

Towards an End to Schizophrenia

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What is NISAD?

VISION: To find the means to prevent and cure schizophrenia.

MISSION: To undertake world-class research to improve the lives of people suffering from schizophrenia, and to protect future generations from developing this devastating disease of the brain.

Established in 1996 by a group of concerned parents, scientists and health professionals, the Neuroscience Institute of Schizophrenia and Allied Disorders (NISAD Schizophrenia Research) is an independent non-profit Australian medical research organisation.



In the words of Professor Stan Catts, NISAD's founding Chairman:

“Patients with psychotic disorders will not ask us to do this for them - it is up to us to make sure there is no delay in finding the means to prevent or cure these diseases.”

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The Institute Without Walls

NISAD is an 'institute without walls' harnessing the research capabilities and infrastructure located in teaching hospitals, universities and research institutes across Australia and overseas.

Led by Scientific Director Professor Vaughan Carr, NISAD's network of over 100 scientists is working on an integrated research strategy encompassing the latest neuroscience research in the fields of neurobiology, genetics, and pharmacology and cognitive neuroscience.

Chaired by Peter Dempsey, former CEO of Baulderstone Hornibrook, a distinguished Board of Directors provides leadership and direction. The Board membership includes expertise in areas such as finance, media, academia and the public sector.

NISAD's central office and organisational hub is located within Sydney's Garvan Institute of Medical Research. The central office team, led by Executive Director Deborah Willcox, is responsible for managing the scientific program, raising funds for the research, and for a variety of programs aimed at improving public awareness of schizophrenia.



What is schizophrenia?

Schizophrenia is a biological disease of the brain. It typically appears in young people aged between 15 and 25, and affects slightly more males than females. It alters the way the brain functions, causing a range of severe symptoms including hallucinations, delusions and cognitive impairment.

The World Health Organisation identifies this illness as the third biggest cause of long term disability, that will affect around 1 percent of all populations. At least 30 percent of all sufferers attempt suicide, and around 10 percent succeed - making the illness a major cause of youth suicide.

Along with other psychotic disorders, schizophrenia's impact on families affected is uniquely disruptive. Sufferers usually do not recognise they are ill, and often refuse diagnosis, counselling and treatment. In many cases this leads to alienation from parents and siblings, and inability to develop and fulfil educational, professional or relationship potentials. Around 85 percent of sufferers are dependent on government support.

In financial terms, the cost of psychotic disorders to the Australian community is at least \$2 billion annually.

Why does schizophrenia research warrant special help?

Unlike illnesses such as Alzheimer's or cardiovascular disease which largely disable or shorten the lives of older people, schizophrenia is a major cause of lifelong disability starting in youth, and a leading cause of youth suicide.

Despite this, schizophrenia research has never received the funding levels warranted by the dreadful toll this illness takes on every generation of youth, and the huge number of families it affects. This inequity has been in part due to the unique stigma associated with the illness, and to the equally unique factor that schizophrenia renders most sufferers incapable of campaigning for help themselves. Yet another cause of the dearth in schizophrenia research has been the absence of tools for productively investigating the sources of psychotic disorders.

However, over the last decade scientific advances in neuroimaging, neurobiology and genetics have provided new tools and new knowledge for the task. Importantly, public opinion has also begun to discard the false concepts which have dominated mental health issues.

In these dramatically altered conditions NISAD can justifiably assert that the major impediment to discovering the means to prevent and cure schizophrenia is lack of support for research.

NISAD Research - What we do

NISAD is an 'institute without walls' comprising a team of scientists who investigate schizophrenia utilising the world-class research and infrastructure facilities in Australian universities, hospitals and research institutes.

The NISAD network also encompasses leading national and overseas organisations in a continual exchange of information, as well as in collaborative partnerships on specific research projects.

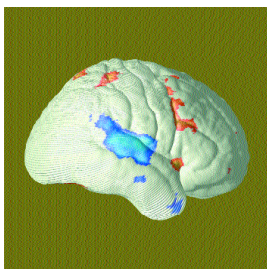
Studies have demonstrated that even if governments committed unlimited resources to delivering the best treatments via mental health services, the effect on the overall community burden of schizophrenia would be minimal (Andrews *et al*, 2000).

The only way to relieve this burden is with the new understanding and treatments to be gained from increased research.

A decade ago, little was known about Alzheimer's disease. Today, after a concerted research effort, new Alzheimer's medication is in clinical trials, which may free many individuals and their families from the burden of this brain disease.

NISAD's aim is to similarly accelerate the research effort in schizophrenia to bring relief to the 1 in 100 families who will be affected.

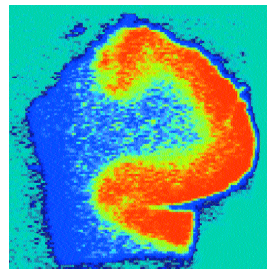
In pursuit of this goal, NISAD conducts research in a number of major neuroscience disciplines including neuroimaging, clinical studies, brain tissue neurobiology, and genetics. The Institute is also active in public awareness projects to promote greater understanding of schizophrenia and its research.



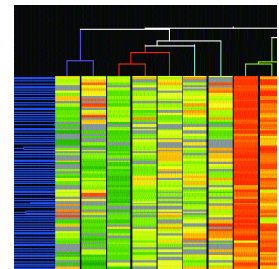
Neuroimaging



Clinical Studies



Neurobiology



Genetic Research

Scientific Research Panels

Chaired by Scientific Director Professor Vaughan Carr, NISAD's peak scientific body is the Research Council comprised of leading neuroscientists and clinicians. It is responsible for the planning, direction and management of the research program. The Research Council oversees 3 research panels, each focussed on a critical area of scientific expertise relevant to schizophrenia.

Cognitive Neuroscience Research Panel

The Cognitive Neuroscience Panel focuses on investigating the biological underpinnings of the mental processes governing cognition (e.g. perception, action, memory, language and attention, etc.) in order to identify the functional disorders observed in schizophrenia.

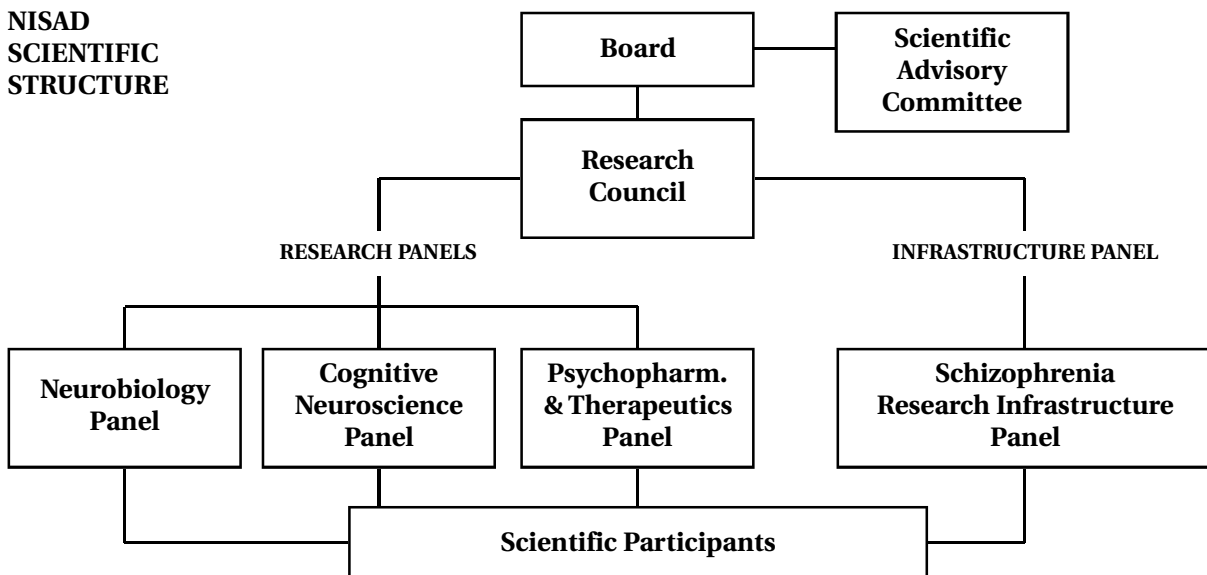
Psychopharmacology and Therapeutics Research Panel

The Psychopharmacology and Therapeutics Panel researches the effects of medications and/or other drugs in patients and 'at-risk' populations. It also provides a platform for initiating trials of new treatments, both pharmacological and non-pharmacological.

Neurobiology Research Panel

The Neurobiology Panel targets specific brain systems to identify the abnormally functioning neurons and neurotransmitters which could be responsible for the hallucinations, delusions, thought disorders and other symptoms of schizophrenia as well as isolating the defects in gene action which may be the cause of the disease.

NISAD SCIENTIFIC STRUCTURE



NISAD's Research Achievements

Before NISAD commenced operations in 1996 there was no schizophrenia research institute in New South Wales.

Since 1996 NISAD has made a number of world-first research findings and initiated a range of innovative schizophrenia research infrastructure facilities that are now significantly contributing to the Australian and worldwide schizophrenia research effort.

Advances in molecular genetics, brain imaging and other technological improvements are edging us closer to our goal - to find the means to prevent and cure schizophrenia.

Key findings of NISAD's scientific team:

- Demonstration of a link between deficits in grey matter thickness (brain structure) and reduced brain activity (brain function) during performance of a planning task in people experiencing their first episode of schizophrenia. *This is the first neuroimaging study to demonstrate that specific deficits in brain structure affect brain function in schizophrenia.*
- Identification of changes in the level of certain genes in blood samples from schizophrenia patients compared to controls. This suggests that blood samples may be used as a biological basis for diagnosing the disorder, and as a means of identifying the degree of risk carried by individuals. *This new knowledge may be used in future as part of a schizophrenia prevention program.*
- Demonstration of a similar 'restricted' visual scanning pattern in people with schizophrenia and their close relatives - when viewing emotion-evoking images. *This provides the first evidence that visual scan path dysfunction may be a marker in schizophrenia.*
- Evidence that brains affected by schizophrenia contain abnormal numbers of cannabinoid neurons. *This may explain why cannabis usage is associated with schizophrenia onset in some people.*

The momentum of research has been accelerating since 1996, and success has flowed from enhanced research activity across the spectrum, from clinical studies through to bench-top neuroscience.

With continued effort, more findings, and more integration of research results, the 'critical mass' necessary for major research breakthroughs can be achieved.

NISAD Research Infrastructure

To provide scientific researchers with the necessary tools, NISAD has also created a number of critical infrastructure facilities that are supporting the worldwide schizophrenia research effort:

■ *The NISAD Schizophrenia Research Register*

The NISAD Schizophrenia Research Register is a volunteer database of people with schizophrenia, family members and healthy controls who are interested in participating in schizophrenia research. The first of its kind in the world, the Register now lists over 1100 volunteers and has supported over fifty schizophrenia research studies.

■ *The NSW Tissue Resource Centre*

The NSW Tissue Resource Centre (TRC) stores and distributes post mortem human brain tissue that is well characterised both clinically and pathologically for projects related to schizophrenia. The TRC holds over 250 cases and has supported over fifty schizophrenia research projects in Australia and internationally.

■ *The NISAD 'Gift of Hope' Tissue Donor Program*

The NISAD Tissue Donor Program enables individuals with schizophrenia and those without a mental illness to indicate their willingness to donate their brain for research studies in schizophrenia after death. The benefit of this program is that volunteers are tested on a range of clinical investigations once enrolled and the results of such studies are available for later correlation with post-mortem findings. To date over 250 people have joined the program.

■ *The Hunter DNA Bank for Schizophrenia and Allied Disorders*

The DNA Bank is a facility that stores DNA obtained from blood samples from volunteers with schizophrenia, relatives of people with the disorder and people with no history of mental illness. Launched in late 2003, the DNA Bank already has over 100 samples. Once sufficient samples have been obtained, researchers will be able to apply for access to this material for research projects investigating the genetics of schizophrenia.

■ *The 'Virtual' Brain Bank for Schizophrenia Research*

Over the next three years, MRI images of more than 250 brains will be collected, analysed and catalogued using advanced analysis techniques to reveal anatomical differences in schizophrenia-affected brains. The source images will be from eight different NISAD-supported studies currently underway, and will include brain images from schizophrenia patients, cannabis users and healthy controls.

The Human Story

Schizophrenia is a uniquely human disease affecting many millions of individuals and their families. Each has a unique story to tell. Here are just a few of these stories, providing a glimpse into the tragedies caused by this illness:

Ben's Story

My son Ben had a talent, he could write. There were many things he couldn't do, because of his schizophrenia. He couldn't hold down a job, though he tried. He couldn't drive a car, it was too frightening. He couldn't control the things that were going on inside his head. He could never make me or his mother really understand the terrifying things that were happening to him. He couldn't look after himself or speak to anyone, for days at a time. He couldn't avoid the stares of people in the streets. He couldn't avoid the nightmares.

But he could do some things. Some days, a few, were good. He would enjoy being with other people and being creative. He could play sports and before his first psychotic episode he had been a junior champion in soccer, tennis, billiards and pool, and would love creatively beating his father in any of them!

With his friends it was music. They would get together in someone's room and write songs. They made a lot of noise. After Ben died I found his lyrics to the songs. Here is one of them:

DREAM WEAVER

Dear dream weaver please paint me a picture - One with all good so my thoughts become richer
Dear dream weaver- a good one if you will - These nightmares are scary my life's unfulfilled
You promised all I received none - We were two now I am one
Dear dream weaver 'bout life I need to learn - It's something I crave and it's all that I yearn
Dear dream weaver please help me get a break - I need it you know it my life is at stake

Mister dream weaver your ways unjustified - You promised me the world - Now I know you have lied
Mister dream weaver you know it's your fault - I worshipped you like a god and followed you like a colt

When Ben died five years ago, the worst nightmare of any parent came true for me. I had to bury my own child. In a developed country like Australia we believe this to be against the natural order of things. Parents should die before their children, and usually do.

Yet we don't have to look far outside of our own time to see that this has not always been the case. In Europe in the Middle Ages children often died before their parents, of the plague, cholera and typhoid. Nineteenth century cemeteries in Australia hold the graves of many children and young people, a lot of them dying from diseases which have only recently been defeated- Typhoid, Tuberculosis, Whooping Cough and Polio.

The scourge, the devastation of schizophrenia is still with us, still taking our young people, our children. My child will never travel, have a job, settle down with someone and have children of his own, never develop his sports or his writing.

Surely a developed country like Australia, with its dedicated scientists, health professionals, research facilities and resources can be doing more to defeat this grim reaper of our youth. How many more young people have to die?

By Ben's father, Peter Foggitt.

Marilyn's Story

Schizophrenia changes everything, relationships to job and career, to life expectancy. To give you some idea what schizophrenia is like on a daily basis let me give you two examples.

Firstly, the paranoia. We've all seen people standing on street corners talking into mobile phones. But for me, every time I go out and observe this, I immediately think it's something to do with me. I have to spend 10 to 15 minutes reassuring myself that it's probably OK, they are not following me.

Secondly, I refer to the very real possibility of suicide. There are some days when I cannot go shopping at my local shopping complex. This is because I feel I might "give in" to the occasional impulse to throw myself over the balcony of the 5th floor.

I have known people with schizophrenia who have sadly "acted out". A woman jumping off a bridge and ending up with brain damage; a man jumping from a window and ending up in a wheelchair.

Finally, to add insult to injury, we are often taunted or abused because people cannot see anything (physical) that would constitute a "disability". That is because the problem is not visible; it's internal, inside our heads, deep in the brain chemistry, structure and (mal) functioning of the brain. You would need specialized, high-tech imaging to see these. But from the person in the street there tend to come comments like what I've had said to me; "You've 2 arms and 2 legs - so what's the problem?" or people think we are lazy or have an attitude problem or need religion or yoga to fix us up.

Relationships: Schizophrenia medication affects the physical side as well as the emotional side of relationships. And relationships in general can be difficult due to symptoms and medication side effects - so then isolation can be a problem.

Career and jobs can be problematic. Study can be difficult and we are often discriminated against in the workplace. There are few work environments that can accommodate our fragile conditions. Mostly, we end up in low paid or no job because we have a stress related illness. I am an educator by profession but cannot work full time in that role.

Life expectancy reduction is a reality. With schizophrenia we have a 10 year less life expectancy than average. And suicide claims 1 in 10.

I have spoken here of just a few of the aspects of schizophrenia that affect every aspect of our lives every day. Please, help support NISAD's research into this devastating illness.

I have three lovely children (and a grandson) who had to grow up with half a parent - that's me, with disabling schizophrenia, after my husband abandoned us. I don't want them (or anyone else) to have to suffer this cruel condition as yet with no cure.

By Marilyn Mitchell.

Consumer / Advocate. Patron of the NISAD 'Gift of Hope' Tissue Donor Program

Gabriel's Story

I didn't know it at the time, but my son Gabriel was a typical case of schizophrenia onset. Up to the age of around 17 his academic record indicated a bright future; he had excellent relations with his teachers, fellow students and his family, plus good health and a range of interests normal for a teenager in the 1980s.

Then, little by little over the following 2 years, things started to go wrong. He met someone at school who introduced him to cannabis. He lost interest in his studies, and dropped plans for going on to university. He got a job as a trainee in movie production, but was dismissed after 4 months. He started staying in his room, not joining the family for meals, neglecting his appearance and personal hygiene. Nothing we said to him had any effect. We thought it was a bad case of adolescence, and tried everything to help - in vain. He denied anything was wrong.

Then it got worse. He started staying up all night and sleeping all day. We heard him talking to himself in his room. We asked him about this, and he denied it. When he did mix with the family, he was preoccupied with his own thoughts. He ignored us, his mother, father and younger brother.

The crisis happened at dinner one night in 1989. Gabriel was giggling to himself all through the meal, ignoring our requests to share the joke. His younger brother snapped, and punched him in the face. That's when his mother and I knew we had to take desperate measures.

I told Gabriel that he was making his family very unhappy, and that he had to move out. I would help him find an apartment of his own. For the first time in months he gave me his full attention, and told me that I was not his father; that I used to be his father but wasn't any more. It was only then I realised that what we were trying to deal with wasn't just adolescence, it was mental illness.

It all came out. He told us he had been staying up all night to receive messages from the 'white noise' on a detuned TV set. The noise had told him he was a special person from another planet, born here to save the world from evil, and that he would receive instructions about this task in future.

Shortly after, he was diagnosed with schizophrenia and taken to a psychiatric hospital. This was the beginning of 14 years of non-compliance with treatment, many arrests, drug abuse, overdoses, and many of the other disasters associated with this illness.

But he survived. Today, at the age of 39 and with the help of the new 'atypical' medications, he has completed a 2-year treatment and rehabilitation program. He is now living in a supervised household with four other patients, and working in a protected workshop.

By Gabriel's father, Alan Tunbridge.

How to Help NISAD

Funds raised for NISAD Schizophrenia Research go directly to support the quest for the means to prevent and cure schizophrenia.

From the beginning, NISAD has avoided the expense of advertising campaigns, and gained its major support from people and organisations who recognise the unique difficulties of raising funds for schizophrenia research.

Please consider the following suggestions of ways to help NISAD's quest:

1. **First and foremost, please register your details to receive **HeadLines**, the free NISAD publication which keeps you informed about the Institute's latest research. Just call (02) 9295 8407.**
2. **Make a **donation** today - every dollar counts.**
3. **Join The NISAD Society - a simple way to make regular automated contributions. See the application form overleaf.**
4. **Become a **NISAD 3-Year Corporate Sponsor** - See details overleaf.**
5. **Nominate NISAD as your **Official Charity** for your next event or fundraising day.**
6. **Create an opportunity for NISAD to **make a presentation** - at any venue from boardroom to building site.**
7. **Research your organisation's corporate giving structure, and **help facilitate a NISAD application for funds.****
8. **Introduce a **Workplace Giving Program** into your workplace - or help NISAD Schizophrenia Research to join your current one.**
9. **Support NISAD's 'Spark of Genius' annual gala dinner by **buying a table.****
10. **Commemorate your life with dignity by leaving a **Bequest to NISAD** in your Will.**

Some of NISAD's most successful fundraising ventures have arisen from the new ideas of supporters. So please think about how you, your friends and associates, and your organisation can help.

3-Year Corporate Sponsorships

One of the most effective ways your organisation can make an impact is to commit to a 3 -Year Corporate Sponsorship. Such 3-year commitments ensure a constant stream of funds that enables NISAD to embark on research that may provide urgently needed answers sooner. With another 2,000 young Australians diagnosed with schizophrenia each year, and 30 percent attempting suicide, these answers cannot wait.

Platinum:	\$50,000 per annum	Gold:	\$25,000 per annum
Silver:	\$10,000 per annum	Bronze:	\$5,000 per annum

As a NISAD Schizophrenia Research Sponsor your organisation will receive:

- **An invitation to the NISAD Annual Corporate Sponsors Lunch**
Attended by senior business leaders, senior State and Federal public servants, political leaders such as the New South Wales Minister for Health or the Minister for Science and Medical Research, and leading medical researchers. It is an opportunity for NISAD to publicly acknowledge our sponsors.
- **A Dedicated Plaque of Appreciation**
A tangible acknowledgment of our appreciation of your financial commitment. Corporate Sponsors are able to publicly display these plaques in foyers and public spaces within their organisations - it is important that staff and clients understand the level of social responsibility extended by your organisation.
- **Positive Communication**
NISAD Schizophrenia Research will profile your organisation in both written and electronic forms. We will also, in partnership with you, work to develop positive media opportunities.
 - **HeadLines:** NISAD's official publication, distributed to a 12,000 readership including corporate supporters and government departments, formally acknowledges our 3-year Corporate Sponsors.
 - **NISAD's Website** received around 500,000 hits last year. Sponsors are acknowledged with a link to their website. Upon request NISAD will write an article endorsing your organisation to be displayed on your own website - the ideal way to highlight your support of research.
 - **Workplace Presentations:** NISAD stands ready to provide meaningful presentations to staff or clients at any venue - from boardrooms to building sites.

There are no easy answers to the devastation schizophrenia causes in the lives of so many individuals and their families. Please support NISAD's quest for answers.

For further information about 3-Year Sponsorships, please contact Lee Drury on (02) 9295 8362.

Join The NISAD Society

NISAD Schizophrenia Research invites you to belong to a group that matters. A group made up of individuals who are prepared to support hard science with no easy answers. Belong to a group who back NISAD's world-class research team - a team dedicated to finding the means to prevent and ultimately cure schizophrenia.

Your annual \$240 tax deductible donation made in four \$60 automatic instalments provides NISAD Schizophrenia Research with a steady stream of funds that will enable us to meet the research challenge head on, to unlock the debilitating disease that is schizophrenia.

Every cent of your donation will go to hard science. As a NISAD Society Member you will share in our progress:

- **NISAD's publication, 'HeadLines' will be mailed tri-annually.**
- **A complimentary invitation for you and three guests to NISAD's Cocktails & Consciousness annually. An entertaining and enlightening experience shared with like-minded business leaders.**
- **An invitation to 'A Spark of Genius' - NISAD's Annual Gala Event.**
- **An annual tax-deductible receipt mailed at the end of the financial year.**
- **An opportunity to invite NISAD Schizophrenia Research to make a presentation or run a workshop for your workplace.**

To join The NISAD Society please complete and return the form below.



I authorise the Neuroscience Institute of Schizophrenia and Allied Disorders (NISAD) to debit my credit card the amount of \$60.00 quarterly, commencing

_____ / _____ **2004.**

Name: _____

Title: _____

Company: _____

Address: _____

_____ Postcode: _____

Phone (W): _____ (H): _____

Email: _____

Bankcard MasterCard Visa Amex

Card No: _____

Exp: _____ / _____

Cardholder's Name: _____

Signature: _____

Date: ____ / ____ / ____

I am aware that I am able to alter or cancel my automatic donation at any time upon giving NISAD 1 month's notice.

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