

NEWSLETTER
Spring 2022 Edition



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President report:



In July, I had the opportunity to attend the BDSRA US Family Conference. It was very special, including because it made me realise that, despite how it sometimes feels, we are not alone. There are scientists and families fighting this disease in all corners of the world – all doing our best and all seeking the best life possible for our children. It is a community that I am very proud to be part of. And soon, after a few false starts (covid...grrr), we will soon be ‘together again’ for our 2022 Family Retreat in Sydney. I cannot wait to meet those that I have only ever met over ‘coffee chats’ and ‘meet the expert’ zooms.

This is also the last time I will write to you as president of BDSRA Australia. I am extremely proud of what BDSRA Australia has achieved in the last four years, including the revival of the BDSRA Research Grant program (through which we have granted in excess of \$300,000 for research in Australia and New Zealand), the establishment of our eminent Medical and Scientific Advisory Board, the engagement of our Head of Medical and Scientific Affairs and our Family Support Officer, our collaboration with Dementia Support Australia and, of course, the continued listing of Brineura, the only treatment for any form of Batten disease, on the Life Saving Drugs Program in Australia.

Amber Rundle (a current board member) will be standing for the role of president at the AGM. I strongly encourage everybody to support her. Her new leadership will bring fresh ideas, direction, and energy. I also encourage anybody interested in getting involved – and having their voice heard – to consider standing for a general position on the board (two positions will be available).

Thank you for your support – and for those coming to the Retreat – I apologise in advance for any damage caused during the ice skating!
Kate



Photo of US "mom" Bekah Bowman and Kate Beattie

Research update

There will be a detailed research update in the next newsletter issue

Dr Ineka Whiteman, our Head of Research and Medical Affairs, is always busy behind the scenes learning and collaborating, supporting and advocating for our families. She also represents us on a national and international stage. Here are several of the many things Ineka has been up to in recent months:

- managing our Batten Disease Research Grant Program
- panelist on the international 'Ask-An-Expert' webinar (*May*)
- organised and facilitated BDSRA Australia's 'Meet the Researchers' webinar (*May*)
- attended and spoke at 2022 BDSRA Family Conference. Cleveland, Ohio. (*July*)
- presenter in the US 'Ask-An-Expert' webinar (*August*)
- attended International Dementia Conference (*September*)
- launched her 'Max and Abby' Children's book via webinar and media appointments (*September*)
- attending Translational Research Conference for the Management of NCLs in Chicago (*November*)

Keep an eye on our facebook page or website news page to see our regular updates

Events

Upcoming



Family Retreat

We are coming together as a community, for an in-person weekend, with exciting parent & kids program at the Mercure Hotel Sydney Liverpool NSW.

Sat 12th - Sun 13th November 2022

For more information, please click [here](#)



Virtual Coffee catchup - Topic TBC

Join us for a relaxed chat

Friday, 25th November - 1:00 PM - 2:30 PM (AEST)

Please click [here](#) to register

Past



Bounce4Batten and International Batten Disease Awareness Day

Every year on the 9th of June, we bring awareness to those affected by Batten Disease. Our Bounce4Batten campaign floods social media with bouncing photos, we bounce for kids who get their childhood & lives stolen, to bring awareness and raise funds to provide support for these families and to find a cure! Please join us next year!



Virtual Coffee catchup - NDIS parent discussions

We held two NDIS parent discussions on Monday 22nd & Friday 26th August. If you missed it and would like the notes from the discussion, please get in touch with us!



Book Launch

Dr Ineka Whiteman released her book "Max & Abby" with a webinar on

Tuesday evening, 13th September. We thank guest speakers, Deborah Moore - Illustrator, Marie Alford - Head of Dementia Support Australia and Keynote speaker, Meg Chin - Family Support Team Leader and Social Worker at Very

Special Kids, Victoria's Children's Hospice. If you missed it and would like the recording, please email your request. To read more or find out how you can get a copy, [click here](#).



Virtual Coffee catchup - Book Launch & Sibling Support discussion

On Friday, 16th September we had a low key debrief and chat about the topics raised at the Book Launch earlier that week.



National Carers Week Morning Tea (Carers NSW)

To celebrate National Carers Week 2022, BDSRA Australia organised a much deserved morning tea for our caregivers in greater Sydney. On Thursday, 20th October, 8 mums came together at Eden Gardens for some informal peer support, to chat, laugh and enjoy some delicious food!



Family support



Kenzlie's Starlight Wish

Starlight Foundation granted Kenzlie's Wish of going to SeaWorld, Australia Zoo and Dreamworld. We had a wonderful family trip, a chance meeting with Ineka and Kenzlie was even able to feed penguins which is

her favourite animal!
- Mandy McWaters, Kenzlie's mum

[Read more](#)

To learn more about how to have a Wish granted by Starlight Children's Foundation or MakeAWish Foundation, or to share your family's experience in the newsletter please contact Liz at support@bdsraaustralia.org

Our New Angels



Rachel

Rachel was just a few days shy of her 22nd birthday when she gained her angel wings on Friday 27th May. Rachel is remembered for her laughter and love of life. BDSRA Australia & the Batten community, send our love to Kathy, Greg, Hannah and the extended family.



Holley

The beautiful Holley Lavington bravely battled CLN2 Batten Disease. She gained her angel wings on Sunday 21st August 2022. She was 10 years old. Holley is remembered for her resilience, cheeky laugh and big hazel eyes. We are sending all our love and condolences to Mum Bettina, brother Jamie, Father Jason and family & friends.

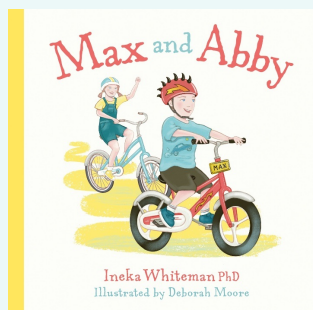
If you have lost a child to Batten Disease and would like to connect with other bereaved parents in Australia and New Zealand, via our Bereaved Facebook group or our Bereaved Virtual Coffee Catchups on zoom, please contact Liz at support@bdsraaustralia.org for more information.



Here are some wintery photos sent in from families. We can reflect on some of those fun moments as we say goodbye to winter and look forward to summer and enjoy the activities and opportunities the warmer weather provides!

[Click here for more family stories and Memorial Gallery](#)

Resources



Book for families

Told through the eyes of big sister Abby, Max and Abby shines a gentle light on the challenging topic of childhood dementia and regressive disability, revealing the highs and lows of life as a sibling of a child with additional needs.

Read more [here](#)



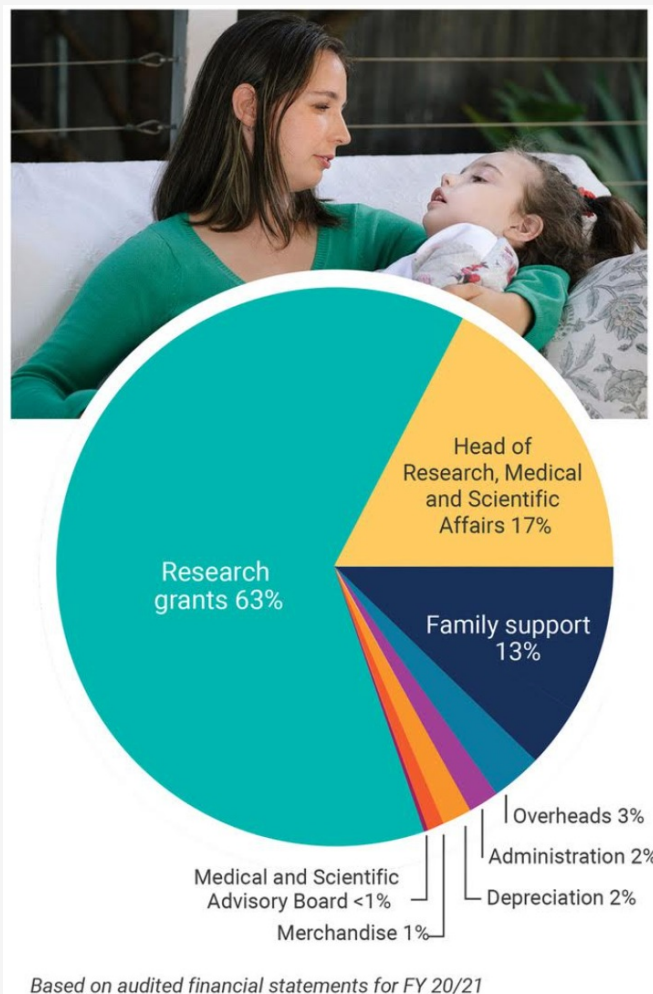
Dementia Support Australia

Childhood Dementia Support DSA offer practical strategies and advice to families caring for children diagnosed with dementia.

Read more about the support they can provide to families on their updated webpage [here](#)

Donations

This is how your generous donations to BDSRA Australia were spent – on real outcomes and practical support. Read more [here](#).



Thank you so much for your support!

Regular Donors

These 8 people are presently BDSRA's regular monthly donors. They make a monthly payment through our Give Now platform each month. Some have been making this regular payment over years and years others have signed up more recently. Between the 8 of them over the years they have donated over \$175,000 to BDSRA.

Dean Apostolou
Anthea Weeks
Laura Smith
Jacqui Henningsen
Katy Eschler
Bernadette Jackson
Kelly Sweet
Jane King

Thank you so much for your support. These donations make it possible for BDSRA Australia to carry out the work we do supporting families and raising money for research into research programs relevant to Batten Disease.

We also have many one off donors who we greatly appreciate for their financial support.

Treasurer message

I would like to personally acknowledge one of our regular donors Kelly

Sweet. For over 6 years, Kelly has made a monthly donation to BDSRA. She made her first donation in March 2016.

On the entry beside reason for donation Kelly wrote:

“My daughter goes to school with a sibling of a child with this disease. I see her everyday and admire her mother for being so bright and happy and friendly”

That child with Batten Disease was my granddaughter Mia, the sibling my grandson Toby and the mother my daughter Peta.

As treasurer each month when I read the remittance report I would see this message and it touched my heart every time.

Thank you Kelly.

Mandy Meredith Treasurer BDSRA Australia

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Fundraising

ASX Refinitiv

Regatta Day is on 11th November in Sydney. Meg Garrido will be volunteering at the event and we have an item in the silent auction. The link for the auction will be posted to Facebook once it is live.

Golf Day will be taking place in February 2023. So far we have only one prize to put in that silent auction. Please email fundraising@bdsraaustralia.org if you or someone you know has anything else that can be offered, such as a week in a holiday home or an item. We need to notify ASX of the items by 25th November.

Raffle tickets for the ASX Refinitiv Charity Foundation Raffle 2023 are now available!

The raffle closes on 3rd March 2023 and is drawn on 9th March 2023.

[Purchase Raffle Tickets](#)

Family Fundraiser

Emma Crofts and Dressage in the Wheatbelt, have fundraised for BDSRA Australia at their recent event Crystals in Kellerberrin dressage show in September.



Emma's niece is affected by Batten Disease and her efforts have raised \$1420. Thank you Emma for raising awareness and donating this money to further BDSRA Australia's work in funding research and supporting families. [Read more](#)

If you have a family member or friend fundraising for BDSRA Australia and would like to share, 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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