



"I didn't think it would happen to me"

Caitlin's story...

I am a student at Penrhos College and of my two years there, I have heard many stories about Amanda Young.

Amanda was a student of Penrhos who was sadly killed by meningococcal. At school we have had many lectures about meningococcal and even more fundraising events to raise money for the Amanda Young Foundation that was set up not long after Amanda's death by her parents Lorraine and Barry. Early in the year I distinctly remember one talk given to us by Lorraine and Barry. I was greatly moved by the presentation and listened intently to symptoms of the fatal disease. Little did I know that I would soon experience those exact symptoms.

My name is Caitlin and I am 14 years old. I am going to share with you my story of surviving meningococcal disease.

During the second week of my July school holidays, I woke one morning normally, feeling fine. It wasn't until I stood up and started to walk that I felt like I had been punched in the head because I was overcome by a tremendous headache. As my day progressed, so did my headache. It became so bad that I could hardly move my head. My parents needed to go out, and neither wanting to leave me home or drag me to appointments with them, I was taken to my grandparents house for the afternoon. It was there that I had my second Panadol as the first one had no effect. During the car trip to my grandparents I had a doona over my head as the sunlight felt like it was going straight through me.

At 5pm my parents came to pick me up, finding me in a worse state than I was before. The second Panadol had done nothing and by the time I got home again I could hardly lift my head. I was dizzy and disorientated and hoped that a shower would help, but it made no difference. By this stage I was as pale as a ghost and could hardly walk a few steps before my headache would overcome me again. My mother, being the wise woman she is, decided to take me to an After Hours Doctors Clinic where hopefully I could get something to make me feel better. I managed to walk to the clinic, in my pyjamas and waited for the doctor. We waited for twenty minutes and I was freezing, wearing slippers, my pyjamas and two thick winter jackets. Even with those I couldn't stop

shaking, while the whole time holding mum's hand tight. At one stage I looked at her skin against mine and realised that my skin was usually darker than hers. As we waited I slipped one of my slippers off and noticed my toes going a light purple colour, with purple splotches progressing up my legs.

Finally the doctor could see us. She asked me many questions and examined my freezing body. She found some purple pinpricks on my stomach and was worried at the state of my toes. Then came the dreaded news. She told us that she thought I had meningococcal and continued to tell us that even if I didn't, it was best to treat the worst case scenario first and then work backwards. As soon as she said meningococcal my heart sank and when she looked away I turned to my mum and I could feel tears welling up in my eyes. All I could think of was that I only knew about people who had died from meningococcal and had hardly ever heard of anyone surviving. By now I felt really dreadful. I was freezing, dizzy, had a massive headache and most of all, scared.

At around 7pm I got my first shot of antibiotics in my bottom muscle (that still hurt three days later!) and I know now, that first dose of antibiotics is potentially what saved my life. I lay on the bed in the doctor's surgery, snuggling into my father's chest as I held my hand out while the doctors put a drip in my arm. I was very cold but thankful that I had mum and dad there with me. As doctors don't usually put drips in people they didn't have all the right equipment, so it ended up that my dad was left holding up the bag of fluids for the drip. I didn't have to wait long before the ambulance arrived, the two men were fabulous and their warm smiles took my mind off things and made me feel a little bit better.

Although my mum and dad were trying to tell me that everything would be all right, the panic in their voices made me worried. The trip in the ambulance was ok, although they didn't put the siren on. As they pulled my wheelie bed out of the ambulance I heard two familiar voices that made me feel a lot better. My sister and one of my brothers had made it to the hospital before the ambulance and knowing that they were there made me calmer.

Inside the hospital was a bed waiting for me and after being weighed, I lay down. Still freezing I hadn't let go of the jackets and now had two hospital

blankets on me as well. I could hardly feel my feet because they were so cold. Being at Princess Margaret Hospital meant that I was with all the babies in emergency and I distinctly remember their wails and how they went piercing through my head. I had one jacket over my eyes in an attempt to filter out some of the light. So many doctors and nurses came and checked on me that night, and I don't think I could name one of them. I was so dehydrated and all I wanted was more water but the effort of sipping was too much. In Emergency I was given another dose of antibiotics, this time through the drip and a blood test, plus so many other things that I don't even remember.

I recall back at the doctors surgery, while swinging my legs back and forward under the chair I could see the rash on my legs darken and spread, I tucked my legs away behind the chair childishly hoping that it would go away, not wanting to believe what was happening. I spent around six hours in emergency and for me they passed reasonably quickly, but I know for my family they would have been gruelling. I was so disorientated, confused and dizzy. I remember at one point my dad holding my hand and telling me to breathe in and out slowly. I now know that my heart rate was through the roof and I was gasping for air. Even though I wasn't, I felt as though I was paralysed, the effort of rolling onto my side too great. People often ask me if I was scared and I tell them I was absolutely petrified! All these people were buzzing around me, prodding and jabbing me and all I could do was lay there. The whole time my headache didn't leave and photophobia persisted.

At around 11pm I was wheeled into another room where I was given a spinal tap. By this stage the antibiotics had started to kick in and I was starting to feel myself again. I hadn't eaten all day and then my mum gave me a lollipop. Its instant sugar boost woke me up, but because my mouth was so dry, it was hard to suck. For the spinal tap I had to lie on my side and curve my spine. I held my mum's hand so tight, because just the sound of it frightened me, but this I think was the turning point of my recovery, mentally.

As soon as the doctor had some of the liquid in the needle, he told me the fluid was basically clear and that it was a good sign for a full recovery, my whole attitude changed. I remember my mum and dad's relief when the doctor left the small room telling them that I would be fine now and not to worry. From that moment on my condition gradually improved. I remember my dad saying how I must be better as I made a cheeky remark.

"As my day progressed, so did my headache. It became so bad that I could hardly move my head."

"I was freezing, wearing slippers, my pyjamas and two thick winter jackets."

"the sunlight felt like it was going straight through me."

From the Chairperson

It was with a great deal of pleasure that I accepted the invitation to Chair the Amanda Young Foundation.

The vital role of the Foundation in highlighting the need for members of the community to be aware of the swift and lethal nature of meningococcal disease and to seek urgent medical treatment is perfectly demonstrated by Caitlin's story in this issue of the newsletter. I look forward to joining with the dedicated band of volunteers in making a contribution to this important work.

The Board of the Amanda Young Foundation has been reviewing and updating its planning and implementation strategies to maximise the effectiveness of education and youth leadership programs. The Foundation is now working with health promotion students from Curtin University of Technology and this collaboration is increasing the resources available to support the health promotion activities in schools.

The Foundation will soon be appointing a Development Officer to increase the activities in support of the key objectives of the Foundation. This appointment follows the conclusion of the administrative support arrangement with the Meningitis Centre. The new arrangements will further enhance the provision of education and health promotion activities of the Foundation.

The Foundation members continue to work enthusiastically in fundraising activities and early planning is underway for our annual events – the fun Rowing Regatta, Young Leaders Summit and the Charity Ball at Burswood.

I look forward to your support.

Jeanette Hackett, Chairperson

Amanda Young Foundation News is written by Barry Young and compiled by Lorraine Young on behalf of the Amanda Young Foundation. Printed by Worldwide Online Printing Cannington. Photos courtesy David Bayliss (Community Newspapers), David Ryall and Christine and Paul Jones.

Prevention better than cure

Our attention has been drawn to an article by Professor Fiona Stanley, which appeared in the West Australian in February 2004.

"International research shows that every dollar spent in early intervention saves \$7 down the track and can also have a significant impact on the justice and welfare budgets.

It is not only more cost effective it is more humane. Survivors of serious diseases need ongoing often expensive treatment.

Resources focused at the start of a disease pathway are far more effective. This can actually prevent chronic disease from developing"

We believe our information and education programs regarding meningococcal disease is consistent with the policy being advocated by Professor Stanley and we trust in a small way we are making a worthwhile contribution – Caitlin's story gives us a great deal of satisfaction.

Health Insurance Fund of WA



HIF of WA recently celebrated their 50th Anniversary with a "Fifties Ball" at Burswood. Guests were entertained by "Hip Mo Toast" Big Band and enjoyed a delightful meal during a most pleasant evening. Statewest Credit Society generously provided a great raffle prize and the proceeds of the raffle and silent auction were donated to the Amanda Young Foundation.

Our thanks to CEO Stephen Brown and organisers Trudi Benger and Ruth Gourley for their hospitality and generosity.

HIF will also assist with the distribution of our new design fridge magnets and we thank them for their support in getting the message across.



Gold Medals

The Amanda Young Foundation 2004 Community Gold Medal Awards were presented at the Mardi Gras Ball by triple Olympic Gold Medallist Rechelle Hawkes.

The individual medal was awarded to stalwart Wendy Zuideveld who has been a prime mover with the Foundation since its inception. Her drive and infectious enthusiasm has played a crucial role in the success of our annual Ball and Fun Regatta. Her meticulous attention to detail, hospitality in hosting the sub-committee meetings and her absolute commitment to the cause made her a standout choice for the award.



The Gold Medal in the Corporate sector was awarded to Corporate Theatre who have themed each charity Ball conducted by the Foundation. From our "Out of Africa" to "Night of Knights" to "Moulin Rouge" and "Mardi Gras Rio" each brilliantly setting the scene for a great evening of enjoyment. Their generous discount has enabled the Foundation to conduct affordable events and break into a most competitive market.

Special thanks to Geoffrey Swan and Vaughn Emery for their invaluable contribution.

National Bank – Armadale

Our thanks to the staff at Armadale National for their ongoing support. The Branch continues to feature a display of our Volunteers Awards, poster, pamphlets and water bottles are offered to clients.

Staff members burnt the midnight oil taking care of money matters at the Mardi Gras Ball and they have offered their services during the forth coming Amanda's Garden Fete.

Thanks team for your fantastic support.



Penrhos College

Once again we are indebted to Penrhos College for their continuing support in publicising our events throughout the community and hosting our Committee Meetings.

Penrhos Middle School has adopted the Foundation in 2004 and conducted a series of events highlighted by a Kylie virtual concert on September 18.

Special thanks to Melissa Powell and her team for their kindness and consideration.



Oklahoma

The 27th March production in Kalamunda under a grand marquee was an outstanding success. An appreciative audience enjoyed a superb performance of this popular musical by talented local artists.

Our grateful thanks to Jane, Glade and Anthony Pike and the audience for their generous support in donating \$1250 to the Foundation.



Grant Thornton Golf Day

Grant Thornton Chartered Accountants corporate golf day at the Vines is an annual event, which brings together many special people. Thanks to Geoff Kidd we are provided with an opportunity to participate and challenge the ability of the golfers on a par 3. The 2004 event raised more than \$1200 for the Foundation and enabled us to distribute our information material.

A wonderful venue, great hospitality and generous caring people makes the day a highlight on our calendar.

Ups and Downers Square Dance Club - Armadale

We are fortunate to enjoy the support of the Ups and Downers Square Dance Club who have organised a series of events in support of the Foundation. Taffy Jones, on behalf of the Club, presented the Foundation with a cheque for \$1630.50.



Victor Maric took part in a walkathon and covered 100km in 19 hours and 45 minutes. Mr Maric has been participating in the 100km walk for 8 years and finds it a great way to help a good cause and keep fit. "The walk is a fantastic way to keep fit no matter how old you are of what ever fitness level" he said.

Dr Steve Webb

Rottnest Swim - 5 hours 28 minutes 09 seconds Royal Perth Hospital Intensive Care Consultant demonstrated his superb fitness by swimming to Rottnest in the Annual race on 21st February. He was sponsored by staff colleagues at Royal Perth, Joondalup and Sir Charles Gairdner Hospitals and as a result collected \$1320 for the Foundation. Thank you Steve for your support.



Research

I have been given the honour of writing a small piece on my work and what the Amanda Young Foundation has provided to help me achieve this.

Let me introduce myself. My name is Noel Chow, and I am a PhD student with the School of Medicine and Pharmacology at the University of Western Australia based at the Royal Perth Hospital Campus. My project is characterising potential virulence genes in *Meningococcus* serogroup B. I have been delving into the unknown world of meningococcal genetics for well over 2 years. My supervisor, Dr Steve Webb, would be considered the brainchild behind this project. He is a medical doctor as well as a scientist. It is this combination that has helped him provide me with guidance on the project.

The basis of my project came from a previous study that found certain meningococcal genes were expressed at a relatively higher level when grown in blood than when grown in media. My project was to characterise these genes by knocking out the expression of the individual genes and then comparing the behaviour of these knockout mutants to the original parent. To date, the creation of these mutants has been successful. In the last couple of months I have been assessing the behaviour of these mutants and just recently, completed an experimental phase on their growth habits.

The Amanda Young foundation has been very generous in providing travel funds for me to travel to the UK and also registration and accommodation to a conference in America. Why England first of all? I first approached my supervisor to see whether it would be feasible to gain some work experience with another group working in the same field. It so happened that Dr Webb has an ongoing collaboration with the Paediatrics Infectious Diseases group at the St Mary's Hospital campus of the Imperial College of London. This group work on various meningococcal serogroups, and serogroup B is a big part of their study. It was decided beginning of this year that by mid May I would be in England to continue my project with this group. I hope to gain some technical and analytical skills with their group for the 3 and a half months that I am there. Also on the cards is the travel to Milwaukee, Wisconsin in early September where I will attend the International Neisserial Conference. It will be great to meet other scientists that are working in the same field and find out what their projects are like.

It has been a blur completing a PhD for the last 2 and a bit years. There have been lots of ups and downs but overall I have been very fortunate to be involved in research that will benefit the community. My heartfelt thanks go to Barry and Lorraine for their hard work and tenacity, qualities which have made the Foundation for what it is and to the Amanda Young Foundation for the great financial support I have received to continue my doctoral studies in England as well as attend a conference in America! Who wouldn't be excited?

Welcome Jeanette Hackett

The Foundation is delighted that the recently appointed Deputy Vice Chancellor of Curtin University has taken over from Barry MacKinnon as Chair of the Amanda Young Foundation.



Professor Hackett has had a long association with both Curtin University and Penrhos College, her enthusiasm and experience will be invaluable to the well being of the Foundation. She worked as a lawyer before joining Curtin's School of Business Law in 1980 and has been a long serving councillor of Penrhos College and a Chair of the council for several years.



MARDI GRAS

MARDI



MARDI GRAS



Amanda's Garden unsung heroes

Amanda's Garden is open to the public again this year on 20th, 21st and 23rd, 24th October. Several improvements have taken place in the Devonshire tea and Plant sales areas. Special thanks to Brian and Joan Glenister and Sue Parker for their untiring efforts during the year to make the place spick and span and tending to the pot plants. Cally and Claire have attacked the weeds and Barrie Isles has been a man on a mission with his mower and whipper snipper. Thanks team for your wonderful support and also to our resident sign writer Syd Race and Potter Pat Johnston who beavers away all year collecting plants for the fete.



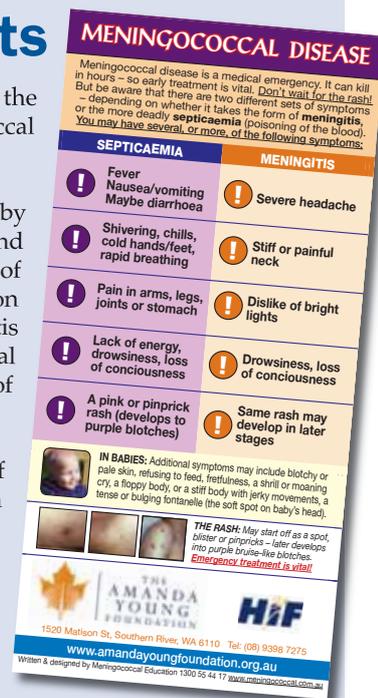
Fridge Magnets

We are proud to announce the production of our new meningococcal disease fridge magnets.

The magnets were designed by Media One and we thank Kay and Tristan for their input. A feature of the new design is the distinction between symptoms of meningitis and septicaemia and the equal emphasis given to the two forms of the disease.

Incidentally, this method of presentation was a recommendation flowing from Amanda's coronial inquest.

Copies are freely available. Contact Barry or Lorraine on 9398 7275



Open Garden

Alexander Heights garden enthusiast Gillianne Sagers kindly opened her garden as part of the open garden scheme and donated the proceeds of \$550 to the Foundation. The Garden was open on 11th and 12th September and the azaleas and camellias provided a very colourful display. Thank you Gillianne and helpers for your support.

Welcome Rebecca

Curtin University Health Promotion third year student Rebecca Gaspar has volunteered to assist in our health promotion activities. Rebecca attended expos at Beeliar and Armadale Primary Schools and is working on strategies to expand and evaluate our program delivery.

Don't Catch the Killer goes to universities

Late last year the Medical Directors of Universities in New South Wales, Queensland, South Australia and Western Australia held their conference in Fremantle. Thanks to Dr Christine Pascott Director UWA Medical Centre, our video, poster and pamphlets were distributed and received a positive response from doctors, finding the contents appropriate to the needs of Tertiary students.

Spreading the message

Since our last newsletter in February we have been active in talking to the following schools and groups and disseminating information.

Presbyterian Ladies College
Penrhos College
Lynwood Senior high
Mater De College
Stoneville Pre Primary



Mundaring Pre Primary
Mercedes College
Canning Vale Primary School
Beelair Primary School
Noranda Primary School
Armadale Primary School
Dale Christian College
Rockingham Senior High School
Morley Senior High School
Australian Women Army Service

Distance Education
Australian University Games
Zonta Club Swan Hills
Defence Force Welfare Association
St Christopher's Guild Attadale
Roleystone Ladies Group
Mothers Union Wongan Hills
Mothers Union Dalkeith
WA Practice Nurses Association
St Nicholas Duncraig
University of Western Australia
Orientation
Peel Health Campus
Groove Radio
ABC Drive Countrywide

Water Bottles have been provided to:
WA Calisthenics State Team
Schoolgirls Breakfast
WA Football under 16, under 18 and schoolboy teams
State Lacrosse team
Peel Junior Soccer Association
Wanneroo Netball Association

Thornlie TAFE

Our thanks to Lorna Pallister and Christine Bailey for organising an information session at Thornlie TAFE. The video "Don't catch the killer" was well received and many questions flowed from an interested audience. Some enterprising fund raising was undertaken by selling water bottles and chocolates and a sausage sizzle resulted in the presentation to the Foundation of a cheque for \$1075.



Our thanks to Bruce Morgan and staff at Courier Australia for their ongoing support in the distribution of our annual thank you.

Eco-Health Young Leaders Summit

19th-22nd April 2004

The annual Young Leaders Summit was held at Point Walter earlier this year. It is open to all year 11 students from our state and on this occasion 38 students attended.

The general aims of the summit are:

- To make students aware of environmental issues and the need to preserve our planet
- To make students aware of the need for good health through a healthy lifestyle
- To give students the opportunity to develop their leadership skills through team building, setting clear goals, self motivation and taking charge of their life
- To use these skills to make a difference
- To learn about meningococcal disease and the need for community awareness

We were again delighted by the response of students and some comments received during evaluation included:



"Everything about the camp was inspiring and motivational. It made you a team player and learn about yourself"

"I loved it! Can I come back next year?"

"It has given me a new perspective on how I view the environment, how I deal with stress and my health"

"Helped me develop as a person, it was a fantastic experience"



20th September 2004

Dear Mr & Mrs Young,

The students at Armadale Primary School would just like to thank you for coming and giving us an informative talk about Meningococcal disease.

The talk you gave was extremely educational and heart touching too. You taught us all a great lesson to be careful and that you can pick it up from things other than sharing drink bottles. You also taught us the signs of Meningococcal and how you can tell if you've got it.

The talk you gave is one we will all take through our lives knowing the risks and consequences involved in Meningococcal. We now know that the doctors aren't always right and persistence is the key. What you said was great in the fact you taught us a lesson of life, without you many of us wouldn't have learnt. With that we greatly thank you for not only teaching us all about Meningococcal but also sharing your experiences of not only yours but others. With you doing this it will decrease the amount of deaths from Meningococcal and make everyone that hears your story become much more careful. We are sorry for your loss but very thankful that you shared this experience with us so that we could learn from it.

From all the students of Armadale Primary School, thank you very much.

Cassandra Joss



Appealathon

Our grateful thanks to Channel 9 Appealathon for their magnificent Support in 2003 - 2004. A series of Community Service Announcements in prime time played a crucial role in lifting the profile of the Foundation and drawing attention to the signs and symptoms of meningococcal disease. The CSAs featured our young ambassadors Peter and Suzi and Dr Clay Golledge and carried the message that early recognition and treatment provided successful outcomes.

The culmination of this outstanding support took place on 23rd June during an afternoon tea ceremony at Channel 9 during which we were presented with a cheque for \$55,000. Thank you Appealathon.

CHECK OUT OUR
WEBSITE

Thanks to Jaz Creative for their ongoing support.
Visit www.amandayoungfoundation.org.au



I arrived in my private, isolated room at 12am exactly. Dad went home to try to get some rest while mum slept in the room with me. That night, although I was tired I got absolutely no sleep, but during the next few days I had plenty of time for that.

Because meningococcal is an infectious disease I wasn't allowed to see anyone other than my immediate family, my doctor and nurses for two days. The next day I basically spent reflecting. I couldn't believe what had happened to me. My mum basically spent every minute with me and I really appreciate her being there and dad and the rest of my family and friends, because without them, I probably wouldn't have made such a rapid recovery. The doctors said that after a little bit of rest I would make a full recovery.

I think the days that followed were my hardest. I was contacted by public health and asked to write down the names of the people I had been in contact with during the last week, just in case I had infected them. As I am a rower with the College, I was organised to go on a camp with the squad the day after I got sick, so I am very thankful that I wasn't sick a day later where I could have infected many of my friends. The second day was the worst, because I realised that I could have infected many of the people I care about. It got me thinking about whom I had hugged and spent time with, and of course the people at the top of my list were my family and closest friends. I felt absolutely dreadful that even though I would be fine, I may have made one or more of the people I really care about sick.

During the days that followed I was feeling fine, to the point where I couldn't understand what I was still doing in hospital. On the third day, I was finally allowed out of my room so I walked with my family down to the cafeteria and back, but even that little expedition made me very tired.

Apart from getting easily exhausted, I have made a full recovery. Remarkably I still have all my limbs, fingers, toes and my life. I can't say that this event has changed my life, but I do know that I now appreciate things and try my hardest to make a conscious effort to be happy, because within a day my life could have gone from being normal, to me no longer existing.

The whole point of me telling my story is to inform people of how quickly this disease progresses and that early detection does save lives. I thought that I would be one of the least likely candidates to contract meningococcal because even as many of my friends have pointed out, I never share drink bottles for the exact reason of catching meningococcal. So it just shows that even though I was consciously careful about it, I still got it. Most of all I would like to thank my friends and family for being there for me and I would also like to thank Barry and Lorraine Young, who ultimately saved my life. Because of the awareness we had on meningococcal, my mum took me to the doctors and if she hadn't done so, I wouldn't be here. It is through Barry and Lorraine Young's persistence and hard work that meningococcal is now more known and taken very seriously. I owe my life to them, to my GP for her prompt treatment and the wonderful staff at PMH, and for that I am very grateful.

Fun Rowing Regatta 27 February 2005 - Canning Bridge



ANNUAL BALL Roaring 20s

21 May 2005
Burswood Plaza Ballroom

Stay tuned for more details...



*The Amanda Rose is available at
Amanda's Garden Fete.*

Contact Barry or Lorraine Young on 9398 7275.



*Our thanks to Ian Dawson of
Dawson's Garden World
for donating these
wonderful specimens.*

