



Porphyria Association Inc **2008 Annual General Meeting**

When: **Tuesday 30th Sept 2008 @ 1.30pm**

Where: The Nerve Centre
54 Railway Road, Blackburn, Vic
(Tea and coffee provided)

Enquiries: The Nerve Centre: (03) 9845 2737 or (m): 0408 337 173
e-mail: porphyria@mssociety.com.au

(Interstate & country members are welcome to forward comments by post, phone or e-mail)

.. We need an enthusiastic new committee ..

Several options are available regarding the future of the Porphyria Association Inc:

Option one

- We **need** to supervise paid staff and/or trained volunteers to manage networking.
- We **need** continuance of funding to pay for an experienced Administration Officer - it is **no longer** feasible or practical for this ongoing task to be managed by Porphyria Association Inc volunteers.
- We **need** people to raise funds to pay for the coordination and management of video conferencing so that all States are represented on the Committee. (Telephone and video conferencing facilities are here at The Nerve Centre Blackburn).
- We **need** people from all States to undergo peer support training to take support and/or crisis calls.

Option two

- Legally windup the Porphyria Association Inc (**a very drastic option!!**) and divert the balance of funds raised into website management only.
- Divert all queries to genetic support services in each State.

Remember: Many organisations have a mission of finding a cure. The Porphyria Association Inc is still working towards getting information, diagnosis and basic timely treatment acknowledged by health professionals and, to a certain extent, the general public. This should be readily available across Australasia.

MINI BULLETIN

- We wish to acknowledge the Lord Mayor s Fund (Melbourne) for the generous grant that enabled us to employ Jenny, our Administration Officer. It has proved such a boon we wish we had been able to do it years ago. The Porphyria Association can no longer function on volunteer workforce.
- To submit stories for inclusion in *Our Stories* booklet, e-mail Catherine at porphyria@mssociety.com.au with subject for Catherine, or leave a phone message for her to contact you. We gratefully acknowledge the Genetic Support Network of Victoria for the grant to produce this booklet.
- For progress on Clinuvel s trials on prevention treatment for people with EPP see their <http://photoprotection.clinuvel.com/>
- We still have a few copies of the Swedish Porphyria Association booklet *Patient and Doctor s Guide to Medication in Acute Porphyria 2005* for sale or it can be ordered direct from porfyri@swipnet.se OR porphyricentrum@karolinska.se

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(please read these notes in conjunction with those on page 1)

1. Election of new committee (if available).
(Note we are not legally an incorporated body without a committee.)
2. (a) Alternatively, delegation of tasks to facilitate legal winding up of the Porphyria Association Inc; or
(b) Explore the possibilities of putting the Association into abeyance until an alternative solution is found to continue to carry on the purpose and value of the Association.
3. Catherine McLean will continue to work on the booklet of *Our Stories* .
4. Introducing Jenny Swyer our administration officer.
5. The current paid Administration Officer is contracted until the AGM. The position will need to be re-negotiated by a new committee plus funds obtained for the continuation of wages. Or her position will be needed to process winding up documents.
6. Explore the legal options using the balance of raised funds into maintaining the information-only website.
7. The 2007 executive President, Vice President, Secretary and Treasurer, are available for consultation but have declined to take any official vacant positions on the said Committee for the forthcoming year.

Annual Membership is now due and owing

To comply with the Rules of the Porphyria Association Incorporated, members are:-

- Required to complete a membership form and pay the annual fee of \$5 in order to be eligible to vote at meetings.
- Voting may be undertaken by proxy.

The End