

DECEMBER 2009

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MND RESEARCH INSTITUTE OF AUSTRALIA

It is very pleasing to report for the first time in its history, the MND Research Institute was able to make available up to \$1 million for research grants in a given year. While this amount was available for allocation for research grants commencing in 2010, the Research Committee allocated \$675,000 for new research projects. With ongoing projects from previous years, \$773,000 will be spent on grants in 2010.

Funding for two MND research projects was allocated to researchers at Flinders University in South Australia. Dr Mary-Louise Rogers and Professor Robert Rush, Department of Human Physiology, were awarded a grant for a project titled '*A bio-marker for Motor Neurone Disease*' while Dr Hakan Muyderman, Medical Biochemistry & Human Physiology was awarded a grant to research '*The Role of TDP-43 in astrocytes in Motor Neurone Disease*.' Articles on both projects appear in the enclosed MND Research Institute of Australia Annual Review.

At their respective annual meetings held in November, the MND Research Institute and MND Australia voted to merge into a single entity. A united voice for MND in Australia is the way of the future and the merger is expected to be completed during 2010.

Please find enclosed with this newsletter

- The Australian MND DNA Bank flyer
- MND Research Institute of Australia International MND Research Update
- MND Research Institute of Australia Annual Review

A THANK YOU

Fundraising is an important component of the income required to run the MND Association. During the year, we ask members and supporters to support the numerous fundraising activities we undertake. Without your support it would be difficult to maintain services at existing levels and we are extremely grateful for the wonderful support we continue to receive. Thank you so much.

A special thank you also to the wonderful volunteers who assisted with Awareness Week activities, the Walk to D-Feet MND and Channel 9 Telethon Home open inspections.

Peter Whitehouse
Executive Director

Motor Neurone Disease Association of SA Inc

Christmas Closure Dates



Our office will be closed from Thursday 24 December and re-open on Tuesday 5 January 2010.

In you need to speak with John Gilligan, Client Support Coordinator during this time, please call him on 0422 182 896.

We would like to thank you for your continued support of the Association and wish you all a safe and enjoyable Christmas with your families.

Peter, John and Ricki

Hi Everyone

Well time once again to state the bleeding obvious – another year has passed!!

As is the case every year we once again lament not having had the time to do all that we would have liked. I suppose if we remain focused on the goal of never being content with what we have done but striving to do more, then hopefully there will come a time when we may be less inclined to make the earlier statement. Perhaps the introduction of a 20 hour working day would enhance our capacity to provide all with a much greater level of assistance. Imagine a 20 hour working day – LOL, which according to my son means “laugh out loud.”

I am always mindful when I speak of assistance that there is, and in all likelihood will always be, wide variation in the level of assistance provided people. Invariably this arises out of the necessity to prioritize the assistance we can provide people. Until such time as funding issues no longer remain the barrier to providing more assistance variations in the degree of assistance will persist. That said I am always available to assist you in any way I can, and my mobile phone is switched on 24/7. You need simply to call me. I may not always be able to get back to you as soon as we might both like, and being human there are inevitably times when I may forget to return your call, but if you jog my memory I rarely forget the same thing twice.

Early in the New Year we are having a planning day. Needless to say this will be an opportunity to review the year that has passed, reflect on achievements and disappointments, and plan our attack for the New Year. I would welcome feedback regarding what you think we do well, and conversely what we do poorly and subsequent to this any suggestions for bettering the service.

My spin on the above is a relatively simple one. Start out by having more of everything. More time to contact and visit people, more information resources, more volunteers to assist and provide company where appropriate for people, more equipment to loan, more collaboration between service providers and health professionals, more communication between carers and clients to name but a few.

Given this is the last Newsletter for the year I would like to take the opportunity to publicly thank my boss Peter, and Ricki for all the support and assistance they have provided me over the past year. Many of you may know very little about either of them since out of necessity your paths would rarely cross. In 37 years of Nursing, Peter is without doubt the finest boss I have worked for, a magnanimous person, and Ricki I think would probably do my job better than me – she has a heart of pure gold.

Finally to all reading this article I sincerely hope you have a wonderful Xmas and New Year and that in the face of many insurmountable obstacles many of you face, I hope this festive season is one that brings you peace and happiness.

Till next time

John

Client Support Coordinator

Walk to D-Feet MND

Sunday 18 April 2010

4km walk



A great way to keep fit, socialize and support a very worthy cause. Bring your family Bring your friends Bring your dog!

Adults \$25 (includes a t/shirt)

Children under 18 \$10 (includes a bandana)

Family \$55 (2 adults & 2 children under 18)

Free sausage sizzle, fruit and bag with promotional items
Wheelchair and stroller friendly

Registration forms and further information will be available in early 2010.



You can also raise funds through donations and sponsorship. Prizes will be awarded to the top adult and child fundraisers.

A lucky dog will also receive a prize!

Sponsors to date



MND Awareness Week

2-8 May 2010

More information early next year

MND Logo on Jockey silks update



Danny Penna with “Hidden Tears” who won at Strathalbyn in October. Hidden Tears was ridden by Australia’s leading female jockey Claire Lindop. Danny and his wife Angela designed the silks to spread awareness of MND in honour of Jim Branford, Angela’s father.

YOUR STORIES

A Tribute to Carol Dearman

Written by her daughter Sharyn Colliver

Mum had so many wonderful qualities it is hard to know where to start.

Her selflessness was incredible. She would always put the needs of others before her own, right to the end. Even when she was suffering in hospital she wanted to make sure that those around her were comfortable.

An ice block she had been given, she gave to her granddaughter Maddi, and on her last day when she could no longer talk, she wrote down messages to Wendy and Ivan telling them there were books to read in the lounge area and to help themselves to tea, coffee and milo in the kitchen.

Watching her gradually lose the ability to do the things she loved was so painful yet she tried so hard to shield us from a lot of her frustration, so as not to upset us.

Dad has only just told me of the number of times he would catch Mum in tears when she could no longer work the scissors to do her scrapbooking or she was no longer able to hand-write those beautiful cards and letters she would send us all to make us feel special.

I will cherish those cards I kept, not just Xmas and Birthdays but the cutest Easter cards, Congratulations on work promotions, General encouragement like Believing in you Dreams and Bon Voyages. There were quite a few of those!

And then of course my all time favourites, the so called anonymous Valentines cards every year, which meant the world to a single girl in the big smoke, many kilometres away from home. She certainly had an endless supply of unconditional love.

Mum had so many plans and projects that she never got to finish but I hope to take on some of those to honour her and finish them how she would have wanted.

Although I hate MND with a passion for what it did to my strong, vivacious, creative Mum it is vitally important that we all continue doing what we can to support research into the cause and cure, so we can prevent others from enduring what must be the worst disease on the planet.

Drawing on my positive nature, one of the many traits I got from my beautiful mother, I do acknowledge there was one very precious gift MND gave me. By coming to terms with the fact that Mum was not going to be with us for as long as we hoped, I made sure I spent much more time with her than you normally would in day to day life.

We always had a very close mother daughter bond, however our roles reversed and I became the mother caring for the child in need.

In caring for her we became even closer and shared some priceless quality times. I would sit on her bed and massage her weary body and we would chat about everything and anything or sometimes there were no words spoken, just a warmth and love of me being able to return all of the care she had given me, knowing I was giving her great comfort.

The smell of Lavender hand cream, Lavender massage oil from Thailand, Lemon body balm and Peppermint foot lotion will forever comfort me as I will know that mum is still close by.

Mum was such a fighter that she gave us much more time together as a family than many other MND families and I will always admire her amazing strength to keep up the fight until it was no longer possible, and we had to tell her it was okay to give up and go in peace.

I will always cherish one of our last "on the bed" moments when I told her she was going to be a Grandma again. Her happiness filled the room and she was larger than life. I know in my heart that she would have done anything to hang in there another 6 months to see the birth of her daughter's first child, had the MND not had other plans. But I also know that she will be with me in spirit around the 24th May and I hope that looking for signs of her presence will help me through the labour of bringing a new life into the world.

I am sure Mum will pass on some of her wonderful traits to this baby and if I can be just half the mum she was to me then it will be a very lucky soul indeed.

No doubt you will all have your special ways of keeping mum in your heart but I would just like to share a couple of mine.

Seeing a beautiful sunrise will remind me of the one we shared together, just her and I, on the morning of my wedding last May.

I will know Mum is around when ever I see a butterfly as we both read a wonderful book on the gifts we are given by previous generations and how to leave a footprint for the next generation. The Monarch butterfly does this well and we shared the same peace and sense of purpose after reading the book.

And of course seeing anything Purple will bring on the very best thoughts of Mum. I used to think that I gave Mum the purple bug after returning from the US in 1986 but I now realise it was already in my veins from Mum, especially when I see the photo of me in my purple crocheted dress at around the age of 5. We just got crazier once I came out of the purple closet and we shared the same feeling of happiness whenever we were surrounded by purple.

Lastly Christmas. Mum always made Xmas day a special family day and I think I may have missed only 1 Christmas together in 40 years. I would always come back from Sydney as it meant so much to Mum and we were always happy when we got together as a family. This year will be very tough without her but we will take comfort in the fact that she will be with us in spirit, finally free to move around without the shackles of MND. She will no longer be sitting in her wheelchair unable to completely join us at the table. She will be surrounding us with her warm fuzzies as we toast her and talk about our wonderful memories.

Mum wouldn't want us to remember those constraints of the last 2 years. She wants us to draw on and remember her strength, courage, determination and all of those other wonderful positive attributes of her personality, especially her love.

So don't be sad, but smile with happiness for having known her and also know that she is still surrounding all of us, giving out those warm fuzzies whenever we need them.

On behalf of Mum THANK YOU for bringing her so much happiness through your friendships and caring for her when she needed it most.

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MND Newsletter

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