

MARCH 2010

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Support the National Disability Insurance Scheme Campaign

As part of MND Week each year MND Australia and the State Associations undertake a **Call to Action** to address national issues that impact people living with Motor Neurone Disease in Australia. This year we are asking members to support the National Disability Insurance Scheme (NDIS) campaign. A NDIS will change the way services for people with disabilities are funded and structured providing a no-fault insurance scheme for everyone who has, or acquires a significant disability.

The Key message with the **Call to Action** is that it is time to change the way services for people with disabilities are funded and structured in Australia so that people diagnosed with MND can access disability services as soon as a need arises no matter where that person lives or how old they are. People diagnosed with MND need a rapid response to their support needs and so waiting lists are not an option. Services to support people living with MND and their families must include:

- Timely Assessments
- Respite, home care support and personal care
- Case management and care packages
- Equipment, assistive devices and home modifications

MND Australia and the State MND Associations are asking their members, families and supporters to write to their Federal and State politicians to let them know of their care needs. This is especially important in South Australia as it will assist with our campaign seeking State Government funding to support and expand our client support services. The South Australian MND Association remains the only mainland MND Association not receiving funding support from its State Government.

[Within the Newsletter, there is a sample letter with some options/ideas that can be used for writing to politicians.](#) If readers have any queries or require additional information, please contact the MND Association.



Please support our annual Walk to D-Feet MND on Sunday 18 April at the Adelaide Sailing Club, Barcoo Road West Beach. This is our major fundraising event for 2010 and the support of members, families and friends would be most welcome. Late registrations on the day from 10.00 am, with the Walk starting at 11.00 am followed by a free sausage sizzle. Walk t/shirts available on the day.

Great giveaways and raffle with exciting prizes to be drawn on the day.

Entry Options

- **Complete and return** the enclosed registration form
- **On-line** registration including your own sponsorship page: go to www.mndasa.com.au
- **Additional registration forms** can be downloaded from www.mndasa.com.au or by phoning the MND Association on 8234 8448 or freecall 1800 777 157 (country callers)

Drug Trials

Two human drug trials, Ceftriaxone trial and KNS-760704 trial, were specially mentioned in the closing presentations at the 2009 International Symposium on ALS/MND in Berlin last December.

Ceftriaxone

Researchers think that increased levels of a chemical called 'glutamate' may be related to cell death. For this reason, researchers want to study drugs that decrease glutamate levels near nerves. Studies of Ceftriaxone in the laboratory suggest that it may protect motor neurons from injury.

The results from the Ceftriaxone study were presented by Dr Merit Cudkowicz, an associate professor of neurology at the Massachusetts General Hospital of Harvard Medical School. (Dr Cudkowicz is an expert in co-ordinating MND clinical trials in the USA). The purpose of the study was to evaluate the safety and efficacy of Ceftriaxone treatment in MND. The study consists of three stages. The *first stage* looked at whether Ceftriaxone enters the cerebrospinal fluid (the fluid that surrounds the spinal cord, also called CSF) in amounts that are high enough to be of possible benefit. The *second stage* looked at the safety and side effects of the study drug when taken daily for at least 20 weeks. Dr Cudkowicz presented the results of the successfully completed stage I and stage II trials. The results were so encouraging that the *third stage* will be started soon. Its overall purpose is to determine whether the drug prolongs survival and slows decline in function due to MND.

KNS-760704

At the second day of the Symposium, researchers presented the encouraging results of the Phase II clinical trial looking at the safety and tolerability of a drug called KNS-760704 in MND patients. The two-part Phase II trial found that KNS-760704 was safe and well-tolerated in MND patients for up to nine months. The trial results also showed trends suggesting the potential for reducing the rate of decline in the functional capability of patients, for example, how far people can walk unaided, lifting objects, dexterity in eating, and survival. The researchers emphasised that KNS-760704 is still in the early days of development for patients and that further testing in a large, longer-term, carefully monitored Phase III trial is needed to establish the necessary evidence that the drug is both safe and effective for MND patients. Phase III testing of KNS-760704 in MND may begin in mid-2010 at sites in Europe and North America under a protocol under development by Knopp Neurosciences Inc., in consultation with global regulatory authorities.

Dr Belinda Cupid, research manager at the MND Association who attended the symposium, explained:

"Phase II clinical trials determine the size of the dose, the timing of the dose and how the drug is to be taken for the next phase of testing. Although Phase II testing provides some indication of a drug's ability to treat a disease, the number of patients involved at this stage is much too small for the findings to be relied upon. Phase III clinical trials are important as they aim to show whether or not the drug actually has a beneficial effect on patients. This stage of testing will usually involve hundreds of patients which is enough to allow a reliable assessment of the drug's effectiveness. Phase III results will determine whether or not a drug is to be approved to treat a disease."

The Australian MND DNA Bank

Progress with DNA collection

The MND DNA Bank now has over 2500 samples and well on the way to its target of 1000 people with MND and control samples to match these by early 2011.

During 2010 the DNA Bank wishes to collect blood samples and questionnaires from:

- 200 people with MND
- identical twins of people with MND
- both parents of people with sporadic MND
- all family members of people with familial MND
- 90 men over 50 years of age with no family history of MND
- 30 women over 75 years of age with no family history of MND

On **Monday 16 August** this year, Dr Roger Pamphlett and Ms Lorel Adams from the DNA Bank will be visiting Adelaide to collect DNA samples. Details of this visit will be advised shortly. Alternatively, if you would like to give a sample now, you live in a rural area, or are unlikely to attend the Adelaide collection day, arrangements can be made for an immediate collection. There is no cost to you.

To do this

- Please call Ms Adams (02) 9036 5456 or email, dnamnd@med.usyd.edu.au
- A questionnaire with a reply envelope will be posted or can be completed over the phone
- Arrange for you to have a blood sample taken locally or in your home if needed.

A Decade of Discovery

Leading British scientists were asked, "***What were the most exciting scientific developments of the past 10 years – and what comes next?***"

Professor Colin Blakemore, Professor of Neuroscience at the Universities of Oxford and Warwick and President of the Motor Neurone Disease Association of the UK replied as follows

"My scientific moment of the last decade came on February 12, 2001, when the journal Nature published a "working draft" of the entire 3-billion-letter sequence of human DNA. One-third of that massively expensive international enterprise - comparable in its significance to splitting the atom, or discovering radioactivity - was produced at the Wellcome Trust Sanger Institute, near Cambridge.

But just as with those other breakthroughs, much more was needed to deliver the benefits of the Human Genome Project. In fact, Professor Steve Jones has recently dared to ask the "Emperor's New Clothes" question of whether the subsequent research has lived up to its promise.

I can see what he means, given that the many comparisons of DNA from healthy people and those with diseases have yet to produce a flood of new treatments.

Prediction : *The coming 10 years will be the decade of genetics, a time when amazing new technologies will start to transform our understanding of how our bodies develop, work and go wrong. Recent advances in the study of genetic errors in the rare inherited forms of motor neurone disease might cast light not only on that terrible condition, but on many other incurable diseases of the brain."*

MND & THE INTERNET

Unproven therapies for MND and the internet

With the internet being as accessible and unregulated as it is, MND Associations often receive calls and e-mails from people regarding treatments being offered both here and overseas that claim to treat or cure MND. Often, these treatments are promoted on websites that feature in internet search results when people search for information about MND. It is very difficult for people living with MND and their families, desperate for effective treatments and a cure, to sort fact from fiction, and paid advertising from good quality health information.

Stem cells, in particular, are still considered a relatively new form of science, and with the range of claims being made every day about new cures, it's not surprising people are confused. There are many success stories related to unproven therapies and unproven stem cells therapies posted on the internet. Unfortunately there are just as many stories where these therapies have not been successful or where the improvement is for a very short time only. This highlights the need for properly conducted research trials to assess the effectiveness of any therapy offered.

Information about current research and alternative and unproven treatments will help people to make informed decisions regarding any treatments being offered via the internet. Talking to your doctor, neurologist or MND association will also help you to make informed decisions. There are a number of resources available on the MND Australia website to help you decide about any claims being made about treatments or cures for MND:

The International ALS/MND Alliance Statement on Alternative and Unproven Treatments and the MND Australia Research Policy: <http://www.mndaust.asn.au/policies/>

Links to the Australian Stem Cell Centre Patient Handbook and Latest Research Updates: <http://www.mndaust.asn.au/latest-research/>

Treatments for any health conditions can be:

- beneficial or
- have no effect or
- cause harm through side-effects, adverse events or life-shortening effects.

There are many steps that must be taken before any treatment or medication can be offered to people living with MND. It is imperative that any intervention is proven to be safe and proven to improve outcomes for people living with MND. At present we know that there is no evidence to suggest that the therapies, such as the stem cell treatments being offered by various clinics, improve outcomes for people with MND and they could in fact be harmful.

MND Australia keeps abreast of the latest research and will support and promote any new treatments that have been proven through research and scientific peer review to improve survival or symptom management for people with MND. Research has increased and improved dramatically over the last few years and many researchers both in Australia and overseas are working collaboratively to better understand MND so that effective treatments and ultimately a cure will be discovered.

Contact your MND Association for more information.

SUPPORTER FUNDRAISER NEWS

Four Terraces Run – Strathalbyn

The beautiful country town of Strathalbyn has four Terraces that surround the town and a perfect setting for a fundraising run/walk. Local businessman, Grant Lyon was inspired by the courage and determination of a Strathalbyn resident, Patricia McAulay who has MND, he decided the Four Terraces Run for 2009 would raise funds for the MND Association.

With the help of a few friends, business colleagues and the Strathalbyn Football Club, Grant received an overwhelming response from the community with the event being a tremendous success raising nearly a \$1,000. With the wonderful community support they received, Grant is planning for the Four Terraces Run to become an annual event raising funds for the MND Association and MND research.

First across the line in a record time of 13.18 minutes was Andy Delmont with Susie Thomas winning the female section with a time of 15.17 minutes. The inspirational Patricia McAulay who was determined to complete the Walk, crossed the line in a creditable 50 minutes.

Pictured are Andy Delmont, Patricia McAulay, Susie Thomas, Grant Lyon & Peter Whitehouse

SUPPORTER FUNDRAISING NEWS

Thank you

The MND Association would like to thank the following supporters for arranging fundraising activities over the past months.

Whistler Wines

Australia Day Gourmet BBQ

Australia Day was celebrated at Whistler Winery in the Barossa Valley with a Gourmet BBQ.

The Pfeiffer Family of Whistler Wines are marvellous supporters and invited the MND Association to serve a Gourmet BBQ as a fundraiser. They once again donated a Whistler Wines GSM Jeroboam (a 3 litre bottle) as first prize in the raffle.

Over 400 persons attended to celebrate Australia Day and enjoy the excellent Whistler Wines, the food and music in the beautiful bush setting of the Whistler Winery. Over \$1,000 was raised.



Pauline Baxter 3rd prize winner, Peter Whitehouse CEO of MND, Karen Nilsson 1st prize winner. Absent Mavis Traeger 2nd prize

ElectraNet : Quiz Night

From Pat Watson, ElectraNet Pty Ltd.

“Did you know that the Canadian PE instructor James Naismith was the inventor of basketball? Or could you have worked out that “TLA” was a three letter acronym for “three letter acronym?”

If you did, you should have been at the San Giorgio La Molara Hall at Payneham on Friday, 5th March, amongst the very best (and not so very best) quiz contestants from ElectraNet.”

The evening was ably hosted by ex-ElectraNet colleague Graeme Crook as the quiz-master extraordinaire. Apart from the challenging quiz questions, there were also a number of other games of both skill and chance to add to the enjoyment of the evening.

We were fortunate that Peter Whitehouse from the Motor Neurone Disease Association (this year’s nominated staff charity) joined us and gave a moving talk on this terrible disease.

The tally at the end of the night exceeded \$1200, which will be matched dollar-for-dollar by ElectraNet at the end of the financial year. A truly enjoyable time was had by all.



The winning team was the “United Nations” led from the front by Peter “Einstein” Maschmedt, and who still claim not to have Googled any answers from their table!

MND Awareness

Tour Down Under Community Ride - Stephen Warren, Sharon Perkins, (pictured), John Gilligan and Graeme Hinton participated in the **Tour Down Under Community Ride** with the team name “Cure Motor Neurone Disease” prominently marked on the back of the community ride jersey. We are aiming next year to have a large contingent riding with “Cure Motor Neurone Disease” jerseys and attracting sponsorship for the riders.

Mustangs on the Move held an Australia Day Charity Run in support of Clayton le Clercq and the MND Association

City of Onkaparinga - Casual Day

Booth Transport - Casual Day



SUPPORTER FUNDRAISING NEWS

Karen Schumacher Country Night in memory of Lee Cox



What a fun night! Karen undertook the incredible task of arranging for this fundraiser to happen in six weeks. The Kilburn RSL donated the venue and Peter Simons organized the entertainment with his "Boogie Boys, Murray Mac, Charlie McCracken and the Family Band. All the musicians donated their time to perform on the night. 200 people supported this fundraiser in memory of Lee Cox. \$2,473.35 was raised on the night.



Leslie Fox, (Lee's mother) Karen Schumacher, Steven Warren (Chairman MND Association), Peter Simons and Ricki Higham



Michael & Trudy O'Hara (Managers of the RSL Club) with Karen

Family Fun Day in memory of Jim Branford Ascot Park Bowling Club

Helen Branford and her family continue to raise money for research to find a cure for MND. The raising of money for a cure was something Jim, Helen's husband, tried to do as he battled the disease. The family thought it would be appropriate to have a "Bowls Day" as Jim was an avid bowler and they want to continue to spread awareness about MND.

Jim was a member of the Ascot Park Bowling Club who offered their venue for the day. The weather was perfect. After a delicious lunch and the handing out of prizes won on the chocolate wheel everyone was given the opportunity to try their hand at Lawn Bowls. Members of the Ascot Park Bowling offered advice to the novices. Many bowlers commented "*I could easily become addicted to playing this game!*" The children were treated to face painting, games and balloons. After the game, afternoon tea was offered and the major raffle was drawn.

A fun day was enjoyed by everyone who attended. Helen's family raised \$1,712.30 and are still receiving donations.



Angela, Paula and Helen draw the Chocolate Wheel prizes



Helen bowls the first ball of the day

FUNDRAISING

Channel 9 Telethon

“Take 9 Movie Card”

Over \$100 savings on normal ticket prices

Purchase a “Take 9 Movie Card” for **\$15.00** and you will receive:

- 2 FREE movie tickets
- 9 movies for only \$9 each for you and a friend or family members (a surcharge of \$4 will apply to all 3D and Special Event Films)
- Plus a bag of fruchocs on use of card first visit (not on use of free tickets)
- Chance to win a Wallis Gold Pass
- Tickets available from early March 2010 and valid for use until 28 February 2011
- Available at all sessions every day (unless session is sold out)

Phone our office on 8234 8448 to purchase your card or complete the enclosed order form.



Australian  Central

ACCU Raffle

Thank you to all of our supporters who have purchased tickets and/or helped us to sell tickets in the 2010 Australian Central Community Lottery.

We are well on the way to reaching our goal of selling 200 books of tickets. Our aim is to raise \$4,000.00 for MNDASA.

We currently have 79 books of tickets left to sell.

If you can help us to sell our remaining tickets, we would be grateful for your assistance. Tickets sell for \$2.00 each and the full amount from each MNDASA ticket sold will be donated to MNDASA.

Please call the office on 08 8234 8448 if you can help us to sell our final supply of tickets.

Entertainment Books

The Motor Neurone Disease Association is selling Entertainment Books again this year. We would like to thank everyone who supported our Association by purchasing a book last year.



The 2010 / 2011 information order form flyer is enclosed with this newsletter. If you would like to purchase a book, please complete the flyer and return in the enclosed reply paid envelope or contact the office on 8234 8448.

If your order is placed before *Friday 16 April* you will receive 6 bonus offers for restaurants brand new to the Entertainment Book.

Books will be available from the Association after **Thursday, 22nd April 2010.**

MND Awareness Week : 2 - 8 May

If you are aware of any businesses or if any of our members and friends wish to order MND merchandise to purchase, or to sell on our behalf, please do not hesitate to give us a call at the office on 8234 8448 or email admin@mndasa.com.au

The **MND Service of Remembrance** will be held on 27 June this year. More information will be available shortly.

Memorial Donations

Special thanks to everyone supporting the work of the Motor Neurone Disease Association of SA Inc by memorial donations in lieu of flowers when a loved one passes away.

The donations received from families, friends, and colleagues are promptly acknowledged.



We welcome articles, stories, poems etc from all of our MNDASA members and friends. If you would like to send us an item for the next MND Newsletter please send us an email at: admin@mndasa.com.au or post your information to PO Box 2087 Hilton Plaza SA 5033.

MERCHANDISE

MND 'Never Give Up' Wristband \$2.00



MND Ballpoint Pen \$2.00



MND Greeting Cards (Cornflower Design) Pack of 5 \$5.00



MND Greeting Cards (Fresh Cherries) Pack of 5 \$5.00



MND Greeting Cards (Butterfly Design) Pack of 5 \$5.00



MND Badges / Lapel Pins \$5.00



MND Silk Cornflower Brooch \$2.00



MND Socks (large) \$6.00



MND Socks (small) \$6.00

New Merchandise

A cute **plush puppy** has joined our merchandise items. The puppy has MND Australia embroidered on one side and is available for \$5.00. Approx 16cm long and 11cm high.



In early May will have a supply of **dog leads**. The leads are blue with the white MND Australia logo printed on it.



Polo shirts. A plain deep blue polo with the MND Australia logo embroidered on the left hand side. Available in S, M L, XL. Priced at \$25.00



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Association of SA Inc

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MND Newsletter

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