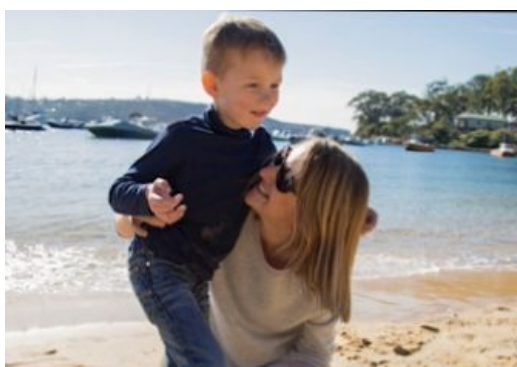




I recently spoke to medical specialists about 'the parent's perspective' of Batten disease. I told them that my son's condition has affected my life in a profound way. I explained why a diagnosis is important to parents - even when the news is terrible - and how it can lead to a world of support from others facing the same battle.

Today, I am thrilled to welcome Ms Laura Smith as BDSRA Australia's new Family Support Officer and to announce a number of new initiatives directed to supporting families, including a new relationship with Dementia Support Australia to provide support to families affected by Batten disease, a childhood dementia.

Kate Beattie
President, BDSRA Australia



NEW Family Support Officer

BDSRA Australia is excited to introduce **Ms Laura Smith** as our **new Family Support Officer**. Laura works as a Social Worker at a hospital rehabilitation centre in Geelong, Victoria. She holds a Masters of Social Work and has previously worked for the National Disability Insurance Agency and as a Wish Coordinator for Make-A-Wish Australia. Laura is mum to Maggie (aged 6) and to Matilda, who was diagnosed with late infantile Batten disease (CLN2) in 2012 and passed away, aged 7, in November 2013. She is also the author of the beautiful blog - www.teamtilda.wordpress.com Laura is available to provide support to all families affected by Batten disease and will be developing new family support procedures over the coming weeks and months. If you have any ideas how BDSRA Australia could better support families, please contact Laura at support@bdsraustralia.org.



BDSRA Australia would also like to thank Ms Nicole Onrust, our previous Family Support volunteer, for all the love and support she has given to families in her role over the last few years.

Dementia strikes children too

Batten disease is said to be one of the most common forms of childhood dementia, yet there is little to no specialist support for families facing this battle. BDSRA Australia is excited to announce that it will be working with Dementia Support Australia (DSA), an Australian government-funded national partnership led by HammondCare, to provide support to families with children affected by Batten disease. Dementia Support Australia, with the assistance of BDSRA Australia, will train consultants to better understand Batten disease, its impact on patients, carers and families, and to provide timely, professional and pragmatic support to families affected by this childhood dementia and related behaviours. Call 1800 699 799 to talk to a Batten disease trained DSA consultant. You can learn more about DSA by visiting



Experience register

Have you had to explain Batten disease to your therapist? Have you had trouble finding a doctor who has experience managing Batten disease? After much hard work by many of our families and our Information Officer, Julie Ojeda, we are excited to announce the creation of an 'Experience Register'. This register identifies medical practitioners, allied health therapists, carers, schools and others across Australia that have experience managing Batten disease. If you would like to see the register - and if you can suggest other professionals or organisations who should be added to it, please contact Julie at info@bdsraaustralia.org

Important: please note that this Experience Register is a source of information for families, but is not, and ought not to be taken as, a recommendation of any particular service provider by BDSRA Australia.

Events



Parents and Carers Lunch – July 2019.

It was lovely to see so many parents and carers at the BDSRA lunch in Sydney on 14 July 2019. Thank you again to our wonderful speakers, Dr Angela Schultz from the University Medical Centre, Germany, and Ms Lisa Tilbrook, Senior Speech Pathologist and NDIS Plan Manager. Thank you also to BioMarin Pharmaceuticals Inc for sponsoring the event.

AGM

The BDSRA Australia Annual General Meeting will be held on Sunday, 17 November 2019 at 11 am to 12.30 pm at Manly Library, Ground Floor Meeting Room, 1 Market Place, Manly, NSW, 2019. All families are invited to attend the AGM and all financial members of BDSRA Australia are entitled to vote at the AGM. If you would like to become a financial member, please contact treasurer@bdsraaustralia.org. If you would like a copy of the Notice of AGM and attachments, please contact info@bdsraaustralia.org. BDSRA will be hosting a casual family lunch after the AGM at a nearby venue. If you are interested in attending, please let Mandy know asap at treasurer@bdsraaustralia.org.

Max, our superhero

Max's family recently shared their story about Batten disease with Channel 9 News, Sydney. See that story [here](#)



BDSRA Australia research - Professor Mark Sands, Washington University

In a project co-funded by the Australian and US Chapters of BDSRA, researchers at the Washington University School of Medicine (St Louis, USA) led by Professor Mark Sands, investigated the effects of cannabidiol (a component of medical cannabis) on seizures in a mouse model of infantile Batten disease (CLN1). Preliminary data suggest that cannabidiol may play a role in 'neuroprotection', with reduced brain

cell degeneration and reduced markers of inflammation in some areas of the brain in cannabidiol-treated CLN1 mice. Read more [here](#).

News

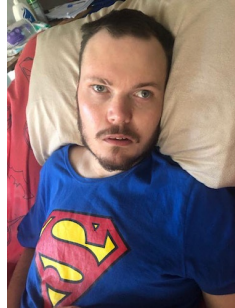
An important reminder that the University of Newcastle is carrying out a survey on the diagnosis experience of parents/guardians of children diagnosed with Batten disease. The survey closes at the end of October. If you wish to participate, please go to the NCL Survey link at <https://is.gd/BattenDiseaseSurvey>. For further information contact info@bdsraustralia.org or see [here](#).

For a clinical trial and translational research update from the BDSRA US Annual Family Conference, see [here](#).

Amicus Therapeutics has announced positive interim results from its ongoing clinical study of gene therapy for CLN6. Read more here: [here](#).

Our new angels

Joshua Ward



Joshua Ward passed away on 17 September 2019, aged 29 Years. Bronwyn and Shaun thank all the friends they have made and BDSRA Australia for their support over the years. Our thoughts and love are with the Ward family.

Saniah Khan



Our beautiful princess Saniah Khan passed away on 1 June 2019. She was diagnosed with Batten disease in 2009. Saniah was affectionate, humble, always had a smile and a good sense of humour. She wanted to be an art teacher. Fly high beautiful girl.

Azalia Morrow (NZ)

Beautiful baby girl Azalia gained her wings on 13 October 2019, at home surrounded by her loving family. Her family thank all who have given them support over the last six months since her diagnosis.

Brad Timms (NZ)

This boy of ours has filled us with pride. He is our HERO and that is what will carry us through this journey. We will hold on to our hearts the love and memories his sister and he left us with.

Fundraising

Art Union Raffle

BDSRA Australia needs your support. We are a benefiting charity of the ASX Refinitiv Foundation **Art Union Raffle**. First prize is a Lexus CT200H luxury car, valued at \$45,631. Tickets are \$20 each (through to \$500 for 50 tickets). Please purchase your ticket from the link provided [here](#). All proceeds from tickets sold through this site go to BDSRA Australia.

Cushman & Wakefield Can Sing

A huge thank you to Cushman & Wakefield for selecting BDSRA Australia as its charity partner for the 'Cushman & Wakefield Can Sing' competition and for raising awareness and \$17,500 to support improved family support in Australia. See more [here](#)

Charity Race Day – a success

We had more than 80 people turn out to support BDSRA Australia at the ASX Refinitiv Charity Race Day at Rosehill Gardens, Sydney. It was a fabulous day, raising an incredible \$28,000 for BDSRA Australia. Read more [here](#).

Our Everyday Heroes - "nobody can do everything, but everyone can do something"

BDSRA Australia relies on donations and fundraising in order to support families and research. Our Everyday Heroes this month are Lynda- Jane Stone and Sarah Smith, competing as **Team Imogen**, in the Tough Mudder on 17 November 2019 in memory of one of our beautiful angels, Imogen. Please consider supporting Team Imogen here: <https://toughmudder-sydney-2019.everydayhero.com/au/team->

[inogen](#) And thank you to our own Julie Ojeda for her Tough Mudd-ing in support of BDSRA Australia.

A very special thank you to another one of our very special Everyday Heroes, Violet Milne (aged 10), who ran 14 km in the City2Surf and raised about \$700 for BDSRA Australia in memory of her close friend, Mia.

Violet also organised a school fundraiser celebrating Bounce4Batten on International Batten Disease Awareness Day, raising about \$2000. Violet is raising money for a cure so that other kids won't know the grief of losing a friend.

Have you considered raising money for BDSRA Australia? It is easy with "Everyday Hero", which can turn any event, large or small, into a fundraiser, with direct, tax deductible, donations to BDSRA Australia. To learn more or create your own Fundraising Page with our charity as your choice, follow this link:

<https://give.everydayhero.com/au/get-started>

Donations

Thank you to everybody who donated to BDSRA Australia recently. Without your support, we would not exist. A special thank you to St Joseph School Peterborough who raised awareness and money for research in relation to Batten disease. We deeply appreciate your efforts.

Without your support, we would not exist. You can support BDSRA Australia by giving at

<https://www.givenow.com.au/battendiseasesupport>

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

info@bdsraaustralia.org.au

