



Dear Members and Friends,

I hope this email finds you well. As the new President of BDSRA I wanted to introduce myself and give you an update on the latest happenings at BDSRA. Recently, and not so recently, there have been people changes within BDSRA, some very generous donations received and exciting developments on the research front. Read on for more!



BDSRA President Hamish Murchison (far left) with out going President Harry Partridge (back row) and some of our wonderful volunteers and committee members.

People Changes

In November 2016, the management of BDSRA underwent a generational change of sorts when our founder and long time President Harry Partridge stepped down. His 20-year commitment to Aussie Batten kids and their families is unparalleled and as a community we are truly lucky to have had him serve us for so long. In February this year we presented Harry with a small gift to thank him for his service. After 11 years as Vice President, Sara Millenbach also decided to step down. Sara was a co-decision maker for many BDSRA milestones and was instrumental in fundraising activity in that period with some big events raising funds and awareness in WA (alongside was her husband Jeff). Recently our Secretary Jane Seychell also stepped down after 8 years, having assisted at

The current position holders are now as follows:

Committee

President – Hamish Murchison

Vice-President – Michael Feitz

Public Officer – Vanessa Anderson

Secretary – Mandy Meredith (appointed 30 June 2017 to replace Jane)

Treasurer – Ian Tweedle

Volunteer Roles

Family Support & Information – Nicole Onrust

Merchandise Control – Naomi Foster

Communication & Media – Peta Murchison

Fundraising Support – Vacant (Mandy filling in until the position is filled).

All positions are unpaid and we are very

every family conference in that 8 years with her caring and supportive nature. It is impressive to see such longterm commitments made by those serving on the committee. Their legacy is a thriving organization that has supported and championed research for so many children and families affected by Batten over the years. We thank Harry, Sara and Jane for their many years of service. Of course along with Vanessa Anderson who has dedicated 17 years to the organization and continues to be involved. We are deeply indebted and grateful to our volunteers past and present, who keep the charity moving forward.

Donations update

BDSRA has been very fortunate to receive over \$200,000 in donations in the first half of this year. This generosity has directly enabled a doubling of our research funding (more on that below). I would like to take this opportunity to thank the Stilwell family and their very generous friends and family, who have made up the major portion of donations received.

grateful for everyone's ongoing time and hard work.

Position vacant – we are currently looking for help with a Fundraising Support role. If you would like to get involved in BDSRA and help out, I would love to hear from you.

We wish Harry, Shawn, Susan and their family all the best as they take their fight against Batten to the U.S. Thank you also to the many others that have made donations to the organisation. I am pleased to report that the organisation is in a strong financial position.



Shawn, Susan & Harry Stilwell

Batten Awareness Day – 31 March 2017

The awareness day this year was headlined by the Bounce4Batten social media campaign run by Peta Murchison. Bounce4Batten partnered with [Only About Children](#) to attempt a Guinness World Record for the most people jumping online. OAC involved their 38 campuses around Australian and generated great PR.

Bounce4Batten continue to prove its value as it has grown strongly since it began in 2014

and this year received widespread press coverage and participation from around the world and from our political leaders and celebrities. All follow on donations from the awareness were directed to BDSRA Australia. A big thank you to Only About Children and [Haus Of Comms](#) for their unwavering support and hardwork and to everyone that jumped on board [#bounce4batten!](#)



juliebishopmp
Following

juliebishopmp Today is National Batten Disease Awareness Day, rare degenerative genetic condition affecting kids' movement & development #bounce4batten

load more comments

karmmehq @sazzeledazzle

jonathanallanlord Love your work Minister Bishop

theoriginalgrannygrunt You are a great role model....I'm so proud of the way you care for others well done.

ania_janka

lachie.gov.au @this.is.jordanr @georgia.gov.au

bounce4batten Beautiful bounce @juliebishopmp our family and all families affected by Batten disease are so

1,894 likes

MARCH 31



bounce4batten
Follow
...

guysebastian
Following

guysebastian I met this little angel Mia and her inspiring family last week. It was heartbreaking to learn about the devastating impact Batten's disease can have. Today is #bounce4batten day raising awareness about this disease. Please look up bounce4batten.com for info on how you can help and watch Mia's mum Peta Murchinson's TED talk.

load more comments

xxmizmaryxx Praying the lord above heals this beautiful angel

noahsarc12 Thank you for supporting and letting people know re this disease . . @guysebastian God Bless

bounce4batten Thank you @guysebastian you are one very special person.

pink_pawpaw 15 Hope she gets better

2,589 likes

MARCH 31

Add a comment...

Research Update

I am delighted to relay that in early July 2017, BDSRA Australia committed to fund three different research projects for a total research commitment of USD110,000. This is more than double the research commitment made last year. The research projects that we will fund are as follows:

Research Title	Researcher	Institution	Type of NCL
Towards human translation: Technical support for developing gene therapy for ovine models of CLN5 and CLN6 Batten disease	Nadia Mitchell	University of Otago at Christchurch	CLN5, CLN6
Cannabidiol for the treatment of intractable seizures in infantile batten disease	Joshua Dearborn	Washington University in St Louis	CLN1
CRISPR/Cas gene editing of Batten disease genes in patient-specific stem cells	Anthony Cook	University of Tasmania	CLN2, CLN3

Nadia's work continues on from David Palmer's research on CLN5 and CLN6 affected sheep, which BDSRA has funded for many years. We were also excited by Joshua Dearborn's novel research into the use of cannabidiol (a marijuana plant extract) for treatment of intractable seizures. Anthony Cook is being funded for the first time by BDSRA and we are enthusiastic to support a new researcher in the Batten's field.

Funding research is one of our core purposes as a charitable organization and it is incredibly exciting to see us able to fund three different projects this year. The increased research funding is only possible because of the extraordinary generosity of our donors. I continue to be hopeful that the legacy of our children will be a cure for Batten through the generosity of our community.

I would like to acknowledge the support and leadership of the U.S. chapter, who kindly manage a scientific panel that reviews and scores research applications and co-ordinates funding between different Batten related charities around the world.

Looking Ahead

With new people come new ideas and energy. As the new team has settled into their roles, we have identified areas that most urgently need attention including:

- a revamp of the digital assets of BDSRA, including our document storage, website, emails and donation portal.
- a review of our policies and procedures to ensure we are fully leveraging our talented people; and
- preparing for our 2018 family conference.

If you have any feedback or would like to be involved in any way I would love to hear from you.

Finally a little bit about myself. I am the father of Mia Murchison, our gorgeous 8-year-old girl affected by CLN2. We were living in Singapore when Mia was diagnosed in 2013, and have been back on the Northern Beaches of Sydney ever since. Mia has a little brother Toby (6) and another sibling on the way later this year, which is very exciting. Initially I practiced as a solicitor in Sydney before moving into aircraft finance – an industry I remain involved with today. I am thrilled to be involved in the BDSRA and its fabulous, caring and supportive community.

I would love to get your feedback on any aspect of the above or on the organisation generally, either by email hamish.murchison@gmail.com or phone 0499 097 188.

All the best,

Hamish