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May 15, 2026

Batten Disease Global Research Initiative Announces 2026 Research Grant Recipients

The **Batten Disease Global Research Initiative (BDGRI)** is proud to announce the recipients of its 2026 Research Grant Round, with a total of USD $150,000 awarded to three innovative Batten disease research projects.

Following a rigorous international review process, the selected projects were chosen for their scientific merit, translational potential, and alignment with the top Research Priorities for Batten Disease, identified within the BDGRI Research Strategy.

The 2026 Grant Recipients and funded projects are (in alphabetical order):

Professor Alex Hewitt
Menzies Institute for Medical Research, University of Tasmania, Australia
Project Title: *Determining the gene correction threshold required to cure CLN2 disease*
Award: USD $50,000

Associate Professor Ruchira Singh
University of Rochester Medicine, New York, USA
Project Title: *Preclinical studies comparing potential therapeutics in a patient-derived human retina cell model of CLN3 Batten disease*
Award: USD $50,000

Associate Professor Tim Yu and Professor Milen Velinov
Boston Children's Hospital and *Rutgers Robert Wood Johnson Medical School, USA*
Project Title: *An Antisense Therapy for DNAJC5 Knockdown in CLN4 Batten Disease*
Award: USD $50,000

These approaches are designed not only to deepen scientific understanding but to accelerate translational pathways toward real-world therapies for affected individuals and families. From personalised genetic medicines to advanced human cellular disease models, the 2026 grant portfolio highlights a growing era of innovation and hope across multiple forms of Batten disease.

"For families living with Batten disease, this research is far more than a scientific endeavour - it represents hope for more time, more quality of life, and ultimately a future where no child is lost to these devastating disorders," said Dr. Ineka Whiteman, Director of the BDGRI. "These

projects embody both scientific excellence and the urgency felt by families around the world who are waiting for better treatments."

In a significant development for the Batten disease research landscape, in late 2025, BDGRI partnered with the **Batten Disease Clinical Research Consortium** (BDCRC), a National Institutes of Health (NIH)-funded consortium based in the United States, to identify eligible BDGRI applicants for consideration through the new BDCRC Pilot Project Award mechanism. Associate Professor Singh's project was selected through this collaborative process and will receive $50,000 funding directly through the BDCRC Pilot Project Award.

The BDGRI consortium is also proud to acknowledge the generosity of its 2026 Funding Partners, **Jack's Thousand Days Foundation** and the **Allandale Foundation**, whose contributions helped strengthen this year's research funding pool.

"The BDGRI consortium has been privileged to fund great research into Batten disease," said BDGRI Committee Member, Dr. Joanna Nightingale. "This type of investment, dedicated to areas of Batten disease identified as being of significant importance to the wider community, is often the catalyst that enables innovative, early-stage research to move forward and ultimately attract larger-scale funding and translational opportunities."

The integrity and robustness of the 2026 grant review process were supported by a distinguished international Grant Review Panel comprising sixteen experts - including eight scientists and eight clinicians from seven countries.

For more information about the Batten Disease Global Research Initiative and the 2026 Grant Projects and Investigators, visit **BattenResearch.org**.

About the Batten Disease Global Research Initiative

Founded in 2024, the Batten Disease Global Research Initiative (BDGRI) is an international consortium of leading patient advocacy organizations united by a shared mission to accelerate research for all forms of Batten disease, also known as the neuronal ceroid lipofuscinoses (NCLs). Guided by the top **Research Priorities for Batten Disease**, BDGRI aims to invest in the most promising research worldwide to advance understanding, improve care, and drive the development of future therapies.

The founding members of BDGRI are the **BDSRA Foundation** (US), **BDSRA Australia**, BDSRA Canada, and **Batten Disease Family Association (BDFA UK)**.

What is Batten Disease?

Batten disease, commonly known as the neuronal ceroid lipofuscinoses (NCLs), is a group of rare, inherited neurodegenerative disorders that primarily affect children and young people.

Caused by genetic mutations that impair lysosomal function and lead to the accumulation of toxic waste material within cells, Batten disease is progressive and devastating.

Symptoms commonly include vision loss, seizures, cognitive decline, loss of speech and language, severe motor impairment, and premature death. There are 13 known forms of Batten disease, classified according to the affected gene (CLN1–CLN14 disease; there is no CLN9 gene).

While there is currently no cure, ongoing advances in gene therapies, enzyme replacement therapies, antisense oligonucleotides, and small-molecule approaches continue to offer hope for future disease-modifying treatments.

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