

From the Executive Officer's Desk

March 2011

The New Year has started with a busy program. The Board met to review its strategic plan to give the association its direction for the next three years. No major changes of direction, just sharpening the lens on what we do: our focus on patients, their carers and families; raising awareness and funds to support those activities not funded by the Health Department of WA; collaboration with allied health services; increasing our contribution to research, and following best practice in management of the association.

This year we reconfirmed our long standing Patrons for a further three years: Jon Sanders AO. OBE, Keith Potger, and Ken Judge. In addition, Narelda Jacobs was appointed as our new fourth Patron. Narelda's profile appears later in the newsletter. Already Narelda has made a substantial contribution to MNDAWA by raising awareness through her position in the media, as well as being our MC at major events. Thank you to all our Patrons for their long time support, and welcome to Narelda. We look forward to a long and mutually beneficial relationship.

David Helfgott concert

Through the generous hospitality of Kevin and Petrice Judge, approximately 150 people enjoyed David Helfgott playing the classics in his inimitable style in Kevin and Petrice's home.



Organised by the Beer and Beef Club of Perth, the evening included a rousing band performance from the Royal Agricultural Society WA Brass, and auctions of memorabilia and unique items from more than 40 supporting people and companies (see page 2). Proceeds from the evening will come to MNDAWA and the ECU Diploma of Brewing. The performance by RASWA Brass was a tribute to Allan Conroy, a long time president and musician with the band, and who succumbed to MND in 2009. Special thanks go to Narelda Jacobs, our MC for the night and to Mark Whiteman, our auctioneer. Thank

you too to David and Gillian Helfgott. Our grateful thanks also go to the organisers who coordinated the function: Kevin Judge, Warrick Welsh, Bob Stirling and Ken Judge. It was truly a unique event.

Rare Diseases Symposium Awakening Australia to Rare Diseases

This symposium brings a number of international speakers to Perth to present information on research, patient empowerment, patient care and support, networks, partnerships and collaboration. Participants will have the opportunity to engage in discussion of the issues affecting them in collaborative workshop sessions. The outcomes of these workshops will further the development of a national plan for Australia to care for people with rare diseases. I have represented the Association in the planning process. For full details go to the link on the MND home page www.mndawa.asn.au where you will find the program and the registration process. If you need help please phone the MND office on (08) 9346 7355.

When: 17-20 April 2011

Where: Esplanade Hotel, Fremantle

Cost: MNDAWA members interested in attending can apply to the MND Association for funds to cover their attendance at one session for \$66.00

Staff changes

On Friday 18 February, we bid a sad farewell to Samantha Whittle, who was a Care Advisor for the past four and half years. Sam is recognised for her dedication, her compassion and her determination to get things done. Sam is now a Social Worker with

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NEWS FLASH!

There is some breaking news about drug trials in Australia for a new drug that might bring benefit to MND patients. Dexamipexole is a newly synthesised drug created by Knopp Neuroscience Inc. Although it is not currently known how this drug works in the body, laboratory studies have demonstrated that this drug has neuroprotective properties. I will be writing to all patients in the next week with more details. If you wish to check the web site here is the link, however the opportunity for Australians to participate in trials will be very limited once the trials commence.

http://clinicaltrials.gov/ct2/show/study/NCT01281189?term=ALS&rank=77&show_locs=Y#locn

The US National Institute of Health Clinical Trial website lists 501 studies that have been completed, are currently recruiting or are pending. <http://clinicaltrials.gov/ct2/results?term=ALS>

As you can see the researchers around the world are very active in their search for a cause and cure.

More information on pg 7

Contact Details

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 Centre for Neurological Support
 The Niche
 Suite B/11 Aberdare Rd
 Nedlands WA 6009
 Phone: 9346 7355
 Fax: 9346 7332
 Email: admin@mndawa.asn.au
 Web: www.mndawa.asn.au

Office Hours

9:00 am - 4:30 pm Mon-Fri
 For after hours, call **0439 918 052** to speak with a trained volunteer.

Emergency

If you have an urgent matter please contact Sir Charles Gairdner Hospital on **(08) 9346 7391** or your nearest Emergency Department

Membership

MNDAWA is a member of MND Australia, with a delegate on the Board. It also has strong links with other MND Associations around Australia and internationally, and the MND Research Institute of Australia.

Staff

Executive Officer.....Dr Sue Colyer
 Care Advisor.....Diana Menzie
 Care Advisor.....Rose Gibbins
 Care Advisor.....Cherylyn Vickery
 Care Advisor.....Jude Humphreys
 Education and Development Advisor.....Cindy Evans
 Accountant.....Ling Lee
 Office Administrator.....Soraya Kumail
 Project Administrator.....Raquel Rodriguez

Regional Contacts

Mrs Sandra Marlow - GERALDTON
 Ph: (08) 9964 9034

Newsletter Panel

Editor.....Dr Sue Colyer
 Sub-editor.....Raquel Rodriguez

April Newsletter

We encourage readers to send us stories of their holiday adventures, achievements, life in general or a joke to evoke a smile. We would love to hear from you!

Items for the newsletter can be sent to admin@mndawa.asn.au

By: Monday 28 March 2011

Disclaimer: The articles provided in this newsletter sometimes contain personal opinions that may not reflect board policy. Research articles are selected from reliable sources, we do our best to ensure currency and accuracy.

Patrons

Ms Narelda Jacobs
 Mr. Ken Judge
 Mr. Keith Potger
 Mr. Jon Sanders, AO, OBE

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 Hon Accountant.....Mr Tony Silipo

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 Dr R. EdisRPH Shenton Park Neurologist
 Prof F. Mastaglia.....SCG Hospital Neurologist
 Prof Nigel Laing.....Research
 Trevor Jones.....Assistive Technology
 Chris Kingsnorth.....Occupational Therapist
 Judy Griffiths.....Grief and Loss Counsellor
 Helen Sjardin-Howard.....Speech Pathologist

Care Foundation Trustees

Karen Smart (Senior Trustee)
 Ross Whiteman
 Marie Macdonald
 Peter Murray
 Dean Finlay
 Bruce Ponting

Online donations

You can now access three online options for donating to MNDAWA from our website home page using:



MNDAWA Platinum Partners

Halls Head Cricket Club
 Jim Kidd Sports
 Maritime Union of Australia
 Australian Manufacturing Workers Union
 Apache Energy
 Stadium Snappers

Thank you to all the Helfgott Concert Sponsors

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- ◇ David and Gillian Helfgott
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- ◇ Indian Ocean Brewing Co.
- ◇ Intercontinental Perth Burswood
- ◇ John Silvester
- ◇ Glenn Mitchell ABC Radio Sport
- ◇ Kitchen Headquarters
- ◇ Limones Restaurant
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- ◇ Parmelia Hilton Perth
- ◇ Philip Gardiner MLC
- ◇ QANTAS
- ◇ Quilpie Opals Perth
- ◇ Richard Winterton
- ◇ Rod Constable
- ◇ The Royal Agricultural Society of WA Brass
- ◇ Royal Fremantle Golf Club
- ◇ Satay 4 U - Alan Chang
- ◇ Sheila Walker & Tosh Tielman
- ◇ Simplot Australia
- ◇ The Cumquat Tree Gift Shop
- ◇ Watershed Wines - Wal Pausin

MND Upcoming Events Diary

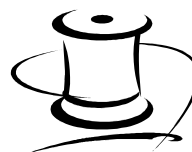
	Event	Date	Time	Venue	
M a r c h	Labour Day Public Holiday	Mon 7 March 2011	MND Office will be closed		
	Craft Group	Thurs 10 March 2011	10am-2pm	The Niche - Passmore Room	
	MND Volunteers Meeting	Thurs 10 March 2011	10:30-11:30am	The Niche - Passmore Room	
	Carers Lunch	Tues 22 March 2011	11:30am-1pm	The Niche - Passmore Room	
	Past Carers Group	Wed 23 March 2011	11am	Mandurah Dome Cafe - take the shuttle bus from the train station to Dome Cafe. RSVP attendance by 22 March to Heather Joppek on (08) 9314 3863	
A p r i l	Craft Group	Thurs 14 April 2011	10am-2pm	The Niche - Passmore Room	
	MND Volunteers Meeting	Thurs 14 April 2011	10:30-11:30am	The Niche - Passmore Room	
	Carers Lunch	Tues 19 April 2011	11:30am-1pm	The Niche - Passmore Room	
	Easter and Anzac Day Public Holiday	Fri 22 - 26 April 2011	MND Office will be closed		
	Past Carers Group	Thursday 28 April 2011	2pm	9 Stonefield Crt, Padbury. RSVP attendance by 27 April to Els Burggraf on (08) 9307 5521	
M a y	Awareness Week 1-7 May 2011	Walk to D'Feet MND	Sunday 1 May 2011	9am-2pm	Burswood Park Registrations online soon!
		MND Professional Day	Wednesday 4 May 2011	11:30-1pm	The Niche - Conference Room (for allied health professionals only)
		Blue Cornflower Day Street Appeal	Friday 6 May 2011	TBA	Perth CBD and various shopping centres
	MNDAWA Volunteers Thank You Lunch	Wednesday 11 May 2011	11:30am-2pm	Zamia Cafe - Kings Park (National Volunteers Week) RSVP by Wednesday 4 May 2011	
	Craft Group	Thursday 12 May 2011	10am-2pm	The Niche - Passmore Room	
	MND Volunteers Meeting	Thursday 12 May 2011	10:30-11:30am	The Niche - Passmore Room	
	Carers Lunch	Tuesday 24 May 2011	11:30am-1pm	The Niche - Passmore Room	
	Past Carers Group	Thursday 26 May 2011	2pm	14 Pumice Crt, Forrestfield RSVP attendance by 25 May to Lesley Williams on (08) 9453 2002	

Nifty's March highlights...



MND Volunteers Meeting

Thursday 10 March 2011
10:30-11:30am
The Niche - Passmore Room



Craft Group

Thursday 10 March 2011
10am-2pm
The Niche - Passmore Room



Carers Lunch

Tuesday 22 March 2011
11:30am-1pm
The Niche - Passmore Room

Past Carers Group

Wed 23 March 2011
11am at Mandurah Dome Cafe
RSVP attendance by 22 March to Heather Joppek on (08) 9314 3863

Care Advisor's Corner - March 2011

Hello everyone!

Yes, we are into March and the weather has been at times in the extremes, but with any luck there is some respite in the wings. This will make outside activities more inviting and getting to appointments a little more pleasant.

For those of you who enjoy the atmosphere of being by the beach, taking a stroll with family, loved ones and the family pet - you can hire Beach wheelchairs at Metropolitan areas as well as in the Margaret River Area. They are very easy to use and designed to travel over grass, paved areas and soft sand.



You may like to incorporate this activity with a **Couple's Break** or a **Carer's Break** in one of the same locations. If this is of interest to you, your Care Advisor can assist in organising these breaks when they are of best benefit to you.

If you wish to view the Beach Wheelchairs, you can access the information on the internet or phone the contact number supplied below :-

Bunbury - 2 chairs available.

Contact Enable Southwest on ph (08) 9792 7500

Busselton - 2 chairs available.

Contact Equinox Café on ph (08) 9752 4641 or www.busselton.wa.gov.au by searching Equinox Café

Dunsborough - Contact Naturalise Community Cafe Centre on ph (08) 9755 3966

Cockburn - Contact City of Cockburn (Coogee Surf Life Savers) booking Officer on (08) 9411 3432

Out Door Cinemas



There is also the opportunity to enjoy the cooler weather at our amazing and accessible outdoor cinemas in Perth. What better way to enjoy the Australian tradition of picnicking and soaking up the wonderful ambience of cinema at the same time. This can be a great way to spend some one-on-one time or involve the whole family making it an occasion to be shared. Perth outdoor cinema locations:

Movies by Burwood

See the movie on a 13-metre screen with surround sound in the lovely settings of Burswood info@moviesbyburwood.com

Luna Outdoor Cinema

Located in the heart of Leederville, featuring a tropical garden setting (155 Oxford Street, Leederville) luna@lunaplace.com

Camelot Cinema

One of Perth's intimate cosy outdoor venues located on Lochiel Street, Mosman Park www.lunapalace.com.au

Somerville Auditorium - University of Western Australia

A magnificent venue that is the venue for Perth's International Arts Festivals Lottery West Film Season.

Galaxy Drive – In

Want to experience the last operating drive-in cinema in Perth? Lot 26 Goollelal Drive, Kingsley www.galaxydrivein.com.au

The Care Advisors at the Niche are available to assist with any queries relating to all aspects of care for our patient members and we welcome new ideas that can be of assistance to us. As Australians, we are very inventive and find solutions to problems that are not always mainstream or perhaps cannot be brought off the shelf. If you are one of these people and wish to share an idea or have resolved a problem, we would welcome your input, which may also benefit others.

The Care Advisors will be running Pamper days 3 times a year, Carers Luncheons once a month with a midyear Christmas outing and supporting educational sessions run by the Education and Development Advisor. So there are many opportunities to meet up and get together.

That is all for now from the Care Advisors Corner. We look forward to seeing you all, whether it be at your home, at one of the MND clinics or at one of our functions where it will be our pleasure to be of assistance.

Bye for now,

Rose Gibbins
MNDWA Care Advisor

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Call 1300 65 1300 for more information
Servicing all areas of WA

1300 65 1300

Professional Counselling

For those of you who would like to talk things over with a professional counsellor, we now have a list of therapists who have expressed an interest in working with people living with MND.

Please ask your Care Advisor for more information.



MNDAWA has a small but growing and diverse number of volunteers, many of them busily working away on their own unique projects in their own unique ways quietly behind the scenes. Each month we will share a story gifted to us by one of those volunteers.

Joy's Story



Joy Diver is an MNDAWA pioneer. She has been a volunteer for our association since before its conception in 1982 and is one of the driving forces behind the Craft Group, a social networking group that meets once a month and has raised thousands of dollars for MND in its lifetime.

Joy was introduced to MND when her father was diagnosed in Mandurah in the 1970s. In the 1980s an advert was placed in the Western Australian newspaper by Jim Symonds, a newly diagnosed man who had moved to WA with his family from the Eastern States. Jim and his family were feeling alone and isolated so through the paper he asked for

others to join him for a support meeting once a month in a small church hall in Wembley. Joy answered that advert, as did a number of other people who also felt the need for help, support and sharing. Joy has been meeting with MNDAWA volunteers once a month from that time.

From this small seed has grown MNDAWA, our association that is dedicated to providing support, help and care to people with MND, their families and the allied health professionals who work beside them. In Joy's words "It doesn't matter how much or how little you volunteer, it all makes a difference. It provides great satisfaction and makes you feel good".

Joy and the Craft Group volunteers meet every second Thursday at The Niche between 10am – 2pm and no skills are required. If you are interested in volunteering please do drop in.

Volunteer Projects

MNDAWA is looking for a volunteer to take photographs of our equipment so that we can set up an online database. We want to make it easier for people with MND, and the allied health professionals to select appropriate tools for enhancing independence. If anyone out there has skills at creating online databases we are looking for you too!



Please do not hesitate to contact Cindy Evans at the MND Office on 93467355 or Cindy.Evan@mndawa.asn.au

Ask The Expert 2011

"Ask The Expert" is an MNDAWA 2011 initiative that will give people with MND, their primary support networks, and the health professionals with opportunities to learn more about different aspects of motor neurone disease.

These sessions are informal and will be held in various locations around the metropolitan area depending upon where the request has come from. The experts who attend are donating their time so please be prepared to ask any question that you have.

If you would like to request an expert on any MND related topic DO NOT HESITATE to ask!!! We will do our best to find the professional to answer your questions.

This month's seminar:

**Saturday 19th March
1.30pm – 3.30pm**

Molecular and Neurogenetics professor Nigel Laing
Genetic traits in familial MND
The Niche, 11 Aberdare Road, Nedlands. 6009

To make a request for a topic please contact Cindy Evans, MNDAWA Education and Development Advisor on :

Phone: (08) 9346 7355
Mobile: 0410 752 281
Email: cindy.evans@mndawa.asn.au

INCURABLE OPTIMISM!



MND Week and Global Day 2011

Seeking Incurable Optimists to participate in media campaign

During MND Week (1-7 May) and through to Global Day on 21 June MND associations around Australia will be working hard to raise awareness of MND nationally.

Following the example of MND UK, we will adapt the Incurable Optimist Campaign. Patrick Joyce, father of three and living with MND, set himself a challenge to paint the portraits of 100 incurable optimists before he loses the ability to paint forever.

At the recent International ALS/MND Alliance meeting, the UK MND Association invited associations worldwide to join in and find their own Incurable Optimists. For more information see Patrick's blog: <http://patricktheoptimist.org/>

This year, rather than solely focusing on the incurable nature of MND, we'll be highlighting the amazing and positive spirit of the MND community and how this spirit keeps us fighting MND. We know how devastating a diagnosis of MND is. Not just for the individual but for family and friends too. We are looking for people living with MND who would be willing to share, through the media, their own stories of incurable optimism.

MND Australia needs people from local communities who are living with MND or have been affected by MND and who

would be willing to be contacted by their local media during MND Week. We often get calls from local papers and radio stations wanting to interview a person in their area and we need to be prepared with a list of willing contributors/ambassadors.

If you are interested in being involved please take a few moments to fill out the questionnaire on the next page and return it by post by **4 April 2011** to Carol Birks, MND Australia, PO Box 990, Gladesville NSW 1675, via fax to 02 9816 2077 marked 'Attention Carol Birks, MND Australia' or email to carolb@mndaust.asn.au.

Alternatively, fill out the Register as a Media Contact Form online at the MND Australia website www.mndaust.asn.au

See over page for registration form →

Bunbury Police v Eaton Cricket Club T20 Cricket Match

Sunday 23 January 2011 saw the Twenty20 cricket match between Bunbury Police v Eaton Cricket Club held at the Eaton Cricket Club on Pratt Rd Eaton. The day aimed to raise funds and awareness of Motor Neurone Disease in WA, and honour Mal Hicks.

Thanks to everyone who participated in the Twenty20 cricket match, those who helped with prizes and everyone who donated, the day was a great success.

Unfortunately Mal couldn't be there as he was enjoying a well earned holiday with wife Vicki.

The first game started off in style. Eaton batted first and got off to a steady start, Greg Ward and Darren Royle kept things tight in the first few overs with Royle picking up an early wicket. Butch Cassidy claims to have been swinging the ball at right angles but unfortunately didn't snare a wicket. Warrick Walker proved to be the destroyer taking 3 wickets and only going for 8 runs in his 2 overs. After 20 overs Eaton made a total of 151.

WA Police opened up with Mal's two sons Clayton and Reagan. Clayton was out for 0 and started the collapse. At one stage WA Police was 5 for 29 and things were looking bleak.

Enter Greg Ward. Wardy smashed the ball to all parts of the ground, was well supported by Butch Cassidy.

Once Butch was dismissed Darren Clifton came to the crease, with Wardy put on a 53

run stand. It looked like the WA Police was going to enjoy victory. Unfortunately a couple of quick wickets turned things against us when Wardy was dismissed for 36, Darren Clifton out for 26, and Jeff Haisma going for a duck.

Warrick Walker and Darren Royle nearly got us over the line with a last wicket stand of 39 before Warrick was run out for 13 and left WA Police all out for 140, just 11 runs short.

The second game started off at a blistering pace. Eaton batted first and got off to a flying start and never seemed to slow down.

An early bowling change saw Matt Tidman take a wicket with his first ball and things were looking up. Shane Brownlie kept things tight for his four overs but unfortunately the Eaton batters seemed to enjoy the Police bowling, making the reasonable total of 233 off their 20 overs.

Unfortunately the Police was never really in the hunt. Ian Harris and Brad Humble got us off to a good start, but unfortunately Brad injured his knee and could take no further part in the match. Ian Harris made a very well constructed 59 before retiring. But a quick succession of wickets saw Eaton well in front when the rain stopped play after 15 overs. Matt Tidman and Matt Bayliss were the other contributors with the bat.

Overall Eaton was the inaugural winners of the Mal Hicks Trophy.

There were a number of raffles throughout the day and between games. The band "them guys" entertained the crowd. Big

thanks to the year 7 class and Mrs. Gleeson at Picton Primary who raised \$90 with their bake sale.

Big thanks also go to Mick Rogers and the Eaton Cricket Club; Mick Rogers (president of Eaton C.C.) donated the balls for the matches and helped provide the commentary caravan.

Saturday 29 January marked the commencement of the cricket season in Bunbury. This round saw Eaton v Marist in 1st, 2nd and 3rd grade matches played at Forrest Park in Bunbury. This was also a fundraising day as Mal played for Marist previously.

Marist players donated part of their ball fees as well as barbecuing some burgers after the match, that added over \$800 to the total.

Big thanks to the Marist Cricket Club for their support.

A signed Eagles jumper will be auctioned at Eaton Cricket Club's trophy night and bids so far look to reach to \$800. In total, with the Eagles jumper to be auctioned at the end of cricket season, we estimate over \$8,000 dollars was raised for Motor Neurone Disease, so big congratulations to all that participated, assisted and donated.

Over all, the 2 days were a great success and played in good spirit. We look forward to doing it again next year.

Mick Byrne

(Congratulations to all! Ed.)

MND Week and Global day 2011 media campaign participants form

Name:

Contact Number:

Suburb: State:

Email:

Age Group:

less than 39 50 – 60 60+
40 – 50

Please tick one of the following:

- I have MND
- Carer of a person with MND
- family member
- friend of a person with MND
- Researcher
- person working with people living with MND
- Other (please specify)
-
-

Tell us a little about yourself: **(please use another sheet of paper if required)** how long you have had MND, or been caring for a family member or friend with MND, or been researching MND, or working with people living with MND and what were you doing before your life was touched by MND or how has working with people living with MND affected you?

Tell us about what makes you an **INCURABLE OPTIMIST**:

I hereby authorise MND Australia and JMM Communications to use the information provided above for media purposes.

Signature Date

I thank you for taking the time to complete this form and for your interest in participating in MND Week and Global Day 2011. We will be in contact with you if our media contacts would like to interview you or if we require any further information. Carol Birks, National Executive Director, MND Australia.

I am willing to be interviewed by the media for: Print Radio TV

Gifts and Donations

General Donations

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 Peter Bloomfield
 M Berg
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 Jeanette Eaton
 Deborah Moylan
 Amy Anderson
 Shirley Burrows
 Melany Hall
 Paul Davison
 Alison Hass

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Stephen Brown

- Emanuel Manolios
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Peter Godfrey

- G & H Fairclough
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- Lawrence Jones

Bruce Veitch

- Mike Rowe

Alan Whitfield

- Graham Field

Ross Delaveris

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Cornflower Boxes

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(continued from page 1)

Report on Dexamipexole trials

A phase II trial of KNS-760704 (Dexamipexole, completed in 2009, found that the drug was safe and well tolerated by people with MND for up to 9 months. The trial results also showed trends suggesting the drug's potential for reducing the rate of decline in patients' functional capability, although the relatively small numbers of people involved in the study means that these findings cannot be relied upon. Knopp Neurosciences is hoping to begin a large-scale Phase III trial of KNS-760704 in 2011.

During 2011 recruitment will commence for a phase three study of the drug dexamipexole at 61 study locations in the United States, Europe and Australia. The purpose of this study is to determine whether dexamipexole (150 mg twice daily) is safe and effective in the treatment of ALS/MND.

This is the first time that an international phase III clinical trial has included Australian sites. This development is testament to the work of Australian clinicians in collaborating and engaging with their international peers.

The trial will be spread over 61 sites so only a relatively small number of people will be recruited to the trial in Australia. In addition there will be very strict inclusion and exclusion criteria.

The trial will be a randomised, double blind, placebo-controlled study which means that half of the participants will be given a placebo (not the drug) and half will be given the drug. All involved will be 'blind' as to whether the participant is taking the placebo or the dexamipexole.

The research sites in Australia will be the MND Clinics at:

- Bethlehem Hospital, Caulfield South, Melbourne
- The Royal Brisbane and Women's Hospital, Herston, Brisbane
- The Prince of Wales Hospital, Randwick, Sydney
- St Josephs/Westmead Hospital, Westmead, Sydney

These sites are currently seeking ethics approval in preparation for when recruitment commences. This may take some months. Only a very small number of Australians can be involved in the trial. For more information and updates regarding recruitment go to the web sites provided on page 1.

About Clinical Trials

Clinical trials are research studies in human volunteers that determine whether potential treatments are safe and effective. It is extremely important to establish that the side effects of any new drug are not more threatening than the disease itself and to prove beyond reasonable doubt that the drug is beneficial. The only fool proof way of doing this is by monitoring the effects of the drug in a group of patients and comparing the progress of these patients with the progress of a similar group not taking the drug.

Clinical trials are divided into four phases:

Phase I examines the safety of the potential new treatment, often in just a few (5 – 20) people. In many cases, this phase involves healthy volunteers rather than patients. Participants are monitored for adverse reactions or side effects; if any appear that are judged to be too dangerous, the drug will not advance any further through the clinical trials process.

Phase II determines the optimal dose size, timing of doses and drug delivery route (e.g. by mouth, by injection) for the next phase of testing. Although Phase II testing may provide some indication of the drug's ability to treat the disease, the number of patients involved in this phase is too small for such findings to be relied upon.

Phase III aims to show whether or not the drug actually has a beneficial effect on patients. This stage of testing will usually involve hundreds of patients, which is enough to allow a reliable assessment of the drug's efficacy. Phase III results will determine whether or not a drug is approved for use to treat the disease.

Phase IV occurs after the drug has been approved for sale. With the drug in general use, further data can be gathered on its effects in an extremely large number of people over an extended period of time.

MND Australia

Bequests to MNDWA

Wills are a convenient means for making charitable gifts to the people and causes you hold dear. Making a bequest to MNDWA will help ensure our continued efforts in making a difference to the lives of people living with MND continue into the future.

Contact the office on (08) 9346 7355 or admin@mndawa.asn.au for information.

Continued from front page

RPH, where she will be doing similar work with people with brain injuries.

As we said goodbye to Sam, we welcomed Jude Humphreys, who has filled the vacancy. Jude comes to us with a background in exercise sciences and disability care, and a wealth of life experience. We welcome Jude to our team.

Next big thing on the MND Calendar is Awareness Week, 1-7 May 2011. To launch Awareness week we will hold our annual walk from Burswood Park around the "little bridges" on Sunday 1 May 2011. Here are the details of MND Awareness Week in Perth:

Walk to D'Feet MND - Sunday 1 May 9am - 2pm

RASWA Brass, sausage sizzle, and other activities. The West Australian Newspaper is our media partner supporting the walk. Sign up soon to Everyday Hero and register your team to raise funds for MNDAWA. This year you can also register your dog for the walk when you sign up. Online registrations will open soon - keep a look out for the links to Epic Events on the MND home page in mid March.

Q&A Day - Wednesday 4 May

A professional gathering to learn more about MND and care of people diagnosed with MND, to be held at the conference room in the Niche. The Care Advisors will soon be contacting their professional colleagues with details.

Blue cornflower Day - Friday 6 May

Street appeal in Perth CBD and selected shopping centres to raise funds and awareness. We will have collectors at the following suburban shopping centres: Belmont Forum, Whitfords City Westfield or Karyinup Shopping Centre, and Garden City Booragoon. More volunteers are needed to help. Call Cindy if you can help in the morning or any time to 3pm during the day.

MND Call to Action in Awareness Week

As part of MND Week each year MND Australia and the state associations undertake a **Call to Action** to address national issues that impact people living with

MND in Australia. This year we are asking members to support the Every Australian Counts Campaign, which is the national campaign for the introduction of a National Disability Insurance Scheme (NDIS). See the insert in this newsletter – it encourages you to take action to raise awareness of this national campaign to improve support for people with congenital or acquired disabilities.

Incurable Optimists

Read about the campaign of Incurable Optimist, Patrick Joyce in the United Kingdom! MND Australia is also looking for some of our own Incurable Optimists to tell their stories about living with MND. See Patrick's blog and pages 5/6 of this newsletter.

Non-event a great success!

Our Christmas/New Year "non-event" resulted in more that \$29,000 received in donations. There were some interesting responses to our different approach. Some supporters enjoyed the humour and hopefully took full advantage of not coming to one of our events by making the most of the festive season with family and friends. Others were less amused, but obviously equally supportive. One substantial bequest was received as part of this donor appeal that help to boost this wonderful result. With sincere thanks to all our generous supporters. Wishing you all well in 2011.

Dr Sue Colyer
Executive Officer

New MNDAWA Patron Narelda Jacobs

Our new Patron has a high media and community profile. Narelda Jacobs is the presenter of Perth's Ten Evening News at 6.30pm.



Narelda has been a journalist at Network Ten for over 10 years and is the first indigenous female news anchor for a commercial network.

Narelda's on air profile has given her the opportunity to help charities deliver to West Australians in need. She's an Ambassador for Breast Cancer Care WA and the David Wirrpanda Foundation. She's the patron of a specialised program for indigenous students at Balga Senior High School and is a Disabilities Ambassador.

In August 2010 her close friend Robyn Hornsey lost her battle with Motor Neurone Disease. Robyn had been diagnosed 12 months earlier, and her illness and passing had a profound effect on all who knew her. Narelda has come onboard as a patron of the Motor Neurone Disease Assoc WA in memory of Robyn Hornsey.

An Everyday Hero - Luke raises money for MND

Luke is encouraging his family, friends and supporters to donate to MND via Everyday Hero to acknowledge his efforts in marathon runs, swims and triathlons. Luke is running and swimming to honour Bev Ormiston.

On the first weekend of February, Luke completed the Athletes Foot-Saucony Busselton Half Marathon & Pro Busselton Charity Fun Run & Walk on Saturday 5th. He was placed 3rd in the 5km Half Marathon out of 143 competitors with a time of 00:17:05.

Then on Sunday 6th February, he then swam in the 3.6km Busselton Jetty Swim in a two person team. Luke and his partner were placed 21st out of 121 teams with a time of 01:16:23, out of the 1150 competitors.

Support Luke in his next event: April, May + August!



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