

HOPE FOR HD

First Edition
October 2014

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- Penny's & Anna's

SALVOS SEPTEMBER DEDICATION



Thanks heaps!

Welcome to our first edition of Hope for HD. Following our amazing September Awareness Month we would like to share with you some of the wonderful activities which created more awareness of HD and raised much needed funds. As you can see we have dedicated lots of space to nice photos and we have taken the opportunity to share some of the stories and challenges from those people who actively took part.

The SALVOS STORES partnership was a fantastic opportunity for us to get our name into the wider community plus it gave us access to good media exposure. This all helps in promoting our name and to top it all, they were also taking donations for HD in NSW and Queensland.

Walk 4 Hope is your event and the Huntington's NSW Board and I would love to see it grow. So, I

encourage everyone who possibly can to take part next year. The more people participating in some way the greater awareness for HD. This September there were two walks – one in Speer's Point on Lake Macquarie with around 300 people taking part and in Parramatta Park on a beautiful sunny Sunday with 30 kgs of sausages consumed! It was a sea of pink and green.

How much did you raise? \$72, 294.02.

A huge THANK YOU to everyone who got behind HD in September. And now the story begins.....

Best wishes

Robyn Kapp - Executive Officer

RHIAN

“Huntington’s Chorea (also known as Huntington’s disease or HD) is something very dear to my heart. My beautiful mother Lile has been suffering from Huntington’s for almost 10 years now and as a result, is in a nursing home-something that has been harder than anyone could ever know. My grandmother also suffered from HD. This heartbreaking hereditary illness is still yet to find a cure. HD is something that takes over your whole life and any idea you may have of the future. Having a 50/50 chance of also getting HD is something I try not to think about, but man is it scary! I can only hope that by the time my brother and I are our mother’s age, that there may be some kind of cure or preventative. Mum tells me every day how lucky we all are and “there is always someone worse off”. Her perspective on life is incredible. She is the most selfless, kind hearted person you could ever meet and despite everything, never ever complains. I honestly have no idea how she does it. She is the strongest person I know and I am so blessed that she is my mum.

Now it’s my turn to try and do the best I can to help her and other people in similar situations. Any help that you guys can give is hugely appreciated and I thank you from the bottom of my heart.”



WALK4 HOPE

28 SEPTEMBER 2014 EVENT UPDATE

Stories of hope

AMANDA

“Hello I’m Amanda and the Huntington’s disease cause is close to my heart. There is no cure, so awareness and support are vital.

On 5th Sept I pledged to walk 10 marathons in 30 days; 420 kms - from couch potato to 14 kms daily - a mission! Why 10 marathons? ‘Ten’ signifies the number of families directly impacted by HD within my own family. A ‘marathon’ reflects the stamina, emotional strength, sheer determination and overwhelming exhaustion an HD family experience daily. I’ll post the progress of my journey here.

On 28th September my beautiful family and I will be walking in the memory of loved ones and out of compassion for family battling daily. Please help me spread the word by sharing this message and support us by making a donation.”

Day 27 - 19.2kms (54.8kms to go)

Day 26 - 10.2kms (74kms to go)

8th marathon walked out of compassion for my own family. I love you all to the moon & back!
XOXOXOXOXOXO



ANGELA

“I have 5 children and 2 of my beautiful daughters I have been tested gene positive for HD. For me it is about getting as much awareness out there for HD as I possibly can so I decided to organise a family walk at Speer’s Point. We thought it was just going to be family and friends but it turned out to be a much bigger event with 300 people walking for hope at Speer’s Point. Everyone was so kind, Coles my employer got behind the event and donated all the sausages, which believe me were a lot! Our local Lion’s Club came down to cook and they also donated the onions. We will definitely do this again next year for HD the community support was just brilliant.”



FREDDY

“I’ve created this page because I want to make a difference. I’m inspired by the work that Huntington’s NSW do so I wanted to support them by raising money. Please help me help them by giving whatever you can using the ‘Give Now’ button. The more people that know about Huntington’s NSW, the greater their impact, so please also spread the word by sharing my page with your friends and family. Thank you in advance for your generosity, it means a lot!”



PENNY & ANNA

My family has fought with HD for generations and we urgently need a cure for this horrible disease! Please help me raise awareness and funds! Penny’s mum sadly passed away aged 53. My dear, dear friend is affected everyday by HD. This hideous condition runs in her family. Awareness and funds desperately need to be raised to eventually find a cure for HD.



Salvos Stores aid cause

► THE EDITORIAL TEAM

SALVOS Stores has dedicated September to help raise funds for those with an incurable brain disease. At the Sutherland Salvos Store a video is being shown to educate people about Huntington's disease. Manager George Ye said he was happy to have a poster displayed in the store.

Sales staff member Matthew Mellor is also helping raise awareness and there is a collection tin in the store. The disease affects the nervous system and is caused by a defective gene passed from parent to child.

Signs include emotional, cognitive and motor difficulties characterised by jerky movements. Sometimes there is rigidity, loss of body-function control and dementia. Other symptoms include a slowing down of thought and judgment, lack of awareness of problems and planning difficulties.

Men and women are at equal risk of inheriting the disease, with onset most typically occurring when people are aged in their 40s or 50s.

There are medications to help control emotional and movement problems but there is no treatment to stop or reverse the disease. In some patients speech is slurred and swallowing, speaking and walking abilities decline while some patients are unable to recognise family members.

Huntington's NSW will hold its first Walk 4 Hope fund-raiser on Sunday at Parramatta Park. Details: huntingtonsnsw.org.au or 9874 9777

DIARY UPDATE

November 1

Halloween Haunt Sydney
Black tie or a touch of Halloween
Sydney Town Hall, NSW 2000, 6:30–11:30pm



A 'spooktacular' evening of entertainment and fundraising in support of Huntington's Research
Book: <http://www.halloweenhauntsydney.com/>

November 8

Family Fun day & AGM at Camp Breakaway, San Remo.

November 21-23

Youth and family information day in partnership with HDYO. Matt Ellison from HDYO in attendance
For info 9874 9777 or info@huntingtonsnsw.org.au

December 2

Giving Tuesday
Support HD and get your workplace involved.
#GivingTuesday is a day to celebrate and give to not-for-profit organisations. It's not all about money; it's about celebrating the fantastic work organisations do. Register <http://givingtuesday.org.au/join-movement/>

► For comments and suggestions call or email
THE EDITOR: 02 9874 9777
info@huntingtonsnsw.org.au • www.huntingtonsnsw.org.au

September is over, but our Walk 4 Hope continues.
You can help us reach our destination by making your donation today.

 **Huntington's**
New South Wales
ABN: 54 571 730 306

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Organisation: _____

Address: _____

Tel/Mob: _____

Email: _____

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