

NEWSLETTER
Spring 2023 Edition



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President's Report



Photos: Bobbie with daughter Tayla (left), Daisy with Lilly, Kyle and Theo (right)

On Friday 17th November we held our AGM which was a comprehensive reflection of what has been another significant year for BDSRA Australia.

Perhaps one of our most significant and very recent achievements this year, with endless gratitude and thanks to our incredible Ineka Whiteman who has been instrumental in making this happen, is the announcement that Australia has been selected as one of the sites for the **Theranexus and BBDF Batten-1 CLN3 clinical trial** commencing in 2024. This is a remarkable outcome for our Australian CLN3 families and will bring us one step closer to having the first treatment for CLN3 approved by the FDA. Without stealing too much of Ineka's thunder I will let her expand on this further in her report below.

At the close of this year's AGM we said **goodbye and thanks to Bobbie Riddle** who stood down as an ordinary board member. Bobbie has been a volunteer and management committee and board member collectively for 7 years. In this time Bobbie has made huge contributions to the association through her Hope 4 Tayla quest, sharing her lived experience with our community, researchers and CDI, advocating fundraising efforts, Facebook birthday fundraisers, selling Burn for Batten candles and other BD merchandise, organising our kids program at the 2022 family retreat and most recently, took over from Meg, our relationship with the ASX Refinitiv Charity Foundation of which Bobbie has worked hard to source several silent auction items for their fundraising events. We will miss Bobbie's 'no problem, can do' attitude, her honesty and sense of humour. We thank her for all she has done and support her as she goes onto spend more time with her family and continue focusing on supporting her beautiful Tayla.

Taking over from Bobbie, we **welcome Daisy Hamilton** to the board! Daisy lives in Queensland and works as an Early Years Specialist in Early Intervention for an NDIS partner organisation called EACH. Daisy also has 10 years' experience in early childhood education, having worked as both a teacher and director for a number of different childcare centres, including two years working in Qatar. Daisy has a Bachelor of Teaching (Early Childhood) from the University of New England and is about to complete her Education Certificate IV in Allied Health Assistance (Occupational Therapy). We are so grateful to welcome Daisy to our Board, and know that her valuable skill-set and drive will be a great asset to our organisation.

And just like that it's Christmas time!! If you haven't bought your **ASX raffle tickets** yet I encourage you to make the most of the festive season and use the tickets as a gifting opportunity to family and friends, teachers, therapists, support workers or anyone else who supports you. It's a great way to say thanks and make a meaningful difference at the same time. Profits from every ticket sold through our unique online portal go directly to BDSRA Australia. You can secure your tickets now using [this link: BDSRA Australia raffle tickets \(asxrcfau.com\)](https://asxrcfau.com).

I'd like to wish all our Batten children and siblings, families and friends a very happy and safe Christmas filled with joy and laughter, while we also give thanks and reflect on the lives of our precious passed angels and think of their families and loved ones at this time of year.

As we come to the end of another year I'd also like to acknowledge and give thanks to the incredible contribution our Board and Management Committee members make towards the association, the families and community we support. All members bring their own strengths, insights and ideas to the table, giving our monthly meetings great purpose with much robust and constructive discussion, even if we do always talk into the night! Everyone works collaboratively and harmoniously and contributes with heartfelt passion to our cause and our mission. The majority of our members are mothers of affected or passed children and are volunteering their time in between the day-to-day grind of living with Batten disease, being a fulltime carer and balancing work and family life, which is no easy feat.

Warmest regards,
Amber

Congratulations



*Photo: Vanessa and family with the Governor
(left to right) Cody, Her Excellency the Honourable Margaret Beazley AC KC, Vanessa OAM, Graeme and Tasmin.*

As many of you may already be aware, our very own Vanessa Anderson was recognised on this year's 2023 King's Birthday Honours List and was awarded the Order of Australia (OAM) medal for her service to the community, in particular through Batten Disease awareness. This is a remarkable achievement and Vanessa is truly deserving of this incredible recognition.

Vanessa has been raising awareness and fundraising for Batten disease since her son, Jordan, was diagnosed with the late infantile Batten disease in 1996. Jordan passed away in 2002. Vanessa joined BDSRA Australia in 2000 and managed BDSRA Australia from 2001 until 2015. She has held various leadership roles since then and remains involved to this day, currently in the position of Public Officer of BDSRA Australia.

We congratulate her and say a huge thank you for all she has done for our families and our organisation over the last 22 years.

For the full story and Vanessa's photos, read [here](#).

[View the recording](#) of the official Investiture Ceremony, where Vanessa was awarded her OAM medal - Ceremony 11: Wednesday, 20 September 2023, 10:00am

with Dr Ineka Whiteman, Head of Research and Medical Affairs

NCL2023 Congress Research Report

International Congress on Neuronal Ceroid Lipofuscinoses, Hamburg, Germany
26 to 30 September 2023

I was excited to attend NCL2023 in September in the beautiful city of Hamburg, Germany. Attended by over 200 in-person delegates, this bi-annual meeting provides a forum for scientists, clinicians and biotech industry partners to present and discuss the latest advances in basic science, translational and clinical research across all forms of Batten disease. Below is daily overview from the scientific program.

Day 1: A Global NCL Patient Group meeting was held, which I was privileged to co-chair with Dr Frank Stehr from the NCL Stiftung, Germany. Eleven patient groups and six industry companies attended, with discussions focusing on potential collaborative initiatives. Biotech partners delivered clinical program updates and engaged in open dialogue with our patient groups.

Day 2: Basic Science day: today's presentations detailed the latest discoveries in NCL biology, novel roles and functions of various NCL-related genes and proteins. Researchers showcased cell and animal models of NCL, in addition to new biomarkers that serve as useful, objective indicators of disease progression.

Day 3: Translational Research day: presentations focused on therapeutic approaches to treat various forms of Batten disease, including small molecule, cell- and gene-based therapies.

Day 4: Clinical Research day: clinician investigators and biotech companies presented some of the latest results from new and ongoing in-human clinical studies. This is an exciting time for NCL therapeutic development, with seven studies currently active around the world, including treatments with gene therapy, small molecules and repurposed drugs across four forms of Batten disease, and several others in the pipeline (a summary of all studies can be viewed here: <https://bdsrafoundation.org/research/clinical-studies/>)

In the poster sessions, I was pleased to present research on the CLN3 disease timeline of symptom onset and progression, developed in collaboration with leading clinicians from USA, Germany, Denmark and Australia. We will share more on this work in the near future.

Day 5: Family Day: This is an NCL congress tradition, where families are invited to attend a half-day session dedicated to them. Lay summaries from all the scientific and clinical talks from the week (there were over 60!) were presented to families, with time for questions and discussion. At lunchtime, a 'Marketplace' was set up for families to visit booths with information about specific research projects, clinical trials, patient resources, advocacy groups and more.

We would like to thank Co-Chairs Dr Angela Schulz and Prof. Jonathan Cooper for the extraordinary work and efforts in bringing this event and scientific program together.



NCL2025 announcement

And we're thrilled to announce the next international NCL congress **is heading down under to Australia!** NCL2025 will be held in late 2025 on the east coast of Australia, with details to be announced in the coming months. Congratulations to Professor Stephanie Hughes from Otago University, who has been appointed Congress Chair. Planning is now underway, and BDSRA Australia is delighted to be part of the Congress Organising Committee.

Stay tuned for further updates soon!

Webinar showcasing NCL2023 and other research highlights

More detailed insights into some of the key highlights and standout presentations from NCL2023, along with other major research takeouts for 2023 will be shared at the forthcoming Research Year in Review webinar on 14th December, co-hosted by BDSRA Australia and the BDSRA Foundation (USA). Head to the 'Upcoming Events' section below for further details and registration link.

Clinical Program Updates



Phase III trial of Batten-1 for treatment of CLN3 disease

We are delighted to share some very exciting news on the CLN3 clinical trial landscape. On 16th November, the Beyond Batten Disease Foundation announced the candidate study sites for the forthcoming Phase 3 clinical trial for Batten-1 (miglustat) for the treatment of CLN3 disease.

Sydney Children's Hospital has been selected as one of the nine candidate sites around the world, with Dr Alexandra (Alex) Johnson as the Principal Investigator. This is an enormous achievement for our region's Batten community. To be included on an impressive list of world-leading clinical centres (and as the only site in the southern hemisphere) speaks to the expertise, professionalism and dedication of our NCL clinical community here in Australia. This comes after much hard work and advocacy over the past two years, and I would like to sincerely thank our Medical & Scientific Advisory Board, particularly Dr Alex Johnson and Prof John Grigg, for their constant support and advocacy for our Batten families.

Study enrolment is expected to commence in 2024.



BATTEN-1: IMPORTANT NOTE TO FAMILIES: Recruitment for the Batten-1 (miglustat) Phase 3 study is set to commence recruitment in Q1 2024. If you are interested in participating in this study, and your child has been diagnosed with CLN3 disease and is currently aged 4-16 years (or turning 4 in 2023-24), we recommend you fill in [this online form](#) to register your interest, as soon as possible.

'Batten-1' clinical trial for CLN3 disease

The Beyond Batten Disease Foundation (BBDF) and biopharmaceutical company Theranexus, presented very encouraging interim results for efficacy and safety after 12 months of treatment in their Phase I/II trial for CLN3 disease at NCL2023 Congress in Hamburg, Germany.

The new data further supports the 6-month treatment results announced in mid-June 2023, and show after 12 months of treatment:

- an average 32% decline in neurofilament light chain (NfL) levels was observed in patient serum (a 17% reduction was observed after 6 months' treatment). NfL is a recognized biomarker of neurodegeneration.

If you have any questions, please feel free to reach out to Dr Ineka Whiteman, Head of Research and Medical Affairs any time at research@bdsraaustralia.org

- there was a 64% reduction in NfL observed in the cerebrospinal fluid (CSF); and
- a reduction in glycosphingolipids (GSLs), including a 45% reduction in Gb3. (accumulation of GSLs are known to be toxic to neurons).

Clinically, there was notably less worsening of motor symptoms evaluated by the modified UBDRS physical assessment subscale after 12 months, compared to the expected progression observed in natural history cohorts.

To read more head to the Sept 29 press release: [Highly Promising 12-month results in the Phase I/II trial of Batten-1](#)



REGENXBIO CLN2 gene therapy program update

In August and September, we shared several encouraging developments on REGENXBIO's CLN2 gene therapy programs including the announcement that the first patient had been dosed in the Phase I/II ocular trial of RGX-381 ([see here](#)) and that encouraging preliminary 6-month results were seen in the RGX-181 brain-targeted gene therapy program ([see here](#)).

This news was a tangible beacon of hope for our worldwide community, which made REGENXBIO's [November 8 announcement](#) regarding its intention to halt the development of RGX-181 and RGX-381 programs all the more difficult for our communities to hear. BDSRA Australia is heartbroken over this decision. We worked swiftly with our global patient advocacy partners to issue a joint statement on this matter on November 10, a copy of which can be read [here](#).

REGENXBIO has demonstrated to us that they are indeed actively exploring a range of partnership opportunities to enable the continuing development of its CLN2 gene therapy programs. Through ongoing discussions this past month, including with President and CEO Ken Mills, we have been encouraged to hear REGENXBIO has already taken proactive and practical steps in seeking solutions for the programs – and we will continue to support and urge them for as long as it takes.

On Thursday November 30, BDSRA Foundation hosted an open webinar to share the latest updates on REGENXBIO's CLN2 disease programs, followed by a Q&A. You can watch a recording of this event [here](#).

We will be sure to keep our community updated as soon as new information is available.

Clinical trial update resources

The BDSRA Australia website provides an interactive search tool that enables users to locate current clinical trials listed on Clinicaltrials.gov, for all NCLs or by subtype.

Check it out here: [Resources and Support for patients and families](https://bdsraaustralia.org/resources-and-support-for-patients-and-families) (bdsraaustralia.org).

In addition, a current summary and updates on NCL clinical programs has been compiled into an interactive table, in collaboration with the BDSRA Foundation. Visit this page for latest updates: [Clinical Studies – Batten Disease Support & Research Association](https://bdsrafoundation.org/clinical-studies-batten-disease-support-research-association) (bdsrafoundation.org).

For any questions on any of these programs, feel free to reach out at research@bdsraaustralia.org

RESEARCH OPPORTUNITIES

SPEECH & LANGUAGE STUDY – CLN2 and CLN3 disease

We Still Need Your Help!

Thank you to all those families who have already signed-up and participated in the **world-first research study** into the **characterization of speech and language in individuals with Batten disease** (CLN2 and CLN3 disease).

To complete the project, the research team is seeking a few more participants and they would be grateful for your help.

Participation is open to individuals worldwide who are:

- affected by CLN3 or CLN2 Batten disease
- age 6 months and older
- who are verbal or non-verbal

Bereaved caregivers are also invited to take part in this study.

To find out more about the project and how to get involved, download the flyer via this [link](#)

or contact the team at Murdoch Children's Research Institute, Melbourne Australia at geneticsofspeech@mcri.edu.au

USING AI TO IDENTIFY GENETIC CONDITIONS – Calling all NCL families

In one paragraph, how would you describe your child's condition?

The National Human Genome Research Institute (NHGRI), part of the National Institutes of Health (NIH), develops and studies computer-based technologies to better understand medical conditions that have known or suspected genetic causes.

The team is currently studying how different artificial intelligence (AI) models, including public models like ChatGPT, can identify genetic conditions. These models are a growing part of healthcare, and this project seeks to compare how well different models work.

For this study, they are collecting short descriptions from people with genetic conditions (or their carers) so that these different models can be tested. Participants are asked to send **one paragraph describing the condition** (eg. Batten disease, and subtype) in your child. Please use whatever description is **most natural** for you. That is, use your own words in the way you might describe the condition to a clinician meeting you for the first time. All contributions will be de-identified.

The study is open to international families. A copy of the information leaflet can be downloaded [here](#).

Please send descriptions to the NIH project team by emailing:
medicalgenomicsunit@nih.gov

For any queries, please feel free to reach out to the above email, or contact me at research@bdsraustralia.org

Research Publications - Selected



A selection of recent research publications in Batten disease are provided below. Read summaries and links to each article [here](#).

Assessment of CLN2 disease gene therapy in primate model

A CLN2 gene therapy previously trialled in patients has been re-assessed in non-human primates using an alternate, less-invasive route of CNS-directed administration. Read

more [here](#).

An exciting new role for the CLN5 gene

Lysosomal function is potently enhanced by an enigmatic but important lipid known as bis(monoacylglycero)phosphate (BMP). This groundbreaking study shows the CLN5 gene encodes the enzyme responsible for production of BMP. Read more [here](#).

Review: Treatment of non-epileptic episodes of anxious, fearful behavior in adolescent CLN3 disease

Recurrent non-epileptic episodes of frightened facial and body expression can be common in post-adolescent patients with CLN3 disease. This review discusses the potential underlying mechanisms causing the episodes, and possible approaches to minimise and manage the attacks. Read more [here](#).

A novel role for CLN7 protein? Loss of MFSD8 alters the secretome during Dictyostelium aggregation

Using a 'slime mold' amoeba model, researchers have revealed that loss of the mfsd8 gene (responsible for causing CLN7 disease in humans), disrupts protein secretion and protein localization within the cell. This lays important foundations for follow up work investigating the role of altered protein release in CLN7 disease. Read more [here](#).

Neuronal progenitor cells-based metabolomics study reveals dysregulated lipid metabolism and identifies putative biomarkers for CLN6 disease

This study is the first to analyse the metabolic profile of CLN6 disease-affected neuron-like cells and, importantly, could lay foundations for the development of novel biomarkers for monitoring CLN6 disease. Read more [here](#).

Efficacy of dual intracerebroventricular and intravitreal CLN5 gene therapy in sheep prompts the first clinical trial to treat CLN5 Batten disease

The findings from this study, now available in the public domain, prompted the initiation of the first in-human Phase I/II clinical trial testing brain- and ocular-directed

administration of AAV9 gene therapy for the treatment of CLN5 disease. This international trial remains ongoing and actively recruiting. Read more [here](#).



Integrative human and murine multi-omics: Highlighting shared biomarkers in the neuronal ceroid lipofuscinoses

'Omics' approaches are methods that generate new information on disease-modifying factors and molecular signatures, and are important in improving our understanding of rare diseases like NCLs. This study examines 'omic' profiles in both human and mouse datasets, employing a new approach to define dysregulated cellular processes across species, stages and NCL forms. Read more [here](#).



Language Delay in Patients with CLN2 Disease: Could It Support Earlier Diagnosis?

The nonspecific early symptoms of CLN2 disease often delay diagnosis and appropriate management. Seizures are generally recognised as the first presenting symptom of CLN2 disease, but emerging data show that language delay may precede this. An improved understanding of language deficits in the earliest stage of CLN2 disease may support the early identification of patients. Read more [here](#).

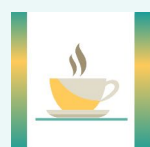


Acidified drinking water improves motor function, prevents tremors and changes disease trajectory in Cln2R207X mice, a model of late infantile Batten disease

In mouse models of CLN1, CLN3 and now CLN2 disease, it appears that acidified drinking water is associated with attenuated neuropathological changes and improved motor function. Although the mechanisms for these associated benefits remain unknown, researchers suggest altered gut microbiota may play a role. Read more [here](#).

Events

Upcoming



Virtual Coffee catchup - Bereaved Catchup TONIGHT

Join us for a relaxed chat, an opportunity to connect or re-connect, share and support each other. Meet new people or catch up with old friends. Each meeting is a unique mixture of people and we go with the flow. Open to bereaved parents from around Australia and NZ.

Wednesday, 6th December - 8:00 PM - 9:00 PM (AEDT)

Register your RSVP [here](#).



Research Year In Review webinar

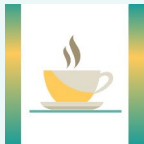
☀️ Join us for our final webinar event of the year! ☀️

We're co-hosting the '2023 Research in Review' with our friends at the BDSRA Foundation. Join panellists Ineka Whiteman, David Pearce, Jonathan Cooper, Kourtney Santucci, and Tony Cook as they discuss the major NCL research takeouts and highlights for 2023, with Q&A.

Thursday, 14th December - 10:00 AM - 11:00 AM (AEDT)

Registration is required. To receive the webinar link, register [here](#).

Past



Virtual Coffee catchup - Hospital Admission Preparedness

On Monday 20th November, we had a group discussion on everything about hospital preparedness, from organising paperwork and one-pagers to sharing experiences and lessons on how to make the process smoother. Notes have been taken from the discussion.



National Carers Week Morning Tea (Carers NSW)

To celebrate National Carers Week 2023, BDSRA Australia organised a much deserved high tea at Eden Gardens for our caregivers in greater Sydney. It was a great turn out. There is nothing quite like sharing a table of scrumptious food with those who have similar experiences as mothers, caregivers and advocates for their child/ren.





Kiaana with her mum Alicia

Kiaana Inspires

Kiaana, with the support of her dedicated mum, inspires our community with her achievements and overcoming the odds.

In 2011 at age 16, Kiaana was diagnosed with CLN3 (Juvenile) Batten Disease, after more than 10 long years of trying to find answers. Now aged 28, Kiaana is a playful, music-loving young woman and an inspiration to other families fighting this same heartbreaking disease.

Speaking with Alicia, Kiaana's mum, she tells of the struggles and constant advocating to ensure the world sees Kiaana, and others like her, for who she is and what she is capable of - not just as a 'diagnosis' or defined by what's described on paper.


In recent years, Kiaana has had two sudden major downturns that threatened to devastate as Alicia pushed for the hospital interventions, disability support and at-home care that Kiaana needed. She has made an amazing recovery each time, sometimes regaining back skills even weeks and months later. They have also had some wins through the AAT process for NDIA to recognise and meet Kiaana's disability support needs. Read more [here](#).

To share your family's experience in the newsletter or for further information on how we can support you, please contact Liz at support@bdsraaustralia.org

Family Register - Reminder



Have you filled in the Family Register form?

Our new Family Register form, created in May 2023, is an important way for BDSRA Australia to keep families informed of **clinical research opportunities**, and for us to better understand Batten disease in our region and the **needs of our families**. If you haven't completed it (in the last 6 months) we ask that you take the time to complete it, just 2-3 minutes. Your details are kept **STRICTLY CONFIDENTIAL** at all times. Fill in the form here! [BDSRA Australia Family Register form \(google.com\)](#) 

Remembering Our Angels - Online Memorial



BDSRA Australia's Memorial gallery

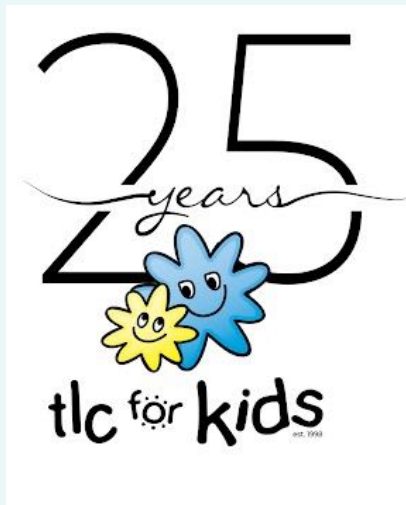
BDSRA Australia has a Memorial gallery to remember our Batten Angels. Scroll past the family stories to see it [here](#).

If you had a child/ren pass away from Batten Disease in Australia and New Zealand and wish to have them included in our online memorial, please contact Liz at support@bdsraaustralia.org

Special Occasions

We think of our bereaved families, as this can be a particularly difficult time of year as we remember our loved ones who have left our arms but not our hearts. It's important to have space to grieve, to remember, to celebrate them and the ripples that continue to play a part in our lives now. In this busy season, remember the tips for self care too. Families are welcome to reach out for a chat with our Family Support Coordinator Liz Sanson, and don't be afraid to seek help if you are ever

Resources



Note that all TLC services are provided through referral by approved healthcare professionals **only**, no self referrals. To learn more, discuss with Liz, our Family Support Coordinator or visit their website [here](#). For a referral, please speak with your local hospital social worker or health care provider.



Your role as carer is so important.

CarerHelp is for carers who need information and resources to help them

TLC for Kids

Their services include:

Rapid TLC - rapid requests are actioned within 24-48 hours, providing instant relief to families needing urgent support.

TLC Distraction Box - provides healthcare professionals with the perfect tools to guide young children through painful examinations and procedures

TLC Ambulance - an immersive and engaging experience; it offers a special day out for children in palliative care and their families to visit their most treasured destinations

Tap 2 Distract - digital distraction app with a variety of child-friendly games, each with a specific purpose to help distract and reduce fear for a child during a medical procedure, an immunisation or whilst they are experiencing any form of stress or discomfort. Note: a helper may be required for those with vision impairment and possible use as cause and effect type input.

Carerhelp

CarerHelp can empower carers to cope with the hard times, and to make space for the good times as well. When carers feel ready for their role, everybody benefits.

The website offers:

feel informed and prepared for caring for someone who has a serious condition.

Caring is a journey. Carerhelp have developed [five pathways](#) that are commonly experienced over time when caring for someone with a life-limiting illness. In each of these pathways, you will find relevant resources, tools and information to help you in your caring role.

Many CarerHelp resources are also useful for health professionals and care workers who work with patients or families in these situations.

- Access to high quality information and [resources](#) that support them in the carer role
- Knowledge of the services available to carers
- An understanding of what to expect when someone is dying
- A greater sense of control over their role
- Better communication with the health care team, family and friends
- Greater wellbeing

Visit the [website](#) for more details



Managing behavioural challenges in Batten disease

Dementia Support Australia offers free, nationwide specialised Childhood Dementia Support with trained consultants who understand childhood dementias like Batten disease, its related behavioural and cognitive challenges, and the impacts these can have on the child, their family and carers.

No referral needed. Simply call the 24-hour helpline on 1800 699 799, fill out the contact form or chat with DSA online. To learn more, visit [here](#).

Not on social media?

Keep up-to-date on BDSRA Australia's latest news and events on our website! We frequently add items to our website [News page](#), so feel free to head over anytime to check out the latest in research and support news!

Thank you so much for your support!

Wow! How have we reached festive season already!!! Where has this year gone?

I would love to take this opportunity to sincerely thank everyone who has supported and donated to BDSRA Australia this year. We can't achieve our goals without you all, so THANK YOU from the bottom of our hearts.

If anyone is looking for a place to direct donations in lieu of gifts this Christmas, fundraisers are often a great way to do this. You can make donations directly through our website or in different formats such as starting social media fundraisers. We have often found these to be incredibly successful and a heartwarming way to direct gifts.

I hope everyone has a magical, safe and happy Christmas making special memories with their families!

Amanda Gilpin
Treasurer

Fundraising Subcommittee

Next year we're forming a **Fundraising Sub-committee** and we are still looking for more volunteers who would like to put their creative ideas to good use for our incredibly worthy cause. If you can participate or are interested in facilitating the committee, we would love to hear from you! This is open to our Batten families and also the wider community of family, friends and supporters who want to make a difference.

If this is something you are interested in, email either treasurer@bdsraaustralia.org or info@bdsraaustralia.org.

[Donate Now](#)

As a not-for-profit organisation, BDSRA Australia relies primarily on fundraising initiatives and philanthropic donations to provide all our programs, services and support. Bringing awareness to Batten Disease can make a difference in our communities from advocating for early diagnosis and tailored supports to raising funds for research and putting Australia on the map for clinical trials and much much more!



ASX REFINITIV CHARITY FOUNDATION

CORPORATE AUSTRALIA HELPING THOSE IN NEED



SUPPORT & WIN!

**1ST
PRIZE**
valued at
\$26,820*

**2ND
PRIZE**
Valued at
\$1,499

**3RD
PRIZE**
valued at
\$1,380



**HYUNDAI i30
AUTOMATIC HATCHBACK**



Sleek design. Thrilling performance.

A pleasure to own. When you discover what we have added to the i30, you begin to realise how serious we are about offering premium as standard. The i30 comes packed with everything you're looking for – and much, much more.

*Includes GST & Dealer Delivery. NSW Vehicle Duty, NSW Private Registration, NSW CTP. Colour white. Prizes are not transferable and the car cannot be redeemed for cash. Image shown may be an overseas model and may differ to local specification.

MacBook Air



MacBook Air with M1 is an incredibly portable laptop – it's nimble and quick, with a silent, fanless design and a beautiful Retina display.
Kindly donated by Aspect Logic

**Robert Oatley
premium wine**
(5 cases of 12 bottles)



**TOTAL
VALUE
PRIZES
\$29,699**

Prizes are not transferable or redeemable for cash. All prize ticket values refer to Australian Currency. Motor Vehicle photographs are for display purposes only. The ASX Refinitiv Charity Foundation raffle will be drawn on Thursday, 14 March 2024 at 200pm. Results posted www.asxrefinitivcharity.com.au on Thursday, 14 March 2024.

ASX Refinitiv Charity Foundation

The ASX Refinitiv Charity Foundation Raffle is now live and our charity is committed to selling \$10,000 worth of tickets. We are calling on our loyal families and friends to use their networks and promote this raffle as **profits from all tickets sold through our unique online link go directly to BDSRA Australia**. This is a great time to buy for family, friends, therapists and teachers as gifts. The prizes include

1st prize: Hyundai i30 Automatic Hatchback - valued at \$26,820

2nd prize: MacBook Air - valued at \$1,499

3rd Prize: Robert Oakley premium wine (5 cases of 12 bottles) - valued at \$1,380

Please click on the link below to **purchase your raffle tickets today and share this direct link** with your family and friends.

[Batten Disease Support and Research Association Australia \(asxrcfau.com\)](http://BattenDiseaseSupportandResearchAssociationAustralia(asxrcfau.com))

ASX Gala Dinner - Auction Items needed by 25th January

Are you able to help BDSRA Australia by providing an auction item or organising a table for the next ASX event? The ASX Gala Dinner will be held in February 2024 and all proceeds raised from tables and auction items that are provided by (or on behalf of) BDSRA Australia go directly to our organisation.

If you are interested in attending or can donate an auction prize please get in touch with Nikki at info@bdsraaustralia.org or Bobbie at briddle@bdsraaustralia.org

If you have family, friends or community members fundraising for BDSRA Australia and are happy to share with us for our next newsletter or on our social media, please let us know!



Facebook fundraisers!

Why create a Facebook fundraiser? It's quick, simple and it's effective!

1. Start a post
2. Click the 'More' (3 dots) button in the 'add to your post' section
3. Click 'Raise Money'
4. Select the charity '**The Australian Chapter of the Batten Disease Support and Research Association**'
5. Write why you are fundraising, it could be:
 - In lieu of a birthday gift
 - In memory of someone who has passed
 - To give us a boost before the New Year or Tax Time for BDSRA Australia to keep making a difference!
6. Click the big blue 'Post' button and it will be live, reaching your Facebook community with your personal message and an easy user-friendly button to donate directly to BDSRA Australia!

Need help? Email Nikki at: info@bdsraaustralia.org



Bottles4Battens - Return and Earn NSW

Christmas, New Year parties and school holidays are great opportunities to collect both plastic and glass bottles to raise money for BDSRA Australia.



Share our unique barcode below with family and friends, school and sporting groups in your community and encourage them to collect eligible containers and donate all or some of their drink container refunds to support our charity.

For easy reference, why not screenshot or take a photo of this code below to save on your phone!

Ready to recycle?

Batten Disease Support and Research Association Australia



Scan your barcode at the machine

Personal Details Update: To ensure you are kept informed and up to date on all our news and events, please be sure to let us know if your circumstances or contact details have changed.

Please email Nikki Hopkins at info@bdsraaustralia.org



**Wishing our
Batten families
and supporters
a Merry Christmas and
happy new year.**

**From the team at
BDSRA Australia**



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Batten Disease Support and Research Association Australia is a registered charity.

Australian Registered Body Number: 073 435 202

Australian Business Number (ABN): 56 056 138 99

Our mailing address is: 74 Mclachlan Ave Shelly Beach NSW 226

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