Amanda Young Foundation

Support Program News Spring 2014

Special Q & A Edition

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

Secret Facebook Group - contact Lisa to join

CASE MANAGER UPDATE

Welcome to the fifth edition of the Support Program Newsletter.

At the biennial Meningoccoccal Conference in August, we were fortunate to have medical practitioners experienced in the field of meningococcal discuss the latest research. Much discussion was around the vaccines, for which we now have the Men B vaccine.

As you may be aware, the Cost Effectiveness Committee rejected the application to have the vaccine placed on the Immunisation Schedule. This was the second time it was considered, and the onus is now on the community to have themselves and their children immunized, for a cost.

After the conference we hosted a lunch for the Support Program, and Dr Steve Webb and Dr. Charlene Kahler kindly volunteered their time to conduct a Question and Answer session. The transcript of this session makes up most of this newsletter.

Due to the low numbers attending the last three get togethers, there won't be a get together in the second half of this year, but stay tuned for one in early 2015.!

Warm wishes, Lisa

IN THIS ISSUE

Mel and Karen at the Support Program Lunch

UPCOMING EVENTS

25/26 October 2014	**Amanda's Garden Fete**

Meningoccocal Support Group Q & A Session

Transmission and vaccination

Is there a test to see if someone is a carrier of meningococcal septicaemia? If so, do we have treatment to stop someone being a carrier?

1 in 10 on average will be able to culture, the Niesseria meningiditis, the bacteria causing meningococcal disease. Not all meningoccoci are the same, some are capable of causing disease and some are not. Not all meningococci have the antigens that cause disease, and also not all people are susceptible to the disease. This explains why it is a rare disease – it requires the right strain of meningococcus to land in the throat of the person with the right susceptibility. There are other factors – it is known that smokers are more susceptible, recent upper respiratory tract infection. 9/10 of us do not carry the meningococcus but one may latch onto us for a period of time, and then disappear, and then a different strain may latch on. The positive aspect of having carried the meningococcus is that if you did come into contact with a strain, then you are naturally immune and you will not become sick with that strain even again. [We heard in the conference that the predominate strains are Type B, C, W, X and Y]. The chance of you coming into contact with a strain that you are not immune to reduces as you are exposed to different strains. It's only when your natural immunity has not been acquired that you will become unwell.

There is a test for carriers - we did used to test for carriers when they were close to someone who became unwell to determine who we needed to treat. But the test is uncomfortable and it isn't easy to find the bacteria amongst all the other organisms on the back of the throat, or easy to culture them. And if you are clear at any one point in time it doesn't mean you will be clear next week, or month, or year, so testing for carriers doesn't serve any purpose. So now, if there is an index case, we now treat everyone who has been in close contact with that case with antibiotics, which will clear that strain with reasonable success, but does not mean next week they won't have it again.

Is the disease socio-economically driven towards the lower end?

The disease does not discriminate, it can affect anyone. It is more common in people who live closer together, and this affects the frequency with which new strains can occur. Back in the 1940's, 50's and 60's there were outbreaks in young males living in army barracks, due to large numbers of them living in close confines. People on lower incomes tend to live in more crowded conditions, so it is a consequence of crowding. There was a recent outbreak at the residential colleges of Princeton. This triggered the impetus for the vaccine. There was an outbreak in Auckland amongst Maori families had many people living in the one house.

Comment: Once the vaccine in NZ cleared the outbreak, they stopped vaccinating! Why was that?

That sounds irrational, and it may be, but it also may not. Diseases have waves of epidemic and if you can break the back of the epidemic, you may have the situation where you do not need to keep vaccinating to keep it at bay. The NZ case was a very virulent strain that the vaccine was designed for, and the vaccine created sufficient 'herd' immunity (enough individuals) to break the chain of transmission, then you do not need to keep vaccinating. Other examples are the childhood diseases such as measles and diphtheria have disappeared as a consequence of the herd having immunity from vaccination. Although it is important to keep vaccinating, it would probably be some decades before we saw a rise in cases, as currently there is not a mass of susceptible people in the community.

We have eradicated diseases in the past since the advent of vaccines, and we are on the cusp of eradicating meningococcal disease. The issue is that it does require constant surveillance. Africa has an outstanding positive outcome from mass vaccination with a complete reduction in meningococcal group A disease in the last decade, but what has popped up in strains X and W. That has taken 20 years for these outbreaks to occur. We are aware of this potentiality scientifically, so conjugate vaccines that prevent multiple strains are the path forward – which in the past with early formulations of the vaccine could not be created. In the mid 90's there was no vaccine for A or C. We now have a vaccine for B, and vaccine technology is improving all the time.

Comment: There are fears of resurgence in diseases due to the decline in vaccination rates in children.

For example a pertussis outbreak and some measles cases this year. If there are cases, it is a major public health issue where people are tracked down and mass vaccination response occurs. Measles is a benign disease for the large majority. But it can be a very harmful disease to a small group.

If a family were given antibiotics at the time another family members was diagnosed, will they still need the vaccination?

Yes. The antibiotics just clear the colonising bacteria present in that individual, but does not stop you becoming recolonised in the future. The vaccine makes that individual immune to the bacteria.

Support Group Q & A Session continued

When will the medical fraternity receive information about the vaccination?

Doctors, in all of medicine, have some many diseases they need to know about. They are bombarded with information, especially GP's – keeping abreast of all areas is a huge challenge. They get their information from a range of sources, including the Health Department. Sadly, it takes time for the information to percolate. The Australian Medical Association does have interest in public health, but they have to choose the diseases that are more related to indigenous health and tobacco smoking - in terms of disability and life years lost, the most disadvantaged members of community are Aboriginal people so these areas have the greatest impact. Prevention is very cost effective. It is difficult as they only have a certain amount to spend. If they spend it on one thing, they cannot spend it on something else. They have competing priorities and have to try and think about the best benefit.

After Effects Questions

What permanent medical conditions are patients left with?A significant proportion do make a good recovery. Particularly if the disease is caught early, and antibiotics are given early. As people get sicker, a number of complications can occur. In some children, there are subtle, but detectable impacts on learning and concentration. The dreadful leg and arm ischemia that occurs can cause the tissue to be not viable, resulting in loss of fingers, toes, limbs and scarring. There is a range of long term consequences, but also psychological sequalae due to the experience people go through to survive.

How common is growth plate arrest in meningococcal septicaemia in survivors?

I am not aware of the answer to this. In children, there is a zone at the end of the bones which pushes out new bone. If this is damaged, then the one will not grow. I don't know if it is well described in young children. Surgeons will cut the bone in the middle, extend it by an inch, secure with plates, and then encourage the bone to grow.

Do we know whether meningococcal & its treatment affects future fertility?

There are many examples of survivors who have conceived children. Dr Booy did suggest males may potentially be affected by the high fever but there are no cases. Although some survivors have had children, does not mean that across the averages there is a reduction in fertility – it has not been studied. Again, the question of treatments in intensive care affecting fertility has not been explored.

How might a pregnant mothers baby might be affected if she contracted meningococcal. Do we know of any cases where this has happened?

There is a case in WA where a lady was pregnant when she caught meningococcal and went on to have the baby. A few years ago, an outbreak of swine flu had a predilection of for pregnant women, particularly the late stages. We have many women across Australia, with severe breathing difficulties. A number passed away, and a number of the babies passed away. It is possible for a pregnant woman to catch meningococcal.

Long term, how might a survivors general health be affected i.e. is one more susceptible to the flu.
As far as I'm aware, there is not a heightened susceptibility to influenza. There is study in children survivors for immunity, but not in adults. However, anecdotally survivors report increased susceptibility to illness, and as the immune system has had a major assault, it would not be surprising. We are all continuously coming into contact with infections and fighting them off. Blood tests showed that a third of people had come into contact with the influenza pandemia in 2009, but only 1 in 3 could remember having a cold. After meningococcal, the threshold for becoming unwell with the colds and viruses may be lower. The infections may not occur more frequently but the symptoms may be more marked.

What's your opinion on wearing a mask?
In Asia, if you are sick, it is socially acceptable to wear a mask. If we all wore masks, we would reduce the upper respiratory tract infections, but our society does not recognise this as acceptable – it is nice to see people's faces!

What is it about connecting survivors with each other that helps their recovery?
Only survivors can answer that – but having people who have been through the same experience would rationalise what has happened and share experiences. It's a special club – one in every 100,00!

Support Group Q & A Session continued

Are you aware of any workers comp cases lodged or challenged in Australia?

No, I am not. As the strains can be picked up in daily life, the likelihood of proving it to be work related would be remote. Health care workers and lab workers may be an exception. If you daily business is growing meningococci and plating them out, then this is possible. We have regular cases where lab workers become infected. If staff think they may have exposed themselves, they can go and get a shot of antibiotics – so it's very controlled. All staff have a training process explaining what to do. I know of a case who had his strain tested and it turned out to be not the one he was dealing with in the lab, but one he'd picked up on rounds at the hospital. Staff do have to wear personal protective items to prevent contagion. The research lab has protective airflow plus masks, gloves, gown and disinfectives close if anything is spilt.

How long does meningocci live outside the body?

Originally, it was thought that meningococci would not live very long on fomites (inanimate objects). But recently there is some suggestion that saliva may keep it alive for longer. It does all depend on your bacterial 'titre' – if you had 1 it may die, but if you had 1,000 then maybe it might survive. In real time, its hard to know how important this is, as crowding is such a risk factor. Massive outbreaks have occurred in wars, and as soon as they moved the bed apart six feet, it stopped the outbreak.

Is there a possibility it could transfer from saliva on glasses in pubs?

Until someone does the study – to try and prove this is difficult. 10% of people carry it anyway, so the risk may be very small from a pub situation.

How can we reduce the cost of the vaccine?

Companies making the vaccine would have spent several hundred million dollars on the vaccine. So they need to recoup their costs, and then make a profit for their shareholders. Also governments talk to each other and know the price. Also, the cost of manufacturing – it is more complex than the other vaccines to date. They have to grow thousands of litres of Niesseria, extract the genes and wash them – then express all the other proteins, grow them up, purify those proteins, and then batch match the purification process so everything is standardised, so they can match proportions to achieve the final formulation. It's a highly regulated process, and because they have four antigens on the B strain, it is highly sensitive. They need to predict how many doses will be bought as its costly to make. It's easier to make a large volume than continually make small volumes.

Where would I get the vial from?

You need a GP script, and the chemist will order the vaccine from the warehouse. It must be kept in the fridge and lasts for 12 months.

Thankyou to Drs Webb and Dr Kahler for their time and expertise in answering our questions at the 2014 AYF Meningococcal Seminar.

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, but not on the Immunisation Schedule.

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.