

ME/CFS SOCIETY (SA) INC
Minutes Annual General Meeting
13th November 2004 1-3 pm
Venue: DIRC, 195 Gilles St, Adelaide

Minute Secretary: Peter Mitchell

1. **Introduction:** The Chair and President, Peter Cahalan, opened the meeting by welcoming all present.
2. **Present:** There were approximately 40 people in attendance. The following names were recorded:

Apologies: Margaret Tucker, Jenny Grinter

Proxies: Margaret Tucker, Jenny Grinter nominated Peter Cahalan as proxy.

3. **Minutes of Previous General Meeting:** The minutes of the AGM held on 8 November 2003 were presented, read and accepted as correct.

Moved: Margaret Wing, seconded Emma Wing.

Carried

4. **Election of Management Committee:** Geoff Wilson, as returning officer, reported that he had received three nominations for the Management Committee by the time of close of nominations: Emma Wing, Donna Briesse and Peter Mitchell. This being less than the number of vacancies to be filled, they were declared elected. The ongoing members of the Committee are Peter Cahalan, Geoff Wilson, Margaret Wing, and Adrian Hill.
5. **Election of Office Bearers:** Dr Peter del Fante was asked to take the chair for the election of Office Holders. He was able to declare that the following nominations were received by the time of close of nominations:

Peter Cahalan for President
Geoff Wilson for Treasurer
Peter Mitchell for Secretary

They were declared elected unopposed.

6. **Treasurer's Report:** Geoff Wilson presented the Treasurer's report, and presentation of audited Financial Statements. In summary, the Society had had a reasonable year financially, bolstered by an anonymous donation of \$12,000 (the 3rd year in a row that this donor had made such a donation. There had been an increase in funds of just over \$2000 for the year.

Motion: That the financial reports for the period ending 30 June 2004 be accepted.

Moved: Jenny Gay, seconded Kevin Chigwidden

Carried

7. **President's Report:**

Peter Cahalan began his report by acknowledging that there was a much larger attendance at this AGM than there had been in 2003. He outlined a number of

achievements for the year. The *ME/CFS Guidelines* are now published. They took two years to develop and resulted from the efforts of a working party of medical practitioners and researchers with two Society representatives. Peter tendered thanks to the chair, Prof Justin Beilby, and to Associate Prof David Torpy, Dr David Gilles, Dr Richard Burnet, Dr Rey Casse, Dr James Hundertmark, Dr Milton Bowman, Dr Bruce Wauchope, Dr Ian Buttfield, Dr Richard Kwiitek and the Society representatives Paul Leverenz and Kristin Clark. He also particularly thanked Dr Peter Del Fante who assiduously worked on every stage of the drafting, and our partners: the Department of Human Services (now Health) and its representative Mr Bruce Whitby, the Adelaide Western Division of General Practice and the University of Adelaide Department of General Practice.

The *Guidelines* have now gone out to every GP in the State and CFS societies in other States have seized on them eagerly. The Guidelines are now available for downloading on the NSW Society's website, as it is on our own. Victoria and the ACT have also sought bundles of them. Peter noted that there's no doubt that it's a document of national significance and it's a matter of pride that South Australia has produced it.

We made a submission to the Parliamentary inquiry into Multiple Chemical Sensitivity. Member Lorenzo Pizza prepared a draft submission. Then Peter Evans and Peter Cahalan refined it and it went off to the inquiry. Peter Cahalan was then called upon to speak to our submission before the Committee on 25 October.

As part of the process, we co-convened with the Task Force on Chemical Injury a workshop in September. Twenty people attended, the great majority of them members of the Society. The Parliamentary Committee's report should appear in the first half of 2005.

The Management Committee takes the view that in the long run we need to be more closely aligned to other disability societies. This is not always the most efficient way to deliver services. So in the past two years we have kept in touch with Cystic Fibrosis SA regarding possible collocation at some time. We have to keep the option open for sharing accommodation with CFSA and/or other groups. Peter reported that we have also tried to develop our profile with other disability organisations by being active members of the Neurological Council of SA. This brings together over 20 organisations. Like everything else it is run by volunteers – in this case mostly the paid employees of larger organisations.

We have continued our involvement in the Council's joint exercises at agricultural field days. Our thanks go to Denise Stephens and Donna Smedley who staffed our section of the Council stall at the Lucindale Field Days in March.

As well as that, it was at our urging that the Council sent a letter, which we drafted, to the Minister for Health. In it the Council asks for the Department of Health to undertake a review into how it funds disability organisations and to then make public what its criteria are for the massive inequities in the funding available to various organisations. Peter committed the Society to continuing to work with our fellow organisations on the Neurological Council for the interests of all those people whom we collectively fight for.

In relation to communications, the focus for the Society has been on getting the

information that comes into the office passed on to members as quickly as possible. So we have posted a regular flow of items on our website www.sacfs.asn.au through webmaster Peter Scott. Peter Cahalan believes it is now the most actively updated CFS society website in Australia. We have also taken to sending irregular (but fairly frequent) e-bulletins to those members whose email addresses we have. That's about half. The response from them has been very positive. But we want to bring the other half of our members, who don't have easy access to the internet, into the flow of communications. We aim therefore to recruit several volunteers who are willing to come into our office and just get on the phones to these members to keep them more or less abreast of what their networked co-members are learning. In the meantime our thanks go to volunteer Michael Ritter, who handles this and a range of other IT issues.

Other activities reported on included:

- Awareness Day. Over 100 people attended to hear a panel drawn from the working party on the *Guidelines* reflect on the publication and what had come out for them from the project.
- Badge Day.
- *Talking Point*. Our magazine has come out quarterly, edited by Peter Scott, our webmaster.
- Country visit. A personal highlight for Peter was addressing the North Yorke Peninsula support group in Wallaroo in August. Peter gave his thanks to convenor Jane Gill and all other support group leaders for their continuing work over this year. Marion, Fran, Julie, Pat and Melanie.
- SAYME. The SAYME group – our support group for younger members – had a good year though a quieter one than previous years. There was a hiatus in the production of its magazine but that was sealed with the publication of the latest magazine in October. It's now back on track thanks to the efforts of Emma Wing and outgoing editor Elizabeth Cahalan. Thanks also go to events coordinator Sarah White and to the person who provided consistent support to SAYME throughout the year, our office coordinator Donna Briese.
- Research database project.

Management Committee: the Committee met monthly throughout the year. Glenn Domieka resigned after three years as committee member. Secretary Denise Stephens also retired near the end of term. Four new members then joined the committee: Emma Wing, Donna Breise, Donna Smedley and Peter Mitchell. Donna Smedley has since had to retire. Thanks go to these new members and to the ongoing members Marg Wing, Adrian Hill and Geoff Wilson.

Peter thanked especially Donna Briese for her work in managing the office so well, and Marg Wing, who comes in on Thursdays to support. Thanks also to the Support and Information Line: Jon and Vicki Foote, Alex Harris, Elaine Balfort, David Andrews and Marilyn Pennack.

Peter set out these future directions: continuing to improve our communications with members; having a stronger program of lectures and seminars; focusing on young people and their families; pushing forward our research database project; building our base of volunteers.

In conclusion, Peter wished members all good health and, if that was not possible, then a strong spirit.

Motion: That the President's report for 2003/4 be accepted:

Moved: Linda Brett, Seconded Kevin Chigwidden

Carried

8. Any Other Business

8.1 Volunteers: the President called for volunteers to put their names down on a list with task preferences. A pleasing number of those present did so.

8.2 A question was asked from the floor regarding the possibility of volunteers telephoning members from home. This was taken on board for the Management Committee to discuss.

Meeting ended 1:45 pm

Note: a DVD was made of the meeting and a copy is held in the Society's office.