Kayaking for Kemo Kids

Kayaking Exploits By Dave McPherson

Dan presents Dave with a certificate of appreciation in the Oncology Unit.

I first met Bob Glenister at a Hawkesbury Canoe Classic dinner in 1998, where he was guest speaker. He talked about his daughter Rebecca and her fight against leukaemia and the wonderful support he and his family had from The Children's Hospital at Westmead. I was so moved that I offered to help in any way I could.

In the 1999 Sydney to Brisbane K4KK marathon, I paddled the day with Bob's team from Terrigal to Swansea. With the help of my wife and family and work mates at Energy Australia, in particular Warrick Laing, Michael Drinnan and Don McFarland, and the members of the Central Coast Canoe Club we were able to present Bob with a cheque towards his fund raising.

Bob invited me to do the whole trip from the Gold Coast to Sydney in 2001 and from Brisbane to Sydney 2003 – incredible events run over 23 days covering over 1000km each trip. Averaging 50 km per day at the mercy of the open sea, with out any sea support vessels and battling 4 to 6m seas, 40 – 50 knot winds. It was tough at times but with all the support we received from the people at our land stops encouraged us to continue.

Also, there was Brian Southall from Central Coast Canoe Club and Rod Totten from Windsor Canoe Club, some of our land crew who we could not do without.

In 2001 and 2003, the Kayaking for Kemo Kids team stayed at our home at Tumbi Umbi – there were bodies all over the house. It has been an honour to be associated with this event and help raise much needed funds to help with the terrific work carried out at The Children's Hospital at Westmead.

Kayaking for Kemo Kids has contributed over $390,000 to the Tumour Bank since Bob's solo paddle in 1998. Funds are raised through sponsorship, donations, gala dinners, auctions, head shaves, raffles and many other ways.

If you wish to contact Kayaking for Kemo Kids, please visit us at our website www.k4kk.com.au.

Dave in Kayak3, 2003 trip.

Artificial Neural Networks can predict clinical outcomes of neuroblastoma patients (continued)

treatment strategies."

"Using 19 genes instead of 25,000" said Khan "also allows the translation of our findings to the clinic since simple prognostic assays can be developed based on this small number of genes". In fact, three of the genes encode proteins secreted into the blood, raising the possibility that they can be used as serum markers in a simple blood test. In collaboration with industry, Khan's lab is now developing clinical assays based on these 19 genes and planning to test for the presence of these markers in other patients with NB.

Khan cautions that more studies are required. His lab has now begun a larger validation study using 300 NB tumor samples from national trials based in the US and UK.

the children's hospital at Westmead

Corner Hawkesbury Road and Hainsworth Street
Locked Bag 4001Westmead NSW 2145 Sydney Australia
Tel 02 9845 0000
Visit our website: www.chw.edu.au

For more information:
The Tumour Bank website address is
www.chw.edu.au/tumourbank
or you can email us on TumourB@chw.edu.au

Newsletter February 2005 Edition

the tumour bank

the children's hospital at Westmead

Tumour Banking Networks

Dr Dan Catchpoole
Head of Tumour Bank

In 2004 we saw The Children's Hospital at Westmead Tumour Bank go from strength to strength. Not only did we support 5 research projects around the world, but we saw 8 papers published in international scientific journals describing the results of projects involving tumour samples from the Tumour Bank. On the 2nd page of the Newsletter, you can read about one of these research projects, conducted by Dr Javed Khan at the National Cancer Institute in Washington DC, USA, who reports a novel approach for the diagnosis of neuroblastoma.

Not only has the activity of the Tumour Bank here at the Children's Hospital at Westmead been prolific during the past year but so has the Australasian Biospecimens Network (ABN). The ABN is a nationwide network of tumour and tissue banks who are working together to facilitate medical research into human diseases, including cancer, through the provision of ethically consented, clinically annotated and high quality tissue specimens which are key to the international competitiveness of Australian biomedical researchers. The ABN has recently received funding from the federal government National Health and Medical Research Council (NHMRC) which will allow it to build a structured national network. This will collect, process and disseminate tumour tissue as well as strategically collect specific tumour types, such as rare paediatric tumours, that can only be collected in substantial numbers through the formation of such a network. All tissue banks within the network abide by the same ethical guidelines and the tissue collected is only that for which we have obtained consent from the donor, also that we abide by the Privacy Acts.

Most recently, the ABN held its 2nd Annual National Scientific Meeting in Darling Harbour. We were honoured to have Professor Alan Pettigrew, CEO of the NHMRC open the meeting as well as participate during the day. The day was filled with interesting and informative presentations from experts from as far afield as the UK and Singapore who discussed topics relating to the ethical and legal issues faced by tissue bank managers, through to technical papers describing new methods for processing tissue for various research applications. We had a full house for the entire meeting with participants from around Australia and New Zealand. The success of this meeting emphasises how tissue banks play a central and vital role within the Australian medical research community.

Kids! Bring us your artwork and it may appear in the next edition of our newsletter.

The Tumour Bank at the Children's Hospital at Westmead would not have been able to come this far without the support of Kayaking for Kemo Kids. This small but eager band of sea kayakers, lead by Bob Glenister, have raised over $400,000 for the Tumour Bank. Whilst Bob has been the driving force behind this tremendous result, he will be the first to admit that he hasn't done it alone. Hence, it was with great pleasure that The Children's Hospital at Westmead and the Tumour Bank paid tribute to one of Kayaking for Kemo Kids strongest supporters, Dave McPherson who, despite his 60 years, has joined Bob on not one, but two of the 23 day kayaking marathons down the NSW coast line from Brisbane to Sydney. Please turn to page 4 to read more.

When you visit the Children's Hospital at Westmead please look out for new editions so we can keep you up to date with what we are leaning about cancer and please do not hesitate to contact us with any enquiry.

Research Project

Artificial Neural Networks can predict clinical outcomes of neuroblastoma patients. By Dr Javed Khan

Dr Javed Khan (3rd from right) and his research team.

Patients in North America who are diagnosed with neuroblastoma (NB) are currently stratified by the Children's Oncology Group (COG) into risk groups based on age, tumour staging, histology, and amplification of the gene MYCN. This guides what treatment these patients receive. However, despite this careful stratification, patients who have high-risk NB have poor survival, and it is not possible to predict which of these high-risk patients will survive or succumb to the disease. Researchers at the National Cancer Institute (NCI) have used artificial neural networks (ANNs) and DNA microarrays to successfully predict the clinical outcome of patients diagnosed with neuroblastoma. These findings appear in the October 1, 2004 Cancer Research.

Neural networks are specialized pattern recognition learning algorithms modeled after the human brain; they learn by experience. ANNs are often used in identification programs, such as fingerprint or voice recognition software. Javed Khan, M.D., and his team at NCI's Pediatric Oncology Branch, adapted an ANN algorithm to identify patterns in NB tumor gene expression. The study was performed in collaboration with colleagues from the NCI, Germany and Australia.

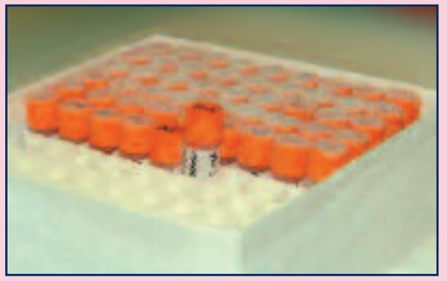
First, the researchers performed gene expression analysis on over 25,000 genes to create global gene expression profiles of primary tumors from 49 patients whose clinical outcome was known. The patients were divided into either good or poor outcome groups. "Neural networks were trained to recognize or predict "alive" or "dead" expression profiles from the samples" said Khan, "and then we determined if we could predict the outcome for the test samples using these trained ANNs". They found that the ANNs could predict the clinical outcome with an accuracy of about 88 percent.

From these 25,000 genes, the researchers tried to find the minimal number of genes that could act as a predictor set. The ANNs identified 19 genes whose expression levels could accurately predict outcome. Using these 19 genes, ANN prediction accuracy increased to 95 percent, and performed much better than the current COG risk stratification. Two of the genes in this group, have previously been connected to NB prognosis, and several of the others are known to be involved in neuronal development.

Using the 19 predictor genes, the ANNs were also able to partition the subset of high-risk patients into good and poor outcome groups. "What was most exciting," said Khan "was that we were able to predict which of the high-risk patients would fail conventional therapy. This has major clinical implications since we are now able to distinguish a group of ultra-high-risk patients who will not respond to conventional therapy and therefore require alternative

Continued on last page

all about the tumour bank



The long-term goal of research into childhood malignancies is to reduce the incidents of cancer and to improve the outlook of children suffering with this disease. It is through research that we will gain the knowledge about cancer that will eventually lead to new approaches in therapy. However, such research is dependent upon the availability of cancer specimens for the scientists to study.

The Tumour Bank

The Children's Hospital at Westmead Tumour Bank is a collection of cancer specimens, donated by patients and obtained through the normal course of treatment. These samples are placed in long term storage and made available to research scientists around the world for future investigations into the improvement in the diagnosis and treatment of children with cancer.

Since its inception in 1998, the Tumour Bank has stored over 20,000 samples from 2000 patients, representing 50 different types of cancers.

The aim of the Tumour Bank is to encourage and facilitate research to improve prevention, diagnosis and treatment of childhood cancer. By providing samples to research groups within the Hospital, around Australia as well as throughout the world, the Tumour Bank will prove to be a valuable resource as it helps us to…

- understand the molecular mechanisms which lead to cancers in children,
- develop tests that enable screening for those children at an increased risk of cancer,
- aid the establishment of new molecular-based diagnostic tests which will assist in the selection of the most appropriate treatments
- identify targets for potential new cancer remedies.

The Tumour Bank has already provided tumour specimens to research groups around Australia. Findings from some of these investigations will be briefly described in each edition of this newsletter.

Many people and departments throughout the Hospital have a role in the activities of the Tumour Bank. In particular, the Tumour Bank is supported by…

- The Oncology Research Unit.
- The Oncology Department.
- Histopathology and Haematology Departments.
- Medical Records Department
- Computer Services
- Public Relations
- Fundraising

Tumour Bank Coordinator Jane Carpenter with Adam and his Mum in the Oncology Clinic.

Consent

Many patients and parents support the Tumour Bank through the donation of tumour tissue, blood and bone marrow samples. These samples are removed from patients in the operating theatre or in the clinic during the normal course of treatment.

A consent form tells patients and parents about the Tumour Bank. This form, once signed, gives permission for samples to be stored in the Tumour Bank and later given to scientists studying childhood cancers.

Your decision to give us permission to collect samples from your child for the purpose of research is voluntary.

If you decide not to give your permission, or to withdraw it at a later time, your child's care will not be affected in any way.

Collection and Storage

The Tumour Bank receives resected tumours and biopsies as well as blood, bone marrow and Cerebral Spinal Fluid specimens that have been removed for diagnostic purposes from patients in the operating theatre or in the clinics.

Once the diagnostic process is complete, the residual tissue specimens are transferred to special low-temperature 'cryogenic' vials and immediately 'snap' frozen in liquid nitrogen. This freezes the samples very quickly and preserves proteins and genetic material within the sample. Once frozen, the samples are placed in numbered boxes and stored in a freezer at -80ºC.

In some circumstances, specimens stored within other Hospital departments may be requested by the Tumour Bank to further support research applications.

Database

Once stored, each sample is recorded on the Tumour Bank database. Information recorded includes…

- Age of the patient and age at diagnosis.
- History of the cancer.
- Type of cancer.
- Results of pathology tests.
- Type of treatment received.

Privacy

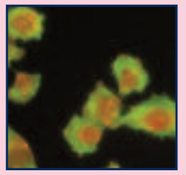
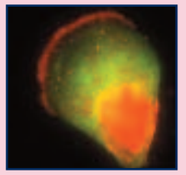
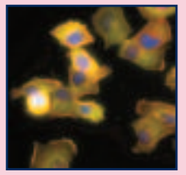
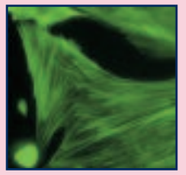
When the samples are provided for research, **your child's name will not appear on the sample.** At no time will any personal contact details (address, phone number) be issued with the specimens. **You and your child will therefore remain entirely anonymous** to the researchers who receive any Tumour Bank specimen.

However, if the findings of the research could help us with your child's treatment, the coding on the sample will allow the Tumour Bank staff to forward the results to the Doctor who is caring for your child.

More Information!

Our website address is www.chw.edu.au/tumourbank or you can email us on TumourB@chw.edu.au

Thank you for your support!

Cancer cells. The green colour indicates a protein associated with tumour development.

Photos courtesy of Julie Hughes