



## Amanda Young Foundation

# Support Program News Autumn 2014

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

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



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

### CASE MANAGER UPDATE

Welcome to the fourth edition of the Support Program Newsletter.

We conducted our last get-together with a guest speaker on the topic of nutrition and good health. I've included an article about this below.

Since the last newsletter we have also had another highly successful AYF Garden Fete, which survivors were also invited to.

I've had a couple of new referrals in the last two months, and also undertaken some promotion of our program in the local newspapers, featuring our very own Tay. While the health department send out letters to new cases of meningococcal, sadly we have very few new referrals, and rely greatly on word of mouth. So if you know anyone who is recovering, please forward on our newsletter and encourage them to make contact.

I did have my baby – Llewellyn was born on December 22<sup>nd</sup> and weighed a healthy 9.25 pounds. He is now too heavy for me to carry!

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

Warm wishes, Lisa



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### UPCOMING EVENTS

**17<sup>th</sup> May 2014**      **AYF Ball: Havana Nights**

**1<sup>st</sup> August 2014**      **Support Group Get-Together- Meningococcal Seminar Day – Lunch at Burswood**

## Nutrition and good health

The March get-together featured a nutritionist, Helen Frost, recommended by one of our members.

Our cells are replaced continuously in our bodies, and our blood cells are replaced every 4 months. So any dietary change takes 4 months to see an effect. Three signs of toxicity in your body are:

1. Reduced energy
2. Pooing less than once a day
3. Weight gain

For health success, eat live, nutrient dense food, exercise, regular maintenance (such as massage) and positive thoughts.

It's useful to think of all the items in your fridge, in the pantry and on the supermarket shelves as body parts. Our bodies consist of water, air and food. Live, organic, fresh, raw food is the best for your body. How close to the tree, ground or paddock is this food?

To ensure you are eating the best food, there were some tips:

- The longer the use-by date, the less alive the food is
- Avoid additives. Around 50 additives in our processed foods are banned in other countries.
- If you eat bread, choose wholemeal bread with grains, not white bread
- Juicing is a good way to increase fruit and vege – and recommended is 80% vegetable and 20% fruit. Just one apple has 400 nutrients

The 12 worst “dead” foods:

1. Donuts
2. Hot Dogs
3. Processed meats and bacon
4. French fries
5. Chips, crackers and cookies
6. White bread and pastries
7. Candy bars/ice cream
8. Alcohol
9. Soft drink
10. Frozen meals
11. Fats and oils
12. Most cereals

In order to achieve good health, the recommendations include:

- Taking deep, not shallow, breaths
- Drink 8 glasses of water a day
- 5-9 cups of fruit and vegetables a day
- Lean proteins, whole carbs and good oils
- Right breakfast with enough protein
- Cut sugars, fats, salt, additives, takeaway, junk food, alcohol, drugs
- Exercise
- Fresh air
- Good thoughts

The session provided us all with some inspiration to improve our diet!

### DUNNS HERBAL CLINIC

We are fortunate to have a herbal clinic in our midst. The family of Tay (a meningococcal survivor) run **Dunn's Herbal Farm and Clinic** located in Wanneroo.



They run clinics, tours, seminars and beauty therapies. The clinic involves iridology, diet and nutrition program, tongue and pulse analysis and blood analysis.

Kathy Dunn has kindly offered some support to the AYF Support program by way of a seminar topic. If any survivors are interested in this, please contact Lisa to put forth your interest.



[www.dunnsheerbfarm.com.au/](http://www.dunnsheerbfarm.com.au/)

## FREQUENTLY ASKED QUESTIONS

**Q: I have headaches – how long can they last?**

**A:** According to research cited by the International Headache Society, a reported 32% of survivors of bacterial meningitis suffer from persistent headache (Bohr, et al, 1983). There does not seem to be any indicator for how long these headaches last, but if it does last more than three months, it should be investigated with your GP.

## MENINGOCOCCAL VACCINE UPDATE

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 5th 2014 – which is responsible for the majority of cases in Australia.

### **Type B Vaccine (NEW):**

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 for A C W and Y.

## Tammy's Story



On Sunday the 10th November 2013 I watched my partner play baseball at 9.30am then went swimming for 45 minutes at a public pool. I had a headache off and on during the past week. Thought it was only stress related and my neck felt a little strange on the Sunday. I enjoyed my swim and I cleaned my house as I was selling it and had people coming over to view it.

I went to my partner's house for left over BBQ meat, salad and lamb shanks dinner. At around 9pm I went back to my home as I had a friend staying and my son was packing to leave to go up north for work on Tuesday. We were up until midnight talking then went to bed.

About 4am on Monday 11th November I woke up feeling like I needed to vomit. I started vomiting at around 4.15am and it was at about 6.30am diarrhea started and I lost control of my bladder. I felt very unwell and thought it was food poisoning. I was vomiting for around 4 hours. My friend gave me paracetamol and water and she left around 7.30am.

Around 1.30pm on Monday I asked my son for lemonade. He went out and brought back some hydrating drinks and cold ice as he said I was very hot. I did not eat anything because I just threw it back up.

As the day went on I must of fallen asleep as I can't remember some of the things I have been told, like being hot

and experiencing light sensitivity and not really too with it when my kids spoke to me. I do however remember showering a lot.

At around 4.30pm my oldest son called my partner to come over as he could see I was very sick. My partner arrived about 5.15pm. He decided to take me straight to Armadale Hospital as he thought I needed something to stop me from vomiting. I remember having another shower and getting dressed – not sure why I did that. I walked down my stairs and into the kitchen and then went into the garage to get into my car. I remember my partner reversing out of the garage and telling him to turn left. I don't recall anything after this moment.

My partner helped me into the emergency area of the hospital. Just before I got to the door I collapsed and he had to carry me. He said that's when he knew I was dying. Once in emergency some people helped him and they called a doctor.

I was in intensive care for 4 days, and then in hospital for another 7 days learning how to walk again and try to control the pain in my legs, feet and head. The headaches are like migraines and I still get them if I have done too much. I had the rash on my ankles and feet, which is now healed leaving scars. My feet and ankles are stiff when I have been sitting for too long.

I personally wish to thank Dr Kieran Lennon and his team in ICU at Armadale Hospital. Without you all I would not be alive today!

My wish is that this information may someday save another life.



## 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 GROUP GET TOGETHERS

The last support group get-together was on March 8<sup>th</sup> 2013. We had a small group attend. While attendance at these events has been low, they will continue on a six-monthly basis. It is greatly appreciated if you RSVP your attendance so we know whether to go ahead with the event.

#### Lunch at Crown!

The next get together is planned for August. Come along to Crown Perth for a lovely lunch as part of the Meningococcal Seminar Day. You can attend just the lunch, or for the whole seminar day. At the lunch you will meet other people affected by meningococcal disease.

**DATE: Friday August 1<sup>st</sup>**

**TIME: Lunch only OR attend the day**

**VENUE: Crown Perth**

A reminder will be sent close to the date.

### 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



**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. **Nutrition and Good Health –** Helen Frost, Nutritionist. **Headaches:** <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3139051/>

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