

# BrainWave

Schizophrenia Research Institute Volunteers ■ 2008



The key image of the Australian Schizophrenia Research Bank's TV, poster and press ad campaign.

## Welcome to the new-look newsletter for volunteers



From Prof. Vaughan Carr, Chief Executive Officer.

As an SRI volunteer, you are in good company. Over 4,000 Australians are joining you to help us find the ways to prevent and cure schizophrenia. I thank all of you for directly contributing to the Institute's past success, leading to the launch last year of the Australian Schizophrenia Research Bank (ASRB) - a true milestone. It could not have happened without you.

The BrainWave newsletter will aim to keep you in touch with activities at the ASRB, the Schizophrenia Research Register, and the 'Gift of Hope' brain donor program. These activities are helping to drive along the research which could result in new treatments, or perhaps even a means of prevention. With that in mind, I would like to make three special requests:

- If you have volunteered for the ASRB but not yet sent in your completed Consent form, please do so as soon as you can.
- If you are participating in one program, please consider signing up for others.
- Our research can only happen with the help of volunteers like you, so if you know someone who might be interested in joining, please tell them what we are trying to do.

## BANK VOLUNTEERS TOP 2000

Australia's biggest ever schizophrenia research project, the Australian Schizophrenia Research Bank (ASRB), has attracted the interest of 2,400 volunteers across Australia since its launch in April 2007 - with more than 200 people having already commenced the assessment process.

With such a large response, it will take some time to enrol and assess everyone who has volunteered. We assure all those who have volunteered that you have not been forgotten. The Clinical Assessment Officers (pictured right) are working hard, and you will be contacted as soon as possible. Meanwhile, we thank you for your patience!

The aim of the 5-year nationwide project is to recruit 2,000 people with schizophrenia and 2,000 people with no history of psychiatric illness, and to obtain brain scans, blood samples (for DNA profiles) and clinical information which will be compiled and cross-referenced into a unique database, of enormous value to Australian and international researchers.

With major support from the National Health and Medical Research Council, the Pratt Foundation, Ramsay Health Care, Perpetual Trustees and

Cont. over:

### ASRB COAST TO COAST RESEARCH



NEWCASTLE



BRISBANE



SYDNEY

*Newcastle Office (L-R): Dr Carmel Loughland, Janette Howell, Jaci Richards, Michelle Poole.*

*Brisbane Office: Dr Kelly Mouat.*

*Sydney Office (L-R): Siobhan Quinn, Yen Lim, Carollyne Youssef.*

*Melbourne Office (L-R): Rebecca Wilson, Antonia Stuart.*

*Perth Office: Lisa Dawson.*



MELBOURNE



PERTH

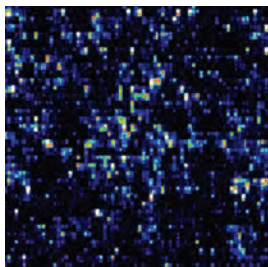
McKesson Asia Pacific, the ASRB is coordinated from the Institute's centre in Newcastle, with participating centres in Brisbane, Melbourne, Orange, Perth and Sydney.

The national recruitment campaign, which was first aired in May 2007 and featured Russell Crowe's voice has been selected by Givewell Australia as a finalist for the Best Communications Program in 2007 in their 5th Annual Australia Charity Awards. The winner will be announced in

late April. This recognises the fantastic work of Singleton Ogilvy & Mather, Plush Films and Black Dog Photography in developing this landmark campaign, which was all done *pro bono*.

**If you haven't signed up for the ASRB yet, just call 1800 639 295 or visit [www.schizophreniaresearch.org.au](http://www.schizophreniaresearch.org.au).**

**PLEASE NOTE: Relatives of people with schizophrenia are not eligible as volunteers for the ASRB. Many thanks!**



Each dot in the Microarray image above represents a gene, and the dot's colour and brightness the degree of expression of that gene. Many such images are used to obtain a single genetic profile.

## FOCUS ON GENES

Genetic profiling of ASRB volunteers from a simple blood sample will yield valuable information to 'The Bank'. Schizophrenia is characterised by a variety of symptoms, including hallucinations, delusions, changes in emotion and cognition, which vary with the course of the illness and between individuals. Since there is such variation in the disorder, it has been suggested that there could be several schizophrenia subtypes, each with a different developmental course. SRI researchers at the University of Newcastle conducted a study to discover if an individual's schizophrenia type could be identified from a genetic profile obtained from a blood sample. Expression of 18 genes with brain-related functions was altered in those with schizophrenia, and distinct gene expression profiles were associated with 'subtypes' defined by age. *Such gene expression profiling from blood samples may in the future provide a template for individually 'tailored' treatments, and larger scale studies on the same lines may lead to a diagnostic tool to assess at-risk status in the early phases of the illness.*

# Happy Birthday to The Register!

One of the first initiatives that SRI established, the Schizophrenia Research Register was 10 years old in November 2007. Since its launch, the Register has made a significant contribution to supporting and increasing the amount of schizophrenia research in Australia.

The Register has grown to over 1,600 volunteers and has supported 57 schizophrenia research projects with over 1,500 'participations' from Register volunteers during this period of time. Results from Register-supported work have been presented at a large number of national and international research conferences, and 37 publications in peer-reviewed scientific journals have resulted from this work. In addition, 13 research higher degrees have been awarded to Australian students who used the Register for their research.

### Research Register Stats:

Total number of people registered	1659
Volunteers with Schizophrenia	1052
(Males 58%, Females 42%)	
Volunteers with Affective Disorder	19
First Degree Relative volunteers	462
Healthy Controls	126

In addition, Register staff regularly provide community lectures and presentations to raise public awareness about schizophrenia.

Schizophrenia remains one of the most poorly understood conditions and there is still a great deal of work to be done. We need to develop methods for identifying people at risk, new early intervention programs, better treatments, and a better understanding of the genetic factors that underlie the development of the illness. Our volunteers have done a

great job participating in so many research projects. Thank you - especially to all those volunteers who joined the Register in 1997, and are still with us! Your contribution, no matter how big or small, takes us all one step closer to finding a cure.

Volunteers who have not yet had a chance to participate in a study and are keen to do so should contact the Register office STD free on 1800 639 295 or via [register@schizophreniaresearch.org.au](mailto:register@schizophreniaresearch.org.au)

## Current research projects recruiting from the Register

If you would like to participate in any of these studies, please contact 1800 639 295 to find out if you are eligible.

☐ **Cortical contributions to category learning in healthy adults & patients with schizophrenia.** Located at the Prince of Wales Medical Research Institute, this study will examine how different brain areas contribute to probabilistic category learning and evaluate a therapeutic intervention strategy in people with schizophrenia.

☐ **Smoke Study: Smoking Motivators and Key Cognitive Effects.** This study at the University of Newcastle is examining the impact of nicotine on attention and memory in smokers with schizophrenia and non-psychiatric control smokers.

☐ **Learning, reasoning and schizophrenia.** This study at Macquarie University will investigate how problems with probabilistic reasoning (including the tendency to jump to conclusions) contribute to delusions.

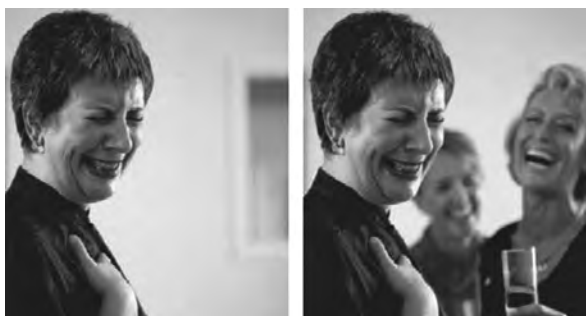
☐ **Thinking styles of people with schizophrenia.** Also located at Macquarie University, this study is examining how 'inner speech' monitoring contributes to auditory-verbal hallucinations in those with schizophrenia.



□ **Improving emotion recognition in schizophrenia.** This study at Macquarie University will investigate predictors of improved emotion processing ability in schizophrenia following training with the Micro-Expression Training Tool - a brief training program designed to improve recognition of facial emotion expression.

## FOCUS ON SOCIAL COGNITION

Impairments in social cognition are a common feature of schizophrenia. The ability to appreciate social contextual information when interpreting another's emotions and motivations may be an important component overlooked by current remediation strategies. SRI researchers at Macquarie University conducted a study using Register volunteers that examined how schizophrenia affects visual attention to social contextual information. Volunteers had their eye movements recorded using the EyeLink Gaze Tracker system while viewing photographs of individuals expressing various emotions. They were asked to judge the mental state of the person shown without social context, and then to reassess the emotional content after the contextual background had been added. Schizophrenia volunteers were less accurate in assessing mental states, and paid less attention to social context compared to healthy controls. These findings suggest that people with schizophrenia experience problems integrating social context, which may contribute to difficulties in inferring mental and emotional states in others.



Facial expression image shown with (right) and without (left) its social context background.

## Record Response for 'Gift of Hope'

In association with the wonderful response from the launch of the ASRB, and with the continued interest of kind volunteers, the 'Gift of Hope' Brain Donor Program reached a milestone in October last year with more than 500 enrolled donors. This result has kept the brain donor team on its toes, and busy enrolling new donors onto our recently updated database.

Donors to the program are essential to our research. By donating their brain tissue at death they are providing an essential resource to our researchers in the fight against schizophrenia and other major psychiatric illnesses. Our donors also participate in clinical and neuropsychological assessments, which together with the brain tissue will provide crucial data to establish possible factors or links in behaviour, lifestyle and genetics.

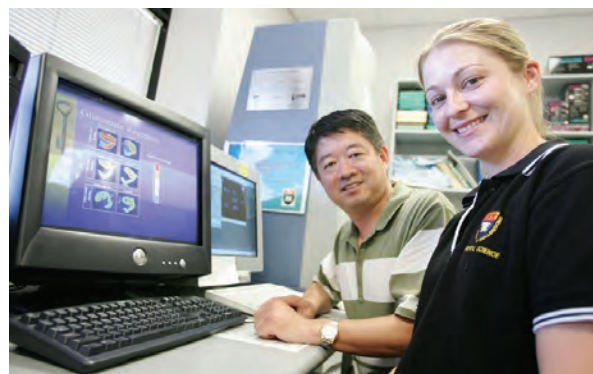
It is very encouraging to witness the enthusiasm with which so many people are willing to assist in such critical schizophrenia research. These people, from many walks of life, are united in the quest to solve the complicated puzzle of finding a cause and a cure for schizophrenia and other allied disorders.

If you are interested in enrolling in the Brain Donor Program or would like more information, please contact Juliette Gillies on (02) 9351 2410 or [braindonors@schizophreniaresearch.org.au](mailto:braindonors@schizophreniaresearch.org.au).

To those donors still awaiting assessments, please be assured you have not been forgotten and your vital participation in our program is invaluable.

## FOCUS ON TISSUE RESEARCH

SRI researchers at the University of Wollongong have used post-mortem brain tissue to examine the posterior cingulate cortex (PCC), an area of the brain involved in memory, spatial orientation and monitoring eye movements, and known to be altered in schizophrenia. The only machine of its kind in the Southern Hemisphere, the Institute's powerful Beta Imager was used to investigate several neurotransmitters (the chemical messengers of the brain) in this region, and found significant changes in muscarinic, glutamate, GABA and cannabinoid receptors in schizophrenia. These findings suggest that these changes in the PCC are associated with the functional deficits seen in schizophrenia. Increased understanding of these changes will help us to understand how they lead to the symptoms and functional problems in schizophrenia, and will ultimately help to identify causes and better treatments.



Prof. Xu-Feng Huang and Dr Kelly Newell with the Institute's Beta-Imager at the University of Wollongong.



Therese Garrick and Juliette Gillies at the NSW Tissue Resource Centre.



Retiring Patron of the Gift of Hope program Marilyn Mitchell with members of the Institute's Central Office team.

## A Salute to Marilyn Mitchell

Marilyn Mitchell has worked for 18 years as an advocate for people with schizophrenia, speaking at conferences and universities, and on TV and radio interviews in support of the Schizophrenia Research Institute, as well as other related organisations. In March 2008, Marilyn retired as Patron of the Gift of Hope Brain Donor Program, and attended an informal ceremony to accept a plaque and an engraved commemorative gift of appreciation from CEO Prof. Vaughan Carr and members of the Central Office team. In her acceptance speech Marilyn commented, "I have other important work to continue with relating to schizophrenia, so it's not over yet. With schizophrenia, there's always more work to be done."

## The Future of SRI Volunteer Research

The volunteer research programs described above have been extremely successful and the cornerstone of the Institute's success. Although they have grown relatively independently over time at different sites, there is now considerable overlap in their databases and administration requirements. To facilitate the growth and continued success of these valuable scientific resources, we are bringing these programs together to improve management and allow information sharing, making it easier for volunteers to be on multiple programs.

During 2008, the activities of the **Schizophrenia Research Register** will be merged into the **ASRB**. This will involve current Register volunteers being asked whether they would approve the transfer of their details to the ASRB.

New ASRB volunteers will also be asked to consider being contacted for other research projects in the future. Please note, this is not a condition of joining the ASRB, merely an option offered to volunteers.

The 'Gift of Hope' brain donor program has been operating side-by-side with the University of Sydney's 'Using our Brains' (UoB) donor program for many years. The UoB program focuses on brain donation by people without neuropsychiatric illness, but does include other illness groups. Both programs operate in exactly the same way and are overseen by the same SRI group at the University. Given this overlap, we have decided to bring these two programs together under the 'Using our Brains' title, retaining a strong focus on acquiring donors with schizophrenia, but within the newly expanded donor program.

This restructuring will not lead to any of the programs being stopped or suspended. We want to reassure all SRI volunteers that there will not be any major differences in how our programs operate or in the SRI staff who contact you.

Our Clinical Assessment Officers will now work across all these programs, which will enable the programs to operate more efficiently and effectively.

If you have any concerns please contact SRI and we will be happy to assist you.

### HELP THEM HELP US

As a person with schizoaffective disorder for 37 years I still wonder why I have this disease. Do you wonder too? Do you wonder if the future holds the knowledge that would bring the relief of easier treatments, even possibly a cure?

The researchers at the Schizophrenia Research Institute also wonder - and work towards the knowledge that will give us the answers. They need us to do their research. Without us they will not find the answers to these questions. If you like, you can participate in their research.

As a participant in 7 studies in the last 12 years, I believe I have contributed to this search. This gives me some degree of satisfaction. I hope that one day, just like the day penicillin was discovered, we will all be able to look back and see how the world, our world and our children's world, has changed for the better.

In all the studies I have been involved in, I have been treated with respect, sensitivity and confidentiality. I have been encouraged to express any concerns I might have had, and the responses have always been open.

At any time I could have withdrawn from any project, but I have never felt the need to do so. Also I believe I have had no ill effects from my participation.

If the Institute approaches you to participate, I hope you will be able to join in, and to help them help us.

Regards, **Anne Oughton**

**Please let us know your preferences by completing and returning this Response Slip via email, fax or post:**

Your Name: \_\_\_\_\_ Email: \_\_\_\_\_  
Address: \_\_\_\_\_

- ☐ I would prefer to receive BrainWave in PDF format by email
- ☐ I would also like to receive HeadLines - SRI's free newsletter - by mail
- ☐ I no longer wish to receive BrainWave or further correspondence from SRI

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