

JUNE 2007

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AWARENESS WEEK FUNDRAISING SUCCESS

BURNSIDE VILLAGE BADGE DAY

If you visited Burnside Village during Awareness Week this year, there's a good chance you will have met some of the wonderful volunteers at the MND stall in the heart of the shopping centre.

The MND stall is run each year by Mrs Joy Sidey, who at ninety-one years young is as active as ever in participating in fundraising activities and promoting awareness of MND.



Doris Banks, Maysie Oliver and Joy Sidey
at Burnside Village



Dawn Dilmetz, Maysie Oliver and Helen Stephens

Volunteers took turns in assisting Mrs Sidey to receive donations and sell MND chocolates, badges, cards, wristbands and cornflower seeds.

Public awareness of MND appears to be gradually increasing. Many of the passers-by commented that they knew of the disease.

MNDASA would like to thank Mrs Sidey and all of the Badge Day volunteers for their outstanding efforts.

The day was a resounding success with more than \$900.00 being raised.

MND DNA COLLECTION DAY

Dr Roger Pamphlett visited Adelaide on 21st May to collect DNA samples from South Australian donors. More than twenty individuals supplied blood samples on the day. It is pleasing to report that the response from SA participants donating DNA samples is the highest per capita in Australia.

A number of people attended the lunch provided by Sanofi Aventis to listen to Dr Pamphlett give an informative talk about current research into MND.



Dr Roger Pamphlett

REPORT FROM THE EXECUTIVE DIRECTOR

Once again, the State Government through the Department for Families and Communities has declined the MND Association's request for funding to support its clients services it provides to clients throughout the State. The MND Association of South Australia remains the only mainland State MND Association not to receive State Government funding.

Since its founding in 1986, the MND Association has provided highly regarded support and information to people and their families affected with Motor Neurone Disease. In monetary terms, this is valued at in excess of \$1.5 million – money that has been raised by the Association with the support of family and friends and from philanthropic trusts who value the work of the Association.

The request to the Department was for less than \$50,000 a year. Not a large amount considering that some organisations receive multi million dollar handouts from the Government each year. Unfortunately there is little equity as to how the Government fund disability organisations. All we can do is to continue to lobby the Government to fund the Association so we can continue to maintain the excellent and much needed services to MND families.

On a more positive note, it is pleasing to report the Association has received funding in excess of \$76,000 from organisations such as the Thyne Reid Foundation, Macquarie Bank Foundation, Australian Hotels Association, Community Benefit SA and Australian Executor Trustees. Without this continuing support from such organisations, the Association would have difficulty in maintaining services at existing levels.

Peter Whitehouse
Executive Director

HOTEL CARE COMMUNITY PROJECTS



The MND Association has received funding from the Australian Hotels Association (SA) Community Care Projects to upgrade its office computer systems. The MND Association is most grateful to the AHA (SA) for its support that will result in improved office efficiencies and maintenance of client files.

Hotel Care was established in 1995 and has donated more than \$3 million to charities and community groups. Through the support of the Independent Gaming Commission, Hotel Care donates up to \$600,000 a year which forms part of the \$9 million South Australian hotels give back to the community each year.

MEDICAL EXPENSES TAX OFFSET

On 8 September 2006 the Australian Tax Office (ATO) published two Interpretive Decisions (ATO IDs) that may assist with tax rebates for the cost of modifying vehicles and repairing and maintaining speech aid equipment. The details are:

ATOID 2006/250:

Accepts that the cost of purchasing and installing a folding ramp to allow wheelchair access to a car is a medical expense and able to be claimed as part of the medical expenses rebate for tax purposes

ATOID 2006/252:

Allows the purchase and maintenance of a speech aid to be subject to the medical expenses rebate for tax purposes.

For more information see your accountant or visit: <http://law.ato.gov.au>

CERI's COLUMN

Time passes very quickly, and here we are a quarter of the year on from the last newsletter. I am sure there have been many changes in your lives as there have been in ours.

The positions of MND Support Coordinator and Speech Pathologist have both been very busy.

We have received a donation from the Digital Bridge Unit of accessories to aid computerised communication systems. We are very grateful for their donation and look forward to being able to offer them to our clients in supporting their assistive communication.

Life today is becoming more reliant on computers and it is challenging to keep abreast of new inventions and ideas! Sometimes non-technological equipment is more easily accessed. To this end we enclose a photograph of one of our clients using a communication system which I have put together for those clients who prefer non-technological equipment. We're calling it the 'MND COMMUNICAP' and it is proving to be most successful. Thanks to Alicia Harding who sent in this photo of her Mum, Marilyn Hill, using the MND COMMUNICAP.

This system offers fast access to communication and is useful in situations where computers may not be available, where the client may have lost the ability to talk or move limbs, but who may have retained some slight head movement. If you would like more information on the MND COMMUNICAP please feel free to contact me.

Also, we are looking for some sponsorship or similar monies to fund the making of this equipment!

We use a baseball cap, torch and Perspex stand. We are now making these devices very regularly and plan to purchase the equipment in bulk. If you have any ideas or thoughts, please let us know.



Ceri MacLeod and Marilyn Hill using the
MND COMMUNICAP

Returning to technology, we are planning to roll out our Pilot Project with web cams in late August or September. This project involves setting up web cams and computers in client's homes so that they can more easily communicate with family, friends, health professionals and the team here at MNDASA, without the need to necessarily travel long distances. Specialised software will enable clients to use the computer to type conversations alongside the visual image when oral communication is no longer possible. This software will also enable access to the computer, (e.g. via laser pointers) even when weakness in upper limbs limits physical access.

This year was my first Memorial Service with MNDASA. I appreciated the opportunity to meet all who attended. The whole experience was very moving. If you have any thoughts on future commemorations please do contact us. We welcome your comments and suggestions on how you feel we can support all those who are touched by MND.

We hope to set up some carer's group meetings soon. These have been on hold recently due to re-organisation. Any thoughts or ideas you may have with regards to these meetings would be most welcome (e.g. venue, topics, regularity etc.).

As I have already mentioned (maybe too many times!!!!), we welcome your input; your ideas and feelings, whether you are a client, carer, friend, health professional or have an interest in MND. Maybe you would like to contribute to this newsletter? If so please contact us at MNDASA.

Ceri MacLeod

MND Support Coordinator & Speech Pathologist

TWILIGHT CONCERT & STEW & SHIRAZ DAY AT WHISTLER WINES

The Pfeiffer family of Whistler Wines in the Barossa Valley have long been supporters of MNDASA

In March 2007 they held a Twilight Concert attracting about 150 people. Patrons sat amongst the gum trees and enjoyed a picnic dinner and wine whilst listening to live music. Members of the Pfeiffer family manned a bar-be-que stall and local MND supporters Tia Schubert and Marjorie Coats sold raffle tickets with a sensational prize list to raise funds for MND.

Peter Whitehouse, Executive Director of MNDASA attended the function and presented Chris Pfeiffer of Whistler Wines a certificate of appreciation for their continued support.



Peter Whitehouse and Tia Schubert enjoy a wine and soak up the atmosphere at the Whistler Wines Twilight Concert in March 2007

In June, Whistler Wines hosted a STEW & SHIRAZ day at which a raffle to raise funds for MND was drawn. The event was extremely successful and more than \$3500.00 was raised in support of the MND Association. MNDASA wishes to thank our everyone at Whistler Wines and our MND supporters, Tia Schubert and Marjorie Coats in the Barossa for their support.



Marjorie Coats and Tia Schubert have raised thousands of dollars to support MNDASA. They are pictured here at their 2007 MND Awareness Week stall in the Barossa.

MND COMPUTER MARKETS



Every three months a Computer Market is held at the Festival Function Centre in Findon to raise funds for MND.

Computers, printers and laptops and accessories are donated by the public to MNDASA. These items are then sold at our MND stall at the MND Computer Market.

The MND stall is run by Theo Toonen and we are pleased to announce that Theo and his team of volunteers ran a very successful MND Computer Market stall on 20th May 2007 which gave rise to a profit of \$1450 for MNDASA.

YOU CAN HELP TO MAKE OUR NEXT COMPUTER MARKET A SUCCESS

DO YOU KNOW SOMEONE WHO IS KEEN ON COMPUTERS?

If so, please tell them about our MND Computer Markets.



The remaining markets for 2007 will be held on the following dates from 9:00am-2:00pm:

SUNDAY 19 AUGUST 2007
SUNDAY 4 NOVEMBER 2007



DO YOU HAVE A COMPUTER IN GOOD WORKING ORDER THAT YOU NO LONGER USE?

If so, please give us a call on (08) 8357 0245.

Your computer / printer / laptop / accessories can then be sold at our stall at the next MND Computer Market.

FUNDRAISING NEWS

THE \$130 CLUB

Each month our \$130 Club members have the chance to win a \$50.00 prize (either a gift basket or MYER voucher to the value of \$50.00)

Congratulations to the following \$130 Club winners

Feb 2007 **Barbara Skewes**

Mar 2007 **Barbara Skewes** (yes, twice in 2 months!)

April 2007 **Trevor Ayliffe**

May 2007 **Kim Johnston**

Thanks to all of our \$130 Club members for your support. We'll publish the winner of the major prizewinner in our next Newsletter.

FUNDRAISING MERCHANDISE

This year we had a large number of requests for Awareness Week fundraising merchandise from our members and friends in metro and country locations.

We'd like to say a big **THANK YOU** to all of the people involved in our 2007 Awareness Week activities.

Even though Awareness Week is now behind us, orders for MND products are still going strong. If any of our members and friends wish to order MND stock to sell on our behalf at any time throughout the year, please don't hesitate to give us a call at the office on (08) 8357 0245. We currently have the following products available:

- **WRISTBANDS**
- **GREETING CARDS**
- **BADGES**
- **CORNFLOWER SEEDS ... and ... MND SOCKS**

MND SOCKS ARE HERE



The wait is over!

We've just received a shipment of MND socks from our supplier, so please give the office a call if you'd like to purchase these great sports socks.

These comfortable padded socks come in small or large sizes and at only **\$5.50** a pair they're a fantastic buy!

ENTERTAINMENT BOOKS



Thank you to everyone who has purchased a copy of the 2007/2008 Entertainment Book from MNDASA this year.

We've still got the 2007/2008 books available for sale, so if you haven't placed your order yet, it's not too late to do so.

Entertainment Books cost only \$60.00 each (plus \$7.00 for postage and handling) and they offer great discounts at many of SA's excellent restaurants, leisure operators and casual dining outlets.

MNDASA receives \$12 per sale.

Please phone the office on (08) 8357 0245 if you would like to purchase a book.

MARCH OF FACES BANNER



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

MNDASA has produced two banners and it is likely we will be producing a third banner in 2007.

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

YOUR CORNER

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 Alternatively you can post your information to PO Box 359, Unley,

My Mum, Marilyn Hill

22/8/1946 - 16/5/2007 ~ aged 60 years

Article written by Alicia Harding



Mum was diagnosed with Motor Neurone Disease just over 2 years ago, by Professor Stephen Davis, in Melbourne. Since then she went through many heartbreaking changes in her life. She went from being a very strong and totally independent woman, to being reliant upon others, often strangers, for every little thing.

Mum fought a very brave and courageous battle against this horrible disease, with great dignity. She remained in her own home, with community nursing support until December 2005. Following this she entered residential care at Crouch Street Hostel, in Mount Gambier, until March 2007. At this time she chose to move to the Philip Kennedy Hospice in Adelaide, to be closer to my two children. She loved and adored her two young grandchildren. Jessica (3 1/2 years) and James (17 months) provided the light of her life and made the end stages of her life much more enjoyable.

Most valiantly, Mum did her best to remain with us, but passed away very peacefully at 4.35 pm on Wednesday 16th May 2007, with her family by her side. We obviously miss her deeply, but know she is now in a much better place and is no longer suffering. We will always remember her and the strong and inspirational attitude she held.

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Dearly loved wife of Andy, loved and loving mum of Alicia and Daniel, mother-in-law of Paul and very much loved and ever loving Nan Nan of her darling grand children Jessica and James. Sister to Barry, Richard, Meg (twin-sister) and Gill, loved auntie to their families. Missed by so many, but never forgotten.

We owe a big thank you to everyone, but especially Margaret and Ceri at MNDASA for all their support, help and encouragement.

Ceri, towards the end you were amazing, getting Mum any little things she wanted to try, even if it was not really very successful. At least we gave her every opportunity she wanted and made a very hard journey a bit easier.

To the Crouch Street Hostel staff thank you for your care and kindness. And finally the staff at The Philip Kennedy Centre and especially the hospice staff, a huge thank you. You guys were amazing! No request of Mum's or ours was too much and you helped us get through this very trying time with comfort and support. We will never forget this experience, and I am glad we were able to make Mum's final wish of spending her last days with us in Adelaide come true.



THE GIFT OF MOTHERHOOD

Motherhood is a priceless gift
that cannot be bought or sold,
But its value is far greater
Than a mountain made of gold
For gold is cold and lifeless,
It can neither see nor hear,
And in the time of trouble
It is powerless to cheer
It has no ears to listen,
No heart to understand,
It cannot bring you comfort
Or reach out a helping hand
So when you ask God for a Gift,
Be thankful if He sends
Not diamonds, pearls or riches,
But the love of a mother!



"Our Beautiful Eileen"



Article written by Annie Jager

I have had the privilege of working with the most beautiful lady Eileen Hattam for the past 35 years.

Eileen has always had an amazing personality, wonderful sense of humour, always wanting to please and interestingly always sung or hummed her way around the work place.

She always rode her bike to work until one day the tyre blew on the train crossing and we then encouraged her to get her drivers license. Eileen managed the license and then the big purchase of her first car, a Holden 1958 model, white with turquoise! It was just beautiful to watch Eileen sitting straight trying to see over the steering wheel, not at all relaxed, but the best outcome was that she had achieved the skill and no longer had to be out in the cold for the winters. There were many laughs with her car stories.

Working with a staff of over 100 at Shell Roadhouse, Taillem Bend Eileen was extremely popular with all staff. There were lots of young people to work with and Eileen was the taxi to take them home after their shifts.

No matter how many customers were in the restaurant, Eileen would always "be fine" when asked if she needed assistance. Her little legs just ran. When we shifted business to Jager's BP – Taillem Bend, Eileen moved with us. She certainly knew all our customers and we have always called her "Mrs. Public Relations", in short "Mrs. P.R.". She knew all the families and the children by name.

18 months ago Eileen suffered with sinus and complained of a problem with her throat and tongue. She visited the doctor, specialists, x-rays and nothing seemed to be a problem. More doctors, more specialists were sought when Eileen's speech became affected, but still no outcome.

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Eventually one specialist decided that Eileen had had a small stroke and this was the cause of her slurred speech.

We just had to accept this until she eventually went to a specialist who rang back for her to revisit him and he informed Eileen that he was not convinced that Eileen had had a stroke and referred her to a Neurosurgeon. It was quite a wait for the appointment and by the time of the appointment, Eileen's speech had really deteriorated. Of course, there was no good news with the diagnoses of Motor Neurone Disease.

"The Motor Neurone Disease Association of SA was rung and the visit to them was amazing. They made appointments for Eileen with all the relevant people. Their loving care and assistance with the offer of needs to make Eileen's life more comfortable has been wonderful.

Eileen has now lost the ability to talk and eat. She has had a PEG inserted for feeding. The help of the Palliative Care Officer, Outreach and Speech Therapists have also played a significant role in ensuring Eileen has all needs met.

This most wonderful friend, workmate and "lady" has a spirit beyond. Nothing will beat her and the endeavours and fighting spirit has nothing but amazed us, although all who know her really should never have expected anything else.

The love for this lady is just beautiful. The young people she worked with adore her and the love and care they have for Eileen has been amazing to see. We miss her being part of our workplace, but her spirit will always be with us with all the stories and memories shared. My favourite story is when a customer came to the counter and asked, "is there any toilet rolls?" Eileen's response being, "No, sorry, only chicken, beef or ham!"

As the MNDASA is a non government funded association, we have a donation tin on our counter with a little story of Eileen. The response from our customers and the enquires about Eileen has been fantastic.

Eileen is still driving, doing her footy tips, has a machine that she can type into which talks and is interested in everything.

What a lady is our Eileen. We can all take a lesson from her spirit and determination.

We are so proud of her.

Nuclear Transfer Strategy Shows Promise for ALS Drug Screening

Roberta Friedman, Ph.D., ALS Association Research Department Information Coordinator

[Quick Summary: Researchers may have come up with a new cell source to allow stem cells to take on the characteristics of a disease, an approach with promise for ALS drug discovery.]

Research reported in this week's Nature suggests a possible new way to tap into the potential of stem cells for drug discovery. Harvard investigator Kevin Eggan, Ph.D., and colleagues suggest that it may be possible to use previously fertilized egg cells to produce disease specific stem cell lines using somatic cell nuclear transfer, also called therapeutic cloning. This gives hope for new therapeutic approaches for amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease).

Prior efforts at nuclear reprogramming have relied on eggs which have proven difficult to obtain.

The new method indicates it may be possible to use cells left over from in vitro fertilization to generate stem cells that carry the genes responsible for disease such as ALS. In fact, the researchers have found that it may be possible to use fertilized eggs that would routinely be discarded in the course of in vitro fertilization efforts because they carry too many chromosomes to develop normally.

"Our results provide several previously unexplored and technically feasible avenues toward the production of 'genetically tailored' human ES cell lines that are not constrained by the limitations of oocyte donation for research," the investigators wrote in their report.

Eggan and colleagues found that, in mice – and perhaps in humans - the cellular mechanisms required for genetic reprogramming are still present even after an egg is joined with a sperm. The chromosomes of newly fertilized mouse eggs can be removed and replaced with chromosomes from either a mouse embryonic stem cell or a skin cell from adult mice. In both cases, the reprogrammed cell went on to divide properly and could be used to produce embryonic stem cells lines. /

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If this work can be replicated in humans, nuclei of adult skin cells could be placed into already fertilized eggs before they divide. The scientists could then produce stem cells that retain the ability to produce any type of cell. This suggests that with similar nuclear transfer from skin cells of ALS patients, embryonic stem cells might be produced for studying that disease.

Scientists believe that such embryonic stem cell lines might be useful in studying ALS because they will be able to generate large numbers of the motor neurons killed by ALS. The ability to produce large numbers of these motor neurons would be useful for drug discovery.

Please see The ALS Association's web site under the research tab for further information about stem cells:

<http://www.alsa.org/research/article.cfm?id=715>

MND NOTICEBOARD

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, 5061.

FOR SALE Wheelchair Accessible Van



1997 Toyota Hiace commuter van, 116790 kms, 5 speed manual, Rego no VXR251, Extra step at side entrance with hand rails, Hydraulic lift in rear of van, Price approx \$17,000 Negotiable, Good condition, Available now. Please phone Chris on (08) 8823 2993 or email: greenham@yp-connect.net

MND MEMORIAL SERVICE

The annual MND Memorial Service was held on Sunday 11 May 2007 .

The service was conducted by Rev Trevor Whitney and our thanks go to Rev Whitney, Sally Davis and Sue Edwards for making the service so special.



A Blessing

May you know that absence is full of tender presence and that nothing is ever lost or forgotten.

May the absences in your life be full of eternal echo.

May you sense around you the secret Elsewhere which holds the presences that have left your life.

May you be generous in your embrace of loss.

May the sore of your grief turn into a well of seamless presence.

*May your compassion reach out to the ones we never hear from
and may you have the courage to speak out for the excluded ones.*

May you become the gracious and passionate subject of your own life.

May you not disrespect your mystery through brittle words or false belonging

May you be embraced by love in which dawn and twilight are one

and may your longing inhabit its deepest dreams within the shelter of the Great Belonging



FAREWELL SUE

The message on the chocolate cake read "Happy Retirement Sue" at Sue Edward's retirement function on 21 February 2007.

The event was attended by a host of people that Sue had come into contact with during her 20 year career with the Neurological Resource Center and MNDASA. Helen Sjardin-Howard, National President of MND Australia, and Carol Birks, National Executive Director of MND Australia flew in especially for the occasion.

A number of colleagues, volunteers, and MNDASA members made speeches on the day, thanking Sue for her service over the years and wishing her well for the future.



A crowd of colleagues, volunteers, clients and MNDASA members gathered to farewell Sue Edwards at her Retirement function in February 2007



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