

# AVERT Newsletter

No. 4. December 2006



**This newsletter is for *everyone* who is a part of the AVERT team.** This includes people living with stroke, their families and carers who support our research program, investigators and stroke unit staff in Australian and overseas hospitals; members of the important committees overseeing the trial; and all other supporters including volunteers and donors.

**We thank you all for your support and wish you a Merry Christmas and a Happy and Healthy New Year!**

## In this Edition:

### [Phase 2 Results \(this page\)](#)

Julie presents the results the Phase 2 safety and feasibility study conducted at Austin Health and Vincent's Hospitals from 2004 - 2006. This study included 71 people with stroke who were followed up for 12 months after their stroke.

### [The Big NEW \(Phase 3\) Trial. \(Page 2\)](#)

Now looking for 2104 people with stroke from all over Australia! Fiona Ellery (Trial Manager) provides a report on progress in the last 6 months.

### [My Stroke Joke \(Page 2\)](#)

Bryan Yeates provides a poetic and personal response to his stroke.

### [Enrolling in AVERT: a son's perspective \(Page 3-4\)](#)

Dorcas interviews Robert Lee, the son of Sylvia Lee, who participated in the AVERT Phase 2 study.

### [Assessing activity early after stroke \(Page 5\)](#)

Henry Zhao, Medical student from The University of Melbourne talks about his research project.

### [Looking at brain scans \(Page 5\)](#)

Katrina Clarkson, Medical student from the University of Edinburgh, tells us about the work she undertook for an elective while here at AVERT Central in Melbourne.

### [Visitors from a Swedish stroke unit \(Page 6\)](#)

A new collaboration with a physiotherapist and nurses from the Karolinska University Hospital stroke unit was formed in November this year.

## Associate Professor Julie Bernhardt



## AVERT Program Director

Firstly, I would like to thank you all for your ongoing support of the AVERT Program. As you know, this research aims to find more effective ways of reducing death and disability after stroke through changes to rehabilitation practices.

We are entering a very exciting phase now. Thanks to funding from the NHMRC and the Heart Foundation, we have started the really BIG, landmark trial of very early rehabilitation. Our reputation is spreading, and Australia is leading the way in very early rehabilitation research.

In October the Phase 2 Safety and Feasibility results were presented at the Stroke Society of Australasia Conference in Adelaide. Our main findings were that the large study appeared both safe and feasible. Nothing unexpected here but a very important part of our sound approach to working out whether the intervention works and is cost effective. I was also asked to talk about meeting the challenges of doing a trial like AVERT. You all got a mention, because trials like these need support from so many sources.

Anyone wanting more detailed information – please let me know.



**Fiona Ellery**

**AVERT  
Trial Manager**

**The big NEW trial. Looking for 2104 people with stroke from all over Australia**

I am the manager of the big NEW trial, AVERT Phase 3. This means that I am responsible for coordinating the day to day running of the project from our central office and training staff at each of our sites.

In July, we had an investigators meeting held in Melbourne. It was a successful meeting where we introduced the Phase 3 study to the newly expanded trial team. We now have ethics approval for all but one of the hospitals represented at the meeting and we have started recruiting at a few sites already. It has been great to meet the hospital teams from the different stroke units across Australia.

By Christmas, we will have staff from 8 hospital stroke units actively participating. They are:

- Austin Hospital, Vic
- Royal Melbourne Hospital, Vic
- West Gippsland Hospital, Vic
- Royal Perth Hospital, WA
- Flinders Medical Centre, SA
- Newcastle Mater Misericordiae, NSW
- Wyong Hospital, NSW
- Westmead Hospital, NSW



The new, expanded AVERT Team!

We are proud to announce that we have 35 patients enrolled so far. We need to enrol a total of 2104 patients over the next 4 years, so we still

have a long way to go!

We are however extremely pleased about the level of enthusiasm that the hospital staff and the participants have for this project and predict that we will meet our target recruitment within the expected time frame which is fantastic!

As each of our hospitals involve approximately 6 – 10 staff for the AVERT trial, there is going to be plenty to do!

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**My Stroke Joke**

I'm not the sort of bloke  
That you'd think would have a stroke  
Because I hardly ever drink  
And I never ever smoke

My diet is inoffensive  
And I'm certainly not obese  
But I'm highly hypertensive  
And it's likely to increase

I ride my bike to work and back  
And I seldom ever sit  
I really like to ride my bike  
And move about a bit

So lack of exercise  
Is not part of the equation  
Which leads me to surmise  
There is some other explanation

Could it be anxiety  
About the rising petrol price  
Of the signs of global warming  
And the melting polar ice

Failure to detect  
Any underlying cause  
Has led me to suspect  
The changing I.R. laws

I am worried and concerned  
About the ordinary bloke  
And I'm blaming Johnny Howard  
For my stupid bloody stroke

- B. Yeates 2006

Bryan Yeates was the first person to enrol in AVERT Phase 3, and he has offered his personal response to having a stroke.



## **Enrolling in AVERT: a son's perspective**

When Sylvia suffered a stroke in May 2005, she was taken to the Austin Hospital, Melbourne. Sylvia was a suitable candidate for AVERT Phase 2, however, due to vascular dementia and decreased alertness, she was unable to decide for herself whether she wanted to participate in AVERT. Her eldest son and power of attorney, Robert, was approached to respond on her behalf. Subsequently, Sylvia was recruited into AVERT.

Dorcas Quah, blinded assessor, recently caught up with Robert for the following interview:

### **How did you find out your mum had had a stroke?**

*I can't quite remember. I think my wife was called by the hostel (where Mum was living).*

### **How did you feel?**

*It was a surprise. There was a definite sense of shock as well as concern. I didn't know what to expect [when I saw her], so there was fear as well. I had a sense of helplessness because there was nothing I could do.*

### **What did you know about stroke before this?**

*I was aware of some of the causes of stroke, the damage that blood clots can cause. Mum had arrhythmias, so it was no surprise that her dementia was vascular, but the stroke was still a shock.*

### **What was your experience of agreeing for your mother to participate in the trial?**

*I felt convinced that by participating in AVERT, Mum would be given an opportunity to optimise her quality of life. Anything that improved her chances of recovery – we were up for it.*

*My primary considerations were her quality of life, her prognosis and Mum's own wishes as we understood them.*

*Andrew (my brother) and I jointly made the decision after also discussing it with Geoff (our other brother) on the phone. We were all of the same view that Mum would have been up for it.*

*Mum's view about her life was to always leave things in a better state than you found them. We often talked about things like donating organs and research. [Even though she's gone now] at least part of her can contribute to improvements elsewhere. [Participating in AVERT] fitted into her life philosophy.*

### **Did you feel pressured at all in your decision to agree for your mother to be part of AVERT?**

*No, not at all. I understood it to be an accelerated rehab trial, developing a new method for treating stroke and that there was the possibility of accelerating and optimizing her recovery, although there were no guarantees.*

### **What are your thoughts about being responsible for enrolling someone in a trial?**

*I felt privileged to be the one who had the opportunity to make sure she was seen right. I was pleased to be able to make sure she was looked after. I saw it as a repayment in a way, for all her years of looking after us. I considered it both a privilege and a responsibility.*

*I like to think she was able to help people. By contributing to research, she was actually looking after others.*

### **How do you think her experience was of being involved in the trial?**

*Hard to know – her memory wasn't that good and was worse with her stroke. Mum didn't seem distressed by it at all.*

*I was pretty impressed that they got her up straight away. We were very happy with the treatment Mum received with the program in hospital. I was also happy with the follow up*



*which provided us with a sense that the program was still operating; that it was worthwhile.*

**In hindsight, if you were to relive that situation again, would you still agree for her to participate in AVERT?**

*Absolutely – for two reasons: 1) we were always looking for the best opportunity for Mum’s health and 2) our experience of her being in AVERT was positive. I would not hesitate to do it again.*

**What do you remember and miss most about your mum?**

*I miss her being an audience for us (3 brothers). She always liked to laugh at things we said. She loved reading and poetry and had numerous little sayings which we’ve all picked up.*

*I regret missed opportunities to say what I wanted to. I respect the fact she had a long, valued life. Her funeral was a celebration of her life. She was a wonderful, terrific woman.*

Sadly, Sylvia passed away about 6 months after the stroke. Our sincere thanks to her and her family for their participation in and contribution to stroke research.



Mother’s Day 2004: Sylvia with two of her sons, Geoff (left) and Robert (right) and her granddaughter, Tamara.

### Excerpt from Desiderata

(a favourite poem of Sylvia’s, and her life’s philosophy)

Go placidly amid the noise and haste,  
and remember what peace there may be in  
silence.

As far as possible without surrender  
be on good terms with all persons.  
Speak your truth quietly and clearly;  
and listen to others,  
even the dull and the ignorant;  
they too have their story.

Therefore be at peace with God,  
whatever you conceive Him to be,  
and whatever your labors and aspirations,  
in the noisy confusion of life keep peace with  
your soul.

With all its sham, drudgery, and broken  
dreams,  
it is still a beautiful world.

Be cheerful.  
Strive to be happy.

~ Max Ehrmann ~

## Assessing activity early after stroke



**Henry Zhao**

**Advanced Medical  
Science (AMS) student**

**University of Melbourne,  
AUS**

I am a third (about to be fourth) year medical student at the University of Melbourne undertaking the Advanced Medical Science program with the National Stroke Research Institute. I started in July 2006 and will finish half way through 2007.

After a stroke, day to day activities can often become hard to manage. In the AVERT trial, it is important that we measure daily activities to evaluate the benefits of rehabilitation. The tool we are using to do this is a commonly used stroke outcome measure called the modified Rankin Scale (mRS). It is scored after interviewing the patient (or the patient's carer) to determine the activities they can still do after their stroke.

My study aims to work out whether hospital staff with different experience using the mRS, (medical students, doctors, physiotherapy students, physiotherapists) come up with the same mRS score for the same patient. I talk to patients within the first week after stroke and ask if they will agree to participate in my study. This involves a friendly chat with three different staff on a single day.

So far we have interviewed about 30 patients and we hope to have about 80. When I complete the study I hope to be able to advise the AVERT investigators on whether staff experience on the mRS matters when doing this test.

Throughout my study I have really enjoyed working with stroke patients and families. It is fascinating talking about their lives and how stroke affects them. I am learning a lot about people and about stroke, and this will benefit me in my years ahead as a doctor.

## Looking at brain scans



**Katrina Clarkson**

**Final Year  
Medical Student**

**University of Edinburgh,  
UK**

I am a final year medical student at the University of Edinburgh, Scotland. As part of our training we organise an 8-week elective, usually abroad, to experience medicine in a different country and culture. I chose to come to the Austin Hospital in Melbourne because I had always wanted to come to Australia, and because they are a centre of excellence for care and research in stroke. I eventually want to become a specialist in this area.

I spent four weeks doing a short research project with the AVERT team at the National Stroke Research Institute. My work was to look at brain scan information collected from Phase 2 of AVERT. When I had done some reading and discussed ideas with my supervisors, I was keen to link the scans to how people had got on after their strokes.

I decided to focus on the patients who had had the worst strokes, because the potential for improvement was greater than in those who had had mild strokes. I learnt a lot about stroke, how useful the scans are or are not, and what else influences how serious the impact of a stroke is on that person.

I also thoroughly enjoyed being in Australia and was impressed by the warm welcome I received from the friendly and helpful team. I learnt more about how research is done at a world class level, which was important to me because there is so much still to be learned about brain problems.

I hope to do research myself in the future as part of my job, to help find better treatments and improve the lives of my patients.



### Visitors from a Swedish stroke unit

We recently had three visiting fellows from Stockholm, Sweden: Marie Halvorsen (Physiotherapist), Sahereh Roshandel (Nurse) and Agneta Stoker (Nurse Assistant), shown below.

The group came here to learn about behavioural mapping; a technique we have developed and used over the last 5 years to look at very early activity in people with stroke. This technique involves observing patients who have agreed to take part, over a single day. At each observation point we record where the patient is, what the patient is doing, and who is helping them. This provides us with rich information about their care.

In their time here, we provided training in the technique, and showed them some fine Australian hospitality. The visit has ended with a collaboration formed between our countries. We will help them look at the level of physical activity of patients managed in their stroke unit at the Karolinska University Hospital over the next 12 months. We will use our technology and expertise to enter and analyse their data.

Since we have already collected data in Melbourne and Trondheim in Norway. In the future we may be able to compare very early stroke care here in Melbourne (Australia), Trondheim (Norway) and Stockholm (Sweden).



Marie, Agneta and Sahereh on the ward at the Austin Hospital stroke unit.

### Want to know more?

Some of our publications about very early rehabilitation in stroke include:

Bernhardt J, Dewey H, Collier J, Thrift A, Lindley R, Moodie M, Donnan G. A very early rehabilitation trial (AVERT). *International Journal of Stroke*. 2006;1:169-171

Bernhardt J, Dewey HM, Thrift AG, Donnan GA. Inactive and alone: Physical activity in the first 14 days of acute stroke unit care. *Stroke*. 2004;35:1005-1009

Bernhardt J, Chan A, Nicola I, Collier J. Little therapy, little activity: Rehabilitation within the first 14 days of organized stroke unit care. *Journal of Rehabilitation Medicine (in press)*.

If you want a copy of these publications, email us at [avert@nsri.org.au](mailto:avert@nsri.org.au)

Further information about the Very Early Rehabilitation program can be viewed on the National Stroke Research Institute website at <http://www.nsri.org.au/avert.htm>

### Want to contribute to AVERT?

This newsletter showcases just some of the ways people have become involved in the AVERT Research Program. We thank you all for your contribution.

We have been fortunate to have had volunteers with a range of skills help us with a number of projects; from computer programming, to setting up our financial reporting system, and even entering data.

We currently need help with improving our web based data management system and fundraising for some wheelchairs.

If you have the inclination to give us a hand, feel free to contact us at [avert@nsri.org.au](mailto:avert@nsri.org.au) or by phoning 03 9496 2888.

