



Dear Families and Friends

It has been a difficult year. However, during 2020, BDSRA Australia has awarded over \$177,000 for research in Australia and New Zealand; launched www.bdsraaustralia.org; established a collaboration with Dementia Support Australia to provide 24/7 support to our families; engaged a qualified social worker to support to families in crisis; and kept our families connected through monthly zoom 'coffee catch ups' and our 'meet the expert' series.

All of this has been possible due to the hard work of our supporters and volunteers – all people who care deeply about making the life of families living with Batten disease easier. I thank them, and you, for your continued support.

Help us turn hope into a cure with a tax deductible donation at: <https://bdsraaustralia.org/index-donate.php>

Have a safe and happy holiday.

December 2020,
Kate Beattie



Dementia Support Australia support services available to families

BDSRA Australia is excited to announce the launch of Dementia Support Australia's (DSA) Batten disease support service. This is a free service for all families and carers needing additional support and guidance around the challenging behavioural aspects of Batten disease.

"I never really thought of my child as having 'dementia', but now that I have learned more about it and the

behaviours and challenges that come with childhood dementia, I can see how clearly relevant this is to us. I want to know more about how we can better manage the dementia aspects of her illness.” - CLN2 mum

DSA is ready to support you with a phone or in person assessment of your child, advice, strategies and written recommendations tailored specifically to your child about managing the difficult behaviours associated with Batten disease, together with on-going support and guidance to implement those recommendations. Families can access this support 24/7, 365 days a year by phoning 1800 699 700 or through a self-referral at www.dementia.com.au. Please see [here](#) for more details.



2020 BDSRA Australia Research Grant Winners

BDSRA Australia has recently awarded more than \$177, 000 as part of the new Australia and New Zealand Batten Disease Research Grant.

“Given that it is the first year of the research grant program, we were not sure what sort of local interest there might be. Those concerns quickly dissipated when we saw the number and quality of applications from across both Australia and New Zealand” said Dr Ineka Whiteman, Head of Research, Medical and Scientific Affairs for BDSRA Australia. “We are very proud to support such world-class, promising research right here in our region.”

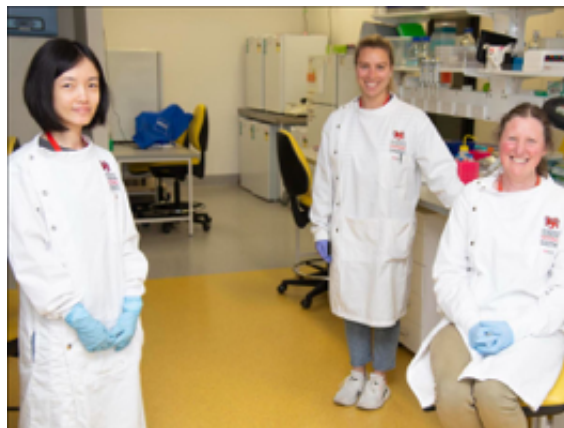
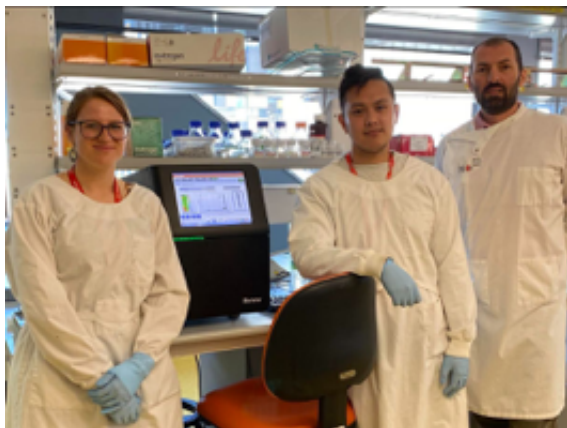
The funding will support one-year research projects through 2021 that aim to increase our understanding of Batten disease and have the potential to advance therapeutic strategies.

The grant recipients are:

- Professor Alex Hewitt from the University of Tasmania for the project entitled *Development and validation of a gene editing therapy for CLN2-related disease*, with the award of \$50,000 (left top)
- Associate Professor Anthony Cook from the University of Tasmania for the project *Isogenic induced pluripotent stem cells (iPSC) models with CLN3 variants for high throughput drug screening* (\$49,000) (right top)
- Dr Nadia Mitchell from Lincoln University (NZ) for the project *Advancing gene therapy strategies and natural history studies in ovine CLN5 and CLN6 Batten disease* (\$AU 56,440) (left bottom)
- Associate Professor Ronald Clarke from the University of Sydney for the project *Membrane interaction of small molecules capable of improving Batten disease cell phenotypes* (\$21,256) (right bottom)

BDSRA Australia thanks our Medical and Scientific Advisory Board for assisting in the selection of the successful projects. Congratulations to all our recipients!

Further details on the successful projects and research teams can be found on our website at www.bdsraaustralia.org/research



Harper's Wish

Harper recently fed the giraffes and zebras at the Melbourne Zoo and enjoyed a private tour of the Melbourne Sea Life Aquarium as part of his Make-a-Wish. Thank you to Make-a-Wish Australia for giving Harper's family a day full of smiles. You can read Harper's story [here](#).



ASX Refinitiv Raffle

Do you want to win a Mazda Auto Hatch G20 or a Lenovo 11.6 Convertible Chromebook? You might not, but you can certainly help BDSRA Australia by trying. BDSRA Australia receive all funds from sales of raffle tickets in the ASX Refinitiv Charity Foundation raffle via the link below... good luck everyone:
<https://www.asxrcfau.com/console/rafflepages/2>

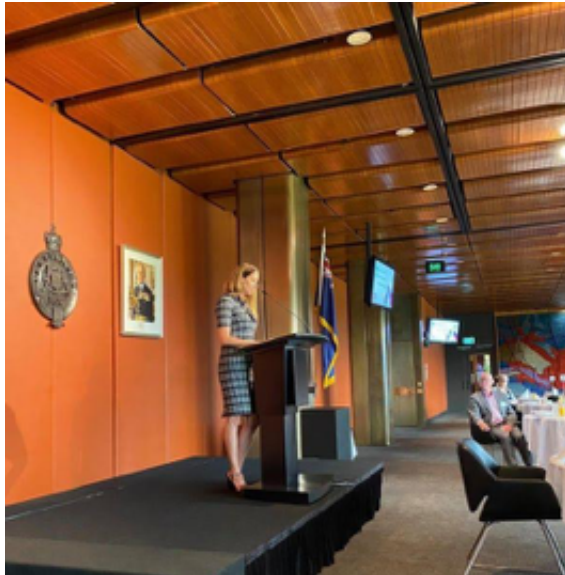
A message from our Family Support Officer, Jen Buchanan

A number of families have asked about guardianship and administration in circumstances where their child or children with Batten disease can no longer make decisions for themselves or are making decisions that are putting them in danger. Up to the age of independent decision making (which differs between States and Territories, but is

typically from 16 to 18 years old), a parent can make decisions for their children. After that, a concerned person can apply to appoint a Guardian and/or Administrator, most commonly, a family member. If you wish to discuss this further, please get in contact with Jen (support@bdsraustralia.org) or contact your local legal aid or community legal advisory service.

Batten disease and the Childhood Dementia Initiative

There is an estimated 700,000 children and young people living with dementia worldwide. Amber Rundle and Bobbie Riddle recently represented BDSRA Australia at the launch of the Childhood Dementia Initiative (CDI) at Parliament House in NSW. Childhood dementia is caused by more than 70 individual genetic conditions, with Batten disease being one of the most common. CDI seeks to drive research to find solutions for children and families across the world that suffer from childhood dementia. More information can be found [here](#).



New resources available at www.bdsraustralia.org

The following two resources are now available on our website.

- “The potential role of music to enhance the lives of children and young people with NCL (Batten disease)”: an investigation into the potential role of music to enhance the lives of children and young people with Batten disease. To read the report, head to our Resources page at www.bdsraustralia.org/resources.
- A 'Clinical trials resources for families' brochure with information on the clinical trial process, understanding key clinical trial terms and definitions, and how to stay up-to-date on latest clinical trial news. There is also a short video tutorial 'How to search for clinical trials' in the 'ClinicalTrials.gov' global database, presented by our Head of Medical & Scientific Affairs and Head of Research, Dr Ineka Whiteman. To access these resources go to: <https://bdsraustralia.org/resources>

Our supporters

BDSRA Australia was recently one of the beneficiaries of the ASX Refinitiv Charity Foundation 'Charity Trading Day', with the ASX donating 100% of funds received from cash market trading and Nabtrade donating 100% of brokerage raised on the day. We wish to thank ASX Refinitiv Charity Foundation for their continued support: see [here](#), [here](#) and [here](#).

The wonderful women of the Country Women's Association of Victoria Inc recently raised over \$33,000 for BDSRA Australia from their Thanksgiving Fund: see [here](#). We thank the CWA for this incredible effort, and the kindness and charity they have shown to our families.

A further big thank you to the 32 NRL fanatics and golfers who joined together to watch the State Of Origin, compete for the coveted golfing 'Blue Jacket' and raise \$2500 for BDSRA.

We also thank everybody who donated to BDSRA Australia recently, especially during this difficult year, including everybody who bought a 'Burn for Batten' hand poured Crackling Candle Co candle, raising over \$1500 for BDSRA Australia. Your support allows us to provide essential services to our families.

You can support BDSRA Australia by giving at <https://www.givenow.com.au/battendiseasesupport>



Personal Details Update: For all our families, so we may keep you informed and up to date, if your circumstances or contact details have changed, please inform Julie Ojeda:

info@bdsraaustralia.org.au

