ELIJAH
6 weeks early

DILLON
13 weeks early

JASPER
3 weeks early

2005 – Miracle Babies Foundation

2012

- The uptake into trials is low
- It makes sense
- It’s policy

Policy

Australian National Health and Medical Research Council (NHMRC)

In 2004, *encouraged* the 'appointment of consumers as decision-makers in research..'

Policy

INVOLVE

Funded by the UK National Institute for Health Research (NIHR) where it states

“our research is carried out with, or by, the public rather than to, about, or for the public.”

- Driven by the needs of patients and public
- Engaged at every stage
- No funding is allocated unless consumers have been engaged

INVOLVE

NHS
National Institute for Health Research

newsletter

Winter 2012-13

Welcome

From Simon Denegri, Chair of INVOLVE

A warm welcome to the Winter issue of the INVOLVE newsletter.

Perish the thought that you are stranded by

In this issue:

Welcome 1
INVOLVE Coordinating Centre news 2
Interesting articles and publications 4
Supporting PPI in paediatric research 5
PEOPPLE project 6

Since 2012

Appointed Honorary Research Associate, NHMRC Clinical Trials Centre

First parent to be an Associate Investigator on a NHMRC neonatal trial

Joined PSANZ Consumer Advisory Panel (CAP) and Clinical Trials executive committee

Joined the NHMRC Clinical Trials Ready Development Committee

Contributed to the dissemination of the results of BOOST II and APTS trials

Assisted in obtaining a waiver of consent for the TORPIDO 30/60 Trial

Led the consumer contribution to the Australian arm of the FiCare Trial

Chief Investigator on WHEAT Trial

To date, co-authored 16 publications.

Contributor to THRIVE Global with 5 published articles to date

Inaugural Consumer Involvement Award: Australian Clinical Trials Alliance 2019

How do we take this further

Large scale perinatal trials

1

Train and Educate Patient as Partners

2

Create a Global Register of Parent Partners

3

Parent and Consumer Led Priority Setting