

Integrated Care Programme for Children

Workstreams

ICP for Children Steering Group

DDH Screening Programme

NMD pathway development

Hepatitis B perinatal prevention programme

Consultant paediatrician delivered service – Waterford UH

Care coordination for Children with Life Limiting Conditions

ICP for Children Steering Group

The Integrated Care Programme (ICP) for Children has been established to improve the way in which health and social care services are designed and delivered to children and their families so that care is coordinated and integrated at all points on the care journey. The Programme has a Steering Group which is representative of the services that deliver care to children. The ICP for Children has established a Nursing Expert Group for Children's Services as well as a Paediatric Health and Social Care Professional Expert Group to support the work of the programme. The Integrated Care Programme for Children has three key strategic priorities:

- Establish a framework for Integrated Care for Children
- Implement the National Model of Care for Paediatric and Neonatal Health services in Ireland
- Identify, evaluate, prioritise and progress service improvement initiatives

ICP for Children Steering Group

Name	Representing	Name	Representing
Claire Browne	Health and social care professionals	Dr Cathal Morgan	Social Care Division
Susanna Byrne	Office of Nursing and Midwifery Services Division	Brian Murphy	Primary Care Division
Dr Philip Dodd	ICP for Children Sponsor, National Clinical Advisor and Group Lead for Mental Health	Dr John Murphy	ICP for Children Clinical Lead
Suzanne Dempsey	Nursing operations representative	Prof Alf Nicholson	ICP for Children Clinical Lead
Dr David Hanlon	ICP for Children Sponsor, National Clinical Advisor and Group Lead for Primary Care	Dr Brendan O'Shea	Irish College of General Practitioners
Eilish Hardiman	Acute Hospital Division	Martina Queally	Chair of Group, CO CHO 6
Siobhan Horkan	Programme Manager, National Clinical Programme for Paediatrics and Neonatology	Grace Turner	ICP for Children Senior Programme Manager
Dr Kevin Kelleher	Health and Wellbeing Division	Aidan Waterstone	Tusla
Aileen Killeen	Programme for Health Service Improvement		

Selective Ultrasound Screening for Infants at Risk of Developmental Dysplasia of the Hip

Developmental dysplasia of the hip (DDH) is the most common and most important orthopaedic problem affecting newborn infants. Its incidence is at least 1:100 births and if undetected in early infancy it can result in lifelong hip problems including limp, leg shortening and ultimately hip replacement.

While clinical examination for DDH introduced in all Irish newborn nurseries in the 1960s using the Ortolani and Barlow techniques has been very effective, it has become apparent over time that it will not detect all cases. This has led to the recommendation by the Integrated Care Programme for Children and the DDH Subgroup of the HSE's National Child Health Review Steering Group that a selective ultrasound of the hip screening programme should be implemented for eligible infants at risk of developmental dysplasia of the hip (DDH) 6 weeks of age, to allow greatest opportunity for non invasive treatment.

DDH Ultrasound Implementation

Steering Group

Purpose of the group

The steering group has been established to ensure that the ultrasound screening programme is implemented in line with national recommendations for ultrasound screening of infants at risk of DDH.

Objectives

- To provide leadership and guidance on the implementation of the national recommendations for DDH Ultrasound screening programme.
- Develop policies, guidelines and protocols including a standardised national reporting template for DDH ultrasound reports.
- Identify a lead person within each radiology department who will oversee the implementation of the screening process.
- Identify a lead orthopaedic consultant for each hospital who will support treatment post diagnosis of any result other than Graf type 1.
- Establish KPIs and regular audits within the service to ensure compliance with the recommendations of the DDH subgroup.

Developmental Dysplasia of the Hip – Selective Ultrasound Screening Programme Implementation Steering Group

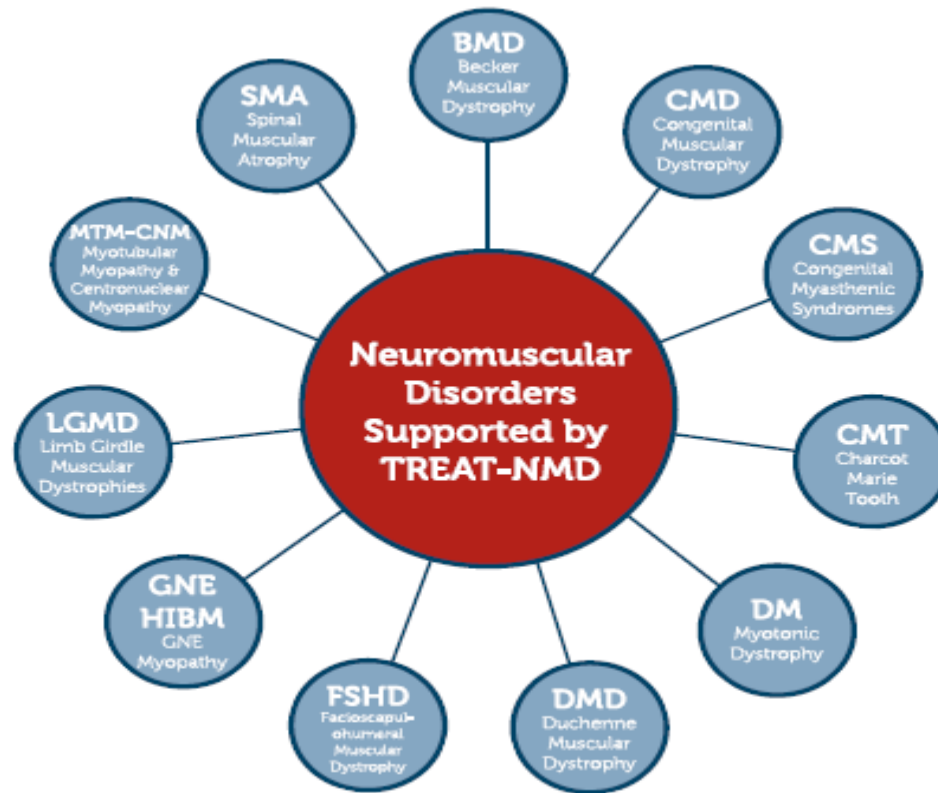
Name	Representing	Name	Representing
Dr Caroline Mason Mohan	Consultant in Public Health Medicine	Mr Joe O’Beirne	Consultant Orthopaedic Surgeon
Helen McDonald	DDH Coordinator	Dr Ailbhe Tarrant	Chair, Consultant Radiologist
Dr John Murphy	ICP for Children Clinical Lead	Grace Turner	ICP for Children Senior Programme Manager

Integrated Care Pathway Development for Children and Families with Neuromuscular Disorders

A rare disease, disorder or condition is defined as that which affects less than 1 in 2,000 people. Neuromuscular disorders (NMD) are among these rare diseases. They are complex and progressive, often affecting multiple body systems. NMD are often the result of genetic mistakes (or mutations) that affect muscle stability, the ability of muscle to regenerate or interrupt the communication between nerves and muscles.

Examples of neuromuscular disorders include; Duchenne Muscular Dystrophy (DMD), Congenital Muscular Dystrophy (CMA), Becker Muscular Dystrophy (BMD), Spinal Muscular Atrophy (SMA) and Charcot Marie Tooth (CMT/HMSN). Further examples are included in the diagram below.

Integrated Care Pathway Development for Children and Families with Neuromuscular Disorders



Integrated Care Pathway Development for Children and Families with Neuromuscular Disorders

Children, adolescents and their families with a suspected or confirmed diagnosis of any neuromuscular disorder (NMD) require access to a broad range of healthcare services and supports in the community and acute hospital from a range of different providers and agencies at any given point in time. The Integrated Care Program for Children aims to standardise the care journey of a child with NMD and their family through the paediatric healthcare system from initial presentation and diagnosis, to transition to adult services, by developing an Integrated Care Pathway.

This Integrated Care Pathway (ICP) will be developed to support child and family centred multidisciplinary care for children and adolescents with NMD, with a particular focus on standardisation, communication and integration between the various service providers involved. It will also focus on how services communicate with children and families themselves, and with each other. While some clinical pathways do exist for some children with NMD they are specific to children with a specific diagnosis, different points in the child's care journey, particular professions or areas of specific clinical management. No integrated care pathway exists in the Irish context to capture the entire care journey to give guidance to service providers with regard to delivering standardised, child and family centred, integrated care. Once designed, the integrated care pathway will be initially tested, then analysed and refined, prior to national implementation.

Integrated Care Pathway for Children and Families with Neuromuscular Disorders **Steering Group**

Name	Representing	Name	Representing
Gerry Clerkin	HSE Quality & Patient Safety, Social Care Division	Margaret Rafferty	ICP-C Project Coordinator, HSE Paediatric Community Team
Miriam Condron	Parent Representative	Andrea Tobin	HSE NMD Tertiary Services
Margaret Good	Muscular Dystrophy Ireland	Grace Turner	ICP for Children Senior Programme Manager
Dr Declan O'Rourke	Chair, National NMD Service	Christine Twomey	Parent Representative

Integrated Care Pathway for Children and Families with Neuromuscular Disorders **Project Group**

Name	Role	Name	Role
Sheela Fox	NMD Clinic Coordinator, Enable Ireland, Cork	Gillian O'Dwyer	NMD Service Manager, Enable Ireland, Cork
Margaret Good	Muscular Dystrophy Ireland	Dr Sheena Owens	Psychologist, HSE NMD Tertiary Services
Caralyn Horne	HSE Quality & Patient Safety	Margaret Rafferty	Chair, ICP-C Project Coordinator, HSE Paediatric Community Team
Marie Hynes	Senior Respiratory Physiotherapist, Temple Street	Bevan Ritchie	Head Of Care, LauraLynn Irish Children's Hospice
Andrea Mernagh	Clinical Nurse Specialist, Temple Street	Andrea Tobin	HSE NMD Tertiary Services

Development of an Integrated Care Pathway for Permanent Childhood Hearing Impairment

- A multidisciplinary working group is being established to develop an integrated care pathway for the aetiological investigation and subsequent management of infants with permanent childhood hearing impairment (PCHI). The care pathway will build on the success of the Universal Newborn Hearing Screening (UNHS) programme and will seek to ensure that infants identified with a hearing impairment are investigated and managed according to nationally agreed standards.
- The pathway development will take into account:
 - The best interests of children and their families
 - Relevant national and international policy documents and reports
 - Relevant national and international research, standards and evidence-based practice.

Working Group to Develop an Integrated Care Pathway for Permanent Childhood Hearing Impairment

Name	Role	Name	Role
Dr Joanne Balfe	Consultant general paediatrician	Brendan Lennon	Patient advocacy representative, Deaf Hear
Dr Alison Blake	Consultant ophthalmologist	Teresa McDonnell	Parent representative, Sharing the Journey
Patsy Costello	Speech and language therapist, Cochlear Service	Darina McGuirk	Public health nurse
Sara Daly	Speech and language therapist, Deaf Hear	Prof Alf Nicholson	ICP for Children clinical lead
Dr Sam Doyle	Clinical geneticist	Gary Norman	National clinical lead, audiology
Maree Farrell	Visiting teacher for deaf and hard of hearing	Mr Peter O'Sullivan	ENT consultant
Dr Wendy Ferguson	Infectious diseases associate specialist paediatrician	Jyoti Thapa	Principal audiological scientist
Mr Fergal Glynn	Consultant ENT surgeon, Cochlear Implant Service	Grace Turner	ICP for Children, senior programme manager
Laura Grant	Parent representative, Our New Ears	Dr Nick van der Spek	Consultant general paediatrician
Madeline Hickey	National director, Special Education Support Service	Mr Peter Walshe	ENT consultant

National Perinatal Hepatitis B Prevention Programme

A multidisciplinary working group is developing a care pathway for pregnant women who are hepatitis B positive and the babies born to these mothers. The roles and responsibilities for the various healthcare professionals involved will be defined as well as the quality standards and performance indicators for monitoring the screening and prevention programme.

The purpose of the working group is to:

- Agree a national policy for universal hepatitis B screening for pregnant women
- Design the care pathway, with associated responsibilities and guidelines, for the management of hepatitis B positive pregnant women and the babies born to these mothers
- Develop recommendations in relation to the governance of the perinatal hepatitis B prevention programme
- Make recommendations on the quality standards and performance indicators for monitoring the screening and prevention programme
- Make recommendations in relation to data collection relevant to the programme

Working Group to Develop a National Perinatal Hepatitis B Prevention Programme

Name	Role	Name	Role
Dr. Karina Butler	Paediatric Infectious Diseases Consultant, Our Lady's Children's Hospital, Crumlin	Ms. Michelle Megan	Director of Public Health Nursing, HSE
Dr. Cillian De Gascun	Consultant Virologist & Laboratory Director, UCD National Virus Reference Laboratory	Dr. John Murphy (Chair)	Clinical Lead, ICP for Children and Consultant Neonatologist, National Maternity Hospital, Holles Street
Dr. Wendy Ferguson	Infectious Diseases Associate Specialist Paediatrician, Rotunda Hospital	Dr. Karen Power	National Clinical Programme for Obstetrics and Gynaecology
Dr. David Hanlon	National Clinical Advisory and Group Lead, Primary Care, HSE	Ms. Sheila Sugrue	National Lead Midwife, Office of Nursing and Midwifery Service Division, HSE
Dr. Julie Heslin	Specialist in Public Health Medicine, Department of Public Health, Kilkenny, HSE	Dr. Lelia Thornton	Specialist in Public Health Medicine, Health Protection Surveillance Centre, HSE
Professor Aiden McCormick	Consultant Hepatologist, St. Vincent's University Hospital	Ms. Grace Turner	Senior Programme Manager, Integrated Care Programme for Children
Mr. Colm McDonnell	Chief Medical Scientist, University Hospital Limerick		