 NSW
ANNUAL
REPORT
2012–13

TALKING ABOUT ALZHEIMER'S ACROSS AUSTRALIA
FIGHTDEMENTIA.ORG.AU
Acknowledgements
The Australian Government funded programs of Alzheimer’s Australia NSW are: the National Dementia Support Program (NDSP) which includes early intervention or Living with Memory Loss program; National Dementia Helpline and Referral Service; Counselling Services; Education and Awareness; Dementia Memory Community Centres (at North Ryde, Bega, and Port Macquarie); Dementia Awareness Week activities; Your Brain Matters dementia risk reduction and brain health program; Regional Partnerships (with the Murrumbidgee Local Health District; Greater Western Local Health District, and the New England Division of General Practice); and includes part funding of the library and carer education services. The Australian Government has also funded the Bega Mobile Respite Service through the National Respite for Carers Program (NRCP).

The NSW Government, through NSW Family and Community Services (Ageing Disability & Home Care) and NSW Health funds a number of programs including the Dementia Advisory Services (Mid North Coast, Southeast NSW, Southwest Sydney, Southeast Sydney); Carer Education; Support Group Leader Training Program; Aboriginal dementia awareness program; Disability & dementia training program; and Dementia Awareness Week activities.

We would also like to acknowledge the generous support from numerous clubs, trusts and foundations, with whose help we are able to broaden awareness to many communities and support people living with dementia across NSW.

Alzheimer’s Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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GM Fundraising: Simon Crowson
GM HR & Volunteers: Anneliese Coghlan
GM Marketing & Communications: Andrew Mills
GM Media: Sarah Price
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Alzheimer’s Australia NSW is a quality accredited organisation.
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Board of Directors:
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Ambassadors:

Pictured L to R:
PJ Lane
Maxine McKew
Sir Michael Parkinson CBE
Ita Buttrose AO OBE (also AA National President)
Natarsha Belling
Doris Younane
VISION

A society that is committed to the prevention of dementia, and that values and supports people living with dementia.

MISSION

To minimise the incidence and impact of dementia through leadership, innovation and partnerships in advocacy, policy, education, services and research.
**AlzNSW Strategic Plan**

**Major Goal Areas**

1. **FOR THE GENERAL PUBLIC:**
   We aim to build a community that understands effective risk-reduction strategies, where the stigma around dementia is reduced.

   By 2015
   * We will significantly increase the understanding of dementia risk-reduction strategies across NSW
   * We will significantly reduce the stigma about having dementia.

2. **FOR PEOPLE WITH MEMORY CONCERNS:**
   We aim for a more timely diagnosis for people with memory concerns with a smooth referral to AlzNSW for early intervention support.

   By 2015
   * Working with GPs, specialists and others, we will put in place measures and tools to improve timely dementia diagnosis and easy referral of diagnosed patients to us
   * We will raise awareness of dementia and AlzNSW
   * We will add new support programs tailored for people newly diagnosed and their carers

3. **FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CARERS:**
   We aim to significantly improve the quality of life for people living with dementia and their carers, through service improvement initiatives and partnerships with other organisations.

   By 2015
   * Reach: we will increase the reach of our current services to areas in most need (Western Sydney, Greater Western NSW, Tweed, Illawarra) and underserved client groups (younger onset dementia, culturally and linguistically diverse (CALD), and Indigenous groups)
   * Quality: we can demonstrate that all our programs deliver the outcomes that make a difference to people living with dementia and their carers
   * Influence: we have demonstrated thought-leadership and innovation in the sector and worked in collaboration with others to develop excellence in dementia service delivery and policy.

4. **BUILD A STRONG ORGANISATION AND SECTOR:**
   To support all these activities, we aim to increase funding to us and the dementia sector and strengthen our organisation.

   By 2015
   * We will achieve a sustainable funding base by maximising Government funding and increasing non-government fundraising by 10-20% pa
   * We will increase our social and medical research funding by 20% pa
   * We will invest further in our people and systems
   * We will continue to actively support more national initiatives

5. **MAINTAIN SIGNIFICANT GROWTH:**
   To cope with the rapidly increasing dementia challenge we aim to significantly grow our organisation’s capacity and outreach
A NEW STRATEGIC GOAL HAS BEEN ADOPTED BY THE BOARD OF DIRECTORS – WHICH IS TO MAINTAIN SIGNIFICANT GROWTH TO COPE WITH THE RAPIDLY INCREASING DEMENTIA CHALLENGE

In the May 2012 Federal Budget the Australian Government introduced its $3.7 billion ‘Living Longer, Living Better’ aged care reform package with $268.4m dedicated to fund more dementia packages and services over the next five years.

Within this package, Alzheimer’s Australia NSW (AlzNSW) received funding to continue its vital work in supporting people living with dementia, their families and carers through support for the National Dementia Helpline, Living With Memory Loss program, carer education, and counselling and support services.

Since the Government’s announcement, AlzNSW has maintained a high level of advocacy with policy makers and Government bureaucrats to ensure dementia remains front-of-mind so that these reforms are implemented promptly and equitably.

Dementia was officially recognised as the ninth National Health Priority by the Council of Australia Governments (COAG) in December 2012. This is a huge step forward in recognising the importance of dementia and the huge growth in numbers that we face in coming years.

AlzNSW launched three excellent new Discussion Papers during the year which raised numerous thorny issues that were identified by our wonderful Consumer Advisory Groups. The discussion paper topics were ‘#5: Dementia & the move into residential aged care’, ‘#6: Football, head injuries and the risk of dementia’ and ‘#7: Living alone with dementia’. I congratulate all staff involved with the production of these papers, as well as their subsequent promotion through the media.

At the November 2012 AGM, I was elected to be your new Chairman, and I would like to pay tribute to the outgoing Chairman, The Hon. Professor Peter Baume AC, who has so skillfully guided the organisation for the past years. At the AGM Maree Gleeson AO and Dr Robert Yeoh AM both resigned as directors after many years of dedicated service.

I would like to thank them both for their outstanding contribution to the organisation, which is much stronger as a result.

A new strategic goal has been adopted by the Board of Directors – which is to maintain significant growth to cope with the rapidly increasing dementia challenge. As a result we aim to significantly grow our organisation’s capacity and outreach. I am pleased to report that AlzNSW recently received funding from the Australian Government to appoint twelve new Younger Onset Dementia Key Workers. This funding has allowed us to move into geographical areas not previously served by the organisation – including Western and South Western Sydney, the Illawarra, the Central Coast as well as other regional areas. The impact of these new roles is starting to be felt already.

Throughout the past year, AlzNSW has welcomed international dementia experts including Dr Serge Gauthier (Canada) and Prof Julian Hughes (UK) who spoke at packed venues. It is very important to bring in experts in science and medicine to build awareness in the media, and government about this terrible condition.

Finally, I would like to congratulate the whole AlzNSW team, as well as my co-directors and the AlzNSW Advisory Council for their ongoing dedication and valuable contributions throughout the year.

Jerry Ellis AO
Chairman
CEO’S REPORT

IT WAS ANOTHER SUCCESSFUL YEAR FOR ALZHEIMER’S AUSTRALIA NSW DURING WHICH WE CONTINUED TO GROW STRONGLY

It was another successful year for Alzheimer’s Australia NSW during which we continued to grow strongly, expanding our services across NSW and developing new and innovative ways to advocate on behalf of people living with dementia and their families and carers. Our awareness-raising initiatives proved to be creative and successful. We have never lost sight of our responsibility to do all we can to raise awareness about the impact of dementia on our community, on families and on so many individual Australians. We have, of course, continued to deliver high quality, compassionate services including education, counselling, information and carer support.

At Alzheimer’s Australia NSW we are committed to excellence in all we do and maintain quality accreditation through QIP. In the past year we adopted an Aboriginal Engagement Plan to guide our increasing work in indigenous communities and continued to devote considerable attention and resources to the many different CALD communities across NSW.

We have delivered a range of memorable events through the year. Dementia Awareness Week was overwhelmingly successful as were our Memory Walks in Sydney, Newcastle and Wollongong. We released three, well-researched discussion papers and developed a range of material to assist GPs in the diagnosis of dementia. I am pleased to report that our events and publications are always of the highest quality and have been very well received.

Our staff continues to grow in size, in expertise and in their commitment to our cause. A staff survey undertaken in the year revealed a strong sense of staff connectedness and devotion to the work we are doing. We are very fortunate to have many very gifted, professional and hardworking staff who understand the dementia challenge and who are committed to doing all they can to achieve improved outcomes for their clients and patients. We have received constant feedback about the quality of our staff from clients and carers.

Mr Jerry Ellis AO, has provided exceptional leadership to the Board and all Directors remain committed and deeply interested in the work of the organisation. Senior management and staff feel supported and inspired by our Board’s interest and support.

Whilst there is a long way to go, it is possible to sense a change in the public interest and support for the dementia cause. Awareness of our organisation is expanding, media interest in the cause developing and Government support growing. We hope that we are coming close to that tipping point when the cause of supporting people living with dementia and their families and carers becomes absolutely mainstream and more widely understood and supported. Partly that is being reflected in the very strong partnerships that we are entering into with Governments, residential aged care providers, and a range of community organisations.

We receive regular approaches from a range of parties who wish to partner with us, donate to our cause or provide volunteer support. We look forward to the day when the rights of people living with dementia and their families and carers are centre stage, understood by the community, supported by Governments and in receipt of generous donor and volunteer support.

The Hon John Watkins
Chief Executive Officer
Become a Dementia Champion

My favourite memory is:

Teaching the grandchild how to sail

Visiting my grandparents' garden as a child. It had a mulberry tree withベンツ and love.
FIGHT DEMENTIA CAMPAIGN

ALZHEIMER’S AUSTRALIA’S FIGHT DEMENTIA CAMPAIGN WAS CREATED WITH TWO SEPARATE BUT RELATED STRATEGIES, WITH A VIEW TO PROMOTING A SOCIAL MOVEMENT FOR DEMENTIA.

Firstly, with the guidance of Interbrand, a leading international branding consultancy, we developed a revolutionary new look for Alzheimer’s Australia’s brand and image. The advice we gave to Interbrand early in the process was that we wanted to let off “a great explosion” to combat the lack of understanding and support for dementia in the community.

Secondly, to ensure this “great explosion” had the desired effect we worked with Porter Novelli, a leading public relations agency. With their ongoing support the Fight Dementia Campaign was developed.

The campaign has focused on promoting awareness using the stories of people directly affected by dementia. The campaign has been supported by:

• 7,500 Dementia Champions
• 21,500 Fight Dementia Facebook ‘Likes’
• 3,500 Twitter followers for AA
• our National President, Ita Buttrose who engaged her 30,000 Twitter followers.

This online army of more than 60,000 people put pressure on the Government to put in place a funded action plan in the 2012-13 Federal Budget to combat dementia.

On 20 April 2012, in response to the Fight Dementia Campaign, the Prime Minister and the Minister for Mental Health and Ageing announced an investment of $268.4 million over 5 years to tackle dementia as part of the Living Longer. Living Better. aged care reform package. This package addresses dementia across the health and aged care system and responds to a number of the priorities from the Fight Dementia Campaign.

The Fight Dementia campaign has involved many individual events, the most recent of which was in the lead-up to Valentine’s Day on 14 Feb. 2013, where supporters sent thousands of cards asking our political leaders, “To plant the seed of a memory that will last a lifetime”. On Valentine’s Day Alzheimer’s Australia staff and supporters took to the streets around the country, encouraging the wider community to send cards. Thousands of cards were received at Parliament House in Canberra.

Thank you to all the supporters of the campaign and to Porter Novelli and Interbrand for your guidance and support. Together we achieved many of the campaign’s goals.

We are very pleased with the commitment of the incoming Abbott Government to set aside funds for research in dementia over the coming years.

This does not mean that the Fight Dementia campaign is over. We will always have more to do in seeking extra funds and resources for people living with dementia.
At AlzNSW we work within a quality framework that ensures policies and procedures are in place, monitored, reviewed and kept up-to-date in line with changing operational and legal requirements. The following are the key policy areas addressed in 2012-13:

Protecting our reputation in the media:
Alzheimer’s Australia NSW’s reputation and image is governed by how it is perceived externally.

The Media, Marketing and Communications Policy aims to protect AlzNSW’s reputation by providing staff and stakeholders with the requirements and their obligations for the use of agreed corporate identity guidelines in relation to all communication activities. AlzNSW has an obligation to ensure that all external PR and Communication activities meet corporate governance requirements, communicates key messages and conforms to corporate identity guidelines (branding) and Alzheimer’s Australia protocols.

Social Media Policy - moving ahead on the web:
AlzNSW embraces use of social media as a corporate communications and community building tool, but we must also recognise the risks associated with its unregulated use. The Social Media Policy provides clarity to employees and volunteers on their professional and personal use of social media in order to protect AlzNSW in the face of an ever-changing social media landscape. It intends to establish a culture of openness, trust and integrity in activities around Web 2.0 and social media activities, while understanding that all comments made via social media platforms are as public as if the same comments were made to the media or at a public forum.

Protecting Intellectual Property and respecting the work of others:
The policy document on Intellectual Property and copyright aims to protect the Intellectual Property of both Alzheimer’s Australia NSW and others and looks to minimise the risk of copyright infringement by meeting the legal obligations defined and governed by the Copyright Act.

Building company relationships:
This policy provides guidelines for AlzNSW staff, volunteers and contractors to adhere to when working with for profit companies. It acknowledges that AlzNSW has mutually beneficial relationships with a range of companies including manufacturers and suppliers of medicines, medical devices and aids to daily living, dietary supplements, health management organisations, aged care agencies and insurers. Support from companies for AlzNSW’s work is acceptable within the context of this and related policies which aim to protect AlzNSW’s reputation as an unbiased source of advice, information and support for people living with dementia, their families and carers. While AlzNSW and the companies we cooperate with may share common interests in regard to research, public health and philanthropy, some of these companies have a motivation and an expectation of commercial return. It is therefore essential for AlzNSW to be clear about where those interests overlap and where they diverge.

Creating a transparent complaints process:
Having a complaints policy and procedure in place highlights the value of complaints in monitoring and improving the provision of all AlzNSW’s activities. The document includes the procedures to be followed to ensure complaints are managed appropriately, in a timely manner and that no complainant is victimised or discriminated against as a result of making a complaint. It encompasses all types of negative feedback from the formal complaints where a resolution is explicitly or implicitly expected to informal suggestions.
Transparency in reporting:

We have changed a lot of our reporting systems in an effort to improve our reporting and create a more transparent system. The intranet is being used to distribute monthly reports to managers in a reasonable timeframe, improving the efficiency and access to reports. The monthly reporting contains better financial information from a program manager’s perspective, which combined with a more effective design, allows for easier allocation of available resources.

Managing the risk:

AlzNSW is committed to a structured and coordinated governance approach which identifies, quantifies, responds to and monitors the consequences of potential risks within the organisation and externally to the organisation. There are five areas of risk:

- Governance
- Corporate
- Workforce
- Community
- Operations

Each of these areas carries with it the potential for an internal or external impact on the organisation. We are in a position to assess and respond to potential risks if and as they appear through internal systems and processes, like strategic planning, quarterly reviews and monitoring, quality and risk management and financial reporting.

Cross-border collaboration:

As part of our efforts at AlzNSW to continuously improve how we do things, there are a number of collaborative undertakings between states occurring in a bid to increase the capacity of our service delivery for people living with dementia, their carers, families and friends. There are five areas we are collaborating on:

- Communications
- Fundraising
- IT (information technology)
- Helpline
- Better Business Group

Collaborating across states on these areas will help AlzNSW to better understand the cost of services and how to deliver the most from the funds we have available.

Improving technology within AlzNSW:

Improvements to technology within AlzNSW has meant all staff are up-to-date with the current computer applications. A video conferencing capability will be added in 2013-14 to better integrate regional offices and improve service delivery.
FUNDRAISING

By: Simon Crowson - GM Fundraising, AlzNSW

Memory Walk & Jog:

Fundraising efforts continued with Memory Walk & Jog events held in Sydney, Hunter and Illawarra this year. A record 3,731 people took part in these three events. The major supporter of Memory Walk & Jog was Bupa aged care. The events also had the support of Guardian Funerals, Hansen & Cole Funerals, David Lloyd Funerals, Community Options Illawarra, IRT, Share and Leichhardt City Council.

Sydney Memory Walk & Jog

A record 2,000 runners and walkers took part in the annual Memory Walk & Jog around the Bay Run at Lilyfield in May and raised $168,000 in online donations.

2013 Australian of the Year and Alzheimer’s Australia National President Ita Buttrose and Bupa Ambassador and former World Ironman Champion Guy Leech joined the crowds to walk and run in the race against dementia.

The CEO of AlzNSW, The Hon. John Watkins, said this year’s annual fundraising event was the most successful yet, with a record crowd turning out in support of people living with dementia, their families and carers.

Hunter Memory Walk & Jog

More than 1,200 people united at the inaugural Hunter Memory Walk & Jog at Speers Point Park on Sunday 9 September to show their support for people living with dementia, their carers and families.

More than $70,000 was raised online by the event, which will go towards supporting the AlzNSW Memory Van, and AlzNSW CEO The Hon. John Watkins said the organisation was overwhelmed with the level of support we received for Memory Walk & Jog.

Illawarra Memory Walk

The Illawarra Memory walk was held at Stuart Park, North Wollongong on Saturday 15 September, with more than $30,000 being raised online to support the AlzNSW Memory Van visits to the area.

More than 500 people took part in the walks to show their support for people living with dementia and their families, including McLeod’s Daughter actress Doris Younane, an AlzNSW Ambassador, who was also the MC of the event.

Memory Walk & Jog was a huge success in 2012/13 and we look forward to continuing to grow the events even further in future years.

Generosity can be appealing:

There were four direct mail appeals again this year sent at Spring, Christmas, Easter and Tax. These appeals greatly assist AlzNSW to continue to deliver services which help people living with dementia. We would like to thank those who gave generously to our appeals this year.

Community fundraising has never been easier:

Efforts were taken to make fundraising for AlzNSW more effective and modern with the introduction of a number of new fundraising avenues and initiatives like the regular giving program. New online Dementia Fighter and Community Fun-raising donations pages were launched in July and December as part of the regular giving and community fundraising programs. You can also donate to Alzheimer’s Australia NSW through your payroll system at work under the workplace giving program.

The introduction of additional fundraising avenues online now allows people to give regular donations or utilise the system to promote and fundraise for their community events simply and easily. By simplifying the giving process and encouraging regular donations Alzheimer’s Australia NSW can count on a more reliable source of income, helping us to plan ahead with less administration costs and increasing the amount available to deliver services to those living with dementia, their carers, family and friends.

There were 300 active members of the community who supported us in raising close to $50,000 as part of our
team Memory Joggers. This year fundraisers took part in the City2Surf, Blackmores Sydney Running Festival and, for the first time, the Sydney Harbour 10K. Next year the opportunities to donate to AlzNSW will expand even further as participants to a number of running, cycling, swimming and walking events choose to raise funds for AlzNSW.

A busy fundraising year ended in style with the launch of our first national fundraising campaign 'Bring It To The Table' (BITTT), kindly sponsored by IPSOS. Friends and colleagues gathered for dinner parties, movie nights, Onesie Wednesday, backyard barbecues, trivia and games nights to raise awareness and funds. AlzNSW was fortunate enough to have two very special ambassadors join us this year for BITTT. Kitchen Whiz host and former MasterChef contestant Alice Zaslavsky came on board with author of Like Grandma Used to Make and Dirty Girl Kitchen creator Rebecca Sullivan. Alzheimer’s Australia NSW would like to thank Alice and Rebecca for their support. BITTT will be back next year and we hope to continue to grow this annual fundraiser.

**Trusts and Foundations:**

This year has seen a great continuation of new and existing support from various Trusts and Foundations. With this support, AlzNSW has been able to increase its service delivery, reaching more of those currently experiencing and living with dementia in NSW. We would like to sincerely thank all of those who have generously supported our fight against this increasingly prevalent condition.

**Bequests:**

A bequest to AlzNSW enables us to extend our services to meet the growing demands of our ageing population. AlzNSW received seven gifts in Wills last financial year. These generous bequests have provided vital funding for dementia services, participation in research initiatives, as well as provide education, knowledge skills and risk reduction strategies to people with dementia, their families and carers.
DEMENTIA AWARENESS WEEK (DAW) IS OUR SIGNATURE AWARENESS EVENT AND ONCE AGAIN PROVED TO BE AN OVERWHELMING SUCCESS.

With events being held across NSW, DAW raised much-needed awareness about dementia, as well as funds to support people living with dementia, their carers and families.

THE THEME WAS: BRAIN HEALTH - MAKING THE CONNECTIONS.

Sydney provided the backdrop for the launch of the world’s first, publicly funded health program to tackle the dementia epidemic, Alzheimer’s Australia’s Your Brain Matters program.

International dementia expert Dr Serge Gauthier (Canada) was on hand to help launch the brain health program, which aims to help cut soaring rates of dementia.

It comes on the back of increasing evidence that looking after your brain, body and heart can help reduce your risk of developing dementia. A recent study found that if risk factors, including smoking, obesity and lack of physical activity, were reduced by 25 per cent, there would be three million fewer cases of Alzheimer’s disease worldwide.

Your Brain Matters is a guide to keeping the brain healthy by looking after our mind, body and heart and is for people of all ages.

“The development and roll-out of Your Brain Matters has been made possible by funding by the Federal Government in the 2012 Budget,” the CEO of AlzNSW The Hon. John Watkins said.

“The Australian Government is the first government globally to introduce public policy around dementia risk reduction through the Department of Health and Ageing, which means it is being recognised as a chronic disease and not just a normal part of ageing, and for that we congratulate them.

“It’s important to understand that while there is, as yet, no cure for dementia there are things we can all do now – like keeping your brain active, being fit and healthy and looking after your heart – which may help to reduce our risk of developing dementia, or slow cognitive decline in those already diagnosed with dementia.

“There is evidence to suggest that, for example, if we reduced the physical inactivity rate in Australia by 5 per cent every five years, dementia prevalence would be cut by 11 per cent by 2051. That’s around 100,000 fewer Australians living with dementia as a consequence of addressing just one risk factor.”

Federal Minister for Mental Health and Ageing, Mark Butler, welcomed the initiative. “The Gillard Government is proud to partner with Alzheimer’s Australia to tackle dementia and Your Brain Matters is an important part of that effort,” said Mr Butler.

Dr Gauthier, the director of the Alzheimer’s Disease Research Unit at the Centre for Studies in Ageing at McGill University in Canada, said Australia is showing remarkable leadership in the fight against Alzheimer’s disease through its research programs and support for a public health approach to prevention.

Dr Gauthier was in Australia for a nationwide seminar series for Alzheimer’s Australia, starting with a public seminar on Monday 17 September in Sydney at NSW Parliament House.

“Evidence-based programs like Your Brain Matters, developed by Alzheimer’s Australia, are crucial in trying to stem the incidence of dementia,” Dr Gauthier said.

Ita Buttrose, National President of Alzheimer’s Australia said, “Your Brain Matters has the power to be a game changer in the way we all think about dementia. We may be able to help ourselves reduce our risk of dementia in our everyday lives.”

More information on Your Brain Matters: A Guide to Healthy Hearts & Minds can be found at www.yourbrainmatters.org.au. A copy of the evidence paper, Targeting Brain Body and Heart for Cognitive Health...
and Dementia Prevention: Current Evidence and Future Directions, can be found at www.fightdementia.org.au.

**TV & CINEMA CAMPAIGN 16 - 28 SEPTEMBER 2012:**

Titled ‘There’s a difference…’, our community service announcement (TV commercial) has been very successful in both raising awareness and where to get help. The campaign ran across metro, regional and rural NSW. The commercial can be viewed on our YouTube channel: [http://www.youtube.com/watch?v=xAjEvacz-S8](http://www.youtube.com/watch?v=xAjEvacz-S8)

**CARER SUPPORT GROUPS**

More than 50 ‘Morning Tea’ grants were approved across NSW for dementia Carer Support Groups.

**GP AWARENESS CAMPAIGN**

Our new GP awareness campaign highlighted the benefits of timely diagnosis and where to get help, by directly targeting doctors in appropriate medical publications. A new website for GPs was also launched and it consolidated relevant materials suitable for GPs and their patients. Visit [www.detectearly.org.au](http://www.detectearly.org.au)

**GP Info campaign:** InfoMed PL distributed our popular ‘Worried about your memory?’ brochures to more than 750 larger GP clinics across NSW. This program continues to expand the reach of information to health consumers and the general public in the convenient locations of larger GP clinic waiting rooms.

**Ethnic and Aboriginal awareness programs:** In addition to an extensive Aboriginal media campaign, our TV and Radio community service announcement were translated into various community languages to further broaden our reach. Languages include: Arabic, Chinese, Greek, Italian, Spanish and Vietnamese.

Our fourth short film in this series ‘It’s not a disgrace - it’s dementia’, aimed at the Spanish community, was launched on our YouTube channel. We have already completed short films in Assyrian, Khmer (Cambodian) and Croatian languages, along with Ukrainian, Serbian and Arabic. More community language resources are underway.

You can find them at: [www.youtube.com/alzheimersaustralia](http://www.youtube.com/alzheimersaustralia)

**Acknowledgement:** Dementia Awareness Week is supported by financial assistance from the Australian Government and the NSW Government.
A generous philanthropic grant from the Heine Family Foundation has resulted in the creation, by AlzNSW, of an innovative care program in Western and Southwestern Sydney, and the Hunter region of NSW in July 2012, offering a best practice and multi-component program to carers.

The program includes the following key elements:

- Individual counselling and advice – tailored to individual and family needs
- Information and education through structured education sessions, speaking at carer support groups and facilitating and coordinating workshops
- Peer support – coming together with other carers to share experiences and strategies
- New evidence-based social and therapeutic programs for carers.

Since the program commenced, AlzNSW has:

- Recruited qualified staff to deliver carer support activities
- Undertake consultation with key stakeholder groups to inform the development of the program and in particular:
  - identify carer support service needs and gaps
  - identify priority target areas for program delivery
  - establish referral pathways to the program
- Delivered 316 individual and group counselling sessions to 285 participants (many were multiple sessions)
- Eighteen people attended ‘Living with Memory Loss’ courses, and 74 people attended ‘Social and Support Activities for Carers’ courses

What people say about the new services:

**Catholic Care Coordinator at Liverpool, November 2012:**

“The AlzNSW Counsellor had been seeing one of my client’s carers for a few weeks when I noticed a real shift in her person. The carer had always been totally consumed by her mother and the problems that she has with looking after her. Daughter was often near to tears when talking about the behaviours she had to cope with. After a few counselling sessions I could see a real change in her attitude and approach to life. It was the first time I had spoken to her where she seemed happy”.

**Hunter Region Counsellor, May 2013:**

“Many of the older residents live outside town and are characteristically very resourceful and independent. An example of this is an 85 year old man with a heart condition who cares for his ailing wife while maintaining a 100 acre vineyard. It took some time for him to accept support.”

“I heard about you from the garden maintenance man. He said he noticed the difference in (name of client) who said they had been to see you.”

**Carer attending the Carer workshop pilot in Mt Druitt, November 2012:**

“Being careful of my own non-verbal messages. Be more understanding of Mum’s feelings, understanding that what she feels is real to her, even though totally unrealistic to me. Letting her help me, for example, giving a massage as well as receiving one.”

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**NEW SERVICES FOR CARERS IN WESTERN SYDNEY**

By: Anne Lunnon, Manager - Support Services, AlzNSW
ALZHEIMER’S DISEASE CAUSES DIFFICULTIES WITH SPEECH THAT DOESN’T MEAN WE SHOULDN’T TALK ABOUT IT

TALKING ABOUT ALZHEIMER’S ACROSS AUSTRALIA
FIGHTDEMENTIA.ORG.AU
The move to paperless pay:
In August 2012 we commenced a market evaluation of HR and payroll providers to find a solution that would best meet the business needs of AlzNSW in the move to an outsourced and paperless payroll system. Micropay was selected as the preferred payroll provider and the transfer of payroll commenced in January 2013. ConnX was chosen as the HR employee payroll portal with configuration beginning in February 2013. All staff were HR trained and online by the 30 June 2013. Micropay and ConnX were chosen for their unique combination of HR and payroll capabilities which has allowed AlzNSW to move to a completely paperless payroll and HR system. All data is stored securely and can be accessed easily by staff and management with a permanent electronic record of all balances and transactions. Superannuation has been outsourced to an electronic payment system saving hours of staff time writing cheques each month and ensuring regularity of payment.

Recruiting Younger Onset Dementia Key Workers:
Recruitment for the National Younger Onset Dementia Key Worker Program began in February 2013. Of the 40 positions available nationwide 11 were recruited in NSW along with a team leader. Never had AlzNSW needed to recruit this volume of people to the same positions at the same time. To simplify the process, assessment centres were established in partnership with Hays recruitment in NSW, an extensive assessment centre candidate selection process was designed and carried out. The use of assessment centres instead of individual interviews significantly reduced the amount of time required by the three interviewers in selecting the final team. There were four assessment centres and through a series of role-plays the final candidates were selected and offered positions by May 2013 for commencement of the program on 1 July. Key Workers are located in Blacktown, Sutherland, Wollongong, North Ryde, Newcastle, Port Macquarie, Central Coast and Cooma.

The recruitment for the Younger Onset Dementia Key Worker Program, along with other new positions, saw the number of staff at AlzNSW increase from 102 people to 121 employees during the course of the financial year.

Assessing staff satisfaction:
At the request of the board the inaugural AlzNSW staff climate survey was designed in conjunction with the strategic plan objectives in September 2012. The survey attracted a 90% staff participation rate when it was conducted in November 2012. The survey demonstrated that at AlzNSW staff are highly engaged and committed to the organisation and what it does, with 83% of respondents agreeing with the vision and mission of AlzNSW. Areas that were identified for improvement include innovation and creativity, integrity and trust, leadership and technology and organisational systems. To improve some of the areas identified by the survey, AlzNSW has developed an action plan and is working to increase communication between levels of management with regular meetings, greater opportunities to transfer knowledge between levels, and technological improvements including the introduction of video conferencing. AlzNSW plans to conduct future staff climate surveys and monitor improvements against results from the inaugural 2012 report.

Volunteers:
AlzNSW is extremely grateful to have fantastic volunteers who donated their time and expertise to numerous AlzNSW events and functions held throughout the year. The number of volunteers at AlzNSW has increased by 92% from 167 volunteers in the previous financial year to 321. Without the generous time donated by volunteers to events like Memory Walk & Jog in Sydney, Hunter and the Illawarra, Dementia Awareness Week, Valentine’s Day, Blackmores Sydney Running Festival, Christmas 2012 and Seniors Week 2013 concerts would not be possible.

The Sydney, Hunter and Illawarra Memory Walks saw an estimated 360 volunteers pull together and put in some 1,800 hours at an approximate value of $36,000 to make Memory Walk & Jog happen. There are also people who volunteer regularly at our offices in Bega, Hunter, Illawarra, North Ryde, Port Macquarie and Sutherland.
who allow the work of AlzNSW to go on. AlzNSW would like to thank all our volunteers for all that they do throughout the year.

Celebrating 30 years in style:

To coincide with the 30th anniversary of AlzNSW a thank you morning tea was held at Government House in Sydney on 7 November 2012. There were more than 100 people in attendance and many of the guests included people living with dementia and their carers, volunteers, those involved in the establishment of AlzNSW, board members and long serving members of staff. Special guests included the Her Excellency Professor Marie Bashir AC CVO, Governor of New South Wales, AlzNSW CEO The Hon. John Watkins, Chairman Prof. Peter Baume AC and Mrs Jenny Baume, Chairman elect Mr Jerry Ellis AO and Mrs Ann Ellis, Australian of the Year 2013 and Alzheimer’s Australia National President, Ita Buttrose AO OBE, AlzNSW ambassador Doris Younane and AlzNSW Advisory Council chairperson Barbara Cail AM. One of our members, Barry Freeman, spoke about his experience of caring for his wife, Joan, who has dementia. Morning tea was served outside on the veranda.

Photo: Volunteers Marg Ryan and Debbie Linden from Bupa Care Services Corporate Office, helping out at our Valentine’s Day event.
This year has been highly productive for the team with the launch of a number of important discussion papers which have generated much public debate and media attention. We have also seen the continuation of the popular ‘planning ahead forums’ which are open to the public at various venues in Sydney and regional areas.

Easing the difficulty of transition into Residential Aged Care:

Carers often remark that moving a loved one into residential aged care is the most difficult decision they are faced with. Working with industry partners, UnitingCare Ageing and Baptist Community Services, the discussion paper, The Most Difficult Decision: Dementia and the Move into Residential Aged Care, was launched in November and highlighted the difficult choice and emotional time for carers. The paper highlighted that there were things providers could do to make the experience easier and better for carers and people with dementia moving into residential aged care. By investing time in the settling and moving in period, the process can be made more pleasant for everyone involved and can also lead to a reduction in complaints from family members. A $660,000 grant was received from the Department of Health and Ageing in June 2013 to assist smaller providers of residential aged care to benefit from the knowledge gained by AlzNSW. The grant allows AlzNSW to build on that knowledge and support providers to implement some of these changes and make the move into residential aged care a more positive one.

Advocating for player protection:

The launch of Football, Head Injuries and the Risk of Dementia, in March, saw AlzNSW make clear its position on better protection for players against head injuries and concussion to reduce the risk of developing later-life cognitive impairment and dementia. The position paper was launched in the context of what was happening more widely among the football codes with former players in the United States initiating a class action against the NFL and the NRL and other football codes dealing with the issue of on-field concussions. The issue featured strongly in the media across Australia. Our contribution to the discussion has been positively received and assisted in raising awareness of this ongoing and important issue.

Maintaining independence:

The launch of the discussion paper Living alone with Dementia in June shone the spotlight on what is an under-resourced and under-serviced population group that is set to increase in number in the future. People living alone with dementia often face additional challenges, due to the fact they are living alone, and rules that prevent people from accessing services if they do not have a carer. People living with dementia, should not be disadvantaged simply because they live alone. Staying independent for as long as possible should be encouraged and AlzNSW hope that by starting the conversation policy makers will take note and make changes to help people live alone a lot longer.

Evaluation of the Dementia Advisors:

An evaluation was undertaken with our Dementia Advisory Service (DAS) positions with a grant from the Dementia Collaborative Research Centre (DCRC) to determine if the DAS workers were performing the role of a key worker. The evaluation found that they are largely fulfilling the role of a key worker for people with dementia and their carers. The evaluation has been a useful review in terms of service improvement and has supported the development of uniform program guidelines around how the DAS service is delivered.

Top-shelf library services:

There was continued support of library services across the four Dementia Memory Community Centres in North Ryde, Hunter, Port Macquarie and Bega with 724 new items added to our catalogue. We have also been supporting small collections in Cooma, Bateman’s Bay, Mid-North Coast Dementia Advisory Service, Orange, St George/Sutherland Dementia Advisory Service and Wingecarribee Dementia Advisory Service.
The DVD shelves have been given a make-over with Community Development Support Expenditure (CDSE) grants contributing to new dementia DVD resources available for loan through the library. Blogs for Younger onset Dementia http://youngerondsetdementiaandme.blogspot.com.au/ and latest Library News http://alzheimersnswlibrary.blogspot.com.au/ continued to be updated with a third blog for Carer Support Groups introduced and regularly updated.

Throughout the year the library:

- had 684 consumer visits
- had 660 professional visits
- posted 2,236 items to consumers across NSW
- posted 1,508 items to professionals throughout NSW
- loaned 4,526 items
- emailed 1,847 articles to Healthcare professionals
- responded to 1,265 reference questions
- distributed 209 newsletters to 1,486 e-mail inboxes with 27,300 page views

**Shaking the movers and shakers:**

There were two important policy submissions this year. The submission to the Senate Standing Committee on Community Affairs - Inquiry into care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD) raised concerns about access and quality of care for people with BPSD both within mainstream services and in access to specialised services for those with more severe behaviours in NSW. The submission highlighted the fragmented system in NSW, issues with BPSD management in hospitals, community and residential care, and showcased some of the better examples of behaviour management policy and practice in NSW.

The pre-budget submission to the NSW Government (2013-14) called on the state government to fully fund the NSW Dementia Services Framework Implementation Plan – with a set of five priorities identified by Alzheimer’s Australia NSW at a total cost of $60 million per annum. The allocation of a total of $60m per annum would assist in the achievement of these priorities:

1. Healthy Ageing programs to contribute to dementia risk reduction - $15m pa
2. Funding to support the Local Health Districts (LHDs) to deliver improved dementia care - $8m pa
3. Engagement with primary health care and Medicare Locals by Local Health Districts (LHDs) to improve care coordination for people with dementia - $4m pa
4. Implement initiatives to support improved clinical practice in hospitals and community health services to benefit people with dementia - $9m pa
5. Fund community based services for people with dementia living in their own home or residential aged care, to prevent and decrease hospital admission rates - $24m pa.
CONSUMER ENGAGEMENT

By: Jo-Ann Brown - Senior Social Researcher, AlzNSW

THROUGHOUT 2012-13, AlzNSW CONTINUED ITS TWICE ANNUAL MEETINGS WITH THE EIGHT CONSUMER ADVISORY GROUPS ACROSS NSW.

The Consumer Advisory Groups meet in North Ryde, Newcastle, Port Macquarie, Armidale, Orange, Wagga Wagga, Cooma and Wollongong, and were consulted about:

• The new policy and service developments for younger onset dementia

• Online Resources – what would consumers like to see?

• New developments around early diagnosis of dementia

• Dementia – the 9th National Health Priority – what does it mean?

• New Fight Dementia Campaign - $200 million over 5 years for dementia research

• Dementia terminology for fundraising and media

• And suggestions about AlzNSW discussion paper topics.

Pictured: Members from the Cooma Consumer Advisory Group (left to right): Front Row: Patricia Crowe, Keith Montague, Christine Kauffline; Middle Row: Ruth Blattman, Jo-Ann Brown (coordinator), Sandra Owen, Verity Jackson (AlzNSW Cooma); Back Row: Kevin Dunne.
Telling stories

Throughout the organisation, our members are at the heart of what we do and this is no different in the Media Department. The success in the increasing level and quality of media coverage gained by AlzNSW over the past few years is largely due to members’ generosity in sharing and telling their stories.

There have been several members from across the State who have been willing to tell their stories, which has greatly helped generate a better understanding of the condition, reduce stigma surrounding dementia, let others know there is help available and encourage people to talk more about it. A couple of notable highlights included a story in Fairfax Media’s Good Weekend magazine in March about Younger Onset Dementia and which featured members from NSW, and a story on Channel Nine’s A Current Affair program in June, which also featured members from NSW.

These were both excellent stories which reached large audiences and generated a very positive response.

Social Media

This is an exciting area that AlzNSW is continuing to grow and allowing us to reach a wider and more diverse audience. We have a strong and engaged audience on our Facebook page, which had more than 5,300 fans by the end of the financial year.

Our Twitter account has also proven to be an effective way for us to let people know about news and events. We had more than 1,100 followers by the end of the financial year.

We also continued to develop online short film resources in English and in a host of other languages as another way to share information and reach out to people, which have also been increasing in popularity. These live on the Alzheimer’s Australia YouTube Channel, ensuring people from around the State, the country and, indeed, the world can access these high-quality resources. Some of our education short films in languages other than English have proven very popular not only in NSW, where they were developed with local communities, but in those communities internationally as well, where access to good quality information about dementia is sometimes not as readily available.

Growth of the department

The Media Department has also grown and we were very pleased to add a Media, Marketing and Communications Officer to the team to help in meeting the increasing demands of the department.
Alzheimer’s Australia NSW has stated its commitment to Aboriginal communities in NSW during the statewide launch of an engagement plan in Port Macquarie in May. The document outlines a commitment to improving equity and access to culturally sound dementia services for Aboriginal and Torres Strait Islander peoples of NSW.

The CEO of AlzNSW, The Hon. John Watkins, said “consulting, nurturing and maintaining positive and respectful relationships with Aboriginal and Torres Strait Islander peoples was the only way to ensure culturally safe dementia services.

“We know from recent research by Professor Tony Broe, a Senior Principal Research Fellow at NeuRA (Neuroscience Research Australia), who conducted the Koori Growing Old Well Study, that the rate of dementia prevalence in Aboriginal Australians is three times that of Australia’s non-Indigenous population,” Mr Watkins said.

“Preliminary results from the study suggest the prevalence of dementia in Aboriginal Australians over 60 years of age is more than 13 per cent. But when it is adjusted for the younger age of the Indigenous populations, the rate is 21 per cent or three times the general Australian rate of 6.8 per cent.

“This is a shocking disparity and one which deserves focus and attention. Through this engagement plan and statement of commitment we are aiming to work in partnership with communities to ensure we develop culturally safe dementia services to help people in need.”
The plan includes a commitment to: building and strengthening positive relationships with Aboriginal and Torres Strait Islander people and communities in NSW; ensuring services are relevant and appropriate; and increasing the number of Aboriginal and Torres Strait Islander people within the organisation. The Engagement Plan and Statement of Commitment to the Aboriginal and Torres Strait Islander Peoples of Australia includes a new artwork (shown below) to represent AlzNSW’s relationship with both traditional and urban Aboriginal communities.

A new resource for carers of people living with dementia in the Aboriginal community was also launched.

The short film, You’re Not Alone: Discussion Dementia - Losing the Dreaming, features Birpai Elder Uncle Bill O’Brien discussing his experience of caring for his mother, who had dementia.

The resource will be freely available to help carers of people with dementia. Importantly, it emphasises the help that is available and that people are not alone on this journey. It can be found on Alzheimer’s Australia’s YouTube channel at www.youtube.com/alzheimersaustralia.

The launch was held to coincide with National Reconciliation Week.

Increasing engagement with Aboriginal communities:

AlzNSW has appointed our first Aboriginal Project Officer. The appointment of Sheree Drylie to the position, based in Port Macquarie, has enabled AlzNSW to increase our reach into Aboriginal communities through culturally appropriate engagement projects in the Hunter, Southern NSW, the Mid-North Coast, Western NSW, Tweed and the Illawarra. Latest research shows that the rate of dementia prevalence in Aboriginal Australians is three times that of Australia’s non-Indigenous population. By engaging with Aboriginal communities we are able to increase dementia awareness, train Aboriginal health workers in dementia

The painting to the above represents AlzNSW’s relationship with both traditional and urban Aboriginal communities.

The large blue area represents Alzheimer’s Australia, while the blue dots within the travelling lines represent the flow of information and understanding into the communities, the red dots symbolises the flow of cultural understanding and awareness back into Alzheimer’s Australia which then changes the colour of Alzheimer’s Australia Aboriginal services and supports.

The painting is depicted in the shape of boomerang which symbolises the importance of the return of information back to the community.
Expanding services into Western Sydney and the Illawarra:

Commonwealth funding has enabled us to establish a new project worker in Wollongong, who will be joined by two Younger Onset Dementia Key Workers, progressing our vision for a Dementia Community Resource Centre in the Illawarra.

A generous commitment of funds by the Heine Family Foundation over three years has allowed AlzNSW to expand services into Western Sydney. Additionally, new Commonwealth funding for Younger Onset Dementia Key Workers has enabled us to locate two new key workers in Western Sydney. Funding from both these sources has enabled AlzNSW to open a new office in Blacktown which will house five staff from mid-July 2013.

Increasing Outreach Counselling:

AlzNSW is expanding the number of locations where counselling is available to families and people in early stage dementia. Seven new locations this year include Liverpool, Mt Druitt, Camden and Fairfield in west/south-west Sydney, Port Stephens and Long Jetty on the central coast. Counselling pilots have started with the Assyrian and Croatian community in Western Sydney.

“Every Bloke Needs a Shed” - Men’s shed project

The “Every Bloke needs a Shed” pilot project is a new initiative of AlzNSW funded as part of Community Builders, NSW Department of Human Services. The goal of the project is to increase social engagement of socially isolated older men through participation in local men’s sheds men with a particular focus on men with early-stage dementia and male carers of people with dementia. The project encompassed the Hunter region and involved seven men’s sheds. The Every Bloke Needs a Shed project was formally evaluated and the results show that participation contributed to a sense of belonging and purpose contributing to self-esteem, self-worth and social inclusion. Other “shidders” gained important knowledge about dementia and their own brain health and how to communicate and support people with dementia. A short film on the project was launched at the Alzheimer’s Australia 15th National Conference in Hobart in May 2013 and there are plans to develop a program manual with training resources that can be used by other Men’s Shed in Australia.

Dementia and disability education:

In recognition that people with disabilities are living longer, ageing, and that many conditions, such as Down Syndrome, have higher risks for dementia, we have developed new education models on Intellectual Disability & Dementia and Physical Disability and Dementia. AlzNSW worked closely with the University of NSW and with the Physical Disability Council NSW on the development of the education program. A number of sessions to up-skill disability workers and improve the capacity of that sector to understand dementia and its impacts have been a delivered. A training DVD is being developed to enable the education to be delivered beyond the life of the project.

Your Brain Matters - brain health program:

This is the first nationally funded dementia risk reduction program in the world. Your Brain Matters contains stronger messages about looking after the heart, body and brain for a more holistic approach to dementia risk reduction. There have been a number of Your Brain Matters presentations delivered to communities across NSW and information distributed through the Memory Van. In NSW, a partnership program with Medicare Locals, local councils and universities is helping them incorporate Your Brain Matters brain health strategies into their own health promotion programs.

New programs for carers:

The ‘engaging in meaningful activities’ resource was developed with family carers in mind, but can also be used by paid carers and stems from carers asking “What can I do with the person I am caring for?” The program incorporates Montessori principals to focus on the person’s remaining abilities rather than loss of function. The program has been delivered in a number of locations in Western Sydney and training has been extended to leaders of carer support groups, so they can pass the knowledge on to carers.
Increasing engagement with GPs and specialists:

AlzNSW has been active in working with Medicare Locals to distribute dementia information to GPs and Practice Nurses via newsletters, GP dinners and education sessions. We have initiated work on a GP referral tool potentially linked to patient care software used by GPs with the aim of facilitating referrals, especially newly diagnosed people, to AlzNSW. We have worked closely with Professor Henry Brodaty and his team at the Dementia Collaborative Research Centre on our new Detect Early campaign and website targeted at GPs to promote more timely diagnosis of dementia.

Raising awareness in Culturally and Linguistically Diverse (CALD) communities:

A series of nine short films for CALD communities designed to encourage acceptance that dementia is a medical condition - and not a normal part of ageing - were developed and made available.

*It’s not a disgrace - it’s dementia* is a series of language specific films for non-English speaking communities, viewed around the world via Alzheimer’s Australia’s YouTube channel. The films are available for Spanish, Arabic, Serbian, Ukrainian, Khmer, Croatian, Portuguese, Assyrian and Vietnamese speaking communities.

The series won a NSW Multicultural Health Communications Award with AlzNSW taking out the NGO over $5,000 Visual category.

The awards were judged by an independent panel appointed by NSW Health and were presented to Michelle Basic and Danielle White from AlzNSW and producers Why Documentaries at NSW Parliament House.

You can find the award-winning DVD series on our YouTube Channel: [http://www.youtube.com/playlist?list=PLAwhBH4G05iKAMS5wlMSFSuncvoBYuRM](http://www.youtube.com/playlist?list=PLAwhBH4G05iKAMS5wlMSFSuncvoBYuRM)

Use of technology to expand service delivery:

AlzNSW has been increasing the use of technology to deliver counselling services to regional areas via Skype. There is a blog to support carers updated regularly by carer support group leaders and we have been using webinars to deliver important messages to Healthcare Professionals and staff to support their training. A number of short film resources are freely available online via YouTube and we will continue to build on and provide more online opportunities for our consumers. A new DVD community awareness resource called “Worried About Your Memory” has been developed with the aim of having it played anywhere where people “wait” such as GP surgeries, pharmacies, Centrelink & Medicare offices, local hospital waiting areas.

Partnerships to improve dementia care:

AlzNSW has created a new specialist consultancy service to assist organisations to improve dementia care practices. Consultancy has included working with a number of residential aged care providers to support them in enhancing their dementia care. AlzNSW works in partnership with a number of organisations including, but not limited to, Medicare Locals, Local Health Districts, Aboriginal Lead Agencies, ACON, Physical Disability Council, NSW police and local, state and federal governments on projects which build their capacity to deliver services and address the needs of people living with dementia. There are a number of ethno-specific agencies that assist AlzNSW to access people from CALD communities, particularly in South Western Sydney. AlzNSW values all those relationships and looks forward to continuing to improve and build capacity with a number of organisations we have partnerships with.

Completion of our Research on Younger Onset Dementia:

In October, we delivered to the NSW Government our research report into the Service and Support Needs of Younger Onset Dementia, the result of a two year research project funded by the NSW Government. The research findings have implications for policy and the provision of services and support to people with younger
onset dementia and their family members/carers. It is pleasing to see that recommendations in the report are being translated into practice both by government and service providers.

Showcasing our work nationally and internationally:

Our staff were well represented at the 4th National Dementia Congress held in Melbourne in February and the Alzheimer’s Australia 15th National Conference held in Hobart in May, presenting oral papers on their innovative and quality practice. These included:

- Shaping a Better Future: Enhancing the Capacity of Communities to improve responsiveness to dementia (focusing on our Tweed project work and presented by Christine Vanucci)
- Engaging in Meaningful Activities in the Home (a training program for carers and presented by Denise Herrmann and Pam Davis)
- “Drawing Myself Out”: Individual art therapy for carers of people with dementia (presented by Marg Coutts)
- Improving inclusion through collaboration: Addressing the Needs of People with Disability (presented by Mary Bills)
- Where in the world are they? Creating multimedia resources that utilise social strategies and social media to engage with the CALD communities. (presented by Michelle Basic)
- Minefields and Barriers, Where are all the Men? (reporting on our Men’s Shed project and presented by Stuart Torrance)

Staff have also written articles on dementia specific counselling and younger onset dementia (YOD) for the Counsellors and Psychotherapists Association quarterly magazine, published November 2012.

Feedback from our service users:

We surveyed callers to the National Dementia Helpline and the results demonstrate that the Helpline continues to provide a high quality service that meets or exceeds the needs and expectations of more than 90% of callers for all indicators measured.

Our Living with Memory Loss early intervention program continues to be highly valued by participants, with more than 90% of participants stating that they felt their knowledge of dementia had improved. For people with a diagnosis of dementia, 82% said they felt less isolated whilst the statistics were even higher for carers, with 95% stating they felt less isolated and alone.
THIS YEAR WE HAVE ACHIEVED

8,000 CALLS
TWO STAFF 75 HOURS PER WEEK 9AM-5PM MON-FRI
AVERAGE CALL LENGTH 15 MIN

HELP LINE

THANK YOU

EDUCATION
303 SESSIONS

MEMORY VAN
113 VISITS 21,200 KM
EQUAL TO ONE BIG LAP AROUND AUSTRALIA

VOLUNTEER CARER PROFESSIONAL COMMUNITY AWARENESS
4172 ATTENDEES 48 WEEKS A YEAR
OUR DONORS

THANK YOU TO ALL WHO MADE A DONATION DURING 2012 - 2013 AND PARTICULARLY THE FOLLOWING WHO GAVE $500 OR MORE.

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Mrs Helen Hallett  Mrs Hazel Paton  Dr Merryn Phillips
Mr John Hamilton  Mr Stanley Pendall  Ms Alison Porter
Mrs Helen Hamilton  Mrs Lynette Perini  Dr Meredith Hinds
OUR VOLUNTEERS

THANK YOU TO ALL WHO GAVE THEIR TIME TO SUPPORT AlzNSW DURING 2012 - 2013

AlzNSW Advisory Council
AlzNSW Ambassadors
AlzNSW Board of Directors
Sydney & Regional Consumer Advisory Groups

ORGANISATIONS

Armidale Central Rotary Club
Bupa Care Services
Institute of Chartered Accountants Australia
Macquarie University students
Memory Walk Illawarra Community Group
Port Macquarie Tri Club
Rotary Club Newcastle
Sunrise
St John Ambulance
The Kings School, North Parramatta
Westpac

INDIVIDUALS

Genevieve Boudan
Pierre Boudan
Bec Boyden
Jenine Bradburn
Nikki Bramwell
Elizabeth Brandis
Heather Brennan
Margaret Brewer
Mariola Brock
Kayley Brooker
Greg Brown
Roslyn Buckley
Geoff Bullock
Charlotte Burns
Sue Bush
Alex Campbell
Gabrielle Cardillo
Stephanie Cardillo
Bernard Carran
Michael Carroll
Ashleigh Cassidy
Diane Cassidy
Gary Cassidy
Lorraine Champ
Harrison Chan
Wendy Chandran
Julie Charlton
Emily Cheeseman
Patrick Chen
Belinda Cheng
Vickie Choy
Ainsleigh Christlo
Vicki Clay
Jasone Coghlan
Terese Cole
Alan Collins
Leo Connors
Maureen Cooke
Marie Cooper
Eliza Courtney
Suzi Cousins
Margaret Craig
Esma Cram
Dominic Cinnion
John Cinnion
Shane Cinnion
Michele Cunningham
Jamie-Lee Curley
Brian Curry
Jan Curry
Julie Curry
Pam Curry
Clare Daly
Greg Daly
Jann Daly
William Daly

INDIVIDUALS

Chris Davis
John De Bres
Cathy Dehaas
Ansh Dhalwah
Marina Dick
Katrina Dixon
Lachlan Dixon
Christine Dixon
Elyse Doolan
Gemma Doughty
Jan Draper
Karen Drutman
Chris Dunstan
Kay Dyson
Jill Edmondson
Helen Edwards
Jill Elias
Augusta Farina
Maureen Farrell
Christine Filippek
Jennifer Fishburn
Jan Fitzgerald
Melanie Fleet
Joy Fogg
Emma Frampton
Jenny Franks
Nicci Freeman
Ross Freeman
Mikayla Gerbec
Patricia Gilroy
Maree Gleeson
John Glerum
Judi Glerum
Luis Gomez Fort
Rebekah Gomez Fort
William Goschnick
Lesley Gow
Jenny Graham
Caroline Grundy
Anthony Hamilton
Kamal Hamka
Juliana Hammond
Michael Hammond
Liana Hancock
Peter Hansencombe
Teresa Hardie
George Hatzis
Johnny He
Daphne Henderson
Annette Hickey
Coralie Hicks
Gail Hodson
Arenla Hodzic
Pam Hulland
Wendy Humphries
Rowan Huxtable

INDIVIDUALS

Theresa Huxtable
Wilma Ibbotson
Elise Imbrotis
Dianne Imison
Wendy Irish
Bronwyn Ishenwood
Peter Iskandar
Bernadine Jamieson
Rohinie Jayatilake
Judy Jelsma
Emma Jennings
David Johanson
Jessie Johnson
Les Jones
Sonya Kabela
Nicholas Kable
Sonia Kayed
Gayle Keegan
Julie Keevers
Gillian Kerr
Ayemana Khan
Christine Kidd
Richard Kidd
Ann Lang
Sergio Lanzi
Pat Larson
Robert Lawton
Isobel Lee
Robert Lee
Darius Leo
Mark Levy
Tanisha Lewis
Judy Lindsay
Robert Lose
Maureen Lunnun
Jill Lutton
Susan MacDonald
Karen MacDonald
Margaret MacMillan
Pat MacMillan
Katherine Madden
Mariel Malabanan
Arthur Mason
Kath Mason
Susanne Masters
Margaret Mayhew
Jeff McCabe
Lorraine McCabe
Pamela Mdonagh
Keith McLarty
Christine McLeod
Gloria Medo
Alexandra Merenкова
David Mijalkov
Kristina Mikheeva
Arti Miller
# THE YEAR IN REVIEW

1 JULY 12 - 30 JUNE 13

## 2012

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<tr>
<th>July</th>
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<td><strong>Policy and Research</strong></td>
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<td>Dementia becomes a National Health Priority after COAG Ministers agree</td>
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<td>Launch of Discussion Paper #5 ‘Dementia &amp; the move into residential aged care’</td>
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<td>Dementia Awareness Week 2012</td>
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<td>TV campaign across NSW</td>
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<td>AA lecture tour Dr Serge Gautier</td>
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<td>Detect Early’ GP awareness campaign phase 1 launch</td>
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<td>AGM Annual Report published</td>
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<td>In Touch Summer edition</td>
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<td><strong>Fundraising</strong></td>
<td>Regular Giving program launched</td>
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<td>Spring Appeal</td>
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<td>Hunter Memory Walk</td>
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<td>Illawarra Memory Walk</td>
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<td><strong>Community Awareness &amp; Memory Van</strong></td>
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<td>Coffs Harbour ’Ageing Well’ Healthy Living Expo</td>
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<td>Wollongong seminar ‘Unravelling the myths about dementia’.</td>
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- **Policy and Research**
  - Launch of Aboriginal Engagement Plan
  - Launch of Discussion Paper #7: ‘Living alone with dementia’

- **Marketing, Communications and Media**
  - Cinema Campaign (movie Quartet)
  - Valentine’s Day ‘Fight Dementia Campaign’
  - ‘In Touch Autumn edition’
  - ‘Detect Early’ GP awareness campaign phase 2 launch
  - Prof Julian Hughes (UK) lecture tour: ‘Models of Dementia Care’
  - ‘In Touch Winter edition’

- **Fundraising**
  - Easter Appeal
  - Sydney Memory Walk
  - Bring It To The Table campaign
  - Christian Bakker Younger Onset dementia Roundtable event
  - Michelle Bourgeois talk ‘Unlocking the silent prison’
  - GP Conference & Expo - AlzNSW attendance
  - ANZSGM Scientific Meeting - AlzNSW attendance

- **Community Awareness & Memory Van**
  - Senior’s Week - Premier’s Concert
  - Brain Health Week
THE DIRECTORS PRESENT THIS REPORT ON THE ENTITY FOR THE FINANCIAL YEAR ENDED 30 JUNE 2013.

Directors

The names of each person who has been a director during the year and to the date of this report are:

The Hon. Professor Peter Erne Baume AC
Mr Alistair Garrard Bell
Ms Lucille Barbara Bloch
Mr Jeremy (Jerry) Kitson Ellis AO (appointed 22 Nov.12)
Mr Barry James Groundwater
Mr Ian Watts Horton
Ms Gabrielle Kibble AO
Dr Richard Matthews
Mr John Gerard Morrison
Mr Nicholas Kevin Francis O’Neill
Ms Catharine Josephine Retter
Ms Eesvarathevi (Eesa) Witt

Directors have been in office since the start of the financial year to the date of this report unless otherwise stated.

Company Secretary

The following person held the position of Company Secretary during the financial year:


Principal Activities

The principal activity of the entity during the financial year was:

To provide services to Australians living with dementia through the provision of support, education, awareness and advocacy programs.

No significant changes in the nature of the entity’s activity occurred during the financial year.

Operating Results

The net deficit of the entity for the financial year amounted to $11,026 (2012: Surplus $290,396).

Review of Operations

The net deficit for the financial year was a turnaround of $301,422 from the previous financial year. The main contributing factors to this result were:

(a) bequest income of $299,240, a decrease of $351,527;

(b) State/Federal and non-government grants amounted to $7,225,510, compared to $5,863,090 received in the previous year;

(c) capital grants from both government and non-government sources amounted to $11,100, compared to $337,936 in the previous year;

(d) net losses on sale of investments of $313,131 compared to $19,471 in the previous year;

(e) impairment of investments write-back upon sale of $109,120, compared to impairment of $344,992 in the previous year, and

(f) employment benefits expense increased by $940,478 in the delivery of additional service programs.

State and Federal Government grants received increased by 19.4% to $6,710,711. The percentage of government grants to total revenue, excluding bequests and loss on sale of investments, of 67.8% compares to 65.4% for 2011/2012 and 64.9% for 2010/2011. The increase in grant revenue reflected the awarding of new recurrent grants and non-recurrent grants which commenced during the financial year.

Objectives

The company has a three year strategic planning cycle. The strategic plan for the years 2012 to 2015 has been reviewed, with a 5th major goal area added.
The current strategic plan has 5 major goal areas:

(i) For the general public to aim to build a community that understands effective risk-reduction strategies, where the stigma around dementia is reduced.

(ii) For people with memory concerns to aim for a more timely diagnosis with a smooth referral to AlzNSW for early intervention support.

(iii) For people living with dementia and their carers to aim to significantly improve the quality of life, through service improvement initiatives and partnerships with other organisations.

(iv) To build a strong organisation and sector to support all these activities, to aim to increase funding to AlzNSW and the dementia sector.

(v) In order to cope with the rapidly increasing dementia challenge AlzNSW aims to significantly grow the organisation’s capacity and outreach.

Strategy for achieving the objective and performance measures

Each of these goals has a specific set of actions identified to achieve the goal. A report on progress against each action is presented to the Board each quarter.

The company is required to report regularly to funding bodies on progress against contractual work plans, and financial outcomes. The Board also receives monthly financial reports against agreed budgets and quarterly reports from departmental managers on activities.

The education programs offered by the company are offered to professionals in the aged care industry and also to family carers with the aim of improving the care and support to people living with dementia.

The conduct of regular Consumer Advisory Committees across NSW, social research into the issues confronting people living with dementia, and the engagement of parliamentarians through the Parliamentary Friends of Dementia meetings are all methods of empowering consumers and advocating for more support and services.

The role of media, marketing and public relations is to increase recognition of the role of the company in the care of people living with dementia and the nature and scale of the condition. The effectiveness of these activities is evaluated by reference to a media monitoring service and market research.

The Your Brain Matters program is a community education program that teaches dementia risk reduction. This program is regularly presented to community groups and clubs and leaflets are available to the public from the two Memory Vans that visit metropolitan and regional community venues.

In terms of sustainability, the key issues are diversification of income, quality accreditation and strong financial management. The company retains quality accreditation through QMS. Also the structure and strategy of the fundraising department has been reviewed and a new direction established and has been implemented. Financial issues are regularly reported through the Investment Advisory Committee, the Audit and Risk Committee and to the Board of Directors.

Note:

Highlights from the financial results have been included in this report. The Summary Financial Statement and the Audited Financial Report for the year ended 30 June 2013 are available on request from Alzheimer’s Australia NSW reception. The Audited Financial Report may also be viewed on our website at: http://www.fightdementia.org.au/common/files/NSW/20131021-NSW-RPT-Financial.pdf
INFORMATION ON DIRECTORS

The Hon. Professor Peter Erne Baume AC
Director (Chairman non-executive to 22 November 2012)
Qualifications: MB, BS, MD, Hon DUniv (ANU), Hon LittD (USQ), FRACP, HON FRACGP, FAFPHM
Experience: Emeritus Professor, past physician at Royal North Shore Hospital, past Senator for NSW, past Government Whip, past Minister for Aboriginal Affairs, past Minister for Health, past Minister for Education, Professor of Community Medicine at the University of NSW, past Chancellor of the Australian National University, past Director Sydney Water Corporation, past Chair of the Kolling Institute of Medical Research, past Governor Foundation for Development Cooperation, past Chair Family Drug Support, past Chair of the Australian Sports Drug Foundation, past official visitor, ‘past official visitors’ advisory committee.

Mr Alistair Garrard Bell
Director
Qualifications: B.Ec (Sydney), MAICD
Experience: Senior commercial and financial executive with broad-based experience in fiscal and operational management of international businesses operating in a variety of markets.
Special Responsibilities: Mr Bell is a member of the Investment Advisory Committee and the Audit and Risk Committee.

Ms Lucille Barbara Bloch
Director
Experience: Previously an Executive Member on the Management Committee of a retirement home with a
frail care unit. Past Treasurer of ESRA, which provides help to new immigrants. Lucille was the primary carer for her husband, Keith, who had Fronto-Temporal Dementia.

Special Responsibilities: Chair and AlzNSW representative on the National Consumers Advisory Committee of Alzheimer’s Australia, member of the Sydney-based Consumer Reference Standing Committee, and facilitates a monthly Carers’ Support Group. Member of Health Consumers NSW Management Committee.

Mr Jeremy (Jerry) Kitson Ellis AO
Chairman (non-executive)

Qualifications: MA (Oxon), LL.D honoris causa Monash University, HonDEng, C.Q.U., FTSE, FAICD, FAIM, HonFIEAust


Mr Barry James Groundwater
Director


Experience: Worked for Southern Cross Care (NSW & ACT) Inc for 19 years until he retired in February 2007. During this time held roles including Regional Manager and Manager of Cardinal Gilroy Village, Merrylands.

Special Responsibilities: Mr Groundwater is a member of the Investment Advisory Committee and the Audit and Risk Committee.

Ms Gabrielle Kibble AO
Director

Qualifications: BA, Diploma of Town and Country Planning, FPIA, Hon.DSc (UNSW), Hon. DLitt (UWS)

Experience: Chair of NSW Heritage Council until 31 December 2011, Chair of the NSW Planning Assessment Commission, Chair of the Joint Regional Planning Panel for Western NSW. Ms Kibble has extensive experience in the public sector as CEO of the Department of Urban Affairs and Planning from 1987 to 1997, and Director General of the NSW Department of Housing. In the past, Ms Kibble has also been an Administrator of the Wollongong City Council and the Liverpool City Council, as well as a Director of the Sydney Olympic Park Authority, Chair of Sydney Water and Trustee and Deputy Chancellor of the University of Western Sydney. In 1997 Ms Kibble was awarded the Sidney Luker Memorial medal of the Royal Australian Planning Institute.

Dr Richard Matthews AM
Director

Qualifications: MB, BS

Experience: Past Deputy Director-General of the Strategic Development Division at NSW Health and until June 2007, carried the dual role as Deputy Director-General and Chief Executive of Justice Health (previously known as Corrections Health Service). Chair General Practice Education and Training (GPET). Dr Matthews

Mr Ian Watts Horton
Director

Qualifications: BComm (UNSW), FAICD, FCIS

Experience: From 1975 to 1998 occupied various senior positions within the investment management industry. Member of the Board of IFSA in 1998, Chair of IFSA’s and also Member of AICD’s Corporate Governance Committees from 1994 to 1997. Member of the Sydney Medical School Foundation and Chair of the Microsearch Foundation from 2011.

Special Responsibilities: Mr Horton is Chair of the Investment Advisory Committee and is a member of the Audit and Risk Committee.
INFORMATION ON DIRECTORS

has co-authored various publications on health issues and is a Director on various Boards within the health network including Neuroscience Research Institute (NEuRA), National Director Calvary Healthcare (LCM), GPNSW and on the Advisory Board Centre for Healthy Brain Ageing (CHeBA).

Mr John Gerard Morrison
Director
Qualifications: B Comm, CPA, FAICD, FTIA, FAICS
Special Responsibilities: Mr Morrison is a member of the Investment Advisory Committee, Chair of the Audit and Risk Committee and a Director of Alzheimer’s Australia Research.

Mr Nicholas Kevin Francis O’Neill
Director
Qualifications: LLB (Melbourne), LLM (London)
Special Responsibilities: Mr O’Neill is a member of the Nominations and Remuneration Committee.

Ms Catharine Josephine Retter
Director
Experience: Member of the NSW Government Carers Advisory Council, member of the Consumer Dementia Research Network, past chairperson of Austcare refugee week. Career background in marketing, management and writing, and for the past decade in book publishing and distribution. Director on various boards in the publishing sector including chair of the Australian Book Group Pty Ltd, past CEO of Driza-Bone Pty Ltd. Ms Retter was the primary carer for her husband who had Alzheimer’s and vascular dementia.

Ms Eesvarathevi (Eesa) Witt
Director
Qualifications: RN, Grad Dip Aged Care, MN
Experience: Board member since November 2006. Ms Witt has extensive experience in aged care nursing having worked in Community Health, and as an ACAT Registered Nurse in Sutherland Hospital. Other positions held were as Clinical Nurse Consultant in residential care, Acute Aged Care and currently in Psychiatry of Old Age at Prince of Wales Hospital. Ms Witt is experienced in facilitating groups, mentoring nurses and health professionals in other disciplines in dementia care, managing challenging behaviours and supporting carers of persons with dementia. She has been part of various research teams looking into depression in residential care and development of behaviour management manuals with UNSW and USyd.
The major source of income for AlzNSW continue to be Government grants which account for 66% of total income. Non-government income accounted for 34% of total income and this has doubled since last financial year.

The top three areas of expenditure are Education and Awareness activities (33%), Support Services (29%) and Regional Services (20%) which reflect the continuing focus by AlzNSW to deliver quality support and educational services across the state.