



## Amanda Young Foundation

# Support Program News Spring 2015

The Amanda Young Foundation Support Program offers those affected by meningococcal disease and their families:

- **Advocacy**
- **Referral and services funding**
- **Regular support**
- **Information**
- **Equipment**
- **Social Gatherings**
- **Newsletter**

Please feel free to call or email Lisa with any concerns, large or small, or simply to say hello!

**Support Mobile**  
0433 309 425

[support@amandayoungfoundation.org.au](mailto:support@amandayoungfoundation.org.au)



Secret Facebook Group - contact Lisa to join

### CASE MANAGER UPDATE

Welcome to the 7th edition of the Support Program Newsletter.

I hope everyone is keeping well and enjoying life.

I am fortunate to live in a trial area for the NDIS (National Disability Insurance Scheme) and have started the process of moving on the program which is all very new. I thought I would include an update about this new initiative, in the event that any of you or your families may either be living in a trial area, or be eligible for the scheme in the future when it is rolled out in your area.

I have also included some photos of the foundations greyhound, Mighty Tay, with his namesake, our support program member, Tay.

I hope you enjoy the newsletter and look forward to your feedback.

Warm wishes, Lisa



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### UPCOMING EVENTS

**2 to 5<sup>th</sup> October** **Romancing the Stone Open Garden**  
3 Lillian Rd, Maida Vale

**24 & 25 Oct 2015** **Amanda's Garden**  
1520 Matison St, Southern River

**Sat 13<sup>th</sup> Feb 2016** **Support Group Get-Together- 2pm.**  
**Sticky Beaks Playground Café, Kings Park**

# NDIS – What is it?

## National Disability Insurance Scheme

In 2014, the National Disability Insurance Scheme was introduced in Australia, which supports people with a permanent and significant disability that affects their ability to take part in everyday activities.

Trials of the National Disability Insurance Scheme (NDIS) have started in a number of locations around Australia for people with a disability, up to the age of 65.

A person with an impairment that is likely to be permanent and the impairment makes it difficult to take part in everyday activities can access the Scheme. A person needs to meet disability or early intervention requirements, as well as age and residence requirements.

Existing national and state-based services and supports will continue until eligible people start their plan with the NDIS.

From 1 July 2014 Western Australia started participating in a two-year trial of the NDIS.

The NDIS trial in WA is unique because there are two different disability service models being run in separate locations.

The trial runs for two years, after which time one of the models will be rolled out in WA



## State Government My Way - South West

The State Government's WA NDIS **My Way** model started in the Lower South West on 1 July 2014, and Cockburn and Kwinana joined on 1 July 2015.

To determine if you are potentially eligible to participate in the WA NDIS **My Way** trial, step through a short assessment at [http://www.dsc.wa.gov.au/Am\\_I\\_Eligible/](http://www.dsc.wa.gov.au/Am_I_Eligible/)

## Commonwealth Government NDIA - Perth Hills

The Commonwealth Government's NDIS model is being run by the National Disability Insurance Agency (NDIA) in the Perth Hills. The office is located in Midland. To determine if you are potentially eligible, visit:

<http://www.ndis.gov.au/ndis-access-checklist>

To find out more about the Perth Hills trial, visit the NDIS website - <http://www.ndis.gov.au/about-us/our-sites/wa>

For those not in the NDIS trial areas of Perth Hills or South West, there are a range of services available to assist with daily living. Commonwealth Respite and Carelink Centres provide free and confidential information on local carer support, disability and community services. Centres are located throughout Australia and you can contact your nearest Centre by phoning 1800 052 222.

## MEET MIGHTY TAY!

Mighty Tay, the Amanda Young Foundation's second greyhound, had his first race in September and came second! This greyhound is special as he has been named after a member of our support program, Tay. Here are some photos of Mighty Tay, with Tay, his namesake (top), and Kate and Charley, Tay's family.



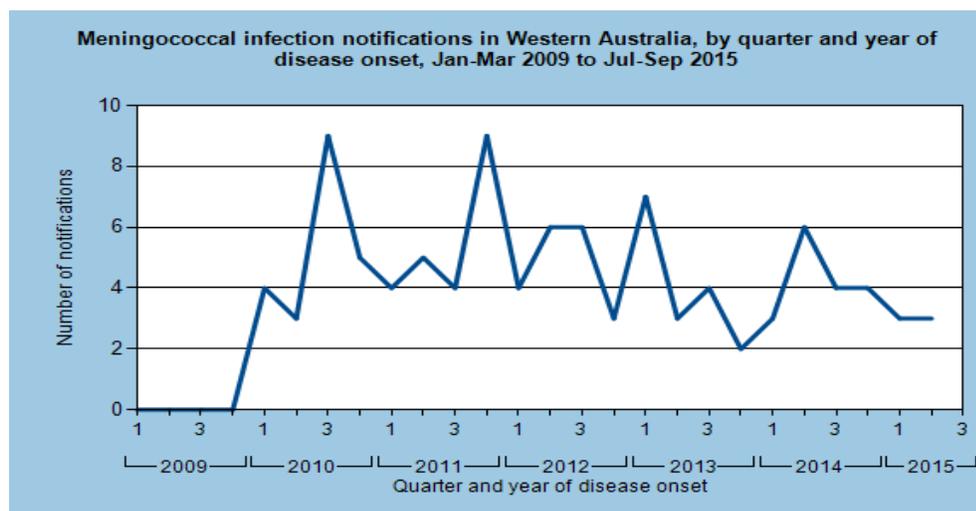
# Men B Vaccine Rejected by PBAC

In July, we were disappointed to learn that the Meningococcal B vaccine was not successful in gaining Pharmaceutical Benefit Scheme status and made accessible for all children on the NIP (National Immunisation Program). This means that Australian families will have to continue to source the vaccine on the private market and pay from their own pocket. This is the third time the vaccine has been presented to the Pharmaceutical Benefits Advisory Committee (PBC), and we thank all Amanda Young Foundation supporters who shared their stories or made a submission.

Meningococcal B is now the most prevalent strain in Australia today. Since the successful introduction of the Meningococcal C vaccine back in 2003, there has been a reduction of Type C cases around Australia. We hope that the concerns around the vaccines implementation can be addressed and the vaccine may be added to the NIP to protect our community.

## WA Incidence

In WA, we have experienced 14 cases so far to mid-September.



## 2010 – 2015

**Number and rate of meningococcal infection notifications in Western Australia, by quarter and year of disease onset, Jan-Mar 2009 to Jul-Sep 2015**

Year	Jan-Mar	Apr-Jun	Jul-Sep	Oct-Dec	Total	Rate *
2010	4	3	9	5	21	0.9
2011	4	5	4	9	22	0.9
2012	4	6	6	3	19	0.8
2013	7	3	4	2	16	0.6
2014	3	6	4	4	17	0.7
2015	3	3	8 <sup>^</sup>	-	14	-

## Vaccination

### Type B Vaccine (Not funded):

INFANTS require 3 DOSES at 2, 4 and 6 months, followed by a booster at 12-18 months. OLDER INFANTS, children and teens require 2 doses 2 months apart. Type B vaccine is not part of the Australian childhood the immunisation schedule, so the onus is on families to seek a prescription from their GP and purchase the vaccine.

### Type C vaccine:

For adults and older children, the C vaccine provides protection against C-strain but a booster may be required for long term protection. For babies under 12 months, C-disease is so rare that vaccination is not recommended.

### Vaccine A C W & Y

For overseas travellers, there is a vaccine which covers A, C, W and Y

# Recovery

If you are or care for a meningococcal meningitis or septicemia survivor, it is recommended to have a full medical check-up six weeks after the illness.

Survivors may feel tired for up to a year after meningococcal, and find you become unwell easily.

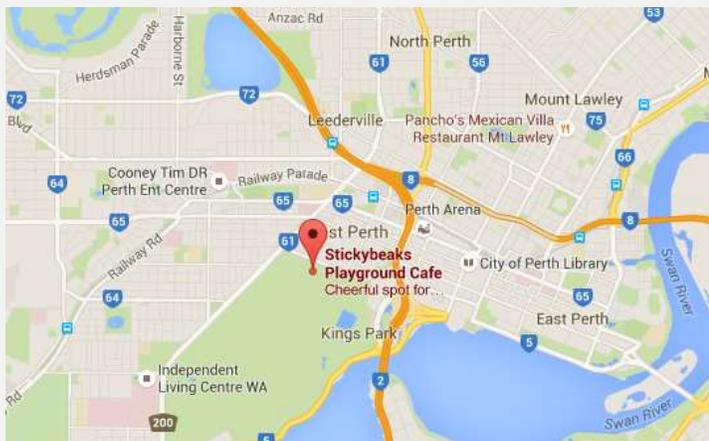
Many survivors may have ongoing health problems relating back to meningococcal disease. Feel free to contact the Support Program with any personal support needs you would like to discuss. The service is confidential and free.

## SUPPORT GROUP GET TOGETHER

**DATE: Saturday 13<sup>th</sup> Feb 2016**

**TIME: 2pm**

**VENUE: Sticky Beaks Café, Kings Park**



A reminder will be sent close to the date.

Please RSVP.

## SUPPORT PROVIDED

- ❖ Information about after effects
- ❖ Regular phone calls and/or emails
- ❖ One to one meet-ups
- ❖ Counseling referrals and financial assistance – survivors and family members
- ❖ Audiology referrals and financial assistance
- ❖ Equipment (computers, mobility aids)
- ❖ Tutoring/educational support
- ❖ Library

Meningitis – A Guide for Families
Feather – A Child's Death and Life. Robert Peters (Meningitis)
Up and Running. Mark Patikin (Meningococcal Survivor Memoir)
Close to the Bone-Life threatening illness as a soul journey. Jean Shinda Bolen.
Enduring Miracles – Surviving the Effects of Valley Fever. Afton Zapata
Learning to Walk – Recovering from meningococcal septicaemia. Lisa Burnette
It's only a leg! Hugh Drake
Addups and Takeaways. Harry Dumpleton
Never Tell Me Never. Janine Shepard
Lesley's Story. Martha McNey (Meningitis Survivor)
The Woman with a Worm in her Head. Pamela Nagami (p233 Call me spot)
Stronger Now – Nicole McLean
The Australian Immunisation Guide

## Toddler Vaccine Trial

Toddlers from 12 to 14 months of age are needed for a research project, undertaken by the Vaccine Trials Group at the Telethon Institute for Child Health Research and Princess Margaret Hospital for Children trialling a new vaccine designed to protect against Meningococcal ACW. Parents interested in finding out more about this study can contact:

**Vaccine Trials Group: 9340 8542**

**E-mail: [menacwy@icmr.uwa.edu.au](mailto:menacwy@icmr.uwa.edu.au)**

**<http://vaccine.childhealthresearch.org.au/>**

**Disclaimer** This newsletter is published in Perth, Western Australia for those affected by meningococcal disease. While every effort has been made to ensure accuracy, any advice in the newsletter is intended as a guide only and does not constitute medical advice. Newsletter content does not necessarily represent or reflect the opinions of Amanda Young Foundation. Any feedback or contributions are most welcome. **Unsubscribe? Please email [support@amandayoungfoundation.org.au](mailto:support@amandayoungfoundation.org.au)**

**Newsletter Sources - Meningococcal Vaccine:** Amanda Young Foundation Newsletter – March 2014;

[http://www.public.health.wa.gov.au/3/1520/3/meningococcal\\_infection.pm](http://www.public.health.wa.gov.au/3/1520/3/meningococcal_infection.pm); NDIS: Article source: <http://www.ndis.gov.au/>; <http://www.dsc.wa.gov.au/>

For more information about AYF events, see [www.amandayoungfoundation.org.au](http://www.amandayoungfoundation.org.au) or contact the Support Case Manager.