

Are you, or have you been, the caregiver for a person who was diagnosed with an inherited retinal disorder (IRD) before they turned 18 years old?

I am a PhD student undertaking a research project at the University of Technology Sydney. The study aims to explore how caring for a person diagnosed with an IRD as a child impacts the carers' life and if the impact changes as the person being cared for gets older. I am interested to understand the social, emotional, physical and financial impact of being an unpaid caregiver (you might be the parent, child, spouse, family member for example).

So, if you

- Are or have been a caregiver (unpaid), who speaks English and resides in Australia,
- The person you care for has an inherited retinal disease (IRD) such as Leber congenital amaurosis (LCA), severe early childhood-onset retinal dystrophy (SECORD), early-onset severe retinal dystrophy (EOSRD), or retinitis pigmentosa (RP) for example, that they were diagnosed with prior to turning 18 years of age, and
- The reason that you are caregiver to the person with IRD is only because of their visual impairment due to the inherited retinal disease, then

I would appreciate it if you could share your experience with me,

Please email me at Maria.H.Kokoszka@alumni.uts.edu.au if you are interested in participating

I plan to conduct focus group interviews with up to 5 caregivers. The focus groups will either be face to face in Sydney or via videoconferencing (virtually) using MS Teams, depending on whether we have 5 respondents from Sydney. The focus group discussion will take between 1 to 2 hours of your time. You will be offered compensation for travel to the focus group venue and parking.

UTS Centre for Health Economic Research and Evaluation (CHERE)

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