Dear families, friends and members,

Battens in Australia had a pro-active period involving the National Awareness Day on 31st March, the Royals visit which included two of our families in a special meeting and an ABC TV program starring Pauline of WA and her unique garden. In coming issues we will share more about these and other special events. Hope this finds you all well as we lead into winter days.

Vanessa, Jenny and the BDSRA, Australian Chapter.

**BDSRA FOCUS**

😊 **Who’s who in the Zoo:** The BDSRA office has been in need of support recently, and we have two new persons on the team. Let me introduce our office persons who you may have contact with:

- **Admin support—** Jenny Smythe—1 day pw (right)
- **Manager—** Vanessa Anderson (left)
- **MYOB/audit—** Evan Nicholas - 1 day/quarter (left)

😊 **Family Support Program:**
You may have received the Program of Activities and Speakers for the next Battens Family Meeting (10/10/14) on the Central Coast of NSW at Camp Breakaway. If you haven’t received your forms or the Program and would like them, please email Vanessa. We encourage and welcome all families to attend, especially bereaved families too.

😊 **Memberships 2014/2015:** The Australian Chapter’s membership appeal drew 26 memberships to-date. Please consider supporting your Organisation by joining and help the BDSRA to both be present and sustain its services to families and the community. The fee is $25 per family/individual/organisation. You can download a membership form at [http://www.battens.org.au/membership-and-support](http://www.battens.org.au/membership-and-support)

😊 **Facebook Pages for Battens:** There are many facebook pages that you can be linked up with for support and forums - personal families’ pages and/or the USA page: [www.facebook.com/bdsra](http://www.facebook.com/bdsra)

😊 The Australian Chapter’s page is a ‘whats happening’ page and can be found at [https://www.facebook.com/AustralianBDSRA](https://www.facebook.com/AustralianBDSRA). Please ‘like’ and ‘share’ our page and help to spread Battens updates. There you can find ways to assist the cause and gain support.
International Partners Advance Batten Disease Research Targets *(update by www.bdsra.org on 24/4/14)*

**COLUMBUS, OHIO (April 24, 2014)** The Batten Disease Support and Research Association (BDSRA), in collaboration with international and family foundation partners, has announced grants totalling $408,000 to advance the development of treatments and cures for Batten disease.

Co-funders BDSRA-Australia, the Batten Disease Family Association of the United Kingdom, Noah’s Hope, and Hope 4 Bridget joined with BDSRA to support projects that span the United States, the United Kingdom, Australia, and Germany. Investigations to identify drug targets, drug discovery, and expand a patient registry have been funded through awards to six researchers:

- David Palmer, PhD, Lincoln University of New Zealand
- Stephan Storch, PhD, University Medical Center Hamburg-Eppendorf, Germany
- Angela Schulz, PhD, University Medical Center Hamburg-Eppendorf, Germany
- Jonathan Cooper, PhD, King’s College, London
- Jeffery Gerst, PhD, Weizmann Institute of Science, Israel
- Erika Augustine, MD, the University of Rochester

The DEM-CHILD NCL Patient Database project led by Schulz is the first worldwide attempt to collect and analyze clinical data of all NCL forms through a consortium of NCL clinicians from 11 countries. Expanding a worldwide patient registry for Batten disease is a BDSRA strategic funding priority because of its necessity to understand the disease, identify novel biomarkers, advance clinical trials, and develop effective therapies.

With an emphasis on cutting-edge scientific inquiries to build on existing investigations in gene therapy, enzyme replacement, and drug discovery, BDSRA continues to identify and fund research with the highest potential to formulate treatments.

BDSRA and its co-funders select grant recipients through a scientific merit review process in which proposals are evaluated according to standards that screen significance of the project to advance NCL research, strategy to accomplish objectives, and potential for translation to treatments and cures.

As a rare, fatal, inherited disorder of the nervous system, Batten disease has no known treatment or cure. Batten disease is the most common, inherited neurodegenerative disorder found in children, and is also known as a group of disorders called Neuronal Ceroid Lipofuscinosis (NCL). There are multiple forms of the disease, which is most commonly diagnosed between infancy and school age.

BDSRA is the major support and research organization in North America for Batten disease. The first research grant from BDSRA was awarded in 1992, and since then more than $7.4 million has been allocated toward the search for treatments and cures. The organization is the largest provider globally for Batten disease patient and family support, education, research, and awareness programs.

*BDSRA-AUS: “The search for a Treatment and/or Cure for Batten Disease depends on our support to continue these projects. Help us to strengthen Research into Batten Disease, sustaining now and into the future”*
Programs and Support

Information Sharing—Services and Resources

Pre-Genetic Testing Financial Assistance:

We all want a healthy baby, one who grows into a healthy child. Unfortunately, in some cases it’s not always how things turn out. Certain genetic conditions can cause birth defects or start to show up as a child develops and certain factors, such as knowing you have a family history of a genetic disease or being of advanced maternal age, can increase the likelihood of your baby being affected.


Or contact at http://agsa-geneticsupport.org.au/

Photographic Memories:

“Heartfelt” is a volunteer organisation of professional photographers from all over Australia dedicated to giving the gift of photographic memories to families that have experienced stillbirths, premature births, or have children with serious and terminal illnesses.

Heartfelt is dedicated to providing this gift to families in a caring, compassionate manner.

Contact 1800 583 768 or visit website www.heartfelt.org.au

Need Legal Help in NSW?:

At LawAccess NSW we are working to enhance access to our service for people with disability and to raise awareness of our service with people with disability, their family and carers, disability advocacy services and disability support services. LawAccess NSW is a free government telephone service that provides legal information, referrals and in some cases, advice to people who have a legal problem in NSW. Please contact for further information: Community Outreach Coordinator—1300888529 or visit www.lawaccess.nsw.gov.au

YourCare is a new social network, designed to help people with disabilities, their families and carers find goods, services and social support.


We aim to bring you the best of the service sector, connecting you to suppliers who are enthused and willing to respond to your needs.

NEXT ISSUE:

A story from the Battens Families of the experience, with photos, of meeting The Royals whilst staying at Hospice, Bear Cottage.

Information Sharing—Equipment

The Talking Photo Album is an easy-to-use speech output tool that holds standard 4 x 6" photos in clear plastic sleeves. Great for talking stories, communication books, step-by-step instructions, memory books and personal information.

Contact T02 9975 8419 or visit www.technability.com.au
**Fundraising**

**NATIONAL BATTEN DISEASE AWARENESS DAY: 31ST MARCH**

And RECENT FUNDRAISERS

**QLD:** The MAD (Make a Difference) team at Marsden State High School raised money for Battens (over $300) by donating into 3 different jars, each with a mission. Photos below are of the two teachers who didn’t have to go through with their dares and the other is of Lou Oberholzer one of our Deputy Principals having his moustache shaved. He hasn’t gone without a moustache for as long as he can remember. It was a really good event.

**WA:** East Fremantle Sharks Football Club devote a game to Battens and raised $4597. The 22 players who played on Saturday plus coaches, members, staff, supporters and volunteers now know something about Batten Disease and will remember the day that we played in support of the disease. Battens families were special guests at the event, including Luke and Curtis in specially made shirts:

“There is a picture attached of our players sitting on the floor post game which I love; there are a couple of reasons I love it, first, each and every one of them is totally focused on the person speaking and secondly, every one of them has a smile on their face. Who were they listening too and why are they smiling? They were listening to Luke’s post match address and smiling because he told them to kick more goals next week, we might have to get the boys on the payroll! To be involved in community support affords the opportunity for our Club to come together and focus our energy on more than the game, it creates a lot of goodwill amongst our people and I can sense the pride that our people have in the Club when they are investing in community outcomes outside of the white line.”

**NSW:** Leichhardt Zone Playgroup: Our cupcake stall at the Funday exceeded our hopes and raised over $550. We had a fantastic day and people were very generous.

**S.A.:** Lorraine Daley co-ordinated a Bunning’s BBQ and had a wonderful team of helpers who together raised $2803. Hard work!!!

**W.A.:** Kensington Primary School held a Footy Jumper Free Dress Day and raised $361—fantastic effort.

**S.A.:** Wendy Smith has been fundraising with raffles and merchandise. So far Wendy has raised $128—great work Wendy.

**Fun-Run Extraordinaire in W.A.**

Sara raised $7671—amazing support!!! “Well we did it 12kms around the streets of Perth, no rain and so much love and amazing energy around the course. Such a well organised event, great volunteers and plenty of passionate supporters and participants. A huge thank you to Hayley who ran with me, the first time I have run it with somebody and I got to show the Sydneysider some of Perth during the run.”

Tahnee Bell raised $2747: “I’ve been thinking about participating in more charity and fundraising events for a while now and this year decided to just do it. The HBF run was a solid choice considering my love of fitness and I’ll be running it with a friend (hopefully a few more if I can pester them enough). Any funds I do manage to raise will go towards the Batten Disease Association.”. Thanks Tahnee.....
**Fundraising continued...**

**Donations made ‘in memory’**

**In Memory of Chris Hibberd:**  
Peter McKenzie  
A Tucker  
G & L Tuless  
H. Berry  
M Bell  
Miscellaneous collection  
G & H Hibberd

**In Memory of Gus Mainwaring:**  
Sandra Catalano

**In Memory of Mackenzie-Rose:**  
Graeme & Vanessa Anderson  
W & J Foster

**In Memory of Kianna’s Quest:**  
Don Chapman  
In Memory of Matilda Smith-Berger:  
Newton Turner  
Jana, Lauren & Jenni Phillip Burnham  
Richard Turner  
Paul Brown  
E Weeks  
Jacqui Thomas  
Suzanne Howard

**In Memory of Jordan:**  
Ian Tweedie  
G & V Anderson

**In Memory of Chloe:**  
Ian, Elke & Emily Yeaman

**In Memory of Bradley Linnane:**  
Kate Linnane

**In Memory of Tori Evans:**  
Keryl Evans

**In Memory of Sheree & Sonya Kuhr:**  
Kat Eschler

**In Memory of Jody Lawrence:**  
Robyn Lawrence

**In Memory of Brodie & Amanda:**  
Pauline Sibley

**In Memory of Gus Mainwaring:**

- Sandra Catalano

**In Memory of Mackenzie-Rose:**

- Graeme & Vanessa Anderson
- W & J Foster

**In Memory of Kianna’s Quest:**

- Don Chapman
- In Memory of Matilda Smith-Berger:
  - Newton Turner
  - Jana, Lauren & Jenni Phillip Burnham
  - Richard Turner
  - Paul Brown
  - E Weeks
  - Jacqui Thomas
  - Suzanne Howard

**In Memory of Jordan:**

- Ian Tweedie
- G & V Anderson

**In Memory of Chloe:**

- Ian, Elke & Emily Yeaman

**In Memory of Bradley Linnane:**

- Kate Linnane

**In Memory of Tori Evans:**

- Keryl Evans

**In Memory of Sheree & Sonya Kuhr:**

- Kat Eschler

**In Memory of Jody Lawrence:**

- Robyn Lawrence

**In Memory of Brodie & Amanda:**

- Pauline Sibley

**Workplace and On-Line Donations**

**Workplace Donations:**

- Staff at Australian Health Management (Medibank)

**Regular Donors On-Line:**

- Amanda Blakers, Jerome Bell, Anthea Weeks, Dean Apostolou, Shirley Tsui, Debra & Glen Hampson, Jessica Page, and Penny McNiff

**General donations**

- Sue Woods
- Ruth Spooner
- Debra Morrison
- Christina Van Leent
- Denise Dssau
- Bettina James
- Ralph Hunt
- Alison & John Reynolds
- Russell Brown
- Adrian Rowe
- Claire Howard
- Bruce Barnhill
- Jarod Lyon
- Robin Peard
- Judy Acason
- Amanda Cameron (to celebrate for Dylan)
- Valerie Severin
- Jasmine Sidiropoulos
- Karina Walker
- Camille Brin
- L Jansson
- B & T Joyce
- Leeming SHS Education Support
- Lions Club of Soldiers Point
- Sharon Rowell
- Craigie Baptist Church
- Craft Group
- G. Grondin
- Damian & Amanda Walsh
- Robin Bell
- Rotary Club of Hillarys

**Upcoming fundraising**

1. **Runners and Walkers..... Joint Battling Battens Team in South Australia for our 12 km scenic walk—contact Vanessa for more details.**

2. **NRMA NSW— New sponsorship has been agreed for coming months**

3. **Rogue Runners of WA— Supporting battens in the coming year**