

ORGANISATION	INHA ROLE	DATE
European Foundation for the Care of Newborn Infants <a href="http://www.efcni.org">www.efcni.org</a>	Parent Advisory Board Member	Board Member 2010 to date
NIDCAP Federation International <a href="http://www.nidcap.org">www.nidcap.org</a>	Board Member & Family Advisory Council Chair	Board Member 2012 to date
HSE National Advocacy Unit-Patient Reference Group	Contributor to the National Healthcare Charter for Children & still contributing on other ongoing matters ie New Childrens Hospital, Paediatric Charter, HIQA Service Standards	2013
Socks for Life Exhibition EU Parliament	Raising Awareness of Preterm Birth	2014
National Neonatal Transport Programme	3 year advocacy campaign to secure funding for a 24 hour national neonatal transport service	PPI 2011 to 2015
HRB Mother & Baby CTN	Patient Collaborator	PPI 2014 to 2019
INFANT Centre Cork	Patient Collaborator	2014 to date
EFCNI Standards of Care for Newborn Health Project	European wide project drafting standards for improved services and outcomes. <a href="https://newborn-health-standards.org">https://newborn-health-standards.org</a>	Launched 2018 and currently at implementation stage

National Transport Medicine Programme (now called the National Ambulance Service Critical Care Retrieval Service) <a href="http://www.nascrs.ie">www.nascrs.ie</a>	Patient Collaborator .	PPI 2011 to date
Primary Eyecare Steering Group	Patient Collaborator	PPI 2013-2016
Paediatric Hospital Group	Patient Advocate	PPI 2015
Service Users Group Trinity College Nursing & Midwifery	Patient Users Group Member	2012
European Medicines Agency	Patient Advocate	PPI 2015 to date
Cos Star-Core Outcome Set Standard For Reporting- University of Liverpool study	Patient Advocate	PPI 2014-2015
Screening to Improve Health in Very Preterm Infants in Europe (SHIPS) European study	Patient Collaborator	PPI Ongoing since 2015
Neoview Study CUMH Cork	Patient Collaborator on a study investigating webcam technology in the NICU	PPI Ongoing
Bright Horizons Study- Coombe Hospital	Patient Collaborator developing strategies for follow up of premature infants	PPI Ongoing

Core Outcome for Studies in Prevention of Preterm Birth	Patient Advocate with Global Obstetrics Network- Netherlands	PPI Study published in the Journal of Obstetrics & Gynaecology 2015
Sobi Kiobrina Trial	Patient Advocate	PPI 2014
iHope Study- Dr James Duffy.Developing Core Outcome Set for Pre-Eclampsia	Patient Advocate	PPI 2016-2019
Supporting the Peer Supporter Study- Dr Gillian Thompson UK	Patient Advocate	PPI 2018
Healthy Pregnancy In Ireland KEDS Proposal with Dr. Fergal Malone Rotunda Hospital	Patient Advocate developing animated videos promoting healthy pregnancy	PPI 2015
Investigating Pre-Eclampsia Biomarkers to reduce preterm deliveries- Dr Fionnuala Ni Ainle Rotunda Hospital	Patient Advocate	PPI 2016
Unicorn Study- Prof Eleanor Molloy Crumlin/Coombe hospitals	Patient Advocate investigating therapies to improve neurodevelopmental outcomes post brain injury at/prior to birth	PPI 2016
Hi_Lo Study to investigate therapies to prevent thromboembolism in pregnancy- Rotunda	Patient Advocate	PPI 2015

<p>PCORI Funding application with Prof Ewoud Schuit- Improving treatment decisions through network meta-analysis using individual participant data from randomized and non-randomized studies.</p>	<p>Patient Representative</p>	<p>PPI 2016</p>
<p>National Strategic Group MSc Nursing Advanced Practice</p>	<p>Patient Advocate</p>	<p>PPI 2012</p>
<p>PCORI Funding application with Prof Ben Mol:- Tocolysis to improve neonatal outcomes</p>	<p>Patient Representative</p>	<p>PPI Feb 2106</p>
<p>PCORI Funding application with Prof Ben Mol:-the effectiveness &amp; safety of progesterones to prevent preterm birth:an individual participant data meta-Analysis</p>	<p>Patient Representative</p>	<p>PPI Aug 2016</p>

<p>IRELand Study-randomised placebo controlled trial of low dose aspirin initiated in the first trimester for optimizing pregnancy outcome in pregestational diabetes</p>	<p>Patient Representative</p>	<p>PPI Ongoing</p>
<p>James Lind Alliance- Setting Preterm Birth Research Priorities With Multiple Professions &amp; Service Users in the UK</p>	<p>Patient Representative</p>	<p>PPI 2014</p>
<p>Pathfinder-Parental Information on Therapeutic Hypothermia Following Neonatal Encephalopathy</p>	<p>Prof. Eleanor Mollow</p>	<p>PPI 2017</p>
<p>SafeBoosC Trial under Prof. Gene Dempsey CUMH-RCT on cerebral near infrared spectroscopy &amp; a treatment guideline V's treatment as usual for extremely preterm infants during the first 3 days of life.</p>	<p>Prof Gene Dempsey</p>	<p>PPI</p>
<p>POPART Study comparing administering surfactant at the back of the throat in addition to CPAP to CPAP alone for the treatment of Respiratory Distress Syndrome</p>	<p>Patient Representative</p>	<p>PPI 2016</p>

Strider Study RCT of Sildenafil therapy in early onset intra-uterine growth restriction		PPI 2016
Neonatal and Childrens Brain Consortium Of Ireland  Creating a unique national collaborative multidisciplinary research group including parents to optimize the investigation and management of neonatal brain injury as well as providing supervision of the PhD students assigned to each of the 5 projects under the NEPTUNE arm of the consortium <b><i>www.nbc.ie</i></b>		PPI & Steering Group Member 2018 – present
Core Outcome Set for Growth restriction-developing a COS for FGR		PPI 2018
PARROT Placental growth factor in assessment of women with suspected preeclampsia to reduce maternal morbidity- a stepped wedge cluster RCT		PPI 2018
The National Childrens Healthcare Charter- developing the charter to deliver quality improvement initiatives		PPI 2013
ANP Retrieval Steering Group- developing a curriculum for Advanced Nurse Practitioner Retrieval Role		PPI 2017

RCT of cerebral oximetry combined with a treatment guideline vs tx as usual in preterm babies	Prof. Gene Dempsey	PPI 2020
COSNEON – COS for intervention studies of babies born growth restricted		PPI 2019
COSTIL – COS in Stillbirth		PPI 2019
ELICIT COS to evaluate the impact of interventions to improve decisions about trial participation		PPI 2019
EPITOME- exploring methods of participant inclusion in Delphi Studies		PPI 2018
FIREFLY- Follow-up of Inflammatory Responses and multi-organ outcomes following neonatal brain injury	Prof Eleanor Molloy TCD	PPI 2018
ICHOM – Standard Set for Preterm and Hospitalised Infants		PPI 2018
Co_Opt- Study of pregnancy treatments to prevent complications and preterm birth	Dr. Sarah Stock	PPI 2019
Serene	drug trial to prevent neonatal seizures	PPI 2018
		PPI 2018 to present

National Neonatal Therapeutic Hypothermia E-Register Development Working Group- preparing the inaugural and annual Neonatal Therapeutic Hypothermia report and developing the e-register		
Continuum Study	COVID-19 Neonatal to Adult understanding of immune responses study	PPI 2020
COMET POPPIE Working Group –People and Patient Participation, Involvement and Engagement	PPI	2019 – present
RECAP	Research on European and Adults Born Preterm	PPI 2018-present
ETAPA Early Targeted Paracetamol for PDA in Extremely Preterm Infants	Dr. Jan Miletin	PPI 2020
NUTRICEM Marie Sklodowska Curie Actions Innovative Training Networks, Call H2020-MSCA-ITN-2020	Dr. Tanya Cassidy MU	PPI 2020
Prometeus Project –developing blood oxygen & blood sugar monitoring devices to protect brain development of preterm infants. And to develop an app for families of PTB which delivers real time health information		PPI 2020
EUPATI National Platform	Patient Member	2018 - present
HRB CRCI- WG	PPI working group	PPI 2020
PEOPLE Doctoral Program RCSI- Antibiotic Resistant Microbes in the ICU	Antibiotic Resistant Microbes in the ICU	PPI 2021



BMJ Open Paediatrics	Reviewer	2018 – present
BE SAFE, safer care through Health infographics. Maternal and Newborn Doctoral Research Programme		PPI 2020
Chameleons Project	Developing a PhD programme for Finnish University	PPI 2021
Connect4children Advisory Board	Pediatric Development For Asthma	PPI 2021
In4Kids Network HRB funding application	PPI CTN-2021-007 995536, co-applicant	PPI/Executive Steering Group 2020
Margaret McCallig PhD-Whole Body Vibration Emissions in the NICU	Advisor/PPI	PhD Advisor 2020 – present
Infant Feeding In Emergencies –TUI Kevin St Research Proposal		PPI 2020
National Office For Research Ethics Clinical Trials	Patient Representative	2021
Sara Kift – PhD doctoral program – Current Practice of Developmental Care in the NICU	Advisor/PPI	PhD Advisor 2021
Cross-sectional case-control analysis using advanced echocardiographic functional parameters to compare young adults born preterm to those born at term. O Frankin	Prof. Oral Franklin OLCH	PPI 2021
NPEC Audit VLBWI	VLBW Audit	PPI 2021
Pre-Nat Hub2 Erasmus Funding Call	Developing an educational neonatal hub for educators, social care and ahps	PPI 2020

IPPOSI Patient Education Programme	Student Mentor for 11 students in the UCD/HPRA course	2021
PANTHER-Promoting Attachment In Neonatal Encephalopathy & Therapeutic Hypothermia	Collaborator, €32901.25 HRB ref 5457, 12 months, TCD	Co-Applicant 2018
PROMoting PERInatal mental HEALTH in Ireland (the PRO-PERIHEALTH project): A Doctoral training programme in perinatal mental health	Core Partner CDA-PA-2021-007	PPI 2021
Development and validation of a risk stratification tool for assessment of maternal and neonatal morbidity and mortality using data from the National Maternal and Newborn Clinical Management System	Co-applicant SDAP-2019-017 36 months €303217 1/4/20	Co-Applicant 2020-2023
IPPOSI Education & Training Advisory Group	Developing Patient Education Course for PPI	2021
Network of Childhood Illness Organisations	Founding Member & Committee Member	2019
The Safety, Short-term and Long-term Outcomes associated with Therapeutic Hypothermia in Mild HIE; A Between Centre Comparison of Hypothermic versus Normothermic infants	HRB 8920 Dr. Brian Walsh	PPI 2021
Analysing the therapeutic potential of anti-inflammatory drugs on brain development, neuronal activity & long term outcomes after	LP-POR-2022-029 Dr Eve Jimenez Mateos	Co-Applicant Aug 2021

birth asphyxia		
How mothers milk trains infant immunity	ILP-2022 Bernard Mahon, Tanya Cassidy	PPI Sept 2021
STARFISH sustained inflammation in preterm infants and multiorgan dysfunction correlates with longterm outcomes	Prof Eleanor Molloy ILP-POR-2022-055	Co-Applicant Sept 2021
Increased gut permeability;the missing link between maternal stress during pregnancy and infant neurodevelopment impairment	Dr Siobhain O'Mahony ILP-POR-2022-080	PPI Sept 2021
Reducing neonatal/maternal mortality be rapid detection of sepsis in resource-limited environments.	Prof. Sean Doyle, SFI SDG Challenge 21/FIP/SDG/9917	Co-applicant Sept 2021
Platypus - preterm perinatal inflammation and immune function in NEC and sepsis	Prof Eleanor Molloy	Co-applicant Jan 2022
PROTECT Study - study of pentoxifylline for NEC or LOS in preterm infants	Prof Eleanor Molloy DIFA	Co-Applicant PPI Jan 2023
Health Products Regulatory Authority Ireland		Patient Forum Member
PPI Ignite Network Ireland		Patient Advisory Board Member
Nectar Neonatal Encephalopathy: optimising Communication with families on Research	Prof Eleanor Molloy	CoApplicant June 2022
National Clinical Trials Office Stakeholder and Management Committee		PPI Aug 2022
Family Sleeps	Prof. Lorna Lopez & Aoife Brennan MU	PPI April 2022
AI-Preemie	Prof. Patricia Maguire UCD	PPI 2021
Neuroplast BV Stem Cell CT	Prof. Boris Kramer	PPI 2022

multi-center, double-blind, randomized, placebo-controlled, delayed-start phase II/III study to assess the efficacy and safety of Neuro-Cells in (sub)acute spinal cord injury patients		
IPPOSI PPI Working Group		PPI Representative March 2023
Together – AMR- teamwork for goals orientated enhancement of technology and healthcare policy through evidence based research in antimicrobial resistance	Dr Deirdre Fitzgerald-Hughes	Co-applicant March 2023
Camellia – Cerebral Palsy & Multiorgan Lifelong Management to Improve Outcomes	Prof Eleanor Molloy	Co-applicant April 2023
Hear My Voice - A Patient and Staff Stories Project regarding Antimicrobial Resistance (AMR) and Infection Prevention and Control (IPC), and Sepsis, knowledge, practices, experiences, and perceptions	RCSI University of Health Sciences – Prof Fidelma Fitzpatrick	Co-applicant June 2023
Expert Taskforce to Support Expansion of the Role of Pharmacy	Dept. of Health initiative	Taskforce Member October 2023 –

ALPACAS – Altering Persistent inflammation And multiorgan outcomes in children at high risk of Cerebral Palsy	Prof Eleanor Molloy –ILP-POR – 2024-054	Co-Applicant 2023
Disability in Marginalised Groups & Communities	Dr. Catherine Rossiter – National Disability Authority Research Promotion Scheme 2023-2024	Co-Applicant 2023
A deeper understanding of ‘mothers’, milk, and microbes: supporting optimal feeding practices and health outcomes	Dr Robert Leigh Maynooth University- Emerging Investigator Awards	Co-Applicant 2023
Made With Patients Global Awards Jury, Patient Engagement Open Forum	Judging best patient engagement initiatives across industry, academia and voluntary sector	Jury Member 2024
EUPATI Learning Lab Faculty Position	Developing & delivering patient engagement education to industry partners internationally	Faculty member 2024
IPPOSI Education & Training Working Group	Developing a Research Ethic’s module for the IPPOSI Patient Education Program	Faculty member 2023-2024
Medical School Poznan Poland	Delivering week long neonatal education to 4 <sup>th</sup> & 5 <sup>th</sup> year Medical Students	Faculty member 2024
PrePOP Study- preterm birth prevention with oral probiotics	Prof Fionnuala McAuliffe UCD	Co-Applicant 2023
Defining Neonatal Sepsis Consortium	Dr. Dearbhla Byrne, Trinity College Dublin	Patient Representative Feb 2024
Health Technology Assessment of Immunisation for treatment of all children against RSV	Health Information and Quality Authority Ireland	Patient Representative May 2024
Assessing Seasonal Patterns in Preterm Births and Stillbirths- a multinational analysis of preterm births and still births	Dr. Clara Calvert,Usher Institute, University of Edinburgh, Scotland	Embedded Patient Researcher Feb 2024

Developing a Model For PPI in Maternal and Neonatal Trials	Kathleen Hannon Trinity College Dublin	Embedded Patient Researcher Feb 2024 – Feb 2027
Quality and Safety Measures in Maternity & Neonatal Services in Ireland	UCD IRIS Centre & National Quality and Patient Safety Directorate and National Women and Infants Health Programme	PPI March 2024
Surgical Handover in Trials Core Outcome Set Development	Jessica Ryan, Declan Devane, Anastasija Simiceva, Walter Eppich, Dara O’Kavanagh, Christine Cullen, Aisling Hogan, Deborah McNamara, Mandy Daly	PPI March 2024
HSE Obstetric Event Support Team	To provide oversight over obstetric clinical incidents occurring within Maternity Networks	Patient Representative – 2023
IPPOSI Patient Education Program 2025	HRB Funding application to further develop the program – PI D Mitchell IPPOSI	Co-Applicant 2024