

January 2010



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New ALS (MND) Drug Slips Through Telling Phase II Clinical Trials

ScienceDaily (Jan. 4, 2010) — A drug already used to treat symptoms of epilepsy has potential to slow the muscle weakening that comes with amyotrophic lateral sclerosis (ALS), scientists report after completing a Phase II clinical trial -- an early, small-scale test to show if the drug works and continues to be safe.

daily life activities such as speaking, walking and dressing that typically slip away as the disease progresses. The drug is a member of the benzodiazepine family -- anti-anxiety and muscle-relaxing agents that work in the brain and spinal cord.

The study, by a scientific team from Johns Hopkins and Indiana University, reveals there's enough benefit from this new use of talampanel to propel it into larger trials that will definitively tell its worth.

The trial in 59 volunteers with ALS -- also called Lou Gehrig's disease -- showed that talampanel can be safe for patients with the disease and that any recorded side effects are tolerable, says Johns Hopkins neurologist Jeffrey D. Rothstein, senior scientist on the new study. Rothstein heads the Robert Packard Center for ALS Research at Johns Hopkins.

Phase II trials are designed to show on a small scale if a drug is safe and if it works. So the present trial included ways to measure the drug's benefits, which came across as clear, if not statistically significant. "The research demonstrates that talampanel appears able to slow the progression of disabling ALS symptoms," Rothstein says. "The effect isn't overwhelming at the dosage of medicine used in this early, very small trial," he adds. "Still, having promising human data is reason enough to keep it in the drug pipeline where we can really find out where it stands for patients."

A report online December 4 in the journal *Amyotrophic Lateral Sclerosis* says the drug talampanel showed some ability to slow the loss of major

Rothstein says the promise of talampanel is especially important in ALS because the always-fatal neurodegenerative disease has foiled therapy for years.

With the exception of riluzole, the single FDA-approved drug for the disease, there's no other treatment to slow or stop it. "Riluzole can extend life only modestly and hasn't been shown to slow ALS symptoms," says Rothstein, "so the need for better therapy is real. Barring a cure, we'd still be glad for agents strong enough -- either singly or in combination -- to put ALS in the chronic disease category."

In the study, ALS patients in the talampanel-receiving group (40 of the 59) at both Johns Hopkins and Indiana University took a month to ease into the trial-desired dose of the drug. Most stayed there for the remaining eight months of the study.

Periodically, clinicians rated the 40 who got talampanel and 19 control subjects (those who took a placebo) on a measure of isometric arm muscle strength. Testing also included the rate of decline in breathing and the ALS Functional Rating Scale (ALSFRS) -- a standard measure of abilities that include speech, swallowing, handwriting, breathing, walking and food-cutting.

To see if the drug was safe for ALS patients, subjects received a variety of laboratory blood tests, an electrocardiogram, a neurological exam and other measures.

In most of them, talampanel slowed progression of ALS. Results stood out, especially, in the ALSFRS, where patients' decline in abilities slowed 30 percent.

Several facts about talampanel make it especially attractive to try as a possible therapy, Rothstein says. The drug's talent is its ability to block specific receptors on ALS-vulnerable nerve cells that are dock-

ing sites for the neurotransmitter glutamate.

An excess of glutamate trips excitotoxicity -- a process that can kill the motor neurons that enable movement. Earlier studies by Rothstein and others on cell and animal models of ALS consistently confirm excitotoxicity as a source of damage in the models and ALS patients. Levels of glutamate are elevated in spinal fluid and in the brain in as many as 40 percent of ALS patients whose disease appears to arise spontaneously.

Talampanel and other molecules that whisk glutamate out of harm's way prolong life in animal models of ALS while also preserving motor neuron life and muscle strength.

Also attractive, Rothstein adds, is that talampanel is a small molecule that can penetrate into the brain and spinal cord where it's needed.

Currently, a large international trial of talampanel is under way, due to end in 2010.

The just-completed Phase II trial was funded and organized by Lilly Pharmaceuticals which manufactures the drug.

The research team also included first author Robert Pascuzzi and Lisa Haas, both with the Indiana University School of Medicine, Jeremy Shefner, with Upstate Medical University, Syracuse, N.Y., Amy Chappell, John Bjerke and Roy Tamura, with Lilly Research Laboratories, Indianapolis, Indiana, and Lora Clawson, with the Johns Hopkins University, Baltimore.

Story Source:

Adapted from materials provided by Johns Hopkins Medical Institutions, via EurekAlert!, a service of AAAS.

Citation: Johns Hopkins Medical Institutions (2010, January 4). New ALS drug slips through telling Phase II clinical trials. *ScienceDaily*. Retrieved January 5, 2010, from <http://www.sciencedaily.com/releases/2010/01/100104181531.htm>

Survey Results

In November 2009, we sent out a survey to people who are listed on our database as "volunteer" and also to people who receive a complimentary copy of the newsletter as a way of identifying who these supporters are, if they wish to stay involved and to ask them to consider ways in which they may be able to continue to support the association. Here are the general results.

Volunteer Survey 2009

The return rate was 19 out of 76 forms posted or 25%, of these respondents, nine indicated that they will continue as volunteers in some capacity, and 10 declining to continue. Their reasons for becoming involved initially was due to personal experience with MND when a parent, sibling or spouse was diagnosed, to help with fund raising for services and research, to care for people, and because MND is such a terrible disease.

These volunteers helped by putting out cornflowers, organising the Street Appeal, raising awareness, fundraising through craft stall and holding a "soup and sweets lunch." A suggestion to improve the way we support volunteers was to encourage friends and families of sufferers to become active members.

It became clear that people listed as volunteers in the database really fall into two categories: *supporters* – those who help with specific activities when they can (e.g., collecting for the Street Appeal, or putting out cornflowers), and *volunteers*, who are active on a regular basis with on-going activities, such as Carers' Lunches, Pamper days, Craft Group, Newsletter folding and other mailouts. In our database we will code these two categories of helpers, so that we are not contacting people inappropriately.

Thank you to all respondents. Your views are important as the Association works to improve its volunteer service, both for the volunteers and the people for whom they provide a service. We are in the process of formalising the MND volunteer service and recently introduced a special photo ID tag and polo shirt with logo, so that volunteers are more visible at events.

A sincere thank you to all our volunteers who have contributed so much to MNDAWA over the years, and who continue to support us.

Newsletter Survey 2009

The newsletter survey went to 429 recipients who are (were) not listed in the database as financial members. The return rate was 84 or 19.5%, of whom 44 wished to continue to receive the newsletter, whereas 40 declined for various reasons.

Twenty-one respondents (48%) offered a donation for the newsletter, and 12 (27%) applied for membership. Twenty-three or 53% of respondents will be added to our email newsletter distribution list. Thank you to everyone for this support. Building our membership base and expanding our scope into the community is important, not just to support the association, but to show that there is a critical mass of people who care about those diagnosed with MND and are prepared to support when, where and how they can.

Respondents suggested that we could improve the newsletter by providing more on research, getting information on events earlier in our diary, and including some humour. In respect to providing research information we always include, as we are with this newsletter, the reports that come from the MND Research Institute of Australia as it is a "clearing house" for Australian MND research. In addition, we pass on other international research articles that we consider come from reliable sources. As this association is a care service provider and does not conduct research we are dependent on the availability of suitable articles and information from other sources.

Another suggestion was to hold more events in the South West of the Western Australia. I am aware that many of our recent events have taken place in the north of Perth and that we have neglected our members and clients who are "south of the river". Our future plans will include some southerly event locations to make travelling easier for those residing in the South West.

And the outcome from these two surveys?

We will update the database and mailing lists in the next weeks, so that our lists are more accurate and we don't send out unwanted correspondence. However, some people who have indicated that they wish to be removed from a list did not give a name, so they will probably continue to receive the newsletter and other unwanted correspondence until their name is confirmed with the office by phone or email. We had not coded the questionnaires in anyway so we were unable to identify respondents from the form alone. I apologise for not making that requirement clearer on the form.

Thank you to all respondents for taking the time to complete the survey. A special thank you to everyone who made a donation or applied for a new or renewed a membership. Your present and past support is greatly appreciated by the Association as it strives to provide care services, equipment and a range of other supports to people living with MND in Western Australia.

Dr Sue Colyer
MNDAWA
Executive Officer



Howard Street, Perth

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Date	Event	Time	Venue
January			
Tues 19 Jan	Carers Group	11:30am - 1pm	The Niche - Conference Room
February			
Thurs 4 Feb	Craft Day	10am - 2pm	The Niche - Volunteers Room
Sat 20 Feb	MND Get together	To be confirmed	
Tues 23 Feb	Carers Lunch	11:30am - 1pm	The Niche - Conference Room
March			
Thurs 4 Mar	Craft Day	10am - 2pm	The Niche - Volunteers Room
Tues 23 Mar	Carers Group	11:30am - 1pm	The Niche - Conference Room

From the Executive Officer's Desk

Happy New Year! Welcome to the new decade! I trust that you all enjoyed a restful and pleasant festive time with family and friends.

The staff enjoyed a break away after the last hectic weeks of 2009. You will have seen in the December newsletter lots of short items about the events in which we were involved in November and December. We are now back in the office, where we have worked hard this week to clean up, and plan for the year. In the February edition you will find the calendar of programs for carers and patient members, including Carers lunches, Get-togethers and Pamper Days. The new funding from the Health Department will allow us to extend some care services and to develop new programs to support all members.

In the December edition you were alerted to the arrival of Cherylyn Vickery as our newest Care Advisor. We welcome Cherylyn, who commences on 11 January 2010, to the MND Care Advisory team.

This edition of the MND newsletter is an abbreviated version to wrap around the recent Annual Review from the MND Research Institute of Australia. This review outlines the range of research studies that the Institute funds in attempts to understand the disease, from any genetic clues, effects of exercise to possible neuroprotective proteins and communication in MND. MNDAWA makes an annual contribution and also channels specific research donations to the Institute.

During 2009 the national office of MND Australia amalgamated with the MNDRIA to create a substantial national body that

will present a unified voice for research, patient care and community awareness. There will be many advantages of this amalgamation that are yet to be realised.

I have also included an online article received just this week, which cites some potential benefits from a drug used to treat epilepsy.

Over the break, I had some homework to complete as I processed the survey forms that different groups of our members and supporters returned: volunteers, non-member recipients of the newsletter and the annual client evaluation. The results are reported on page three of this newsletter. I thank everyone who responded. We will take note of your comments and suggestions, bearing in mind a paraphrase (with apologies to the author) of a quote attributed to Abraham Lincoln (16th President of USA, 1809-1865):

We can satisfy some of the people all of the time, and all of the people some of the time, but we can not satisfy all of the people all of the time.

We will do our best to bring something for everyone in the MND newsletter.

So we are off and running into the new decade, with a mixture of events already – severe bushfires close to Perth this year, a great win in the Test match against Pakistan today, and a varied program of events planned for MND.

On behalf of the Association, I wish all our members, supporters, volunteers and staff the best of 2010.

Dr Sue Colyer
Executive Officer

NEW WINE FOR SENIORS (heard through the grapevine)

Californian vintners in the Napa Valley area, primarily producing Pinot Blanc, Pinot Noir and Pinot Grigio wines, have developed a new hybrid grape that acts as an anti-diuretic. It is expected to reduce the number of trips older people have to make to the loo during the night.

The new wine will be marketed as Pinot More!

After Hours Assistance

The Care Advisors suggest the following steps if you require assistance out of office hours. Please use this as a guide.

MND information and advice:

Call the MND after hours number: 0439918052

For General Health Care Needs:

- Contact your Locum GP for medical assistance
- Attend your closest Public Hospital out-patient department
- Telephone help line: health direct Australia 1800 022 222

Emergency Respite Needs:

Perth Home Care Services - Crisis Care Service 9244 5411

Emergency Health Care Needs:

Dial "000" and ask for an ambulance

Laughter is the best medicine...

EURO ENGLISH

The European Commission has announced an agreement whereby English will be the official language of the European Union, rather than German, which was the other possibility. As part of the negotiations, the British Government conceded that English spelling has some room for improvement and has accepted a 5-year phase-in plan to be known as 'Euro English'.

In the first year, 's' will replace the soft 'c'. Certainly this will make the sivil servants

jump for joy. The hard 'c' will be dropped in favour of 'k'. This should klear up konfursion and keyboards kan have one less letter.

There will be growing publik enthusiasm in the sekond year when the troublesome 'ph' will be replaced with 'f'. This will make words like fotograf shorter.

In the third year, publik akseptanse of the new spelling kan be ekspekted to reach the stage where more komplikated changes are possible. Governments wil enkourage the removal of double letters which have always ben a deterent to akurate spelling. Also, al wil agre that the horibl mes of the

silent 'e' in the languag is disgrasful and it should go away.

By the fourth yer peopl wil be reseptiv to steps such as replasing 'th' with 'z' and 'w' with 'v'.

During ze fifz yer, ze unesesary 'o' kan be dropd from vords kontaining 'ou' and after ziz fifz yer, ve vil hav a rel sensibl riten styl. Zer vil be no mor trubl or difikultis and evrivun vil find it ezi tu understand ech oza. Ze drem of a united Urop vil finali kum tru.

Und efter ze fifz yer, ve vil al be speking German lik zey vuntnd in ze forst plas!

HOWLERS

These gems, collected by two teachers in Ohio, are (said to be!) actual answers given in history tests and Sunday School quizzes by 5th and 6th grade children.



Ancient Egypt was old. It was inhabited by gypsies and mummies who all wrote in hydraulics. They lived in the Sarah Dessert. The climate of the Sarah is such that all the inhabitants have to live elsewhere.

Moses led the Hebrew slaves to the Red Sea where they made unleavened bread, which is bread made without any ingredients. Moses went up on Mount Cyanide to get the ten commandos. He died before he ever reached Canada but the commandos made it.

The Greeks were a highly sculptured people, and without them we wouldn't have history. The Greeks also had myths. A myth is a young female moth.

Johann Bach wrote a great many musical compositions and had a large number of children. In between he practiced on an old spinster which he kept up in his attic. Bach died from 1750 to the present. Bach was the most famous composer in the world and so was Handel. Handel was half German, half Italian, and half English. He was very large.

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