



Amanda Young Foundation

Support Program News Autumn 2017

CASE MANAGER UPDATE

Welcome to the next edition of our newsletter, and to our support program if you've recently come on board. Please remember our secret Facebook survivor group is the best place to get up to date information, email me if you'd like to be added.

As a survivor, I am keen to keep up to date with any new developments in after effect research but currently, the research and media focus is on vaccines. WA

has had the ACWY vaccine approved as part of the free schedule for teenagers, so I have some information direct from the Health department about this on Page 2.

We also feature the story of Eliza, who is currently affiliated with Meningococcal Australia.

Keep well during the winter months and please don't hesitate to get in touch.

Support group get-together

Saturday 5th
August 2017

1.30 pm
Last Drop Inn, 7
Hokin St, Warnbro



Come along and catch up with others affected by meningococcal disease, in a positive, friendly meet-up.

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Future Events

AYF Support Group Get Together

2pm Sat Aug 5th - Last
Drop Inn, Warnbro

Perth Kilt Run

mid September

Romancing the Stone Open Garden

56th, 7th & 8th Oct
3 Lillian Rd Maida Vale

Amanda's Garden

Sat 21st/Sun 22nd Oct
1520 Matison St
Southern River

Curtin Golf Day

24th November

AYF SUPPORT PROGRAM

Provides support to those affected by meningococcal disease and their families in WA

SERVICES

Referrals
Support
Counselling
Social Gatherings
Information
Equipment

CONTACT

Lisa - 0433 309 425

support@amandayoungfoundation.org.au

Secret Facebook Group
(request to join)

WA LEADING THE WAY WITH MENINGOCOCCAL VACCINE FOR 15-19 YEAR OLDS!

The **Meningococcal ACWY Statewide Vaccination Program** is a three year targeted program in response to a recent increase in meningococcal infection caused by a particular type of the bacteria, 'serogroup W'. The program will be offered to adolescents aged 15-19 years because they have some of the highest rates of meningococcal carriage and illness and can transmit the bacteria to people who are at increased risk of infection, including young children.

Although numbers are low, meningococcal W cases have been increasing annually since 2013 with one case notified in that year and 14 cases in 2016. Prior to 2013, serogroup W was uncommon with only six cases diagnosed in the 13 year period from 2000 to 2012. It is anticipated that this program will reduce the spread of this potentially life threatening infection within the community.

The vaccine protects against four groups of meningococcal bacteria: A, C, W and Y. The vaccine is safe and effective. Studies have shown that the effectiveness of the meningococcal ACWY vaccines is between 80 to 85 per cent in adolescents. Meningococcal ACWY vaccination programs have been implemented in adolescents aged 13-15 years in the UK since 2015, and adolescents aged 11-12 years in the US since 2005, and the vaccine has been found to be safe and effective.

In 2017, the program will entail school-based immunisations in Years 10, 11, and 12.

From July, additional vaccination clinics will be conducted at community health clinics and some university health centres to capture 18-19 year olds and other age-eligible persons not attending high school. From October, subject to vaccine availability, general practitioners (GPs) will also offer the vaccine to adolescents 18-19 years old. In 2018 and 2019 the program will target incoming Year 10 students only.

Parents can expect to receive meningococcal W vaccination consent materials through their child's school in Terms 2 and 3. They are urged to complete and return the form to their child's school promptly so their child can receive the vaccine.

Information

For more information about meningococcal disease, please visit the HealthyWA website, http://healthywa.wa.gov.au/Articles/J_M/Meningococcal-disease

For information about the Meningococcal ACWY Statewide Vaccination Program, information can be found on <http://healthywa.wa.gov.au/News/Free-meningococcal-vaccines-for-WA-teenagers> and http://healthywa.wa.gov.au/Articles/J_M/Meningococcal-vaccine

If you are an 18-19 year old, you are encouraged to request the vaccine from your GP from October 2017 when it will be available. You remain in a high risk age group. To see some stories from our WA survivors who have experienced meningococcal disease, please see our [Stories](#) page on the AYF Website. Anyone can request the vaccine, and for those not receiving the free vaccine, the cost is approximately \$40 for the dose.

AYF will be helping with the promotion efforts for the vaccine so watch this space!

AYF FUNDRAISING EFFORTS

AYF relies heavily on the efforts of fundraising, including some annual events such as the Open Garden, Romancing the Stone events, and the Kilt Run. We also have a couple of initiatives currently which you can help out with!

Order your 2017 | 2018 Entertainment Book or Digital Membership now.



You'll receive hundreds of valuable offers for everything you love to do, and help our fundraising at the same time. Hurry! Bonus Early Bird offers are going fast!

**[Click to Order Entertainment Book](#)
or call Linda at AYF on 9277 4237**

Petals Florist Network

Part proceeds for all flower gift orders from Petals will go to the Amanda Young Foundation.

Please **[click here](#)** to place your order.

We are keen to hear from any survivors or family members willing to undertake fundraising for the foundation, to continue our awareness and support programs

South Australia has just launched a free meningococcal B vaccine to Years 10, 11 and 12. The B vaccine is not available in WA on the schedule.

It is recommended Year 8 students have a booster vaccine to top up their vaccines earlier in life, including tetanus, diphtheria and pertussis. South Australia recently obtained information on vaccination rates under Freedom of Information, and identified 19,242 students did not attend or chose to opt out of having these vaccinations.

This is concerning and SA are urging more parents to ensure their children have their vaccinations in Year 8.

In WA, Year 8 students currently receive human papillomavirus, diphtheria-pertussis-tetanus, and varicella (chickenpox).

Have your teenagers had their top-up vaccinations?

SUPPORT PROGRAM LIBRARY

Brochures, DVD's and information on meningococcal disease

Books:

- 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

RECOVERY

If you are or care for a meningococcal meningitis or septicaemia 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 support needs you would like to discuss. The service is confidential and free.

support@amandayoungfoundation.org.au

ELIZA'S STORY

It's been nearly 20 years since Meningococcal first entered my life. Back then in 1997, Meningococcal disease was a disease that my family had never heard of, but one that changed the paths of our lives forever.

As a fit, health 16 year old, waking up one September Tuesday morning with a headache, nausea, vomiting and fever - I thought I had food poisoning or possibly the flu. Throughout the day, my symptoms progressively worsened. I decided to pop a couple of paracetamol and try to sleep it off. As fate would have it, a phone call would wake me and my mother would discover a rash covering my body and the tips of my toes turning black. This phone call saved my life.

I was rushed to my local hospital where I was immediately diagnosed with Meningococcal Septicaemia. My diagnosis came rapidly as just one week beforehand, another local teenager had presented with the same early symptoms and was diagnosed by lumbar puncture.

We all had no idea just how serious my condition would become. The Careflight helicopter was called to transport me to a larger hospital. I was placed in an induced coma and awoke 2 weeks later to the news that both of my legs had been amputated on the 2nd day of my coma. I was shocked to hear this but so grateful to be alive. My fingers were amputated a week later and the process of removing the dead skin and skin grafting started. The necrotic tissue covered around 50% of my remaining body. It involved 50+ trips to theatre for dressing changes and skin grafting. Six months was spent in hospital battling golden staph on top of all the associated issues with Meningococcal disease such as daily dialysis and chronic lung issues.

I had an unorthodox rehabilitation - all I wanted was to be at home so I was able to return home with the assistance of an amazing physiotherapist and be treated as an outpatient. I had much work to do as the disease had ravaged my body and I weighed a tiny 29 kg. Watching a double leg amputee run on amazing carbon legs gave me the inspiration walk again and to one day run again. After much hard work I received my 'sprint' prosthetics and I knew I wanted to take it to the highest level I could. The Sydney Paralympics were just around the corner. After competing in a number of competitions and beating even single leg amputee's I unfortunately suffered another setback when injury forced me to abandon my dreams of running. However the discovery of wheelchair racing fulfilled my ambition of representing my country and travelling the world and racing soon became my life. I represented Australia in 2002 at the World Championships and then onto the Commonwealth Games, taking home a silver and a bronze medal respectively. I raced in Olympic and Paralympics as well as numerous other events. In 2007 I gave the sport away as my husband and I became pregnant with our first child. We have since had 3 beautiful children - Eva 8, Elka 6 and Jensen 5.

Meningococcal disease awareness has changed so much in the last 20 years. We have seen the development and inclusions of vaccines which has seen a decline in some strains while we have seen a rise in other strains. We still have a way to go as lives and limbs are still being lost. This is why I am passionate about working with advocacy groups such as Meningococcal Australia (which I am the director of) and the amazing Amanda Young Foundation.

In a side note... I have returned to wheelchair racing and looking to compete on the international stage once again. I am also a personal trainer - so balancing 2 jobs, 3 kids and racing can be a challenge however beating Meningococcal disease taught me that I could do anything I set my mind to!

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.

Sources - SA vaccine rate (pg 1)- <http://www.adelaidenow.com.au/news/south-australia/2000-sa-high-school-students-did-not-have-a-booster-for-tetanus-diphtheria-and-pertussis/news-story/6d74710ae6610a2428865e213fd5cb2b> - WA ACWY Vaccine (pg 2) - WA Health Department Communicable Diseases Directorate

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