

# National Stroke Foundation Annual Review

2010 achievements... 10 years of progress... tomorrow's challenge





# From the Governor General

As Patron-in-Chief of the National Stroke Foundation, I commend this edition of the Foundation's Annual Review, which reflects the achievements of 2010 and the progress made over the last decade in tackling Australia's second biggest killer.

This review carries another important message too. In these past ten years, the National Stroke Foundation has heightened our understanding

#### This review shows us that there is a great deal more to be done

of stroke, the risks and warning signs, the prevention and early treatment measures, and the ongoing support needed by stroke survivors and their families.

You have helped guide Australians and our governments from a time when fear or lack of information hindered public discussion to today, when the facts and data and personal stories are shared openly, constructively and compassionately. You have encouraged stroke survivors to speak out about their struggles and triumphs through recovery, and to dispel the myth that stroke only happens to us when we are old.

While much has been achieved, Australia continues to see 60,000 strokes every year. This review shows us that there is a great deal more to be done to ease the current suffering.

I admire the National Stroke Foundation's direct and steadfast campaign to raise public awareness of stroke and to equip Australia with vital knowledge in managing its risks and impacts in our own lives and the lives of those we care for.

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Governor General of the Commonwealth of Australia Ms Quentin Bryce AC



### A successful year of growth

2010 was a year of growth for the National Stroke Foundation – and it was a successful year.

We opened two new offices, one in Brisbane and one in Sydney, to add to our network that includes Perth, Hobart and Canberra and the national office in Melbourne. All of our program areas expanded and this review highlights just a few of their achievements.

Taking advantage of today's technology we created a new signs of stroke website with medical animations showing how the brain is affected by stroke. The website received some 700 visits when it was launched on the first day of National Stroke Week. A free stroke iPhone application was also released showing which hospitals in the locations

selected have stroke units. The *Clinical Guidelines for Stroke Management 2010* was launched by the National Health and Medical Research Council in September and set the benchmark for stroke treatment. A total of 107 hospitals, including

15 private hospitals, took part in the second National Stroke Audit of Rehabilitation Services.

Working with beyondblue: the national depression initiative and Relationships Australia, we created a training program for counsellors to identify and treat stroke-related depression. This evidence-based response to the needs of stroke survivors and their families exemplifies how we can improve stroke awareness and care.

There were 58 applications in 2010 for research funding for small projects, honours and clinical research development grants, 17 more than the previous year. Successful applicants are listed in this report.

We presented the views of the National Stroke

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President Professor Richard G. Larkins AO

Foundation, health professionals and the stroke community in submissions to government and Parliamentary inquiries in support of health policy development and the national health reform agenda. Increased involvement with federal and state governments raised awareness of stroke and our organisation.

Ensuring that stroke figures more prominently in discussions about health will be a major objective in 2011. In 2010 we began examining community perceptions about Australia's second biggest killer, and the role of the National Stroke Foundation as a leader in stroke awareness, prevention, stroke services, post stroke care and research.

Ensuring that stroke figures more prominently in discussions about health will be a major objective in 2011 We appreciate the generous donations we received from across the country and for government and business support. The growth in funds raised through our appeals demonstrates the impact stroke has on individuals and their families. It shows that people believe that more should be done to

counter stroke and to care for stroke survivors.

This review provides a ten-year snapshot showing changes in the way that stroke is recognised, managed and treated in Australia. There has been progress but much more needs to be done.

Our ability to save lives, stop stroke and end suffering relies on more Australians understanding and caring about stroke. It needs more Australians speaking out strongly so that stroke is recognised as one of Australia's top five health issues of concern. This will support us as we work to have the National Stroke Foundation accepted as a top ten health charity.

But we must all act quickly – every day we delay lives are lost and people suffer.

Chief Executive Officer Dr Erin Lalor

# Managing a fast-growing organisation

### Review of operational requirements

A review in 2010 considered operational requirements in light of the National Stroke Foundation's growth and strategic objectives. Management considered reporting structures, external positioning of the organisation and staff requirements. Staff identified key areas for development including improvements in human resource systems, and internal and interoffice communication. Strategies arising from the recommendations will underpin the anticipated continuing growth in 2011.

#### **Budget Planning and Monitoring**

A revised budget process was trialled in 2010, including procedures to ensure that detailed planning was undertaken to identify 2011 programs and activities for budgeting. The revised processes also aimed to improve monitoring costs associated with providing programs and enhancing organisational efficiency. With key performance indictors in place we are better able to monitor and report on achievements and outcomes related to our overall goal.

#### **Business cases**

As part of our increasing management professionalism, we created detailed and rigorous business cases for four programs - FAST, Know your numbers, StrokeLink and StrokeConnect. The consistent, documented business cases will be used for promoting the programs to potential corporate or government partners. They are also a sound basis for fine-tuning and developing our programs.

Financial	Performance

Revenue	2010 (\$,000s)	2009 (\$,000s)	2008 (\$,000s)	2007 (\$,000s)
Community Support - Non-Bequests	8,398	7,063	6,621	3,938
Community Support - Bequests	896	1,972	91	5
Corporate Support	215	338	352	629
Government Support	2.117	1.475	915	797
Product Merchandise	52	73	131	96
Inerest Income	100	56	90	116
				-
Total Revenu	<u>ue</u> 11,778	10,977	8,200	5,581
Expenses				
Priority Area 1 - Prevention & awareness	2.228	1,619	1,333	1.129
Priority Area 2 - Stroke services	1,169	1,042	847	582
Priority Area 3 - Life after stroke	991	879	751	317
Priority Area 4 - Research	312	254	40	65
Priority Area 5 - Fundraising*	4,877	3,988	4.348	2.700
Priority Area 6 - Governance & Accountability	4,077	3,900 924	4,340 838	2,700
Total Expense	es 10,704	8,706	8,157	5,405
Surplus From Ordinary Operations:	1,074	2,271	43	176
Other Investment Income	100	100	20	
Restatement of Investments to Fair Value	128 145	103 353	(170)	-
Restatement of investments to Pair value	140	303	(178)	-
Total Othe	er 273	456	(139)	5,405
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OVERALL RESULT Financial Position Assets Cash (inc. Deposits)	<b>1,347</b> 2,866	<b>2,727</b> 2,495	<b>(96)</b> 1,498	<b>176</b> 2,415
OVERALL RESULT Financial Position Assets Cash (inc. Deposits) Receivables	<b>1,347</b> 2,866 296	<b>2,727</b> 2,495 347	<b>(96)</b> 1,498 207	<b>176</b> 2,415 262
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**Ratios and Expenditure Notes:** 

	Direct fundraising expenses to income ***	23%	22%
ng	Administration expenditure to income	9.3%	8.4%

\* Includes major developmental investment into a donor acquisition program

\*\* Increase in 2009 represented in part by "Australian Listed Shares" from a Bequest received

\*\*\* Does not include income and expenses associated with major developmental investment

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### Stroke – 10 years ago

Only **34 stroke units** in Australia's hospitals. **23%** of stroke patients receiving stroke unit care.

**60%** of people could correctly identify one sign of stroke.



### Telling Australians about stroke

National Stroke Week focusing attention on stroke A new FAST website was launched to mark National Stroke Week 2010. The website - http://signsofstroke.com.au/ - has medical animations and explanations of what happens during a stroke, how the brain is affected, the warning signs of stoke and the importance of emergency care. Some 700 visits were made on the first day of Stroke Week. A free stroke iPhone application was also released to educate people about the signs of stroke and to show the location of stroke units. There were 242 downloads in the first few weeks. A total of 3816 National Stroke Week packs were sent to community partners to run their 2010 Stroke Week events, an increase of 65% on 2009.

## FAST – telling Australians about the warning signs of stroke

Community understanding about what a stroke is and how to react to signs that someone is having a stroke is a powerful way to reduce death and disability. Every second counts – it is vital to call 000 immediately.

FAST stands forFace: Has the person's mouth drooped?Arms: Can they lift their arms?Speech: Is their speech slurred?Time: Time to call 000 – FAST

**Case Study:** Rosemary Reeve realised she was having a stroke because she recognised the symptoms, and she knew what to do because of the FAST wallet card she was carrying. Rosemary attracted the attention of a passerby who immediately called an ambulance. Prompt medical treatment made a major difference to her recovery.

#### Know your numbers – providing free blood pressure checks

High blood pressure is a major cause of stroke. Some 740 blood pressure checking stations in pharmacies and other locations took part in Know your numbers in 2010, including for the first time sites in New South Wales, resulting in approximately 60,000 blood pressure checks.

#### strokesafe – reaching into the community

More than 1900 people were briefed on stroke and stroke prevention by 70 trained volunteers in 2010, through our strokesafe community education program. Grants are enabling strokesafe to be extended into regional Victoria and to Perth and nationally through an online seminar.

### Enabling best care for stroke patients

#### Clinical Guidelines for Stroke Management 2010

Covering the entire patient journey from acute care to community care, the revised national guidelines were launched by the National Health and Medical Research Council in September. An important tool in both acute and post-acute care, the guidelines set a benchmark for optimal treatment of stroke based on the latest Australian and international research.

#### Stroke Audit Program

A total of 107 hospitals, including 15 private hospitals, took part in the second National Stroke Audit of Rehabilitation Services 2010. The audit has uncovered negligible improvement in the six areas highlighted as priorities in stroke rehabilitation since the 2008 audit. The audit showed that gaps in access to care are significant, demonstrating that system inefficiencies are impeding stroke recovery.

### Quality improvement workshops

Three workshops were held in Melbourne, Sydney and Brisbane to assist and encourage health teams to use information they gained from the 2009 National Stroke Audit of Acute Services for quality improvement activities.

#### Australian Stroke Coalition

Five working groups continued to collaborate on activities to improve various aspects of stroke care. Two of five projects undertaken were aimed at assisting implementation of the clinical guidelines. They were a care plan template for discharge planning and a rehabilitation assessment tool that can determine a stroke survivor's ongoing rehabilitation needs.

#### StrokeLink

Continuing expansion in 2010 was the feature of StrokeLink - the comprehensive quality improvement program providing outreach visits by National Stroke Foundation staff. The number of health teams taking part in StrokeLink grew to 33. Staff members helped to identify and plan efforts to reduce differences between what the Foundation's best practice guidelines recommend and what the local stroke audit data demonstrates is actually provided. Metropolitan and regional sites across Queensland were visited. The Queensland Department of Health renewed funding for another three years.

#### Framework for Acute Stroke Services

The framework, which outlines the components required for optimum hospital-based acute stroke services was reviewed and revised.

**Only 47%** of stroke patients arrived at hospital within 3 hours.



**Only 2%** of eligible stroke patients given a clot-busting drug (thrombolysis) which was being tested in research programs.



**No** specialised programs to coordinate care for people with stroke in the community.

**No** dedicated research funding program for stroke in Australia.

### Supporting stroke survivors

### Understanding depression after stroke

With beyondblue: the national depression initiative, the National Stroke Foundation developed a pilot training program to extend counsellors' understanding of stroke to help them support survivors and carers experiencing depression. The training program is supported by a DVD that highlights the risk and the symptoms of depression after stroke. The Governor General, Her Excellency, Ms Quentin Bryce AC, launched the DVD in Sydney. Relationships Australia counsellors in Tasmania and New South Wales can now offer support in Tasmania and in five regions of New South Wales.

### StrokeConnect – sharing, supporting, connecting

StrokeConnect has been implemented in 23 hospitals nationally, with 450 stroke survivors and carers joining the program. StrokeConnect aims to link survivors and carers with information about stroke, peer support programs, and support and advice. A StrokeConnect forum was held in Western Australia and more are planned for WA in 2011 and hopefully other states. StrokeConnect Online is a new peer support forum for stroke survivors and by December 2010 had more than 300 members.

#### Road to Recovery

Reaching across three states, the Road to Recovery project explored self management and the role of peer support groups. The Stroke Foundation and stroke support groups developed new activities aimed at improving members' self management outcomes. Our thanks to the six Stroke Support Groups that participated in the pilot project: Northern Districts and Swan District (Western Australia), Monash, Box Hill, Boroondara (Victoria) and Hobart. Our thanks also to the federal Department of Health and Ageing for its support.

#### Stroke Support Group Toolkit

A toolkit has been developed for new stroke support groups and to improve the viability of existing groups. The first of its type nationally in Australia, the toolkit provides information on how to run a group, promote and plan a program and deal with conflict.

#### **Heartmoves for Stroke**

In partnership with the Heart Foundation we have developed a training program for fitness instructors that will ensure exercise programs will be more accessible and safe for stroke survivors.

#### StrokeLine – 1800 stroke (787 653)

This health information line responded to 2119 calls in 2010 from stroke survivors and carers seeking health information, referral and support.

### Learning more about stroke

There were 58 applications for research funding in 2010, which was 41 more than last year. The National Stroke Foundation Board approved grants to the following applicants:

#### Small project grants

- Caroline Hills: Increasing practice after stroke to optimise upper limb rehabilitation: A phase II trial
- Gail Robinson: Executive dysfunction in stroke: verbal and non-verbal generation
- Di Marsden: How fit is the stroke survivor?
- Kim Brock: Improving outcomes for the upper limb in severe stroke: the efficacy of rehabilitation interventions based on the Bobath concept
- Michelle McDonnell: Aerobic exercise to improve cognition following stroke\*
- Bronwyn Simpson: Feasibility of a home-based program to improve handwriting legibility after stroke: a pilot randomised trial
- Kylie Boots: Work after a stroke: identification of cognitive difficulties using a work place assessment model

- Angela Vratsistas: A closer look at arm rehabilitation: a study investigating the dosage of therapeutic and upper limb outcomes after stroke
- Susan Hillier: Music therapy and support in a stroke rehabilitation unit\*
- Thomas Lillicrap: Brain temperature measurement and modelling

\*Supported by the generosity of Thyne Reid Foundation

#### Clinical Research Development Award

• Amanda Osborne: Evaluation of the implementation of constraint induced aphasia therapy within the constraints of the workplace

#### Honours grants

- Alexandra Walter: Oedema management of the hemiplegic upper limb
- Jeffery Mahoney: Drug intervention to improve language rehabilitation after stroke as modelled in healthy individuals
- Jenna McAfee: The impact of creative, non communication based leisure activities on quality of life in people with aphasia
- Vergis Marianne Krupha: Defining the impact of dysprosody in stroke related speech disorders for redesigning intervention

### Stroke – Today

**73 stroke units** in Australia. **50%** of stroke patients receive stroke unit care

B6% of people can name at least one sign of stroke.



### Relying on financial support

#### Donations

We received donations from supporters across the country. The growth in funds raised through our appeals demonstrates the impact stroke has on individuals and their families. It shows that people want to help us to stop stroke, save lives and end suffering.

#### **Regular giving**

Complementing our appeals program is the growth in the number of supporters who commit to regular monthly donations. Regular Giving is a vital program for the National Stroke Foundation because it means we can plan and budget ahead with greater certainty.

#### Philanthropic support

The first of a series of briefings for current and potential donors was held in Melbourne in November. They heard how stroke care has progressed, the often devastating impact of stroke and the need to achieve much more to beat stroke.

#### **Bequest support**

More than 1000 guests attended David Brownbill Society functions in Melbourne, Brisbane, Sydney, Hobart and Launceston, and for the first time in Adelaide and Perth. The Society recognises supporters who have left a bequest to the National Stroke Foundation. It allows us to celebrate their generosity in person while encouraging others to consider this form of support. Special thanks to the Trust Company for supporting Society functions around the country.

#### Events

- Counterstroke Golf Classic The annual event raised almost
  - \$60,000. Some 500 rounds of golf were played on Victoria's Mornington Peninsula courses in February – Settlers Run, Portsea, The National, The Dunes and Flinders – and 200 rounds on the Bellarine Peninsula's Thirteenth Beach and Barwon Heads in September.

#### Food for Thought

This inaugural awareness and fundraising event was held in Sydney in November. It featured high-quality cuisine by the *Sydney Morning Herald* Chef of the Year, Mark Best, and Simon Sandall, Head Chef at Opera Point Events with an emotive photographic exhibition of stroke survivors and their stories.

#### **Community fundraising**

We acknowledge and thank individuals and groups who raised funds through community activities. Highlights included Mark Scanlon from Western Australia who swam the English Channel to raise \$31,706, and Maureen Lesjak from Victoria who held a dinner and raised \$13,753.

#### Adele Coleman: Communicative fitness: assessing the effects of a portable technical device on increasing daily talking time, language quality, communicative effectiveness, self-efficacy and quality of life in people with aphasia

- Gurpreet Kaur: Ummm, about an hour? – How accurate are physiotherapists at estimating therapy time in stroke rehabilitation?
- Sally Hollingsworth: It's all about smoke and mirrors! The clinical implementation of mirror therapy to restore lower limb function and mobility following stroke and traumatic brain injury. A randomised trial.

#### Fellowships and Scholarships (joint funding with the Heart Foundation)

#### Fellowship:

• Toby Cummings: Does early physical activity improve stroke cognitive function? AVERT cog: a sub-study of a randomized controlled trial

#### Scholarship

• Juusop Klim: The impacts of a chronic disease management plan for survivors of stroke

**65%** of patients arrive at hospital within 3 hours – increased calls to 000 after community awareness campaigns.



**10%** of eligible patients now given a clot-busting drug (thrombolysis).



**23 hospitals** able to connect survivors with people and services to help them recover. Training programs for counsellors, toolkits to help set up stroke support groups, programs to help more stroke survivors participate in exercise

survivors and carers to communicate online.

**Research programs** funded to explore stroke rehabilitation and improved community support. Greater understanding of stroke leading to improved treatments and prevention.

### Communicating what we do

#### Raising the profile of stroke

As the voice of stroke in Australia. the National Stroke Foundation aims to have stroke recognised as one of the country's top five health issues. Research conducted for us by Colmar Brunton indicated that more Australians were aware of the implications of stroke but it is still number fourteen out of thirty one health issues. To move stroke up the ladder of importance, we began a project in 2010 to determine the best way to gain greater prominence for stroke and our work with the Australian community. We need Australians to care about stroke.

#### Media exposure

Australia's metropolitan, regional and suburban print and electronic media plus professional and academic publications were used extensively in 2010 to explain stroke and discuss National Stroke Foundation programs. Our share of media grew with the publication of more than 450 print, radio and television stories.

#### Online and social media

Social media was a maior focus in 2010. By the end of the year we had 800 active Facebook friends and 650 Twitter followers. Using these platforms and YouTube enabled us to have conversations with stroke survivors, carers and their relatives and friends and provide new audiences with immediate access to stroke information. Our website www.strokefoundation. com.au attracted almost 240,000 visitors during the year. For health care professionals the most popular pages were the new Clinical Guidelines and the audit of stroke rehabilitation services.

#### Talking with governments

We continued to work closely with governments across Australia. Know your numbers and the StrokeLink programs were delivered in Queensland through our ongoing partnership with the state government. We worked closely with Clinical Networks in Victoria, New South Wales, Queensland, Western Australia and South Australia. Our work with the federal government centred on improving quality of care for stroke patients, influencing the prevention agenda through our work with the National Vascular Disease Prevention Alliance and the Australian Chronic Disease Prevention Alliance, plus regular submissions and representation to departments and bodies considering national health reform and other policies.

# Thank you to our partners and supporters

We thank the following governments, philanthropic trusts and foundations, companies and organisations for their commitment to our work:

- Australian Government Department of Health and Aging
- Department of Health -Victoria
- Department of Health and Human Services - Tasmania
- Queensland Government
   and Queensland Health
- The Collier Charitable Trust
- Danks Trust
- Bruce Wall Trust (c/o Tasmania Perpetual Mutual)
- Thyne Reid Foundation
- Eric Ormond Baker Charitable Trust (c/o Equity Trustees)
- The RE Ross Trust
- Allergan
- Boehringer Ingelheim Pty Ltd
- Corrs Chambers Westgarth
- Direct Mail & Marketing
- Draft FCB

- Drummond Golf
- Marque Restaurant
- Maxwell Williams
- Metro Tasmania
- News Ltd
- Omron
- Opera Point Events
- Sanofi Aventis
- Shave Human Resources
- Southern Cross
   Broadcasting
- Starcom Mediavest
- Studio Neon
- Taylors Wine
- The Trust Company
- Val Morgan Cinema Advertising
- Veolia Environmental Services
- The Pharmacy Guild of Australia
- YMCA
- Rotary

### We need to:



- Help more Australians to understand that stroke is a leading cause of disease burden in Australia.
- Grow our organisation so we can deliver our key programs nationally – Know your numbers, StrokeConnect, StrokeLink and FAST.
- Maintain on-going communication with governments to ensure stroke is recognised as a top five health issue.
- Improve education in primary care to ensure effective prevention programs are in place.

- Monitor hospital stroke services and support health professionals to improve quality of care.
- Develop more community-based services for survivors – carer training, individual support, and advice to prevent recurrence of stroke.
- Increase funding and support more stroke research in Australia.
- Gain the financial resources needed to achieve these goals.

Every day we delay lives are lost and people suffer.

### Patrons and Board

#### Patron-in-Chief

Her Excellency Ms Quentin Bryce AC Governor General of the Commonwealth of Australia

#### Patrons

David Brownbill AM Sir Gustav Nossal AC Lady Southey AC

**President** Professor Richard Larkins AO

Vice Presidents William J Forrest AM

Andrew F Buckle OAM

#### Treasurer

Graeme Bowker (Retired December 2010) Paul Shanley (from December 2010)

#### Board

The honorary Board includes business, research, medical and consumer representatives.

#### Directors

Susan Aveyard Associate Professor Julie Bernhardt David Evans Paul Leeds Professor Richard Lindley Michael Hill Christina Tonkin (Appointed May 2010)

Chief Executive Officer Dr Erin Lalor

**Company Secretary** John Buchanan

#### **Medical Directors\***

Professor Christopher Bladin MD, FRACP (To 1 September 2010) Professor Christopher Levi MD, FRACP (To 1 September 2010) \*The National Stroke Foundation has gained clinical advice over a number of years with formal honorary appointments of medically trained clinicians. Following a review of the way in which clinical advice is provided, the Board established a Clinical Council to facilitate these needs. We would like to thank Professor Levi and Professor Bladin for their contributions as medical directors over many years.

#### Clinical Council

(Commenced 1 September 2010) Professor Richard Lindley (Chair) Assoc. Professor Julie Bernhardt Dr Annie McClusky Assoc. Professor Bernard Yan Professor Christopher Levi Dr Michael Pollack Professor Sandy Middleton Dr Tammy Hoffman Assoc. Professor Simon Koblar

### Finance, Investment and Risk Committee

Graeme Bowker (Retired December 2010) Paul Shanley David Evans Andrew Miles Dr Erin Lalor Wendy Fromhold (Ex officio) Matthew Oakley, Evans Buchanan (Ex officio)

#### **Governance and Nominations**

**Committee** William J Forrest AM Andrew F Buckle OAM

Solicitors Corrs Chambers Westgarth (Pro bono)

Auditors RSM Bird Cameron

### Australia's Second Biggest Killer

Stroke is Australia's second single biggest killer after coronary heart disease and is a leading cause of disability.

The National Stroke Foundation works with the public, government, health professionals, patients, carers and stroke survivors to reduce the impact of stroke on the Australian community.

Studies have shown that stroke can be prevented. Outcomes are improved with fast treatment, early access to dedicated stroke unit care and a coordinated community care program. Ongoing research into stroke will assist with eliminating the unknowns and improving treatments.

#### Facts

In Australia there are 60,000 strokes each year.

1 in 6 people will suffer a stroke in their lifetime.

Stroke kills more women than breast cancer and more men than prostate cancer.

About 20 per cent of all strokes occur to people under 55 years old.

#### Join us on our mission

To stop stroke, save lives and end suffering, we rely mainly on the community, with support from governments and philanthropic and corporate organisations.

#### You can help by:

- making a tax deductible donation online or by post
- leaving a bequest in your Will
- becoming a corporate partner or sponsor
- volunteering
- holding your own fundraising event
- taking part in fundraising events
- spreading the word about stroke.

#### Contact us

For information or advice about stroke call our StrokeLine 1800 stroke (787 653) – a free call

For information about the National Stroke Foundation visit **www.strokefoundation.com.au**