

## The Australian Chapter of Batten Disease Support and Research Association Inc. - BDSRA

October 2015

**Australia/ New Zealand**

Issue 33



Dear families, friends and members,

I would like to take this opportunity to introduce myself to you all and express my intention to do the best I can to raise awareness, promote research, and achieve wherever I can for the Australian Chapter of Batten Disease Support and Research Association (BDSRA Australia).

I would also like to give a short summary outlining my background. I originally trained in Applied Science at the University of Technology Sydney, then followed a career in Information Technology that includes over 10 years as a Head Teacher in TAFE NSW which ended about 7 years ago.

Since then I have worked with various organisations in the Not for Profit sector as a manager while achieving additional qualifications in Logistics, Teaching and Management all of which I hope will assist me in this new role. Additionally I have volunteered my time to a variety of charities including Surfing for the Disabled.

I do not have a family member who has been affected by Battens, I am however the mother of 4, now ranging from 20-30 years of age, as well as a grandmother. I will use my life experience, volunteering and professional background to assist with my steep learning curve to understand as much as I can about Battens!

Vanessa and I have been in contact for some months now, as she is guiding me and helping me to take on the Managers role. I am grateful that Vanessa has agreed to continue to support me for an indefinite period and continue her great work with family support. I would also like to congratulate Vanessa on the great job she did in organising the 20th Anniversary events.

I had the pleasure of attending the AGM and 20th Anniversary meeting on 26th of September 2015. During these events I met Margie Frazer (BDSRA Executive Director from USA). It was great to chat with Margie and get a worldwide perspective on research projects and supports that exist in other countries.

I was fortunate enough to meet some families ( including all the way from WA and NZ !) with whom I am looking forward to keeping in touch and assisting wherever I can. Also present were research, medical and pharmaceutical representatives giving me an opportunity to make contacts that will be very useful in this role.

I am looking forward to working with the BDSRA Australia Committee to achieve the best results possible for you all. I met President Harry Partridge at my interview for the role, and Vice-President Sara Millenbach from WA at the 20th Anniversary events. Both have both given me a warm welcome and I look forward to meeting the rest of the Committee as the opportunity arises.

I am a person who loves to come up with ideas, my thoughts are always focused on mastering challenges in a positive way. Eleanor Roosevelt once said "With the new day comes new strength and new thoughts."

I will endeavour to add a new strength lending my new thoughts to you all.

Sincerely,

Jenny Rixon

Manager, BDSRA Australia

P: 0478525583

E: [manager@battens.org.au](mailto:manager@battens.org.au)

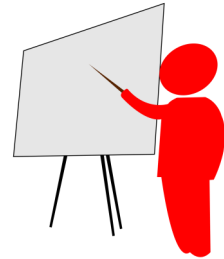
### Inside this issue:

BDSRA Managers Introduction	<b>1</b>
Research & services	<b>2</b>
Information Sharing	<b>3</b>
AGM, 20th Celebration & Moomba	<b>4</b>
Fundraising & Awareness	<b>5</b>
FYI	<b>6</b>

## Updates locally

### Teachers Blog

An exciting new project is underway to set up a teaching blog to assist with Battens children of all ages and their learning environment. At this stage the project is in its infancy, and we are calling for input from educators and parents with resources to share. For further information contact Vanessa at [vanessa@battens.org.au](mailto:vanessa@battens.org.au) or by phone 0243345785.



### BDSRA Top-Up Research Scholarship

We are pleased to announce that BDSRA Australia will be offering a top-up research scholarship program commencing in 2016. The object of this scholarship is to advance research in Australia relating to Batten Disease and to inspire independent researchers to become part of the international research efforts to develop a cure for Batten Disease. Applications close 30th April 2016. A Scientific panel will rate the applications received based on certain criteria. Further information can be gained at our website or at this link:

<http://agile2.ucc.usyd.edu.au/ro/opportunities/scholarships/1652>.



## Scholarship

## Updates worldwide



### RESEARCH

### BDSRA United States

In 2014, the BDSRA reached out to dozens of researchers to invite Letters of Intent (LOI) or short proposals to preview work they would like to accomplish in the following year with a maximum of \$60,000. Once these LOIs were narrowed to requests for full proposals, nearly 30 researchers from universities, children's hospitals, and industry stepped in to provide peer reviews on a volunteer basis.

Noah's Hope, Drew's Hope, Hope4Bridget, BDSRA-Australia and the Batten Disease Family Association in the United Kingdom have partnered with BDSRA to co-fund these important projects.

One of the recipients of the funding is The Barn project run by David Palmer—University of Otago, NZ. This project will be directly funded by the BDSRA Australia.

Details of all projects selected for funding may be found at <http://bdsra.org/past-grant-awards/>

# Programs and Support

## Information Sharing

Family and friends of Marsden and Tyrone may donate in memory via the Battens Give Now page to HELP FIND A CURE !

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



The families of these very special people would like you to know of their passing and to Remember them fondly:

**Marsden Hill of New Zealand  
Tyrone O'Neill of Victoria**

### Volunteer success!



Recently Vanessa nominated Alanna Gayko for the 2015 Volunteers Award to acknowledge her tireless efforts towards the Batten Disease cause spanning over 15 years. The NSW Volunteer of the Year Award is an annual awards program launched in 2007 by The Centre for Volunteering to recognise the outstanding efforts of the 2 million plus volunteers in NSW, and to promote the importance of volunteering to the community. At an Awards ceremony last week, Alanna won the 'Adult' major category. Read more at this press release:

[http://www.volunteering.com.au/wp-content/uploads/2015/10/Winners-C.Coast-Volunteer-of-the-Year-Awards\\_07.10.15.pdf](http://www.volunteering.com.au/wp-content/uploads/2015/10/Winners-C.Coast-Volunteer-of-the-Year-Awards_07.10.15.pdf)

As a winner of this region, Alanna now heads to the State finals in Sydney in on December 4<sup>th</sup>. So proud of you Alanna and good luck in the next step to be the NSW Volunteer of 2015.

If you would like a copy of the book contact [vanessa@battens.org.au](mailto:vanessa@battens.org.au)



## Moomba Festival 2016

### Birdman Rally ~ Penguins

BDSRA Australia has made a commitment to raising awareness by advertising at the Moomba Festival, Melbourne 11-14 March 2016.

To **maximise our impact**, and possibly do some fundraising we are considering entering in the **Birdman Rally Penguins Category**.

We are seeking ideas for participation !!!! Or anyone brave enough to be an entrant on behalf of Battens. This is a great opportunity to raise awareness and fundraise. For information visit <http://www.melbourne.vic.gov.au/enterprisemelbourne/events/moomba/Pages/BirdmanRallyEOI.aspx>

If you would like to participate, or have any ideas contact Jenny before 1 December 2015 - [manager@battens.org.au](mailto:manager@battens.org.au) (Ph 0478525583 )



## Fundraising and Awareness

### Annual General Meeting + 20 Years Celebration !

**AGM:** On Saturday 26th of September 2015 the BDSRA held the 20th AGM at Kirribilli, Sydney NSW. The meeting resulted in the re-election of the office bearers -

President—Harry Partridge

Vice President—Sara Millenbach

Treasurer—Ian Tweedie

Secretary—Jane Seychell

Audited reports were accepted as submitted, and Jenny Rixon was introduced as the new Manager, with Vanessa Anderson taking on a new role as Family Support Liaison. The meeting thanked Vanessa for her dedication over the years, and the valuable contribution that she has made to the organisations success.



**B:OMARIN®**

**Celebrating 20 years :** The AGM was followed by a celebration of 20 years since commencement of the Australian Chapter of the BDSRA. The event was sponsored by Bio-Marin Pharmaceuticals Australia, many thanks ! Celebration attendees, providing updates on research, treatment and diagnosis, included -

Kathryn Evans—BioMarin Pharmaceuticals Australia

David Palmer—University of OTAGO, NZ

Imke Tammen—University of Sydney

Alexandra Grubman—University of Melbourne

Michael Fietz—PathWest Lab WA

Deepak Gill—Neurologist Westmead Childrens Hospital

Dianne Petrie—Genetic Alliance Australia

We were fortunate enough to have representatives from the **BDSRA-USA**, (Director Margie Frazier and partner David Frazier), in attendance providing information from a worldwide perspective.

The event was attended by over 40, including supporters, siblings, family and friends of BDSRA affected children.



### 2016 Family Conference—Save the Date

Planning is underway for the 2016 Family Conference. If you have any ideas that you would like considered please contact me, Jenny (Manager).

Last year it was held at Camp Breakaway in NSW. I am told that the venue was a great one as it had all of the facilities that our families need.

If anyone knows of something similar, or suitable , please contact me by email or phone before the end of this year, as we will need to book well in advance.

At this stage we are looking at the conference running over the last weekend in October 2016, so **SAVE THE DATE!**

I may be contacted by email [manager@battens.org.au](mailto:manager@battens.org.au) or phone 0478525583.



# Fundraising and Awareness continued...

## Fundraisers



### In VIC

'Going bald for Battens' in Honour of



Tyrone who raised over \$2300



### in WA

Marie Setter raised \$511 from card making



### in NSW

Sarah Krauth and Rachelle Potter's cake stall in June that raised \$310.55

Darryl Hayes held a Trivia Night at Belmont Freemasons in October. Many thanks to Darryl and prize donors—



Richard Jones, Manager & Mike DeWinton, Chief Pilot of Westpac. Rescue Helicopter  
Steve Langham, General Manager, Piggs Peake Winery



## General donations

### Regular Donors:

Nicola Edwards  
Amanda Blakers  
Dean Apostolou  
Martin McNiff

### General donors:

Ruth Carter  
D. Haupt  
V. J. Bloor  
Grapp Pty Ltd EB Charitable Trust  
P & G Sanson  
Neil Hendry

### Scope Club of Allora Inc.

N F Coudrey  
Harry Partridge  
Ainslie Schieb  
Arlene Cranmer  
Georgie Parker  
Hayley Snowdon

### Nicholas Bewick

Meredith Fonti  
Joanne McLennan  
Donna-Marie Sheldon  
Cathy Norris

## Donations made 'in memory'

In Memory of David Partridge  
John and Dorothy Wheeler

In Memory of Isla Donegan  
Love from Nanny and Poppy

In Memory of Chris Hibberd  
Gary and Helen Hibberd

In Memory of Matilda Berger  
In lieu of a leaving gift, Michelle Clift opted a donation

In Memory of Jordan Anderson  
Joan Ciclovan in bequest

In Memory of Joey Weeks  
Weeks family



### How you can help - Perpetual Donation

BDSRA is launching a new type of perpetual donation.

This type of donation requires a commitment of \$10 per month on a continuing basis, which is all tax deductible.



### For less than a cup of Coffee each week ! And includes Free BDSRA Membership!

The money will go towards BDSRA expenses, fundraising, family conference, support and research. Our goal is to get 1,000 perpetual donors by the Family Conference in October 2016. Each family can assist by doing it themselves, and get 10 others to also support us in this way.

The advantage of this to BDSRA is that it would provide a stable base of funding that would enable better planning, more family support, research and scholarship programs. So if you are looking for a way to make a difference without, or as well as, running events this is it!

**So if you have someone special who you want to honour by contributing regularly, to work towards a future with a cure or treatment, please make the commitment now!**

**You can also win** - Each perpetual membership (one ticket for each month of membership) will go in the draw for fantastic prizes to be drawn at the Family Conference in October 2016. For more information visit our website <http://www.battens.org.au/become-perpetual-donor-today>



### Disabled Friendly Home For Sale QLD

My home has 3 bedrooms, 2 living areas (one area quite large), formal area, kitchen, dining, toilet and bath/shower area and is open plan living. My double garage (which is at the back of my home and only a very short distance to the home) has been converted for a high care disabled client residential area with a separate room for support person and open toilet shower area. Hoists, shower chairs/bath beds can be moved quite easily in this area and into the shower area.

The larger living area in the main home is also setup with a lift to the main area of the home (which has three steps). There is also a winch (in the larger living area) attached to the ceiling area for transferring the disabled client from/to wheelchair/lift chair/bath bed or onto mattress on the floor for physical therapy etc.

Disabled clients can enter either through the front door or down the driveway into the back entrance. The high care disabled client can also enter via the front or rear entrance. Doorways are extra wide. My disabled friendly home would be perfect for a residential home for disabled clients, both low and high care. My home is located in Darling Heights, QLD and is very close to the University.

Andrew Duncombe, mobile: 0419 028 058 from Colliers International is the agent looking after the selling of my home. If you are interested, please contact Andrew to arrange a viewing. With thanks, Camille Brinin