



CHILDREN'S CANCER INSTITUTE AUSTRALIA REPORT TO APEX

FROM SMALL BEGINNINGS, BIG THINGS GROW



Professor Michelle Haber AM, Executive Director CCIA

In 1975 two men met in a hospital waiting room in Randwick, Sydney Australia. Their lives had been thrown into chaos as each grappled with the realisation that their child had leukaemia. Their consequential stories were symbolic of the then cure rate for those suffering from childhood cancer, one child died and the other lived. What did not die however, was their resulting commitment to childhood cancer research.

Both men were members of Apex Australia and, united by their suffering, they were motivated to create something lasting. What was to eventually become the Children's Cancer Institute Australia for Medical Research (CCIA) was founded on their friendship and dedication to "rendering altruistic service and building better communities"¹ and nurtured by the broader association.

In 1976 the Apex 'help a kid make it' campaign commenced nationally. Over the following three years 60,000 miles were covered, 300,000 pieces of literature were mailed and 10,000 phone calls were made by Apexians across the country raising more than \$1 million. By 1983 The Apex Centre, housing the Institute's first laboratory with three researchers, was opened.

APEX AND CCIA, PARTNERING FOR A CAUSE

Together, we have come a long way. Now with six research programs and over 140 staff and students, and with planning for a new purpose-built facility on the University of New South Wales campus well underway, we are experiencing success in our research that we could only have hoped for. Some things however, have not changed; the same three inaugural researchers are still with the organisation and Apex Australia has continued to provide support and funding for what we consider a joint cause.

¹ Apex Ideals from apex.org.au

“Without Apex our organisation would literally not exist. Past and present members of Apex should be immensely proud, as we are, of the small seed that was planted 30 years ago, that has become the organisation we are today, so much closer to our vision of saving the lives of all children with cancer and eliminating their suffering through world class medical research”.

Professor Michelle Haber AM, Executive Director CCIA

Over the course of our partnership, Apex has provided significant funding including the \$1.3 million foundation fund and regular generous annual grants. This has supported considerable organisation growth, with, over the last few years, a specific focus on funding particular research programs.

BUILDING LOCAL KNOWLEDGE WITH AN INTERNATIONAL FOCUS

CCIA’s current five year strategic plan has been designed to set the organisation on the path to becoming a world leader in childhood cancer research. This was an ambitious goal that is fast becoming a reality.

Our collaboration with major national and international research bodies and inclusion in significant international studies is demonstrated evidence of the importance we place on coordinating and pooling knowledge so that all childhood cancer sufferers around the world will reap the benefits of what we do here in Sydney, Australia. An example of such collaboration is our ongoing Minimal Residual Disease clinical trail for CCIA’s Minimal Residual Disease program for children with acute lymphoblastic leukaemia which uses a CCIA derived diagnostic test to tailor therapy and has recently expanded from Germany to now include The Netherlands as well as Australia.



FINANCIALS AND CORPORATE GOVERNANCE

At CCIA we adhere to a strong principle of stewardship of all funds and ensure financial resources are used carefully and wisely. In 2006, fundraising income represented 29.1 percent of CCIA’s total revenue, almost \$7 million. Fundraising expenses totalled almost \$2.6 million with a net return in the order of \$4.4 million. Administration expenses were kept to a minimum, representing 3.8 percent of the organisation’s total expenses². Recently CCIA implemented a very extensive business improvement program with a strong focus on compliance and risk management to further assist us in being good stewards of the funds we receive.

² See CCIA’s Annual Review 2006 for more financial information

REPORT ON 2005 GRANT TO THE MOLECULAR EPIDEMIOLOGY GROUP

In the 2005/2006 financial year, Apex Australia supplied a generous grant of \$37,150 to the work of CCIA's Molecular Epidemiology Group.



Dr Lesley Ashton, Group Leader

Epidemiology is a branch of science which investigates the distribution of a disease among the population in order to determine its cause. Our research involves investigating the influence of genes and other molecules, and is therefore referred to as 'molecular epidemiology'. Specifically Apex Australia funding went towards four key areas of research which have been outlined below.

Area 1

We are investigating the theory that delayed exposure to childhood infections may place some children at an increased risk of developing Acute Lymphoblastic Leukaemia (ALL), the most common type of childhood cancer.

Key Outcomes

- 600 families were enrolled in a study to examine the causes of ALL and have provided details on early infections and DNA specimens;
- CCIA have received approval from Medicare Australia to access the Childhood Immunisation Register to examine vaccination uptake of children with and without ALL; and
- Characterisation of gene variations involved in immune response to early childhood infections commenced, with functional studies underway.

Area 2

Brain tumours and other cancers of the central nervous system (CNS) are among the most common types of cancer found in children, with a very poor survival rate of 50 percent. To find out the causes of CNS cancers and whether anything can be done to prevent these in some children, we are developing a better understanding of environmental and genetic influences and the relationship between these.

Key Outcomes

- Began characterising genetic variations in 250 children with CNS tumours from the Sydney Children's Hospital, specifically investigating the role of a family of genes known to play an important role in how the body processes carcinogens (chemicals that have the potential to cause cancer, in the environment); and
- Joined a federally funded national case-control study which is recruiting families of children as they are diagnosed with CNS tumours in treatment centres around Australia. This large national study is aimed at identifying environmental and genetic factors that cause CNS tumours in children.

Area 3

Of the children who are alive five years or more after their diagnosis of cancer, the majority (70 percent) will go on to develop one or more of the life-altering health conditions known as 'late effects'. We are examining what can be done to prevent this, to ensure that children diagnosed with cancer in the future, once treated, can expect to live a normal, healthy life.

Key Outcomes

- Successfully traced over 800 childhood cancer survivors from a 30 year period through collaborative links with the Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital, and cross-referencing a number of public databases such as the Electoral Roll, National Death Index and Marriage Registry; and
- Recruited 400 survivors into the study who are providing DNA samples so that we can examine their genes, and are completing a questionnaire about late effects they have experienced as well as lifestyle factors.

Angela Boland, Childhood Cancer Survivor



Area 4

By studying healthy babies in NSW we are examining the connection between genes and ethnicity to determine the role that gene variations may have in the development of childhood cancer.

Key Outcomes

- Collaborated with Sydney Adventist Hospital to collect specimens of umbilical cord blood from babies born to mothers at the hospital; and
- Recorded data about every child's ethnic background, then analysed their cord blood sample and begun comparing the frequency of these gene variants in healthy newborns with that found in children with cancer.

EXTENDING THE PARTNERSHIP

Apex Australia and CCIA have a partnership built on longevity, respect, accountability and a shared vision. We look forward to the opportunity to continue to work with you in 2007 and beyond, and are excited about examining mutually beneficial ways of extending our very important partnership.