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HSANZ NG News

Wishing you all the best for Christmas and a very happy 2008!

Report from the HAA Conference

The HAA Annual Scientific Meeting was held at the Gold Coast Convention and Exhibition Centre in October 2007 with the occasion marking the launch of the HSANZ Nurses Group.

A two day nurses program was included within the HAA Meeting and was attended by 142 nurses from around Australia and New Zealand.

Twenty-two nursing abstracts were received for either oral or poster presentations with a majority being accepted for the Nurses Free Communication Sessions.

Our invited guest speaker was Dr Pamela McGrath NH&MRC Senior Research Fellow from the Central Queensland University who spoke on the 'Impact of patient relocation' and facilitated a Master class on 'Haematology and Palliative Care'.

The two day program also included sessions on 'Adolescents and Young Adults', 'Impact of Innovations in Haematology/ BMT', 'Transfusion in Haematology Setting', an 'Overview and Update on MDS' and 'Logistics of Home Transfusion'.

The final session of the nurses program was titled the 'Fall Guys' in Haematology / BMT' which was an open forum on 'Remote Area Issues: A Haematology Nursing Perspective' and 'Tissue Typing and Sibling Donors' which highlighted the need for the development of guidelines on Sibling Donor Tissue Typing.

Overall the nursing program was well received and the attendees liked the opportunity to attend the HSANZ, ANZSBT and ASTH sessions.

As the convenor for the nursing program, I would like to take this opportunity to thank the chairpersons, presenters and attendees for their professionalism and enthusiasm that contributed to the success of the nursing program.

Though the success of any conference / meeting is usually rated when the opportunity comes to 'chill and let loose' and no doubt there is no exception to the rule after a great night of 'shark diving' and jiving at Sea World on the Gold Coast.

Until next year ….Perth 2008.

Festive Greetings and a safe New Year

Rosita Van Kuilenburg

Inside this edition

Special points of interest:

- *Practice Corner—What are you doing on your Unit?*
- *Ask the Expert—email in with your questions and your answer will appear in the next issue.*
- *How Do I—write an abstract? Make a presentation? Understand statistics? Let us know what you want to know.*
- *Tea Room Guru—What's your beef?*

Write in with all your comments, questions & articles

From the President

Season's greetings to you all

be that the season of Christmas, Hannukah , Eid-Al-Adha, Yule, Zartusht-No-Diso, Omisoka or Hogmany. December's certainly a busy month!

It's been amazing year– to think, around this time last year, a group of haematology nurses from Sydney and surrounds gathered around a table in North Ryde, broke bread and decided on the initial steps of a plan to raise the profile of haematology nursing as a specialty and create a network of expertise, sharing and learning across Australia and the Tasman.

And here we are, 12 months on , a Society of specialist nurses and a part of the peak haematology society in Australia and New Zealand with over 250 nurses on the database (many of whom are members or have applications in process).

The NSW DOH communications officer recently emailed me for contact details, a small but telling step our road to recognition as a specialized professional work force.

The newsletter is growing , the first issue had 4 pages and we have now more than doubled that, in the space of a year, to 9, which is thanks to you who are sending in pieces and sharing your practices and ideas. Keep that coming. The next issue will come out in February.

In this issue, two of the three HAA Travel scholarship winners have shared their papers. Three travel scholarships are offered by HSANZ for nurses to go to the annual scientific meeting which is being held in Perth Next October from Sunday 19th –Wednesday 22nd. An exciting development for next year is the introduction of a haematology nurse study day to be held on Saturday 18th October at the Conference venue. This will be free to participants, thanks to the support of a number of Pharmaceutical companies, and will be aimed at Junior and local nurses. We hope that this will become a regular educational initiative to support haematology nurses at all levels around the country.

Well, all I have left to say is, have a good break if you have one, and don't work too hard if you don't!

Moira

If you would like to join HSANZ, please click on the following link, or fill out the form in the accompanying pdf. Please do not hesitate to contact any of the representatives, if you have any queries about this application form www.hsanz.org.au/join/documents/08HSANZMemForm.pdf

News from the States and Territories

From WA

Hi! I would like to introduce myself. I am Krys Emery and, together with Julie Toovey, have taken over from Barb as the WA reps while she is enjoying a year off with new baby Ellie. Julie Toovey is the Haematology/Oncology CNS for Fremantle Hospital and I am the Haematology Research Nurse at Royal Perth Hospital.

In WA we have a busy year ahead as we plan for the HAA conference in October. Neither Julie or myself have been involved with the planning of HAA before, so if you have any tips please send them our way! Also, if you know of an exceptional speaker or have a topic that you would like covered at HAA, please drop me an email!
Merry Christmas and we look forward to a busy 2008!

Krys and Julie

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From VIC

Hi all - Merry Christmas and Happy New Year!

Vigorous discussions are taking place to ensure our educational meetings get off to a good start and continue so throughout the year. All going well the first meeting should be taking place late Feb - I will be in contact with the many institutions in Victoria and Tasmania. Please feel free to contact me to be placed on the mailing list or with any suggestions you may have.

For those of you whom have contacted me in regards to Royal Melbourne Hospital's Short Courses the following are occuring in 2008:

6 May: Care and Management of the Oncology Patient (Junior Level)

27/28 May: Advanced Haematology Short Course

19/20 November: Bone Marrow Transplant (HSCT) Short Course

I am happy to inform you all that the Education Department has moved to new and improved facilities (Yah!!)

Anyway, I hope you all get a chance to recharge and celebrate too much!!!

Looking forward to 2008!!!

Cheers Jo

Please contact me on:

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E-mail: joanne.west@mh.org.au

From the travel grant winners .....

Outpatient Administration of Consolidation Chemotherapy for Acute Myeloid Leukaemia

The 187 bed Calvary Mater Newcastle Hospital is situated in Waratah, Newcastle, in the heart of the Hunter region. It is a teaching hospital affiliated with the University of Newcastle providing tertiary services to the Hunter and New England area and Country NSW.

The commencement of the M13 trial in 2004 for patient with core binding factor AML was the catalyst for the development of our outpatient chemotherapy program. This ongoing trial requires the patient to have 6 consolidation chemotherapy treatments.

What the patient's say:

"Support team could not have been better", "Whenever there was any questions or minor problems the staff were there to help at any time".

In an already overstretched unit it was recognised that getting this patient group into hospital in a timely manner was going to be extremely difficult.

An outpatient autologous transplant treatment option had been available for several years. In this program conditioning and stem cell reinfusion occurs as an inpatient with subsequent follow-up care attended in the outpatient setting. Consolidation chemotherapy is an extension of this service.

In December 2004, after collaboration with several members of the Haematology Unit management team including the Haematologists, day unit co-ordinator, pharmacist, CNC and NUM we commenced our first patient on this program. Up to now we have had 7 people complete the program and currently have three patients at various stages throughout the program.

Patients have been on either the M12 or M13 trials, and using a combination of CADD legacy plus pumps and day ward treatments they have received their chemotherapy (including high dose cytosine) as outpatients. All patients received pegylated G-CSF on completion of their chemotherapy.

Part of the criteria established was for all patients to have central venous access. Central lines were initially the most common form of access but many of these become infected after each treatment regime and required removal and then reinsertion prior to their next treatment. For patient comfort and increased patient safety we modified our treatment plan and now utilise PICC lines, both single and double lumen. From this change in practice we have had improved patient comfort and safety and a marked decrease in line related infections.

Patients became totally pancytopenic with WCC dropping as low as 0.2 with no neutrophils, Hb to 68 and platelet counts to 5. One patient was refractory to random donor platelets and received HLA matched platelets. 2 patients on the M12 trial required admission for neutropenic sepsis.

From a clinical perspective this method of treatment appears to be both effective in relation to bed management and patient care.

To evaluate the effectiveness of it from a patient's perspective we decided to ask the patients to complete a satisfaction survey. This survey was undertaken in June of this year. We surveyed the 6 patients who had completed their treatment and the one patient who was actively on the program at the time. All of these patients were posted the survey with a stamped addressed envelop so that they could maintain the anonymity. The outcomes of this survey were very positive:

All patients felt comfortable having chemotherapy in this manner.

All said that they were offered enough support making comments such as *"Support team could not have been better", "Whenever there was any questions or minor problems the staff were there to help at any time"*.

Where to from here? Our next stage is to establish some formal protocols allowing this to be an accepted potential treatment .

Debbie Carr,

Coorrdinator,
Haematology Day Ward,
Calvary Mater Hospital, Newcastle, NSW

Developing a Febrile Neutropenia Protocol for the Emergency Department

This presentation for the HAA 2007 conference was an audit of the previous febrile neutropenia protocol and the change in practice following the introduction of a new, more comprehensive protocol in June 2007. The time until patients received interventions became the focus; the time to be seen in emergency, the time until the first antibiotic and the time until various tests were taken (blood, chest x-ray, sputum, urine). Patients who presented with a covering letter and pre written test order forms were separated to see if this expedited the process.

Overall results were variable with a number of tests taking longer after the introduction of the protocol, most likely affected by the seasonal demands of winter on the emergency department. It was felt that although the numbers were small, those who presented with the febrile neutropenia letter/package were seen quicker and commenced antibiotics sooner.

Our conclusions included the need for ongoing audit, further education for emergency staff, reviewing the types of patients who are given the covering letter/package, expanding the criteria for who is given the letter/package and reviewing the contents of the package. For example, reducing the letter to a wallet sized card and having prepared packages in the ED with test requests, specimen containers and so on, thus reducing the burden on patients to remember to bring the package with them.

I would like to take the opportunity to thank the HSANZ for the travel grant. It was a very valuable experience, not only presenting at this conference for the first time but also having the opportunity to network with other haematology professionals.

Allan Hayward,

Clinical Operations Manager,
Institute of Medical and Veterinary Science/Royal Adelaide Hospital,

Inaugural BMT Conference in Saudi Arabia

I was lucky to be invited to the first International Congress on Bone Marrow and Stem Cell Transplantation in Saudi Arabia in November. This was a three day event which consisted of three medical and scientific days and a nursing symposium. Many well known international speakers from both the nursing and medical fields were invited and this, combined with the local and regional speakers, provided a very interesting and high quality forum.

The King Faisal Specialist Hospital and Research Centre (KFSH) do the most autologous and allogeneic stem cell transplants in Saudi Arabia and in the Middle East. Transplants in the adult population are usually for haematologic malignancies. There is a very high rate of related donor transplants in the Kingdom. This is due to large families and intermarriage over the years. The paediatric transplant programme consists of transplants for large numbers of non-malignant haematological conditions such as Thalassaemia, SCIDs etc. The paediatric programme utilises Cord bloods from around the world. A Cord Blood Bank has been opened at KFSH and is accruing cords. They will be linking up to the NMDP network. It is also hoped to establish a regional bone marrow donor registry. It is currently difficult to find donors on the world book for those patients who do not have a related donor.

The nursing symposium had input from nurses transplanting in other centres in the Middle East. There were speakers from Egypt, Lebanon, Jordan as well as those from KFSH. These speakers talked about setting up transplant programmes in their countries and the various issues that arise from transplanting patients in these countries. An example of this is trying to track down the donor of one patient so that the patient could have DLI. They were a family of camel herders and roamed the deserts of Saudi Arabia. They only met up every six months and there was not able to be any contact in between times as there is no telephone or cell phone coverage out in the desert. Other nursing presentations included ethics in bone marrow transplantation, quality of life issues, training and retention of BMT nurses, psycho-social aspects and genital GVHD. Representatives from EBMT and NMDP also talked abou their organisations. It was a stimulating and interesting symposium. The conference is aiming to be a regular event with the next one planned for 2009.

Catherine Wood
BMT Coordinator
Wellington, NZ

Ed: Catherine spoke on genital GVHD which must have been something of a nerve-wracking challenge in that particular cultural environment.

Desperately seeking.....

Hello all! I've returned from the HAA 2007 conference all fired up (and yes, danced out!) It was great to hear everyone's presentations and to realise that there are a number of projects going on that a number of us are all thinking about. So now I'm looking for a way of sharing ideas on innovative practice in the haematology world and thought the newly formed HSANZ Nurses Group would be a great forum.

I'm looking to hear about and exchange ideas about other units' experiences with transferring whole or parts of care from the inpatient setting to the outpatient setting. I'm particularly looking at some of our chemotherapy regimes that have always been given as an inpatient and seeing if all or part of the protocol can be given in the outpatient setting. Have you done something similar, modified regimes to suit opening hours, used novel delivery methods, or done anything that helps patients to remain at home for some of their treatment?

I'm also looking at ways of improving the experience for those returning to the hospital emergency department with febrile neutropenia. Specifically, ways of flagging the patient to triage as they arrive and setting them on the right track for prompt treatment. So, if you have developed something that has been worthwhile (or even if you have some tips on what to avoid!) I'd love to hear from you.

Thanks

Allan Hayward
Clinical Operations Manager
Division of Haematology
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Adelaide

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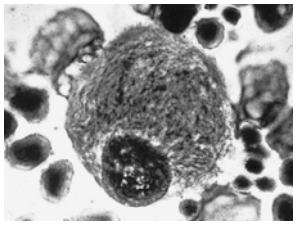
How well do you know Gaucher Disease?

Gaucher disease (GD) is a rare and under-diagnosed disorder that statistically affects less than 500 people in Australia and NZ combined. It is genetically inherited but can manifest in many forms. Patients can live their whole life without presenting with symptoms, or they might have varying degrees of haematological, visceral and skeletal manifestations. In rare cases, the CNS is involved leading to death before 1 year. Currently there are approximately 100 patients known in ANZ.

GD is an autosomal recessive lysosomal storage disorder caused by a deficiency in the enzyme b-glucocerebrosidase, resulting in absent or inefficient conversion of glucosylceramide to ceramide and glucose.
Occurs primarily in macrophage lysosomes during the phagocytic degradation of red and white blood cells.
The accumulation of glucosylceramide within the lysosomes of monocytes and macrophages produces multiple organ and skeletal complications. Clinical symptoms arise due to the displacement of normal cells by lipid-engorged Gaucher cells.

A typical Gaucher cell showing a displaced nucleus and wrinkled tissue paper appearance.Pseudo-Gaucher cells may be present in other haematological disorders such as lymphoma, leukemia, and
various bleeding disorders.

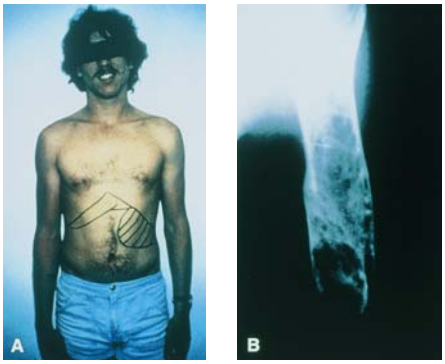


Three disease states have been classified based on the presence and severity of neurological involvement:

- Type 1 is distinguished by a lack of central nervous system involvement and striking phenotypic variation.

- Type 2 is a severe neuropathic form that affects infants and results in a life span of approximately 2 years.

- Type 3 is a less severe neuropathic form with variable CNS involvement, onset and progression.



Type 1 patient with mild hepatosplenomegaly (A) but with severe bone involvement (B)

Presentation and age at symptom onset are highly variable. Symptoms are multisystemic and include some or all of the following:

Anaemia	Thrombocytopenia
Splenomegaly	Hepatomegaly
Reduced QoL	Bone pain
Avascular necrosis	Skeletal complications
Pathologic fractures	Growth and pubertal delay

A survey conducted by Genzyme Australasia and the Gaucher Association of Australia in 2004 showed that the most common presenting-symptoms included a tendency to easily bruise and bleed (66%), an enlarged abdomen (34%), fatigue (34%), and bone or joint pain/fracture (31%).
The incidence of Gaucher according to type is: Type 1: 1 in 59,000 (Meikle et al. JAMA 1999)
Type 2: 1 in 100,000
Type 3: 1 in 50,000 to 100,000

The definitive diagnostic test is to conduct an enzyme assay for glucocerebrosidase activity on peripheral leukocytes. This can be performed at the following centres:

1. Adelaide Women and Children's Hospital, Dept of Genetic Medicine. Tel: 08 8161 6701
2. Royal Brisbane Hospital, Division of Chemical Pathology. Tel: 07 3636 8428

Other interesting facts about Gaucher disease:

GD is more common in the Ashkenazi Jewish community with an incidence of 1 in 500 to 1000

Gaucher patients have an increased risk of haematological cancer, particularly multiple myeloma, yielding an estimated relative risk of 5. (95% confidence interval [95% CI]: 2.8, 10.8).

Most untreated patients have massively raised levels of chitotriosidase – an enzyme produce by activated macrophages (note: 5-6% of patients lack this enzyme as a result of a genetic deficiency). Other elevated markers include: ferritin, ACE (angiotensin converting enzyme) & TRA (tartrate-resistant acid phosphatase).

An Australian patient survey showed that on average there was a 3-year delay between the onset of first symptoms and diagnosis. Patients typically had to see 3 to 4 physicians before a correct diagnosis was obtained. In 45% of patients surveyed, the family GP took no action and reassured the patient that there was nothing wrong.

Gaucher Disease is treated by giving Enzyme Replacement Therapy (Cerezyme® - imiglucerase-rch) which is available for patients in Australia and New Zealand who meet the specified criteria and conditions. Please refer to the following web site for further information on eligibility and application and registration forms: http://www.health.gov.au/internet/wcms/publishing.nsf/content/health-pbs-general-supply-criteria

The Gaucher Association of Australia offers support for patients and families who have been diagnosed with Gaucher disease.
gaucher.aust@bigpond.com
PO Box 983
Sunbury Victoria 3429
(03) 9740-7203

Additional Reading

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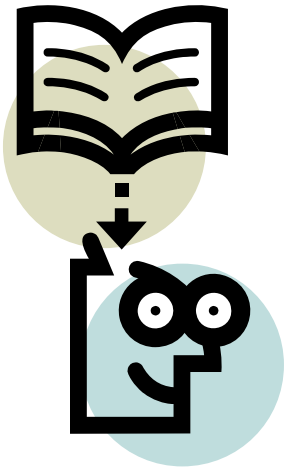

Now try the HSANZ NG Gaucher Disease Book Quiz!

Answer the following question to win!

1. What is the inheritance pattern of Gaucher disease?
2. The definitive diagnosis of Gaucher disease is by:
   a. Enzyme Assay of glucocerebrosidase
   b. Bone Marrow Biopsy
   c. Chitotriosidase levels
3. In Australia, what is the average delay between presenting symptoms and diagnosis?
4. Gaucher disease is a multisystemic disorder – name three areas of the body affected.

The first 10 correct respondents will win a copy of *"Haematology at a Glance, revised 2nd Ed."*, by Mehta & Hoffbrand!

Send your answers to: angela.booth@cancerinstitute.org.au

Tea Room Guru

Dear TRG,

A colleague asked me recently about my patients and the sorts of diseases they had – well, I said, where shall I start? I found a good place to start and was in the process of describing my patient's ages and their diseases and treatments, not mentioning their names of course 'cos that would breach confidentiality, and in came several other people who were interested including the local pharmacist and his wife. Then, a friend came in and had the cheek to ask if I had the permission of my patient's to discuss their details. Of course not I said, but it doesn't matter because I haven't mentioned their names, honestly – what a ridiculous suggestion to think I might have had to ask them if I could share their medical details – what do you think?

Well, the person that raised the question was right. "Maintaining patient confidentiality and obtaining the consent of patients to share information about themselves are core principles of the medical (healthcare) profession(s)" (Chester, 2003), and this has to do with privacy, confidentiality and trust between the patient and the clinician.

Data routinely collected from patients' medical records and reused for research and quality programmes is becoming more commonplace. Whilst it has the potential for increasing medical knowledge and improving the provision of healthcare; the use of data is not without its complications (Rector 1999). Why ? you may ask, the data is anonymised. This maybe true, but, although the data held in databases may be apparently anonymised by removing identifiers such as name and address, if a large number of detailed variables are collected, or there are rarely occurring conditions included (e.g. BMT) then it may be possible to link the data back to individual patients (Sweeny 2002). Consequently, anonymised data is still subject to data protection principles in the UK (DOH 2002) and in Australia the NHMRC has clear guidelines for the use of such data (NHMRC 2007).

Gaunt (2000) made an pertinent statement in that "The most significant threat to the security of information in its organisation is its staff" and went on to discuss that the awareness and understanding of data protection legislation and guidelines for audit and research in among health professionals is highly variable. The majority of staff state that they are aware of data protection principles but are unclear about privacy and data protection laws and what they mean in practice (Meredith, 2005) and it is common to find that when faced with a specific situation they are often unclear of the action that should be taken (Behlan & Johnson 1999). Gaunt (2000) also points out that just having 'an awareness' does not ensure implementation of the data protection policy objectives. In addition, Gaunt (2000) states that despite professionals' acceptance of data protection principles, many do not accept personal responsibility for data security, even though personal responsibility is often highlighted in their job descriptions. This is a serious concern in the field of health informatics where personal clinical data (although apparently anonymised) is being held and can be rapidly searched or shared.

Mulligan (2004) guides us to a few legal provisions protecting confidentiality in Australia, namely:

- There is no general right to privacy in Australian law. Although there has been a gradual expansion of circumstances in which confidentiality may be defended by the courts, civil action is infrequent. The most recently reported South Australian case involving breach of confidence in health records was decided in 1994
- In parallel with legislation in other Australian States (*Health Administration Act* 1991 [NSW] s.22, *Health Services Act* 1988 [Vic] s.18, *Health Services Act* 1991 [Qld] s.100), the South Australian *Health Commission Act 1976* (s.64) prohibits employees from divulging personal information relating to any patient obtained in the course of employment unless authorised or required by law or by their employer.
- Other State statutes either permit or require medical practitioners to release specific kinds of patient information (eg, mandatory reporting of child abuse, *Children's Protection Act* 1993 [SA] s.11), providing a defence to action for breach of confidence in specific circumstances.

The Commonwealth *Privacy Act* 1988 (s.14) includes a set of Privacy Principles derived from the internationally recognised "Guidelines governing the protection of privacy and the trans border flows of personal data". The Privacy Act applies to Commonwealth agencies and has recently been amended to apply to the private sector, including private medical practices.

In addition, Kluge (2002) in his book discussing some general principles of health informatics ethics offers the following as guiding principles;

(1) All persons have a fundamental right to their privacy, and use of data about

(2) Manipulation of a subjects' data must be disclosed in an appropriate and timely fashion

(3) Any data legitimately held about a person must be assured every available security

(4) The subject of any set of data has every right to amend said set of data if appropriate

(5) The fundamental right of control over manipulation of personal data is conditioned only by legitimate and appropriate needs

(6) Any infringement of a person's privacy may only occur in the least intrusive fashion

(7) Any infringement of a person's privacy rights must be disclosed and justified in an appropriate and timely fashion

Annette Braunack-Mayer (2003) in her paper discussing 3 case studies of instances where patient information was shared and confidentiality breached, concludes with the following:

- Careful consideration of the ethical implications is required before patient information should be shared without the patient's knowledge.

- Routine and apparently uncontroversial releases of information can be perceived as problematic by patients.

- The ethics of such "ordinary" breaches of confidence can be explored by considering the patient's autonomy, the patient's best interests, and the public interest in preserving or breaching confidentiality.

- Patient autonomy can be supported and ethical problems may be avoided when patients are given as much information as possible about foreseeable information disclosures.

So, to answer your question – think very carefully before you disclose patient information to anyone and listen to your friend!

All the best for Chrimbo ….. ……

.and don't forget to wash your hands!!! **TRG**

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If you have any of life's questions, personal problems or niggling concerns about a major decision and you can't trust your star sign – write to me: Tea Room Guru, c/o The Editor, HSANZ – NG News.

2008 Dates for the diary

Feb 13 –17—BMT Tandem Meetings, San Diego, USA

Feb 28—NSW HSANZ—NG meeting, Sydney

Mar 30—Apr 2—EBMT, Florence, Italy

Apr 17—NSW HSANZ—NG meeting, Sydney

Jun 12-14, CNSA Winter Congress, Gold Coast

Jun 12-15 EHA, Copenhagen, Denmark

Jun 19- NSW HSANZ—NG meeting, Sydney

Aug 21 NSW HSANZ—NG meeting, Sydney

Oct 19 –22 HAA , Perth

Nov 20—NSW HSANZ—NG meeting, Sydney

Dec 6-9 ASH, San Francisco, USA

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