



Amanda Young Foundation

Support Program News Autumn 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



Secret Facebook Group - contact Lisa to join

CASE MANAGER UPDATE

Welcome to the sixth edition of the Support Program Newsletter.

I hope everyone is keeping well and enjoying life. For the newcomers in our 'special club' we welcome you. This newsletter features an article about Post-Traumatic Stress Disorder, which is relevant as we acknowledge the 100th anniversary of the ANZACs.

In February we had a small get-together with a couple of survivors. While the attendance at these events is small – a good sign that our group members are getting on with their lives – I will continue to hold these events bi-annually. If anyone has a special request for these events, please let me know. The next one will be held further South in Warnbro.

I have included some photos of a great rugby practice match we attended recently, with the permission of Nick, the recipient of the support.

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

Warm wishes, Lisa



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UPCOMING EVENTS

22nd August 2015
Support Group Get-Together- 2pm.
Last Drop Tavern, Warnbro

4/5th October
Romancing the Stone Open Garden

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

Post Traumatic Stress Disorder

Post-traumatic stress disorder (PTSD) is a mental health problem that can develop in people who have experienced or witnessed a traumatic event that threatens their life or safety (or others around them). This could be a serious accident, physical or sexual assault, war-related events, or a natural disaster.

For survivors of meningococcal disease, hospitalisation, time in intensive care, ongoing pain and treatments can all contribute to PTSD.

Symptoms of PTSD

A person with PTSD has four main types of difficulties, being:

- re-experiencing the traumatic event – through unwanted and recurring memories and vivid nightmares. There may be intense emotional or physical reactions when reminded of the event. These can include sweating, heart palpitations or panic
- avoiding reminders of the event, such as thoughts, feelings, people, activities or situations that bring back memories of the event
- negative changes in feelings and thoughts, such as feeling afraid, guilty, flat or numb, developing beliefs such as 'I'm bad' or 'The world's unsafe', and feeling cut off from others
- being overly alert or 'wound up' – sleeping difficulties, irritability,

lack of concentration, becoming easily startled and constantly being on the lookout for signs of danger.

People with PTSD can also have what are termed 'dissociative experiences', which are frequently described as:

- 'It was as though I wasn't even there.'
- 'Time was standing still.'
- 'I felt like I was watching things happen from above.'

A health practitioner may diagnose PTSD if a person has symptoms in each of the four areas for a month or more, which lead to significant distress, or impact on their ability to work and study, their relationships and day-to-day life.

It is not unusual for people with PTSD to experience other mental health problems (such as depression, anxiety or substance misuse) at the same time.

When to seek help for PTSD

A person who has experienced a traumatic event should seek professional help if they:

- don't feel any better after two weeks
- feel highly anxious or distressed
- have reactions to the traumatic event that are interfering with home, work and relationships
- are thinking of harming themselves or someone else.

Some of the signs that a problem may be developing are:

- being constantly on edge or irritable
- having difficulty performing tasks at home or at work

- being unable to respond emotionally to others
- being unusually busy to avoid issues
- using alcohol, drugs or gambling to cope
- having severe sleeping difficulties.

Support is important for recovery

Many people experience some of the symptoms of PTSD in the first couple of weeks after a traumatic event, but most recover on their own or with the help of family and friends. For this reason, formal treatment for PTSD does not usually start for at least two weeks or longer following a traumatic experience.

It is important during those first few days and weeks after a traumatic event to get whatever help is needed. This may include information and access to people and resources that can help you to recover. Support from family and friends may be all that is needed. Otherwise, a doctor is the best place to start, to get further help.

Where to get help

- Your doctor
- Mental health specialist with experience in treatment of PTSD
- Australian Centre for Post-traumatic Mental Health Tel. (03) 9035 5599

Remember that the AYF support program provides referrals and funding for counselling for all survivors and families.

Article source: Better Health Online, Victoria

MENINGOCOCCAL VACCINE

The vaccine for C-strain introduced in 2003 has been very effective, and the incidence of C-disease is now very uncommon.

There is a licensed vaccine against the B-strain available since March 2014 – which is responsible for the majority of cases in Australia.

The 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 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 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.



Support Program Achievements



I recently had the opportunity to check out one of our program members in action on the rugby court. Nick (pictured above with his new chair) experienced meningococcal disease in 2002, and 13 years on has become a successful wheelchair rugby player, as well as nearly completing a degree in Film and Cinematography. He fits all this in between dialysis treatment, as his kidneys were affected by the disease.



The program was happy to help Nick with his new rugby wheelchair to further his rugby

career, and allow him to participate with his team, the West Coast Enforcers. To find out more about the Enforcers, go to <http://wheelchairsportswa.org.au/teams/enforcers/>



The AYF support program aims to assist with any support and advocacy needs for those affected by meningococcal disease in WA, and help them achieve their goals. Other ways the program has helped members over the last twelve months include:

- Regular newsletters;
- Social support get togethers (Seminar Day lunch and Kings Park meet);
- Mobile, email, Facebook contact;
- Peer support referrals introducing survivors to one another;
- Provision of equipment (including air conditioner and iPad);
- Funding for ongoing Tutoring
- Medical expenses from meningococcal

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

Due to requests for an event down South the venue for the next get together will be in Warnbro.

DATE: Saturday 22nd August

TIME: 2pm

VENUE: Last Drop Tavern - 7 Hokin St Warnbro



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 Dumbleton
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

Amanda's Centurions

We are inviting you to be part of an enthusiastic, innovative group whose purpose is to raise at least \$1000 each for the Amanda Young Foundation to enable the Foundation to continue with its work.

Our aim is to attract at least 100 members who will become ambassadors for our Foundation, and assist us in raising awareness about meningococcal disease, through their fundraising ventures.

We will support you with

An Amanda's Centurions eKit (with fundraising ideas) ⇒

Ongoing support ⇒

All Amanda's Centurions members will be acknowledged on AYF's Facebook and website. To register your interest in being a Centurion please email your name, phone number and fundraising idea to info@amandayoungfoundation.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**

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

Post Traumatic Stress Disorder: http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Post_traumatic_stress_disorder

For more information about the events, see www.amandayoungfoundation.org.au or contact the Support Case Manager.