

ME/CFS SOCIETY (SA) INC
Minutes Annual General Meeting
4th November 2006 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, acknowledged that we met on Kaurna land and that there were many members who would like to be able to be there, but were unable
2. **Present:** There were approximately 23 people in attendance. The names in the appendix were those recorded. 15 Proxies were received, along with other apologies as noted in the appendix.
3. **Minutes of Previous General Meeting:** The minutes of the AGM held on 12 November 2005 were presented, read and accepted as correct.

Moved: D Shepherd, seconded J Fuhlbohm.

Carried

4. **Election of Management Committee:** Peter Mitchell, as returning officer, reported that he had received three new nominations for the Management Committee by the time of close of nominations. Those three people were declared elected as members of state committee for a period of three years, consistent with the constitution: Melanie Cocker, Richard Cocker, Lynda Brett. The ongoing members of the Committee are Peter Cahalan, Adrian Hill, Emma Wing, and Peter Mitchell. Geoff Wilson retired as Treasurer at the AGM.
5. **Election of Office Bearers:** The following nomination was received by the time of close of nominations:

Richard Cocker for Treasurer

He was declared elected unopposed. Following the motion passed at last year's AGM, Richard's term as Treasurer will be for two years, concluding in November 2008.

6. **Treasurer's Report:** Geoff Wilson presented the Treasurer's report, and presentation of audited Financial Statements. In summary, the Society had another reasonable year financially, bolstered again by an anonymous donation of \$12,000 (the 5th year in a row that this donor had made such a donation), and an ongoing donation from the Bank SA staff fund of \$1000. Geoff stressed that without donations the Society would be running a deficit budget.
7. **President's Report:** Peter Cahalan began his report by acknowledging all those people who are part of our community but unable to join in its affairs because of the severity with which ME/CFS affects them. Peter reflected on a year which began slowly but ended well.

- **Communications** The Society continued to focus on strong communications with all members as its main ongoing activity. The key elements were:

- Our website: Peter Scott has for another year managed the site wonderfully, adding material sent to him from the committee swiftly and easily. The site's high-energy approach has built its audience to over 95 000 unique visits this year – up from the already respectable 30 000 visits in 2004. One result has been an increasing flow of approaches from international societies, e-magazines and others asking to be linked to the Society in some way or another.
- E-bulletins. We maintained weekly bulletins to members.
- *Talking Point* appeared three times during the year. Peter thanked once again Peter Scott, and announced that Jenni Gay, a trained medical librarian, will now assist Peter by sourcing articles for the website and magazine.
- SMS messages: quite effective in reminding people to come to various events from time to time.
- Contacting members not on the internet: Lynda Brett continued to phone members regularly and the Society circulated batches of printouts of e-bulletins on several occasions.

- **Seminars**

- Due to the lack of a coordinator, the year ended up with a slim program. A meeting for parents of young people with CFS in mid-year was not well-attended. The highlight of 2006 was a well-attended meeting where Drs Ian Buttfield and Kerry Callaghan talked as veterans in the treatment of PWCs in this State. At year's end Lorenzo Pizza has stepped forward to take on the coordinating job in 2007. The year will begin with the planned workshop with international experts in March.

- **National Association**

- The ME/CFS Association of Australia Ltd board met for the first time the Board or two days in Melbourne in October. The directors are mainly State presidents although as company directors they are there to take a national perspective.
- The board agreed to develop a common name, logo and other branding material to be used by all State societies; a common website and magazine; common fundraising and other literature; and support for the administrative costs of the Alison Hunter Memorial Foundation, the movement's research fundraising arm. The board decided that it would have to seek increased support

from State societies – from a present \$1 levy per members to as much (or as little) as \$5 a member.

- The State committee is agreed that we have to take this step.

○ **The Multiple Chemical Sensitivity campaign**

- The campaign to extract the maximum benefit from the parliamentary report on MCS was an active one this year. Key aspects of it included:
 - ◇ An invitation to the Society to nominate a representative to an interagency reference group to be established under the Department of Health to follow up on the parliamentary report. But Peter reported that the Department has been extremely slow in actually holding a first meeting.
 - ◇ By contrast the Catholic Education Office has already established an informal working party. MECFS SA representatives Debra Paor, Peter Evans and Peter Cahalan met with CEO representatives Greg Simon and Jayne Ryan to develop policies and procedures to make Catholic schools chemically safer.
 - ◇ Likewise the former Department of Administrative and Information Services, galvanised by Disability Officer Monica Leahy, developed the first Disability Action Plan of any State agency to include a range of actions relating to MCS.
 - ◇ The Society also lobbied Spotless, which has major cleaning and facilities management contracts with the State government, to incorporate MCS considerations in its operations.
 - ◇ Society members were well to the fore at a rally in September on the steps of Parliament House in September. At least 11 of the 25 people present to hear 5 politicians speak were from the Society.

○ **Advocacy**

- Peter Mitchell, Peter Del Fante and Peter Cahalan met with the Director of Primary Health Services for the Central Northern Region, hoping to establish the need for a project officer to research the needs of PWCs. This was not successful, but has led to an understanding of government commitment to funding clusters.
- The Society also maintained our membership of the Physical and Neurological Council, the umbrella body for several dozen disability societies. The end result is not to get resources for the Society but to deliver more assistance to our members.

○ **Pilot research database project**

- The Society was a partner in a project run by Dr Peter Del Fante and Prof Justin Beilby to develop a small database outlining the history of their condition as recorded by PWCs. The initial database ran to 75 people and the final report of the project, which was for some time

bedevilled with delays, came out in mid-year. Kristin Clark, one of our members, was the project officer for the database and did a great job.

- The Society also facilitated research projects undertaken by several graduate students during the year

○ **SAYME**

- SAYME had a quiet year, because Coordinators Emma Wing and Sarah White were heavily burdened with other committee work and with fulltime study respectively. Nonetheless several meetings were held and Emma published several copies of the SAYME magazine. Her efforts were admirable given all her other work for the Society and we were all delighted when she was nominated for a Young Australian of the Year Award. The committee hopes to give more attention to ways of sustaining SAYME in 2007.

○ **Thanks**

- Peter officially thanked a number of volunteers: They include:
 - ◇ The committee. Peter Mitchell, Emma Wing, Adrian Hill, Geoff Wilson, Melanie Cocker and, more recently Richard Cocker; Peter paid particular tribute to Geoff Wilson as long- serving Treasurer. Peter described Geoff as the essence of a good Treasurer, providing sage advice and religious attention to duties.
 - ◇ The office team. Mike Ritter, Lynda Brett, Libby Hughes and Emma.
 - ◇ Support workers. The committee has learned to appreciate very much the outstanding work of Elaine Balfort, Vicki Foote and Alex Harris who handle a great range of enquiries week in and week out. Peter thanked also all support group leaders across the State, represented at the GM by David Shepherd and Marion Hansen.
 - ◇ Fundraising. Peter thanked especially Adrian Hill, Carol Carroll and David Shepherd of Balaklava also generously for their respective roles in Society fundraising.
 - ◇ Peter Greco, 5RPH, long a friend to the Society, continues to provide access to 5RPH for the Society.

○ **Reflections and future directions**

- The committee's focus on communicating with and between members is working well. More members are taking up the idea of taking on some small advocacy task within their capacities and so increasing our collective political clout..
- The Society will need the support of all members in coming to tap into business and philanthropy contacts.

- Peter felt that it was critical to deploy the strength of people from all parts of Australia on delivering services to members and on advocacy for everyone with ME/CFS. He predicted a strengthened magazine and more benefits to follow. Peter assured members that all states intend to maintain their own local strength while building national presence for ME/CFS.
- The MCS campaign has taught us a lot and got some wins on the board. Peter confirmed that the Society will continue with it whilst also maintaining commitment to the broader ME/CFS agenda.
- Peter talked about the critical import of having a positive spirit, as the Society has. He hoped that in 2007 members feel even more unified and hopeful and aware that a thousand small, manageable actions can collectively amount to quite a big deal over time.

Motion: That the President's report for 2004/5 be accepted:

Moved: L Brett, Seconded D Shepherd

Carried

8. Any Other Business:

- Emma Wing talked about our presence at the Disability Expo at Morphettville, to occur later in November.
- The meeting endorsed from the floor the new national directions being taken:

Motion: That we support the adoption of the title ME/CFS Australia (SA) for our Society:

Moved: J Gay, Seconded R Neill

Carried Unanimously

Meeting ended 2:00 pm approx.

Signed: (President)

Date: