Parent Knowledge Network Session summary: Clinical trials

This session of the Parent Knowledge Network featured Jen (Dylan and Jason's mum) and Eli (Hannah's dad) discussing the topic of clinical trials. Each parent shared their different experiences of clinical trials – from first finding out about them, eligibility, impact on family life and choosing to take part in research to help future families (even if your own child may not benefit directly).

This session highlighted how unique and diverse the set of factors are which combine to determine whether or not a child or young person will even be eligible for a clinical trial. There may be parts of this month's session which parents listening may find challenging due to this variance in eligibility for families living with Childhood Dementia. If after listening to the recording, you would like to talk to us our contact information can be found at the end of this document.

Finding out about a trial

Jen shared how quickly a trial can move from seeming out of reach to becoming a real option, along with the recognition that this was their personal experience. A few days after her son Dylan's diagnosis, a family member sent her information about a trial. What at first looked like an exclusion due to age cut-off limitations turned into a possibility of participation which (with the support of their team in Australia) led to their family being accepted to a trial with days to spare. Jen's advice to other families was to actively enquire about trial eligibility (even if your child does not appear eligible) as information online is not always up to date and, with childhood dementia, time is such a key factor. Jen was also clear to highlight how eligibility was not guaranteed and involved multiple stages of testing - so advised being prepared to accept this as a part of approaching trials.

Knowing where to look

Both parents spoke about looking beyond the information first given at diagnosis. Jen reflected that after the diagnosis she did not know where to start, and if she were in that position again, one of the first things she would do is look for clinical trials (see resources section). Hannah's dad Eli reflected on being given a research paper about Hannah's condition at diagnosis, and pointed out that researchers' email addresses are usually listed on published papers, and typically welcome hearing from families whose children have the condition they are studying (even if a current trial may not be suitable). Searching trial websites and contacting researchers directly are both ways families can find out what research is happening for their child's condition.

As these websites and papers can be hard to work through without a health or research background, families may also want to consider asking for support before commencing searches.

The impact on the whole family

Taking part in a trial can ask a lot of a family beyond the treatment itself. For Jen's family, Dylan's treatment overseas meant being split across 2 countries for over 4 months. Jen and her partner took turns staying with Dylan while also caring for his sibling, who had weekly treatment requirements back home in Australia. Jen described the separation as the hardest part, even though said she would do it again in a heartbeat - the reality of spending Christmas in hospital, and being separated did take a toll too. The family impact side of a trial may only become clear once you are living it and Jen's story also reflects how families may need to make decisions about who travels, who stays and how to stay connected if a trial is taking place interstate or overseas. Jen also noted that costs and support can vary greatly between trials. While their family had few out-of-pocket costs and was offered access to a psychologist, Jen shared being aware of some families who have needed to fundraise to take part. It can help to ask early what a trial will cover.

Taking part for future families

Eli's perspective highlighted another reason families may choose to engage in research and trials. After reaching out to a researcher who was initially recommended to them, his family learned about a U.S. clinical trial focused on Hannah's condition, but soon found out that she was ineligible and the trial could not offer direct help. Facing the emotional shift of a fleeting moment of hope, Eli spoke about how he and his family have redirected their focus toward celebrating Hannah's life and cherishing their time with her. Although they understand that existing clinical trials will not directly aid Hannah, they have chosen to participate in specific medication development trials, recognizing that while these efforts will not offer Hannah direct benefits, they will play a role in assisting future children diagnosed with the condition.

Eli explained that research into rare conditions relies on families taking part, and the information gained from each child can lead to better diagnosis and treatment for the next family. He spoke about wanting to change the moment when the next parent is told their child has a condition that causes childhood dementia, so there is more to offer them. For some families, taking part in research is a way to contribute to change across childhood dementia conditions more broadly, even when there is no direct benefit for their own child.

Hope can take different forms

Both parents spoke about hope, and how painful it can be when it is taken away. Eli described a brief moment of hope when he learnt of the trial in the United States, and the hurt that followed. Jen spoke of her gratitude that Dylan is now home and doing well after participating in a trial, alongside the pain of seeing her 2 sons on different paths, as her older son's condition has progressed. Eli reflected that hope is not binary. The hope of a cure for Hannah is one he has chosen not to hold on to, while the hope that what is learnt from Hannah's life will help other children is one he holds onto. Families may find it useful to reflect on what they are hoping for in the search for trials - and how this sits alongside the hope (and available time) they have during life with their children

Reflections from the group discussion

In the discussion that followed, parents shared that most children are not eligible for clinical trials, and that taking part asks a lot of families. It was noted that support is needed both for families whose child gets into a trial and for those whose child does not. Parents also spoke about the sense of purpose that can come from knowing their child's involvement in research may help others. Legacy was a shared theme, with parents describing ways their child's life can help future families, including through research, organ donation, fundraising and advocacy. It was noted that each piece of information gathered adds to the bigger picture, and can lead to treatments or trials being available for families in the future.

Helpful resources discussed in the session

- Clinical Trials (US) main website: A searchable database maintained by the U.S. government that provides comprehensive information on publicly and privately funded clinical studies worldwide. This is recommended as a good place to check what trials are currently available/upcoming for specific conditions.
- Childhood Dementia Global Clinical Trial Landscape Analysis: 2024 Report written by Dr Kristina Elvidge (Head of Scientific Affairs) and Megan Maack (Director and CEO). The report explores the state of clinical trials for childhood dementia. Its findings highlight a severe lack of global trials, particularly gaps in the trial landscape in Australia. The report is being used by CDI in advocacy for more research and clinical trials and will be of interest to families wanting to gain more understanding

on that broader context - however is not intended to give specific condition specific trial recommendations.

If you would like to discuss any of the content of this months' session and how it might relate to your family - please reach out to our Services team services@childhooddementia.org

To view the recording from this session, please register to become a member of the Parent Knowledge Network. Presentation recordings will be shared with members during the monthly reminder emails. Here is a reminder of the Parent Knowledge Network Community Guidelines.

Date: September 2026. This written summary reflects the transcript from the parent lead presentation.