



## Amanda Young Foundation

# Support Program News Spring 2013

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

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

**Secret Facebook Group - contact Lisa to join**

### CASE MANAGER UPDATE

Welcome to the third edition of the Support Program Newsletter. We have made it through another winter, and I've spoken with or made contact with many of you recently, as well as having a lovely afternoon tea at our recent Support Group get-together. Please remember to let me know of any days and times that would suit you for future get togethers.

As some of you are aware, I'm expecting my second child at Xmas. I fully intend to continue to provide support to all survivors, so please continue to stay in touch.

There are many survivors around Australia now that have successfully conceived and had children after their illness. While it did take some years for me to conceive both times, the biggest challenge has been my mobility in late pregnancy and immediately after birth. I have been more pro-active this time around, and consulted a physiotherapist early to strengthen my back. I also invested in a pick-up stick recently – my new best friend! As I can no longer reach the floor!

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

Warm wishes, Lisa



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### UPCOMING EVENTS

5 <sup>th</sup> /6 <sup>th</sup> Oct 2013	<b>Romancing the Stone Open Garden</b>
21 <sup>st</sup> Oct 2013	<b>Rotary Ramble</b> Volunteers Needed!
26/27 <sup>th</sup> Oct 2013	<b>Amanda's Garden Fete - Support Group meet Sat 27<sup>th</sup> 1-3pm</b>
Fri 14 <sup>th</sup> Feb 2014	<b>Support Group Get-Together</b> Details to be advised
Sat May 17 <sup>th</sup> 2014	<b>Support Group Get-Together</b> Details to be advised

## VOLUNTEERING OPPORTUNITY – ROTARY RAMBLE



Support program participants have been extended an invitation to help out at the upcoming Rotary Ramble on Sunday 21<sup>st</sup> October, which AYF is conducting with Rotary. Rotary Ramble is a treasure hunt with check-points around the city. You will have a training session on the day, be fed and watered, and given a T-Shirt and AYF Water Bottle. No special abilities required other than a smile. Check-points will be manned in pairs. If you'd like to volunteer, contact AYF's coordinator, Robyn Bowler at [rjbowl162@bigpond.net.au](mailto:rjbowl162@bigpond.net.au)

## Meningococcal B Vaccine Update

The Australian Therapeutic Goods Administration or TGA has added Bexsero, a multi-component Meningococcal B or MenB vaccine suspension for injection 0.5 ml pre-filled syringe, to the Australian Register of Therapeutic Goods for use in individuals from two months of age and older. Bexsero is the first and only broad coverage vaccine to help protect all age groups against MenB disease, including infants who are at the greatest risk of infection. MenB is a potentially deadly disease which is easily misdiagnosed and can kill within 24 hours of onset. As a next step, Novartis would work with Australian regulatory authorities to make doses of Bexsero available in the private market in the coming months.

In parallel, the Pharmaceutical Benefits Advisory Committee, taking into account advice from the Australian Technical Advisory Group on Immunisation, is expected to make recommendations on reimbursement and potential inclusion of Bexsero in the National Immunisation Program. Bexsero is not anticipated to provide protection against all circulating meningococcal group B strains.

**This is great news for the community, but also to our group of survivors and families who know first-hand the devastating effects of this disease.**

### RESOURCES

#### Home and Community Care program (HACC)

Local support services for people who require assistance with their daily lives can be accessed via HACC. They will assess eligibility, and can offer domestic and personal assistance. You can access this program, along with a range of information at **Community Carelink 1800 200 422**

#### Meningitis Resources

Apart from the one-to-one support provided by the Amanda Young Foundation locally, the Meningitis Research Foundation in the UK has released a couple of very useful resources – Your Guide and My Journal – specifically for survivors. <http://www.meningitis.org/recovery>

## SURVEY RESULTS

An online survey was conducted last newsletter to see how the AYF Support Program is going. We had some wonderful feedback, and great suggestions. As you know, we offer one-on-one support, social get togethers, and financial assistance.

The feedback from the survey indicated that most preferred quarterly get-togethers, and of those that did want personal contact, quarterly was ideal.

We were also asked for more survivor stories, so we will continue to add more to our website.

## LIBRARY

*The Support Program library relates to meningococcal and meningitis, and recovering from a traumatic illness. Feel free to contact Lisa to have a book posted to you, or to suggest a title.*

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)

### **Lisa’s Recommendation:**

Recently I read a book called **“Stronger Now”** by Victorian Nicole McLean. Nicole was in Paddy’s bar in October 2002, when the Bali Bombings took place, and lost her arm as well as suffering horrific burn scars. I identified immensely with Nicole’s recovery, so similar to my own after meningococcal. I have added it to our support library – let me know if you’d like to read it and I’m happy to post it out!

## Abby’s Story

On Australia Day 1998, I returned to my teaching job in a small country town in the South West of WA. I was 21, fit, healthy and at an age where you almost feel invincible. I was filled with enthusiasm about setting up my pre-primary and preparing for the year to come.

That week I noticed nothing out of the ordinary and was very busy. On the first day back at school, I woke up feeling like I had the worst flu ever. I was shivering and despite it being the middle of summer, I went to work in multiple layers of clothing. When I arrived in the staff room, people showed concern about my health but I shrugged them off. A couple of hours later the Principal insisted that I head home via the Nursing Post in town. The nurse who assisted me agreed it was probably a cold or flu and sent me home to rest. I went home, took some Panadol and went to bed. The remainder of the day was horrific! Diarrhoea and vomiting interspersed with frightening nightmares and nausea. I had to close the curtains and turn off the lights, any form of lighting made the nausea twice as bad. Although the day was a blur and I couldn’t remember ever feeling so bad I felt a bit silly calling my family a 4-hour drive away about the flu. Thankfully, at the end of the work day, the School Principal decided to check how I was going – that visit saved my life!

She drove me to the nearest hospital in the neighbouring town. After an observation and increasing stomach cramps, I was incorrectly diagnosed with appendicitis and sent to the nearest hospital via ambulance. Once I arrived at the hospital, I was very stiff

and a rash was developing over my torso. The nurses on duty suspected that I did not have appendicitis and when the doctor arrived, he agreed that the best course of action would be immediate antibiotics. Thankfully, my appendix remained in place! I spent the following few days under close observation in a private room in the hospital, my mum driving from Perth the following day to be with me. I continued to feel unwell during this time, having no control over my bladder and experiencing excruciating pain in my head when trying to lift it off the pillow. The results came in from my lumbar puncture a few days



later and I was diagnosed with meningococcal septicaemia.

The actions of a few people in a short period of time saved my life. The Health Department cordoned off the town the following week and administered antibiotics to anyone who had been in contact with me. I am sure that this caused quite a stir in a small country town but I was unaware of all of this as I convalesced with my family in Perth for three months. This story has been difficult to write even 15 years on. Although I am thankful to have made a full recovery with only an aversion to bright lights and some memory loss, I have never recovered from the ‘Survivor Guilt’. Good people have passed away and others suffer lasting and painful side effects from meningococcal septicaemia and I wonder why I was so lucky? I am eternally grateful to the people who made the decisions that saved my life that day and my family who supported me through the recovery. I now view every day as a blessing and am appreciative for the people that make my life so special!

## 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.

Although nobody can definitely confirm this to be the case, 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 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

### FREQUENTLY ASKED QUESTIONS.....WITH DR. ROBERT BOOY

My child's hearing has been affected – will that change over time?

Some people's degree of deafness noted during hospital admission (or shortly after) does improve over the ensuing months - up to a quarter of cases with early hearing problems can see improvement.

**Lisa's Comment :** I encourage those recovering from meningococcal meningitis them to take advantage of our free referral to Ear Science for a hearing test. If you would like one of these, please get in touch.

Do you have a question? Email it to [support@amandayoungfoundation.org.au](mailto:support@amandayoungfoundation.org.au) – confidentiality maintained.



### Jasmine Jones Jewellery

**Jasmine Jones, who has recovered from meningococcal disease, produces some amazing jewellery and kindly donated some pearl earrings to the AYF Ball this year. Find her on Facebook!**



**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:** [http://vaccinenewsdaily.com/vaccine\\_development/326759-novartis-announces-australian-approval-of-meningococcal-b-vaccine/](http://vaccinenewsdaily.com/vaccine_development/326759-novartis-announces-australian-approval-of-meningococcal-b-vaccine/)

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