

NEWSLETTER
Winter 2023 Edition



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President's Report



Winter collage of children and young people affected by Batten Disease

As we wrap up winter, we are excited to report that our Head of Research and Medical Affairs, Ineka Whiteman has recently taken on the additional roles of consulting to our US partners - the Batten Disease Support, Research and Advocacy (BDSRA) Foundation and the Beyond Batten Disease Foundation (BBDF). These new partnerships mean that **Ineka is now officially working full time in the Batten Disease field**. This is the first time any of these organisations have had access to a full time research or scientific officer, an amazing step which will ensure our collaborative efforts in Batten research will go from strength to strength.

In a recent interview with the BDSRA Foundation, Ineka shared a little about her roles, professional background and personal journey that led her to becoming involved with Batten Disease. You can read the interview [here](#).

Ineka has certainly been on the pulse attending this year's BDSRA Foundation's Family Conference in Texas in July, (see her report below) and this month, along with Tony Cook from our Medical and Scientific Advisory Board, she will be attending the 2023 International Congress on Neuronal Ceroid Lipofuscinoses in Hamburg. We are thrilled to have both **Ineka and Tony representing us in Hamburg** along with our other international Batten Disease affiliates at such an important congress.

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) 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 held various leadership roles within BDSRA Australia since 2001 and remains involved to this day. 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.

This Wednesday, 20th September at 10 am Vanessa will be awarded her OAM medal at the official Investiture Ceremony which will be streamed live [here](#). (a recording will also be available later via this link)

To read more about Vanessa and her service to our Batten community, read [here](#).

In other news, I just want to give a HUGE shout out to all our participants who entered the recent Sydney **City2Surf** and **Beach2Beach** fun runs. The amount raised is quite honestly mind blowing and well above our expectations so we can't thank you enough and hope that you will all get on board again for next year!! To find out how much was raised please see our **Treasurer's and Fundraising reports** below.

Following on from the success of last year's Family Retreat we are now planning **our next Family retreat**, so please keep your eyes out for

further communication as we'll be asking for your thoughts and preferences for the next retreat.

Lastly I'd like to advise that our **AGM will be held on Friday 17th November**, further information will be sent out closer to the time.

Amber

Appeal for new Management Committee members

If you are interested in joining the BDSRA Australia Management Committee we would love to hear from you. As a grassroots organisation we depend on the contribution and support of our Batten Community to be able to continue to achieve our mission of providing education and support for our families and advancing research towards finding treatments and a cure.

We are keen to look at further ways that we can better fundraise and would like to set up a **fundraising subcommittee** so that we can establish some fixed fundraising initiatives that will allow us to sustain the longevity of our association.

We are also interested in anyone who has certain **skill sets or expertise** that would benefit the operation of the Board and management committee, these may include strategic planning, marketing, accounting, legal knowledge or skills.

If you are interested in joining the committee, volunteering your time or would like to find out more, please contact Nikki Hopkins at info@bdsraaustralia.org

Research Update

By Dr Ineka Whiteman, Head of Research and Medical Affairs

USA Family Conference 2023 – Clinical & Scientific Program Highlights

Our friends at BDSRA Foundation (USA) held their annual family conference in Denton, Texas on July 14-16th. With around 300 in-person attendees and dozens more online, it was a buzzing, jam-packed few days. I'm delighted to share some of the highlights and key takeouts from the Clinical & Scientific program. **Dr Jon Cooper**, **Dr Dave Pearce** and I worked together to build a truly family-centred, interactive and dynamic educational program this year, with a focus on in-person presentations and plenty of opportunity for discussions and question time with our guest speakers.

On Day 1, we were treated to a 'Batten Disease 101' interactive session with **Dr Dave Pearce**, heard many practical, take-home tips for **managing behavior, learning and cognition changes** with **Dr Heather Adams**; and learned about the **neuroscience of stress and practical tools to avoid caregiver burnout** with psychologist, physical rehab specialist and Batten parent **Dr Joseph Vigil**.

Our **Ask-A-Doc panel** was one of our most popular sessions again this year, with families invited to ask impromptu questions relating to any aspect of Batten disease diagnosis, care and management. We are grateful to our esteemed panellists **Dr Kourtney Santucci** (Children's Hospital

Colorado, Denver), **Dr Erika Augustine** (Kennedy Krieger Institute & John Hopkins University), **Dr Heather Adams** (University of Rochester Medical Centre, NY), **Dr Gary Clarke** (Texas Children's Hospital, Houston) and **Dr Elizabeth Berry Kravis** (via video link; Rush University Medical Centre, Chicago).

On Day 2, a team of scientists presented a wonderful, cohesive series of presentations on how Batten disease research journeys from lab bench to bedside, from the **Basics & History of Batten Disease (Dr Keigo Takahashi)**, **Models of Disease (Dr Dave Pearce)**, **Learnings from NCL Models (Dr Jon Cooper)** to application of **Experimental Therapy Approaches (Dr Michelle Hastings)**. This 'dream team' laid a perfect foundation for the **Clinical Trial Overview and Update**, where I was able to dive right in with the latest developments in more than 10 clinical programs. The current status of these programs are summarised below. Company representative from **Beyond Batten Disease Foundation, BioMarin, REGENXBIO, Theranexus** and **University of Texas Southwestern** joined our session speakers on the stage for a lively and extended Q&A.

Session recordings (for those listed above) are now available to conference registrants in the mobile conference app and the app's web platform [here](#). Head to 'Agenda', find the session and click 'View Recording'.

Copies of slides can be requested from info@bdsrafoundation.org



Clinical Research Updates

The following link is a summary of clinical program updates across all NCL subtypes, compiled in collaboration with the BDSRA Foundation (USA). Visit this page for latest updates on each program.

[Clinical Studies - Batten Disease Support & Research Association \(bdsrafoundation.org\)](https://bdsrafoundation.org)

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



Gene therapy studies for
CLN2 disease - REGENXBIO

We're excited to share some exciting developments in REGENXBIO's first-in-human gene therapy programs for the treatment of CLN2 disease.

On August 2, REGENXBIO announced the first patient had been dosed in the Phase I/II ocular trial of RGX-381 at Great Ormond Street Hospital in the UK.

RGX-381 is an investigational one-time AAV gene therapy for the treatment of ocular manifestations of CLN2 disease, using the NAV® AAV9 to deliver the TPP1 gene directly to the retina. Initial data from this trial is expected to be shared in 2024. For more details see [REGENXBIO Reports Second Quarter 2023 Financial Results and Recent Operational Highlights](#).

In addition, REGENXBIO's program for brain/central nervous system (CNS)-targeted gene therapy, known as RGX-181, continues. Physicians in Brazil continue to follow the first child with CLN2 disease dosed with RGX-181 under a single patient investigator-initiated study. Initial interim data from this study, including 6-month results, were presented at SSIEM (Society for the Study of Inborn Errors of Metabolism) Annual Symposium in Jerusalem on August 30. A summary of this data can be found here: [Initial Clinical Data of First Pediatric CLN2 Patient Dosed with RGX-181 Presented at SSIEM Annual Symposium](#).

RGX-181 is an investigational one-time AAV therapeutic for the treatment of CLN2, using the NAV AAV9 vector to deliver the TPP1 gene directly to the CNS.



BATTEN-1: IMPORTANT NOTE TO FAMILIES:

Recruitment for the Batten-1 (miglustat) Phase 3 study is set to commence recruitment later this year. 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.

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

'Batten-1' clinical trial for CLN3 disease

Encouraging news for our CLN3 community, with Theranexus and Beyond Batten Disease Foundation announcing in June preliminary results from the Phase I/II trial of Batten-1 (miglustat) for the treatment of CLN3 disease.

After 6 months of treatment, the preliminary data shows:
Reduction of neurofilaments, a biomarker of neuronal death
Stabilization of motor symptoms for treated patients in comparison to the decline expected with the natural disease course
Batten-1 continues to show a good tolerability profile

Results will be presented to the scientific and medical community at NCL2023, the 18th International Congress on Neuronal Ceroid Lipofuscinoses to be held in Hamburg, Germany from 26 to 30 September.



Neurogene Inc. company news

Neurogene and Neoleukin Therapeutics have announced an agreement to merge. Neurogene currently sponsors a Ph 1/2 gene therapy trial for the treatment of CLN5 disease (<https://clinicaltrials.gov/study/NCT05228145>), among several other CNS programs.

Read the company press release [here](#).
Read Neurogene's letter to the patient community [here](#).

In the media - Gene therapy and Batten disease

To mark International Batten Disease Awareness Day on June 9, CGTLive (Cell & Gene Therapy Live) interviewed experts on the potential impact of gene therapy on the Batten disease treatment landscape. Dr Ineka Whiteman and Paulo Falabella, MD, PhD, VP of Clinical Development at REGENXBIO Inc, discussed current standards of care, unmet needs, and emerging therapies for Batten disease. Read the interview [here](#).

RESEARCH OPPORTUNITY - WE NEED YOUR HELP!

Attention CLN2 and CLN3 families

Our researchers need a few more volunteers to help complete this project, which has the potential for far-reaching benefits for our whole Batten community.

BDSRA Australia is co-funding and partnering with Murdoch Children's Research Institute (MCRI) in Melbourne, to support a **world-first research study** into the **characterization of speech and language in individuals with Batten disease**. The project's aim is to improve our understanding of the strengths and difficulties of communication in Batten disease, and to **help develop more effective, targeted therapies**.

Participation is open to individuals worldwide who are:

- affected by CLN3 or CLN2 Batten disease
- age 6 months and older
- 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 MCRI team at geneticsofspeech@mcri.edu.au

We are grateful for your participation!

Family Register - Have you joined yet?

Are you interested in hearing more about ongoing research? Do you want to be informed of upcoming **clinical trial/study opportunities**?

BDSRA Australia's Family Register is an important way for us to keep you informed of **clinical and scientific research developments** in a timely way.

The Register also enables BDSRA Australia to better understand Batten disease in our region, its prevalence, different subtypes and geographical distribution. It also helps us tailor our education and support activities according to the needs of our current and bereaved families.

If you are a parent or legal guardian of someone with Batten disease, and live in **Australia or New Zealand**, you may sign up to be on our Family Register by completing our short online form via the link below. It only takes a 2-3 minutes.

BDSRA Australia ensures that information in this register is kept strictly confidential.

Your involvement is entirely voluntary, and you may request to be removed from the list at any time by contacting BDSRA Australia.

Fill in the form here! [**BDSRA Australia Family Register form \(google.com\)**](#)

Research Publications - Selected



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

Sheep models proving valuable in Batten disease gene therapy research and development

The studies describe some of the key natural history and IND-enabling safety and efficacy studies that contributed to the development of Neurogene's NGN-101 therapy, currently in Phase 1/2 clinical trial for treatment of CLN5 disease. Read more [here](#).

Disease course may be slowed by 'exon skipping' in CLN3 disease

A gene-based technology that acts like a tiny 'molecular patch' over faulty DNA or RNA segments is a potential therapeutic solution showing promise in the treatment of Batten disease. Read more [here](#).

Biomarker discovery in CLN3: intriguing findings in cerebrospinal fluid studies

Biological markers or 'biomarkers' are important tools for evaluating the presence and progression of disease, and objectively measuring the efficacy of potential therapeutics. Read more [here](#).

A novel miniature pig model of CLN3 disease

Mouse models of CLN3 Batten disease have improved our understanding of the cell biology and disease mechanisms of CLN3 disease, and have been important on the path to therapeutic development... Read more [here](#).

New cellular roles for CLN3 protein identified in cell study

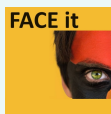
A Texas-based research team has identified new cellular roles for the CLN3 protein, the loss of which contribute to lysosomal impairment and neurodegeneration in CLN3 disease. Read more [here](#).

Assessment of CLN2 disease gene therapy in primate model

In 2020, Sondhi and colleagues published results from an investigative gene therapy study which concluded improvements in vector design and delivery strategies would be needed. In their latest study, published in August this year... Read more [here](#).

Events

Upcoming



Childhood Dementia Day

The FACE it campaign encourages people to make their face colourful and then to share a photo of it on Childhood Dementia Day, bringing a spotlight and awareness to childhood dementias like Batten Disease.

Wednesday, 20th September - on social media
#childhooddementia #FACEit Find out more [here](#).



Virtual Coffee catchup - General Catchup

Join us for a relaxed chat, an opportunity to meet other parents from around Australia and NZ, to discuss topics that attendees raise.

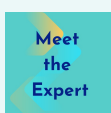
Wednesday, 18th October - 1:00 PM - 2:30 PM (AEDT)
Registration link will be emailed and posted on Facebook very soon!



National Carers Week Morning Tea (Carers NSW)

National Carers Week 2023 is held during the dates Sunday 15 to Saturday 21 October. To celebrate, BDSRA Australia is organising a much deserved gathering for our caregivers in greater Sydney. Last year, 8 mums came together for morning tea at Eden Gardens for informal peer support, to chat, laugh and enjoy some delicious food!

Keep an eye out - more information coming soon!



Meet The Expert - Managing challenging behaviours in Batten disease and childhood dementia

Join the Dementia Support Australia **Childhood Dementia Support team** as we discuss the behavioural and cognitive aspects of Batten disease and practical strategies to support

children, their families and caregivers.
More information coming soon

Past



Virtual Coffee catchup - Bereaved families

In the evening of Thursday 7th September, a group of our bereaved parents caught up via zoom from around Australia and NZ. Each meeting is a unique mixture of people and we go with the flow. It's an opportunity to connect, share and support each other.



Virtual Coffee catchup - Speech and Language

On Wednesday 30th August, we had a group discussion on everything communication in Batten Disease, with **special guest Speech Pathologist Lottie Morison!** Thorough discussion notes available.



Virtual Coffee catchup - Home modifications

On Monday 14th August we had a group discussion on everything home modifications, from the process to get NDIS approval to the types of modifications to consider. Recording will be available soon.



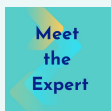
Virtual Coffee catchup - Dads

On Saturday 19th August was our first ever virtual Dad's catchup. **Guest facilitator Joe Vigil**, a Physical Rehabilitation Psychologist and Batten Dad from the USA and a small group of Aussie dads met together on zoom. It was great and unanimous that there should be regular opportunities for dads to connect. Get in touch if you or a Batten Dad you know, are interested in attending a future catch up.



Virtual Coffee catchup - Accessible Vehicles

On Monday 19th June we had a group discussion on everything accessible vehicles, from funding and NDIS to modifications. Notes have been taken from the discussion and experiences collated.



Meet The Expert - Understanding speech and language deficits in Batten disease

On Wednesday, 12th July Speech Pathologist **Lottie Morison** and **Prof. Angela Morgan** from the Murdoch Children's Research Institute (MCRI) Melbourne shared about their ground-breaking and vital research project that is being co-funded by BDSRA Australia.

See the recording [here](#) or visit our [resources website page](#)



Virtual Coffee catchup - General open-topic Discussion

On Monday, 5th June, we had a lively chat covering varying topics - everything from getting to know new people and sharing lived experiences to symptom management and tips for current challenges being faced! Thanks to those who joined us.

If you are interested in attending a future coffee catch up, or would like to receive a copy of the notes taken from any of the above discussions mentioned, please contact Liz Family Support Coordinator via support@bdsraustralia.org

Family Support



McWaters Family Raising Funds and Awareness for Batten Disease

From Bounce4Batten at Inflatable World, boxing tournaments and raffles, to local and national media, the McWaters family have been doing a remarkable job fundraising and sharing their story in support of Batten disease and BDSRA Australia!!

With their beautiful daughters, Maiah (20) and Kenzlie (10), both affected by CLN3 disease, Mandy and Dave McWaters are on a mission to raise funds, support and awareness for Batten disease in their local community and beyond.

Ahead of International Batten Disease Awareness Day in June, [ABC News](#) and [SA Today \(Fleurieu Sun\)](#) shared the McWater family story, their brave battle with Batten disease, and their call to raise awareness and better respite services for children with life-limiting conditions in South Australia.

Throughout June, they worked with several local community organisations to hold THREE separate fundraisers, which together raised more than \$3000!! **We are so grateful for the McWaters family's amazing support, creative fundraising ideas, and helping us raise vital funds and community awareness for Batten disease!** Read more about their activities [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@bdsraustralia.org

Our New Angel



Carmen

Our precious Carmen Katharina Golonski, was 4 and a half when she gained her angel wings on Sunday 27th of August. Her love and light a beacon of hope shines on for us all left behind. She is remembered for her smile, calming presence and fighting spirit. We send all our love to mum Gillian, dad Michael, grandma Michelle and all the family.

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

Children's Hospice WA receives DA approval



It's wonderful to see development is now approved for Australia's fourth paediatric hospice and first outside of the eastern states. WA Children's Hospice is anticipated to open in 2025. See Facebook post [here](#).

Quality palliative care is a cornerstone of holistic, integrated care for children affected by Batten disease and their families, and we encourage families to engage with these services early in their journey.

Despite the unfortunately negative stigmas that are sometimes associated with 'palliative care', the tailored, holistic care and support offered by these paediatric palliative care services is all about living well, and maximising quality of life for the child and their family unit from the outset.

Other facilities across Australia include [Bear Cottage \(NSW\)](#), [Very Special Kids \(VIC\)](#) and [Hummingbird House \(QLD\)](#). Australia's first Adolescent and Young Adult Hospice is [AYAH \(NSW\)](#). If you would like assistance connecting with these services, please reach out to us at info@bdsraaustralia.org

Resources



bdsraaustralia.org

NEW RESOURCES on the BDSRA Australia website

The Resources page of our website has recently had an overhaul! Check out all the latest support and educational resources, including a new **Current Clinical Trials search tool**. Check out our [Resources page](#).

You can now also find previous editions of our Newsletters on our updated ['News' dropdown menu](#).



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](#).

'Max & Abby' book turns 1!

We're excited to celebrate the 1st anniversary of our published children's book 'Max and Abby'!

More than 1000 copies are now in circulation all over the world, and is [NOW AVAILABLE THROUGH AMAZON!](#)

This beautiful resource was developed by BDSRA Australia in collaboration with Dementia Support Australia (DSA), and has been acclaimed by parents, educators and medical professionals as the perfect tool to help young children, especially siblings and peers, understand Batten disease and the changes and challenges that occur in affected children over time. *'Max and Abby'* is now provided as a key resource through DSA's Childhood Dementia Support Program, the BDSRA Foundation USA and Batten Disease Family Association UK.

Order your copy now!

Purchase your copy for AUD \$16.66 (+P&H) via Amazon at [Max and Abby : Whiteman PhD, Ineka, Moore, Deborah: Amazon.com.au: Books](#). All proceeds go to BDSRA Australia's support and research initiatives.

Families! BDSRA Australia is delighted to provide one complimentary copy to all families in Australia with a child affected by Batten disease (currently caring for, or bereaved). Head to our website and fill in the order form: <https://bdsraaustralia.org/Max-Abby>



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!

Donations

Thank you so much for your support!

What an incredible few months of fundraising we've had since our last newsletter!

We are so excited to share that thanks to the amazing efforts of all the City2Surf participants, **\$37,009** has been raised for BDSRA Australia! To top this off, there was another **\$4,522** raised by participants in the Beach2Beach fun run. A remarkable effort by all.

To all the participants in both of these events, **THANK YOU**, these funds will go a long way in helping us continue our vision this year and we hope these fun runs become a new yearly tradition! I don't think any of us expected its success to be quite so big! Bring on next year's event!

See our photo gallery via the link below, we would love to see more photos of those who participated so please share them with us at info@bdsraaustralia.org

Amanda Gilpin
Treasurer

Donate Now

CITY2 SURF

Click here
for photo gallery



Fundraising

ASX Refinitiv Charity Foundation

As one of the benefiting charities for the 2023-24 round of the ASX Refinitiv Charity Foundation program. BDSRA Australia will continue to receive funds from this wonderful organisation and work alongside them supporting their yearly fundraising events.

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 **all tickets sold go directly to BDSRA Australia**. 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 \(asxrcfau.com\)](https://asxrcfau.com)

The next ASX event is the charity Sailing Regatta which will be held on Friday 17th November 2023 at Middle Harbour Yacht Club in Sydney. **We need volunteers for this event as well as auction items by Thursday 26th October**. If you are interested in attending or can donate an auction prize get in touch with Nikki at info@bdsraaustralia.org or Bobbie at briddle@bdsraaustralia.org

Participating in ASX Raceday event

The Racing For Good Luncheon was held on Saturday, 29 July 2023 at Royal Randwick Racecourse. Bobbie and Jay Riddle bought a table of 10 for this event and brought along 8 friends who all had a great time! BDSRA Australia raised around \$1000 for our two donated auction items which we are extremely grateful for. Further monies raised on the day will be divided between all benefiting charities at the end of the fundraising year.



Fun Runs!!

A **big thank you** again for all those who participated in **City2Surf** and **Beach2Beach** in August for your efforts and fundraising!!

If you are interested in participating, putting in a team and fundraising in an upcoming funrun event around Australia, please let us know and we can assist in setting up the charity page for you! Contact Nikki at info@bdsraaustralia.org or Bobbie at briddle@bdsraaustralia.org

Here are some of the upcoming events!

October 8 Perth Kilt Race WA
October 14 True Grit WA
October 15 Melbourne Marathon Festival VIC
October 16 Spring Cycle Challenge, Sydney NSW
October 21-22 Bowral Classic NSW
November 5 Noosa Triathlon QLD
November 5 Canberra Fun Run NSW
December 2 Fisocrem GC50 Run festival QLD



Bottles4Battens - Return and Earn NSW

Convert your litter reduction and recycling into dollars 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 take a photo of this code to save on your phone!

Hi Batten Disease Support and Research Association!

Ready to recycle?



Scan your barcode at the machine

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!

If you need help or want to talk about ideas, or need any of the above materials posted or emailed to you please contact us, we are here to support you!

Email Nikki at: info@bdsraaustralia.org

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

Personal Details Update: For all our families, so we may keep you informed and up to date, if your circumstances or contact details have changed, please inform Nikki Hopkins at info@bdsraaustralia.org



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Australian Registered Body Number: 073 435 202
Australian Business Number (ABN): 56 056 138 99
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