

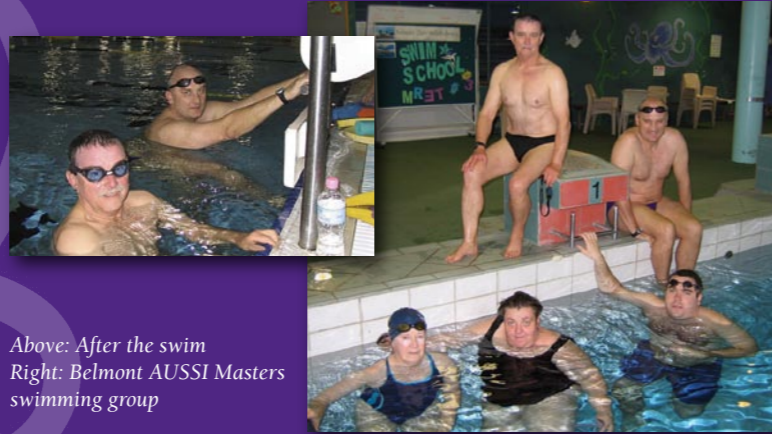
Belmont Aussie Masters support Centre with swimathon

Once again the Belmont AUSSI Masters Swimming Club ran a Swimathon in September as their main fundraising activity for the year. Belmont AUSSI raises funds each year to pay for lane hire at the Belmont Oasis Leisure Centre and also make a donation to The Meningitis Centre. The Club was established in 1983 and holds social events as well as regular swimming sessions and activities.

Belmont AUSSI has supported The Meningitis Centre for a few years now and each year the swimmers give a warm welcome to The Centre's representative who attends the event and the informal 'get together' following the swimming programme.

Belmont AUSSI members hope that their small donation can in some way help promote awareness of the possible symptoms of the disease and encourage others to support The Meningitis Centre.

The Meningitis Centre would like to thank all the swimmers for their support and encouragement.



Above: After the swim
Right: Belmont AUSSI Masters swimming group

Fashion Parade supporters dressed to impress

The Fashion Parade was held during Melbourne Cup week at 2pm on the 11th of November at Pandora Fashions in Osborne Park. Family supporters and friends attended the event and ages ranged from babies to seniors. Attendees were asked to come 'dressed to impress' since it was Melbourne Cup week.



The show started with models wearing casual spring fashions followed by glamorous evening wear. There were even some themed Christmas fashion items including head bands with tiny bells. The head bands proved popular and sold out well before the end of the event. Our volunteer models were naturals and helped make the afternoon a success. As usual Pandora staff made the event enjoyable and entertaining. Following the show people were able to chat over a coffee and cake. The Fashion Parade provides a great opportunity for people to meet and enjoy a relaxing afternoon. The Centre would like to thank the dedicated band of volunteers who give up their time to model and all those who attended the event.



New Publications – Recovering brochure & poster

The Meningitis Centre has recently undertaken a review of the 'Recovering from Meningitis' brochure to update the text and bring it in line with the Centre's brand colours and style. Headings covered in the new brochure will include 'What is meningitis', 'Who gets meningitis', 'Bacterial meningitis', 'Viral meningitis', 'After hospital', 'The most serious complications', 'Can meningitis recur?', and more.

The Centre would like to thank our medical advisors for their help and support with the brochure. The Meningitis Centre updated Recovering from Meningitis Brochure should be available in the next few weeks.

The Meningitis Centre has been asked on a number of occasions if we produce a poster of possible signs and symptoms associated with meningitis. The success of the wallet sized symptoms card has led to the development of an A3 poster, 'Meningitis and Septicaemia' poster, which is similar in content style and format to the symptom card.

The Meningitis Centre's literature provides general information about meningitis, not medical advice. Please consult your doctor to discuss information or if you are concerned someone is ill.

Please contact the Centre on 08 9489 7791 if you would like to receive a copy of the 'Meningitis and septicaemia – Anyone, Anytime Anywhere' poster or 'Recovering from meningitis' brochure. Alternatively email us at meningitis@chr.uwa.edu



Committee

Mr Bruce Langoulant – Chairman and Parent
Mr Bob Ginbey – Telethon Institute for Child Health Research
Mr Michael Kailis – Businessman
Dr Tony Keil – Clinical Microbiologist VISN
Ms Melanie Trainor – Department of Health Communicable Diseases
Prof Deborah Lehmann – Telethon Institute for Child Health Research VISN
Ms Jude Willis – Telethon Institute for Child Health Research VISN
Ms Heather D'Antoine – Telethon Institute for Child Health Research
Jan Adams – Telethon Institute for Child Health Research VTG
Mr Barry Thornton – AMA (WA)
Dr Julie Dockerty – Clinician
Mrs Sarah Johnston – Parent
Mike and Yvonne Graham – Parents
Michael Danzi – Parent
Mrs Treacy Elliott – Project/Support Officer
Ms Linda Gibbs – Coordinator

The Meningitis Centre would like to acknowledge all our volunteers who support The Centre and help us to raise awareness of the disease; we appreciate your involvement and input. The Centre's success in raising awareness has been dependent on the dedication and vision of our committed volunteers. **Thank you.**

Sponsors

The Meningitis Centre would like to thank all sponsors and donors. We value and appreciate your on-going support.

The Meningitis Centre relies on sponsorship and donations to function and to continue to raise awareness of meningitis and finding sponsors is challenging.

If you know of a company who would like to sponsor The Meningitis Centre, or an individual who would like to donate, please encourage them to contact the Centre.



This newsletter was kindly sponsored by



Invasive Pneumococcal Disease and The Vaccine Impact Surveillance Network (VISN) – Twin Successes in WA

Invasive Pneumococcal Disease (IPD) is caused by a bacteria called *Streptococcus pneumoniae* (or the pneumococcus) and can manifest itself in a number of ways including meningitis (infection around the brain) pneumonia (chest infection) and septicaemia (infection in the blood). 90 different types of pneumococci have been identified, but most IPD is caused by only a few of these types.

Everybody can get IPD, but those who are most susceptible include young children and adults over 65 years of age. (Aboriginal people of all ages are more at risk than non-Aboriginal people of contracting the disease).

People who have weakened immune systems and/or chronic disease are also more likely to get IPD, as are smokers and people who drink a lot of alcohol.

As there are so many different strains of *Streptococcus pneumoniae*, a vaccine providing complete protection against IPD hasn't yet been developed. Two vaccines are available, however, that prevent IPD due to the most common disease strains. One, called Prevenar, is specifically for children under 5 years of age (and has been shown to be highly effective in preventing IPD) and the other, Pneumovax23, is for older children and adults.

The Vaccine Impact Surveillance Network (VISN) was established in 1996 by The Meningitis Centre to monitor vaccine preventable disease, most specifically IPD. All notifications of IPD in Western Australia are reported to the network with its principal aims being to identify high-risk populations, evaluate the impact of pneumococcal vaccine programs, identify the common strains (serotypes) of pneumococci and track any antibiotic resistance.

In January 2005, after 3 years of lobbying by The Meningitis Centre, Prevenar was introduced to the Australian Childhood Immunisation Schedule and a gratifying decrease in the reported incidence of IPD has been observed since then. In 2004 the WA annual IPD notification rate was 195, decreasing to 138 in 2005. In 2006 there were further declines, with 129 cases being reported. In children under 5 years, notification rates dropped from 49 (25% of total cases) in 2004 to 18 (14% of total cases) in 2006.

IPD is probably more widespread in the community than these numbers suggest as only cases that have laboratory detection of *Streptococcus pneumoniae* (via a blood test) are included in the VISN database. In particular, the incidence rates in Aboriginal people living in remote areas are likely to be substantially higher since antibiotics (which will decrease laboratory detection rates) are often given before patients are transferred to a regional centre.



Members of VISN research group. Left rear: Dr Tony Keil, Hannah Moore, Judith Willis. Left front: Leanne Brown, Carolien Giele, Prof Deborah Lehmann.

In 2005, just over half (53%) of patients with IPD had known risk factors, predominantly diabetes. To effectively reduce the burden of pneumococcal disease, people with IPD risk factors need to be identified and offered the appropriate preventative vaccine.

To date, there is no evidence that pneumococcal strains not covered by the vaccine have increased however continued surveillance is necessary to detect this risk. This is especially relevant to the Aboriginal population where a higher proportion of children develop IPD from non-vaccine strains.

Continued monitoring of antibiotic resistance in IPD is also of major importance as evidence of slowly increasing antibiotic resistance has been reported in recent years.

VISN data provide a valuable resource for assessing the value of both the Prevenar and Pneumovax23 immunisation programmes. VISN data have recently been presented in a medical journal article investigating the effect of Prevenar on Western Australian childhood IPD rates. It is also anticipated that VISN will be presenting a paper at the Communicable Diseases Conference in March 2007.

Chairman attends Confederation of Meningitis Organisations (COMO) conference in New York

Bruce Langoulant The Meningitis Centre's chairman attended another successful world Confederation of Meningitis Organisations (COMO) conference in New York in mid September 2006. COMO is an organisation of medical and charity leaders from across the world united to increase the international profile of meningitis.

The Conference succeeded in recruiting three new groups out of the U.S. and cementing relationships between existing member groups and saw the development of an action plan for COMO's third year of operation.

On the first day, conference delegates received an overview of COMO's mission statement, framework and operations. The delegates applauded COMO's activities to date which included a significant increase in members, the development of a member Tool Kit, a meningitis white paper and comprehensive web site. A brain storming session was conducted on the second day of the conference and delegates discussed the organisation's role in providing advocacy. Branding initiatives, fund raising options and projects for the next three years were all considered during the session.

Delegates had the opportunity to socialise, network and share experiences in the evening and many attended a dinner in Manhattan and participated in a bus tour of New York.

By the close of the conference delegates felt re-energised and equipped to continue in their efforts to raise awareness of meningitis in their country of origin.

Recently Bruce was appointed President of COMO. Bruce expressed his thanks to the former COMO President, Philip Kirby from the U.K. for all his efforts and vision in steering COMO for the past two years.



Delegates at the COMO conference in New York

Chairman's Comments



I believe 2007 will be an interesting and challenging year both here in Australia and in terms of The Centre's involvement with COMO.

As the Chairman of The Meningitis Centre in Australia and as the former Vice President of international Confederation of Meningitis Organisations (COMO) I attended the COMO world conference in New York and was hugely impressed by the work that is going on across the globe and the passion that member groups have for reaching new audiences and supporting and empowering small meningitis organisations to reach out to their local communities and raise awareness of meningitis and support the effective use of vaccines across the globe.

I now take on the role of President of COMO and look forward to the many challenges and opportunities that I will encounter in the next few years in this role.

Toward the end of last year the Centre raised awareness of the new wallet sized symptom card by sending an email bulletin to GPs via the WA Faculty of the Royal Australian College's electronic messaging service. The response was excellent with many practices requesting copies of the card and other literature. An article about the Centre and our literature was also published in the Perth Hills Division of General Practice Western Australia newsletter.

Last year saw three new volunteer parents added to our committee who have been an asset to the Centre and have come with new ideas and energy. It is a pleasure to welcome all three to our committee.

On behalf of everyone at The Meningitis Centre I would like to express our appreciation for your continued backing and support and trust you will continue to stay with us during this new year 2007.

Conferences and Presentations

The Meningitis Centre was invited to speak at the Annual Scientific Meeting 2006 of the International Society for Prosthetics and Orthotics (ISPO) in Fremantle. We would like to thank Committee member Dr Julie Dockerty for speaking at the conference on our behalf. The presentation given by Julie was very well received and according to one of the attendees was "one of the highlights of the conference."

The Conference was held over the 12 – 14 October 2006 at the Esplanade Hotel, Convention Centre in Fremantle. The ISPO Conference Covening Committee were awarded Lotterywest funding to enable 'consumers and representatives of not for profit interest groups' to register for the conference. The Meningitis Centre would like to thank Lotterywest for awarding funding for representatives to attend and thank the ISPO Covening Committee for their support.

The Centre also continues to give talks and presentations about the impact of meningitis on families. One of our volunteer parent representatives gave a presentation to nursing students at Notre Dame University late

last year about the impact of pneumococcal meningitis. Students asked some intuitive questions and developed insight into the problems faced by families both in hospital and in the community.

Meningitis Centre staff and volunteers attended The Amanda Young Meningococcal Conference at Burswood Entertainment Complex on Tuesday 19 September 2006. The conference was well attended and The Meningitis Centre would like to congratulate The Amanda Young Foundation for organising such a worthwhile and successful event.



Sarah, one of our volunteer presenters with a hospital staff member

My story of meningococcal disease – then and now

My brush with Meningococcal meningitis at age 19 began with a bad headache that crept into my bones making me stiff & sore; it caused me severe diarrhoea, constant vomiting and extreme sensitivity to light. Even though I had the typical rash on my chest a doctor misdiagnosed me on Anzac Day and sent me back to college where I was living, to wait out the symptoms of a bad flu. Within 36 hours of Anzac day 1998 I was rushed to hospital and diagnosed with Meningococcal meningitis after nine hours of interviews and tests.

All the people I had spent time with in the past 2 weeks were at risk of contracting the disease too. I have very little recollection of my time in hospital but do remember being woken hourly to check my brain & body function. I have been told that I was close to renal failure and was lucky to survive the beast. I had lost my ability to eat and to walk because my muscles were so weak. I had lost 12kg off an already lean frame. After 10 days in hospital I began my recovery, which meant almost having to learn how to walk again. My life had changed. My parents cared for me in the following months before I returned to college and university. I found it very difficult to be so terribly thin and I felt very vulnerable; it was so difficult to fit in after such an experience with no counselling at hand.

Slowly but surely my health and my confidence built up again; my family and friends were constant support over the next 12 months. I regained my ability to eat regularly over the year and put back on the weight I had lost. I came out the other side of this disease with no known side effects.

Nine years down the track and I am now a happy and completely healthy 28-year-old woman. My body is a testament to surviving Meningococcal Meningitis. People still look me up and down after finding out I have survived this disease because it is so widely publicised how devastating it can be. My survival has made me a more grateful person and I know my story is not the only one with a happy ending.

My story of Haemophilus Influenzae type B (Hib) meningitis – then and now

My parents tell me at the age of two I was a vibrant, energetic, typical toddler. During the course of one day, I changed completely. I was lethargic, photosensitive and nauseous. I was taken to the doctors who miss diagnosed me and later taken that day to the local children's hospital where I was diagnosed with Haemophilus Influenzae type b (Hib) meningitis. My parents were told by the triage nurse to prepare for the worst. They said your daughter might die and if not, could be left with a range of physical and mental disabilities. I have been told this story many times by my parents who are forever grateful that, for all intents and purposes I made a full recovery.

Although never medically diagnosed, my parents felt that I may have suffered some mild learning difficulties and as a result, I repeated year six. I am now nineteen years old and entering my second year at university where I am studying and loving the Early Childhood Education course. I have just bought my first car and have a part time job in retail which helps to fund my car and busy lifestyle. I love partying with my wide group of school and uni friends and boyfriend on the weekend and to compensate for my excesses, I hit the gym regularly. Our family have maintained contact with The Meningitis Centre and we have met other families who have experienced meningitis.

Although I don't remember anything about my illness, I will be eternally grateful for my complete recovery.

The GOLD Entertainment Book – Western Australian fund raiser

The Meningitis Centre will be selling Gold Entertainment books (in WA only) as a fund raising initiative for 2007. The Gold Entertainment books are \$60.00 and a small portion approximately \$12.00 goes to the Centre. If you live in Western Australia and are interested in finding out more about the books or would like to order a book or two, please contact Linda at the Centre on 08 9489 7791 now to reserve your copy/ies. The Gold Entertainment books will be available in mid May 07.

Perth meningococcal B vaccine study

During late October 2006 the Vaccine Trials Group at the Telethon Institute for Child Health Research and Princess Margaret Hospital for Children in Perth Western Australia held a media launch to mark the second clinical phase studies of a meningococcal B vaccine study. Adolescents aged between 8 and 14 years, and toddlers aged between 18 and 36 months are needed to take part in these very important studies. Journalists from Channel 9 and 10 as well as print and radio media interviewed the study leader, two individuals participating in the trial as well as a family whose son had contracted Meningococcal B disease as a two-year old. The Vaccine Trial's Group may be contacted on 93408542 or mail to: vtg@ichr.uwa.edu.au

Meningococcal disease is an uncommon but life threatening infection. The meningococcal bacteria (Neisseria meningitidis) are a significant cause of disease in Australia, especially in the very young, teenagers, young adults and those with medical risk factors. The meningococcal bacteria can cause meningitis (inflammation of the meninges, the membrane lining of the brain and spinal cord) and/or septicaemia (blood poisoning). Although the risk is low, meningococcal disease can affect anyone, anywhere, at any age.

There are a number of different types or serogroups of meningococcal bacteria, the most common in Australia being meningococcal groups B

Why we supported the meningococcal B study – our story

We are one of the very few lucky ones. Our little boy not only survived the ordeal of meningococcal B, but it would appear, survived without any of the ill effects of this disease (touch wood). I would like to acknowledge and thank our GP and all the medical staff at the state children's hospital for their efforts, expertise and empathy in treating James and helping save him.

James was 22 months old and a bit under the weather with the symptoms of a cold/flu. Peter, his father, was working in the front yard moving mulch. As a toddler, James didn't complain or winge about anything and seemed content resting on the lounge watching TV. Looking back this was the first sign that was dismissed that something was wrong; this was out of character for James. Pete gave James some medication for a slight temperature and then continued to work outside checking on him from time to time, thinking that the medication was working and James was just resting. In reality, his temperature was not being controlled and he was getting worse. By 6.00pm James had vomited a couple of times, had a fever, and seemed pretty lethargic... just a flu we thought, he'd get better overnight.

As a nurse I checked James's body... there were no real markings... no clues other than the fever and lethargy. Our past experience told us that James would bounce back overnight and as a precaution going to the doctors would be all that was needed. We decided to go to the GP and lucky for us the GP agreed to wait to see us as most surgeries were closed. By the time we got to the GP, James was pretty much tired and barely responded to all the prodding and examinations by the doctor... again not complaining about anything... there was one red dot on his chest. The doctor didn't say meningitis or septicaemia but he was wary of the 'quiet child' and suggested we go to the hospital to rule out anything nasty so we could have a good night sleep. So we did.

We arrived at the hospital within ten minutes and went straight through triage... when the doctors removed James's clothing he was unconscious and didn't respond to the needles etc. His whole trunk, arms and legs were now covered by these purple dots. James was treated with the medication and we thought he will be fine.

During the night James's condition worsened. His blood pressure was dropping and renal and liver function deteriorating. We were told it was touch and go if James would survive the night and these 24 hours were important. The medical team decided to try to rectify this by pumping James's body with fluids, plenty of fluids. There were probably more specific things that they did but I remember James turning into the Michelin

and C. Whilst a vaccine against Meningococcal C is now widely available, a vaccine against Meningococcal B, which accounts for 90% of cases in WA, has remained elusive.

In the Vaccine Trial Group's media release, study leader Dr Peter Richmond said there is no vaccine available currently to prevent the Meningococcal B strain of the bacteria which makes these studies of international significance. "Meningococcal B can cause meningitis and blood poisoning and can progress very quickly with devastating effects," Dr Richmond said. "This is the last major cause of meningitis for which we don't have a vaccine. Children between the ages of one month and one year are most at risk from meningococcal with a second peak in adolescents, so it's very important that we ensure that this vaccine is safe and effective in children." The vaccine has already been used in clinical trials in young adults and found to be safe with promising preliminary results. Most study participants will be given the new vaccine while others will receive a government approved vaccine. The meningococcal vaccine to be tested has been developed by Wyeth."

During the media release a volunteer family spoke about their experiences of meningococcal disease and the meningococcal B vaccine study.



James, Simone, Taa, Pete and Bruce

man and appearing to double in size. Pete could barely lift him. James's eyelids were so engorged with fluid that he could not open them. The medical team was trying to avoid ventilating him.

Meanwhile we contemplated what might be left of James. To what extent had his body been damaged so far... and what further damage might be done by the disease and possibly the treatment. We had time to ponder all the possible results and consequences to our boy's life while we kept vigil over him hoping for some sign of improvement.

As you might have realized, in Intensive Care Unit James started to fight back and started to show adequate signs of improvement. He was moved to the general ward and spent the next five days there. James did not lose any fingers, toes or limbs. He has no noticeable ill effects from his encounter. We don't know what damage was done, but we spend each day just grateful for having James with us and have come to appreciate more how lucky he was.

When we found out about The Meningitis Centre and its work we felt an obligation to offer our support where needed. In November we were asked to offer our story as part of the media

release for the vaccine trial for meningococcal B. We were keen to help but I must admit, curious why choose us when there are so many other people who have experienced so much more than us. After some thought I began to realize that James could help promote the meningococcal B vaccine study and help in the fight against this disease.

We know what it is like to be told that your child might die and if not most certainly have some disability or impairment. We know how it feels to be asked and then try to remember who were the people you had seen in the last two weeks and then have them contacted from the health department and be asked to have a course of treatment. We know about the worry of the future and changing plans for the worse. But we were lucky.

I don't know why or how this happened to our James, or for that matter why James got through this ordeal the way he did; but one thing I do know and want, is that every child deserves to be protected from meningococcal B and survive like James.

This research is wonderful and a successful vaccine too long coming. The lives it potentially saves will be many more than those unfortunate few that contract meningitis. I wish the research team Gods speed and every success.

The Centre would like to thank Peter and Simone, James's parents for writing about their experience for the newsletter.