



MessaGes

Myasthenia Gravis Association of Queensland Inc



JUNE 2008

Myasthenia Gravis Association of Qld Inc IN NO WAY endorses any products, medical procedures or medical practitioners mentioned. Articles are provided as a guide, and/or for information purposes only. We take this opportunity to thank Queensland Health who by the provision of a grant, make the work of the Association and the publication of this Newsletter possible, and to those who take the effort to contribute to its success.

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Neurologist
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PRESIDENT'S REPORT

Hi Everyone,

Anita is currently overseas on a well deserved holiday, so it fell to the editor to write the President's report this month.

Our new look Internet website is functioning very well and has received some very complimentary feed-back. However, we have received very little feedback from our members. Feedback from our members is very important as it tells us whether we are providing the services and information that our members want, not what we, the Management Committee, might think you want. So please, give us that feedback so we can make our website and newsletter relevant to you, the members.

Please, set Sunday 31 August aside in your diary for the Annual General Meeting of the Association. As usual it offers members a chance to get to know other MG sufferers and this year the guest speaker is Dr Rob Henderson, who practises out of the Private Practice Specialist Suites at the Royal Brisbane and Women's Hospital and who is the neurological specialist for some of our members and has patients all along the coast of Queensland. I am sure that his presentation will be most informative.

Unfortunately, we have received insufficient nominations for all positions on the Management Committee for 2008/2009, so we will be calling for nominations from the floor at the AGM to fill the vacant positions. It is important that we have sufficient committee members so that we can continue to work for our members.

In this edition of MessaGes, I have included an item on a drug under development for the treatment of MG, called EN101 (or Monarsen). It provides updated information following on from the previous article on EN101 in the December 2006 issue of MessaGes. The item is for information only and does not imply any endorsement of the product or the company, Amarin.

Keep well,

Graeme

CHAT LIST:

Each member of our Management Committee is happy to speak with you, while the following members, who include MG sufferers or their carers, have offered to join our Chat List. If you have a need to have a yarn, particularly about how MG affects you, please ask if it is convenient to talk, and respect the privacy of those whom you call.

In the interests of one's privacy, we have not listed surnames. Do not be embarrassed by ringing a stranger and asking to speak to say, "Fred or Mary". If you wish to disclose your surname, that is your prerogative. Simply explain that you are a MYASTHENIC or a CARER.

Remember there is also the FREECALL telephone number for Australia manned (or is it womanned?) by Shirley and is 1800 802 568. Please do not hesitate to call if you feel the need. If the 1800 802 568 is not answering, please leave a message and Shirley will get back to you as soon as practicable. Your call is valuable to us, so please do not hang up without leaving a message.

CHAT LIST – QUEENSLAND REGIONAL COORDINATORS

HANNA	4054 4538	FAR NORTH QLD
VACANT		TOWNSVILLE
GWEN	4954 5353	MACKAY
JOAN / HAROLD	4928 1438	ROCKHAMPTON
SHIRLEY	5443 1728	MAROOCHYDORE SUNSHINE COAST
JOHN / MARILYN	5532 4547	GOLD COAST
SHARON	4151 7661	BUNDABERG/WIDE BAY
VACANT		DARLING DOWNS

CHAT LIST – QUEENSLAND REGIONAL MEMBERS

JOHN	4783 1556	AYR
YVONNE	4783 4643	AYR
MARK	4067 1784	BABINDA
HENRY	4982 6507	BLACKWATER
DAVID	4053 2291	CAIRNS
RON / HELEN	4051 3286	CAIRNS
SHIRLEY	4128 3596	HERVEY BAY
SHARON	4151 7661	NORTH BUNDABERG
BARBARA	4124 2312	POINT VERNON
RAY / MARY	5443 8667	MAROOCHYDORE
DAVID	5474 5534	NOOSA
MARLENE	5447 4986	NOOSA HEADS
JOY	4165 4647	MUNDUBERRA
BILL / COLLEEN	4926 4847	ROCKHAMPTON
TOM / SCOTIA	4693 3730	PITTSWORTH
HEATHER	4728 7550	TOWNSVILLE
JO	4723 8721	TOWNSVILLE
KELLY	4728 4913	AITKENVALE
CAROL	4773 1213	HEATLEY
VALMA	4068 0702	TULLY
PERLA / GEOFF	4939 2724	YEPPON
IAN	4623 5169	YULEBAR
CAROLYN	5472 0386	COOROY
ROBYN	5520 4242	BURLEIGH HEADS
MAUREEN	5572 7993	MERMAID BEACH
HELEN	5445 4853	SUNSHINE COAST
OWEN	4742 1190	CLONCURRY
PATRICIA	5535 0274	BURLEIGH WATERS
AILSA	4055 1303	CAIRNS
JUDIE	0439 461288	AIRLIE BEACH
BARRY	5483 1783	CURRA

JAMES / ROSEMARY	5530 1558	HOPE ISLAND
DONALD	5563 7207	RUNAWAY BAY
RAJKO	5580 6404	OXENFORD
ELIZABETH	4936 2410	GLENLEE
MELISSA	4662 3337	DALBY
TERRY	5494 2470	MALENY
ROBERT	5492 9754	MOOLOOLAH VALLEY
MOYRA	5576 4979	BURLEIGH WATERS
GLORIA	5534 2669	CURRUMBIN
GEOFFREY	5437 3083	PELICAN WATERS
SARA	0422 109492	BLACK RIVER

WEB-Site Update

Our redesigned website is now up and running, and is available for viewing at www.mg-qld.gil.com.au
 You can now download current and previous issues of MessaGes and we now have links to other MG sites.
 Also you can email us direct from the website.
 Your feedback on the site would be appreciated via an email from the 'Contact Us' page on the website.

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Shirley's Recipe

FILO VEGETABLE PIE

Ingredients:

- | | |
|----------------------------|---------------------------|
| 900g zucchini, chopped | 250ml vegetable oil |
| 225g Feta cheese, crumbled | 3 eggs, beaten |
| 25g breadcrumbs | 1 tablespoon chopped dill |
| 400g Filo pastry | salt & pepper |

Method:

1. Place the zucchini in a pan with half the oil. Cover and simmer gently until very soft, then leave to cool.
2. Add cheese, eggs, breadcrumbs and dill, and season to taste with salt & pepper.
3. Brush pastry sheets with oil and layer two-thirds of the pastry over a greased baking tray.
4. Cover with the prepared filling, top with remaining oiled pastry sheets and seal the edges together well.
5. Brush the top with oil, then bake in a preheated oven at 180°C (350°F) for 35 minutes until golden brown.

Note: Serves 4

Email copy of MessaGes

MessaGes is currently being delivered by email to those members who requested it.

If you have not yet supplied your email address and would like to receive your MessaGes via email, please advise the editor at grapop@dodo.com.au

For the technophiles among you, MessaGes is produced using MS Office Word 2003.

Future Planned Activities

Sunday 31 August 2008
Sunday 7 December 2008

Annual General Meeting – Guest Speaker Neurologist Rob Henderson
Christmas Lunch

Venues and details for the above functions will be advised closer to the dates.

The Management Committee meets on the second Saturday of each month (except January) and all members are invited to attend. If you wish to attend any of these meetings, please contact Shirley on the 1800 number to find out the time and place of the relevant meeting.

MEMBERS FORUM

There were no contributions for the members Forum this month, however the following is the response that the Editor received from an enquiry to Amarin, the developers of the drug EN101 (or Monarsen), regarding the status of the development of the drug:

Dear Graeme,

Thank you for your interest to EN 101, also known like Monarsen. This drug is currently in phase II of its clinical development and results from a international trial in EU and Israel are eagerly anticipated. So far we are very optimistic about the possible value of EN like a Myasthenia Gravis treatment, first results (see below), published in *Neurology* 2007 are very promising and well accepted by scientific society. It is almost impossible to anticipate the regulatory hurdles and speed of recruitment in future trial, but we believe that the drug is now approximately 5 years from the market. I will be happy to assist in your future efforts to provide a cutting edge information to your members and supporters.

Experimental Therapy Shows Promise in Myasthenia Gravis

Caroline Cassels

August 13, 2007 — Preliminary results from a small open-label study suggest an oral antisense oligonucleotide may reduce the severity of muscle weakness in myasthenia gravis (MG), offering hope for a new class of drugs in the treatment of neuromuscular disease.

In the phase 1b trial, which included 16 MG patients, researchers at the Hadassah Hebrew University Medical Center, in Jerusalem, found oral EN101 (Monarsen, Ester Neurosciences Ltd) reduced disease severity by an average of 46%, with patients experiencing improved muscle function, swallowing time, and ptosis.

"This is the first time we've been able to show that antisense is effective and safe when taken orally for a neurological disease. Oral delivery of antisense has long been sought after, since it is expected to improve patient compliance because daily injections won't be needed," the study's principal investigator, Prof. Zohar Argov, said in a statement from the American Academy of Neurology.

The brief report is published in the August 14 issue of *Neurology*.

Safe and Efficacious

EN101 antisense acts against both the catalytic and noncatalytic contributions of acetylcholinesterase (AChE). Designed to induce destruction of the read-through splicing variant of AChE, it has shown promising short- and long-term therapeutic effects in experimental models of MG, both intravenously and orally, the authors report.

The purpose of the current study was to evaluate the safety of short-term administration in MG and to assess efficacy by monitoring changes in patients' functional status.

The open-label trial included 16 patients with stable MG who were receiving a minimum of 180 mg of pyridostigmine daily. To assess MG status, investigators used the Quantitative MG (QMG) score. Escalating oral doses of EN101

were given on the first day followed by a daily dose of 500 µg/kg for 3 days. Following this treatment regimen, patients were monitored for 1 month. Four of the study subjects later took EN101 for 4 weeks on an ambulatory basis.

Reported adverse effects included dryness of the mouth and eye. Although these symptoms may have been related to the study drug, the investigators point out that they could also have been due to withdrawal from chronic pyridostigmine usage.

Clinically Significant

Furthermore, the authors note that all the physical, biochemical, coagulation parameters, blood count, and urine tests were unchanged during the treatment and follow-up phases of the trial. This also held true for the 4 patients who took the drug for 4 weeks.

Overall, the mean change in QMG scores from baseline was 6.13, a mean 46.5% improvement.

"EN101 administration resulted in significant improvement in the severity of MG as measured by the QMG score, which showed a reduction magnitude considered to be of clinical importance. Most patients had improvement in the score on day 4 compared with baseline (no pyridostigmine), suggesting that this oral antisense therapy may have similar efficacy to conventional pharmacotherapy," the authors write.

However, said Dr. Argov, although the findings are promising, the study design warrants caution in the interpretation of these preliminary results.

"This was an open-label study, and placebo effects cannot be excluded, although it is hard to see how placebo can improve swallowing time and ptosis. Furthermore, the consistent improvement over the days and the good correlation between individual components and the whole QMG score would be unexpected for a placebo effect," the authors write.

Broad Treatment Implications

In an accompanying editorial, Henry J. Kaminski, MD, from Saint Louis University Medical Center, in Missouri, notes that this study is the first clinical trial to demonstrate the efficacy of an antisense drug given orally. Further, he notes, the investigators' work has treatment implications that extend beyond MG.

"Argov and colleagues investigated a disease of cholinergic balance at peripheral synapse, but cholinergic imbalance of central synapses, such as Alzheimer's disease and head trauma, may also be aided by EN101-like compounds. Discoveries in MG have led to research in autoimmunity and synaptic transmission, and now a therapeutic approach to MG may be the harbinger for a new class of drugs for neurologic and psychiatric disorders," Dr. Kaminski writes.

The trial was sponsored by Ester Neuroscience Ltd. The authors report that study coauthors S Brawer, PhD, and O Ben-Yoseph, PhD, from Hebrew University of Jerusalem, Israel, were employees of Ester Neuroscience. Study investigator Hermona Soreq, PhD, from Hebrew University of Jerusalem, is the chief scientific advisor to Ester Neuroscience.

Neurology. 2007;69:699-700.

Best regards,
Dr. Dimitar Tonev
Medical Adviser
Amarin Neuroscience
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ANNUAL GENERAL MEETING

Members are invited to attend the Annual General Meeting of the Association to be held on **Sunday 31 August 2008** at the **Carindale Hotel** located at **Carindale Rd Carindale Qld**. (It is part of the Carindale Shopping Centre complex). The hotel has excellent facilities and lunch may be purchased after the AGM from a menu which is reasonably priced and comes highly recommended. Car parking is available in the Shopping Centre. We will have access to the venue from 10am, with the AGM proceedings to commence at 10:30 sharp. After the various reports have been presented, the composition of the Management Committee for 2008/9 will be announced. Guest speaker is Dr Rob Henderson, neurologist. The agenda for the AGM will be published in the August issue of MessaGes.

Following the AGM there will be a short General Meeting for the purpose of setting Subscription Fees for the next year.

To help us and the caterers, please advise of your intention to attend by calling our FREECALL 1800 802 568 as soon as possible, but not later than Monday 25 August 2008. If the phone is unattended, please leave a message advising your name and how many will be attending the AGM.

We look forward to a great roll up and know you will have a great day out.

How do I get there: Below is a 'mud' map of where the hotel is:
(UBD Map 181 Reference N5)



* * * * *

Some Kids Science Answers

Q: Explain one of the processes by which water can be made safe to drink.

A: Filtration makes water safe to drink because it removes large pollutants like grit, sand, dead sheep and canoeists.

Q: How are the main parts of the body categorized? (e.g., abdomen)

A: The body is consisted into three parts -- the brainium, the borax and the abdominal cavity. The brainium contains the brain; the borax contains the heart and lungs, and the abdominal cavity contains the five bowels A, E, I, O, and U.

KEEP YOUR BRAIN ACTIVE WITH THE TRIVIA QUIZ

Here are this month's questions for you to try. (Answers are at bottom of this page)

1. What was the number of the last King Louis to be king of France?
2. By what name was the heavyweight boxer Cassius Clay better known?
3. In 1961 which famous dancer sought political asylum in Paris?
4. In which Australian state or territory is Ardlethan?
5. 'Boston Crab' is a term used in which sport?
6. What is a group of beavers called?
7. What is the chemical symbol for lead?
8. What is the common name for acetylsalicylic acid?
9. In which year was Nelson Mandela released from jail in South Africa?
10. Which country's flag is all green?
11. How many squares are there on a chess board?
12. Who succeeded Wayne Goss as Premier of Queensland?
13. What is the longest river in Europe?
14. Who invented the revolver?
15. What is the capital of Mongolia?
16. What is name of the daily newspaper in Hobart, Tasmania?
17. What is the currency of Guatemala?
18. What was the name of The Phantom's dog?
19. Which author created the character of 'Jeeves'?
20. What is the name of the youth in Greek mythology renowned for his great beauty?

Answers: 1) 18th; 2) Muhammad Ali; 3) Rudolph Nureyev; 4) NSW; 5) Wrestling; 6) A colony; 7) Pb; 8) Aspirin; 9) 1990; 10) Libya; 11) 64; 12) Rob Borbidge; 13) Volga – 3685km; 14) Samuel Colt; 15) Ulan Bataar; 16) The Mercury; 17) Quetzal; 18) Wolf; 19) P G Wodehouse; 20) Adonis.

IT'S MEMBERSHIP SUBSCRIPTION RENEWAL TIME

It's that time of the year again when Membership Subscriptions for the financial year 2008/2009 are due.

The envelope in which this notice was enclosed will advise you when your membership expires. If you look along the top line you should see "YOUR NAME" followed by some figures in smaller print than your address.

The majority of members will have 6/08 which tells you (and us) that you are financial to 30 June 2008. Others may show 6/09 or even 6/10 to indicate they have saved time and postage by paying in advance. However, there are others whose envelopes still show 6/07, 6/06, etc and we continue to send our newsletter to these unfinancial members because we do not know what they want. If you are unfinancial, please take a minute to ring on the FREE call number, 1800 802 568 and advise whether or not you wish to retain your membership and receive "MessaGes".

LIFE MEMBERS and PAID-UP LIFE MEMBERS do not pay further subscriptions.

To those members who have renewed their membership for 2008/2009, we thank you.

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Tear off along this line

Herewith please find my cheque / money order / cash for the sum of \$_____ being annual subscription \$_____ and/or Donation \$_____:

NAME: _____ **Category A – Myasthenic \$15**
Category E – Supporter \$15

ADDRESS: _____

AND FOR: _____ **Category D – Carer \$5**

ADDRESS: _____

Your receipt will be forwarded to you with the next available issue of "MessaGes" following receipt of your payment. If you do not receive your receipt, please ring us on the toll free number 1800 802 568.

We thank you in anticipation of you renewing your membership.

More Kids Science Answers

Q: Name the four seasons.

A: Salt, pepper, mustard and vinegar.

Q: How can you delay milk turning sour?

A: Keep it in the cow.

Q: What happens to your body as you age?

A: When you get old, so do your bowels and you get intercontinental.

Q: What does the word 'benign' mean?'

A: Benign is what you will be after you be eight.

Q: What does 'varicose' mean?

A: Nearby.

Q: What happens to a boy when he reaches puberty?

A: He says good-bye to his boyhood and looks forward to his adultery.