

HOPE FOR HD

Second Edition
March 2015

IN THIS ISSUE

- Where's Maddison?
- Holly Faulkners inspires HD supporters
- 2 Films you must watch
- An inspirational read
- Salvos Stores Lend a Hand

It's our 40th Year!

We thought 2014 was busy however the year ahead is shaping up to be a big one. It's hard to believe we are already heading into the second quarter of the year and there are plenty of things happening on the horizon. This year we recognise that it's forty years since the NSW Association was established and it is only through the dedication and service by many people in every state that we have been able to provide meaningful support and encouragement for families impacted by Huntington's Disease.

At the present time there is no cure for Huntington's Disease but there is hope and we certainly know much more about it than we did forty years ago through the wonderful research undertaken in many places around the world including Westmead Hospital and the Florey Institute in Melbourne.

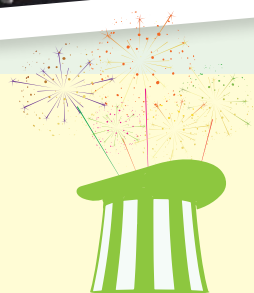
During Huntington's Awareness Month in September we will once again be inviting you to join us for the Walk 4 Hope, confirmation of locations will be announced at a later date keep an eye on the website. The Salvos Stores will also be promoting Huntington's along the eastern seaboard and raising funds.

Thanks to you for supporting us on our journey.

Best wishes,



Robyn Kapp
Executive Officer



MAD HATTER'S TEA PARTY
Celebrating 40 years of Huntington's NSW

Our BIG EVENT. Save the Date!
Mad Hatter's Tea Party
Friday 22 May 5.30 pm,
Intercontinental Sydney

The Great Australian Bike - Maddison

Kicking off from Terrigal on the Central Coast on 6 December Maddison Spence hit the road for a 14,000 kilometre bike ride around Australia. Maddison has a nickname Mad Dog and we know why!

Maddison said "A few years ago I started a list of things I wanted to do in ten years, three of those were to travel around Australia, bike ride from Brisbane to Melbourne and donate to charity. So I thought why not combine all 3 and bike ride around Australia for Huntington's disease as some close friends have been affected."

This is all very well but Maddison had not ridden a bike since he was a child and didn't even know how to change a tyre, but after consultation with You Tube whilst en route he is now an expert!

The cycle around Australia will take him four months and if all goes to plan he will be back to attend a friend's wedding in April. On his way he has met up with Tammy Gardiner, CEO of Huntington's Victoria, Joyce Abblitt, President of Huntington's Tasmania, Rae Walter, Executive Director of Huntington's WA.

As we write this newsletter Maddison is making his way up the WA coast after spending a couple of nights in Perth which involved getting the bike



Photo by Paul McGovern, POST Newspapers.

repaired and a few nights sleep in a bed instead of the side of the road.

We are grateful to Maddison for supporting Huntington's NSW and undertaking this amazing journey and looking forward to welcoming him back to hear the unpublished stories and we are sure there are many.

You can follow his journey via his Facebook page The Great Australian Bike or show your support by making a donation on <https://give.everydayhero.com/au/mad-1>

PS: As we go to print Maddison has raised \$11,791 he is aiming to hit \$20,000 .

SALVOS STORES lend a hand

During the month of September last year we partnered with the Salvos Stores who were collecting donations and promoting Huntington's disease throughout their stores. 99 stores across Qld, NSW and the ACT raised an awesome \$28,606. This was a fantastic result and a 'win win' for Huntington's NSW and Huntington's Qld.

We are thankful for this wonderful support and congratulations to all the stores who were involved. Once again we are looking forward to working with the Salvos Stores this year during September Huntington's Awareness Month.

Make sure you drop in to those Salvo Stores it's a great way to do your shopping and support the community.



From L to R: Brian Rumbold, Robyn Kapp, Karen Bevan, Stewart Swales, Mark Bevan and Pauline Keyvar

Halloween Haunt

Late last year Macquarie Bank put on a "spooktacular" ball at Sydney Town Hall in support of research for Huntington's disease at the Florey Institute organised by our friend Katy Clymo. Our own Holly Faulkner was invited to be the special guest speaker

It was a fun night with plenty of strange looking people walking around dressed up as spooks,



The fabulous Tina Bursill was the host for the evening.

vampires and anything remotely Halloween. Holly wasn't dressed up as a spook but she definitely stole the show. Holly shared her family's Huntington's story and courageously showed a very personal video of her own family.

The 450 strong audience sat in silence as she told her story.

Thank you Holly, you left a lasting impression for all those people at Sydney Town Hall.



P.S. A little bird told us that Holly recently got engaged to Shannon.

MOVIE BUZZ

There are a lot of movies around at the moment talking about Huntington's disease.

The Lion's Mouth Opens – a powerful Lucy Walker documentary featured in the Bondi Flicker Fest about a young tress Marianna Palka confronting her risk of Huntington's disease. <http://www.lucywalkerfilm.com/THE-LION-S-MOUTH-OPENS>

The title was taken from a Bob Dylan poem and his last thoughts of Woody Guthrie.

A Canadian documentary **Do You Really Want to Know** <http://www.doyoureallywanttoknowfilm.com/>

The Inheritance - NZ Film makers Bridget Lyon and Jeff McDonald.

This film has already been screened in Victoria and Tasmania and we are looking forward to our partnership with Bridget and Jeff when screened in Sydney on 24 March. Associate Professor Clement Loy will introduce the film and be part of a Q&A panel with Bridget and Jeff.



2 SCREENINGS:

Tuesday,
24 March at the
Dendy Opera Quays,
6.30pm.

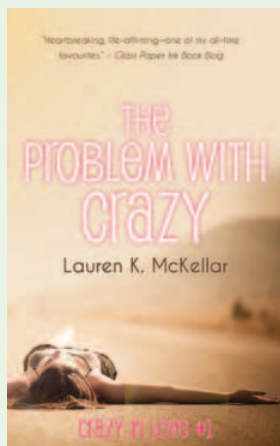
Ticket Prices:
\$25 for the film and
Q&A / \$40 Film,
Q&A plus Post
Screening Drinks

Wednesday,
25 March at
Parramatta Events
Cinema, 10 am.
Ticket Price:
\$25 Film & Q&A.

For bookings <http://theinheritancedocumentary.com/>

BOOK REVIEW: The Problem With Crazy

My name is Lauren, and I wrote *The Problem With Crazy* here on the Central Coast in beautiful New South Wales. I was inspired to write this book after meeting a friend of mine's father, who has Huntington's. It's such a horrible disease, and not one you see publicised a lot, so I wanted to do something to help bring awareness to the condition.



While this is a book aimed at young adults, I think it carries a message we can all appreciate: the importance of living in the moment and doing what you can, while you can. It's all about revelling in the little things, and dancing in the rain.

You can purchase the book on-line via Amazon
<http://www.amazon.com>

Ten per cent of sale proceeds go to Huntington's NSW

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DIARY UPDATE

March 24 & 25
"The Inheritance"

April 11&12
Canberra Times Running Festival



May 22
Big event happening soon:
TBC Mad Hatter's Tea Party
Intercontinental Hotel Sydney

May 17
Sydney Morning Herald Half Marathon

August 9
City2Surf

September 6
Canberra Times Fun Run

September 27
Parramatta Park
Speer's Point TBC
Canberra TBC



► For comments and suggestions call or email
THE EDITOR: 02 9874 9777
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Tel/Mob: _____
Email: _____

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