

Rare Kids Nurse Navigator Program

The Sydney Children's Hospital Network is piloting a 3-year pilot project as part of an Australian government funded grant led by Rare Voices Australia.

Our aim is to:

- provide targeted, nurse-led support for children and young people with rare conditions
- raise awareness about rare diseases
- provide professional development opportunities for health professionals
- empower families to navigate the health system.

Who can we help?

We are funded to provide extra support to families of the Sydney Children's Hospital Network with a rare or suspected rare condition where access to resources or support is particularly challenging. This may include families with one or more of the following factors:

- family is of Aboriginal or Torres Strait Islander heritage
- has an ultra-rare condition
- child has a parent with an intellectual or other disability
- family lives in rural or remote NSW
- family is of a culturally and/or linguistically diverse background
- young person is of close age to transition out of paediatric services without an active transition plan
- refugee or asylum-seeking family
- family with unaddressed mental health and wellbeing needs
- child is in out of home care setting
- family has low socio-economic resources
- more than one child with medically complex care requirements.

Any questions? Get in touch!

Email: SCHN-rarekids@health.nsw.gov.au
Phone: 0475 382 737

