

AUSTRALIAN TMAU SUPPORT GROUP NEWSLETTER

Volume 1 Issue 1 October 2008

The Australian TMAU Support Group (ATMAUSG) consists of people with trimethylaminuria and other as yet undiagnosed or undescribed genetically mediated malodour disorders who come together to give each other support and encouragement and to facilitate greater awareness of these disorders and scientific research into better treatments and a cure for them.. The ATMAUSG receives no financial support from governments but

WELCOME TO THE FIRST EDITION OF OUR AUSTRALIAN NEWSLETTER

Whilst the American newsletter RENEWAL will still be sent to those who have paid a subscription to the TF in NY our new Australian publication will be free of charge to all TMAUers in Australia and overseas who request it. Since this is the first issue it is necessarily brief. However it contains good news and, with your future contributions we hope future issues will be larger and livelier.

If you do not wish to receive the newsletter please email us at brovens@bigpond.net.au or inform us by post or by phone on (02) 9663 0431.

AUSTRALIAN RESEARCH FUNDED

Great news! A research project into TMAU in Australia is being funded by an anonymous but very generous benefactor. This is a wonderful and much-hoped-for stroke of luck for us.

It is envisaged that the researchers will be asking for expressions of interest from TMAUers regarding participation in the study.

At this stage the researchers have asked only for raw statistics of the number of people who would be willing to participate. The Australian TMAU Support Group will not give out member's contact details but will ask anyone who
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ARTICLE ON TMAU IN MEDICAL JOURNAL OF AUSTRALIA

Extracts from an article in the *Medical Journal of Australia* (MJA) on the difficulties a lady from Western Australia has had in getting the mystery of her malodour problem solved have been printed in newspapers around Australia and on various websites such as **ninemsn**. The story appeared in the October edition of the MJA. I have asked for permission to reprint it here but as yet have not received an answer from the MJA. However, if you wish to read it is available from their website if you take up free membership.

This article in the MJA is great news. Many of us who went for decades without a diagnosis know only too well the difficulties not having an explanation for our symptoms can cause. The MJA is a major Australian journal read by virtually all doctors and we hope that many medicos who have never heard of TMAU have had their consciousness raised and that those who report malodour symptoms will now be much more likely to receive understanding and a timely diagnosis. The stories the article prompted in the mainstream media should promote understanding and tolerance generally.

NEED TO CONTACT US?

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AUSTRALIAN TMAU SUPPORT GROUP

Australian Resesarch Funded...cont. from page 1.
has indicated that they would be interested in participating in the research to contact the researchers themselves when the researchers call for participants. We'll let you know when.

Please fill in the accompanying questionnaire and indicate whether you would be interested in participating in the research and send it back to the Australian TMAU Support Group, 8 Ingram Street, Kensington NSW 2033. Remember, we do not require your name or contact details, (not even a senders address) just an indication of whether you would be able and willing to participate.

This is a great opportunity to at last get some research going here in Australia and it would be great to see people put up their hands to help. Imagine someone donating money to get TMAU research done and then finding no TMAUers were interested in participating. Let's not let that happen!

When the research is completed the results will be published in a respected peer reviewed scientific journal and will put Australia on the map in respect of TMAU research.

LET'S HELP GET THE SCIENCE DONE!

SEMINAR/WORKSHOP FOR 2008

Marilyn and a number of other support group members have expressed interest in having another TMAU seminar and support group meeting similar to the one we organized in November 2006. Marilyn has already done some preliminary research on accommodation on or near the Gold Coast in Queensland.

At our last seminar we had about 18 attendees comprised of TMAUers and their families and friends. We now have twice as many TMAUers on our database as we had in 2006 and it's been almost two years since our last meeting. Therefore we thought it would be a good time to find

out if members are interested in another seminar/support group meeting.

So that we can get an idea of the numbers of TMAUers and their families and friends who would be interested in attending we ask that you complete the survey sheet included with this newsletter. If there is enough interest we will begin organizing in earnest—finding a venue, booking speakers and presenters, developing printed materials etc.



CALL FOR COPY

Know something we don't? Have a story, some artwork, a photo, a book review or anything else you think might interest other TMAUers in Australia or overseas? The more copy we can get the more interesting our newsletter will be and the more often it will come out. Post it or email it to Rob. Providing it is not obscene and has at least a minimal nexus with TMAU we guarantee to publish it. We do not do ideological censorship at the ATMAUSG newsletter but believe in freedom of speech for everyone. We welcome all views, scientific, religious, non-theist, left, right... We want lively debate on issues important to you. If others don't agree with you all the better. It will generate debate!

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AUSTRALIAN TMAU SUPPORT GROUP

Australian TMAU Support Group SURVEY

Please tick either the yes or no box after each question and return this survey to:

**Australian TMAU Support group
8 Ingram Street
Kensington
NSW 2033**

Would be prepared to participate in scientific research into TMAU?

YES

NO

Would you like to have another TMAU seminar/meet-up similar to the one we had in November 2006?

YES

NO

Thank you for completing this survey. The results will be published in the next edition of the Australian TMAU Support Group Newsletter.

Rob