

# National Stroke Foundation 2008 Annual Review

Stroke - Fitting the pieces together



# Stroke – Fitting the pieces together

The National Stroke Foundation is a not-for-profit organisation working with governments, health professionals, patients, carers and stroke survivors so together we can beat stroke.

#### What is a stroke?

A stroke occurs when the brain is deprived of blood because an artery is blocked (an ischaemic stroke) or because the artery breaks or bursts (haemorrhagic stroke). Interrupting the blood flow reduces the oxygen available to the brain which causes cells to die, resulting in death and disability. A stroke is not a heart attack.

Stroke can be prevented by keeping blood pressure and cholesterol levels low, exercising, enjoying a healthy diet, limiting alcohol intake and by not smoking. Some causes of stroke cannot be controlled, such as age, gender and a family history of stroke. Stroke can also be associated with diabetes and an irregular heart beat.

The signs of a stroke are:

- weakness, numbness or paralysis of the face, arm or leg on either or both sides of the body
- difficulty speaking or understanding
- dizziness, loss of balance or an unexplained fall
- loss of vision, sudden blurred or decreased vision in one or both eyes
- headache, usually severe and abrupt or an unexplained change in the pattern of headaches
- difficulty swallowing.

**FAST** is the way you can recognise and easily remember these signs:

Facial weakness - can the person smile?

Has their mouth or eye drooped?

Arm weakness - can the person raise both arms?

Speech difficulty - can the person speak clearly

and understand what you say?

Time to act fast - call 000 immediately.

For more information or advice about stroke, make a free call to **StrokeLine 1800 787 653** or visit **www.strokefoundation.com.au** 

# National Stroke Foundation – 2008 Annual Review

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# President's introduction

#### Thank you and farewell



In 2002, with my appointment as President and Dr Erin Lalor as Chief Executive, we looked back at what the National Stroke Foundation had achieved since its inception in 1983 and looked forward to setting a direction for the decade ahead.

In its first 20 years, the Foundation moved from focussing on supporting stroke research to translating research findings into positive outcomes in stroke prevention and treatment.

The review showed us that more needed to be done because stroke was grossly misunderstood. Its low profile meant many people were not seeking the care that could save lives and reduce disability. Evidence-based treatment for stroke was often not available. We pledged that we would work systematically to ensure that these priority needs were met. In 2004, we launched a major public health campaign with the aim of saving 110,000 lives from death and disability over 10 years. Very quickly the strokesafe™ campaign raised awareness of stroke among Australians aged 40 and over.

Health professionals were also targeted to fill gaps in evidence-based care. For the first time there was formal agreement to unify the voice for stroke support and recovery across Australia.

As the strokesafe<sup>TM</sup> program

grew, stroke received greater profile and the Foundation grew. The organisation was restructured and we set ourselves the six priority areas that Erin lists in the Chief Executive's report: awareness and prevention, improving treatment, improving life after stroke, encouraging and facilitating stroke research, fundraising and governance and accountability.

A new advertising campaign was generated, educational materials produced, health professionals received clinical guidelines for stroke rehabilitation and recovery and a stroke survivor's kit was available.

By 2006 stroke was on the national agenda and we were showing results in each of our priority areas. Increasingly we were linking up with other organisations representing health professionals, stroke survivors, and the community as well as national and state government agencies.

In 2007 our National Stroke Audit quantified the resources around Australia available to support the delivery of evidenced-based care. We commissioned research to better understand the needs of stroke survivors and their carers. We consulted

widely, surveying the educational requirements of general practitioners around the country. Approval in 2007 by the National Health and Medical Research Council of our updated National Clinical Guidelines for Acute Stroke Management reinforced our leadership in stroke management.

This 2008 report shows we are continuing to build on what has been achieved in our six priority areas since 2003 but while we can be pleased with our progress we know there is still a very long road ahead.

I will be retiring as President at the 2009 Annual General Meeting (AGM) so this is my final Annual Review. As I retire, I am confident that my fellow board members, the team led by Erin, volunteers, business, philanthropic and individual supporters, partner organisations and governments will ensure that the Foundation continues to be instrumental in saving lives and reducing disability from stroke.

I would like to express my appreciation for your support and advice during my tenure as President as together we have waged the battle against Australia's second biggest killer.

John Lill, OAM
President

# From the Chief Executive Officer

#### The jigsaw puzzle that is stroke



Implementing our mission – to stop stroke, save lives and end suffering is like the challenge posed by a jigsaw puzzle, there are so many pieces that must be fitted together.

The picture that we want to emerge as we assemble the puzzle is our vision of saving 110,000 Australians from death and disability over ten years.

We started assembling the puzzle by selecting six key pieces. Our priority areas fit neatly together to support improving outcomes along the stroke pathway. They are:

- Awareness and prevention educating Australians about stroke
- Improving treatment

   developing policy and implementing programs to help reduce death and disability
- 3. Improving life after stroke helping stroke survivors and their families to gain better access to comprehensive and coordinated services
- 4. Encouraging and facilitating stroke research learning more about Australia's second biggest killer

- 5. Fundraising gaining financial support for our programs that will help Australians beat stroke
- Governance and accountability – managing our organisation professionally.

The annual review reports achievements in each of these areas.

A feature of 2008 was the expansion of our working partnerships with peer organisations, governments, health professionals and their associations, stroke survivors and carers, business, community service groups and individuals.

A particularly productive relationship was forged with the Heart Foundation, which resulted in the joint release by our two organisations of Time for Action, a blueprint for a national action plan to better tackle cardiovascular disease, Australia's biggest killer.

The document sets out 34 policy recommendations and formed the basis of Heart Foundation and NSF submissions to important reviews established as part of the national health reform agenda.

The Australian newspaper published an opinion page article authored by the two organisations.

We played a significant role in the work of the National Vascular Disease Prevention Alliance and its work towards

an absolute risk assessment program in general practice. The aim is to improve detection of people at high risk of cardiovascular disease to ensure they receive treatment and management needed to avoid heart attacks, stroke, type-2 diabetes and kidney disease.

We continued to work closely at many levels with all federal and state governments and we were particularly pleased with the support and recognition we received in 2008 from the Commonwealth, Victorian, Queensland and Tasmanian governments.

Our association with health professionals and their organisations provided two-way benefits. Our work was enhanced by their cooperation for projects such as the first-ever audit of post-acute stroke services.

The National Stroke
Foundation's first earlyassessment educational
module for managing patients
with transient ischaemic attack
(TIA) was delivered to General
Practitioners.

We worked with the Stroke Society of Australasia to establish the Australian Stroke Coalition bringing together clinical networks and professional associations and colleges.

We have long been concerned that the needs of stroke survivors and carers were not being met. To start to address this, we have developed the first national stroke strategy. Again it was a cooperative effort – the strategy is based on wide consultation with stroke survivors and carers, health professionals, academics, non-government organisations and government representatives.

The NSF would not have been able to achieve such a successful year without the financial, in-kind and practical on-the-ground support of business, trusts and foundations, individual donations and the work of volunteers cemented together by the professional hard work of our staff and the leadership of our Board.

We would like to thank our President, Dr John Lill who is stepping down following seven years of dedicated service to the NSF, during which time the organisation has grown dramatically and the issue of stroke has been firmly placed on the national agenda.

There are still many more pieces of the jigsaw to put in place but the picture is becoming much clearer.

On Kalor

Dr Erin Lalor
Chief Executive Officer

# Awareness and prevention



#### **National Stroke Week**



Victorian Health Minister, the Hon. Daniel Andrews rings in the beginning of National Stroke Week with (I to r) National Stroke Foundation CEO Dr Erin Lalor, Matt Jenkin and his wife Kim Durose, a stroke survivor and Danny McGemmisken, Operations Manager Ambulance Victoria.

The FAST campaign was the 2008 theme for National Stroke Week in September.

Announcing the campaign nationally, the federal Minister for Health and Ageing, the Hon. Nicola Roxon urged Australians to act FAST when they recognise the signs of stroke.

Senator the Hon. Joe Ludwig, Minister for Human Services announced that Centrelink would distribute 1.9 million FAST wallet cards to all Australian pensioners in Centrelink's News for Seniors magazine. This generated nearly 40,000 requests for additional information.

In addition to the Centrelink distribution, the NSF sent out 1.3 million FAST wallet cards plus other FAST materials, which meant that more than three million people learnt the FAST way to recognise and remember the signs of stroke and what to do.

The FAST campaign received valuable financial support from the Victorian Government through its Stroke Care Strategy. The Minister for Health, the Hon. Daniel Andrews joined stroke survivor Kim Durose and Mr Danny McGemmisken, Operations Manager from Ambulance Victoria at the launch of Stroke Week. Kim had a remarkable recovery from a stroke thanks to her husband Matt Jenkin who recognised the warning signs from the FAST campaign in 2007.

Tasmania's Deputy Premier and Minister for Health and Human Services, the Hon. Lara Giddings saw 30 performers acting out the FAST message to the beat of Taiko drums to launch Stroke Week in Hobart.

Other highlights included:

 a 71 per cent increase on 2007 in requests for information and people taking part in Stroke Week

- more individuals asking for Stroke Week packs compared with previous years when most requests came from health professionals and health services
- more than 1400 stroke week packs were distributed nationally containing a guide on how to run an event, FAST samples and a template media release
- more than 80,000 FAST wallet cards and 1000 FAST posters and magnets were distributed across Tasmania and four information booths were set up in the north and south of the state
- FAST wallet cards and strokesafe<sup>™</sup> information were handed to shoppers in Perth and hospitals, health services and stroke support group held community fundraisers and suburban shopping centre displays.

Distributed 3.2 million FAST wallet cards and 500,000 stroke prevention brochures and posters in 2008.



Flinders St Station in Melbourne urges commuters to act FAST



#### Media coverage

There were significant television, radio and newspaper reports of the launch of Stroke Week. The total number of stories about Stroke Week activities was 322 items compared with 206 in 2007.

#### Highlights included:

 almost 70 per cent of news stories mentioned the NSF, the FAST test and in many cases, the FAST wallet card

- about 39 per cent featured interviews with people representing NSF including the Chief Executive Officer, medical directors, state managers, stroke survivors and New South Wales
   Ambulance representatives
- approximately 50 news stories were generated by NSF material used by Members of Parliament and 35 stories were

generated by NSF media release templates in Stroke Week packs.



Life savers hand out life saving wallet cards.



Taiko drummers beat the FAST message in Hobart.

FAST wallet card

#### **FAST** advertising

Advertisements carrying the FAST message appeared on television, in newspapers, on the radio, in cinemas, on billboards and on websites. Media partners' advertising support was invaluable with:

- Draftfcb developing and producing the creative work
- Starcom MediaVest negotiating pro bono advertising and organising placements
- Southern Cross
   Broadcasting providing

bonus spots across the Southern Cross Radio Network

- News Ltd carrying bonus spots in News Limited papers nationally
- Val Morgan including the 30 second television advertisement on 650 cinema screens nationally
- APN and Eye providing billboard space in New South Wales, Victoria, South Australia and Western Australia.









Robertson MP, finds out his numbers.

Dr Erin Lalor, CEO National Stroke Foundation, The Hon. Anna Bligh Premier of Queensland and National Stroke Foundation Board Member Michael Hill celebrate the announcement of funding for Know your numbers.

#### **Know your numbers**

The NSF's Know your numbers program was developed to raise awareness that high blood pressure is a major risk factor for stroke and to encourage people to have their blood pressure checked regularly.

#### **Award**

Know your numbers was a finalist in the 2008 Victorian Public Healthcare Awards. It was honoured in The Premier's Award category for excellence in tackling chronic disease and improving public health.

#### Queensland

In 2008, the Queensland Government provided funding to run the program in South East Queensland. Queensland Minister for Health, the Hon. Stephen Robertson launched the program on 23 October. Radio, television and print media reported on the launch.

In November, the Premier, the Hon. Anna Bligh announced a three year commitment of \$2.5 million to the NSF to extend Know your numbers in pharmacies throughout Queensland.

Paid press and radio advertisements were placed in South East Queensland to promote the campaign. Free bonus ads were published in Brisbane's *Courier Mail* and major regional papers. Paid advertising on Queensland's 4BC and 4BH was supported by free bonus spots.

## Victoria and Queensland testing

A total of 350 pressure checking stations were set up in partnership with The Pharmacy Guild (Queensland and Victoria Branches) Rotary and the YMCA in shopping and leisure centres, pharmacies, workplaces and community health services in Victoria and Queensland.

Of the estimated 15,000 people who had their blood pressure checked:

- just over 50 per cent did not know what their blood pressure numbers were
- only 20 per cent had a normal reading
- nearly 40 per cent had high readings
- about 30 per cent were recommended to visit their GP.

About 293,890 Know your numbers information materials were distributed through pharmacies and partner organisations in both states.

#### strokesafe<sup>™</sup> seminar kit

Health professionals in Victoria, Queensland, South Australia, New South Wales, Tasmania, the Northern Territory and New Zealand purchased seminar kits to educate the community



about preventing a stroke in support of the strokesafe™ national awareness campaign.

The Sunshine Foundation, Eric Ormond Baker Charitable Fund and the Foundation for Rural & Regional Renewal agreed in 2008 to provide funding that will enable the Stroke Foundation to distribute the kits free of charge in rural and regional Victoria in 2009.

Between September 2008, when the NSF opened an office in Western Australia and the end of the year, 720 people attended 13 community education seminars on stroke and improving life after stroke in Western Australia.

Website visitors totalled 113,781 in 2008 – a 60 per cent increase on 2007.

#### strokesafe<sup>™</sup>awards



strokesafe™ award winner, Frankston Hospital, VIC

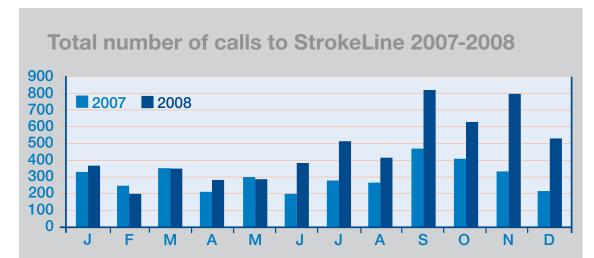


strokesafe™ award winner, Bankstown Hospital, NSW

The 2008 winners of the strokesafe<sup>TM</sup> awards promoted the FAST message in innovative ways through the media and their communities. Category winners received a plaque and \$100.

#### Winners:

- Hospital Team (Rural) WA County Health Service-Midwest Stroke and Rehabilitation team
- Hospital Team (Metro) –
  Equal winners Bankstown
  Hospital (NSW) and
  Frankston Hospital (VIC)
- Workplace RSL Care, Baycrest Retirement Community (QLD)
- General Practice/ Community Health
   Community Health Tongala (VIC)
- Stroke Support Group/ Community Group – Equal winners, Queensland's Gold Coast Stroke Support Group and Bundaberg Stroke Support Group.



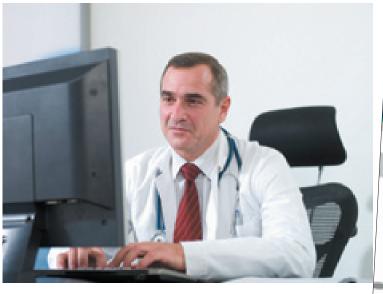
A full time health professional was appointed to manage the StrokeLine free call service in 2008. The 5705 calls received was a 25 per cent increase on 2007. StrokeLine was promoted in advertising, with the distribution of 10,000 fridge magnets and with a pro bono poster campaign in doctors' surgeries.

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#### Rehabilitation stroke audit

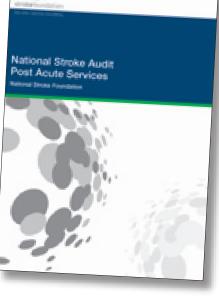


One hundred hospitals took part in the National Stroke Foundation's rehabilitation stroke audit, the first ever audit of post-acute stroke services.

The audit highlighted priority areas to improve post acute

care for people with stroke which centre around:

- evidence-based care
- standardised assessment tools
- comprehensive discharge planning



- community-based rehabilitation services
- stroke rehabilitation research programs
- rehabilitation workforce.

#### Clinical guidelines for stroke management

There continued to be a heavy demand on the website during 2008 for the NSF's Clinical Guidelines for Acute Stroke Management. There were 10,817 downloads of the guidelines during the year, which provide evidence-based recommendations to promote improved early treatment for stroke and transient ischaemic attack (TIA).

Plans were developed to review the National Clinical Guidelines for Stroke Rehabilitation and Recovery, as well as update the acute guidelines, and combine the two for release in 2010.

#### **Guideline implementation**

The StrokeLink program was launched in Queensland in June 2008 with the StrokeLink team visiting nine sites by the end of the year. The program was developed to link best practice care using the guidelines, with what is currently being provided

based on evidence obtained through audit data. The aim is to support improvements in the quality of stroke care delivery through a comprehensive quality improvement program offering outreach visits by NSF staff.

First ever audit of post-acute stroke services.

#### General practice program

In 2008 the NSF created its first educational module for General Practitioners. The TIA and early assessment program was designed for GPs and other health professionals managing patients experiencing a TIA or mild stroke. It was distributed through all Divisions of General Practice throughout Australia, the Royal Australian College of General Practitioners (RACGP) and stroke networks across the country.

Three more modules covering atrial fibrillation, anti-platelet therapy for secondary stroke prevention, and rehabilitation and long term recovery are expected to be finalised in early 2009.

Specific guidelines for general practice, adapted from the acute and rehabilitation guidelines, were published and distributed during 2008. Print and electronic copies were widely distributed with the help of existing health industry partners and through the Royal Australian College of General Practice website.

The NSF has provided feedback into programs driven by the RACGP including the review of the Red Book: Preventive Activities in General Practice and participation linked to the Men's Preventive Health program.



# Stroke services framework

The Stroke Services Framework, (previously National Stroke Unit Program) was developed to support the establishment and improvement of stroke units across Australia. It was renewed in 2008 and launched at the joint Stroke Society of Australasia (SSA) Smartstrokes Conference in Sydney in August. It attracted wide interest with more than one thousand copies being downloaded from the NSF website between October and December.

# Stroke clinical indicators

With the availability of National Stroke Audit data, NSF sought to derive a subset of 'primary' clinical process indicators. The rationale was to ensure they remain part of the audit each time it is conducted. The SSA and the Australia New Zealand Association of Neurologists have endorsed the initiative and similar endorsement is being sought from the Royal Australasian College of Physicians. With this endorsement the stroke clinical indicator set can be considered for inclusion into the Australian Council on Healthcare Standards (ACHS) national clinical indictor program.



Australian Stroke Coalition (ASC)

#### **Australian Stroke Coalition**

The Australian Stroke Coalition was established by the NSF and Stroke Society of Australasia on 11 July, 2008. The Coalition brings together representatives from about 25 groups. It will tackle priorities to improve stroke care, reduce duplication among groups and strengthen the voice of health professionals dealing with stroke nationally and at the state level.

# promoting the NSF GP guidelines appeared in the 6minutes.com.au

An article on

stroke recovery

webletter published for doctors on 24 October 2008.

#### National stroke registry

A joint partnership between the NSF, the National Stroke Research Institute, The George Institute and the Stroke Society of Australasia won a tender awarded by the Australian Commission on Safety and Quality in Health Care in September 2008 to test the operating principles and guidelines to establish a stroke clinical register. This reflects the Foundation's commitment to quality improvement linked with the national audit.

# Improving life after stroke



#### Stroke support strategy



Australia's first *National Stroke Support Strategy* was published in May, 2008 following a summit in March attended by 55 stakeholders from across Australia and from New Zealand. The summit was initiated by the NSF and part-funded by the Australian Government's Department of Health and Ageing.

The strategy is based on consultation with over 200 stroke survivors and carers as well as health professionals, academics, other non-government organisations such as the Heart Foundation and Carers Australia, state stroke associations and stroke support groups, state and federal government representatives and Divisions of General Practice.

With the adoption of the stroke support strategy, an implementation plan will be developed to set out a work plan incorporating governance, budget management, resource requirements, risk management, change management and timelines.

The aim of the stroke strategy will be to implement recommendations made in the NSF Walk in our shoes research report that outlined what survivors and carers said they needed, and conduct extensive consultation to:

- develop programs and processes to improve support and training for primary and secondary health care professionals providing stroke care to ensure the needs of stroke survivors and carers are met, including comprehensive discharge planning, access to programs providing carer training and information about stroke and community services
- establish national programs to develop and disseminate information at the right time and in the best format to educate carers and stroke survivors
- improve existing programs either through better referral processes or modification, to meet stroke survivors' and carers' needs

- develop new programs integrated into the current system where existing programs cannot meet the needs of stroke survivors and carers
- improve post discharge support by developing and introducing community based stroke liaison officers, providing information about services and life after stroke.

#### Thank you

Many contributed to the development of the stroke support strategy. We thank participants at the summit and those who took part in interviews; the Department of Health and Ageing who provided financial assistance and the Advisory Committee:

- Jude Boyd
- Paul Fullerton
- Michael Hill
- Jennie Linto
- Jonathon Sturm
- Susan Williams

The stroke support strategy was prepared by Communio.



National stroke support summit held in March – stroke support strategy published in May. Three new fact sheets for stroke survivors were produced in 2008 covering fatigue, driving and bladder control after stroke.

#### Fitness for stroke

Stroke survivors are at a higher risk of further strokes than people without a history of stroke. The risk of recurrent stroke is six times higher than the risk of a first ever stroke. Effective measures for preventing recurrent stroke include regular exercise but health professionals and stroke survivors struggle to find appropriate exercise programs to help survivors maintain their independence and recover quality of life.

The Heartmoves program, established by the Heart Foundation, is an exercise program that caters specifically for those with chronic disease. Trained and accredited leaders

conduct exercises that are low to moderate in intensity and encourage people to start slowly and work at their own pace within safety guidelines.

Agreement was reached in 2008 for the NSF to develop a module for fitness instructors delivering the Heartmoves exercise program so that they learn more about stroke and are better able to meet the needs of stroke survivors. A second objective is to raise awareness among stroke survivors and stroke health professionals of the existence of Heartmoves programs.

This project is funded by the J.O. and J.R. Wicking Trust, the NSF and the Heart Foundation.

#### Home follow up

The main aim of the Home Follow Up pilot project that got underway in Tasmania is to test aspects of the stroke support strategy, including the best time to follow-up with patients after they go home from hospital and to ascertain how many patients need support and the type of support they require.

In this short term project, a telephone call is made to stroke survivors and carers at six weeks and again at three months after the stroke survivor has returned home from hospital. If the person needs services, he or she is referred to a stroke liaison officer who follows up.

#### Peer support

The National Stroke Foundation is committed to improving quality of life for stroke survivors and their families. In 2008, the NSF delivered programs to help stroke survivors provide support and advice to other stroke survivors face-to-face and also began examining other methods of providing peer support including online and over the phone.

#### Friends

The Friends of the NSF program provides stroke supports groups with information about NSF activities, stroke updates, resources, small grants, and support for stroke week activities. This information is disseminated through a quarterly newsletter.

Information, including contact details of those in Friends of the NSF, and the newsletter is available on the NSF website, (www.strokefoundation.com.au).

Friends have grown over the past year from 42 groups to 55 groups nationally, with the aim to continue to grow the program over the coming years. Feedback has been positive with groups saying that the program provides good support, information

and communication of continuing benefit to stroke support groups.

#### Stroke support groups

Stroke support groups provide opportunities for stroke survivors and carers to share their experiences and gain support from their peers. In Western Australia, for example, an NSF forum enabled stroke support group coordinators to share their experiences of running a support group and attend workshops to discuss what works and what doesn't in a peer support group.

Two respite weekends in Busselton, WA, was another method used to provide carers of stroke survivors with the opportunity to take a break. Carers received information on stroke recovery, community services, support options and planning for their future and gained support from others in the group.

In Tasmania, NSF coordinated meetings of stroke support groups in the north and south of the State enabling members to socialise with other stroke survivors and carers and to ensure they received relevant information

# Self management program

Dream, Believe, Achieve, is a world-first program developed for those with cognitive impairment as a result of stroke to help them on their road to recovery. In 2008 in South Australia, stroke survivors took part in an eight week education program in one of three different models of care. The results will provide valuable advice on the most effective models of care in self management for people with cognitive impairment such as vascular dementia.

A start was also made in 2008 on delivering the self management program in Victoria.

The project began in 2008 and will be completed by December 2009. It is funded by the J.O. and J.R Wicking Trust and the Adelaide Charitable Foundation.

A brochure about stroke was published in Chinese, Italian, Vietnamese, Greek and Arabic and can be downloaded from the NSF website.







#### Strategy development

A research strategy was developed in 2008 based on consultation with researchers from around Australia who advocated supporting investment across different priority areas. Building the sector's capacity was seen as an essential element along with establishing networks and attracting more substantial investment in stroke research.

The Board committed the NSF to implementing a research strategy that:

 supports the sector to conduct quality research

- attracts talent, interest and resources to stroke research
- encourages a partnership approach
- adds value to and builds on existing work
- identifies gaps or under serviced research domains
- leverages available research dollars and recognises other funding sources
- increases the profile and influence of stroke and stroke research
- links with clinical guidelines and evidence based practice.

Research strategy developed – first four grants awarded.

#### Research grants

The NSF awarded four grants from a field of high quality submissions to further research into rehabilitation or quality of life after stroke.

They were awarded to:

 Dr Annie McCluskey, The University of Sydney, awarded the Veolia Environment Services Award (supported by funds raised through the NSF's Stroke of Art program)

Translating evidence into practice: Helping people with stroke to get out of the house

People with stroke often cannot walk far or drive a car. Social isolation is common. Occupational therapists will provide a series of visits to increase confidence, community mobility and transport options. Research shows that these visits can double the number of journeys by people with stroke.

 Dr Jonathan Sturm, Gosford Hospital, New South Wales

A simple intervention to prevent depression and improve quality of life after stroke

Depression after stroke is common and is associated with poor quality of life. Effective strategies to prevent the development of depression may also reduce anxiety, increase participation in rehabilitation programs, improve physical function and quality of life. This study will look at a simple yet practical strategy by use of regular postcards to connect with the stroke survivor.

 Stacey George, Repatriation General Hospital, South Australia

An evaluation of rehabilitation of vision following stroke

This project will evaluate the usefulness of a visual scanning program for people following stroke. A group, who receives visual scanning therapy for six weeks, will be compared to a group who do not, in term of their vision, ability to perform daily tasks and quality of life.

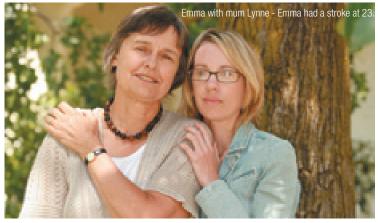
 Dr Toby Cumming, National Stroke Research Institute, Victoria

The effect of very early mobilisation after stroke on cognitive impairment, depression and quality of life

Many stroke survivors experience cognitive problems, which are strongly related to poor recovery. Screening for cognitive deficits after stroke is difficult. This study seeks to identify a valid tool for measuring cognitive impairment that can be incorporated into rehabilitation trials. The relationships between cognitive problems, disability, depression and quality of life will be examined.



# Fundraising



Donor loyalty and welcoming new donors were highlights of 2008 – another year of growth in fundraising.

The frequency of direct mail appeals increased in 2008, featuring a Mother's Day Appeal for the first time. The

story of Lynne's response to her daughter, Emma having a stroke at the age of 23 touched the hearts of supporters. The mail appeal in May/June described Paula's trauma of having a stroke, moments after the birth of her first child.



"When my husband Nick tried to hug me, I couldn't raise my left arm. Everyone around me then realised that I couldn't talk and that something was wrong. I really don't remember much from here. But I know now that I was taken into ICU. I have no memory of the first few hours of my baby's life."

This dramatic story encouraged donors to contribute more than \$1 million to help beat stroke – the highest total for any single appeal.

The generosity did not end there. The 2008 Christmas Appeal featuring stroke survivor Erin, who found out she was pregnant the same day she suffered a stroke, is now the second highest appeal total in our history following the record \$1 million.

Another feature of 2008 was the decision by more than 2000 of our existing donors to pledge a fixed amount each month through their credit cards. This guarantees a fixed income stream for the organisation and is more convenient for supporters. We will continue to encourage this form of giving in the coming year.

#### Bequests

Planned Giving was a major focus in 2008. Donors who let us know that they have willed a portion of their estate to the National Stroke Foundation are made members of the David Brownbill Society. The society is named after the co-founder of the NSF, eminent neurosurgeon Mr. David Brownbill. Members receive a membership

kit and invitations to society events throughout the year. The growth of the bequest program is critically important as it allows the organisation to develop plans well into the future, secure in the knowledge that there will be adequate funding available for our work. An important example in 2008

was the substantial Baldwin Bequest, which will support vital NSF activities including research. Bequest officers were appointed in New South Wales, Queensland and Tasmania during 2008. We also appointed a new bequest officer in Victoria together with a national bequest coordinator.

56,307 new donors welcomed to our team of financial supporters.



Counterstroke golf classic 2008

#### Golf

The volunteer golf committee has been staging the now famous Counterstroke Golf Classic on the Mornington Peninsula for more than 15 years. Held over five days on five separate golf courses, the Classic attracts golfers from all around Victoria.

Over the last two years, the committee has run a second competition on the Bellarine Peninsula over three days. Although still in its growth phase, the Bellarine Classic is

showing great potential to be as successful as its long term partner on the other side of the bay.

Through the diligent work of the volunteer committee, a total of \$100,000 was raised in 2008, bringing the total to about \$1 million over 15 years. The tournaments would not have been possible without the support of the Trust Foundation, Anderson Kelly, NAB, Scotchmans Hill and Maxwell & Williams.

#### Thank you

We acknowledge and thank all those who in 2008 assisted NSF for the first time, or continued a longer term partnership with us. We look forward to working with you on plans that we developed in 2008 for the next 12 months and beyond.

# Trusts and foundations

Important elements of our work depend on the support of trusts and foundations.

They provide support for specific programs, including:

- Fitness for stroke Pierce Armstrong Foundation
- Seminar kits Sunshine Foundation
- Stroke self management program SA – Adelaide Bank Charitable Foundation
- Strokesafe<sup>™</sup> seminar kits

   Eric Ormond Baker
   Charitable Trust and
   Trustees of the late Edward
   Wilson (FRRR)

Trusts and foundations that have supported other activities include:

- ACTA-Page-Hanify
- Family Benefaction
- Fonda Family Charitable Foundation
- JRG & McKenzie Bequest
- Oliver-Affleck Fund
- Tasmanian Perpetual Trustees
- The Bruce Wall Trust Fund
- The Danks Trust
- The Myer Foundation
- The William Angliss Charitable Fund
- Trust Foundation

#### Ball and charity auction



Sandra Sully, MC and Melanie Orval drawing raffle.

Run by a volunteer committee, the Thank God You're Still Here Ball and Charity Auction was held in April 2008 at Flemington Race Course. It was a brilliant night with a disco theme that raised more than

#### **Volunteers**

Volunteers are a not-for-profit organisation's most treasured resource. The NSF's gifted and committed volunteers provide invaluable assistance year after year. The 2008 Thank God You're Still Here Charity Ball and the Counterstroke Golf Classics were outstanding events built on the hard work and talent of volunteers.



Joanne Leeds, Chair of the Thank God you're still here charity ball commitee and Dr Erin Lalor. CEO National Stroke Foundation

\$100,000 for the Foundation. Photos of celebrities attending the ball were taken, including the MC for the night Sandra Sully, and an article appeared in Melbourne's Sunday *Herald Sun*, the following weekend.

#### Special events

Nearly \$20,000 was raised by individuals and organisations who staged events in 2008 for the NSF, including movie nights, fun runs and car rallies.



# Governance and accountability



The NSF is continuing to grow, from 24.5 full time equivalent (FTE) in December 2007 to 40.5 FTE at the end of 2008.

Staff recruitment has focused on adding skills and experience to enhance the organisation's capabilities so that the Foundation can meet a growing demand for services, programs and policy initiatives.

Increased staff members were accommodated in the new premises that were selected in 2007, when it became clear more office space, meeting rooms and storage would be required. Staff efficiency, safety and comfort are greatly improved in the new building, which is not far from where we were before in the Melbourne central business district.

The national operation was strengthened in 2008, with offices opening in Hobart and Perth. The Foundation now has offices in Victoria, where the national headquarters is located, Tasmania and Western Australia with representatives in New South Wales, Queensland and South Australia.

The organisation's growth in numbers and the geographical spread necessitated a review of management systems that cover human resources, information technology and risk management.

Regular employee performance reviews continue to be important – ensuring that the Foundation's high standards are maintained while identifying opportunities to enhance staff skills. Professional development is essential for sustained organisational growth and contributes to staff enjoying a satisfying and rewarding work experience.

The establishment in 2008 of an investment committee – a sub-committee of the Finance Investment and Risk Committee – strengthened the Foundation's ability to wisely and conservatively invest funds for the organisation's future sustainability. The need became increasingly apparent in late 2008 as Australia and the rest of the world headed into difficult financial times.

Increased revenue, the growth in the range of the Foundation's programs and the role of the new state offices required changes to financial reporting and management processes which have been implemented.

Revenue increased 47 per cent from \$5.6 million in 2007 to \$8.2 million in 2008.

The NSF is fortunate in having an honorary Board that includes business, research, and consumer representatives as well as two Medical Directors. Board members are listed on page 19.



The NSF was delighted when the new Governor General, Her Excellency, Ms Quentin Bryce AC, agreed in 2008 to be Patron-in-Chief.

## VALE: Roy Kingsland Boyce (5 August 1933 - 10 May 2008)



We acknowledge the significant contribution that Roy Boyce made as a member of the National Stroke Foundation's finance, audit and risk management committee.

For nearly a decade, Roy focused on ensuring high standards of governance to protect the security of the Foundation's assets. He gave generously of his time from 1999, serving on the finance, audit and risk management committee.

Roy was Managing Partner of Deloittes in Victoria when he retired.

The National Stroke Foundation was fortunate to secure his voluntary services. Roy served as the Australian Club's Treasurer and committee member from 1995-1998 and shared his knowledge with many other clubs and organisations.

Together with friends, he was instrumental in setting up the Nippers program now run by nearly all lifesaving clubs in Australia. Roy was awarded life memberships at Portsea Surf Lifesaving Club and with Surf Lifesaving Victoria.

Roy is survived by Ann, his wife of 51 years, his adult children, Andrew, Jayne and Sally, their spouses and his nine grandchildren.



# Financial performance

Revenue	2008	2007	2006	2005
	(\$,000's)	(\$,000's)	(\$,000's)	(\$,000's)
Community Support	6,712	3,943	3,235	1,388
Corporate Support	352	629	404	702
Government Support	915	797	503	893
Product Merchandise	131	96	125	21
Interest Income	90	116	68	49
Total Revenue	8,200	5,581	4,335	3,053
Expenses				
Priority Area 1 - Preventing Stroke	1,333	1,129	535	681
Priority Area 2 - Improving Treatment	847	582	241	209
Priority Area 3 - Improving Life After Stroke	751	317	202	468
Priority Area 4 - Research	40	65	- 202	400
Priority Area 5 - Income Development*	4,348	2,700	2,435	1,071
Priority Area 6 - Governance & Accountability	838	612	320	447
Total Expenses	8,157	5,405	3,733	2,876
Surplus From Ordinary Operations:	43	176	602	177
Other Investment Income	39	170	002	177
Restatement of of Investments to Fair Value	(178)			
nestatement of of investments to Fair value	(170)			
Total Other	(139)	5,405	3,733	2,876
OVERALL RESULT	(96)	176	602	177
Financial Position				
Assets				
Cash (inc. Deposits)	1,498	2,415	2,130	973
Receivables	207	262	329	80
Inventory	9	2	4	1
Other Financial Assets at Fair Value	719	535	-	-
Fixed Assets	255	90	62	41
Total Assets	2,688	3,304	2,525	1,095
Lightities		T		
<b>Liabilities</b> Payables	594	1,182	613	249
	684	763	729	264
Provisions	001	, 00	, 20	201
Provisions Lease Liability	147	_	-	- 1
Lease Liability	147 <b>1.425</b>	1.945	1.342	- 513
	147 1,425	1,945	1,342	513

28%

10%

#### Ratios and Expenditure Notes:

Direct fundraising expenses to fundraising income.\*\*

Administration expenditure to total income.

\*Includes major developmental investment into a donor aquisition bequest program.

This is necessary to support the future long term funding growth and vision of the National Stroke Foundation.

 $<sup>^{\</sup>star\star}\textsc{Does}$  not include costs and income associated with major developmental investment.

# Board and supporters

#### **Patron-in-Chief**

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

#### **Patrons**

David Brownbill, AM Sir John Holland, AC Sir Gustav Nossal, AC Lady Southey, AC

#### **Chief Executive Officer**

Dr Erin Lalor

#### **Medical Directors**

Professor Christopher Bladin, MD, FRACP

Associate Professor Christopher Levi, MD, FRACP

#### **Board**

The Board, through the Chief Executive Officer, delegates responsibility for the day-to-day provision of services, marketing and administration. Board members in 2008 were:

#### **President**

Dr John Lill, OAM

#### **Vice Presidents**

Andrew F Buckle, OAM William J Forrest, AM Robert Trenberth

#### **Treasurer**

Graeme Bowker

#### **Company Secretary**

John Buchanan

#### **Directors**

Professor Richard Smallwood, AO Associate Professor Julie Bernhardt Professor Richard Lindley

Paul Leeds

David Evans

Michael Hill

lan Collins, AM (appointed December, 2008)

Susan Aveyard

(appointed December, 2008)

Susan Williams

(resigned October, 2008)

#### **Ambassadors**

Judith Halliday Angelo Lekkas Brooke Parsons Ross Pearson

#### **Solicitors**

Corrs Westgarth Chambers

#### **Auditors**

**RSM Bird Cameron** 

#### **Consultant accountants**

**Evans Buchanan** 

## Finance Investment and Risk Committee

Graeme Bowker, Chairman Dr John Lill, OAM David Evans

David Evans

Roy Boyce (deceased May 10, 2008)

Andrew Miles (appointed October, 2008)

Dr Erin Lalor Glenn Sheffield

Matthew Oakey, Evans Buchanan

## **Governance and Nominations Committee**

William J Forrest, AM Andrew F Buckle, OAM Susan Williams (resigned October, 2008)

#### Hospital Peer Support Program Advisory Committee

Ms Denita Wild Mrs Clare Gray Mr Peter Richardson Mr Paul Fullerton Ms Jo Smith

# National Stroke Audit - National Advisory Committee

#### Chairperson

Dr Michael Pollack

#### Members

Dr Geoffrey Boddice Dr Janice Collier Professor Maria Crotty

Ms Sonia Denisenko

Dr Steven Faux

Ms Claire Gillis

Ms Erin Godecke

Ms Dawn Harris

Ms Isobel Hubbard

Dr Lynette Joubert

Dr Genevieve Kennedy

Dr Debbie Kesper

Dr Erin Lalor

Ms Sandra Lever

Ms Jane Levy

Mr Mark Longworth

Mr Chris Price

Dr Andrew M Wesseldine

### Corresponding members

Dr Dominique Cadhilac Ms Monique Kilkenny

## Research Advisory Committee

#### Chairperson

Professor Richard Smallwood.

#### Members

Associate Professor Julie Bernhardt Dr Erin Lalor Associate Professor Chris Levi Professor Richard Lindley Ms Susan Williams (retired).

# **Stroke Self Management Program**

Advisory Group - Phase 2

#### Chairperson

Professor Malcolm Battersby

#### **Members**

Dr Erin Lalor

Professor Richard Lindley
Assoc. Professor Helen Dewey
Dr Velandei Srikanth
Dr Dominique Cadilhac
Assoc. Professor Richard
Osborne
Dr Andrew Lee
Ms Sally Hoffmann

#### Major sponsors for ball

Network Ten, Deutscher-Menzies, Anton Jewellery and Honda together with:

- Australian Radio Network
- WTFN Entertainment
- Fremantle Media
- 3AW
- Hungry Jacks
- Nine Network

#### **Business Companies**

The following companies have been generous with their support:

- JA Davey (Omron)
- Pfizer
- Veolia Environmental Services
- Novo Nordisk
- sanofi aventis
- Activist Advertising
- Ogilvy Healthworld
- Servier

#### Pro bono supporters

Other firms have provided probono services, including:

- Aviva Group
- Evans Buchanan
- Corrs Chambers Westgarth
- IMCD Australia
- Draft fcb
- Starcom MediaVest

#### Governments

We appreciate the support of the following government departments:

- Australian Government Department of Health and Ageing
- Department of Human Services (Victoria)
- Department of Health and Human Services (Tasmania)
- Queensland Government Queensland Health



strokefoundation19

#### Papers and journal publications

#### **PAPERS**

The inaugural Australian national audit of acute hospital services: determining adherence to clinical recommendations with Level 1 evidence. Cadilhac DA, Hankey GJ, Harris D, Hillier S, Kilkenny M, Lalor E.

 European Stroke Conference (Poster), Nice, France, 13-16 May 2008

The national audit of acute hospital stroke services: determining a set of performance indicators for longitudinal national benchmarking and service improvement monitoring.

Cadilhac DA, Kilkenny M, Churilov L,

Harris D, Lalor E.

• Stroke 2008 Conference (Poster), Sydney, 13-15 August 2008

# The inaugural Australian national audit of acute hospital stroke services: determining adherence to clinical recommendations.

Cadilhac DA, Hankey GJ, Harris D, Hillier S, Kilkenny M, Lalor E.

• Stroke 2008 Conference (Oral), Sydney, 13-15 August 2008

#### The Australian national clinical audit of acute hospital stroke services. Cadilhac DA, Hankey GJ, Harris D, Hillier S, Kilkenny M, Lalor E.

 Stroke 2008 Conference (Poster), Sydney, 13-15 August 2008.

Results of a pilot program to increase awareness of blood pressure as an important risk factor for stroke in Australia.

Cadilhac DA, Johnson R, Kilkenny M, Lalor E

 Stroke 2008 Conference (Poster), Sydney, 13-15 August 2008

## Value of audit as a quality improvement tool. Harris D.

• Stroke 2008 Conference (Poster), Sydney, 13-15 August 2008

#### Secondary prevention in acute stroke management: audit results. Harris D, Hankey GJ.

 Stroke 2008 Conference (Oral), Sydney, Australia 13-15 August 2008

# New clinical indicators for acute stroke management.

Harris D, Cadilhac DA.

• Stroke 2008 Conference (Oral), Sydney, 13-15 August 2008

#### A national audit for acute stroke management: the development process - key successes and challenges.

Harris D, Ritchie E, Hill K.

 National Forum on Safety and Quality in Health Care (Poster), Adelaide, 29-31 October 2008

## Stroke self management program phase 1 results.

Hoffmann S, Cadilhac DA, Norton J, Richardson P, Amos A, Lalor E.

• World Stroke Congress (Poster), Vienna, Sept 2008

## Stroke self management program phase 1 results.

Hoffmann S, on behalf of coauthors; Cadilhac DA, Norton J, Richardson P, Amos A, Lalor E.

 International Chronic Disease Congress (Oral), Melbourne, November 2008

# Measuring the effectiveness of chronic disease self management programs.

Hoffmann, S. Special symposium: Linking Chronic Disease Self Management Programs course curriculum to quality and outcomes: Perspectives from patients, researchers, clinicians, funders and policymakers

 International Chronic Disease Congress (Oral), Melbourne, November 2008

# Hospital peer support program and peer role modeling

**program.** Smith J, Fullerton P, Gray C, Richardson P, Wild D, Lalor E, Hoffmann S

 Stroke Society of Australasia Annual scientific meeting (Poster), Sydney 13-15 August, 2008.

#### National audit of acute stroke management – state results (2007). Dawn Harris (Oral),

- Western Australia Stroke Forum, April 2008
- Queensland Stroke Network, Forum Meeting, March 2008

#### Helping you, helping us: A stroke prevention resource for busy health professionals.

Trobbiani K, Johnson R.

 Victorian Rural Health Conference (Poster), Bendigo, Victoria, 30 April – 2 May 2008.

#### **JOURNAL PUBLICATIONS**

## Acute Stroke Management Expert Working Group.

Australian Clinical Guidelines for Acute Stroke Management 2007. Hill K. Int. J Stroke. 2008 May; 3 (2):120-9.

Clinical guidelines for stroke care: why the fuss and is there opportunity for collaboration? Hill K, Lalor E. Int J Stroke. 2008 Aug; 3 (3):173-4.

Identifying the effective evidence sources to use in developing Clinical Guidelines for Acute Stroke Management: lived experiences of the search specialist and project manager. Parkhill A & Hill K. Health Information and Libraries Journal 2008; 26:47–55.

The Australian national clinical audit of acute hospital stroke services. Cadilhac DA, Hankey G, Harris D, Hillier S, Kilkenny M, Lalor E. Internal Medicine Journal 38 (Supplement 4), August 2008.

## New clinical indicators for acute stroke management.

Harris D, Cadilhac DA. Internal Medicine Journal. 38 Supplement 4, August 2008

The inaugural Australian national audit of acute hospital services: determining adherence to clinical recommendations with Level 1 evidence. Cadilhac, D.A, Hankey, G., Harris D., Hillier, S., Kilkenny. M., and Lalor, E. Cerebrovasc Dis 25(suppl 2):76 Abstract 16 Acute stroke: clinical patterns and practise. May 2008

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- 8. AIHW: Heart, stroke and vascular diseases, Australian Facts 2004
- 9. Cadilhac, D., H. Dewey et al. Investing in Stroke - What are the potential cost offsets from the strokesafe™ program. National Stroke Research Institute - Technical Report (Unpublished) 2005.

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#### 10 facts about stroke

- 1. Stroke is Australia's second single greatest killer after coronary heart disease and a leading cause of disability.<sup>1</sup>
- 2. In 2009, Australians will suffer over 60,000 new and recurrent strokes that's one stroke every 10 minutes.<sup>2</sup>
- 3. One in five people having a first-ever stroke die within one month and one in three die within a year.<sup>3</sup>
- 4. The number of strokes will increase each year due to the ageing population unless something is done to reduce the incidence rate.<sup>4</sup>
- 5. In the next 10 years more than half a million people will suffer a stroke.5
- 6. Stroke kills more women than breast cancer.6
- 7. About 88% of stroke survivors live at home and almost all have a disability.<sup>7</sup>
- 8. Close to 20% of all strokes happen to people under the age of 55.8
- 9. Strokes cost Australia an estimated \$2.14 billion a year.9
- 10. The National Stroke Foundation is the only national not-for-profit organisation in Australia dedicated exclusively to stroke.

For information or advice about stroke call StrokeLine 1800 787 653 (free call) Visit www.strokefoundation.com.au