



2013-2014
annual report



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1. Message From the Bedside to Bench Board & Chief Executive

There is a story behind every treatment, health policy, and clinical protocol breakthrough that we have today. The story begins with a patient and an unanswered question, an observation leading to research, and a discovery that is translated into clinical practice.

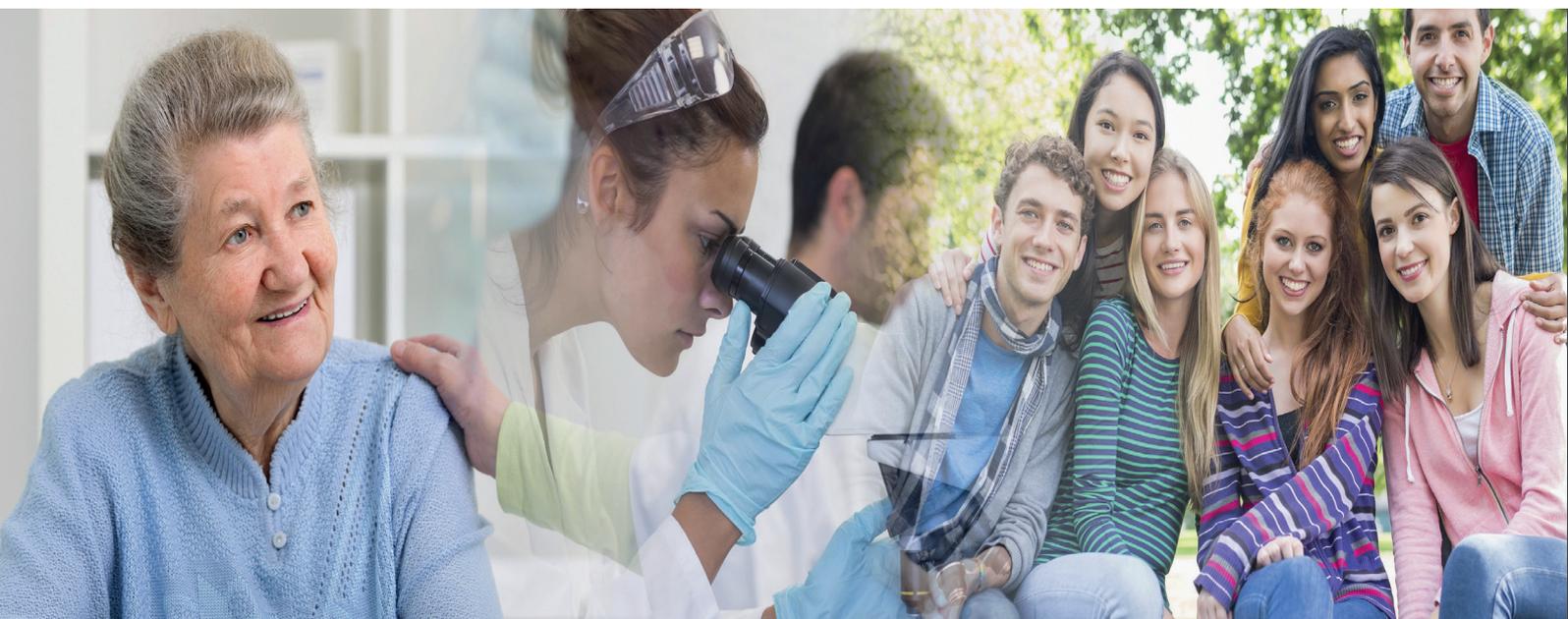
There are however many unanswered questions that research is yet to answer. For too many patients, treatment options are either not available or not accessible; but we will never find the answers if we aren't asking the right questions. To give us the best chance of providing patients with timely access to treatments and health services, we need to ensure that we, as researchers and clinicians, are listening to the issues that patients are facing and clinical trend, to give us clues and direction for research and health service development. Bedside to Bench provides a platform for this to happen, for patients and their families to be heard.

It has been a great honour to launch Bedside to Bench and help provide a closer connection between research and the community that it aims to benefit. At Bedside to Bench our definition of community includes patients, carers, clinicians, researchers, policy makers, industry, and all stakeholders that have a role to play in improving our health system and advancing medical research. It is less about 'us and them' and more about what we can do as a community that values the experience of patients and their families, the expertise of clinicians and researchers, and the contribution of industry.

In the first 18 months of operations, Bedside to Bench has focused on developing programs and products and testing these through pilot projects. This has included workshops at Medical Research Institutes (Children's Cancer Institute Australia, Lowy Cancer Research Institute, Australian Pancreatic Cancer Genome Initiative); qualitative research to support an industry submission to the Pharmaceutical Benefits Advisory Committee (Avastin as a therapeutic agent for ovarian cancer); and a community petition to support an industry submission to the Pharmaceutical Benefits Advisory Committee (25,000 signatures to support Abraxane for use with metastatic pancreatic cancer patients). We have demonstrated success through our Internship Program, with over 40 interns completing the program and our Internal Research Program has also had success with our first peer-reviewed article published in July 2014.

Bedside to Bench is ready to roll out operations on a national basis and our approach will continue to be to work with all stakeholders and leverage the well established health and medical research talent, resources and health services that we have in Australia. We have demonstrated success and most importantly, research institutes, industry partners, the government and the community are ready and waiting for us to fill this very important role.

For those who have supported us through donations; on behalf of Bedside to Bench and all those that have benefited from our work - thank you.



Catherine Holliday

PhD MHP MHSc Grad Dip Nutr BN
Bedside to Bench, Chief Executive

Catherine's professional work has focused on developing solutions to some of the more difficult health system challenges. As Head of Research Strategy at Cancer Council NSW, she has been a leader in community engagement in research, conducting prioritisation processes and developing strategic and operational plans in the field of cancer, most recently in complementary medicine; brain, pancreatic, liver and oesophageal cancers; and personalised medicine. Catherine has significant experience working with government, not-for-profit organisations as well as research and international organisations including close to ten years working in Geneva, Switzerland with the United Nations, Australian Department of Foreign Affairs and Trade, UNICEF and the Global Alliance for Vaccines and Immunisation. She has also worked in the USA in a community health setting. Her PhD thesis investigated the relationship between the global, social and economic drivers of research and how to translate results into policy, practice and population health. She has two masters degrees, the first investigating public-private partnerships in health and the second focusing on the operational and implementation requirement of public health initiatives. Catherine's work has included health system strengthening, public health program development, monitoring and evaluation, governance and compliance. In recent years, she has developed research and organisational strategies for a number of organisations across research, clinical care, policy and advocacy. Catherine is also proud to be a Registered Nurse.



Board of Directors

Mike Hasenmueller (Chair) has extensive experience in adult education and training. He has worked in the UN system at senior management levels, and has demonstrated experience in network building. Mike's role on the Board is to guide the development of the Bedside to Bench business model and program implementation.

Paul Hendry has worked in the Pharmaceutical Industry for over 20 years. Paul sees the value of connecting pharmaceutical companies with the patient community as a way to convince the broader Pharmaceutical Industry that whilst delivering results and returns are important, our main driver must be in saving and/or improving the lives of patients. From a personal perspective his interest comes from the fact that his eldest daughter suffers from an auto immune disease and fortunately can manage that via a combination of drugs. He sees the great value in these lifesaving medicines yet the personal connection between the patient, his daughter, and the drug research/provider company could add value to both parties.

Ursula Hogben has over 15 years legal and management experience in Australia and internationally. Ursula has helped many businesses launch, expand locally and internationally, and bring in investors. Ursula helps business people understand legal issues, manage risk and negotiate confidently. Her role on the Board is to provide legal advice and support network building. In addition to her professional experience, Ursula has personal experience within the health system and plays an important role in bringing this perspective to the Board.

Rebecca Sutherland is the daughter of Rob and Cheryl Sutherland, and brings with her the Bedside to Bench vision. As the youngest member of the Board, Bec's role is to guide Bedside to Bench in reaching younger populations and engaging them in our organisational mission, as well as bringing her creative flare to our work.

Tony Shaw is a patent attorney at Allens Linklaters. He specialises in the preparation and prosecution of patent applications in the life sciences. Tony completed his PhD at the University of Queensland. Upon completing his PhD he won a postdoctoral scholarship at the Imperial Cancer Research Fund. As a researcher, Tony understands the challenges that researchers face and also, the importance of engaging the community in their work.

2. Organisational Summary

Bedside to Bench is a non-profit organisation bringing much needed change to the way we think about, conduct, and translate medical research in Australia across all disease streams.

Bedside to Bench was launched in February 2013, and is dedicated to the late Professor Robert L. Sutherland AO FAA. Rob was a pioneer in translational research in Australia and internationally, and a visionary who adopted a 'Bedside to Bench' approach to cancer research. As his daughter Rebecca Sutherland explains,

"Dad thought that by listening to patients and clinicians at the bedside, scientists could identify the most important research questions to answer at the bench. The importance of working to achieve this ideal was reinforced throughout Dad's own cancer treatment. It is this *bedside to bench* approach that we continue through the organisation in a number of ways, so that in the end, patients receive the benefits of research, sooner"

Bedside to Bench implements community engagement in research programs, helping researchers and industry to connect with the community, so that projects being developed address the most pressing and important clinical problems currently facing patients and their carers – research that has a better chance of making a difference to patients, sooner rather than later, and all the while helping patients to have their voice heard.

This is the Bedside to Bench approach.

Vision: Our vision is to facilitate meaningful connection between health service providers, research organisations, industry and the communities for which they provide a service or aim to benefit.

Services and programs: Our services and programs are aligned with our five strategic goals across Capacity Building, Health Education and Health Promotion, Community Engagement, Anecdotal Evidence, and Research. We also have a fee-for-service program to support the implementation of research, into the clinic.

Outcome: The outcome will be that we will accelerate research through developing projects that have a better chance of being translated into the clinic; we will have a closer connection between the community, clinicians, researchers and industry; and as a nation, we have a better understanding of the value of research.

Unique value proposition: Previous attempts to involve the community in research have been over-politicised, and driven from the perspective of engaging patients without meaningful thought to the reason why the community needs to be engaged or how each stakeholder group can benefit from engaging the community.

Bedside to Bench is an independent and unaffiliated organisation with one level of governance. We were established to be responsive to stakeholder needs, and deliver services that advance translational and clinical research through community engagement, in a timely and effective manner. To our knowledge, we are the only organisation providing this level and type of service, and the only organisation taking a community-based approach to raising the profile of research in Australia.

Company status: Bedside to Bench is a Company Limited by Guarantee and holds full charity status.

Strategic Goal	Services and Programs
SG1 Capacity Building: Provide opportunities for researchers, public health and health practitioners to develop their skills in a supportive environment and increase community-driven program development	<ul style="list-style-type: none"> • Bedside to Bench Internship Program • Certificate IV in Training & Assessment Grant Program
SG2 Health Education and Health Promotion: Deliver targeted and practical health education that empowers individual decision-making	<ul style="list-style-type: none"> • National Health Education and Promotion campaigns to empower individual decision-making and increase uptake of existing health services
SG3 Community Engagement: Facilitate connection between health professionals, researchers, public and private sectors, and the community for more meaningful community engagement	<ul style="list-style-type: none"> • Community Engagement in Research Program at all major Medical Research Institutes and pharmaceutical companies • National awareness campaigns to increase awareness and support for clinical research • Industry program providing qualitative research services to accelerate the regulatory process
SG4 Anecdotal Evidence: Provide an environment where the experience of individuals and specific populations is systematically recorded and used to support health policy and practice decision-making	<ul style="list-style-type: none"> • Annual community-based surveys to understand the experience of patients in the health system, with a specific focus on access to clinical research
SG5 Research: Conduct and support medical research that addresses the needs of the community	<ul style="list-style-type: none"> • Internal Research Program



3. Report on Strategic Goals

SG1: Capacity Building. *Provide opportunities for researchers, public health and health practitioners to develop their skills in a supportive environment and increase community-driven program development*

The Bedside to Bench Internship Program offers individuals a structured and supportive internship where they are able to develop skills and gain practical experience in the field of public health, health education and research. Interns work with Bedside to Bench over a 12 week period to complete a defined project with weekly deliverables. The Program supports interns by providing in-service and professional development opportunities, and at the end of the program, work placement support is provided to all interns. There is also the opportunity for interns to apply for a grant to complete a Certificate IV in workplace training and assessment so that they become qualified to deliver community engagement and health education training sessions within their future workplace(s). To date, Bedside to Bench has welcomed more than 40 interns to the program.

Meet Bedside to Bench Intern : Claudia Lee

I wanted to complete an internship in an organisation that combined my two study areas, media communications and health science (nutrition). Also, since my mum survived cancer, I have been interested in cancer related nutrition. In my internship I wanted to develop my nutritional knowledge, apply my skills and become further educated on foods relating to cancer prevention and treatment enhancement. Moreover, I wanted be able to help promote these health education messages in the community to those who may not have access to this empowering knowledge. The experience of my internship was both personally rewarding and professionally valuable and I would strongly recommend it to individuals studying in the health discipline.



SG2: Health Education and Health Promotion. *Deliver targeted and practical health education that empowers individual decision-making*

Our flagship health education program aims to encourage the community to understand the important of clinical trials, and encourage patients when diagnosed with a disease to ask if there is a clinical trial for them. This year we also ran health education campaigns aligned with Mother's Day and Father's Day. These are times of the year when individuals are often looking for a meaningful way to celebrate the occasion. The focus of our Mother's Day campaign was the importance of knowing your family medical history. For some, the 'Listen to your mother' campaign provided families with an opportunity to talk with their mother about their family history and for others it is a way to remember their mother and talk with their family to develop their medical history together. A tool was provided which individuals were then able take to discuss with their family doctor.

Through our Father's Day campaign, the health message was that getting a second opinion is ok. 'Dad knows best...or does he? Get a second opinion' educated the community to trust their instincts and if they are unsure about a diagnosis or treatment decision, that a second opinion is a reasonable action to take.

These initiatives were unique in that they encourage individuals to have a more proactive relationship with health care professionals and more productive interaction with the health system. They are innovative as they are centred around simple and effective messages, regardless of individual levels of health literacy, yet have the potential to significantly improve population health.



**listen to
your mother**

One of our Facebook followers
Kate Whittaker who posted and
Tweeted this picture carrying
our public health Mother's Day
campaign message.

SG3: Community Engagement. *Facilitate connection between health professionals, researchers, public and private sectors, and the community for more meaningful community engagement*

Our Medical Research Institute (MRI) Program offers patients, carers, and researchers support to conduct meaningful community engagement initiatives. This year Bedside to Bench ran programs at the Children's Cancer Institute Australia, Lowy Cancer Research Institute and with the Australian Pancreatic Cancer Genome Initiative. Our Chief Executive Dr Catherine Holliday was also invited to present the program at the Research Australia and Australian Association of Medical Research Institutes conferences. Through the MRI Program, we help institutes establish the practice of community engagement. There are over 80 research institutes in Australia and our goal is that each one will systematically engage the community in their work through Bedside to Bench. Our program offers research institutes access to:

1. An annual, in-house Community Engagement Workshop. We start by convening community panels made up of patients and carers within research institutes, and then during the workshops, Bedside to Bench provide education and support so that everyone understands the research process. We then facilitate a conversation with the researchers so that the research being developed better addresses the needs of patients and their families. One workshop per MRI will be held in September each year to align with grant development and application processes.

2. An annual Community Engagement Professional Development Workshop for MRI staff who are responsible for community engagement efforts within their institute. Workshops are aimed at providing support to institute staff in relation to interpreting community engagement in research policies and implementing best practice; evaluation of community engagement efforts; how to address challenges; and how to get the most benefit from community engagement efforts in relation to supporting translational research.

Importantly, we will evaluate the program in the context of both process indicators and the impact of the program on translational research. This is yet to be demonstrated and will in itself be a cutting-edge field of public health research.

Associate Professor Karen Canfell leads the Cancer Modelling Group at the Lowy Cancer Research Centre UNSW and has participated in one of the Bedside to Bench workshops.

"It was fantastic on a number of levels; firstly to talk with patients and understand their experience, secondly to get feedback on our research, and finally, to take some time to reflect on how our work can help as many people as possible. We made a number of changes to our research after the workshop that add that extra value needed to really make a difference."

SG 4: Anecdotal Evidence. *Anecdotal Evidence: Provide an environment where the experience of individuals and specific populations is systematically recorded and used to support health policy and practice decision-making.*

Anecdotal evidence is one type of qualitative research and can help us observe a situation from a different perspective or form a hypothesis for further research. Bedside to Bench collects anecdotal evidence from the community, patients, carers, researchers and clinicians in a systematic way to inform directions in research and health service development. A focus of our data collection is in relation to the experience that the community has with clinical research, for example whether they have been asked to participate in a clinical trial. By doing this, the research that is funded and health services that are developed, have a better chance of meeting the needs of all stakeholders and a better chance of being accepted and translated into practice. This will ultimately lead to smarter and more successful investments in health services and medical research. In this context, Bedside to Bench will play a role in auditing whether expenditure and programs in health and medical research, particularly in the non-profit sector, is addressing the needs of the community.

In 2014 we worked closely with a number of community groups to understand their needs. Through our work with the Australian Pancreatic Cancer Genome Initiative, Bedside to Bench met an incredible group of pancreatic cancer patients and carers. We worked with the group to help them understand the research and clinical care environment and identify how they, as members of the community could be more involved and make a difference.

Throughout the year, the group produced a number of newspaper articles, radio and television interviews to raise awareness of the devastating nature of the disease, and the need for more research and supportive care, and Megan Barnes led a courageous campaign to approve a subsidy for the drug, Abraxane for pancreatic cancer patients. With the support of the community, 25,000 signatures of support were collected and it was recently announced that the government will subsidise Abraxane for metastatic pancreatic cancer, reducing its price to patients from \$5000 a month to just \$36.10.

Bedside to Bench will continue to support community efforts, just like this one so that all patients have access to affordable treatments.



Pancreatic cancer patients will now pay just \$36 for treatment, not \$5000.

The research process and developing new or re-purposing existing therapeutics, is complex. Researchers, clinicians, pharmaceutical companies and the government all play an important role, however there is a gap in terms of where the community fits in this ecosystem.

We worked with Bedside to Bench Ambassador, Megan Barnes, in a campaign to approve a subsidy for Abraxane for pancreatic cancer patients.

Abraxane is a drug that was available at an affordable price for other cancer types but not pancreatic cancer. Recent clinical trials show that it is an effective drug for pancreatic cancer patients with metastatic disease, but community support was needed to accelerate a decision.

With the support of the community, 25,000 signatures were collected and it was announced that the PBAC would recommend to subsidise Abraxane for metastatic pancreatic cancer, reducing its price for these patients from \$5000.00 to just \$36.10 a month.

Pancreatic cancer often presents as advanced, metastatic disease where the life expectancy after diagnosis can be just a few months or weeks. Abraxane is not a new drug, but for these patients, it can increase survival by an average of two months.

Two months may not seem like a long time, but to a pancreatic cancer patient and their family it may mean one more family Christmas together, seeing a child graduate from university, or just having time to say goodbye.

Like many patients and their families, Megan Barnes had too short a time to say goodbye to her Dad following his pancreatic cancer diagnosis.

"There are days when I would do anything to spend even one more minute with Dad, to hear him say "Here comes my favourite daughter" just one more time. Just to say I love you a few months longer and to thank him for being the most amazing role model a daughter could ever ask for."

"If we had those two extra months with Dad we would have been able to celebrate his birthday together which fell just 4 days after he passed away."

Image Left: Patients, carers and researchers participating in a discussion about community engagement in research with Bedside to Bench Chief Executive, Catherine Holliday.

SG5: Research. *Conduct and support medical research that addresses the needs of the community.*

Every treatment decision, health policy and clinical protocol that we have today started with a patient and an unanswered question, an observation leading to research, and a discovery that is translated into clinical practice. Through our research program, we will continue to support and conduct research that addresses the needs of the community.

Bedside to Bench has commenced a number of research projects to identify the needs of the community. Research projects included:

- Understanding when, where and how consumers would like to be engaged in cancer research. This research is complete and has been published in Cancer Forum.
- A comparative study of levels of care required for poor prognosis diseases (in progress).
- Identifying how and when individuals learn how to access health care and what support is needed to increase access (in progress).

Julie Morgan has had a rich career working with and advocating for the rights of the most vulnerable populations and herself went through treatment for breast cancer in 2013 and 2014.

“As someone who has experienced cancer, the expertise I bring is the very fact that I have lived through the symptoms before I was diagnosed, been through the treatment, navigated the health system, and continue to deal with the side-effects.”

“I hope that in sharing my experience I can add to the scientific process so that patient-centred care rather than pattern-centred care really does become the new normal. The fact that Bedside to Bench aims to do just that – to spark thoughts about the value that patients and carers bring to research – that’s worth fighting for.”

Understanding how consumers would like to engage in the research decision-making process

Cancer Forum, Vol. 38, No. 2, Aug 2014: 149-153.

Author: Catherine Holliday,⁽¹⁾ Janice Kwok,⁽¹⁾ Kimberley Yip,⁽¹⁾ Cathy Axford,⁽²⁾ Skye Simpson,⁽²⁾ Amber Johns,⁽²⁾ Nik Zeps,⁽³⁾

1. Bedside to Bench
2. Australian Pancreatic Cancer Genome Initiative
3. St John of God Healthcare

Abstract: There is an increasing emphasis on community and consumer engagement in cancer research, from identifying priorities to reviewing grants from a consumer perspective. It is clear that there is great interest from the community and consumers to be more actively involved in research, and many organisations and research institutions have responded by convening consumer advisory panels, including consumers on boards and committees, and including consumers and the community in forums and research seminars. While the opportunities available for consumers to participate in research are welcome, current mechanisms to engage with consumers often appear to be tokenistic and bureaucratic. Bedside to Bench, a research, community engagement and health education organisation, conducted an online, consumer engagement in research survey over four weeks. The aim of the survey was to determine when and how cancer patients and their families how they would like to be involved in research. The survey was developed following feedback from consumers at the Australian Pancreatic Genome Initiative's annual research symposium, that suggested current opportunities for consumers to engage in research were limited. Eighty two cancer patients and carers responded to the survey. The majority of respondents (82%) stated that they were interested in being involved in the decision-making process in relation to cancer research. The greatest area of interest was in having access to the results of research projects (23%) and providing feedback to researchers once the projects are developed (23%). Other areas of interest were the development of research projects with researchers (17%), identification of research priorities (17%), with the lowest area of interest being grant reviews (13%). The results of this study suggest that the majority of consumers want to be involved in research in some way, however, given the option, there is potentially only a subset of consumers interested in the review of research grants. What is clear is that, whatever the mechanisms for consumer engagement, strategies, policies and resources need to be available in order to support all stakeholders improve the practice of research involving consumers. The results of this study will be useful to guide future research and policy decisions in relation to community engagement in research.



4. Organisation Structure and Management

Bedside to Bench was registered in November 2012 and is a public company limited by guarantee, holding full charity status in Australia.

We operate under a constitution that includes a governance structure where the role of the Members is to elect the Core Directors. The process for electing members to the Board is outlined in our Constitution.

The management of quality processes and outcomes at Bedside to Bench are underpinned by our Standard Operating Procedures, based on the Plan-Implement-Review-Improve model. Bedside to Bench uses the PIRI cycle to coordinate continuous quality assurance and improvement efforts.

The organisational structure of Bedside to Bench allows us to be reactive and nimble in the context of health and medical research. The proposed staffing plan in the first three years will bring the total staff number to 11. There will be no middle management and we will implement a flat organisational structure.

The names of each person who has been a board director during the year are: Peter Edwards (Resigned 10.10.14); Paul Hendry (appointed 11.7.14); Ursula Hogben (appointed 5.12.13) Michael Hasenmueller; Tony Shaw (appointed 11.7.14); Rebecca Sutherland (appointed 11.7.14); Brian Amos (Resigned 2.1.14); Melanie Brake (Resigned 31.7.14). The financial and governance audit was conducted by Trumans Chartered Accountants, Chatswood NSW.

5. Financial Summary

Bedside to Bench have commenced operations on a limited budget during the development phase and have tested various funding and revenue-raising mechanisms to support the implementation of our full program of work. In-kind human resources including the CEO and interns were provided to the value of \$310,000.

INCOME	
Rent received	2200
Donations received	65,623
TOTAL INCOME	67,823
LESS EXPENDITURE	
Audit fees	2,500
Advertising and promotion	3,520
Bank charges	314
Conference	827
Depreciation	928
Donations	100
Electricity	702
Filing fees	1,113
Heath Education	10,909
General expenses	2,816
Office equipment	1,127
Rates and taxes	323
Rent	23,409
Salaries and wages	10,893
Staff training	1,205
Storage fees	130
Subscriptions	840
Superannuation contributions	1,008
Telephone	1,013
Travel expenses - domestic	4492
TOTAL EXPENDITURE	68,169
NET OPERATING PROFIT (LOSS) (346)	
Retained profits at the beginning of the financial year	5,032
TOTAL AVAILABLE FOR APPROPRIATION	4,685
RETAINED PROFITS AT THE END OF THE FINANCIAL YEAR	4,685
CURRENT ASSETS	
TOTAL CURRENT ASSETS	6,326
TOTAL FIXED ASSETS	3,086
TOTAL ASSETS	9,412
CURRENT LIABILITIES	
TOTAL CURRENT LIABILITIES	4,727
TOTAL LIABILITIES	4,727
NET ASSETS	4,685

