

## JLA Childhood Disability PSP Steering Group

### Family Representatives

#### Mary Busk

National Network of Parent Carer Forums



*"I am delighted to be involved in this important work for the benefit of children with neurodisabilities and their families. I would particularly like to see the same media interest and attention being given to research outcomes and priorities for our children as currently is the case for other patient groups."*

Mary Busk moved to London over 20 years ago and has three children aged 14, 12 and 10. The process of diagnosis for her now 12 year old, severely learning disabled son was long and negative. As it did not make clear what his needs were, she had to create pathways to diagnoses and care herself.

Recognising the negative impact battling has on families and the benefits of prevention and early intervention, she works with like-minded parents through her local Parent Carer Forum to push for the changes needed in culture and ways of working in health, social care and education to deliver quality, integrated services. She is also the London representative on the National Network of Parent Carer Forums Steering Group.

#### Maureen Morris

National Network of Parent Carer Forums



*"I am delighted to be involved with the Priority Setting Partnership for the James Lind Alliance. Research is so important to the understanding of neurological disability in children like my daughter. Through research there are endless possibilities for her to reach her full potential"*

Maureen lives in Tyne and Wear with her husband and 2 adopted children, Alex who is now 23 and Caitlin who is now 20. At the age of 3 Caitlin was diagnosed as being on the Autistic Spectrum. As she became older other disabilities became obvious and she now has a range of diagnoses of both neurological and physical disabilities. Maureen became involved with her local Parent Carer Forum from its inception in 2008. She is currently the Chair of her local Forum and the regional representative for the North East with the National Network of Parent Carer Forums. Caitlin is currently undertaking a Land Management course at college and enjoys working with the animals

## Third Sector Representative

### Amanda Allard

Principle Officer  
Council for Disabled Children



Amanda has worked in children's policy both as a researcher and campaigner for the last 22 years first for The Children's Society and NCH (now Action for Children) and latterly as Head of Policy and Communications for TreeHouse, the autism education charity. During that time she has covered a diverse range of areas including youth unemployment, leaving care, homelessness, family support and issues facing disabled children and their families. Amanda is passionate about participation and whilst at NCH developed a charity award winning youth arts participation project.

Amanda has researched and written extensively on issues affecting disadvantaged groups of young people.

After a period as a freelance consultant Amanda is now Principal Officer at the Council of Disabled Children. Amanda's areas of responsibility include health, participation and communications.

## Clinical Representatives

### Chris Morris

Allied Health Professional & Senior Research Fellow in Child Health  
University of Exeter



*"It's so fantastic to be starting out on this project after all the proposing, persuading and planning. It will be really great to identify the top 10 research ideas that are important to both families of disabled children and clinicians, and would make a difference to children's health and wellbeing."*

Chris leads PenCRU: the Peninsula Cerebra Research Unit at the University of Exeter. PenCRU carries out a broad programme of applied health services research aimed at evaluating ways to improve the health and wellbeing of disabled children and their families. He also has many years experience working with children and families as an orthotist. Chris is part of the Strategic Research Group of BACD and initiated the idea for a research priority setting partnership after hearing Katherine Cowan present the work of the James Lind Alliance.

**Doug Simkiss**

Consultant Paediatrician & Associate Professor in Child Health  
University of Warwick



*"I was keen to join this priority setting partnership as I think it is an excellent way to identify the most important research issues in childhood disability."*

Doug works as an Associate Professor in Child Health at Warwick Medical School and also as Clinical Director of the Children and Families Division of Birmingham Community Healthcare NHS Trust where he works as a Consultant Paediatrician in a Child Development Centre and a Special School. His involvement with disability issues goes back to school when he went to Bruges as a helper for a man with spina bifida. He was involved with the Phab Club in Sheffield when he was a student, and now provides clinical care for children with disabilities and undertakes research on health issues.

**The Partnership and the priority setting process will be supported and guided by**

**Katherine Cowan**

The James Lind Alliance (JLA), Chair of the Childhood Disability Research PSP



Katherine is the chair of the Steering Group and have been working with the JLA for almost five years. She chairs a number of our Priority Setting Partnerships and also co-wrote and edit the JLA online Guidebook on research priority setting. Her role is to ensure the process is undertaken in a fair, rigorous and transparent way, with input from families and healthcare professionals, and their representatives.

**Mark Fenton**

UK Database of Uncertainties about the Effects of Treatments (UK DUETs)



Mark Fenton started his working life as a Mental Health Nurse. He has since undertaken training in psychoanalytic psychotherapy, sociology, and epidemiology and has worked clinically in acute mental health inpatient units.

He then worked at the Centre for Evidence-Based Nursing at the University of York and the Cochrane Schizophrenia Group at the Universities of Leeds and Oxford. He is also an editor with the Cochrane Schizophrenia Group.

For the last seven years he has been Database Editor of the UK Database

of Uncertainties about the Effects of Treatments (UK DUETs) which was established by the James Lind Initiative, who are funded by the Medical Research Council and the Department of Health. Mark is now employed by the National Institute for Health and Clinical Excellence (<https://www.evidence.nhs.uk/> and <http://www.nice.org.uk/>). UK DUETs can be seen at <http://www.library.nhs.uk/duets/>, and the James Lind Alliance at <http://www.lindalliance.org/>

### Kelly Robinson

Administrator  
British Academy of Childhood Disability



Kelly has worked at the Royal College of Paediatric & Child Health for 7 years, initially providing support to the community child health and paediatric neurodisability specialty groups, and for the past 2 years has worked solely for the British Academy of Childhood Disability. Prior to this, she worked for an international obesity NGO and for a national palliative care association.

She is the proud owner of 2 dogs, Ralphie, a very energetic Hungarian Vizsla, and Lizzie, a rescue Vizsla-cross from Cyprus.

### Previous Members of the Steering Group

We would like to thank Anna Walker, representing the National Network of Parent Carer Forums, for her valuable contributions to the project



Anna lives in Cornwall with her partner Mike, 18 year old daughter Susie Jo, and 13 and 15 year old boys Herbie and Matthew. Susie Jo was born with a range of conditions which affect her sight, mobility and learning. She wears prosthetic eyes and is registered deafblind, uses a wheelchair to get around and has a number of diagnoses which include cerebral palsy and autism. Susie also has a condition called septo optic dysplasia which affects her growth and hormone production and is on daily medication for this.

The specialist college Susie-Jo attends delivers an integrated programme of education, social skills and therapy. She is in receipt of a personal budget and all her care and support when she is at home is arranged by her family

Anna is in her last term as the southwest representative on the National Network of parent Carer Forums. She runs her own training and consultancy company and is involved in a range of projects relating to disabled children, young people and their families. She is also a lay panel member for the Nursing and Midwifery Council, sitting on their Fitness to Practice panel.