THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

MND MOTOR NEURONE DISEASE

FORUM

March 2005

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Moving forward

Therapeutic cloning and motor neurone disease

Motor neurone disease has been highlighted in the news recently. Many of you will have read with interest media reports of a UK research project in which a licence has been granted to Prof Ian Wilmut to conduct therapeutic cloning of human embryos. Stem cells derived from the embryos will be used to produce human motor neurones.

The intention of this research is to produce cells for research in the laboratory that will allow better understanding of the causes of death of motor neurones and also to investigate the effects of drugs which could slow down or stop the death of motor neurones.

Recent human trials of drugs used to treat mice which have been genetically modified to develop MND have been very disappointing. Potentially exciting results have been seen in the animal models of MND, but when the same treatment is trialled in humans with MND, no benefit has been seen. The availability of human motor neurones in the laboratory must be a step forward in understanding the causes of and providing treatments for this disease.

Stem cell research is understandably controversial as there are many ethical issues involved. Therapeutic cloning of human embryos is not legal in Australia (it is legal, with strict guidelines, in the UK).

When Deborah Smith, medical writer for The Sydney Morning Herald, requested a statement to reflect the Association's view of Dr Wilmut's research, the following statement was prepared and sent to the SMH by Helen Sjardin-Howard, President of the MND Association of Australia:

The Motor Neurone Disease Association of Australia supports research which is legal, has sound scientific rationale and has the potential to bring us closer to finding the causes, improving treatments and discovering cures for motor neurone disease.

The Association recognises that the issues of embryonic stem cell research and therapeutic cloning raise significant moral, ethical and religious concerns.

However, in principle we support this UK research project providing it complies with the current law of the country in which it is being conducted, has sound scientific rationale and has the potential to bring us closer to an effective treatment for motor neurone disease

For a background on this story, go to page 10 for an article reprinted from The Times, London, 9 February 2005.

Janet Nash

Sunday 3 to Saturday 9 April is MND WEEK

Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries.
The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.

A message from the Acting CEO

Happy New Year to you all! Much has happened at the Association since the last *Forum* was published. We have farewelled, re-welcomed and welcomed staff and been faced with a very rapid building schedule for our new home. However, due to the hard work and willing teamwork of all staff and unstinting support from the Board and MND Volunteers, we have achieved our aim of moving to the new MND Centre on Friday 25 February. We are **moving forward**!

Staff members are very excited about the move to Gladesville. All services are finally together at one site and the new Centre holds the possibility for us as an Association to be more accessible to our members and volunteers. We hope you will consider becoming a regular volunteer at the new MND Centre. (See elsewhere in the *Forum* for details of the kind of volunteering needed). We also hope that people living with MND and their families will drop by more often to chat with staff, visit the library, attend education sessions or to see the types of equipment available for loan. We thank the Gladesville Project Team and in particular Janet Nash who has had the unenviable task of managing the move, organising and ensuring we get the best deal, on telephones, computers, chairs, plants, pavers, blinds and much more – thank you Janet.

Elizabeth Herbert returned to the fold on a contract basis to organise MND Week. She has managed to get everything in place in a very short space of time and it is all systems go for MND Week! We look forward to your support.

Rebecca Holahan is welcomed as the newest member of our team. Rebecca will provide much needed administrative assistance in our very busy office.

It has been very exciting to be able to combine the Launch of MND Week with the opening of the new MND Centre and we are grateful to Her Excellency Marie Bashir AC, Governor of NSW and Patron of the MND Association of NSW, for agreeing to perform these honours on 30 March. This year we will be hearing from young scientists who have been funded by the MND Association of NSW through the MND Research Institute of Australia. Following last year's new initiative to recognise the efforts of MND volunteers, we will be presenting awards to nominated volunteers and two scientists who have supported MND research and the MND Association of NSW for many years.

In keeping with the theme of **moving forward**, this issue of *Forum* focuses on the potential for research using human motor neurones. This is a complex issue hence our decision to provide you with information to help you better understand the concerns people may have. This issue also looks at how Family Support ensures it continues **moving forward** through the development of special projects to support the specific course of MND in each person. Family support strives to continue **moving forward** by responding to the needs of the people living with MND they support, networking and sharing information with other MND Associations' Family Support workers and by endeavouring to keep up to date with published evidence based MND care and management initiatives.

One constant for the Association is the dedication of our small band of volunteers in supporting and caring for people living with MND. Kevin Langdon, Vice Patron of the

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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.

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Association, remains very much involved by visiting support groups to talk to the coordinators and members about his experiences of diagnosis and living with MND and his long association with MNDA NSW. Kevin has also visited many clubs and organisations over the years to raise awareness of the needs of people with MND. This year, to ensure volunteers keep **moving forward**, Kevin will help us to develop an Ambassador program to train more people on how to approach clubs and organisations around the State and how to give talks on MND. Please let us know if you are interested in becoming an Ambassador for MNDA NSW. Marjorie Harrap, founder of the Association, also continues her invaluable work one day a week, handwriting condolence letters to recently bereaved families and thanking people for donations received in memory of a loved one. Marjorie will continue this commitment by assisting the Association to settle into its sixth home. There are many more volunteers across NSW working hard to raise awareness and much-needed funds. We thank you all and hope you have a successful MND Week!

MND WEEK
3 - 9 April 2005
provides an opportunity to increase awareness of motor neurone disease. This is needed to attract continuing Government funding and donations to support the vital work of the MND Association.

The MNDA NSW Board is actively seeking a new Chief Executive Officer. In the meantime, I will continue to fulfil the role of Acting CEO with much support and commitment from the MNDA NSW team.

To all those who lost loved ones and friends to MND over the holiday period I extend, on behalf of the Board and Staff, our deepest sympathy.

Carol Birks
Acting Chief Executive Officer

All members of the MND Association of New South Wales are invited to attend the launch of MND Week and the official opening of the Association's new Centre by Her Excellency Professor Marie Bashir AC, Governor of New South Wales and Patron of the Association
at Old Gladesville Hospital, Victoria Road, Gladesville
at 11.00 am
on Wednesday 30 March 2005.

If you would like to attend, please phone the Association on 8877 0999 as soon as possible as seating is strictly limited. An invitation card will be required for entry.

MND ASSOCIATION OF NSW CONTACT DETAILS HAVE CHANGED
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General enquiries, Family Support & Info Line: Phone 8877 0999 or Freecall 1800 640 144.
To contact a particular person at Gladesville, dial the number listed below or send an email:

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The MND Association of New South Wales moves to a new Centre at the Old Gladesville Hospital

The vision of finding a new home for the Association was championed by Project Leader, *Bob Howe*, ably assisted by *Bob Templeman,* MNDA NSW Treasurer, and volunteer, *Doug Talbert,* whose legal and property expertise ensured a safe choice.

After exhausting many avenues for possible accommodation that would meet the MND Association's needs, *Alex Malley*, Board Member of MNDA NSW, made the approach to the NSW Health Dept that secured a place for the new Centre at the Old Gladesville Hospital.

Gordon Fuller, Architect, provided an outstanding plan to transform the old dining hall and kitchen with adjacent enclosed verandahs. Gordon's meticulous attention to detail as Project Manager has achieved the maximum potential from the site. The result is a Centre where 14 members of staff can work together with volunteers to help to ensure the best possible quality of life for people living with MND and their families and carers.

Builder, *Michael Vumbaca* from Admire Homes, achieved the seemingly impossible task of completing the transformation of the old building in six intense weeks of work. Michael's expertise in planning kept a well coordinated team of workers on target for completion by mid February.

Suzanne Ballinger, whose own beautiful garden is regularly open for inspection under the Open Garden Scheme, took charge of landscaping and planting the gardens and courtyard to provide the caring finishing touches. A plea for donations of plants produced offerings from many sources including bagloads of blue agapanthus from *Mrs Joan Schmeising*. *Motyaj* gave generous support with provision of planter pots and *Cotswold Furniture* helped with teak benches for the courtyard at cost price .

But more was needed to get everything working.

Phenomenal support has been given by *Microsoft* through their community support programme — the Microsoft Unlimited Potential Software Donation Program. *Microsoft*, who have previously assisted the Association, have provided all the software that is required by the network of twenty computers. This generosity will pave the way for efficient running of our organisation.

The Office at Concord served the organisation well through its years of growth from 1995 onwards, but these premises were outgrown with the expansion of services provided by the Association and personnel.

All staff members were overjoyed with the wonderful touch of luxury so generously given by *Fisher & Paykel*—a beautiful DishDrawer washer to help with all the meetings that will be held on site. This will also boost our pride in a tidy kitchen.

On behalf of the Association, I extend thanks to all these people and organisations who have given so much to help with moving forward in the fight to defeat MND. It has been a privilege and a pleasure to work with all of them.

Janet Nash

Suzanne Ballinger leads her team of volunteer gardeners as they create the garden at the entrance to the new Centre at Gladesville: Andy Quaken, Ian Richter, Suzanne and the Butcher family — Mary, Peter, James and Nicole.

Family Support: moving forward

Special Projects and Carers Services

During the last few issues of *Forum*, Carol Birks, Manager, Family Support has written about different aspects of the Family Support team. For this issue Carol has asked me to write about my role as coordinator of *special projects* and carer's services. The concept of coordinator of carer's services is self-explanatory. However, coordinator of *special projects* requires some explanation.

Visitors are welcome to drop in to the MND Association at any time on week days - for information, a cup of tea, or just to have a look. The new Centre is in Building 4 at The Old Gladesville Hospital, Victoria Road, Gladesville.

Special projects fits nicely into the theme of this issue of Forum – **moving forward** - because it involves advancing the Association's level of service - looking at new ways of continuing to develop and improve the scope and reach of support services for people living with MND, their families and carers. No two people are affected with MND in quite the same way, so the support needs of people with MND also vary greatly depending on the symptoms experienced, the individual and family approach to managing MND and the support offered through the community the person lives in. This community includes networks of family and friends as well as the availability of community care services.

MNDA NSW family support aims to provide a range of support services to cater for individual need. For some people this may be just the right information at the right time. For others it will be regular phone calls or a home visit from the Regional Advisor while some may wish to join a support group or to attend an educational program. Some people with MND have special needs, e.g. those who live in more remote areas, those who have communication difficulties, people with MND who are in residential care and those with young families. MND carers also need systems of support through phone calls, groups, and educational programs.

MNDA NSW has undertaken needs surveys of people living with MND and their families in 1997 and more recently in 2002. These surveys have provided the team with a range of need priorities from members. These surveys have been used, with continuing feedback from members and carers, to develop business plans for MNDA NSW and to identify ways in which family support services can be developed. Special Projects involves exploring new projects to achieve the objectives of the current business plan and finding new ways of addressing the range of needs identified by members and carers.

As coordinator of *special projects* and carers services I work with the family support manager and other members of the family support team to improve the services we offer. Larger scale projects involve looking for funding opportunities to undertake service improvements that potentially involve considerable time and cost. These larger projects help us to build up major resources that are important to overall service development. I work with the manager of family support and other members of the team to write submissions for relevant grants, help to devise a program, and then evaluate and report on the project. Two major funded programs are underway at present. The first is the Volunteer Visitor Pilot Program (VVPP) in Newcastle and the Central Coast. Christina Jason, Regional Advisor for the area, is working very hard on this project with the help of Carol Birks and me. The VVPP has enabled us to train a wonderful group of volunteers who are currently being linked with people with MND in the area. It has also enabled us to develop important resources to train future MND volunteer visitors on an on-going basis. These resources include an educational program and manual for volunteers. The project has also facilitated the development of a bereavement protocol and a brochure to help explain the process of loss and grief.

Funding through the first round of NSW Health's Care for Carers Projects enabled us to develop a program of carers workshops and the MNDA NSW Carers Kit. This Kit has proved to be a valuable resource for MND carers and health and community care providers. The Carers Kit has also been used

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Family Support: moving forward

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to develop educational resources for care providers and volunteers.

Success with our submission for the *Link and Learn Project* through the second round of NSW Carers funding has allowed us to devise the program outlined in **Carers News.** This project provides an opportunity to target improved support and education for regional carers. The Program also presents an opportunity to trial telephone group support as a means of connecting and supporting carers (and later members) in regional NSW. The first phase of Link and Learn is based in Wollongong for carers in southern NSW. MNDA NSW Regional Advisor for this region, Ruth Quaken, is working very hard with me on this project and we have received a great deal of assistance and goodwill from health professionals in the Illawarra area. Target areas for future Link and Learn Programs include Western NSW and Central Coast/Newcastle/Hunter region.

Special Projects can be much smaller in scale and can be squeezed into the busy working routine of our dedicated family support team with some general direction from the *special projects* coordinator. Two of these smaller projects have been devising a variety of sample communication charts for people with MND who have severe speech impairment and compiling an information package for people with MND who have young children.

In response to surveys, people with MND and their carers have indicated the need for health professionals to be better informed about MND and its management. The knowledge base of General Practitioners has presented a particular challenge and through *special projects* we have been investigating ways of providing more up to date information to GPs. Updating and improving our booklet for MND care management in nursing homes is also a current project.

Moving forward and developing care also applies to promoting the best possible care for people with MND within the health and community care sector. Best practice care depends on quality information and collaboration. Information on care of MND is important for a range of health professionals. A major *special projects* initiative last year was to establish MND Special Interest Groups (SIGs) for health professionals. Three SIGs were launched during our Annual Conference in June last year and an MND update a research article and questions for general "e" group discussion are emailed on a bi-monthly basis. In this way MNDA NSW through *special projects* aims to disseminate, pool and improve knowledge of MND care among a range of health professionals.

A fundamental need of people with MND and their families is to be supported well through community services to enable care to continue at home. This is achieved through services such as community nursing, Home Care and Community Options. Funding for these services comes through a number of government departments and availability of services can vary considerably over time and geographic area.

You can help us.
If you are experiencing difficulty obtaining adequate support services please let us know.
Your story is important in this process and we may be able to help you to access vital services.

Special Projects involves working with the MNDA family support team to build awareness within government departments regarding the special and complex needs of people with MND and their carers. This involves writing submissions in response to government proposals and constant lobbying for a system to be in place that enables people with MND to access adequate community support services when needed. This process is ongoing and requires perseverance.

We would also welcome any suggestions for improvements in our services to you and to people with MND in general. These suggestions and *special projects* help us to continue to make a difference and to ***move forward*** in developing the MNDA NSW family support service and promoting the best possible care within the broad range of service provision. We continue to learn from our members and their families.

Anita Richter

Carers news

The *Link and Learn Program* for MND carers in Southern NSW commenced with a two-day residential workshop at the Novotel, Northbeach Wollongong on March 1 & 2. This will be followed by one-hour telephone group sessions for six subsequent weeks. These sessions allow support and education to continue without the need to leave home.

Caring for a person with MND raises complex issues of managing disability, use of appropriate equipment, planning ahead and an understanding of emotional issues and available support services. Increased knowledge and support also comes through sharing ideas with others in a similar situation. Carers must learn ways of taking care of their own health and wellbeing to continue in this role. *Link and Learn* is funded through a grant from NSW Health's Care for Carers Projects. If carers are better informed and supported, the benefit ultimately flows on to the person they are caring for. People living with MND may wish to live one day at a time, but families need to plan ahead to help avoid unforseen difficulties.

If you have been recently diagnosed with MND and have a family and friends who would like to learn more about MND, please speak to your Regional Advisor about organising an information session in your area.

The criteria for the grant emphasised self-care for carers, and support for regional carers. NSW Health is very aware of the important contribution made by carers throughout the State and aims to support a range of carers by inviting submissions for funding from interested organizations. We have been fortunate in the level of interest and quality of the speakers who have been invited to take part in the workshops. Carer Respite Centres across the area have been most helpful in offering to help with respite in the home to allow carers to attend the workshop and participate in the telephone group sessions.

We will be running this Program in two more areas of NSW during the next two years.

Our regular program of carers workshops (one day a week for four weeks) will be held at our new Centre at Gladesville in September this year.

For further information please contact the MNDA office on 8877 0999 or 1800 640 144.

Family Support Dates for the Diary in 2005

March 9,10,11 - Rosehill, Sydey	**Daily Living Expo** A three-day expo to showcase the latest equipment available in Australia from equipment suppliers and manufacturers. In place of the MNDA NSW Equipment Expo this year, MNDA Staff will be on hand on the Thursday to assist people with MND and their families in looking at equipment suitable for their needs.
Friday March 11 - **Concord Hospital** (arranged before the date of moving to Gladesville was known).	**Ask the Experts** and **MND DNA Donor Drive** A new initiative – experts in MND research, neurology, MND care and management and palliative care will be invited to give short presentations and to answer questions from the audience. People living with MND and family and friends are invited to attend. Please RSVP to the MND office (Ph 8877 0999).
Wednesday March 30 - Gladesville	**Launch of MND Week**
Tuesday May 3 - Gladesville	**Information Evening** For people recently diagnosed with MND their families and friends
Thursday May 5 and 12 - Central Coast, Newcastle and Hunter Region	**Learn now/Live well Program** A two-day education and support program for people with MND and their family to assist them to live well with MND. (venue to be announced)
Monday May 23 - Gladesville	**Volunteer education and information day and Launch of MND Support Group Guidelines and the MND Ambassador Program** This new initiative will be for all existing MNDA NSW volunteers and support group coordinators to learn more about MND and the Association. During the day the new Support Group Guidelines will also be launched. This all day session will also provide an opportunity for people wishing to become a volunteer or an MND Ambassador to learn about the types of Volunteer positions available.
Monday September 5 - Gladesville	**Care for Carers Course** Four weekly education and support sessions for family or friends caring for a person with MND

Please contact the MNDA NSW office on 8877 0999 or 1800 640 144 for further information or to express your interest in attending any of the programs or sessions above.

Regional NSW and the ACT

Southern Highlands/Monaro

We had a small but friendly gathering for the first meeting of the year on Saturday February 5th at Clare Holland House in Canberra. We were delighted to see some new faces and hope the meetings will be of some benefit and enjoyment to them.

Sadly, we have also lost members. Involvement in a group such as this has its "up" side but also its "down" side. Facing up to the loss of people you have enjoyed seeing regularly and have become good friends with is difficult and can make you wary of returning to the group. Despite this, many people feel the friendship and benefits of being with others in their own situation are more than worth the sadness at these times. Past carers are encouraged to come to meetings and we hope they will rejoin us when they are ready.

Groups tend to go through periods of change due to membership interests and numbers. We have decided to have a little more structure in the program and, at the time this Forum goes to print, are planning outings and activities for the rest of the year. These activities will include a tour of the facilities available at Clare Holland House, lunch in Braidwood to visit a member there, a visit to The Independent Living Centre at Weston and a discussion led by Julie Kulikowski (social worker at Clare Holland House) on common issues faced by those with MND. All of these followed by chat and a cuppa!

We usually meet on the first Saturday of most months at Clare Holland House, Menindee Drive, Barton at 1pm. Those with MND, their families, carers, past carers and friends are most welcome. Due to the varied nature of activities this year contact me to check on place/time. When the programme is finalised it will be posted on our website at www.mndnsw.asn.au.

Allison Pearson
Ph: 6238 3769
Email: allisonp@mndnsw.asn.au

Newcastle & Hunter

Our annual Bowls Day at the Abermain Bowling Club is now known as The Shirley Paterson Remembrance Bowls Day. The day was well organised by members of the group – the number that attended was greater than last year and monies raised were more than any other bowls day.

We started off with bowls, followed by a BBQ lunch and then we were entertained by Country and Western Singers who came from Tamworth and donated their time to the support group on the day. People in the club were up dancing which was really entertaining. Our fundraiser, Neta Cassidy, already has ideas to use them again for another event.

If you live in the Central Coast, Newcastle, Hunter or Great Lakes region and would like to attend the Learn Now Live Well program in May, please contact Christina Jason or Caroline Gleig on 1800 640 144 for further details and to register your interest.

MND Week. All is in place for the remembrance service and shopping centres for MND Week. Our group will be manning three major shopping centres in Newcastle and one in Maitland. Once again we will be selling cornflowers, cornflower seeds, cornflower metal badges, our own design coffee cups, pens and cornflower stubby beer holders.

Brenda Taute has organised a Charity Ball for MND to be held at the Singleton Civic Centre on Saturday 12 March.

There will be lucky door prizes and an auction during the night. Tickets are $95 each. For more information contact Alistair on 02 4947 1983.

Alistair Fyfe
Secretary

Support Groups

South West Support Group (Panania)
The first meeting of the year was held in February. We had a very informative morning with the guest speaker from Liverpool Carelink Centre. Group members were very interested in the service and how it could help them find community support and information. The group was renamed last year as the venue is close to many Southern Metropolitan suburbs. We meet on the second Tuesday of alternate months Please call the office on 8877 0999 if you are interested in coming. The group loves to welcome new members.

Allison Pearson has developed guidelines for MND Support Groups. These will be presented at a special Volunteer day at Gladesville on Monday 23 May (see page 12).

At the next meeting in April, I am hoping to be able to present a slide show of pictures from our new premises at Gladesville for those who are unable to visit personally. I would love to see you there.

Caroline Gleig
Regional Advisor

Central Coast

January was a busy meeting: we welcomed back Kevin Langdon; we met and welcomed Mary Butcher, who is now the Regional Advisor for our area; and we welcomed lots of new folk. We were sorry to farewell Christina Jason—we thank her for her love and caring and wish her well.

Our involvement in Rotary Club of The Entrance Combined Community Raffle has raised $900 which will support MND research. There was great excitement as Keith Thompson-Burke, a good MND supporter, won 3rd prize which was a nice parcel from Retravision. Thank you to all who helped with this grand effort.

MND Week will soon be with us. We will have stalls at BiLo Budgewoi & Erina Fair on Thurs 7 April, SupaCenta Tuggerah and IGA-Jewels Erina on Friday 8, Lakehaven Saturday 9 April. There will be boxes of cornflowers at many pharmacies throughout the Central Coast and some stores including Erica Dash Podiatry, Erina. We hope to cover the Coast in Cornflower Blue.

Meetings this year will be at Gosford Senior Citizens Centre, Albany Street (North), Gosford at 2pm on Saturdays: 19 March, 28 May, 30 July, 8 October and 10 December. New members and interested persons will be made most welcome.

Looking forward with hope.

Audree Dash

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* or email *ozpals-subscribe@yahoogroups.com.*
- **Internet Chat - Living with MND** Every Tuesday at 1pm & Thursday & Sunday at 8pm EST. Go to *www.mnd.asn.au/* then click on the chat room link. For a chat room which is open 24 hours per day, try *http://neuro-mancer.mgh.harvard.edu/echat42/ALS/.*
- Visit the MNDA NSW website at *www.mndnsw.asn.au* for information, news and links to other sites.

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Research

Dolly the sheep scientist licensed to clone embryos

The scientist who created Dolly the sheep will attempt to clone human embryos after securing a licence to use the technique to find a cure for motor neurone disease.

Ian Wilmut, of the Roslin Institute, near Edinburgh, was awarded Britain's second licence to conduct therapeutic cloning yesterday by the Human Fertilisation and Embryology Authority, clearing the way for experiments to begin within months.

His team, which includes researchers from King's College London, will use the procedure to study motor neurone disease (MND).

By cloning cells from patients with the wasting disease, Professor Wilmut aims to create an unprecedented model for investigating the disorder's causes and development. This will transform the prospects for developing an effective therapy, allowing scientists to test promising drugs on human cells in the laboratory rather than on animals or people.

At present there is no cure for MND, in which the nerve cells that control the muscles degenerate and die. Most people with MND die within two to five years of diagnosis.

While human cloning for medical research has been legal in Britain since 2001, the Roslin-King's team is only the second to be granted the required licence. Scientists at the University of Newcastle upon Tyne became the first to win approval last August.

Professor Wilmut said that the work would not involve reproductive cloning. "Our aim will be to generate stem cells purely for research purposes," he said yesterday. "The eggs we use will not be allowed to grow beyond 14 days. Once the stem cells are removed for cell culture, the remaining cells will be destroyed."

The goal of therapeutic cloning is to generate human embryonic stem (ES) cells that are genetically identical to patients' and can be used to grow either replacement tissues for transplant or model cells for investigating certain diseases. While the Newcastle group aims ultimately to use cloned ES cells to treat diseases such as diabetes, Professor Wilmut plans to employ them purely as laboratory tools.

He aims to produce cloned ES cells using the DNA of adults with a genetic form of MND and coax these to develop into motor neurons — the long nerve cells that transmit messages from the brain and spinal cord to the muscles.

"We will compare the behaviour and chemical profile of neurons with the gene defect to those without," Christopher Shaw, of King's, another member of the team, said. "This will tell us about the earliest events that ultimately lead to cell death."

Groups who oppose all cloning and embryo research attacked the ruling, saying that it was far from certain that adult stem cells could not be used in the research. A representative of Comment on Reproductive Ethics said: "Human cloning remains dangerous, undesirable and unnecessary." ☐

This article has been reprinted from a story written by Mark Henderson, Science Correspondent, that appeared in The Times, London, February 9 2005

MND Research - Hope for a future - a NSW scientific meeting

A scientific meeting – *MND Research - Hope for a future* - will be held at the MND Association's new Centre at the Old Gladesville Hospital at 2.30pm on **Wednesday 30 March.** This meeting, intended for a medical/scientific audience, will follow the official opening of the Centre. Dr Dominic Rowe, President, MND Research Institute of Australia, will Chair the meeting.

Presentations will highlight research funded by the Institute, and other research with a focus on MND.

Presentations will include:

Dr Julie Atkin, MNDRIA Research Fellow MND Research Laboratory, Howard Florey Institute , University of Melbourne
Mechanisms of mutant SOD1 mediated toxicity in ALS

Dr Roger Chung, Bill Gole MND Research Fellow, NeuroRepair Group, School of Medicine, University of Tasmania
Metallothionein-based neuroprotection in motor neurone disease

Dr Sumana Gopinath, Molecular Medicine, University of Sydney
Finding genes causing familial forms of MND.

Dr Valerie Hansen, Bill Gole MND Research Fellow, Dept of Pathology, University of Sydney
Insights into the genetic basis of sporadic MND

Dr Steve Vucic, MNDA NSW Clinical Research Scholar .Prince of Wales Medical Research Institute, University of NSW
Brain excitability in motor neurone disease

If you would like to attend, please contact Janet Nash (Ph: 02 8877 0901 or email janetn@mndnsw.asn.au) as space is limited.

15th International Symposium on ALS/MND

I attended the 15th International Symposium on Amyotrophic Lateral Sclerosis and Motor Neurone Disease that was held in Philadelphia from December 2-4, 2004. The meeting has grown dramatically over the last three years, with over 750 registrants. It is a unique meeting with patients, carers, support and lobby groups, research organisations, clinicians and basic scientists all at the one meeting. The meeting is held in parallel sessions with clinical and scientific presentations run at the same time. There were many keynote speakers, addressing basic biological questions including the mechanisms of aging, and how protein aggregation may lead to neurodegeneration. There was great emphasis on protein aggregation in different neurodegenerative diseases, including polyglutamine diseases, with much discussion on approaches to treatment. Of direct relevance was discussion of a trial of leuprolide in spinobulbar muscular atrophy that is underway in Japan, and may be commencing at the US National Institutes of Health.

For the interested reader, the full abstract book and programme are available at www.mndassociation.org/full-site/symposium/phily/index.htm .
The next ALS/MND Symposium is in Dublin in December 2005.

There was a great deal of new information in the pathogenesis of ALS, with new information about chemokine activation in ALS and other neurodegenerative diseases. There was a lot of new data on microglial activation and modulation of glutamate receptors by glia that may be relevant for motor neurone cell death. Similar to previous years, there appear to be many mechanisms involved in the pathogenesis of motor neurone diseases, and they are not necessarily mutually exclusive.

Regarding therapy in ALS/MND, the results of a randomised trial of non-invasive positive pressure ventilation from the United Kingdom was presented by Stephen Burke from Newcastle Upon Tyne. This trial demonstrated a 50% reduction in death during the study period, showing the potent effect of non-invasive ventilation in ALS/MND. There were other data from trials presented, which included a phase one n=5 trial of hyperbaric oxygen therapy by Walter Bradley from Florida. He concluded that it was safe, and not surprisingly, did not recommend hyperbaric oxygen therapy in ALS. A Japanese study that used endaravone, a free radical scavenger was presented by Yoshino from Tokyo. This drug is already approved for use in stroke in Japan, and did not show efficacy in this n=40 trial. The results of the phase 2 CoenzymeQ10 trial were presented on behalf of the NEALS consortium by Kimberley Ferrante. Although this therapy is effective in the mouse model, there was no effect in this trial (n=31). These patients tolerated CoQ10 up to a dose of 3000 mg per day without major adverse effect. It is unlikely to progress to phase three trial.

Dr Merrit Cudkowicz presented the negative data from the celecoxib trial. This was a phase 2/3 study supported by Pharmacia and then Pfizer. There was no benefit in patients taking 800 mg per day, with no significant adverse effects. Lastly, a multicentre phase 2 randomised control trial was presented by Vincent Meininger from Paris that used pentoxifylline, a phosphodiesterase 4b inhibitor. This very large trial recruited 400 patients at a rate of 100 patients per month! Unfortunately, the patients in the treatment arm showed a deleterious effect on survival, and the trial was terminated.

The other session of major interest was in the refining of surrogate markers in ALS/MND, in order to define these diseases with a higher degree of accuracy. It has long been argued that these are several diseases that are clustered together. Increasingly sophisticated neurophysiology, objective markers of upper and lower motor neurone dysfunction were elegantly discussed by Dr Mitsumoto. Increasing use of diffusion tensor imaging and voxel based morphometry are helping to define the upper motor neurone lesion in ALS/MND.

These are just a few impressions of a packed three days in Philadelphia.

Lastly, Mr Rod Harris from MNDA VIC was elected as the President of the International Alliance of ALS/MND Associations. Congratulations to Rod!

Dominic B. Rowe, Neurologist
MND Clinic Royal North Shore Hospital

Moving forward with volunteers

The MND Association of NSW was founded by Marjorie and Bill Harrap and a group of other dedicated volunteers in 1981. Since that time, volunteers have continually formed the backbone of the Association, providing many hours of unpaid work. Increasingly, as the Association has grown, there have been difficulties in supporting volunteers at the office in Sydney – the necessary space was simply not available.

The new Centre at Gladesville has provided a move forward to overcome this obstacle. The Centre includes a centrally located multi-function room which can be used as one large or (if divided) two smaller meeting rooms, boardroom, library and volunteer activity room. It provides an opportunity for volunteers to work together assisting the Association during MND Week or throughout the year with mail-outs, the library, meetings, photocopying etc.

Volunteer receptionist/s

The Centre has a reception desk which needs to be 'manned' each day. This desk is at the hub of the organisation, positioned near the entrance and CEO's office, and at the meeting point between Family Support, Administration and Fundraising, the copy centre, the kitchen and the courtyard. Unfortunately, a stand of grand old trees blocks the views over the water. Ample parking spaces are available, and a bus stop is nearby.

Come and spend a day as part of our team. If you would like to bring a friend, the reception desk has plenty of room for two people so this is the opportunity for you to have a companiable day with a friend, knowing that the time you are giving will benefit many others. ***Interested people are needed for the position of Volunteer Receptionist now.***

If you can spare one day each week, or month, or quarter and would like to help, please contact Roslyn Adams on 8877 0908.

MND Volunteer Education and Information Day on **Monday 23 May 2005**

All existing volunteers, Support Group Coordinators and people interested in becoming an MND Volunteer are invited to the forthcoming MND Volunteer Education and Information Day at the MND Association's Centre at Gladesville**.** The day will include a varied program with the morning session focusing on education sessions related to MND Care and Management, the Role of the Association and Volunteer Policies and Procedures. The types of MND Volunteer positions available will also be outlined.

The afternoon session will consist of two concurrent sessions. One session will launch the MND Support Group Guidelines and will include an opportunity for support group coordinators to share experiences and ideas. At the other session, Kevin Langdon, Vice Patron of the MND Association of NSW, will launch the MND Ambassador Program.

This Education and Information Day is planned to be an annual event and will be the first step in implementing regular volunteer get togethers at the MND Association. A full program will be sent to all registered volunteer and support group coordinators when finalised.

All MND support groups are encouraged to send a representative to this meeting. Assistance with travel is available from the Association if required.

If you are interested in attending the Volunteer Education day to learn more about MND and volunteering or if you would like to register as a volunteer now, please contact Roslyn Adams on 8877 0908.

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