Kayaking for Kemo kids

OAM Honour for Kayaking for Kemo Kids Founder

After kayaking for more than 4,000 kilometres and raising almost half a million dollars, Kayaking for Kemo Kids founder Bob Glenister has been rewarded with a prestigious Medal of the Order of Australia (OAM).

Bob Glenister's commitment to raising funds for leukaemia research was recognised on 26 January 2003 when he was awarded the honour after completing his fourth epic kayaking marathon from Brisbane to Sydney, paddling into Darling Harbour on Australia Day.

Bob commenced fundraising for The Children's Hospital at Westmead Oncology Unit in 1996 when his daughter Rebecca was diagnosed with leukaemia. Although Rebecca now celebrates six years in remission, Bob has continued his campaign to further research into the disease to prevent other children suffering the same ordeal.

His fundraising efforts from earlier kayaking marathons resulted in the establishment of the Tumour Bank – an Australian first which provides tumour specimens to research scientists from all over the world.

Bob was joined by four other kayakers on his latest mission to raise money for the advancement of microarray genetic technology for the hospital which will tailor treatments to improve success rates.

The K4KK team departed Brisbane on 4 January on a gruelling 22-day marathon down the rugged eastern coastline raising funds at many of the coastal towns where they stopped each night.

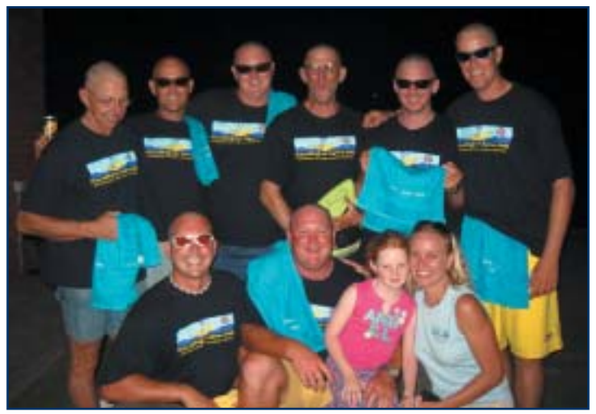
Bob's kayaking partners on the latest trip all volunteered their time to the campaign after having lost family and friends to leukaemia and cancer.

While Bob, Mark Elkington and Dave McPherson had completed prior K4KK marathons, none of them anticipated the challenges they would face on their 2003 campaign. Joined by Paul Officer and Steve Prasser, they endured unrelenting harsh conditions with consistent strong southerly winds and massive swells. At several times in the journey, the team was warned to cancel certain legs of the trip due to the severity of the conditions.

However the team which described themselves as having 'little muscles but big hearts' persevered and completed their journey on schedule, paddling into Darling Harbour on Australia Day, having raised more than $40,000 along the way.

The five paddlers were joined by a volunteer Land Crew team who assisted with fundraising activities and operations. The K4KK team received overwhelming support from many of the communities along the way with the tiny towns of Hat Head and Minnie Water raising more than $18,000 for the cause.

The K4KK team aims to raise $100,000 for The Children's Hospital at Westmead in 2003 and is seeking support from all corners of the community. Donations can be made online at www.k4kk.com.au or by sending to Kayaking for Kemo Kids Inc, PO Box 3122, Asquith NSW 2077.



Left: *Back Row: Rod Totten, Mark Elkington, Bob Glenister, Dave McPherson, Steve Prasser, Paul Officer. Front Row: Liam Thompson, Russell Glenister, Hayley Glenister, Kate Elkington.*

Right: *Sunrise at Woolgoolga*

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 Autumn 2003 Edition

the tumour bank

the children's hospital at Westmead

Tumours and Teamwork: The way forward in Cancer Research

Dr Dan Catchpoole
Head of Tumour Bank

I regret that I have to start this edition of the newsletter of The Children's Hospital at Westmead Tumour Bank on an unhappy note. In January this year, it was with great sadness that we said farewell to the Tumour Bank Research Nurse, Dianne Corrie who decided to make a career change and take on a new job closer to her home. Dianne has been the stalwart for the Tumour Bank for the past 4 years and worked very hard to make the Fishbowl a friendly and happy place where children with cancer felt comfortable and at 'home'. A picture of Dianne, along with details on how the Tumour Bank works can be found on page 2 and 3 of this newsletter.

One of the goals of this newsletter is to provide you with reports of the progress which is being made by researchers who are using the tumour and tissue specimens which have been stored in the Tumour Bank. In this edition we are pleased to inform you of the research being done into brain tumours which is being conducted by Dr Amar Gajjar of St Jude Children's Research Hospital in the United States and Dr Stewart Kellie from the Oncology Department here at The Children's Hospital at Westmead (see page 2).

This research report is a great example of one of the most important parts of successful research – teamwork. No cancer researcher can work in isolation and expect to get very far. Understanding how we get different cancers, how they work or their 'biology', and how best to treat them is very complicated. But just like sport, no one player can win the game by doing everything on the field by themselves. You need a team of players, each with different skills, to work together to get the best result. So it is with cancer research. When people with different scientific and clinical skills work in collaboration, the research done makes the greatest impact for children with cancer. In recent years the Tumour Bank has played a central role in a number of collaborative research projects which involve researchers from The Children's Hospital at Westmead teaming up with others from around the world.

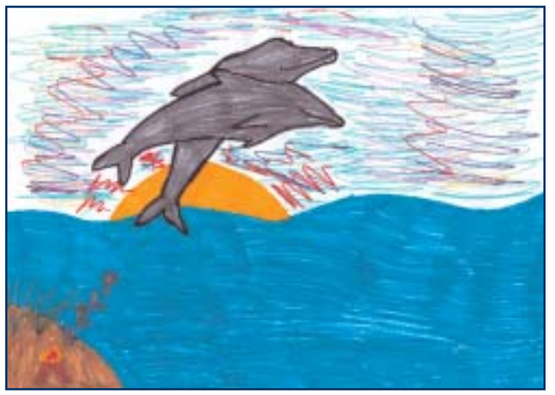
All teams work best if they are cheered on by their supporters. The Tumour Bank receives very strong support from Kayaking for Kemo Kids who continually cheer us on and raise money to support childhood cancer research. However, on Australia Day this year (26th January 2003) the Tumour Bank staff had the opportunity to cheer on the Kayaking for Kemo Kids team of Bob, Dave, Mark, Steve and Paul who spent 24 days paddling sea kayaks down the coast of NSW from Brisbane to Darling Harbour on their fourth kayaking marathon raising close to $100,000 on the way. The biggest cheer came when it was announced that Bob Glenister, founder of Kayaking for Kemo Kids, had been awarded an Order of Australia Medal in the Australia Day honours. This award is richly deserved and couldn't go to a nicer bloke. Please read more of this story on the back of this newsletter.

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.

Email: TumourB@chw.edu.au

pics by kemo kids

Drawing by Georgina Styles (age 12)



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

Research Project

“Brainy Doctors study brain tumours”

By Drs Amar Gajjar and Stewart Kellie

Dr Amar Gajjar

Dr Stewart Kellie

Medulloblastoma and related tumours account for 20% of childhood brain tumors. Therapy for medulloblastoma consists of maximal surgical resection, craniospinal radiation therapy, and chemotherapy. We are completing our first collaborative study, called “SJMB96”, where we studied how this combination of treatments could lead to the improved outcome for medulloblastoma patients. The use of all three of these types of treatment cure more than 75% of children (>3 years).

Whilst the initial results from this study are encouraging, further improvement in outcome is unlikely to be achieved without improved knowledge of tumour biology. Hence, we plan to conduct a comprehensive scientific study of tumour tissue to characterize the clinical significance of abnormalities in the proteins and genetic material, called DNA and RNA, in medulloblastoma. Through this study we hope to identify a molecular ‘fingerprint’ that will improve the accuracy of how we determine the risk a patient is at and help us develop new treatment approaches.

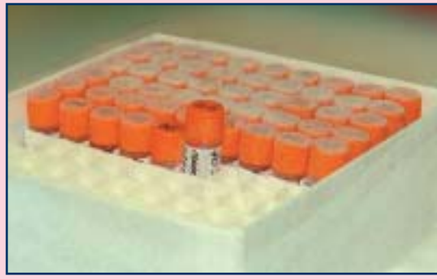
We have conducted a pilot study to assess the feasibility of analyzing fresh frozen tumor samples from patients treated at St Jude Children’s Research Hospital and at collaborating institutions within the US and Australia. In this pilot study 92 samples of snap-frozen primary medulloblastomas were collected from the St. Jude Tumour Bank, the Texas Children’s Hospital, the Royal Children’s Hospital in Melbourne, as well as The Children’s Hospital at Westmead. Despite being stored for a long time and spending up to 4 days in transit to the US we found that most of the processed tumour samples yielded high-quality protein, RNA and DNA for further scientific analysis.

What have we learnt thus far from the proteins, RNA and DNA we isolated form the samples?

- When we looked for a protein called ERBB2, we found that patients whose tumour expressed ERBB2 had a significantly worse response to our SJM96 treatment plan.
- A special technique called ‘real-time PCR’ was used to calculate how active two MYC cancer genes were in the tumours RNA. We found that the MYC gene activity showed no significant relationship with patient outcome or clinical characteristics.
- Alterations of the DNA which code for a gene called p53, which is known to be miscoded in many tumour types, were also found to be miscoded in 21% of the samples.

We look forward to support the ongoing collaboration between the Tumour Bank at Sydney and St Jude Hospital with the expectation that this kind of unique collaboration will give us novel approaches to treat medulloblastoma patients all over the globe.

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 6000 samples from 760 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

The Tumour Bank research nurse, Dianne with young Nicola and her mum in ‘the fishbowl’
Photo courtesy of Dr M. Stevens

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