

SEPTEMBER 2008

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The Australian MND DNA Bank

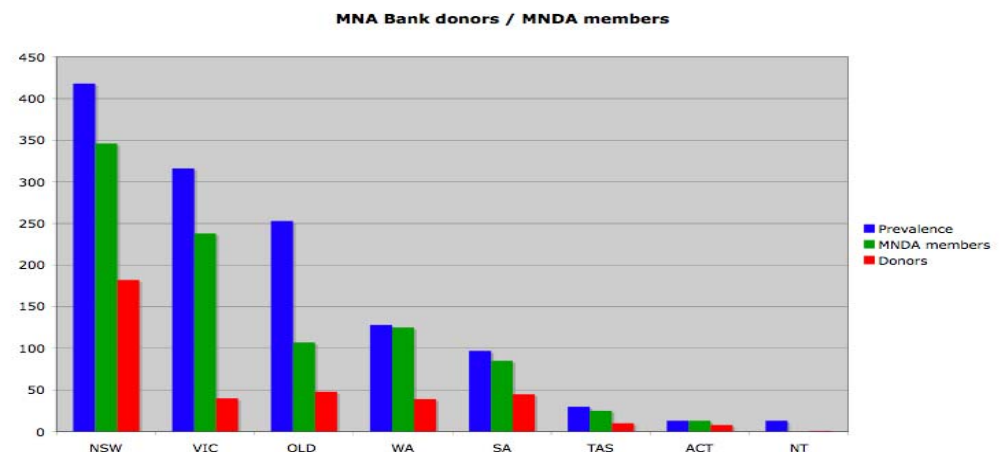
During 2008 the DNA Bank has continued collecting blood samples and environmental data on questionnaires from all States and Territories in Australia. Dr Roger Pamphlett visited Adelaide in May to collect samples from people in South Australia.

Meetings and 'donor drives' are organized by State MND Associations and support groups in capital cities and several country areas.

They arrange for many people to donate via local clinics or pathology collectors visiting homes. Samples and questionnaires can be sent via courier at any time.

The DNA Bank now has 2,250 samples in the Bank. Donors make finding the cause of MND possible.

This graph shows the number of people living with MND throughout Australia, compared with the number of people with MND who are donors to the Bank.



Research using DNA from the Bank

Australian groups currently using DNA from the Bank are:

- comparing differences in the DNA of different tissues of the body and brain in people with MND
- comparing the DNA of twins, with and without MND
- comparing people with sporadic MND with their non-affected parents
- Looking for gene abnormalities in *sporadic* MND that have been found in some patients with *familial* MND
- Looking for environmental factors such as toxins, smoking, season of birth, number of siblings, and age of parents that could lead to susceptibility to MND.

Many articles have been published in international journals in the past year by researchers using material from the Bank. Topics included: MND and environmental toxins, the genetics of Kennedy's disease, gene silencing in MND, and the discovery of the TDP-43 gene mutation as a cause of MND in some people.

NEWS FROM THE EXECUTIVE DIRECTOR

Talking to Young People

The "Talking to Young People Project" funded by a Department of Health & Ageing, Local Palliative Care Grant has just been completed.

The Information Pack is the outcome of a fantastic project undertaken by MND Victoria and MND NSW in response to the needs of younger people when a family member has been diagnosed with MND.

For parents, this new resource "Talking with Young People about MND" can be very helpful.

The Information Pack includes a booklet especially for parents about how to keep communication strong with their children. There are also booklets for 8 to 12 year olds, teenagers, young friends, schools and the health professionals who may be working with the family.

If you would like an Information Pack, please call in to our office or phone 8357 0245 and we will forward you a copy.

Support from United Petroleum for MND Research

United Petroleum will give one cent per litre to the MND Research Institute every time you fill up your car at a United service station and present your United - MND Research Institute community card. The card is FREE.

To receive a card, please contact either Janet Nash at the MND Research Institute of Australia on 02 8877 0990 or email info@mndresearch.asn.au to ask for a Research Institute community card to be sent to you, or phone the MND office on 8357 0245.

United Outlets: South Australia

ADELAIDE AIRPORT	Sir Richard William Avenue, ADELAIDE AIRPORT
BERRI	Cnr Sturt Highway & Zante Street, BERRI
BLAIR ATHOL	369 Prospect Road, BLAIR ATHOL
CROYDON PARK	328-330 Torrens Road, CROYDON PARK
MURRAY BRIDGE	155 Adelaide Street, MURRAY BRIDGE
PORT WAKEFIELD	6 SNOWTOWN ROAD, PORT WAKEFIELD
RENMARK	220 Renmark Avenue, RENMARK
RICHMOND WEST	128 Marion Road, WEST RICHMOND
SALISBURY	1-3 Salisbury Road, SALISBURY
SEATON	169-171 Tapleys Hill Road, SEATON
STRATHALBYN	18 South Terrace, STRATHALBYN
TRURO	52-56 Moorundie Street, TRURO

Thank you

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

Donations are promptly acknowledged to families and individual donors.



Superannuation

The Australian Tax Office website www.ato.gov.au provides information about early access to superannuation for people with terminal medical conditions.

Information about the legislation allowing tax-free lump sum payments and answers to questions about accessing super tax-free can be found on:

www.ato.gov.au/distributor.asp?doc=/content/Content/00158639.htm

ANNUAL GENERAL MEETING

Members and clients are advised the Annual General Meeting of the Association will be held on **Wednesday, 29th October 2008** commencing at 7:00pm at 23A King William Road, Unley.



Light refreshments will be provided. To assist with catering, please confirm your attendance by telephoning our office on (08) 8357 0245 or via email: admin@mndasa.com.au

Walk to D-Feet MND 2009

Volunteer required to join our Planning Team

Our Planning Committee has been meeting for a few months in readiness for another successful Walk. Due to family commitments one of our members is unable to continue in her volunteer role with our Association. Linda Kluske has been a valuable member of our team and we will miss her outstanding organizational skills and wonderful ideas. Meetings occur once a month on a Thursday, increasing to fortnightly early February, then weekly in the month leading up to the Walk.

If you have some time to spare, have great ideas and organizational skills, we would love to hear from you.

We plan to hold at least two Regional Walks in 2009. Locations and dates are undecided. Possible locations could be *Mount Gambier, Clare or Port Lincoln*.

If you are interesting in joining our Planning Team or live in one of the above regional areas and would like to assist, please phone our office on 8357 0245. Thank you

WE ARE MOVING!

The Motor Neurone Disease Association of SA Inc and other neurological and disability support services currently at 23a King William Road will be moving. At this stage we are unsure of the date, but hopefully everything will be in place before the end of the year. Our new address will be

302 South Road, Hilton, SA 5033

Our new phone number and other details are not yet available. As soon as we know we will post details on our website and advise everyone associated with the Association.

Peter Whitehouse
Executive Director

CLIENT SUPPORT NEWS



Firstly, a big hello to all of you. As you know I am new to this role and therefore it would seem appropriate to share a little bit about myself with all of you.

I started nursing straight from school and have now worked in this profession for 37 years – a scary reality. I initially started in the area of intellectual disability nursing and then progressed to general nursing and subsequently mental health nursing. All of this

at a time when nurses were hospital trained. Ultimately the necessity to undertake some University qualification got the better of me and I consequently completed my Bachelor of Nursing several years ago. I am currently labouring to complete a Graduate Diploma in Nursing (Continence Advisor). I never imagined I would still be nursing 37 years later. As a new graduate 30+ years ago, nurses with more than 20+ years experience were viewed as dinosaurs. I can only hope I am not viewed in a similar light. I don't feel like a dinosaur!

My experience in the Neurological area extends back many years as does my relationship with the current CEO of MNDASA, Peter Whitehouse. Peter and I met at the MS Society at a time when Peter was CEO of that organisation. I continue to work at the Society two days/week.

I hope I can carry on the excellent work of my predecessors. Continually evaluating what assistance we provide, how we provide it and what more we could provide, is our challenge.

A Client Survey is being prepared so that we can evaluate our services. The survey will be forwarded to you in due course. Your feedback will be critical in identifying gaps in service provision.

Catch you in the next edition!

John Gilligan

Client Support Coordinator

Carer's Week 2008

Unfortunately, we have not had any response to our Movie/Luncheon Day, so we have cancelled this get together. As an alternative we would like to have a **"Meet and Greet" luncheon** in the MND Boardroom at 1.00 pm on Wednesday, 22nd October. Lunch will be provided. I hope you can join us.

If you would like to attend, please contact the Association on 8357 0245 or complete the tear off slip enclosed in the newsletter by Wednesday, 15th October. This will assist us with catering for the day.



Thank you

Physiotherapy/Occupational Therapy Rehabilitation Classes

A Pilot Program in Rehabilitation for People with a Chronic Neurological Condition conducted by the MS Society of SA

When: Each Monday commencing 13th October and finishing 12th December.

Where: Northern Suburbs - venue TBA

Cost: \$5 per session or \$35 all sessions

For further details including registering your interest please contact Libby Morris on 83600800.

Equipment available from Disability SA

The following is a link to the Disability SA Loan Equipment Website

<http://des.domcare.sa.gov.au/>

If you feel any of these items may be of assistance to you, please contact your Case Coordinator or John Gilligan on 8357 0245.

Hydrotherapy Massage Group

Conducted by: Tori Wilckens – Masters of Physiotherapy and Bachelor of Physiotherapy and Remedial Massage Therapist, Camilla Ward or Rob Sellers

Where: MS Society Pool; 274 North East Road, Klemzig

When: TBA : 1 hour session per week - Mlday
Mondays or Wednesdays

Cost: Dependent on numbers (at least 6 clients per session) covered by Private Health Insurance

Additional Requirements:

Clients are required to have a carer in attendance to assist them with dressing / showering.

Please register your interest by contacting John Gilligan on 8357 0245.

Technical Aid to the Disabled SA (TADSA) which is celebrating its 30th birthday this year is looking for more clients. Following a successful volunteer recruitment drive. TADSA now has around 50 volunteers available to design and build or modify devices for people with disabilities where there is nothing readily available. TADSA is a state-wide charity which uses the skills, time and facilities of its technical volunteers to improve the quality of life of those with disabilities. Over these 30 years, volunteers have built nearly 3,000 projects. The current group of technical volunteers has skills in areas such as woodwork, electrical or mechanical engineering, electronics, plastics and computers.

Readers/clients with a problem related to a disability or ageing, that would like help or anyone wishing to volunteer, can call the TADSA office on 8261 2922 or state-wide 1300 663 243.

FUNDRAISING & SUPPORTER NEWS

This year our Association registered with Everyday Hero and the Sunday Mail City to Bay Fun Run. What an outstanding fundraising success it has been! Thank you to everyone who participated.

Clients, their families and employers took the opportunity to participate. What a fun day was had by all! We had runners and walkers completing various distances. We would like to thank everyone for their support and have included photos and stories of some of our participants. Those supporting MND were *Julee Tonks and RLM (Lockheed Martin) family and friends, Sham Lucas and colleagues from PIRSA Forestry Mount Gambier, Neurosense Physiotherapy, Kaye Dwyer family and friends, Patricia McAulay, Eleisha Ford, Rob Kenny (ATO), Catherine Sampson and Mark Spencer.*

The sun was shining and the weather was perfect for the Lockheed Martin City to Bay Fun Run team on Sunday 21 Sept. Jacqui Brunings, David Culpin, Lovell DeLacy, Mark Reidy and Julie Trimper from Lockheed Martin organised to set up a team to enter the City to Bay Fun Run in order to raise money for MND in support of their work colleague, Julee Tonks. T-Shirts for entrants were organised as well as an after the run BBQ (which raised further money for MND).

Many people pulled together and supported Julee and her work colleagues and raised a total of just over \$7,700. This amazing effort was due to emails being sent to all their friends and family along with Julee's Story, which was then spread through word of mouth, and further emails creating a snowball effect. Word of mouth is a powerful tool. Never give up! " *From Julee Tonks*"



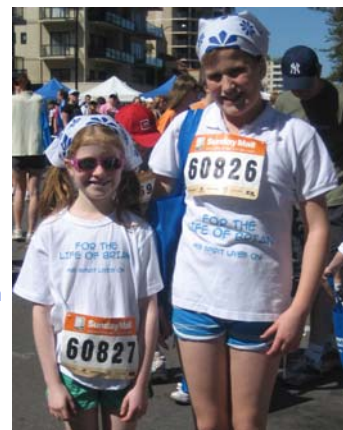
Julee with family and friends



Lockheed Martin Team (RLM)



Brian & Kaye's grandchildren
Gemma & Phoebe



Kaye with her family wearing their special t-shirts

On Sunday 21st September 2008 a group of family and friends participated in the City-Bay fun run in memory of my late husband Brian. It was with mixed emotions that we did the walk as I was missing Brian incredibly but exhilarated by the fact that our grandson Darcy James Dwyer was born earlier that morning. It was Brian's wish to assist someone who was worse off than he to participate on the day. Sadly Brian passed away on the 5th July from the effects of Motor Neurone Disease.

We the family decided to enter in his honour to reflect on what a great man he was and to try to raise awareness about MND. We all wore t-shirts with the message 'FOR THE LIFE OF BRIAN HIS SPIRIT LIVES ON' printed on the front and 'RACE FOR A CURE FOR MOTOR NEURONE DISEASE' on the back.

After the walk we attended a brunch at the Somerton Surf Life Saving Club organised by Tori Wilckens of Neuro-Sense. Tori said some kind words about Brian.

When leaving the premises two ladies sitting outside in the sunshine enjoying a cup of coffee asked of me the significance of the t-shirts. I explained that they were in memory of Brian and that he passed away from MND. They had not heard of MND before. I also mentioned that the State Government did not offer any funding to the MND Association and they were quite astounded by this fact. They resolved to search out more information on the internet re MND and possibly try to raise some money. Hopefully they will.

"From Kaye Dwyer"

FUNDRAISING & SUPPORTER NEWS (Cont..)



Sharn Lucas with colleagues Rob Robinson and Naomi Brick

Sharn's employer PIRSA Forestry supported them to participate in the event. They had green organic cotton t-shirts and on the back was printed "*We run faster than trees at PIRSA Forestry*".

Sharn said, "*Through the Hero pages I was able to rally up friends and colleagues to sponsor me to run the City to Bay, and I raised \$320 for the MNDASA. They did so much for us in the last year that Mum was with us, and with my wedding only four weeks away and celebrating my 30th birthday this year, I have been missing her very much. It was great to have everyone's support, and I hope our donations will help in some small way. Can't believe I ran 12km! I think I'll walk next year.*"

Gift from the Perpetual Trustee Company Ltd



The MND Association was delighted to receive a gift from Perpetual Philanthropic Services for a project to develop a program to educate/train health professionals and carers about MND.

Perpetual Trustees manages over 400

charitable trusts and each year distributes the investment income to numerous charities throughout Australia.

Pictured above is Executive Director, Peter Whitehouse (left) being presented with the gift cheque by the SA State Manager, Perpetual Trustees, John Hender

SPONSORS

We are currently developing a database of prospective corporate sponsors / companies / people who may be interested in sponsoring our Association, either generally, or for specific events held by the Association throughout the year. If you are aware of any prospective people, could you please contact our office on 8357 0245. Thank you

The MND Association would like to thank the following for their wonderful financial support:

- ☺ **Constellation Wines** for raising funds with their staff "Casual Day."
- ☺ **Carly and Michael King** for competing in the City to Surf in Sydney to raise funds for MND
- ☺ **Local Government Association** - District Councils of Yankalilla, Cooper Pedy and Alexandrina, staff from Grant Council (Mount Gambier) and the Local Government Association office.

Barossa Raffle

Once again our tireless supporters in the Barossa have been active with the **MND Barossa Raffle**. \$1,400 was raised. We would like to thank Marjorie Coats and Tia Schubert for the continued support they give to our Association. The Raffle was drawn at Whistler Wines owned by long time supporters, the Pfeiffer family. Barossa identity Neale Stephens, who has MND drew the winning tickets.



Neale with Marjorie, Tia and Chris Pfeiffer

Fundraising Merchandise

MND merchandise is available to purchase from the MND Association any day Monday to Thursday, or on-line from our website.

Xmas Raffle

Look for the flyer on the Lion's Club Xmas Raffle enclosed with your newsletter. We have 150 book to sell (10 tickets per book).

Walk to D-Feet MND 2009

Planning is already under way. Keep **Sunday, 26th April 2009 free.**



Julee's Story (May 2008)

My name is Julee Tonks, I'm 36 years old and I would like to share with you my experience with Motor Neurone Disease (MND).

In January 2006 my brother Garry was diagnosed with MND. Garry began experiencing symptoms approximately 6 to 12 months before his actual diagnosis. It began with the weakening of his right arm, spread to his left arm and his neck. By November 2006 he had lost total use of both his arms and relied on a neck collar to hold his head upright. In December 2006 he had a PEG inserted into his stomach to allow him to be fed intravenously as he had lost the ability to swallow and therefore eat. Garry was living with our parents during this time and Mum was his carer 24/7. She had to wash him, help him go to the toilet, dress him, feed him through his PEG, everything an able bodied person takes for granted, but she also had to watch him deteriorate knowing there was nothing she could do to help or save him. It was totally out of her control and his. From December 2006 he deteriorated rapidly as his diaphragm and chest muscles had been affected which meant he couldn't breathe properly. He was rushed to hospital several times and his last stay in hospital was for 3 weeks in the palliative care unit at the end of January 2007. He never came home.

Garry passed away on 14 February 2007 at the young age of 33 – 12 months after he was diagnosed with MND. Garry left behind two beautiful children who, at the ages of 6 and 8, are still now trying to cope with the loss of their father. One of my most heart wrenching memories of my brother and his children is watching his daughter sitting on his lap and taking his arms to place them around herself for a hug because he couldn't do it himself – he couldn't even hug his own children.

The impact of losing Garry was horrendous. He shouldn't have had MND in the first place – "it's an older person's disease" so we thought at the time. Suddenly Mum and Dad had lost their son, I had lost my brother and Jake and Tayla had lost their father. We were all heartbroken.

Around May/June 2007 I started to experience weakness in my neck. Then around October 2007 I also started to experience weakness in my right shoulder. I couldn't lift my head up off the pillow when I was lying down and I was having trouble with using my right arm. John (my husband) began to have thoughts of Garry's symptoms and suggested we see a Neurologist. MND just didn't enter my mind; after all Garry's diagnosis was a "once off thing", surely both of us couldn't have the disease and both at such a young age. After many tests and consultations with doctors and specialists, on 22 November 2007 I was diagnosed with MND.

Not only has this disease taken the life of my brother, it will now eventually take my life too. It has impacted greatly on my parents who are still dealing with the loss of one child and now have to deal with the fact that they know they are going to lose their other child. No parent should have to bury their children, especially all of them.

Knowing that I have a terminal illness and knowing what my brother went through and what I am and will be going through is absolutely terrifying. When I was first diagnosed I didn't know what to do, I felt helpless and angry.

How dare this happen to me, how dare it take my brother and now me, how dare it put my family through this all over again. What about all my dreams and the future John and I had in front of us? It was all gone in a second.

My life has revolved around horses – I've now had to give up horse riding and my horse as I can no longer physically look after her or ride her. I can no longer go jogging or go to the gym to keep fit (apart from walking), I can no longer hang out my own washing or even wash my own hair! My mum comes over and does my housework for me and my husband and friends help out with other daily household chores, including looking after me. This isn't fair on them!

My friends, my parents and my husband are wonderful and supportive and without them I don't think I could cope – it would be so easy to just give up and let the disease take hold.

I'm still dealing with the loss of my brother and now I have to deal with my own loss and sense of helplessness. My loss of independence, the loss that my husband is going to have to deal with and the emotional rollercoaster he's going through now and will go through as my carer (as my mum did for my brother), the loss my parents are going to feel and have to go through all over again, and the loss my friends will have to deal with. They are all watching me slowly deteriorate and aren't able to do a thing about it. This is one of the worst aspects of this horrible disease. There's absolutely nothing we can do to stop it as at this stage, there is no cure. I'm not sure that the fact that I'll retain my "sanity" is a blessing or not. You see, with MND your senses (taste, sight, smell etc) aren't affected, nor is your mind – so I will be trapped in a body that doesn't want to work, with a mind that is 100% aware of what's happening and going on around me.

We have a "familial" form of MND which means it runs in our family – only 10% of MND cases are familial (or genetic). My Dad's father and my Dad's Uncle both had MND, it's very possible that my Dad, his brother and sister could still succumb to this disease. It's also very possible that Jake and/or Tayla may eventually also get this disease. We are hoping that a cure will be discovered a long time before Jake and Tayla need to worry about it, and obviously before I lose my battle with MND. Having said that and despite all I've said, I'm doing everything in my power to stay positive. I'm receiving a lot of assistance from the MND Association, Disability SA, Occupational Therapists, Specialists and Psychologists. We are also involved in trying to assist with research and fund raising. We are doing everything we can to help find a cure for this "mongrel" disease.

It is so critical that we find a cure and, whether or not it will help me in time, we need to be able to help all the other families and friends out there who are going through the same thing we are or who will be going through it in the near future.

The average life expectancy of a person with MND is 2 to 5 years and although we have no idea on how long I have to live, I'm planning on being around for at least another 20 years! MND Association's motto is: "Never Give Up" and I certainly don't plan to.

ARTICLES FROM MEMBERS

From **Patricia McAuley**

A friend sent this to me. It's been said that God first separated the salt water from the fresh, made dry land, planted a garden, made animals and fish... all before making a human. He made and provided what we'd need before we were born. These are best & more powerful when eaten raw. We're such slow learners...God left us a great clue as to what foods help what part of our body!

God's Pharmacy! Amazing!

A sliced **Carrot** looks like the human eye. The pupil, iris and radiating lines look just like the human eye... and YES, science now shows carrots greatly enhance blood flow to and function of the eyes.

A **Tomato** has four chambers and is red. The heart has four chambers and is red. All of the research shows tomatoes are loaded with lycopine and are indeed pure heart and blood food.

Grapes hang in a cluster that has the shape of the heart. Each grape looks like a blood cell and all of the research today shows grapes are also profound heart and blood vitalizing food.

A **Walnut** looks like a little brain, a left and right hemisphere, upper cerebrums and lower cerebellums. Even the wrinkles or folds on the nut are just like the neo-cortex. We now know walnuts help develop more than three (3) dozen neurotransmitters for brain function.

Kidney Beans actually heal and help maintain kidney function and yes, they look exactly like the human kidneys.

Celery, Bok Choy, Rhubarb and many more look just like bones. These foods specifically target bone strength. Bones are 23% sodium and these foods are 23% sodium. If you don't have enough sodium in your diet, the body pulls it from the bones, thus making them weak. These foods replenish the skeletal needs of the body.

Avocados, Eggplant and Pears target the health and function of the womb and cervix of the female - they look just like these organs. Today's research shows that when a woman eats one avocado a week, it balances hormones, sheds unwanted birth weight, and prevents cervical cancers. And how profound is this? It takes exactly nine (9) months to grow an avocado from blossom to ripened fruit. There are over 14,000 photolytic chemical constituents of nutrition in each one of these foods (no dern science has only studied and named about 141 of them).

Figs are full of seeds and hang in twos when they grow. Figs increase the mobility of male sperm and increase the numbers of Sperm as well to overcome male sterility.

Sweet Potatoes look like the pancreas and actually balance the glycemic index of diabetics.

Olives assist the health and function of the ovaries

Oranges, Grapefruits, and other **Citrus** fruits look just like the mammary glands of the female and actually assist the health of the breasts and the movement of lymph in and out of the breasts.

Onions look like the body's cells. Today's research shows onions help clear waste materials from all of the body cells. They even produce tears which wash the epithelial layers of the eyes. A working companion, **Garlic**, also helps eliminate waste materials and dangerous free radicals from the body.



DIARY DATES



National Carer's Day 2008

☺ **Wednesday, 22nd October**

"Meet & Greet" get together at MND Association 1.00 pm. Please advise if you will be attending.

Lion's Club Xmas Raffle Tickets

☺ **Monday, 1st December**

All raffle books need to be returned

Walk to D-Feet MND 2009

☺ **Sunday, 26th April** - Planning Committee already in progress. Hoping to hold regional walks during the year too.

Awareness Week 2009

☺ **Monday, 3rd May - Friday, 9th May**

Planning Committee already in progress.

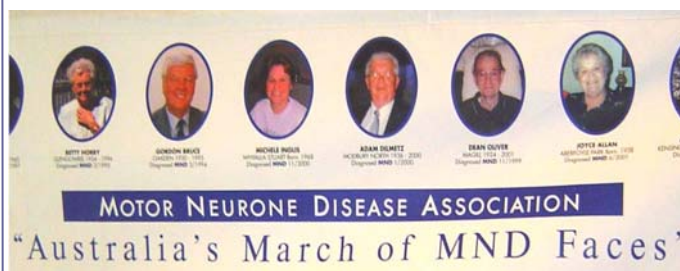
MARCH OF FACES BANNER

The March of Faces banner features a photographic display of people with MND.

MNDASA has produced two banners and we aim to produce a third banner as soon as we have 20 new faces. *At the present time we have seven new faces.*

If you have MND you can be included in the banner once you have completed a permission form and submitted a photograph of yourself. You are welcome to include family or caregivers in the photo if you wish.

Family members are also able to submit a photograph in remembrance of a person who has died from MND. If you would like further information, please contact us on (08) 8357 0245 or email us at: admin@mndasa.com.au



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 359, Unley, 5061.

Do you have an item for sale that may be of benefit to MND clients? If you would like to advertise an item in our next Newsletter, please send us an email at: admin@mndasa.com.au ... or you can post your information to PO Box 359, Unley, SA 5061.



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