

# February 2007

## Age restriction for Rilutek now lifted

Sanofi-Aventis, the manufacturer of Rilutek, and the MND Associations have welcomed the Federal Government's decision to lift the age restriction applied to Rilutek on the Pharmaceutical Benefits Scheme.

Rilutek was previously available on authority for people under 75 years of age with Motor Neurone Disease.

As of 1 February 2007, it will be available without the age restriction for all people with MND. MND currently affects approximately 1,200 Australians.

"While Rilutek is not a cure, it is the only treatment available for people diagnosed with MND and can extend survival by six months," said Associate Professor Matthew Kieran, Consultant Neurologist, Prince of Wales Hospital. "This is particularly significant for people with MND whose life expectancy after the onset of symptoms is an average of three to five years."

The decision to lift the age restriction is a good outcome for Rilutek and provides all newly diagnosed patients with equal access to the treatment and its benefits.

MND is an extremely unfair disease. Most people with the disease gradually lose control of their muscles, resulting in paralysis and increasing levels of disability. In the majority of cases the intellect and memory are not affected, nor are the senses of sight, hearing, taste, smell and sensation.

Rilutek is the only treatment that offers people with MND some hope. It may increase their life expectancy and can increase their quality of life.

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## Diary Dates

### Sunday 18 February

Computer Market

### Saturday 17 March

Twilight Concert

**6 - 12 May**

MND Awareness Week

**20 May**

Computer Market

**21 May**

Research - Blood

Collection Day

(Full details inside this issue)

### Lifting of Stem Cell ban lifts hope for people with Motor Neurone Disease

MND Australia welcomed the decision by both Houses of Federal Parliament to implement the recommendations of the Lockhart Report, lifting the current ban on therapeutic cloning or somatic cell nuclear transfer (SCNT).

The revoking of the ban by the Government now allows embryonic stem cell research to be undertaken in Australia, keeping hope alive for the 1200 Australians living with motor neurone disease (MND).

The MND Associations in Australia supported the recommendations of the Lockhart Review and campaigned throughout the debate for the lifting of the ban. Submissions, letters and emails were sent to members of the Senate and the House of Representatives to raise awareness of the potential of this research for people living with MND.

The goal of therapeutic cloning or SCNT is to generate embryonic stem cells that are perfectly matched to a particular person. It has the potential to increase understanding of the causes of MND and the potential for the development of effective treatments and eventually a cure.

Congratulating MP's on their decision, Helen Sjardin-Howard, Chairperson of MND Australia said, "We are very pleased with the decision made by the House of Representatives as it provides hope for the future for those living with MND and other diseases like it. We congratulate the MPs for recognising the need for, and potential benefits of embryonic stem cell research.

"We will look forward now to increased possibilities for treatments and therapies that may come from stem cell research. If stem cells do not prove to be the panacea for disease, and MND in particular, then they can be put aside and fresh directions can be taken in research."

MND Australia supports research which is legal, has sound scientific rationale and has the potential to bring us closer to finding a cause, treatment or cure for motor neurone disease.

The MND Association is extremely pleased with the decision of Federal Parliament to lift the ban on stem cell research. While this is exciting news that will open new avenues of research into the cause and a possible cure for MND, it will unfortunately take many years of research and trials before a breakthrough/treatment is available to persons affected by MND.

Stem cell research is taking place in other countries besides Australia and we can only hope that this ground breaking research discovers the cause of MND in the immediate future and not in distant years.

The decision by the Federal Government to remove the age restriction of 75 years on the prescribing of Rilutek was also welcomed by the MND Associations.

Sanofi-Aventis, the company manufacturing Rilutek are to be congratulated for their persistence in pursuing the Federal Government to have the ban removed. In society today, no person should be denied a treatment simply because of their age.

The MNDA SA recently held a strategic planning session to develop a raft of strategies for the future development of the Association over the next three years. Members will be informed of the strategies when the strategic plan is finalised in the coming weeks.

**Peter Whitehouse**  
Executive Director

### MND Awareness Week

**6 - 12 May 2007**

Members will be advised in the near future of the plans for MND Awareness week.

A response form is enclosed in anticipation of some events to be held during the week.

Please complete and return to the office if you are able to assist in any way, or to order products & / or Entertainment Book.

## The Stacey MND Genome Laboratory Update

The Australian MND DNA Bank has been able to substantially increase the number of samples collected during 2006. A major contribution to this achievement has been the many successful donor drives organized through the MND Associations in each state. Ms Lorel Adams is now manager of the Bank, a position funded by an NHMRC Enabling Grant.

Many thanks to regional coordinators, local volunteers and the many people with MND, their carers, family and friends who came to donate on these days. Participants appear to be very interested in the presentations on the latest research, and enjoy meeting each other and strengthening support networks.

As a result of the promotion of these donor drives, we have been contacted by many people who were geographically isolated, or unable to travel, but still wished to donate to the Bank. We have been able to communicate via mail or email, and organise local GPs or pathology services to send the samples and data to us. We now have links throughout most states so that we can continue to have donors contributing from their homes.

The Bank now has over 1,400 DNA samples with environmental data from people with MND and controls.

We look forward to visiting Adelaide on Monday 21 May to meet new donors, when further results arising from the MND DNA bank will be presented. Refer details below.

Studies in progress using DNA samples from the bank are looking at susceptibility to MND involving viral receptor genes, the metallothionein family of heavy metal protecting genes, the glutathione synthetase toxin protecting gene, gene silencing, brain differences in the SOD1 gene, introns in the SOD1 gene, and using whole-genome gene chips to look for mutations that may be present only in brain tissue.

### *Associate Professor Roger Pamphlett*

I was pleased to be invited to the recent launch of the naming of the Stacey MND Genome Laboratory at the University of Sydney.

Roger gave an overview of the work of the MND DNA bank, followed by a tour of the department.

The late Jack Stacey was a very supportive member of MNDA SA and research. Unfortunately due to illness, Dianna (Jack's daughter) was unable to attend.

*Sue Edwards*



*David Barr, Sue Edwards, Alison Barr, (Jack's daughter) & Roger Pamphlett at the launch of the Stacey Laboratory.*

## Dr Roger Pamphlett - DNA Blood Collection Day - for Research

Dr Roger Pamphlett will be in Adelaide to collect blood samples from patients with Motor Neurone Disease and from family members or friends.

This research programme is imperative for future results in finding a cure for MND.

### **MONDAY 21 MAY**

The Parkview Room - Fullarton Park Centre  
411 Fullarton Rd, Fullarton  
(cnr Fullarton Rd & Fisher St)

From 11.00am - 3.00pm  
Lunch 12.30pm - 1.30pm

During the lunch break Roger will give an update of his programme.

If you would like to participate please phone the office on 8357 0245 to make an appointment time and forms will be forwarded to complete. (or refer Response form)

If you are unable to attend this session, but would like to participate, please phone the MND office and information will be forwarded. This Fact Sheet has all the contact details.

*If you have already participated you are welcome to come for the talk during lunch*

## Family Support Services

### Retirement

We are sad to lose Margaret Paterson to her retirement! However, we are happy to know that she will now have more time to enjoy her family and her golf! We wish her well and thank her greatly for her outstanding commitment to MNDA SA.

Ceri MacLeod & Julia Brett are now in the double roles of Speech Pathologists and Family Support Services for the Association. Ceri and Julia will share the roles which are now funded for 4 days per week.

Please feel free to phone us at the office on 8357 0245.

### Equipment

There is a limited number of manual and electric wheelchairs available from the MNDA SA. We also have a limited number of communication aids (lightwriters) available.

### Carers' Meetings

Meetings are an opportunity for families, friends and carers of people with MND, to offer support, information and guidance through a difficult time.

We hold meetings in Elizabeth Vale, Modbury & Daw Park. If you are interested in coming along or have any ideas or topics you may wish discussed or presented, please contact us on 8357 0245.

### *Ceri MacLeod*

### Deakin University - Follow up : The economic impact of MND on well-being.

Last year, members of MNDA SA were asked to participate in a research project looking at the Economic Impact of MND on Well-Being. A total of 120 people with MND and 111 partners and carers of people with MND participated in the study. Analyses are currently being conducted and results will be made available through MNDA SA once complete.

For those of you who participated, we would like to inform you that in 2007 we will be conducting the twelve-month follow-up phase of the project. So if you participated in 2006, you will soon be receiving a follow-up questionnaire in the post. We would like to take this opportunity to thank you again for your participation, and we look forward to your continued involvement with this project. If you have any questions or comments regarding this project, Elodie O'Connor can be contacted by phone on (03) 9251 7258 or via email at [elodie.oconnor@deakin.edu.au](mailto:elodie.oconnor@deakin.edu.au)

### March of Faces Banner

More photographs are needed for the March of Faces Banner which helps to promote community awareness about MND.

If you would like to participate in Banner #3, please contact the office and the appropriate documents will be forwarded to you.

## Staff Changes at the MND Association

There has been a changing of the guard with the retirement of two highly respected staff, Sue Edwards and Margaret Paterson.

Sue, the Administration Assistant and previously the Executive Officer, will be retiring on 21 February 2007 after six & half years with the Association. In many ways Sue was the voice of the Association being involved with administration, fundraising, seeking funding for numerous activities and providing information just to name a few. Simply put, if it needed doing it was done by Sue!

Sue was actively involved with the national Association, MND Australia and was the national secretary for eighteen months. She was a South Australian delegate to MND Australia for many years.

Margaret, who retired on 21 December 2006, was appointed as the Outreach Worker in 2001 advising clients and providing information on MND.

Margaret was highly regarded for her dedicated approach and the support she gave to clients and their families. She also earned the respect of other health professionals throughout the State who needed to gain knowledge of MND and for the continuing advice she readily gave to all concerned.

Ceri MacLeod who would be known to clients through her contract employment for the speech pathology project funded by the Paul Newman Foundation, has succeeded Margaret to provide Family Support and Speech Pathology Services.

Wendy McPhee has been appointed as the new Administration Assistant.

### *Thank You*

I would like to thank everyone associated with the MNDA SA now, and past members, for their support over the many years I have been involved with the MNDA SA, and MNDA Australia.

Due to the support of its members, the MNDA SA now has a high profile in the community. Without the dedication and support of many volunteers, staff & board members, this would not have been possible.

I have enjoyed my work at MNDA SA, and to this end I wish Wendy every success in her role as Administration Assistant.

*Sue*

## Fundraising

### \$130 Club

**Congratulations** - to Shirley, Brian, Sue & Dianne on winning the recent monthly draw for the prize of \$50 gift basket.

Thank you everyone for your support.

### Christmas Stocking Raffle

Thank you to everyone who supported the sale of raffle tickets for the Lions Christmas Stocking raffle.

The winning numbers were:

1st Prize	3824	Whyalla
2nd Prize	1351	Renmark
3rd Prize	3356	Flagstaff Hill

The MNDA SA raised \$1500 from this fundraising event.

### Twilight Concert

The MNDA SA received \$700 from proceeds of a gold coin donation given by patrons attending a recent fundraising concert and a raffle which was held in the Barossa Valley.

The Vincent's Chair Trio gave a performance at a Twilight concert held at the beautiful grounds of Whistler Wines on Seppeltsfield Road. Playing to a backdrop of vines, roses and gum trees, Kathy's musical genius was enjoyed by the 200 visitors, many of whom referred to it as a "magical night".

The next concert will be held on Saturday 17 March and anyone interested in attending this evening will be most welcome.

The MNDA SA appreciates the continued support of the hardworking friends in the Barossa Valley.



*Photo of Neale, Tia, Jayne & Marjorie taken at the drawing of the raffle. Prizes donated by Whistler Wines*

## Entertainment Books

The Entertainment books for 2007 will be available for members and friends from early April for a cost of \$60 each plus \$7 postage.

There are a lot of excellent restaurants, leisure activities, casual dining opportunities to save money.

The MNDA SA receives \$12 per sale.

Please phone the office if you would like to purchase the book this year.

## Computer Markets

The 2007 Computer Market dates are as follows  
Sunday 18 February, 20 May, 19 August and 4 November.

All markets are held at the

Festival Function Centre, 292 Findon Rd, Findon.  
Stalls available. Enq ph 8357 0245

## Cards

The MNDA SA is grateful to members who have forwarded their photographs which have been reproduced into cards to raise funds for the MND Association.

These cards together with the cornflower card, have been very well received. Many comments have been made on the quality of the photographs.

Cards are the same size as the cornflower cards, (picture not available) and blank inside.



\$5.00 per pack of 5 cards

## Australian Church Women

It is most pleasing to report the Australian Church Women – SA Unit, has selected the Motor Neurone Disease Association as its charity to support in 2007.

The Australian Church Women seek to unite Christian Women across denominational boundaries and its members come from a wide range of Christian churches. The ACW each year sponsor as a Project an organisation providing a caring support service in the community.

# MND Research Institute—Grants awarded for MND research in Australia—2007

Researchers in Institutions all around Australia working in diverse fields of research are invited to apply for funding for MND research to ensure that every avenue is investigated. The majority of funded projects have been biomedical (laboratory based) research, focussing on understanding the causes or finding effective treatments or a cure for MND.

Recently the MND Associations have encouraged the support of health care research projects - research that will lead to better management and care of people living with MND. Specific funding for health care research has been contributed through the MND Associations of Victoria and NSW, and the MND Victoria Research Grant has been awarded for a health care project in 2007. Funding has also been allocated to contribute to support of the Australian MND Registry (AMNDR) over three years.

## Grants in aid

With limited resources, funding initially provided through the MND Research Institute was mostly for small grants in aid. These have been useful as top-up funding for larger projects funded through other sources, or often as seed funding that allows collection of data to provide the basis for applications for larger grants e.g. funding from the National Health & Medical Research Council (NH&MRC). It is difficult to attract this Government funding to MND research, but in the last two years, three projects supported by MNDRIA have resulted in significant grants being awarded by the NH&MRC: Assoc Prof Roger Pamphlett (Sydney) received \$750,000 for 2006 - 2010, Dr Peter Noakes (Brisbane) \$513,000 for 2007 - 2009 and Dr Julie Atkin (Melbourne) \$514,500 for 2007-2009.

## Fellowships

While grants in aid support MND *projects*, MND research fellowships support the *person* and aim to encourage young scientists to develop a specific interest in MND research. Receipt of a significant bequest allowed the introduction of the first MND Research Fellowship in 2001. Since that time, a further five two-year fellowships have been awarded and all these Fellows are continuing in their pursuit of unlocking the key to MND:

### Sealey MND Research Fellowship

Dr Elizabeth Coulson, formerly from WEHI, VIC and now at the Queensland Brain Institute

### MND Research Institute Fellowship

Dr Julie Atkin, Howard Florey Institute, Melbourne

### Bill Gole MND Research Fellowships:

Dr Roger Chung, University of Tasmania

Valerie Hansen, University of Sydney

Dr Ian Blair, ANZAC Research Institute, NSW

Dr Julia Morahan, University of Sydney.

Dr Ian Blair, ANZAC Research Institute, NSW  
Dr Julia Morahan, University of Sydney.

## Grants in aid

### Dr Gilles Guillemin

St Vincent's Hospital, Sydney

#### *Involvement of the kynurenine pathway in ALS*

We have identified a new neurotoxic mechanism involved in the neuroinflammatory disease. We propose to demonstrate that the tryptophan metabolism plays an important role in the pathogenesis of amyotrophic lateral sclerosis (ALS). Our main hypothesis is that a downstream tryptophan product, the neurotoxin quinolinic acid (QUIN), produced by activated immune brain cells (microglia/infiltrated macrophages) induces motor neuron dysfunction and activation of astrocyte (brain cells taking care of the neurons). This will open a new and important therapeutic door for ALS using different specific inhibitors already available from drug companies for other brain diseases.

### Professor Nigel Laing

West Australian Institute for Medical Research

#### *Whole genome amplification and PCR screening of a WA cohort of 97 familial and sporadic ALS patient DNA samples*

We are currently in possession of genomic DNA samples from a cohort of around 100 Western Australian familial and sporadic ALS patients that have tested negative for mutations in the SOD1 gene. These DNA samples are an invaluable resource for pursuing potential genes involved in the development of ALS. Due to the precious and finite nature of the patient DNA samples (as many of these patients have passed away) we are endeavouring to preserve these samples for current and future use. We aim to preserve these DNA samples by employing the technique of whole genome amplification. This technique has been used successfully in this lab to amplify other precious DNA samples used in the identification of disease-causing mutations. Amplification of the patient DNA samples will allow us to screen these DNA samples for mutations in genes other than SOD1, which have been implicated in the development of both familial and sporadic ALS. Due to the predominant Anglo-Celtic ethnic origins of Australia, the angiotensin gene (ANG), which is involved in blood vessel formation, is an important candidate gene to be screened in our ALS cohort after variations in ANG were associated with both familial and sporadic ALS earlier this year in predominantly Celtic pedigrees. Additionally, the gene VAPB has unequivocally been implicated in familial ALS and is therefore also an important candidate gene to be screened.

## MND Research Institute...Cont.....

### Professor Grant Morahan

West Australian Institute for Medical Research

#### *Discovery of novel genes causing MND*

We do not know what causes most cases of motor neuron disease (MND). Some people have mutations in a gene called *SOD1*. We propose that mutations in other genes that affect the levels of *SOD1* can also cause MND. It is impossible to identify these genes directly in humans. However, we can use a new system we have developed using mouse models to identify candidate genes. The human counterparts of these genes will then be tested using DNA samples from people with MND. If we find mutations in these genes, then we will have a better understanding of the causes of MND, and will be better placed to develop new ways to treat this disease. Our novel approach will streamline discovery of MND disease genes. If successful, it will lead to further funding proposals to NHMRC or NIH.

ZO-EE MND RESEARCH GRANT

### Professor James Vickers

Menzies Research Institute, University of Tasmania

#### *Unravelling the cellular pathology underlying neuronal degeneration in MND*

Amyotrophic lateral sclerosis (ALS) is the major cause of motor neuron disease. There have been significant advances in the understanding of the underlying pathology of this progressive and degenerative condition, and yet the important links between potential causative factors have not been clearly established. One of the critical changes in motor neurons involves the abnormal accumulation of filamentous proteins in axons. This may be related to the blockage of flow of proteins down the axon, leading to impaired function of motor neurons and subsequent degeneration. We have recently derived preliminary data using cultured spinal motor neurons that links the overactivity of excitatory receptors with a pattern of axonal pathology that mimics ALS. This application explores this interrelationship further and also examines the potential role of known genetic causative factors. In addition, potential therapeutic approaches based on stabilizing axonal filamentous proteins will be investigated.

### Dr Bryce Vissel

Garvan Institute of Medical Research, Sydney

#### *The Effect of Kainate Receptor RNA editing in excitotoxic cell death of motor neurons in MND.*

Riluzole, the only approved therapy for MND, directly or indirectly blocks molecules in the spinal cord called glutamate receptors. Blocking these receptors seems to slow motor neuron loss that leads to paralysis. However there are many types of glutamate receptors in the spinal cord and it is not yet known which of these are important for MND progression. We are systematically undertaking genetic studies in mice engineered with a gene that causes motor neuron disease. Our studies are directed to block each of the receptors one at a time. We hope to determine if blocking one of these receptors extends life of the mice we are studying. If we find that we can extend the life-span of the mice, that will indicate we may have discovered a new therapeutic approach for treating motor neuron disease.

### Dr Robyn Wallace

Queensland Brain Institute

University of QLD

#### *Assessing therapeutic peptides in a mouse model of MND*

The biological processes that lead to motor neuron disease are complex and multifactorial. Future treatment of MND is likely to involve a cocktail of neuro-protective compounds similar to the currently used chemotherapeutic combinations, which interfere with several molecular pathways. We propose using a multi-compound approach designed to target both the affected motor neurons themselves, and their supporting cells (astrocytes). We have developed two peptides for this purpose, one designed to promote nerve cell survival (p75-targetted) and one to prevent activation of astrocytes (EphA4-targetted). We will test these peptides separately and in combination in a mouse model of MND. These experiments may lead to a novel treatment for patients with MND.

MND VICTORIA RESEARCH GRANT

### Professor Kate White

Faculty of Nursing & Midwifery

University of Sydney

#### *Letter on future care: development of an individualised disease specific future care plan for MND*

The project aims to assist people with MND and their families to plan their future care, particularly in the later stages of the disease, in consultation with their health care team. The project aims to evaluate the implementation and documentation of an individualised disease-specific future care plan.

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email: admin@mndasa.com.au  
www.mndasa.com.au

## Memorial Donations

The MNDA of SA would like to encourage members to consider a bequest which will benefit other members of the Association, with MND. The cost of equipment such as a light writer (a communication device) is approx \$7000. We rely on donations and bequests, to help purchase these valuable items, or to make donations towards research grants into MND.

All Memorial donations, and general donations are gratefully received and acknowledged, with thanks. Each year we like to support the Australian MND Research Institute with a donation as their commitment to Research is vital in finding a cure for this disease.

## For Your Garden of Daily Living

Plant three rows of peas:

- 1 Peace of mind
- 2 Peace of heart
- 3 Peace of soul

Plant four rows of squash:

- 1 Squash gossip
- 2 Squash indifference
- 3 Squash grumbling
- 4 Squash selfishness

Plant four rows of lettuce:

- 1 Lettuce be faithful
- 2 Lettuce be kind
- 3 Lettuce be patient
- 4 Lettuce really love one another

No garden is without turnips:

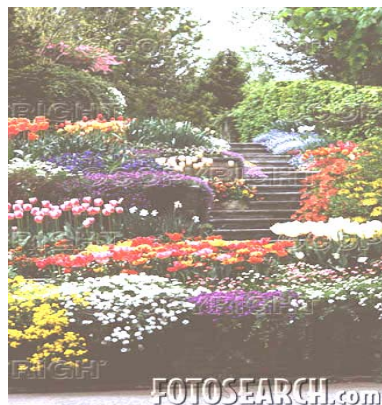
- 1 Turnip for meetings
- 2 Turnip for service
- 3 Turnip to help one another

To conclude our garden we must have thyme:

- 1 Thyme for each other
- 2 Thyme for family
- 3 Thyme for friends

Water freely with patience and cultivate with love.

There is much fruit in your garden because you reap what you sow.



## Bequests

Leaving money to a charity is a very personal and important decision. The Association is deeply grateful for being remembered in this way. The following form of bequest is suitable :

*“I give to the Motor Neurone Disease Association of South Australia the sum of \$ \_\_\_\_\_ dollars for the general purposes of the Association and I declare that the receipt of the Treasurer or other proper officer for the time being of the Association shall be a good discharge to my executors”.*

*Our thoughts are with all our members who have lost their loved ones in recent months.*

