



PRESS RELEASE

FOR IMMEDIATE RELEASE: 9 March, 2023

BDSRA Australia has announced the winners of its annual Batten Disease Research Grant Program, with a total of over \$120,000 awarded to three projects to be carried out in 2023.

Chief Investigator (CI) Dr Nadia Mitchell from Lincoln University NZ, has been awarded \$54,545 for her continued work in the development of gene therapies for the treatment of CLN5 and CLN6 disease, respectively; CI Lottie Morison from the Murdoch Children's Research Institute has been awarded \$13,950 for work in characterising speech and language deficits in Batten disease; and CI Associate Professor Tony Cook from University of Tasmania is awarded \$53,612 for his continued work in patient-derived stem cell models of CLN3 disease. CI Cook's project will be co-funded by the Texas-based Beyond Batten Disease Foundation.

"We are very proud to support this world-class research right here in the Australia/New Zealand region," said Dr Ineka Whiteman, BDSRA Australia's Head of Research and Medical Affairs. "Dr Mitchell and A/Prof Cook's projects aim to answer important questions in the translational research space, where basic science discoveries can be applied in large animal and human cell models. This essential research will help bring us another step closer to trialling potential therapies in human patients."

Beyond laboratory-based research, BDSRA Australia President, Amber Rundle, is pleased to see an allied health-focused project awarded in this year's round. "Speech and communication problems in Batten disease are prevalent and represent some of the greatest challenges in the management and day-to-day life of affected children and their families", she said. CI Morison's project aims to characterise speech and language decline in the two most common forms of Batten Disease (CLN2 and CLN3 disease). "Phenotyping the speech and language symptoms in Batten disease has not been done before," said Ms Morison, "and we believe these may be a valuable measure of disease progression and may serve as useful biomarkers for assessing the efficacy of precision medicine trials."

Since the inception of BDSRA Australia's competitive Research Grant Program in 2020, the organisation has awarded more than \$400,000 toward Batten disease research. Funding is made possible through the generous donations and support of the region's Batten disease community.

Further details on the successful projects and research teams can be viewed on the BDSRA Australia website at <https://bdsraaustralia.org/research>.

The organisation awards grants annually across Australia and New Zealand through a competitive application and review process. For more information visit <https://bdsraaustralia.org/research>.

About BDSRA Australia

BDSRA Australia is a not-for-profit patient advocacy organisation dedicated to improving the lives and well-being of patients and families affected by Batten disease through family support, funding vital research, and advancing education and awareness. For more information visit <https://bdsraaustralia.org>.

Media Contact:

Dr Ineka Whiteman, Head of Research & Medical Affairs

M: + 61 (0)402 843 885 **E:** research@bdsraaustralia.org