THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MOTOR
NEURONE
DISEASE

FORUM

June 2003

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries.

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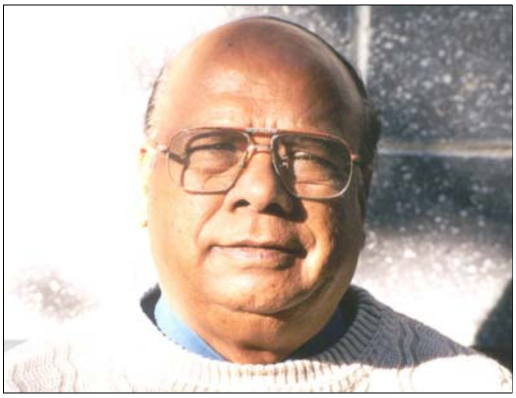
Hari Singh retires as CEO



Mr Hari Pal Singh came to Australia from Fiji in 1987 after 31 years in the Fiji Public service Commission from which he retired in 1987 as Director of Industrial Relations.

Mr Singh was also instrumental in development of sports in Fiji and was the President of both the National Olympic Committee and the Fiji Football Association.

Mr Singh told me that before he came to Australia he had decided to give the rest of his life to the service of the community, particularly those who are less fortunate. While he was adequately qualified and had appropriate experience to get a well paid position in Sydney in 1987, he decided to join Greenpeace Australia as its Director. In the four years he was there, the organisation grew to be a real force. The Greenpeace Board of Directors presented a plaque: *To H.P.Singh, in appreciation of his loyalty, diligence and dedication which often went beyond the call of duty.*

Mr Singh's next task was the amalgamation of the two separate volleyball organisations in NSW – a task which others had unsuccessfully attempted. The amalgamation was successfully completed in 15 months and the Directors of Volleyball NSW presented Mr Singh with a plaque: *In appreciation for your instrumental role in getting volleyball on track.*

Mr Singh joined the MND Association of NSW Inc in 1993 as its first employee. The Association was previously run by volunteers and few people in the broader community knew about MND. Mr Singh had personal experience of the difficulties involved with the disease as his father-in-law had died from MND. He was happy to accept the position on a minimal salary for 20 hours per week, and gave two extra days per week without being paid. His family and friends hand-delivered letters of appeal in their localities: this was the beginning of our marketing and fundraising projects and we have never looked back.

We now have 13 employees and countless volunteers all over NSW. The Association helps people with MND to stay at home for as long as possible by providing advice, equipment and support.

Mr Singh has continued to work beyond retirement age through a commitment to see a Family Resource Centre for people with MND, their families and carers. He will continue to work on this project until he retires on 31 July 2003

On behalf of the Board of Management of MNDA NSW, I express sincere gratitude and thanks to Mr Singh for his wonderful service over the past ten years and wish him all the best for the future.

Dr Robert Marr
Chairman, Board of Management, MND Association of NSW

Rilutek available from 1st July 2003 through the Pharmaceutical Benefits Scheme

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From the President's Desk

Chief Executive Officer - I join with our Chairman in thanking Hari Singh for his ten years of service, both personal and professional, to the Association. The selection of our new CEO is progressing, with the new appointment expected to take place in July.

Family Resource Centre – In the March Forum I reported about progress made towards acquiring a building at Concord Hospital but I regret to report that our hopes of getting a permanent place here at Concord have been in vain. We are now looking for office/storage space somewhere in the Concord, Burwood, Strathfield, Ryde, Parramatta or Lidcombe areas.

Multidisciplinary MND Clinics – The Board of Management will work with relevant health professionals to establish another MND clinic in the Sydney metropolitan area and also one in Newcastle. Dr Roderick Mackenzie, neurologist and MNDA board member, is spearheading a committee responsible for this project.

Life Membership – Recognised as dedicated, long-serving volunteers for the Association, Lloyd Affleck, Jack Davey, Elizabeth Sheard and Colin Thew are welcomed as new life members.

Business Plan – The Business Plan committee, headed by strategic consultant and MNDA board member, Bob Howe, has the final draft ready for wider consultation and discussion at a workshop to be conducted in July 2003. This is an opportunity for members to participate in the development of the Business Plan for 2003 - 2006.

Mission Statement – adopted at a special general meeting on 1st May, the new mission statement of the MND Association of NSW is:

To provide and promote the best possible support for people living with motor neurone disease, their families and carers, to advance research, and to raise awareness.

Regional Advisor – South-West NSW/ACT – The Board of Management approved a new position, in consultation with the ACT, for South-West NSW/ACT in recognition of the need to deliver quality service to members in the regional rural areas. We welcome Allison Pearson, a registered nurse, to this new position.

I thank all volunteers, supporters and staff for helping us during MND Week in April. It was a tremendous effort by a wonderful group of people and you are all very much appreciated by me and my colleagues on the Board of Management.

Our thoughts are with all those who have lost loved ones.

Kevin Langdon
President

Congratulations to MNDA NSW Board Members: Suzanne Ballinger received a Centenary Award in recognition of her dedication to the service of helping others.
Phil Bower has received the Lions International Ken Blackmore Honour Award for outstanding humanitarian service.

Rilutek available through the Pharmaceutical Benefits Scheme from 1st July 2003

Rilutek is the trade name for a drug called riluzole which has a neuroprotective function. It is the only drug that has been shown in scientific trials to have an effect on life expectancy in MND. Rilutek has now been approved for listing on the Pharmaceutical Benefits Scheme from 1 July 2003 for treatment of ALS.

Rilutek will be available only with an authority prescription from a neurologist and some restrictions will apply. For details, phone the Rilutek Hotline on 1800 005 858 or contact your neurologist.

Hari Singh *(continued from page 1)*

It seems he has always been there. Most of us can only remember the MND Association with Hari Singh at the helm. Of course, the Association was founded and very successfully run for twelve years by a strong group of dedicated volunteers before Hari was appointed as the first employee in 1993, but Hari has led the Association to a level of professional service provision that was not imagined 21 years ago.

As the second employee of the Association, I have had the privilege of working with Hari for the past eight years and have witnessed his careful planning to achieve the best possible care for people living with MND. The underlying question behind any decision that Hari has made is "will it help our members?" This has sometimes meant bending the rules or spending large sums of money, but Hari's paramount aim has been to make a better life for people living with motor neurone disease.

As Chief Executive Officer of a group that now includes thirteen staff members, Hari has managed his team as a 'family' - people who share ideas and care about one another - people helping people. The result has been a loyal team of dedicated people who all want to give the best effort they can to make a better life for people with MND, their families and their carers.

Hari's staunch supporter through all these years has been his wife, Tara, a fabulous hostess whose warm welcome and delicious cooking will always be remembered.

We wish Hari well in his retirement and know that his verdant garden will benefit from his extra hours of tending and his family will enjoy having more of his time.

Janet Nash
Information & Research Administrator

Family Support

The 6th Annual Conference for Health and Community Care Providers – *A race against time – The challenge of complex care in MND.*

The Conference held during MND Week was a great success with a record number of health and community care providers attending. One of the aims of the conference was to highlight the need for health and community care providers to ensure regular and timely assessment and the provision of flexible and responsive services, particularly in the event of rapidly changing needs. Since the conference, some service provider managers have requested we inform them if people with MND encounter difficulties in accessing services. Please discuss with your Regional Advisor if you are currently awaiting an assessment or are experiencing difficulties in receiving adequate levels of support.

This record level of interest in attending the conference, and the increasing number of health care providers interested in developing models of MND management, prompted family support to ascertain whether health care providers would like to be involved in discipline specific interest groups. There were quite a number of people interested in this concept and we will be pursuing this initiative later in the year.

Carers Kit

The kit is available in sections with relevant information to help at various stages of the disease. The sections can be requested in full, or as the need arises. Please contact the office for a checklist of the Carers Kit sections if you have not already received one.

Rural and Regional Family Support

Regional Advisors have been supporting people living in the more remote areas of NSW through phone contact and, for most people, an annual visit. Regional Advisor for Northern NSW, Christina Jason, conducts two field trips annually and this year will be visiting the mid North Coast from 23 to 28 June and the far North Coast from 16 to 24 October.

Ruth Quaken, Regional Advisor for Western Metropolitan/Southern NSW, visits the Far South Coast, Southern Highlands and Blue Mountains/Lithgow at least annually. As the Country NSW Regional Advisor, I make field trips to a number of regions annually. I visited Tamworth in March and will visit the Central West in the week starting 28th July.

The primary purpose of the field trip is to meet people with MND and their families face to face, to offer support or advice and to identify whether a referral to a specific health professional is required. The trips also provide the opportunity for Regional Advisors to meet with local health care providers and give in-service education sessions on MND care and management if required.

A recent field trip to South Western NSW and the ACT provided the opportunity to meet people with MND in Cootamundra, Griffith, Darlington Point, Wagga Wagga, Gundagai, Yass and the ACT. Although I have visited a number of these towns before it was my first visit to the ACT and Griffith. The trip was long but very rewarding and offered better insight into the needs of people in those regions, the positive effects of rural support groups and the high quality care and support being given to people with MND in these areas by local health service providers.

We are aware that not all people in rural and regional NSW have been receiving annual visits or equitable levels of support from the Association. Although the numbers of field trips have increased over the last couple of years, more people living in rural areas and the ACT are becoming members of the MNDA NSW. Following discussions with the MNDA ACT, MNDA NSW has appointed a Southern NSW/ ACT Regional Advisor to support people living with MND in the Riverina and South West Slopes, ACT, Southern Highlands and Far South Coast regions. We welcome Allison Pearson to this new position.

We are hopeful that this re-structure will afford a more equitable service to people with MND in rural and regional NSW and the ACT from MNDA NSW family support.

MNDA Volunteer Visitor Pilot Program

The funding agreement for this project, provided through the Commonwealth Department of Health and Ageing Palliative Care funding, has recently been signed. Christina Jason has started the process of arranging meetings with relevant Palliative Care personnel in the Hunter/Central Coast regions. The MNDA NSW project management group will meet this week to finalise and fine-tune the project plan. I attended a two-day workshop in Canberra to meet the other project managers and to discuss the evaluation process. This pilot is part of the Australia wide Caring Communities Program, which will be evaluated as a whole.

We plan to commence recruitment of volunteers in the near future. If you live in the Hunter, Newcastle or Central Coast Regions and would be interested in becoming a MND Friendly Visitor we would love to hear from you. The volunteers will be caring, practical people who are good listeners and understand the impact of MND on a family. A comprehensive training program will be implemented and ongoing support provided.

Carol Birks
Manager, Family Support

Research

Professor Ian Trounce Melbourne University
Mitochondrial calcium handling in ALS.
Mitochondria make the energy for cells to function properly, and also control the levels of calcium in the cell. If calcium is not properly controlled it becomes toxic and may cause the death of motor neurons. This project will use the mouse model to test the possible relationship between the SOD1 mutant gene and mitochondria dysfunction.
If successful it will focus the development of therapies aimed at reducing the interaction of the SOD1 mutant gene with mitochondria.

Dr P. Anthony Akkari
University of Western Australia
Investigation of novel protein binding partners for SOD1 and ALSin genes.
This project will continue studies of new genes potentially involved in MND and validate these by using Yeast Two Hybrid technology.

Dr Peter Noakes University of Queensland
The role of TGB2 in maintaining the function and viability of adult motor neurons.
The survival of adult motor neurons is thought to be controlled in part by neurotrophic (relating to the nervous system) factors. Consequently, neurotrophic factors are potential therapeutic agents for disorders such as MND. However, studies have been mainly performed on immature motor neurons, which lack many of the physiological and pathological features of mature motor neurons. This project will inactivate one gene (TG*B*2) in neurons or muscle at a specified stage in adult development and accordingly, enable the assessment of its therapeutic potential for neuro degenerative disorders such as MND.

Professor Annette Street La Trobe University
Enhancing supportive care through mapping the care networks of those experiencing MND.
This project seeks to provide information about the supportive care needs of people living with MND and their carers by mapping the care networks currently utilised and identifying the gaps in care provision.

Dr Carolyn Sue Royal North Shore Hospital
Characterisation of the role of mitochondrial dysfunction in cell lines derived from patients with ALS.
This project investigates whether the mitochondria are affected in patients with ALS and whether abnormalities in the mitochondria may increase the cells' chances to die. There will also be the opportunity to examine whether treatment can be based on modifying mitochondrial abnormalities in an attempt to improve therapeutic options available to affected patients.

Associate Professor Surindar Cheema
Howard Florey Institute of Medical Research
Evaluating potential therapies in a rat model of MND.
The project has established a large breeding colony of mice, which has been the best animal model available for testing and developing novel therapeutic strategies that may be applicable to human MND. However, due to its small size, the mouse cannot easily receive some drugs which may prove beneficial if testing could be delivered. However, a major breakthrough last year proved that rats could be used for this testing. The project will accordingly order and set up a breeding colony of the SOD1 rats and test the appropriate drugs.

Dr Rodney Rietze
University of Queensland
Stimulation of endogenous stem cells to replace lost motor neurons
This research will determine the appropriate growth factors to stimulate new neuron production in the central nervous system. This will hopefully lead to the development of new regenerative approaches to replace lost neurons in MND.

In December 2002 the MND Research Institute of Australia approved grants to these researchers to assist with their projects during 2003. This year's grants represent a 50% increase, in dollar terms, on the previous year's approved applications.

Professor Garth Nicholson
University of Sydney
Finding new genes causing MND.
The identification of gene mutations causing MND will increase our understanding of the genes underlying susceptibility for familial MND. Identification of gene mutations in familial MND may provide insights to the cause of sporadic forms of the disease and the relationship to environmental factors. When the mechanisms of the affected genes are understood, this should lead to treatment strategies for preventing and treating both familial and sporadic forms of this disease.

Dr Matthew Kiernan
Prince of Wales Medical Research Institute
Axonal excitability and the pathophysiology of MND.
The aim of this research project is to explore the mechanisms involved in the development of cramp, muscle twitching and weakness in MND patients. While these symptoms may suggest overactivity (muscle cramps and twitches) or conversely loss of function (weakness) in the nerves of patients, the factors controlling both the generation of this activity and its continuation are not understood. Dr Kiernan's group has previously found evidence that a novel type of sodium conductance in the nerve is over-expressed in MND patients relative to healthy control subjects. They would like to extend this finding by exploring whether other processes in the nerve membrane are contributing to cramp, fasciculation and muscle weakness, perhaps leading to greater insight into pharmacological approaches that may ultimately assist in the treatment of MND patients.

Address at Government House NSW at the launch of MND Week 2003

Dr Paul Brock

Director of Strategic Research, NSW Department of Education and Training
Member, Board of Management, Motor Neuone Disease Association of NSW

Your Excellency, President of MNDA NSW, Kevin Langdon, members of MNDA, Ladies and Gentlemen.

I thought I could best respond to the invitation to speak today by offering you one very personal, 'insider's' perspective on MND.

In late 1996 my entire world, and that of my wife and our two very young daughters, was turned upside down. Walking into the neurologist's office with a weak and sore forearm, I emerged with a death sentence noosed around my neck. "You have Motor Neurone Disease" and "your life expectancy is between three and five years" are the two sentences still burning in my memory. I learned that the only thing that slowed the inevitable catastrophe was a drug called Rilutek. But it just prolonged life by a few months. And it was unavailable in Australia.

As I mind-numbingly walked alone down the stairs and thought how the hell was I going to break this cruelly premature death sentence news to my young wife and daughters, two sets of Shakespearian lines fought against each other for supremacy in my brain.

Her Excellency Professor Marie Bashir, Governor of NSW with Paul Brock, his daughter Millie and carer Cathie Cummings.

On one side were some lines from *Macbeth* the first of the Shakespearian tragedies that I ever lectured on during my 11 years at the University of New England where I was Senior Lecturer in English. Knowing now that his fate had been infallibly determined, Macbeth roars out that "Life is a tale told by an idiot / Full of sound and fury, signifying nothing".

After all here I was - a perfectly healthy, happy, fulfilled human being, in the prime of life, with hardly a care in the world before I walked into a doctor's office. Had I been a smoker, I could have understood had I been diagnosed with lung cancer. Had I been a heavy drinker, it would have made sense had I been diagnosed with cirrhosis of the liver. Had I been one to indulge myself in drug taking, needle sharing or promiscuous unprotected sex, I could have understood it had I been diagnosed with Hepatitis C or HIV/ AIDS.

But absolutely none of these things was, or is, or ever has occurred in my life.

I felt smitten: like the Biblical character, Job.

On the other side there was a competing set of lines upon which I based much of the very last lecture I gave on the Shakespearian tragedies towards the end of my academic career in mid 1990: the play was *King Lear*. Feeling absolutely abandoned by his daughters, with his power entirely smashed through his own actions and those of his enemies, a near delirious Lear roars around the stage buffeted by a raging tempest, demanding to know how he can possibly cope with the devastation into which his life has now fallen. He gets this answer from his Fool. "He that has a little tiny wit / with a heigh ho, the wind and the rain / Must make content with his fortunes fit / though the rain it raineth every day".

That is to say, you just have to do your best to cope with catastrophe as best you can – endurance is all.

In the words of a much later poet, Robert Frost, there were for me two paths diverging in the woods: one leading towards despair and anarchic nihilism; the other towards striving to make content somehow fit with this disaster. I had to choose one. Which I did. And, in Frost's words, "that has made all the difference".

TRYING TO MAKE CONTENT WITH OUR FORTUNES FIT/ THOUGH THE RAIN IT RAINETH EVERY DAY.

My wife Jackie, and I - after coping with our initial shock, devastation, anger, powerlessness and grieving – all of which emotions we still feel – and having experienced almost simultaneously the various stages of death and dying that Elizabeth Kubler-Ross describes, resolved to make content with our fortunes fit. In practical terms this meant determining to continue to live our lives with our family as normally as we possibly could. To explore every possibility that we could to search for a cure. And to do all that we might be able to do to encourage those seeking to discover the causes and cures for this disease.

Today I would like to share with you some of the things that I and others in my life have done to struggle to make content with my fortunes fit.

Let me return, therefore, to late 1996. The week after my initial diagnosis I played my usual game of golf. On the weekend I continued lobbing tennis balls to Sophie, then aged 5, in the continued hope that she would become, a pretty good cricketer, if I may say so like her dad. I continued regularly to play the piano as I had done for the previous 46 years. I pushed my one year old daughter Amelia, whom we affectionately call Millie, on the swings and bounced up and down on the trampoline with her.

Tests at the very end of that year showed I had a slow and very rare version of MND – Progressive Muscular Atrophy. A second opinion confirmed the diagnosis and that particular neurologist told me I would not still be working by the end of 1997. But, thanks to the magnificent support of our former NSW Director-General of Education and Training Dr Ken Boston and our current Director-General, Jan McClelland who I am delighted to see here today, in 2003 I am still able to work full-time in my very challenging senior executive position of Director of Strategic Research.

Ken and Jan authorized the Department's purchase of this wheelchair; the appointment of a professional carer/assistant to be with me at all times during working hours; and to supplement fully the wheelchair cab allowance provided by the Department of Transport. Furthermore, I am constantly buoyed by the immense personal and professional support I receive from my colleagues in the workplace.

All my adult life I have been something of an activist in organizations committed to what I would call the progressive side of educational, political, religious, social justice, research, and human rights agendas. So, from late 1996 I set about a new set of activist goals: focusing now on the survival of our little family in particular, and the broader MND community in general.

I trawled the Internet and soon became aware of a whole miasma of snake oil remedies and false prophets. I, myself, was for many months beguiled by the claims of a spiritual healer and travelled thousands of kilometres and forked out a good deal of cash for my weekly half an hour hands-on session. I broke this off, disillusioned and disappointed because of a particular experience.

Through the wife of a former political colleague, a brave woman with MND, I became aware of the *ALS Digest* – a website which over the last five years has provided me with much scientific knowledge, personal inspiration and resolute buttressing of my own convictions not to take all of this lying down.

Over the years I have acquired a fairly sound grasp of the issues facing research to find a cure for MND. And, of course, the more I read the more I realized that – unless there is a cure – I, like the many thousands of MND sufferers now and into the future, face the terrifying prospect of all-encompassing paralysis of my whole body – except, ironically, of my brain and consciousness– until I suffocate and die.

Through my determined research and networking, I also came to know two wonderful people: the University of Sydney's Professor John Pollard who is now my Neurologist and Professor Gareth Parry, a New Zealander at the University of Minnesota who specialises in the care and treatment of people with MND.

Because of the absolute centrality of my family to my existence, the exciting yet very demanding functions of my job as a senior executive in the Department of Education and Training, and the incrementally debilitating effects of this disease, I have strenuously resisted the dangers of allowing MND and its agendas swamping my life. But I was galvanised into the public arena by the debates leading up to the federal legislation to permit embryonic stem cell research. And this eventually led to my accepting an invitation to join the Board of the Motor Neurone Disease Association of NSW.

Ever since the significant developments into embryonic stem cell research took off in 1998, I have been convinced, and have done my best to convince others, that embryonic stem cell research holds out a real hope of slowing or even curing this wretched disease. In advocating this, I have also encouraged adult stem cell research.

Indeed, I have strongly supported all of the other scientifically reputable avenues of research for cures: such as 'trophic factors', creatine, and – very recently – minocycline, as well as all the other research being undertaken on a variety of fronts to try to understand the causes of MND.

An allied focus of my activism, especially over the last 18 months, has been a determination to make Australian scientists, politicians, public opinion shapers, and the wider Australian community, understand that stem cell research offers hope to those of us suffering with MND. I became increasingly irritated by the fact that whenever the diseases or incapacities for which stem cell research offered such opportunities were mentioned - e.g. Parkinson's, Alzheimer's , diabetes and spinal cord severance - MND was nearly always ignored.

My campaign of proactive advocacy for the care and cure of MND has been conducted on a number of fronts. First of all, every time I read an article in the press which addressed embryonic stem cell research but which ignored MND, I personally rang up the journalist, 'educated' them about MND, briefed them on the scientific, ethical and moral issues, and urged them not to exclude us in future. Following such phone calls, subsequent articles by these journalists have virtually always included reference to MND.

My second tactic was to write feature articles in *The Sydney Morning Herald* and *The Australian* in defence of embryonic stem cell research from a moral and ethical perspective and to oppose earlier articles in the press which had condemned this research. In particular, I took on a series of public statements issued by many – but not all – members of the Catholic and Anglican Episcopal hierarchies.

I frequently drew attention to MND and focused particularly on the moral and ethical issues involved in embryonic stem cell research using surplus IVF embryos which, otherwise, have to be destroyed in accordance with Australian law. In doing so I drew heavily upon my own intensive study of ethics and morality during my six years of training in theology and philosophy at the outset of my 15 years as a member of the Marist Brothers, a Catholic Teaching Order.

My third strategy was to set out to make Australia's leading embryonic stem cell researchers aware of the possibilities for MND arising from their research. This included my arranging to meet Professor Alan Trounson, who then headed up the Monash Institute of Reproduction and Development and who is one of the world's leading scientists in embryonic stem cell research. I pointed out to Alan that not once had MND been mentioned in the prospectus that he and his Monash colleagues had prepared in what turned out to be their successful bid for the $46 million National Stem Cell Centre. Every other disease and disability for which embryonic stem cell research holds out so much hope was mentioned – but not MND.

To Alan's great credit, he undertook immediately to redress this situation. He asked me to provide him with a short list of International research centres that are focussing on MND / ALS and assured me that he would attempt to set up linkages with them. He has been absolutely true to his word. Later, when he, Premier Bob Carr, some others and I shared the platform at a National Press Conference last August in Canberra, Alan publicly referred to our conversation and recommitted himself to seeking a cure for MND through his research and that of his colleagues. At the end of most of our conversations we have these days, he says - "hang on in the saddle, Brocky, we're coming to rescue you".

My fourth strategy has been a somewhat more 'political' one. I was deeply impressed by Bob Carr's national leadership of unswerving support for embryonic stem cell research. But, once again, not once had I seen any reference to MND in the Premier's campaign.

So I contacted his senior advisor on this matter, Mr Nicholas Rowley, and set up a meeting with him to advance the cause of MND. Since then whenever Mr Carr has spoken about embryonic stem cell research, he has consistently included reference to MND.

In mid 2002, I was approached by a representative of the Juvenile Diabetes Research Foundation who had read some of my newspaper articles, to see whether the MNDA NSW would be prepared to join the Coalition for the Advancement of Medical Research Australia (CAMRA), set up to lobby for stem cell research in general, and the passing of the two Bills supporting embryonic stem cell research in particular, that were eventually presented to Parliament, in particular. I approached our President Kevin Langdon and our CEO Hari Singh who agreed that we should be involved. Kevin, my MNDA Board colleague Paula Trigg and I attended the subsequent meetings.

The other members of CAMRA are: the Australasian Spinal Research Trust; the Australian & NZ Society for Cell and Developmental Biology; the Australian Society of Medical Research; the Diabetes Transplant Unit of the Prince of Wales Hospital/University of New South Wales; the Monash Institute of Reproduction and Development; the Paraplegic and Quadriplegic Association of NSW; the Prince of Wales Medical Research Institute; and the Rett Syndrome Association of Australia.

Under the powerful auspices of CAMRA we travelled to Canberra in both June and August last year and lobbied many Federal Members and Senators – including some of our strident supporters, those still undecided, and some of our most vociferous opponents. We also addressed the national media. The Bill dealing with banning human cloning was passed unanimously; that dealing with embryonic stem cell was passed comfortably in both Houses– despite the most strident and often hysterical / fanatical opposition.

LOOKING BACK, LOOKING FORWARD

In 1998 I attended my first MND Week Launch here in Government House. I had driven to work around the corner in Bridge Street and walked here briskly. Though a far more rare disease than AIDS, I learned that in Australia MND was killing twice as many people as were dying from AIDS each year. Research, we were told, was promising yet still stillborn as far as any significantly improved treatments and cures were concerned.

We were told that still the only thing that slowed the inevitable catastrophe was Rilutek. But it still merely prolonged life by a few months. And it was still unavailable in Australia. And even if it became available, as it subsequently did, it would cost nearly $700 for one month's dosage.

Five years later I arrived today in this wheelchair in which I now virtually live. From the moment I am lifted out of bed in the morning until the bedclothes are pulled up over me every night, in order to live I am literally dependent on my wife, Sophie now aged 11, Millie now going on for 8, my wonderful team of carers, and a variety of devices.

I sit wheelchair-bound in utter frustration unable even to hold a cricket bat no less coach my Millie who is emerging as a splendid cricketer. Sophie is a superb pianist – yet I cannot even lift my hand of useless fingers onto the keys of my piano. While Millie plays the violin, Sophie the piano, Jackie the cello - I now get my creative musical satisfaction by using my nodding head as a baton in conducting our little Brock trio.

So looking beyond today's event what do I think and feel? Well it is similar to my original experience of experiencing two competing forces. On the one hand I am still angry, shocked, frustrated and perplexed as I continue to try to cope with my life of ever diminishing circles. I find it hard to accept the devastating and ever-increasing loss of function and concomitant loss of independence.

I am furious that for an incurable, terminal disease that has been in the medical and scientific literature for exactly 130 years since it was first identified by Charcot in 1873, there is still no understanding of its causes, of how to slow or ameliorate the disease – other than Rilutek, which sometime before September will be available in Australia under the PBS for only $25 - and above all there is still no a cure.

I know it is hard to be objective but, to put this another way, I find it an absolute disgrace that, well over six years since I was diagnosed, scientific research still has nothing to offer to us MND sufferers other than Rilutek!! This is certainly not the situation for diseases like cancer, or heart disease, or AIDS. And, incidentally, we now know that in Australia this perfidious disease kills at nearly three times the rate that AIDS does each year.

But it is not frustration just with the scientific community. During Premier Carr's Forum on Spinal Cord Injury & Conditions a few months ago, one of the world's leading researchers into spinal trauma and neuro-degenerative diseases associated with the spinal cord, Professor Wise Young, asserted that we are dealing not so much with a failure of science but, rather, with a failure of political will to allocate the necessary resources. "Give us a hundred million dollars and we could find the cures in a year or two", he asserted.

But then, to develop a point made by Senator Natasha Stott-Despoja that was greeted with spontaneous and sustained applause during the same 'Hypotheticals' session in the Forum, if the Australian Government had not chosen to spend over a hundred million dollars on this unnecessary, illegal, and immoral war against Iraq, then such resources might be available for healing and saving the lives of Australians like me – to supplement the paltry $100,000 or so funds available to the MND Research Institute of Australia.

To say nothing of the hundreds of billions of dollars being squandered by the USA and the UK in this dreadful business.

On the other hand, however, I am heartened by those who have so significantly helped me make content with my fortunes fit.

Premier Carr, who was kind enough to consult me in the lead up to the Forum at which Christopher Reeve so inspired us all, has exercised tremendous, unflagging, courageous leadership in his advocacy for all forms of reputable scientific research to seeking better treatments and cures for not only spinal trauma but also for MND.

Following discussions, the Premier agreed to call it officially a Forum on Spinal Cord Injury & Conditions and Nicholas Rowley, who had responsibility for organizing the Forum, told me that Christopher Reeve had agreed to the Premier's initiative and would refer to MND in his address: which he did. And now the Premier has established a new medical research and science portfolio under Frank Sartor which will ensure ongoing NSW Government commitment to this quest.

I am heartened by the exciting and committed research being conducted in the USA – for example the Robert Packard Center for ALS Research at Johns Hopkins University and the stem cell research being sponsored by the Christopher Reeve Foundation, as well as recent Australian initiatives such as the recently established National Stem Cell Centre and the even more recently established Deb Bailey Foundation.

I pay tribute to the fantastic work undertaken by the MNDA of NSW: its Board and its staff. In particular the MNDA Board is now widening and strengthening its role to one of advocacy for research agendas. In its support of, and advocacy for, high quality research I believe that the

Association should be able to monitor and critique national and international research from the particular perspective of the interests, needs, and capacities of those with MND, their families and their carers.

Like Christopher Reeve, I would like every researcher working in this field to learn at first hand what those of us with MND, our families, and carers have to deal with on every single day of the ever narrowing circle our lives. To empathise with how we try to make content with our fortunes fit. Promoting such advocacy and communication links is precisely what our Association is in such a powerful position to be able to do.

One of the driving inspirations for me in my involvement in public life throughout my professional career has arisen from responding to what the great sociologist Ivan Illich described as the 'institutionalisation of value'. Too often, he argued, the original values driving the alleviation of suffering or injustice and the promotion of the common good become ossified – or even reversed – by the processes of institutionalization or bureaucratization.

For example, Illich asserted that while schools were originally established to serve the needs of students, their internal structures and organization can sometimes end up serving principally the needs of teachers and bureaucrats. Or, while hospitals were established to care for the sick, too often the real power relationships and internal structures can sometimes end up serving more the needs of the doctors and the nursing staff rather than those of the patients. He could also point to the ways in which the original teachings of great religious figures like Jesus Christ can too often subsequently be commodified, trivialized and distorted by the structures and power agendas set by churches as institutions.

To be aware of and to resist, as far as possible, such institutionalization of value needs to be a recurring catalyst in the setting and implementation of public policy. We in the MNDA NSW can, therefore, serve a noble purpose if we continue to urge researchers to remember that – even though having their research papers published in esoteric journals is an important and legitimate career goal - ultimately their outcomes ought to be driven by the need to alleviate suffering, to enhance the quality of life, and indeed to save lives. And we all know researchers in MND who are so driven.

This is why our Association needs to be pro-active in building bridges between us potential 'consumers' of the research, and the research community. We need to urge inter-disciplinary and collaborative approaches within and across the research field.

MNDA NSW has the opportunity to perform the kind of brokering, generating and communicating functions so superbly modelled by the Premier's Forum on Spinal Cord Injury & Conditions and in its motto – 'Making Connections' – in encouraging and supporting research that directly or indirectly, potentially or actually, can contribute to finding the causes of, advancing better treatments for, and discovering eventual cures for MND.

To scientists, funding bodies, and researchers, may I say this - on behalf of those of us with MND, our families and our carers. On average, those of us with MND survive for only around 30 months after diagnosis. 80% of us die within 3-4 years of diagnosis. Not only are we running out of time. But we are running out of patience when we listen to those of you who tell us, yet again, all about the obstacles to discovering significantly improved treatments for MND and to finding a cure. Re-echoing the blunt words of Christopher Reeve at the Premier's Forum - words quite passionately endorsed by Premier Carr - I say this to those who have the capacity to slow down this murderous disease and to find cures for us - 'Our house is already on fire, and we need you to put it out – now!'

THE IMPACT ON OUR FAMILIES

And finally, there are no words that can adequately give anybody any understanding of the demands made upon our families. In my case, I am in awe of the loving support unfailingly provided by my wife and my daughters. Having MND is a huge financial drain on any family. But the emotional and psychological stresses are even worse. For example, for an inveterate romantic like myself not to be able to hug my wife and young girls is so painful.

I think that most of us with MND try to put on a brave, smiling face and try not to whinge and moan. But every now and then it all gets too much and shares in Kleenex rise accordingly. I would like to finish my remarks today, therefore, by asking Millie to read to you a little poem cycle that she read out to me after one such episode when she saw me upset. Because she was one year old when I was diagnosed, Millie has no memory of me as a healthy 'normal' Dad. I had no idea that she had already commenced a book of her own little poems.

For her parents, both of whom have PhDs in English, this discovery was as much a cause of sheer delight as was the content of what she wrote. But it was delight mixed with a whole range of emotions some of which, I hope, you may be able to share as she reads it to you. So, I am now handing over to Millie to have the last word from the Brock family, today.

NEVER GIVE UP
A POEM CYCLE

"Never give up"
If you give up on something
You might not get it
But if you try you might get it
Before you die

"I'll always love you"
But if I don't I'll be above you
I am in heaven
And you are now below
When you come up
You and I will follow

"My dream is to fly"
My dream is to catch a butterfly
My dream is to live happily ever after
But sometimes things come up
And they might stay.

By Millie Brock
Age 7
January, 2003

Intra-parotid botulinum toxin A injections in the treatment of sialorrhoea in motor neurone disease

Excessive saliva, or sialorrhoea, is a common problem for patients with bulbar involvement in Motor Neurone Disease (MND) occurring in up to 20% of patients. Sialorrhoea results from impaired swallowing in MND rather than excessive saliva production. Between 1,000 and 1,500 mL/day of saliva is produced by healthy subjects, although this volume might be reduced in patients with MND for unknown reasons .

Botulinum toxin A (BTX-A) blocks the release of acetylcholine in motor and parasympathetic nerve terminals, the transmitter responsible for saliva production.

Five patients with clinically definite sporadic amyotrophic lateral sclerosis (sALS) form of MND with bulbar dysfunction and symptomatic sialorrhoea were recruited from the Royal North Shore Multidisciplinary MND Clinic. During the period of January 2001 to June 2002, fifty patients with ALS were referred to the clinic for assessment and further care. Therefore patients with troublesome sialorrhoea constituted only 10 percent of total referrals. Patients were not on anticholinergic medication during the study.

In this study supported by the MND Research Institute of Australia, Dr Rowe has shown the effectiveness of BTX-A to control the saliva of patients with MND.
This data was presented at the Annual Scientific Meeting of the Australian Association of Neurologists in Sydney in May 2003.

Four of the five patients demonstrated marked reduction in the mean amount of saliva produced following one set of injections with BTX-A into both parotid glands. There was a reduction from baseline saliva measurements in the four patients that responded of between 49% and 52% from Day 14 to Day 56. While there was a trend for a reduction in severity or frequency scores across the group from baseline, this was not statistically significant. One patient did not have a reduction in saliva production, despite re-injection on Day 14. Because of continued profuse sialorrhoea in this patient, glycopyrrholate therapy was used subcutaneously to control his symptoms. There were no adverse effects of the single course of intraparotid botulinum toxin, with no reported facial weakness and no subjective deterioration in swallowing. Having demonstrated efficacy in these patients following a single course of botulinum toxin, further treatment continued at 8-10 week intervals.

Conclusion

In most patients with MND, sialorrhoea can be managed with simple oral medication. Intraparotid botulinum toxin is a safe and effective therapy for sialorrhoea in patients with swallowing difficulty secondary to sALS. Saliva production is reduced by 50% by one course of injections. This reduction in saliva production lasts for 56 to 72 days after the first injection and can last for a longer period. Some patients may not respond to botulinum toxin and require other therapies. There were no adverse effects of intraparotid botulinum toxin therapy. BTX-A is expensive at $450 per vial, but is a useful tool in controlling saliva. It is currently not approved for this use by the Australian Drug Evaluation Committee, and is reported here as part of an open trial.

Dr. Dominic Rowe
Multidisciplinary MND Clinic
Royal North Shore Hospital, St Leonards

En-zy-mex, a product used by some people with secretion problems, is produced by Pan Pharmaceuticals.
Use of En-zy-mex should be discontinued pending further information. Contact your Speech Pathologist for advice on similar products available for secretion management.

Editor

Ask the Experts

The 2002 International Alliance of ALS/MND Associations annual meeting was held in Melbourne, Australia, in November. As part of that meeting, the Alliance, in conjunction with the MND Association of Australia, presented two unique opportunities for patients, carers, health professionals and other interested people to "ask the experts". In the morning session, four health professionals, a neurologist and a respiratory physician addressed a range of issues affecting people living with ALS/MND, and responded to questions from the audience of over 170 people. In the afternoon session, five invited researchers, all acknowledged experts in their fields, addressed the very latest in scientific research on the search for cause treatment and cure of ALS/MND.

The International Alliance has produced transcripts of these sessions. The transcripts can be downloaded as either MS Word documents or Adobe Acrobat files. Please visit www.alsmndalliance.org to review these transcripts or contact your MND Association.

The sessions were funded by a grant from the Victorian Department of Human Services, Disability Division. Transcription was undertaken by the MND Association of Victoria.

The International Alliance of ALS/MND Associations is the peak body for patient organisations representing people living with ALS/MND.

Rodney Harris, Board of Directors
International Alliance of ALS/MND Associations

Regional News

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Hornsby
(Anita Richter)

and

Panania
(Caroline Gleig)

and

Penrith/Blue Mountains
(Ruth Quaken)

are coordinated through the MNDA office.
Phone: 02 9743 5872

Central West

Graham Mooney, Social Worker, and Marylou Kemp, Occupational Therapist, from Forbes Community Health attended the meeting on 10 May and talked with the group about the emotional impact of MND. Following the meeting the group gathered by the river for a picnic lunch!

The next meeting will be an informal get together (date and place to be confirmed) and then the group will meet at the end of July when I will be visiting the region. This support group provides an opportunity for people in the Central West, who may be particularly isolated, to get together and discuss common issues. The group is very flexible, willing to travel and anxious to include as many people from the region as possible.

Carol Birks

Central Coast

We tried all sorts of new things this year in MND Week – including four railway stations and, again, Erica Dash Podiatry did really well raising $449. Thank to all our supporters who helped the group to raise a total $2,288 for MND.

Audree Dash

Newcastle & Hunter

Our members and friends were very busy over MND Week manning five shopping centres, and the public awareness was worth the effort. (One member sprayed his hair blue on Cornflower Blue day). $10,897.20 was raised during the week. A few of our members held morning tea parties, which were a great success. Others put merchandise in their local shops and schools. The pens were the most popular item, followed by the cornflower badges.

On the lead up to MND Week we launched our specially designed china cornflower coffee mugs which were a huge success and raised $1,254 – only 30 of 1000 mugs were not sold.

Alistair Fyfe

Coffs Harbour

Thanks to all my dedicated helpers, we had a very successful MND Week this year raising more than $3,800. A special thanks goes to the Casey family in Bellingen.

Lily Jenkins

City to Surf
Walk, wheel or run for MND in the annual event on Sunday 10 August. Entry forms appear in each week in the Sun Herald or at www. sunherald.com.au. If you want to join the MNDA team, phone Elizabeth Herbert on 9743 5872

MND/ALS GLOBAL DAY Saturday 21 June 2002

Global Awareness Day takes place each year on 21 June. This date, the Solstice, was chosen by the International Alliance of ALS/MND Associations as a symbolic turning point or time of change. This year, the Alliance has organised Global Day internet chat sessions at *www.alsmndalliance.org*. Chat times in NSW are 9am, midday, 4pm and 8pm on 21/6/03.

NSW Global Day Events include:

- The ASX Cornflower Blue Ball at the Four Seasons Hotel, Sydney
- Perisher goes Blue for MND
- **Sherwin & Charmaine Misso are hosting a Dinner & Dance at Blacktown for MND. This will be a great evening with dinner included at $30 per person (BYO). Tickets are available from the MND Association—phone 9743 5872.**

FOR INTERNET USERS

OZPALS is a group of people in Australia and New Zealand with an interest in MND who keep in touch by email.
To subscribe go to *www.hotkey.net.au/~ozpals*

Internet Chat – Living with MND

Every Tuesday at 1pm & Thursday at 8pm EST.
Go to *www.mnd.asn.au/* then click on the chat room link.

Also try *http:/neuro-mancer.mgh.harvard.edu/brainchat/classic.shtml* for a chat room which is open 24 hours per day.

Visit the MNDA NSW website at *www.mndnsw.asn.au* for links to many useful and interesting sites.

Fundraising

Orange turned BLUE.
'Trivia Night' on 5 April was a rousing success involving the whole town in a fundraiser held, courtesy of the RSL, which raised almost $2,000. Now, this is a special story. Orange turned blue because of two special ladies. Kerry and Sam who work at Dr Gordon's Rooms in Orange. They were the instigators of the 'Trivia Night' (which was really very serious!) and they plan to do the same sort of thing next year.

HELPING THROUGH YOUR WILL

Your Will can be a convenient vehicle for making a charitable gift of lasting value.

Please consider the MND Association as a living memorial for a loved one.

Join those who support the work of MNDA NSW through bequests from their Estates.

Bathurst
Phil McIntyre moved here from Mittagong when diagnosed with MND. His sister, Maria, is close at hand and he also discovered good neighbours at the Railway Hotel. When Phil wanted to sell his cricketing memorabilia - in aid of MND, of course - he suddenly found that he had even more friends. Nevil Barlow was on hand. A Rotarian and ex-Mayor of the town, Nevil lost his wife, Ruth, to MND only two years ago. Benny Elias went to Bathurst on the night and spoke about his friendship with Scott Gale and beautifully explained MND to the guests. The combined efforts of the team led to over $26,000 being raised for MND and, what is more, everyone in the area is now aware about MND.

Dunedoo appeared on the MND map with a great fanfare. In a town with a population of 800, our intrepid supporters raised over $900.

Goulburn was the scene of activities where Janice McColl raised both funds and awareness for motor neurone disease.

GO, GO, GO, GOLF
Shell Harbour was a first.
Here, on 17 April, Clare Bull raised $1,454 from a standing start. Firstly, they held a garage sale to fund the initial expenses (not missing a trick) then, on the day, they battled the elements.
Thanks to all at Shell Harbour Golf Club for making this day such a success.
At **Mollymook Golf Club**, Graham and Jennie Beasley were also hard at work. The following day (18 April), they raised $1,150 in what has become a popular annual event on the coast.
Asquith Golf Club hosted a special day on 7 May in memory of Herb Haas whose family was joined by a host of friends for a very special day and the MNDA was truly elated to receive $8,050 from the day.
The organiser, Frank Minnici, says this will become an annual event.
Thanks to everyone involved.

THE KAKODA TRACK
Many people have found this to be a journey into reconciliation and renewal. Henry Morris took this difficult path because his brother, Ian, died of motor neurone disease. Along the way, he was accompanied by myriad sponsors who dogged his steps every inch of the way. He needed to finish the course. They followed every footstep with keen interest. However, nothing was going to stand in his way and Henry came home having earned nearly $21,000 for his efforts. We have a new friend at MND and a true friend. Henry has promised to use his experience and expertise to help future fundraising projects.

MND WEEK 2003

There are too many people to thank for the wonderful work they did this year. Over $110,000 has already been banked and that is not the end of it as more money keeps coming in. It will be the next edition before we can, finally, give you the complete picture.

It has been amazing. Some people - like Peg Jameson and Phil Hopkins - take on a particular shopping centre and mastermind the whole show. Like Megan Paton and her mother, Michelle Paton - they bring the whole family to help. Anne Newman did the same. *People helping people* is the slogan of the Association and they demonstrate this first-hand.

This year, there is much to report. Firstly, there were the shopping centres which raised over $14,000 between them. Then, on Cornflower Blue Day, Scott Gale's family took on Circular Quay and the Domestic Terminal at the airport - raising $7,468. Of course, a great part of our success this year, was due to Scott's television appearance on the 'Footy Show" which went to air on 3 April.

HCF opened all its doors to MND by putting posters and boxes in all its branches. Ricki Karaviotis – from HCF - said "we were delighted to help again this year and pleased to double the amount we raised last year." HCF underpinned the breadth of coverage obtained across New South Wales.

PEOPLE HELPING PEOPLE

The MNDA has been blessed. Over the past few weeks it has been able to count on so many people - as ever, Marjorie Harrap our founder but, now, also Peter and Janice Stuart who helped with computer backup and deliveries during MND Week; Coty Cortese and Maria Sepulveda who helped coordinate volunteers and Yvonne Monteith, Kathy Wootten, Rachel Mosman, Sneha Nayak, Debra Larizza and Terry Montag who all come regularly to help in the office . Volunteers are always welcome and there is plenty to do if anyone has some spare time .

Elizabeth Herbert
Development Manager

Dear Editor

My dad Nick has been diagnosed with MND and accepting that funding is a limiting factor to help people with MND, we decided to do our bit. Over months of preparation and organisation we finally had a venue, band and catering. Finding raffle and auction prizes were the next hurdles. Friends and locals chipped in a couple of prizes, but to our surprise we had many more volunteered prizes than expected.

The MNDA fundraiser held at the Sydney Flying Squadron on 17 May was a huge success. The function was a combination of partying hard and raising funds for the Association. It had been raining all week, but the weather cleared to a moonlit night. Over 150 of Nick's close friends attended the event to raise money for the Association and to enjoy a great night out. Nick gave an excellent speech on the symptoms and progress of MND and described how it affects us as a family.

We raffled jet boat rides, bridge climb tickets, harbour cruises, beauty salon and massage gift packs. We auctioned two bottles of Grange, a helicopter trip and a couple of party animals decided to auction off a nude swim in Sydney Harbour. In total $6,895 was raised. After the prizes, the 'Brand new Hillarie's' played their funky tunes and we partied all night.

We hope to make this a biannual event with one around MND Week and the other six months down the track in November. We hope the next one will be bigger and better than the last.

Tom McLoughlin
McMahon's Point

Nick & Tom McLoughlin
HatsOff! They had a lot of fun
They raised a lot of money
and they want to do it all again.

Dear Editor

Home modifications are one of the major expenses incurred with increasing disability.

Making your home wheelchair accessible can entail building ramps to avoid steps, widening doorways and remodelling the bathroom (safety rails, removal of the shower hob and repositioning the toilet).

Is this expense a capital expense which adds to the value of your home? Or is it another essential medical expense added to the burden of disability?

Our Government regards it as a capital expense and will not allow any tax relief for costs incurred in these essential modifications.

I urge all readers to join me in writing to your local MP to lobby for a change in this unfair tax ruling.

Jim Simpson
Five Dock

We welcome your ideas – Forum is your voice – so if you would like to contribute to the next issue, please write to the Editor.

Dear Editor

May I give some advice to people recently diagnosed with MND.

1. Never let anyone help you up by the arm – even if you don't think your arms are affected. We didn't know this and I used to help my husband up by his 'strong' arm and he ended up with a torn tendon in the right shoulder. Have them use a rolled up towel (passed around the back and under the arms with two ends to pull on), a lifting belt (which has handles all around it) or bend their knees, flatten their back and put their arms around your back.
2. Find a good physiotherapist and do regular physio. When my husband was first diagnosed he asked the specialist what he could do: go to the gym? – build himself up? The doctor told him absolutely nothing would work. How wrong he was. Physio will help keep your limbs mobile and strengthen your good muscles to last longer. We found out too late and my husband ended up with a frozen left shoulder.
3. For patient and carer – have patience. It makes a difficult life a little more bearable.

Enjoy every day, no matter how hard.

Sharyn Morris
Scone

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DISCLAIMER
All care has been taken in the preparation of this newsletter.
The MND Association of NSW disclaims any liability for its content.
The information contained within is of a general nature and to be used as a guide.

Editor: *Janet Nash*