr. Brona McDowell – lead Clinical Specialist Physiotherapist Gait Analysis, will also speak at the conference.

HSJ Awards 2016: Most effective adoption and diffusion of best practice

<https://www.hsj.co.uk/more/awards/hsj-awards/hsj-awards-2016-most-effect>

NICE pathway – spasticity in children and young people

<https://www.nice.org.uk/guidance/cg145?unlid=282959725201621519047>

Collaboration in standardized assessments leads to the right service at the right time.

Gillian O Dwyer, Physiotherapist Enable Ireland Cork and Kerry Crowley, Physiotherapist KIDS (Kerry Integrated Disability Service)

AIMS: Objective measures used to assess spasticity and need for medical or orthopaedic management/intervention is not standardised between paediatricians, orthopaedic surgeons, GP's, physiotherapists, occupational therapists, specialist nurses and others working with children with physical and neuro-disability. Standardised measurement improves decision-making and promotes integrated care. This can be facilitated through a structured, integrated care pathway. The purpose of this talk is to show and highlight the benefits of standardised physical assessment in improved inter-disciplinary communication, decision-making, and outcomes.

Case studies will be used to demonstrate improvement in outcomes for this population.

Enable Ireland Orthopaedic Care Pathway was chosen to demonstrate an integrated care pathway at The Forum for National Clinical & Integrated Care Programmes. This forum provides an opportunity to discuss and share 'new ways of working' in the context of a person-centered, integrated care framework, and explore how care providers' and service users' roles are evolving nationally and internationally. Service providers are invited to present live examples of 'new ways of working' developed at local level initiatives and/or as part of the National Clinical and Integrated Care Programmes in Ireland.

All attendees will be given a link to standardised assessment and information on the day.

Information on Clinical and Integrated Care Programmes in Ireland -
<http://www.hse.ie/eng/>

Progressing disability services for children and young people: Guidance on Specialist Supports <http://www.hse.ie/progressingdisabilityservices/>

Samantha Payne, Paediatric Physiotherapist

Samantha Payne has been working as a paediatric physiotherapist for around 15 years. In 2013 she started working with Elastic Therapeutic taping, training with the Esther de Ru Approach and Kinesio UK on their general training (KT1 & 2) and their specialist Paediatric Training (KT3 & 4). Sam has since completed her MSc in Neuro Rehab with a bias to Taping and has trained with Esther de Ru to become a tutor.

Sam will be speaking on the importance of assessment and skin for effective taping in neurological patients and the precautions needed with taping. A sample of kinesio tape will be included in each of the packs on the day.

Spasticity Management Case Study – Use of BTX-a With Strengthening and Gait Rehabilitation in Early Childhood

Raymond Barry & Doireann Lynch

Dr Raymond Barry, Consultant Paediatrician, Mercy University Hospital, Cork, and Dean of the Faculty of Paediatrics, Royal College of Physicians of Ireland, and Doireann Lynch, MISCP, Senior Paediatric Physiotherapist, Enable Ireland Children's Services Cork.

Botulinum Toxin is an intervention used routinely with children with Cerebral Palsy. The use of a standardised Physical Assessment is vital to ensure that all clinicians are assessing the child in the same way, have strong inter- and intra-rater reliability, and are using the same language when clinically reasoning treatment options. This Physical Assessment is the basis of any clinical reasoning within the Spasticity Management Pathway, a part of the overall Orthopaedic Care Pathway in Enable Ireland Cork Children's Services.

The aim of this presentation is to look at the use of Botulinum Toxin injections to facilitate improved outcomes in gait rehabilitation in early childhood. A case study will be used to follow progression from physical assessment, clinical reasoning, intervention, and rehabilitation to repeat assessment.

Ultrasound anatomy of selected muscles will be reviewed and rehabilitation exercise programme reviewed.

Team Work within a Regional Neuromuscular clinic to improve Outcomes: Assessment and Intervention

Niamh McSweeney & Sheela Fox

Niamh McSweeney, Consultant Paediatric Neurologist & Sheela Fox, Senior Paediatric Physiotherapist, Enable Ireland Children Services Cork will speak about the Enable Ireland Neuromuscular pathway and how it integrates with the Cork University Hospital Neuromuscular service.

We run a dedicated clinic for service users with a diagnosed NM condition and through the use of standardised assessments we provide integrated care for these service users. Service users attending our Neuromuscular clinic have a confirmed diagnosis of a Neuromuscular condition e.g. Duchenne Muscular Dystrophy, Spinal Muscular Atrophy, Hereditary Sensory and Motor Neuropathy, Congenital Muscular Dystrophy, and other Myopathies.

The presentation will follow the pathway of a service user with Duchenne Muscular Dystrophy from initial diagnosis to treatment. We will show the use of the standardised North Star assessment as an indicator of the optimal timing for commencement of steroid intervention, as an outcome measure following commencement of steroid treatment and how it is used as a predictor or indicator of loss of ambulation. Integrated care will be demonstrated through the links between the Enable Ireland orthopaedic

pathway, Neuromuscular pathway and CUH Neuromuscular pathway. All of these services then link with both hospital (CUH) and community (EI and Network teams for Non EI service users) services and community links with Muscular Dystrophy Ireland to access practical supports available such as family support workers, transport support and respite support.

We have links with North Star Network and Smart Net Network. Both of these networks are used for best practice information including most recent up to date research, and information sharing for families.

All references will be sent to attendees after the conference.

Surveillance and Management of secondary impairments in clients with complex neuromuscular conditions: Case Studies - Laura Cronin, Senior Paediatric Physiotherapist, Enable Ireland Children Services Cork.

The use of ISO measures as outcome measures for seating postural management of a client with complex spinal deformity whilst awaiting surgery: Case Study - Eva Sheehy Perera, Senior Paediatric Occupational Therapist, Enable Ireland Children Services Cork.

Both of these speakers will be looking at the benefits of integrated care for children with neuromuscular disorders in relation to orthopaedic and postural management.

We will follow case studies of children with Spina Bifida and Neuromuscular conditions who are at risk of secondary musculoskeletal impairments from early to late childhood.

Spina Bifida is a condition which affects about one in every 1000 children born per year in Ireland. Throughout childhood children with high lesion myelomeningocele are at high risk of secondary impairments associated with this condition. Over 60% require a wheelchair over the age of 3 years.

There are approximately 200 children in Ireland with the following neuromuscular conditions including muscular dystrophies (most commonly Duchenne Muscular Dystrophy [DMD]), Spinal Muscular Atrophy (SMA), Friedrich's Ataxia and other degenerative conditions).

Throughout childhood children with neuromuscular disorders develop secondary musculoskeletal impairments due to the natural history of progressive nature of these conditions. The case studies will include how growth was monitored and the postural management strategies that were used in the prevention and early management of secondary impairments. Postural Management will include role of seating and use of ISO (International Organization for Standardisation) measures to improve outcomes for these children.

The importance of integrated care will also be shown from local to regional to national services in the prevention of secondary neuromuscular impairments in order to get to the right service with required postural management supports.

Sarah Clayton

Sarah Clayton is a biology graduate and fully qualified teacher. She started working with families whose children were using night time positioning in 1998, this work was published in Physiotherapy in 2000. In 2004 she co-wrote the first accredited Postural Care courses with Liz Goldsmith. Sarah currently leads an incredible group of passionate, skilled and experienced people to develop training materials and equipment to support the use of therapeutic night positioning.

Sarah Clayton will discuss the measurement of body symmetry and its use as a validated and objective outcome measure. She will also speak about the protection of body shape and restoring body shape.

Gillian O Dwyer and Kerry Crowley will then share information on prevention of early asymmetrical postures through standardised assessment and accessing right service at the right time. Both of these talks will then link in describing posture and association between posture and contractures, hip dislocation, scoliosis, and pain in young adults with physical and neurodisability, to include Cerebral Palsy, Spina Bifida etc.

Finally following both these talks we hope to begin the process of CPIP Ireland.

The aim is to provide a high quality standardised programme, including hip surveillance for children with CP that will identify musculoskeletal problems at network level through regular physical assessments and when required radiological examination to enable effective management of these problems in childhood.

The aim will be to agree a protocol of standardised musculoskeletal examination for children with CP and similar conditions to ensure equity throughout Ireland.

It is based on best practice in Sweden and Australia and meets the principles of care recommended in NICE Clinical Guidelines Spasticity in children and young people with non-progressive brain disorders.

The objective will be to follow our international colleagues to prevent the occurrence of hip dislocation and severe deformities by means of a continuous and standardized surveillance nationally, combined with treatment at early stage and thereby optimize the functional ability and quality of life of those with CP and similar conditions.

The conference will endeavour to improve co-operation and networking between the various professions in Ireland with respect to people with physical and neurodisability.

We hope you will join us to start this national process which will be a cost neutral initiative.

Spasticity Management Case Study – Use of BTX-a With Strengthening and Gait Rehabilitation in Early Childhood: Raymond Barry & Doireann Lynch

Dr Raymond Barry, Consultant Paediatrician, Mercy University Hospital, Cork, and Dean of the Faculty of Paediatrics, Royal College of Physicians of Ireland, and Doireann Lynch, MISCOP, Senior Paediatric Physiotherapist, Enable Ireland Children’s Services Cork.

Botulinum Toxin is an intervention used routinely with children with Cerebral Palsy. The use of a standardised Physical Assessment is vital to ensure that all clinicians are assessing the child in the same way, have strong inter- and intra-rater reliability, and are using the same language when clinically reasoning treatment options. This Physical Assessment is the basis of any clinical reasoning within the Spasticity Management Pathway, a part of the overall Orthopaedic Care Pathway in Enable Ireland Cork Children’s Services.

The aim of this presentation is to look at the use of Botulinum Toxin injections to facilitate improved outcomes in gait rehabilitation in early childhood. A case study will be used to follow progression from physical assessment, clinical reasoning, intervention, and rehabilitation to repeat assessment. Ultrasound anatomy of selected muscles will be reviewed and rehabilitation exercise programme reviewed.

Team Work Within a Regional Neuromuscular Clinic to Improve Outcomes: Assessment and Intervention: Niamh McSweeney & Sheila Fox

Niamh McSweeney, Consultant Paediatric Neurologist & Sheila Fox, Senior Paediatric Physiotherapist, Enable Ireland Children Services Cork will speak about the Enable Ireland Neuromuscular pathway and how it integrates with the Cork University Hospital Neuromuscular service.

We run a dedicated clinic for service users with a diagnosed NM condition and through the use of standardised assessments we provide integrated care for these service users. Service users attending our Neuromuscular clinic have a confirmed diagnosis of a Neuromuscular condition e.g. Duchenne Muscular Dystrophy, Spinal Muscular Atrophy, Hereditary Sensory and Motor Neuropathy, Congenital Muscular Dystrophy, and other Myopathies.

The presentation will follow the pathway of a service user with Duchenne Muscular Dystrophy from initial diagnosis to treatment. We will show the use of the standardised North Star assessment as an indicator of the optimal timing for commencement of steroid intervention, as an outcome measure following commencement of steroid treatment and how it is used as a predictor or indicator of loss of ambulation. Integrated care will be demonstrated through the links between the Enable Ireland orthopaedic pathway, Neuromuscular pathway and CUH Neuromuscular pathway. All of these services then link with both hospital (CUH) and community (EI and

Network teams for Non EI service users) services and community links with Muscular Dystrophy Ireland to access practical supports available such as family support workers, transport support and respite support.

We have links with North Star Network and Smart Net Network. Both of these networks are used for best practice information including most recent up to date research, and information sharing for families.

All references will be sent to attendees after the conference.

Surveillance and Management of secondary impairments in clients with complex neuromuscular conditions: Case Studies - Laura Cronin, Senior Paediatric Physiotherapist, Enable Ireland Children Services Cork.

The use of ISO measures as outcome measures for seating postural management of a client with complex spinal deformity whilst awaiting surgery: Case Study - Eva Sheehy Perera, Senior Paediatric Occupational Therapist, Enable Ireland Children Services Cork.

Both of these speakers will be looking at the benefits of integrated care for children with neuromuscular disorders in relation to orthopaedic and postural management.

We will follow case studies of children with Spina Bifida and Neuromuscular conditions who are at risk of secondary musculoskeletal impairments from early to late childhood.

Spina Bifida is a condition which affects about one in every 1000 children born per year in Ireland. Throughout childhood children with high lesion myelomeningocele are at high risk of secondary impairments associated with this condition. Over 60% require a wheelchair over the age of 3 years. There are approximately 200 children in Ireland with the following neuromuscular conditions including muscular dystrophies (most commonly Duchenne Muscular Dystrophy [DMD]), Spinal Muscular Atrophy (SMA), Friedrich's Ataxia and other degenerative conditions).

Throughout childhood, children with neuromuscular disorders develop secondary musculoskeletal impairments due to the natural history of progressive nature of these conditions. The case studies will include how growth was monitored and the postural management strategies that were used in the prevention and early management of secondary impairments. Postural Management will include the role of seating and use of ISO (International Organization for Standardisation) measures to improve outcomes for these children.

The importance of integrated care will also be shown from local to regional to national services in the prevention of secondary neuromuscular impairments in order to get to the right service with required postural management supports.

Bridging the Gap between Hospital and Community

Eimear Daly, CNS Paediatric Intellectual Disability, MUH & Tyrone Horne, Clinical Nurse Co-ordinator for Children with Life Limiting Conditions, Cork and Kerry (formally Children's Outreach Nurse).

Eimear Daly is a CNS Paediatric Intellectual Disability and acts as a link between the family, acute care (Consultant Paediatricians, Paediatric neurologist, NCHDs, Hospital MDT) and community services (Physical/Intellectual disability services, Community liaison nurses/CNS EI, community MDTs primarily SLT, PT, OT, S/W, dietetics, PHN, GP, Pharmacy). The child and family's needs are met in terms of symptom management, advice, support, advocacy, information sharing and education.

Tyrone Horne's role as CNC for children with Life Limiting Conditions, previously known nationally as CON. Tyrone covers the areas of Cork and Kerry including CUH, MUH and University Hospital Kerry, acting as a co-ordinator between acute and community settings for all children with Life Limiting Conditions, linking with medical teams, palliative care teams, PHN, GP, voluntary services, disability services and anyone else involved in these children's care. Tyrone acts as a point of contact for the family and regularly provides visits to home supporting with symptoms, end of life care and bereavement support. Eimear and Tyrone will present on their roles and their involvement in integrated care. They will also present a case study of a child that they have worked with together hence highlighting their links/contact with community services.

Postural Management and FEDS (Feeding, Eating, Drinking and Swallowing)

Peggyann McCann, Speech & Language Therapy Manager Enable Ireland Cork

Peggyann McCann is the speech and language therapy manager in Enable Ireland Cork Services. All the therapists in her team work with children presenting with issues with feeding, eating, drinking and swallowing.

Posture is a key component of any assessment of eating, drinking and swallowing and without correct postural management and support a child may not be able to develop or progress their skills. As speech and language therapy intervention in Enable Ireland is provided within a multidisciplinary team, intervention involves occupational therapists and physiotherapists. Working within a team also ensures that the speech and language therapist incorporates a basic postural analysis within her assessment protocol and within her intervention plan.

This presentation will highlight the link between posture and eating, drinking and swallowing and will demonstrate the impact of postural issues on a child's ability to progress with eating, drinking and swallowing and any subsequent health issues.

[Download our conference brochure](#) or [book your place online](#)