NEWSLETTER

Spring 2026 Edition

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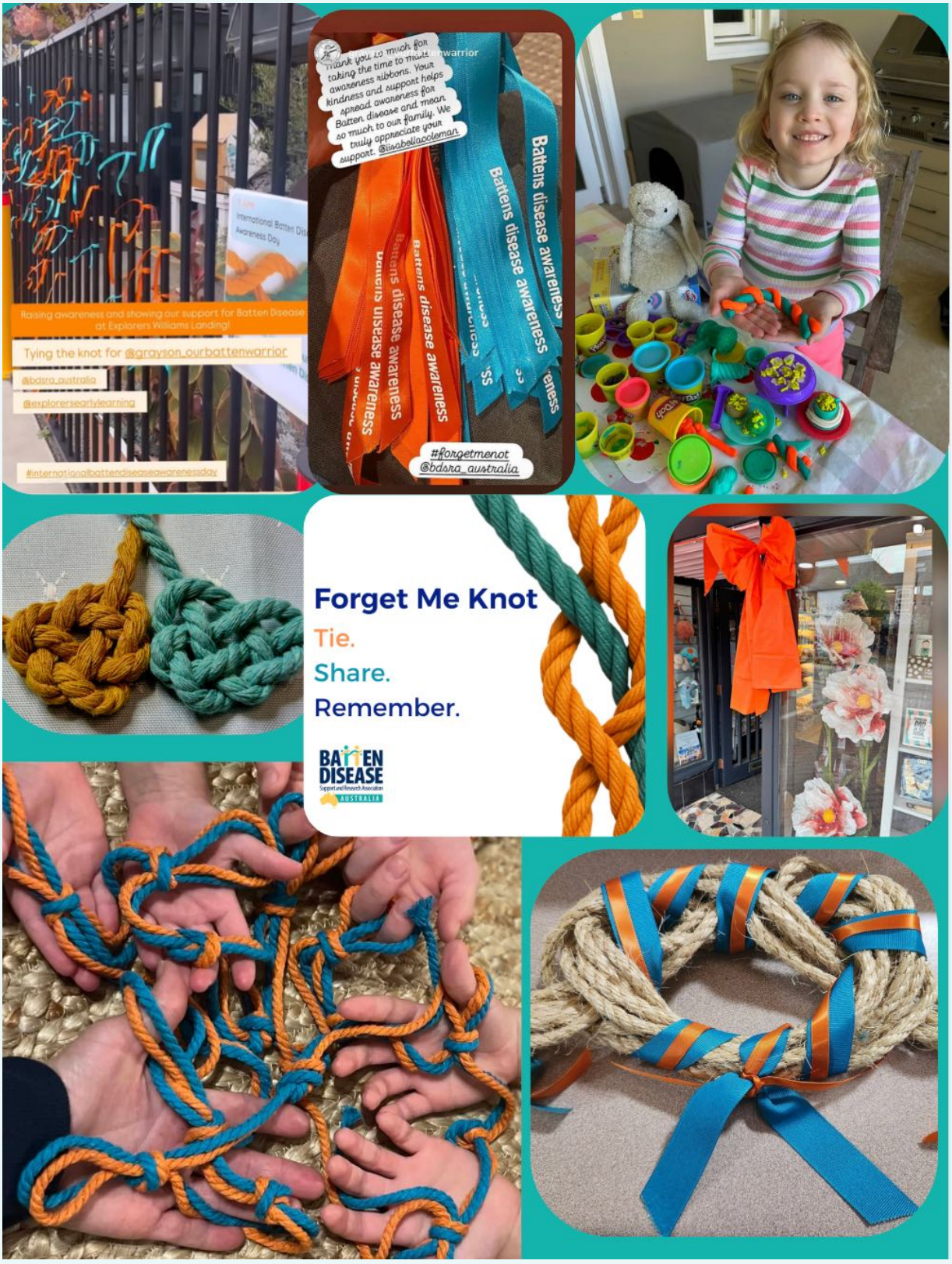
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Board Report



Dear BDSRA Australia community,

The year has quickly flown by, it has been a very busy time for BDSRA Australia. We reflect on the year's successes with some important milestones reached and are already preparing for an even busier 2027.

We start by reflecting on **International Batten Disease Awareness Day** and our **Forget Me Knot** campaign on 9th June. It was wonderful to see families, friends, clinicians, researchers, organisations and supporters across Australia coming together to help shine a light on Batten disease. Thank you to everyone who participated, shared our campaign or helped spread awareness, and reminded our families that they are not alone. Read some of the inspiring stories about our communities raising awareness efforts in the fundraising section of this newsletter.

Thank you also to everyone who supported our **End of Financial Year campaign**. Every donation helps us continue to provide family support, advocate for better care, invest in research and build required services. Whether you donated, shared our appeal or encouraged someone else to learn more about Batten disease, we are enormously grateful. Please consider continuing your support by purchasing or sharing with your network our annual fundraiser, the **ASX Foundation raffle which is now LIVE!** Tickets start from as low $20 so don't miss your opportunity to be in with a chance to win!

In partnership with Rare Voices Australia, we are very pleased to announce we have just launched our **'Living Well with Change'** resources package for Episodic and Fluctuating Rare Disease Disability in the Education Setting. You can download the fact sheets or find out more information from our dedicated webpage. Thank you to all those involved in the project, especially those who shared their valuable lived experience to get to the heart of producing these resources. A special mention must go to Julia and Ben Mickler, Liz Sanson, Nikki Hopkins and Les Turner who volunteered their time and worked tirelessly on this important project.

Batten Speaks has wrapped up another successful year, with our final session exploring '*Goal Setting within the NDIS*'. It's been a great year with 21 out of the 30 speechies in the group, attending 1 or more of our 5 virtual meetings throughout 2026. The group continues to provide a valuable forum for professional development, knowledge sharing and collaboration, strengthening the skills and expertise of speech pathologists supporting individuals and families affected by Batten disease. We look forward to continuing in 2027 and warmly invite any speech pathologists working with Batten families who would like to join this dedicated network of professionals to get in touch with Liz Sanson at support@bdsraaustralia.org

It's been a huge year in the area of research and as you will read below in Ineka's research highlights and updates, we are pleased to advise that applications have just opened for the 2026-2027 **Batten Disease Global Research Initiative** (BDGRI) Grant

Round!

While on the topic of research, we are delighted to share that **Dr Ineka Whiteman, BDSRA Australia's Head of Research and Medical Affairs**, has been awarded an inaugural **Oliver Stevens Scholarship** to attend WORLD Symposium 2027 in San Diego, USA, in January. This scholarship recognises Ineka's contributions to rare disease research and advocacy and will support her travel and participation in this leading international scientific meeting focused on lysosomal diseases.
Ineka will represent BDSRA Australia and our Batten disease community, sharing insights from our research initiatives and collaborations while connecting with international researchers, clinicians and industry partners. **Congratulations, Ineka!** We are incredibly proud of this well-deserved recognition and the opportunity to further strengthen the voice of our community on the global stage.

As always, we want to acknowledge our brave and courageous families. Everything BDSRA Australia does starts with you and your lived experiences and the things that will make a meaningful difference to your children and loved ones living with Batten disease. We would also like to thank our staff, volunteers, clinicians, researchers, donors and partners for the enormous amount of time and work that continues behind the scenes every day to keep this association so active and passionate and allow our mission to remain at the forefront of everything we do.

With warmth and gratitude,
BDSRA Australia Board

A message from former president Priyanka Rai:

After two years in the role, I'm pleased to complete my term and step down from my position as President. It's been an honour to serve alongside such a dedicated board and community. I'm particularly proud of welcoming Maree McCabe as our Patron, and grateful for the chance to contribute to advocacy work that directly supports families affected by Batten disease. I remain committed to BDSRA's mission and excited about what comes next for the organisation.

In Memory of Robert Smith

Our Batten disease community recently lost a valued friend and supporter with the passing of Robert Smith.

Robert and his family have been part of the BDSRA Australia community for many years. **Inspired by his beautiful granddaughter and Batten Angel, Tilda, Robert established The Allendale Foundation** and, through its generous support of BDSRA Australia, made a lasting contribution to Batten disease research and the hope of

better outcomes for families.

We at BDSRA Australia extend our heartfelt condolences to Robert's family and loved ones, and thank him for his kindness, generosity and enduring commitment to our community. His legacy will continue to make a difference for years to come.

Australian Batten Disease Clinics

We are pleased to share that important progress is being made towards establishing the Australian Batten Disease Clinic Program.

Establishing dedicated clinics within Australia's public healthcare system requires considerable planning, coordination and collaboration across multiple stakeholders. We are encouraged by the commitment of our hospital partners and the progress being made.

In **Sydney**, preparations are underway for the commencement of the Batten Disease clinic at Sydney Children's Hospitals Network. In **Melbourne**, discussions with the lead site are also progressing positively, with a shared commitment to establishing its dedicated Batten Disease clinic. Planning is continuing to determine the clinic's structure and anticipated commencement timeline.

These developments represent important steps towards improving access to specialised, multidisciplinary care and emerging treatments for Australian families affected by Batten disease.

We look forward to sharing further updates as both clinics move closer to becoming a reality.

In the Media: Dr Ineka Whiteman on 4BC Drive

In August, our Head of Research and Medical Affairs, Dr Ineka Whiteman, joined Carla Bignasca on 4BC Drive to discuss the challenges facing Australian families seeking access to emerging treatments for CLN2 Batten disease.

The interview followed the story of three-year-old Sonny and his family's efforts to access intravitreal Brineura, an emerging treatment approach aimed at preserving vision in children with CLN2 disease.

While this treatment is already being administered at specialist centres in Australia, access remains limited, with significant challenges for families in Queensland and other states.

BDSRA Australia continues to work closely with clinicians, hospitals and relevant health authorities to advocate for timely, equitable access to this treatment for children who may benefit. Considerable work is underway behind the scenes, and we remain committed to helping overcome the clinical, logistical and funding barriers that currently stand in the way.

Our goal is simple: to ensure that where promising treatments are available, a child's postcode does not determine their opportunity to access them.

Listen to the interview on 4BC here.

Research Highlights

On the cusp of something extraordinary

It's been a little while between research columns, and I seem to have made up for lost time with this one! There's so much happening across the Batten disease landscape right now, and I hope you'll agree it's worth a slightly longer read.

Over recent months, I've had the privilege of joining families, clinicians, researchers and industry colleagues at gatherings in the United States, Norway and the United Kingdom. Each offered a different perspective on the remarkable progress underway in Batten disease research and therapeutic development — and reinforced my growing sense that we are entering an exciting new chapter.

Chicago: A community united by purpose

In July, I attended my fifth consecutive BDSRA Foundation Family Conference in Chicago; perhaps the most exciting yet! As Head of Research and Medical Affairs for the US-based BDSRA Foundation, I also have the privilege of leading the conference's scientific program each year.

Attendance was the highest I've seen across those five years. Families and carers from across the US were joined by more than 100 clinicians, healthcare providers, researchers and industry representatives, including members of the US Batten Disease Clinical Centers of Excellence (CoE) network and the NIH-funded Batten Disease Clinical Research Consortium (BDCRC). Both clinical networks also met face-to-face, strengthening relationships and sharing expertise.

There's an important Australian connection here too. As we establish our **national network of specialist Batten Disease Clinics**, Australian clinics will be recognised as International Partners of the Centers of Excellence Program, actively participating in this international clinical network. When specialist expertise is otherwise scattered across countries and continents, these relationships are enormously valuable.

Our scientific program opened with an introduction to the newly established BDCRC, a major NIH-funded initiative strengthening our understanding of Batten disease and building the clinical research infrastructure needed for future therapeutic trials.

We then heard updates from **12 therapeutic programs spanning five NCL subtypes**, all either currently in, or soon to commence, clinical trials. Sitting there listening, I couldn't help reflecting on how dramatically the landscape has changed in just five years. The breadth of therapeutic development now underway is remarkable.

Recordings of the **Clinical Program Updates** and **BDCRC Overview** sessions are now available on the BDSRA Foundation YouTube channel (programs and recordings listed below in our **Past Events** section). I highly recommend taking the time to watch them if you're interested in understanding the remarkable breadth of research and therapeutic development currently underway.

It was also lovely to have a familiar face from home in Chicago. Our good friend of BDSRA Australia, **Matt Danskin** — dad to Jack, who has CLN3 disease — joined us for the conference. Matt shares his reflections in the **Family Support section** of this newsletter, which I warmly encourage you to read.



Photo: Clinicians from across the Batten Disease Clinical Centers of Excellence network together in Chicago.



Photos: The Family Conference Science Fair, bringing families and researchers together around the latest Batten disease research.

Norway: Two hundred years of CLN3 disease and a very different future

In August, I travelled to the historic copper-mining town of Røros, Norway, for the Stengel 200 CLN3 Conference, marking 200 years since Norwegian physician Otto Christian Stengel first described what we now recognise as CLN3 disease in 1826. Delegates explored the historic town and copper mine, including a visit to the building where Stengel lived and practised medicine two centuries ago.

There was something extraordinary about reflecting on two centuries of medical history while discussing a future in which a robust, growing pipeline of potential disease-modifying treatments is finally becoming a reality.

Unlike the larger US Family Conference, this was a more intimate scientific gathering, with discussions spanning disease mechanisms, clinical care, natural history and therapeutic development. The scientific sessions were interspersed with deeply moving presentations from families sharing their lived experiences of CLN3 disease.

I could almost see the ‘lightbulbs’ switching on among clinicians and researchers as they listened to these powerful stories and witnessed the clinical presentations — moments when something suddenly clicked, a connection was made, or a familiar scientific question was seen in an entirely new light. The conversations that followed were fascinating, bringing fresh perspectives and new questions to the science.

Some of the most valuable exchanges happen outside formal conference sessions. A question over coffee, a discussion about an unexpected finding, or an introduction between researchers working on related problems can open the door to entirely new collaborations. These interactions aren't incidental to scientific progress — they're often where the next brilliant idea begins.

The meeting also highlighted how far our understanding of CLN3 disease has come. We're increasingly moving beyond describing the disease and its progression to asking how we can intervene, how early we need to act, and how emerging treatments might meaningfully alter its course.

A particularly special part of the gathering was the much-loved **'Forget Me Knot' dreamcatcher**, a beautiful symbol of connection across our international Batten disease community. Having been part of the conference in Norway, it's now making its way to Boston for the upcoming NCL Translational Research Meeting — carrying that spirit of connection from one gathering to the next.





Photos: The Forget Me Knot dreamcatcher; together with Stengel 200 meeting organisers Prof. Jonathan Cooper and Prof. Magnar Bjørås.



Photo: Stengel 200 delegates in Røros, Norway

Cambridge: Where science begins to connect

More recently, I was honoured to be invited by Dr Kasparas Petkevicius to speak at the **University of Cambridge's MRC Mitochondrial Biology Unit** and **Cambridge Institute for Medical Research**. My presentation explored current therapeutic approaches and the journey of Batten disease research from bench to bedside, highlighting how patient advocates are active drivers of rare disease research and therapeutic development at every stage, from fundamental scientific discovery through to post-approval access and care. I encouraged researchers to engage directly with affected individuals and families, whose lived experiences offer unique insights that cannot be gained in a laboratory, challenging assumptions, inspiring new ideas and helping shape research that delivers meaningful outcomes for the people it ultimately seeks to benefit.

The timing was particularly exciting, coinciding with remarkable advances in our understanding of the fundamental biology underlying several forms of Batten disease.

At the centre of these discoveries is a specialised lipid called **bis(monoacylglycero)phosphate (BMP)**, which plays an essential role in the normal functioning of lysosomes — the cellular compartments responsible for breaking down and recycling waste materials.

For decades, scientists have been trying to understand precisely what several CLN proteins do within cells, and why defects in different genes cause remarkably similar diseases. Recent research is beginning to connect some of those dots.

In September, two studies published in Nature Cell Biology, including work led by Kasparas and international collaborators, identified a critical role for CLN8 in BMP production. Building on earlier discoveries involving CLN5, and exciting new research implicating CLN6 (currently in peer review) and potentially CLN3, these findings suggest that several Batten disease proteins may be involved in a shared biological pathway.

Why is this so exciting? Rather than viewing each form of Batten disease as an entirely separate biological problem, we're beginning to uncover common mechanisms that could open new therapeutic avenues, potentially benefiting multiple NCL subtypes. These are early laboratory findings, and considerable research is still needed before they can translate into treatments for patients.

For me, this is one of the most exciting developments in Batten disease research in recent years — and a reminder of why investing in fundamental discovery science is just as important as supporting therapeutic programs already progressing towards the clinic.

*Access these papers below in the **Research Updates** section.*



Photo: With Dr Kasparas Petkevicius at the University of Cambridge.

Something bigger than any one program

Reflecting on these experiences, one theme keeps coming back to me.

Having worked earlier in my career in much larger therapeutic areas, including adult-onset dementias and cardiovascular disease, I've always found the closeness of the rare disease community to be one of its greatest strengths. Our patient populations are small, expertise is dispersed internationally, and no single researcher, clinical centre, advocacy organisation or company has all the answers.

Families bring an irreplaceable understanding of lived experience and what meaningful progress looks like. Clinicians, researchers and industry partners bring the expertise and resources to advance care and develop treatments. Patient advocacy organisations help connect these worlds, build partnerships and keep families at the centre of progress. The BDCRC, Centers of Excellence network and our own Batten Disease Global Research Initiative are tangible examples of this collaboration in action.

One comment I heard repeatedly from families and industry colleagues in Chicago has stayed with me: **“the landscape feels different now”**.

And I believe it does.

We have a substantial and increasingly diverse therapeutic pipeline, stronger clinical and research networks, and fundamental discoveries beginning to connect previously separate pieces of the biological puzzle.

For the first time, we can begin to see how many of these pieces might fit together.

Of course, success is not always assured. The path from laboratory discovery to an approved, accessible treatment is rarely straightforward, and for families living with Batten disease today, progress can never come quickly enough.

But I believe there is genuine reason for hope — grounded not simply in optimism, but in the quality of the science, the growing therapeutic pipeline and the extraordinary commitment of this global community.

We are, I believe, on the cusp of something extraordinary in Batten disease research and development.

Our collective challenge now is to turn that scientific momentum into meaningful

treatments and better outcomes for every person and family affected by Batten disease.

And this is where you can help. I encourage you to get behind our **small but mighty BDSRA Australia** and the research, clinical care, family support and advocacy initiatives we work tirelessly to advance, often behind the scenes. Whether through a donation, fundraising, volunteering or simply spreading the word, your support makes this work possible and helps us keep pushing forward.

As always, thank you for your continued support, commitment and dedication to our shared mission.

Warm regards,

Dr Ineka Whiteman
Head of Research and Medical Affairs
BDSRA Australia

*For further **Research Updates**, please see sections below!*

Events

Upcoming



Virtual Coffee catch up - Infantile & late infantile families
Topic: Health & Management plans - Come along for some tips, resources and peer support, bring your questions along too.
Tuesday 24th November - 8:00PM - 9:00PM (AEDT)
Meeting details will be email out and in the Facebook group soon



Virtual Coffee catch up - Bereaved families
Topic: Remembering our angels and planning for the holiday season - Chat & meet with other bereaved parents from Australia and NZ.
Wednesday 25th November - 8:00PM - 9:00PM (AEDT)
Meeting details will be email out and in the Facebook group soon

Virtual Coffee catch up - CLN3 families

Topic: School and Education - Come along for some tips, resources and peer support, bring your questions along too.
Thursday 26th November - 1:00PM - 2:00PM (AEDT)
Meeting details will be email out and in the Facebook group soon



Webinar - Batten Disease Clinical Program Updates
Join **Dr Ineka Whiteman** and **Dr Alex Johnson**, Chair of BDSRA Australia's Medical & Scientific Advisory Board and Paediatric Neurologist, Sydney Children's Hospital, for an update on the latest developments in Batten disease clinical research.

Hot off the press from the **NCL Translational Research Meeting in Boston** (11-13 November) this prerecorded webinar will explore emerging therapies, clinical trial progress and what these developments could mean for Australian patients and families.

The webinar recording will be available later in November. Keep an eye on your inbox and follow our social media channels for details on how to access it.

WORLD Symposium 2027 | 31 January – 4 February | San Diego, USA
WORLD Symposium brings together researchers, clinicians, industry representatives and patient advocates to share the latest advances in lysosomal disease research and treatment.
Complimentary registration is available for eligible patients and immediate adult family members, including access to scientific presentations and on-demand recordings until 12 March 2027.
For details and registration, visit the WORLD Symposium Patient and Family Registration page.



Webinar - 'Transitioning to Adult Care'
This interactive webinar with guest speakers is set to take place in **2027**. Please keep an eye out, further details will be emailed and posted to social media pages in the new year.

Past

Batten Speaks - Working group for Speech Pathologists

On Wednesday 21st October, **Lisa Tilbrook**, from BDSRA Australia's Medical & Scientific Advisory Board, presented on 'Goal setting within NDIS'. Providing practical tips and considerations for every stage.
For more information contact Liz at support@bdsraaustralia.org



National Childhood Dementia Day 2026
On Wednesday 23rd September, our community raised awareness, to start conversations about childhood dementias like Batten disease, so our angels, warriors and their families are not forgotten. Together we make a difference through research, support and advocacy. #ForgetMeKnot #bdsraaustralia Find out more about FMK here.

Batten Speaks - Working group for Speech Pathologists
On Wednesday 12th August, we had a guest presenter from the UK - **Dr. Rebecca Atkinson** who shared about her research "Investigating the impact of music for children with Batten disease", great discussion and practical takeaways for our group of Speech Pathologists.

BDSRA Foundation Annual Conference, Chicago 2026
The recordings are now available as follows:
Session 1 - An Introduction to the Batten Disease Clinical Research Consortium (BDCRC), including Q&A. View printable program.
Session 2 - Clinical Program Updates, including Q&A. View printable program.
Watch the combined recordings here.

Supportive Therapies in Optimal Multidisciplinary Management of Batten Disease.
This session explores supportive care approaches across the different manifestations of Batten disease and the importance of coordinated, multidisciplinary care. View printable program.
Watch the Recording here.



International Batten Disease Awareness Day 2026
Awareness days like this are about so much more than a date on the calendar. Thank you everyone who shared photos on social media, encouraged conversations about Batten disease, organised a fundraiser, made a donation, or simply took a moment to tie a knot in solidarity. *(see Fundraising section below)*

Virtual Coffee catch ups

We held a few virtual catch ups in June on the theme of 'resources'. On Monday 22nd June we had guest speaker **Blair Young-Whitworth**, Director of Family Education and Engagement at Courageous Parents Network (CPN) present and share about their resources. Our evening meetings were also focused around resources for different stages. A short recording of part of the CPN presentation is now available by request, email Nikki info@bdsraaustralia.org

Donations

Together, We're Making a Difference

As we are now settled into the new fiscal year, we want to take a moment to reflect on the incredible support BDSRA Australia received through our EOFY campaign. A huge thank you to everyone who donated, organised a fundraiser, supported an event, encouraged others to get involved or simply shared our message.

We would like to extend our heartfelt thanks to **The Allendale Foundation** for their incredibly generous donation towards Batten disease research projects. Thank you for investing in rare disease research, helping us move research forward and giving families hope for a future cure.

We also want to give a very special shout-out to the **schools across Australia** who have been fundraising for BDSRA Australia through casual clothes day, bake sales, student-led initiatives, or creative fundraising ideas. We have been receiving an incredible number of school donations lately, and it has been wonderful to see students, teachers, families and entire school communities getting behind the Batten disease community and choosing to make a difference for children and families living with Batten disease. We are incredibly grateful for your generosity and enthusiasm.

Looking ahead, the BDSRA Australia team will be reviewing our strategic plan to reflect on what we have achieved so far and on further goals we want to accomplish.

Our fundraising committee is looking for enthusiastic people to join us and we would LOVE to hear from you! You don't need to be a professional fundraiser or have loads of experience. If you have ideas, connections, enthusiasm or simply want to contribute your time and help make a difference, we'd love to have you involved, email treasurer@bdsraaustralia.org today!

Amanda Gilpin
Treasurer

Donate Now

Become a regular donor

It takes just minutes to become a regular donor. You can choose to make a weekly, monthly, quarterly or annual contribution by using our donate now page.
Every contribution has an impact! If you donate just $10 a month that equates to $120 a year! Imagine if 50 people did this, that's $6000 towards the BDGRI grant program that will fund vital research. **Every big or small contribution will make a difference.**

BDSRA Australia relies primarily on fundraising initiatives and philanthropic donations to deliver all our programs, services and support. Your donation helps us keep doing what we do best! Thank you so much for your support!

Bottles for Battens Initiative





A fundraiser and awareness raiser with environmental impact
For the past 7 years, Andreas Mickler, dad of Emily (CLN3), has been collecting empty drink cans and bottles from students and staff at Trinity Grammar School in Sydney to raise funds for BDSRA Australia via the NSW Government's Return and Earn Scheme. We hope this story inspires you with ideas to involve your community to multiply the impact.
Read all about it here.

Bottles4Battens - Return and Earn NSW
Christmas, New Year celebrations, and the school holidays are perfect opportunities to collect eligible plastic and glass bottles to support BDSRA Australia.

Share our unique barcode (below) with family and friends, as well as your local school or sporting groups, and encourage them to donate all—or even just some—of their container refunds to help our charity.

For easy access, feel free to screenshot or save the barcode to your phone!



Fundraising

Thank you for supporting our global awareness campaign - Forget Me Knot 2026

From the bottom of our hearts, thank you for helping make **International Batten Disease Awareness Day** on 9 June 2026 such a powerful and memorable day.

While only in its second year, we were overwhelmed by the support shown for our **Forget Me Knot campaign**. Across Australia and beyond, people tied knots, shared stories, wore teal and orange, hosted fundraisers and helped raise awareness of Batten disease in their schools, workplaces and communities.

Every knot tied was a symbol of hope, love and remembrance. Together, we honoured the individuals and families living with Batten disease, while remembering those we have sadly lost.

Thank you for standing beside our Batten families and helping ensure no affected individual or family is ever forgotten. And remember, the gesture of tying a knot is something that can be done at any time of year. So tie a knot, post on social media

and tag BDSRA Australia.

We'd also like to thank the researchers, clinicians, organisations and advocates who shared our Forget Me Knot campaign and continue to stand with the Batten disease community.

This journey is only possible because of the people working alongside us to improve care, advance research, raise awareness and create hope for families affected by Batten disease. We are incredibly grateful to have you with us.



Highlights from fundraisers for this year's Batten Disease Awareness Day

Emily's Pink Day
Each year, the Lockyer Valley community in South East Queensland comes together with open hearts to support Emily and shine a light on Batten Disease Awareness Day. This year the event raised approximately $7,500!

What started as a local show of support has grown into something truly incredible. Every year, more schools, sporting clubs, businesses and community members join the movement, proudly decorating their spaces in Emily's favourite colour, Pink. Together, they're not only raising vital funds for Batten disease research but also helping to spread awareness, inspire hope and remind families like Emily's that they

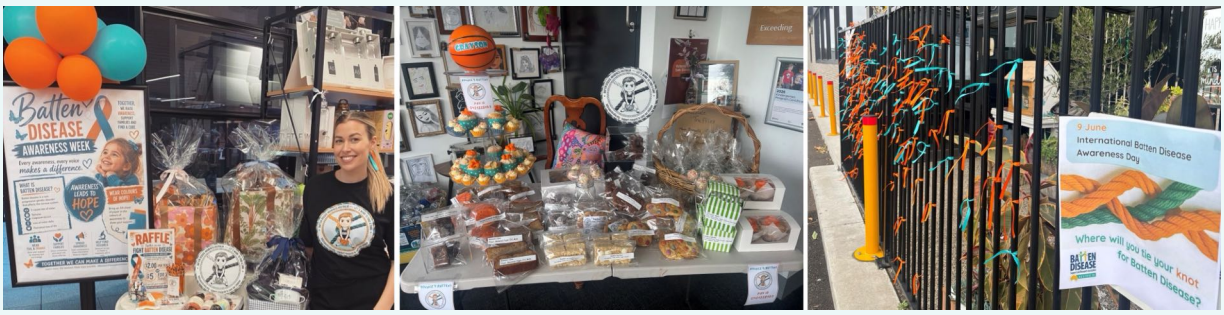
are never facing this journey alone.



Uniting for Grayson

Following young Grayson's diagnosis with CLN2 Batten disease, the Explorers Early Learning community, family, friends, and local businesses rallied together during Batten Disease Awareness Month. To raise awareness and show support, the centre was decorated with orange and teal ribbons.

The community drove fundraising through a "Bounce for Batten" event, bake sales, raffles, merchandise sales, and a silent auction, supported by local businesses that donated goods and services. They were able to raise much-needed funds for BDSRA Australia, for research and to support families, while also helping raise awareness for more people understand a disease that far too few have ever heard of. Though facing a heartbreaking path, Grayson's family found hope and strength in the compassionate response of a community standing beside them.



Uniting for Lachie

- Toukley Preschool hosted two "Wear Bright Colours" days to brighten the spirits of children with Childhood Genetic Diseases, raising $566.
- St Mary's Catholic Primary School held a pyjama day, raising $744.10.
- Lachie's sister organized a "Wear Orange to Dancing" week at her dance studio, raising $250.

Celebrating Kiaana

Ahead of International Batten Disease Awareness Day, Kiaana and her mother Alicia returned to South Australia's Tribe FM 91.1 for a special radio interview to share Kiaana's journey living with CLN3 Batten disease. Celebrating Kiaana's milestone 31st birthday, the mother-daughter duo used the platform to advocate for affected families, highlight childhood dementia awareness, and discuss critical research progress. Their broadcast aimed to inspire listeners across the community with a powerful message of resilience and hope.



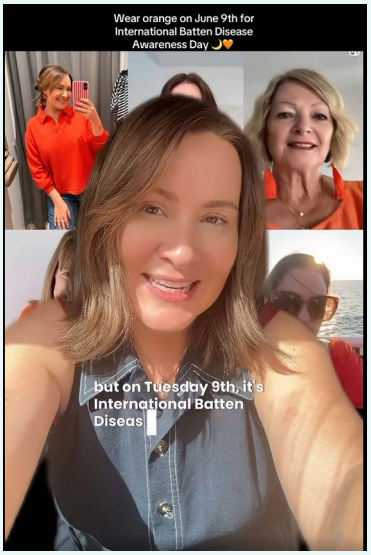
In memory of Mackenzie-Rose

Grahamstown Public School, NSW, hosted a successful fundraiser led by the Foster family to raise awareness for Batten Disease. Through their combined efforts the initiative made a strong impact by selling 6 boxes of 'Forget Me Knot' IBAD balls. Shout out to Lisa Moore for her amazing effort throughout the campaign. Naomi Foster baked sweet treats as a delicious thank-you gesture for the team.



Adelaide Hills Boxing and Fitness Raises $1,000

Mercedes Taaffe-Cooper and the team at Adelaide Hills Boxing and Fitness hosted "The Battle in the Hills." Driven by their Counterpunch program, this year's event successfully raised $1,000 to support BDSRA Australia. This marks the fourth time Mercedes and her fitness community have championed the fight against Batten Disease, demonstrating a deep, ongoing commitment to Kenzlie and the McWaters family, continuing to raise both funds and awareness for Batten disease research.



Online community going orange to raise awareness

Sarah Strozkiy founder of Shessoseasonal is also mother to Sonny, recently diagnosed with CLN2. Sarah challenged their community to wear or find something orange, Sonny's favourite colour and to share a photo to raise awareness for Batten disease. Sarah shared in a post how powerful it was to have the support of her community and the growing impact spreading awareness can have.

Thank you Sarah, Jason and Sonny for continuing to raise awareness in the community and in the media.



Team Isla - Bouncing for Battens

Emmaus Catholic Primary School Mt Clear in Victoria got behind the Hunter family, acknowledging and celebrating Bounce4Batten and beautiful Isla living with CLN1. Isla's siblings, Paddy (Mok-borreeyn) and Harry (Nyereeka), with support by mum Nikita (pictured), are amazing advocates for their sister Isla and Battens. Everyone wore a touch of teal or blue in recognition, and with students taking turns in the activities, there was bouncing non stop from the start of school until the end of the school day!

Fashion for Batten - 2026

On the 12th September, Phyllis Parker (92) held another one of her dazzling fashion parades at Mt Gravatt Tricare Retirement Village, where she and her partner now reside. There were about 70 guests in attendance, mainly residents of which some also participated as models!

A wide collection of fashion (the highlights being Wedding dresses past and present), a strong interest in raffles, and a delightful afternoon tea was enjoyed by all. It was a great success with lots of questions and awareness raised about Batten Disease. Total funds raised was $1700. Read more.





ASX Refinitiv Charity Foundation

The ASX Refinitiv Charity Foundation Raffle is now LIVE and we are committed to selling $10,000 worth of tickets. As you may have seen in our Autumn 2026 newsletter, one of our very own Batten supporters won 1st prize - a new car, next

time, this could be you! We are calling on our families and friends to purchase and share with your own networks to promote this raffle as all tickets sold go towards the sum of the annual donation we receive from the Foundation.

This year's prizes include:
1st prize: MG ZS Excite - valued at $26,990
2nd prize: MacBook Air - valued at $2,099
3rd Prize: Apple Watch Series 11 – valued at $849

Purchase your raffle tickets here and share with your network today.



Upcoming ASX events:

- Thursday 10th November 2026 - Markets Day for Charity
- Friday 13th November 2026 - Sailing Regatta at Middle Harbour Yacht Club
- Thurs 18th & Fri 19th February 2027 - Golf Classic at Pennant Hills Golf Club

For more information contact Nikki Hopkins at info@bdsraaustralia.org.

Family Support

Matt Danskin reflects on his first BDSRA Family Conference - Chicago 2026









Matt Danskin, whose 7-year-old son Jack was diagnosed with CLN3 Batten disease in May 2025, traveled from Melbourne to Chicago to attend his **first BDSRA Family Conference**. Initially overwhelmed, Matt found immediate support, connection, and profound inspiration throughout the weekend. From emotional welcome addresses and insightful sessions led by adults and siblings living with Batten disease to a men's peer-to-peer group and a joy-filled Saturday banquet, the conference offered both a space to share heavy realities and moments to celebrate life.

While the emotional toll peaked during the Sunday Celebration of Life Memorial, which served as a stark reminder of the disease's reality, Matt returned home with a recharged determination and a renewed sense of hope. The experience underscored the incredible resilience of affected families as well as the dedicated collaboration among researchers, clinicians, and leaders driving toward a cure. Ultimately, the

conference assured him that despite the difficult road ahead, his family is not facing this journey alone

Matt Danskin's shares with us his personal reflection on attending his first BDSRA Family Conference after his son was diagnosed with CLN3, highlighting the emotional support, shared resilience, and hope he found within the community. Read the full story here.

We would love to hear from you!
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

Understanding Baseline: A new "normal"



Blair from Courageous Parents Network (CPN) shares about Understanding Baseline and how CPN can help support families navigating the unexpected journey of life with a medically complex child. Read more here.

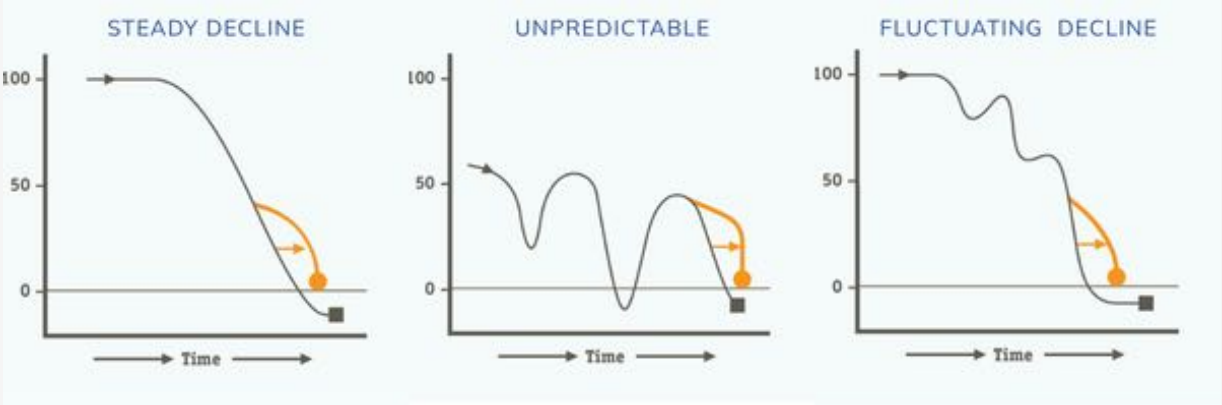
Parents often notice changes in their child's health before anyone else. Changes can sometimes be sudden and clearly linked to an event. Other times they are subtle, unfolding slowly over time until they become part of a larger pattern.

When a change feels lasting rather than temporary, clinicians may describe it as a shift in a child's baseline. Baseline is the reference point used to understand a child's usual state of health, development, and functioning. It is what we compare against when we are trying to understand whether things are improving, stable, or changing.

For children with complex medical needs, baseline is rarely fixed. Over time, families may notice that the “highs” are not as high as they once were, and the “lows” can be more pronounced or prolonged. Parents play a critical role in identifying these shifts. The ability to describe what is changing day to day makes families essential members of the care team. At the same time, naming changes can make them feel more real, which can bring grief, worry, or uncertainty about what comes next.

Continue reading the full article here for more about tracking baseline and how understanding baseline helps with decision making.

Courageous Parents Network offers more detailed information and guidance on these topics, including decision-making, goals of care and advance care planning. Visit the CPN website or the section specific to medical complexity.



Understanding Episodic and Fluctuating Rare Disease Disability in the Education Setting



BDSRA Australia has launched the '**Living Well with Change**' resources. They include 3 PDF fact sheets that can be downloaded, printed and shared.

These resources are for:
- Children and young people living with episodic and fluctuating rare disease disability (referred to as 'students')
- Families, carers, educators and support teams

See the resources: www.bdsraaustralia.org/livingwell

You will also find more information and helpful links.

The resources can help:
- To start conversations
- With planning for meetings

The resources form part of the Rare Disease Disability Toolkit.

Thanks to everyone who contributed to this project. We thank the people who participated in interviews and provided feedback. Your experiences and insights helped shape these resources.

Resources

Disabled Surfers Association of Australia (DSAA)

The Disabled Surfers Association of Australia (DSAA) is a volunteer-run, not-for-profit organisation that gives people with disability the opportunity to experience the freedom, excitement and enjoyment of surfing.

The DSAA runs specially organised surf days and events around Australia, bringing together participants, families, carers, surfers and volunteers. Volunteers provide the assistance and equipment needed to safely get into the water and catch a wave so no prior surfing experience is required to participate.

Beyond surfing, DSAA is about inclusion, confidence, friendship and breaking down barriers, giving people with disability the opportunity to enjoy the ocean and experience something they may never have thought possible.

Belongside Families

Belongside Families is a family-led not-for-profit supporting parents and carers of children with disability, delay, Autism, rare and genetic conditions. All of their support is free, informed by evidence and shaped by lived experience, so it is credible, practical and useful in everyday family life.

Through online workshops, webinars, parent groups, an

online community and one-to-one support, they help families navigate systems, grow their knowledge and feel less alone.



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** (recommended), or fill out the contact form online. **Note, phone calls are triaged quicker than forms.** To learn more, visit here.

Not on social media?
Keep up-to-date on BDSRA Australia's latest news and events on our website! Our instagram is live on our Home page and our key highlights are added to the News page, so feel free to head over to check out the latest!

Research Updates

Compiled by **Ineka Whiteman PhD**, Head of Research and Medical Affairs and **Tahmina Tabassum PhD**, Project Support Officer

BDGRI Grant Applications Now Open!

We are delighted to announce that **applications are now open** for the 2026–2027 **Batten Disease Global Research Initiative** (BDGRI) Grant Round!

We invite Expressions of Interest (EOIs) from researchers worldwide working in Batten disease or related fields, with innovative research proposals that have the potential to advance our understanding of Batten disease and drive progress towards new treatments.

🌎 Researchers worldwide are encouraged to apply!
📅 EOI Deadline: 14 December 2026

For grant guidelines, eligibility criteria, and application details, visit here.



The Case for Master Protocols for Rare Neurological Diseases

This paper emerged from discussions and collaborative efforts following the 2025 Network-Linked Open Conference through NeuroNEXT, led by Drs. Jennifer Vermilion (Chair) and Erika Augustine (Co-Chair) and featuring speakers from the BDCRC, Drs.

Ineka Whiteman and Raymond Wang. In the publication, authors explore opportunities for leveraging master protocol approaches to accelerate therapeutic development across rare neurological disorders. The article is currently available through PubMed, with open-access availability expected soon.

To read more, visit here.

A new piece of the Batten disease puzzle – revealing connections across multiple NCL forms

On 15 September 2026 an important new research, jointly funded by the Batten Disease Global Research Initiative (BDGRI) and NCL-Stiftung, was published in Nature Cell Biology. Led by Dr Kasparas Petkevicius at the University of Cambridge, UK, the study has uncovered the function of the CLN8 protein, solving a longstanding question in Batten disease research.

The research reveals that CLN8 plays a key role in producing BMP, a specialised lipid essential for healthy lysosomal function. The study shows that two Batten disease proteins, CLN8 and CLN5, act sequentially in the pathway that produces BMP – with CLN8 generating the lipid building block subsequently used by CLN5 to form BMP. While CLN8 is one of the rarer forms of Batten disease, the significance of these findings extends beyond CLN8 and CLN5. Previous research has also identified BMP abnormalities in CLN3 disease, together pointing to BMP metabolism as an important biological connection across multiple NCLs.

Importantly, researchers also showed that the biochemical defect caused by loss of CLN8 could be bypassed experimentally, providing an exciting early foundation for future therapeutic research.

Dr Petkevicius was relatively new to NCL research when his work was first identified through the BDGRI funding rounds. This work is a wonderful example of what collaborative research funding can enable – bringing new scientific expertise into the NCL field, supporting exceptional researchers, and fostering international collaboration to accelerate discovery.

To read the article, visit here.

BDSRA Australia Researcher Spotlight

This dedicated series is an invitation for our community to read the stories of the individuals who have dedicated their careers to changing the future of Batten disease research.



Professor Robert Dudley "Bob" Jolly (1930-2025)

One of the pioneers of Batten disease research in New Zealand and internationally.

A veterinary pathologist and Professor Emeritus at Massey University, much of Professor Jolly's distinguished career focused on naturally occurring animal models of lysosomal storage disorders, including Batten disease. He was instrumental in characterising the South Hampshire sheep model of CLN6 disease, which became one of the world's most important models for understanding disease pathogenesis and testing potential therapies.

While many families affected by Batten disease may never have known Professor Jolly's name, they have nonetheless benefited from his curiosity, scientific rigour, and unwavering commitment to improving understanding of these devastating disorders. His legacy lives on in the discoveries he made possible, the researchers he inspired, and the hope his work helped create for future generations.

~ In remembrance of Prof. Jolly~

Prof Stephanie Hughes: *"Without Bob's curiosity, identifying and establishing the first Batten sheep flock in New Zealand, my research path would have been entirely different. From the early days of him or I driving between Wellington and Palmerston North with sheep samples to more recently working with Bob to identify storage material in a Takahe (NZ endangered bird), Bob has been a huge influence. Forever the father of lysosomal storage disorders in New Zealand. You will be missed, Bob."*

Dr Nadia Mitchell: *"Well into his nineties, Bob retained an extraordinary command of lysosomal disorders in livestock. His memory for facts was remarkable, his questions were always thought-provoking, and his enthusiasm for Batten disease never waned. Whenever the phone rang, I knew I would be in for a stimulating conversation. His curiosity, sharp intellect, and enduring passion for science were truly inspiring. His contribution to the field will not be forgotten."*

On behalf of BDSRA Australia, we extend our sincere condolences to Professor Jolly's family, friends, colleagues, and former students, and offer our deepest gratitude for a life dedicated to advancing science in the service of others.

Read the full researcher spotlight article here.

Research Opportunities

Progress in Batten disease research would not be possible without the invaluable participation, insights and commitment of our patient and family community. By sharing your experiences, you help researchers better understand the impact of Batten disease, identify unmet needs, and ultimately improve care and treatment for affected individuals and families.

We are pleased to share the following local and international research opportunities and warmly encourage parents and caregivers to participate, where eligible.

Thank you in advance for taking the time to contribute – your experiences and perspectives are vital to advancing research and improving outcomes for our community.

Co-design Accessible Toys



University of Sydney, Australia

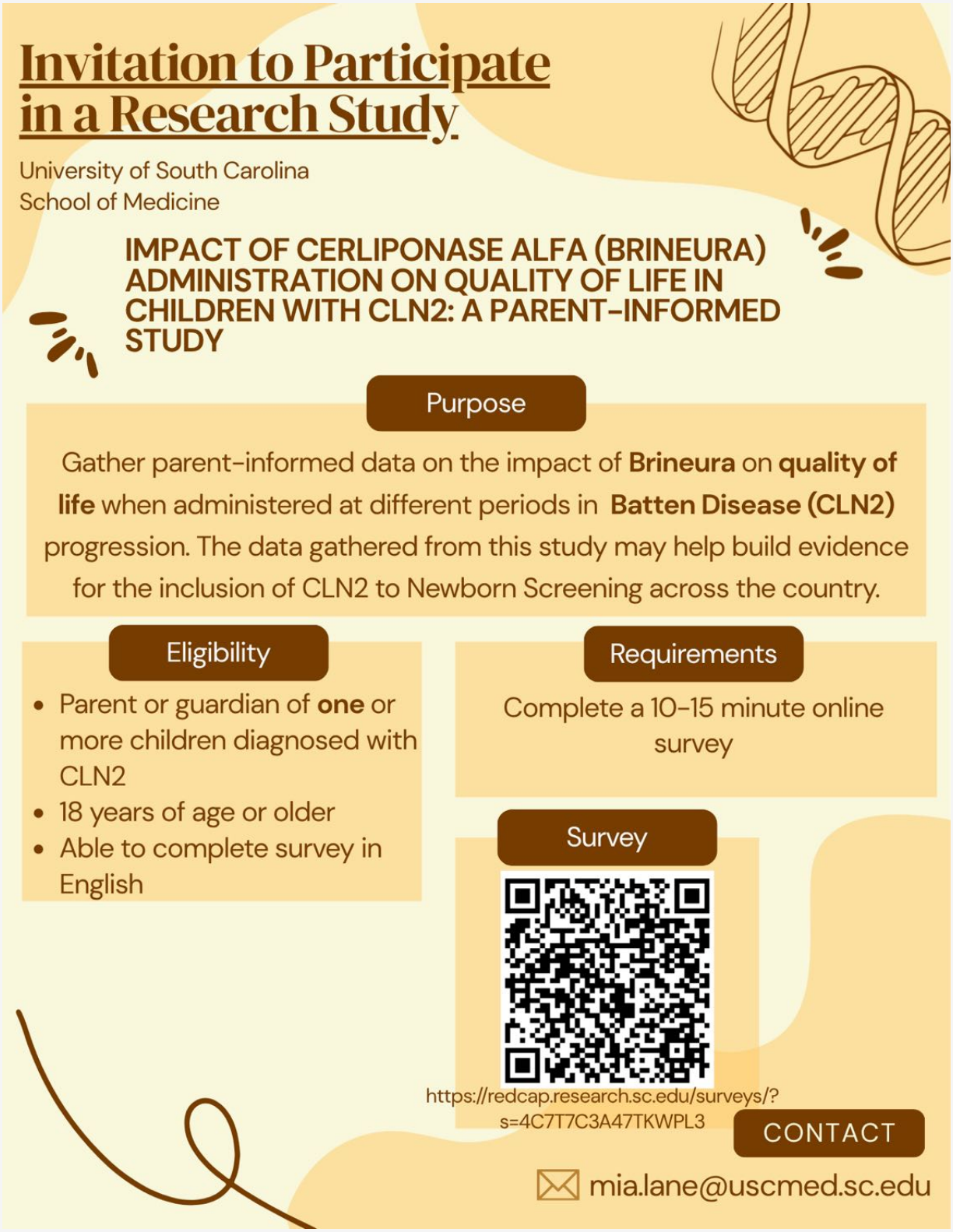
We know that parents are always looking to help their kids enjoy their childhood, but not every toy is suitable for kids affected by Batten disease. When friends and family ask what your child might like for birthdays or Christmas, it's not always easy to list toys that you know your child would like and use. Participation in this research project would allow you to contribute your experience and feedback for designing accessible

toys. It is also open to bereaved parents.

For more information please refer to the flyer above.

To express your interest scan the QR code, visit here or to ask for more information contact Wesley at wesley.bobby-joy@sydney.edu.au

Impact of cerliponase alfa on quality of life in children with CLN2: A parent-informed study



University of South Carolina Floyd School of Medicine, South Carolina, USA
Master's Project - Genetic Counseling Program

This study will investigate if parent-perceived quality of life in children diagnosed with CLN2 is affected by the administration of Brineura at different ages or in children who have not received Brineura. The purpose of this study is to understand how earlier delivery of treatment affects quality of life, and if this information could help build support for the addition of CLN2 to newborn screening.

ELIGIBILITY: Parents or guardians of one or more children diagnosed with CLN2 disease. Participants must be 18 years of age or older and able to complete the survey in English. Survey is open to US and international participants.

STUDY REQUIREMENT: Complete a 10-15 min online survey

For more information visit the survey page or
Contact: Mia Lane, Master's Candidate in Genetic Counselling
Mia.Lane@uscmed.sc.edu

Batten Disease Quality-of-Life Study

Kennedy Krieger Institute, Maryland, USA
In partnership with the Kennedy Krieger Institute, the BDSRA Foundation invites individuals affected by Batten disease, their family caregivers, and bereaved caregivers worldwide to participate in an important research study focused on improving how quality of life is measured.

While traditional clinical assessments focus heavily on physical progression, this patient-centered study aims to build a Batten disease-specific Quality-of-Life (QOL) screener that reflects true lived experiences including sleep, emotional well-being,

family impact, daily routines, and caregiver demands.

Participation is completely voluntary, takes just 15–30 minutes via an online survey, and requires no prior research experience. To share your essential perspective and help shape future clinical tools, visit the survey here or scan the QR code.

For questions, please contact:

- Principal Investigator: Dr. Heather Brown
- Institution: Kennedy Krieger Institute, Maryland, USA
- Email: PalliativeCare@kennedykrieger.org
- Phone: 667-205-4613

Study on How Siblings Find Health & Support Information



University of New South Wales, Australia

Growing up alongside a brother or sister with a long-term condition such as Batten Disease often builds siblings' empathy, resilience, and a deep sense of care for their family. But it can also raise big questions and emotions that they don't always have support to work through.

When reliable information and support isn't easy to find, siblings may turn to social media or AI tools for answers and not everything they find there is accurate or helpful. Right now, there isn't enough research on how siblings in Australia find information and access support, which makes it hard to know what kind of resources would help.

We want to change that. By understanding where siblings look for information, we can build more resources designed around siblings' real experiences.

Siblings can go in the draw to win one of two $50 gift cards after completing this questionnaire until 30th November 2026.

If you have a child who's eligible, we'd love for them to take part. Please also pass this on to anyone who might be interested. If you have any questions, Maddison Smith is happy to help at maddison.c.smith@unsw.edu.au.

Clinical Trial Updates

Clinical trial updates - useful 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 (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 and Advocacy Foundation (bdsrafoundation.org)

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

Exciting progress for CLN7 gene therapy: New Partnership and clinical trial expansion

Elpida Therapeutics and **LifeArc** have announced a major partnership to advance gene therapies for three ultra-rare neurodegenerative diseases: CLN7 Batten disease, SPG50 and CMT4J.

The collaboration will provide financial support and clinical development expertise to help progress these promising therapies through regulatory pathways in the US, UK and Europe. Importantly, the partnership also aims to establish a more sustainable, repeatable model for developing and delivering gene therapies for ultra-rare diseases.

In a further update released in October, **Elpida Therapeutics reported encouraging progress in its CLN7 gene therapy program**. Following treatment of an additional patient earlier this year and completion of an initial 90-day safety observation period, investigators have submitted an amended protocol to the FDA proposing evaluation of a higher dose, alongside updated eligibility criteria and clinical assessments.

The team is also working towards establishing a clinical trial site in Spain, potentially expanding access to families in Europe, subject to the necessary regulatory approvals.

These developments represent important steps towards advancing this investigational treatment and exploring opportunities to reach more children affected by CLN7 disease.

Read more:

- LifeArc and Elpida Therapeutics partnership announcement
- Elpida Therapeutics CLN7 Community Update – October 2026

Exciting Progress in CLN3 ASO Therapy Development

In June, the ForeBatten Foundation released a Community Statement on Project Four Leaf Clover, a collaborative initiative developing an antisense oligonucleotide (ASO) therapy targeting the common CLN3 exon 7–8 deletion, which accounts for approximately 85% of CLN3 disease cases.

This was followed by exciting news in October, when the University of Michigan announced a **US$3.9 million NIH award** to advance this promising therapeutic approach towards clinical trials.

Led by **Dr Michelle Hastings**, the research builds on the team's pioneering work

developing Zebronkysen, a personalised ASO therapy currently being evaluated in two sisters with a different, rare CLN3 mutation.

The new funding represents an important milestone in efforts to extend this approach to a much larger group of individuals with CLN3 disease, although further development and clinical evaluation are still required.

Read the University of Michigan announcement.



Major Milestone for Batten-1: Phase 3 Clinical Trial Moves Closer

In September, **THX Pharma**, **Beyond Batten Disease Foundation (BBDF)** and **Biocodex** announced an important milestone in the development of Batten-1, an oral liquid formulation of **miglustat** being investigated as a potential treatment for CLN3 disease.

Regulatory applications have been submitted in the United States, United Kingdom and six European countries to initiate an international **Phase 3 clinical trial**. The study will involve approximately 27 children aged 4–17 years across 10 specialist centres in the US and Europe, evaluating whether Batten-1 can slow or stabilise the progressive loss of vision associated with CLN3 disease.

The trial has now been registered on ClinicalTrials.gov (NCT07882290), providing further details about the study design, eligibility criteria and participating centres. The study is currently listed as not yet recruiting, with enrolment anticipated to begin in December 2026, subject to regulatory approvals.

This represents an exciting step towards generating the clinical evidence needed to support potential regulatory approval of a disease-modifying treatment for CLN3 disease.

Read more:

- Official THX Pharma, BBDF and Biocodex announcement
- ClinicalTrials.gov – Batten-1 Phase 3 Study (NCT07882290)



BDSRA Australia Family Register

Keep your family details current

Help us stay connected by ensuring your family's information is accurate and up to date in our records. If you've moved, changed details, or haven't completed this form since 2023, please take 2–3 minutes to update the official BDSRA Australia Family Register.

This Register is a confidential contact database that enables us to keep you informed of ongoing Batten disease research, including future research opportunities. It also enables us to better understand the prevalence of Batten disease in our region, including the different subtypes and geographical locations. This helps us tailor our research, education and support activities according to the needs of our families.

The BDSRA Australia Family Register is seperate from the usual 'contact list'. If you've previously shared your details with us by phone calls, emails, family conference regos or at other events, these are not automatically added to our official register without your consent.

We strongly encourage **all current and bereaved families across Australia and New Zealand** to fill in this Register, at-least once, to ensure we have your complete and up-to-date information in our official database

The information collected in this form is kept STRICTLY CONFIDENTIAL.
Your involvement in this survey is entirely voluntary, and you may request to be removed from the list at any time.

You may access the form at any time via our website's Families tab or using the button below.

📋 BDSRA Australia Family Register form

Research Publications - Selected



A selection of recent research publications in Batten disease are provided below. Details and links to each article are **here**.

🔬 The Case for Master Protocols for Rare Neurological Diseases.

🔬 Lysosomal biophysics in CLN3 disease: Connecting membrane transport, molecular homeostasis, and tissue dysfunction.

🔬 Generative Artificial Intelligence in Health Research and Care: A Narrative Review of Applications and Implications for Alzheimer's Disease and Related Dementia.

🔬 The calcium channel blocker diltiazem ameliorates parthanatos in juvenile neuronal ceroid lipofuscinosis.

🔬 The Batten disease protein CLN8 is a stereospecific acyltransferase in bis(monoacylglycero)phosphate biosynthesis

🔬 Batten disease protein CLN8 enables a non-canonical phospholipid synthesis pathway

🔬 CLN8 recycles glycerol backbones for BMP

🔬 Molecular insights into ATP synthase c-ring accumulation in BMP-deficient lysosomes in Batten disease.

🔬 Intracerebroventricular repeat dose CPI-601 recombinant human palmitoyl-protein thioesterase-1 in cynomolgus monkey: safety, pharmacokinetics, and dose selection.

🔬 A 3D human retina model reveals a non-cell-autonomous and non-neuronal mechanism of photoreceptor loss in a lysosomal storage disorder.

🔬 Disruptions in speech, language and social communication in lysosomal storage diseases.

🔬 Naturally occurring lysosomal storage disease consistent with neuronal ceroid

lipofuscinosis in a group of 5 related captive rhesus macaques (Macaca mulatta).

🔬 Phenotypic and Genetic Characterization of 64 Egyptian Children With Neuronal Ceroid Lipofuscinosis.

🔬 Morphometric Brain Changes in a Merino Sheep (Ovis aries) CLN6 Neuronal Ceroid Lipofuscinosis Model.

🔬 From larynx to limbs-neuronal ceroid lipofuscinoses presenting with a predominant dystonia phenotype in siblings.

🔬 Sex-dependent clinical divergence in adult-onset CLN6-Batten disease: a case study of a Chinese brother-sister pair.

🔬 Adult-Onset Recessive Cerebellar Ataxia and Severe Multisystem Disease-Associated Genes: Hypomorphic Alleles and Clinical Interpretation Pitfalls.

🔬 Atlas of lysosomal aging reveals a metabolite signature shared with lysosomal storage disorders.

🔬 Progressive Orexin Deficiency and Age-Dependent Glial and Axonal Biomarkers in juvenile neuronal ceroid lipofuscinosis type 3 (CLN3) Disease.

🔬 Thapsigargin-induced autophagic flux impairment and inflammation are potentiated by CLN3 deficiency and alleviated by 5-aminoimidazole-4-carboxamide ribonucleoside (AICAR) in human ARPE-19 cells.

🔬 Expanding the genotypic landscape of the neuronal ceroid lipofuscinoses: clinical and molecular findings from a tertiary-care center in Argentina.

🔬 A human lysosomal storage disorder toolkit for decoding proteome landscapes in cortical-like and dopaminergic-like induced neurons.

🔬 Bi-allelic TPP1 variants in neuronal ceroid lipofuscinosis 2: clinical findings from an Iranian cohort of 20 patients, founder effect, and in silico analyses.

🔬 Psychiatric manifestations in Neuronal ceroid lipofuscinoses.

🔬 Behavioral and emotional symptoms and quality of life in a national sample of individuals with CLN3 Batten disease.

🔬 Exploratory Analysis of Neuroimaging and Molecular Findings in a Cohort of Neuronal Ceroid Lipofuscinosis: a Descriptive study.

🔬 Topiramate-Responsive Myoclonic Status Epilepticus in a Child with Progressive Myoclonus Epilepsy Due to Neuronal Ceroid Lipofuscinosis Type 8: A Case Report.

🔬 Mapping Clinical Progression to Brain Atrophy in CLN2 Patients Under Cerliponase Alfa Treatment: A Prospective Neuroimaging Study

🔬 Reversible synaptic deficits in early-stage batten disease.

🔬 AI-driven insights into protein misfolding and innate immunity in neurodegenerative diseases.

Details and links to each article above are **here**.

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

Current or Bereaved Batten families in Australia & NZ, please update your details via our Family Register form.

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Australian Registered Body Number: 073 435 202

Australian Business Number (ABN): 56 056 138 994

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