

Dear families, friends and members, we find ourselves at the Christmas Issue again. This year has held many challenges, positive connections, inspiring acts and memorable moments. This issue is dedicated to the many who supported our charity in these past 6 months.

We will remember at Christmas time, our loved ones who have passed but always with us and in our hearts. I hope you all have a festive Christmas and happy New Year.

Vanessa and the BDSRA, Australian Chapter.

### BDSRA Australia 2000—2015

2015 will mark the Australian Chapter of the BDSRA's 20th Anniversary and here are just a few facts to note that in that time:



126 known young persons have lost their battle with Batten Disease in Oz and NZ (this figure would not be indicative of all cases)



With no Government assistance to fund Research, the Oz Chapter has funded over \$300,000 towards Research grants.



We have hosted **Five** International Battens Conferences and **Two** Family Meetings were held

in various locations, each with a minimum of 85 persons attending a weekend together to learn and share.



Together we can cherish this milestone:-

- ☺ Are you a member of the BDSRA? Get on board and support your Charity who supports you.
- ☺ Represent Battens and its cause, at any events you can attend. Educate others—share your story with the Media sources.
- ☺ Hold a fundraiser—it is amazing the amount of awareness and follow-on support that a fundraiser event attracts.

**The BDSRA is making MANY EXCITING PLANS for Next Year of which will be shared with you early in 2015.**



#### Inside Issues to come:

Information  
Resources  
"Collective Sharing"

Research Update—  
worldwide & locally



Remembering the  
many lives lost to  
Batten Disease



Awareness Day in Oz  
31st March 2015



# FUNDRAISING FOR BATTENS

## Events

Many sponsors donated towards these fundraising activities, not all able to be mentioned here, but each have contributed to these great results:

- Tanya Elson's "Coffee for Battens" was well supported locally and raised over \$2600.

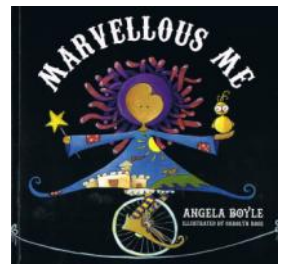


Upon turning 19 Kiaana initiated Kiaana's Quest holding different fundraising and awareness activity.

This year Tribe FM & many local musos got behind and hosted a live to air music concert in the gardens of the radio station featuring many local musicians including Spirit of Alondray & 2013 X Factor finalist Ellie Lovegrove.

- Kiaana's Quest to "Beat for Battens" raised \$1200 plus received a donation for \$300 by Danielle Watson, Willunga Phoenix Soccer Club joined in and held a "Beat for Battens" fundraiser and collected \$354

- Angela Boyle's Launch of "Marvellous Me" donated \$300. *Upon the launch of this book, the author Angela Boyle, provided a generous donation to Battens: Marvellous Me is Angela Boyle's debut children's book, featuring the magical illustrations of Carolyn Rose. Marvellous Me takes the reader on a journey into the magic of their existence. It's a story about remembering that it's who we are not what we do that makes us special and unique. Buy your copy at: <http://www.beingmebooks.com/>*



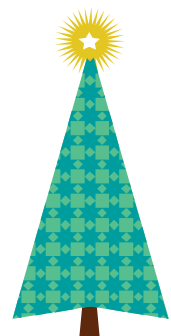
- Pauline in WA continues to fight Battens Disease after losing two granddaughters: Many were moved by Pauline's ongoing support to Batten Disease, via her Open Gardens and local Craft Groups. If you didn't see the ABC program, click here to view:

<http://www.abc.net.au/gardening/stories/s3970384.htm>

"Thank you for forwarding on the story of Pauline's beautiful garden and her experience with Batten disease. What a great job she has done". Prue.



- Anglican Church Toowoomba West Parish donated \$800
- Jean Prater's Morning Tea in Tasmania collected \$60 (in memory of Haylee)
- Tasmin Anderson and friend's lemonade/cup cake stall raised \$27
- Marie Setter creates cards and proceeds of \$720 was raised during the year





# FUNDRAISING FOR BATTENS

## Events continued

- Jane Seychell's designed Christmas Cards are an ongoing item and also raised \$900 by running in the Sunshine Coast Marathon
- Freemasons NSW & ACT fundraised \$425
- East Fremantle Football Club (featured in last issue) raised \$4746



- 


Teal knitted toys handcrafted by Christine Parnell and then handed out for free to create awareness for Battens, Stefo Radevski donated due to this lovely gesture of one lady giving to his daughter. Its working Christine—thank you.
- Joenice McGeown's Craft group raised \$255
- The Northern Garden Group held a "Bring & Buy Stall" and raised \$55
- City-Bay South Australia was represented by several groups of which over \$3000 was raised:

Battling Battens Team who mostly travelled to SA (right) for the event and with 12 on the team, Robert not in photo



(left) Brown Family ..... and (middle) the Olkaparinga Team

The following two large donations were pledged to Research Grants and what a huge impact they will have....

- Mia's Trust Fund has donated its recent fundraising proceeds of \$10,000 to aid research.
- NRMA country services chose Batten Disease to be their nominated charity for 2014. A group of people were involved to result in this amazing cheque donation of \$63,200. Great thanks to Brett for persisting each year with the nomination (whose boss since passed but shared his inspiration by Mackenzie-Rose's journey. Over 40 battens donation tins were placed in all the service outlets during the year. Jane then gave a compelling speech at their fundraising conference about her experience with Battens and little Jai (subsequently no dry eyes in the room). This is an amazing boost to Research funding and the awareness created by each participating NRMA service outlet involved.







## Rogue Runners united for Battens

The Rogue Runners are supporting Batten Disease with an array of fundraising activities (Aug 25: Hawaiian

Pizza Smoothie Challenge, Oct 25: 90km Ultra Treadmill Marathon, Aug-Nov Bearded for Battens, ad Baton against Battens plus many fun runs) and they keep us updated and amused via our Facebook page

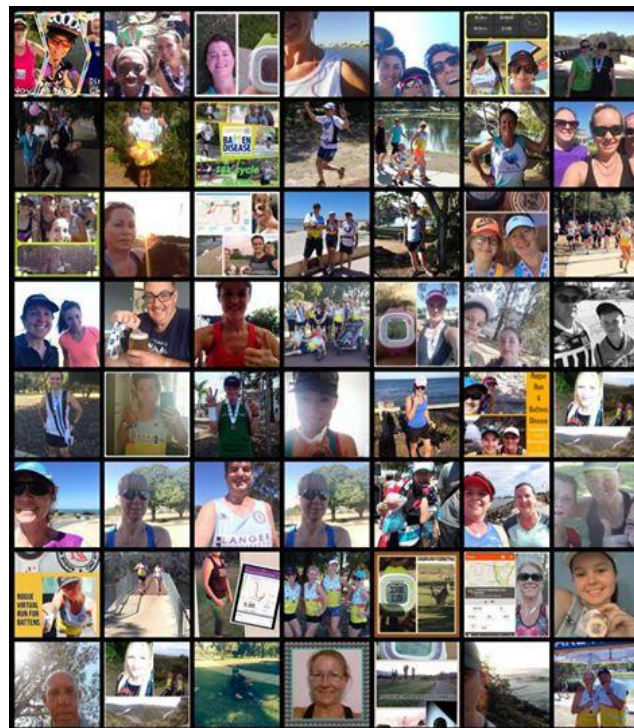
[www.facebook.com/AustralianBDSRA](http://www.facebook.com/AustralianBDSRA)

Here is their Rogue report: Firstly I'd just like to thank all of you who have "stepped up" in support of our fight against Batten Disease so far. It was our 1st time arranging a virtual running event & we really didn't know what to expect.. A little blind faith goes a long way sometimes, especially when you can bank on

such wonderful support from the running community. November 9th, we had near on 200 participants from across every state of Australia, as well as New Zealand, UK & the USA.

The virtual run itself raised \$2414 profit, which lifts our total fundraising for Batten Disease to \$8159.25 as we near the end of our 5th month supporting this cause. We sincerely thank you for making this inaugural fundraising event a success, for without you all "RUNNING WITH HEART" we simply could not have come close to raising the amount of dollars & awareness that we have done. in an effort to bring the possibility of finding a cure that much closer.

*Here are some participants pics and results:*



Dunsborough 5km run  
5km Perth  
5km Perth  
5km Perth  
10km total (Perth)  
Claisebrook WA  
5k (walk) Claisebrook  
5km Butler WA  
Bulimba QLD 5kms.  
21.3 at the group run, at Forest Lakes Qld.  
5km Toowoomba, Qld  
21km east point, NT  
11k Forest Lake, Brisbane  
Coffs Harbour NSW 5km  
21.3km Aldinga Beach/port Willunga Forest Lake, Brisbane Australia  
5km in Brisbane  
family x 5 x 5kms walk, Perth  
21.1 rogue kilometres - Canning River  
5km canning river  
10k Brighton to St Kilda and return,  
2 x Perth 5km - Bridie  
21.1km in New Norcia  
5kms Forest Lake Brisbane

7.5km launceston tas  
5km each, Auckland NZ!!  
21.1 Toowoomba.  
21.1 Albany WA  
11km Aveley WA  
11km Forest Lake, QLD  
5k, Hill Top, NSW  
Canberra 5km

Forest Lake Brisbane (a day late tho)  
13km Canberra  
5km Claisebrook Cove WA  
10km rockhampton qld  
Sunny Corner NSW  
5km New Farm, 30km  
Nudgee QLD.

Kingaroy Queensland jogged 10 and walked 2  
5km in Albany, WA  
5km Rocks Park, Jindalee, Qld  
5km, launceston, Tasmania  
28km Aveley, WA  
5km South West Rocks, NSW.  
21.1km Canning River, Perth  
24km (Dunsborough)  
10km Canberra  
Karawatha Forest brisbane  
Morley/Bayswater WA 21.1K  
10k forest lake qld  
21.1km Kent St Weir to Shelley & return  
Nightcap National Park, Northern NSW 13km  
11km Forest Lake Brisbane  
Queensland 5km albany  
1km Forest Lake Brisbane Queensland  
2.4kms Forest Lake Brisbane Q  
10k yarra valley, vic  
5k Caloundra Qld  
6.5km Dunedin New Zealand!

## Fundraising continued...



Ra Timms and team held a Car Show at Phar Lap Raceway grounds in Timaru in the South Island of NZ. From 9am to 1pm, although some stormy weather was challenging, we had nearly 200 magnificent cars there. All sorts turned up, grass carts, vintage, army, hot rods, drifters, vintage caravans, sports cars, modern cars and motor bikes. The car show was great, Alanna Gayko joined us and we raised approx \$3,000.



### Donations made 'in memory'



#### In Memory of Joey Weeks:

Anthea Weeks

#### In Memory of Chloe Hampson:

Jessica Page

Debra & Glen Hampson

Amanda Blakers

#### In Memory of Matilda Bergers:

Louise Golshevsky

#### In Memory of Mackenzie -Rose:

(for your 12<sup>th</sup> birthday)

Jamie & Wendy Foster

Kylie Anderson

Cartwright family (In Honour from sale of equipment)

#### In Memory of Stevie McCutcheon:

Jane Seychell

#### In Memory of Matilda Berger:

B. Crocker

Rhiannon Modica

#### In Memory of Brodie & Amanda:

Pauline Sibley

Lilly Goot

Rotary Club of Karringup

#### In Memory of Haylee Prater:

Jean Prater

#### In Memory of Jordan Anderson:

(for your 21<sup>st</sup> birthday)

Sandi Herbert

Nancy Rhoades

#### In Memory of Christopher Hibberd:

Garry & Helen Hibberd

#### In Memory of Gregory Ernest Green:

Kellie Farber

### General donations

Grapp Pty Ltd ATF E Charitable Trust

Dean Apostolou

Jerome Bell

Sylvia Sheridan

Marlies Verschoor

Alyson Van Gaalen

Jessica Wilde

Nicola Edwards

Melynda Walker

Lucy Watson

Sharon Leahey

Penny McNiff

Denise Clarke

Cassie Tommasi

Amber Hopkins

Algis Kuliukas

Claire Smith

G Grondin

Jasmine Sidiropoulos

Michael Foote

V J Bloor

KJ & JM McCoy

Staff at Australian Health

Management (Medibank)

Wendy Smith

### Remember these dates for 2015:

18/1/15 Wendy's Movie Night, Kensington Gardens (SA)

28/2/15 Rare Disease Day (Nationally)

6-8/3/15 Moomba Festival featuring Battens on screen (VIC)

31/3/15 National Batten Disease Awareness Day (OZ & NZ)

5/15 Rogue Runner's Quiz Nite (WA)

Email Vanessa for more information.... [vanessa@battens.org.au](mailto:vanessa@battens.org.au)

# Representing of Batten Disease



## Alanna Gayko's ongoing support



**Have you got your  
copy of the Book  
“Perils Of  
Motorcycling”?  
Orders welcomed.**

If you look closely at this picture of Alanna's travels, you will spot a sign saying "Batten Creek". Here is Alanna's explanation: I had travelled up to Lorella Springs in NT for the Off-Centre Rally and was on my way south heading back to Cape Crawford. There were several wet creek crossings on that trip but of course the sign stuck in my mind. At different parts of the trip I was travelling alone with someone not too far behind. I also fell off in the sand probably near this area and some young guys in a 4WD helped get me up. That is part of the story page 129 onwards, where it is not a good idea to wear a new underwire bra!! I also went to a lot of trouble to carry the red jerry can but forgot to fill it up at Lorella on Sunday, nor the bike. That is why I ran out of petrol and Kevin Barber got me some from Cape Crawford.

**Alanna travels far and wide (Nationally and overseas) to advocate for Batten Disease. She has met many Battens Families in her travels - read on...**

### The Perils Of Motorcycling:

Now that I have finished this book...Took less than 24 hours I enjoyed it so much...I am going to give it another plug ..I met Alanna on one of my bike rides...We shared dinner, drinks and some laughs...She impressed me as intelligent, witty and compassionate. Five years later courtesy of Facebook I found out she had written a book in which all the proceeds are going to Battens disease, an insidious, very rare but nevertheless fatal genetic disorder generally occurring in children. My niece is one of the unfortunate children who has contracted this insidious disease (this word was used twice 'cause I couldn't think of another more devastating word).

I was pleased to find out that my initial impressions of Alanna were right. The book is funny, sensitive at times (will make you laugh and occasionally cry) written by some one of obvious intelligence whom sees the world a little bit differently.

Do yourself and Batten Disease a favour ...and buy the book.

Mark 'Smiley' Smith, Sydney – Australia.

*I met Mark 'Smiley' Smith in August 2008 whilst riding up to the Northern Territory on my BMW R60/5 1972 model. We were both co-incidentally staying at the same hotel in Winton, Queensland on our way up to the Off Centre Rally being held at Lorella Springs. In 2013 after both commenting on a photograph of young Charlee (Charlee's Angels) who suffered from Batten Disease and lived in Salt Lake City, Utah, USA, we worked out we had met each other years beforehand. I had mentioned our crossing of paths in my book (on page 129). It is quite astonishing how we have randomly touched each others lives. I hope in some small way we can help Mark's niece Imogen Stone who lives in Wollongong, NSW, Australia and all the other children with Batten Disease around the world.*

*Sadly little Charlee has passed away, but not before a law was passed in her name and honour – Charlee's Law in Utah, USA to legalise the use of medicinal cannabis oil in an attempt to control intractable seizures.*

**Alanna Gayko**





## Representing of Batten Disease continued.....

**Lisa Archer (parent):** I went with Steph Hughes, researcher, to see Cure Kids last week. They funded a year of research and we wanted to share the amazing latest results (refer to David Palmer story recently). The CEO, Vicki Lee was thrilled and asked Steph to put together a

### New Zealand

summary for their Board meeting this week.

Unfortunately an application for this funding round (think it is only done quarterly or biannually) hasn't been put in as Steph is also trying to get funding for CBD study. Vicki said she will try to ensure the Board appreciates there is really good momentum and the research needs to continue and be expanded. She thinks it would be more successful if they can have another partner on board, ie. they will contribute \$x if you do too. *We'll stay tuned on this ...*

Rare Voices Australia (RVA) is advocating, as its number one priority for Australia, to adopt a National Rare Diseases Plan.

Recently RVA hosted its 4th and 5th

National Roadshow meetings in New South Wales and Western Australia, and Parliamentary Friends

of Rare Diseases was launched in recent months at Parliament House Canberra. Thank you to all those who attended these important events (some travelling very long distances).

Thank you to all the patient organisation representatives, researchers, health professionals, department of health personnel and other related stakeholders who have attended these meetings. RVA advocates for a system whereby there is a transparent process in place based on agreed key principles for people living with rare diseases. Australia can no longer afford to ignore the rare disease community. RVA would like to see Australia adopt key policies and a National Strategy that talks to all aspects of rare diseases including access to those few safe, effective and appropriate treatments. Next event will be Melbourne 27th—28th March.. Visit website [www.rarevoices.org.au](http://www.rarevoices.org.au)

### Rare Voices Australia

**Murchisons (parents):** We attended the Rare Voices launch in Canberra which was interesting although we were disappointed that our local member representative wasn't there but gives us an excuse to follow him up.

### In Canberra

Senator Back who we chatted with on Monday had some understanding/interest because of his Vet background, we followed up with an email to him (as requested) and included the article and information from David Palmer's research. We haven't received a reply and it is a long shot but we are endeavouring to get support and hopeful we can contribute in some small way to securing some funding.

**Alicia Brown (parent)** In August attended in a 3 hour session in South Australia engaging with Rare Voices Australia to review the [Scoping Paper](#) for a National Rare Diseases Plan, with specific focus objectives and ques-

### In South Australia

tions for this plan. Families could share their voice for Battens and were invited to contribute ideas and to discuss a prepared briefing that includes one or more relevant initiatives. RVA would like to understand what is required for there to be full support for a Rare Diseases Plan.

An outcome of the half-day session is to provide a concise report that summarises the key issues and opportunities and agreed actions.

**THANK YOU TO EVERYONE WHO ADVOCATES FOR BATTEN DISEASE. SHARE YOUR VOICE.**