

**ME/CFS SOCIETY (SA) INC**  
**Minutes Annual General Meeting**  
**17<sup>th</sup> November 2007 1-3 pm**  
**Venue: DIRC, 195 Gilles St, Adelaide**

**Minute Secretary: Peter Mitchell**

Meeting opened at 1:05pm

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, and so were represented in spirit. Peter thanked members for turning out despite the heat, and noted that a number of members had attended specifically to ensure that the AGM would be quorate. One visitor from Switzerland was welcomed.
2. **Present:** There were 19 people in attendance, of whom 16 were members. Their names are recorded in the appendix. 28 proxies were received, along with other apologies as noted in the appendix (some proxies asked not to be recorded amongst apologies).
3. **Minutes of Previous General Meeting:** The minutes of the AGM held on 4 November 2006 were presented, read and accepted as correct.

*Moved: M. Cocker seconded M. Ritter*

**Carried**

4. **Election of Management Committee:** Peter Mitchell, as returning officer, reported that he had received two new nominations for the Management Committee by the time of close of nominations. Those two people were declared elected as members of state committee for a period of three years, consistent with the constitution: James Hackett and Spencer Langman. Members re-nominating for a further three years were Emma Wing, Adrian Hill, Peter Mitchell and Peter Cahalan. They also were declared elected consistent with the constitution. The ongoing members of the Committee are Lynda Brett, Melanie Cocker and Richard Cocker (treasurer, entering second year of two-year term).
5. **Election of Office Bearers:** The following nominations were received by the time of close of nominations:

Peter Mitchell for Secretary  
Peter Cahalan for President

They were declared elected unopposed. Following the motion passed at 2005 AGM, their terms will be for two years, concluding in November 2009.

6. **Treasurer's Report:** Richard Cocker presented his first Treasurer's report, and explained that presentation of audited Financial Statements would occur later. In summary, the Society had a very sound year financially, bolstered again by an anonymous donation of \$12,000 (the 6th year in a row that this donor had made such a donation), and an ongoing donation from the Bank SA staff fund of \$1000,

along with a similar donation from the Adelaide Bank. Peter Cahalan stressed that we were much healthier now than 5 years ago, when the Society had been relatively close to bankruptcy. There was discussion on the floor about office costs, and at least one offer to seek alternatives. We are currently in discussion with the Physical and Neurological Council re shared accommodation. Further discussion concerned memberships and the delays in processing these, due to shortage of volunteers and a rush of new memberships.

Richard Cocker acknowledged the work of Emma and Margaret Wing, who do a significant amount of work in processing payments and organising cheques etc.

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

*Moved: J. Tosolini seconded J. Clarke*

**Carried**

**7. President's Report:** this year the report is presented verbatim:

“I want to begin by acknowledging the spirit of all those people who fight valiantly against the challenges of ME/CFS. The Society itself is the expression of that spirit.

The last year saw some terrific achievements for the Society as well as the usual vagaries of fortune. It is my pleasure to report to you on the year that has passed.

**1. The 2007 Experts Forum**

For the second time in three years Adelaide was fortunate to be the host city for an important gathering of international and Australian experts on ME/CFS. The forum was organised by the wonderful Alison Hunter Memorial Foundation as part of its long campaign to improve the state of research into the condition in Australia.

Professor Kenny De Meirleir (Belgium) returned to Adelaide after being the keynote expert in 2005. Professor Abijhit Chaudhuri (UK) came to speak about his work in trying to improve pathology protocols in cases where people have died from ME/CFS – an important issue for researching and validating the condition. Dr Dan Petersen (USA) is an eminent figure in the American scene and emeritus Professor Malcolm Hooper has campaigned for people with ME/CFS and MCS (multiple chemical sensitivity).

The four spoke at a packed meeting at Norwood Town Hall on 25 March. They then spent two days in an intensive series of presentations and discussions with Australian researchers and clinicians. I sat in on the meeting and came away struck by how many biological markers of the condition are emerging from research around the world. Such an event with many hundreds of people attending requires lots of work from many people. I want to thank Lynda Brett again for her outstanding coordination of the event, ably supported not only by the whole committee but also by about a dozen other hard-working volunteers. Without their enthusiastic support, it would not have been the huge success it was. I particularly give thanks to Di Fleet for her huge effort in helping to promote the event.

**2. Seminars**

We have struggled in previous years to organise a structured annual seminar program. This year saw a major breakthrough. One of our members, Lorenzo Pizza, stepped forward to organise the program and take pressure off our small and hard-pressed committee. As a result we had our best year of seminars in recent memory. Our thanks to Lorenzo for marshalling speakers and managing the series. His work took a big burden off the committee, and allowed them to focus on other matters.

The seminars were as follows:

- In April, we planned a feedback session on the Experts Forum. As none of the Adelaide experts at the forum were able in the event to make this session, we improvised. I reported on the forum to a small group of people who enjoyed what one called an excellent support group encounter with much interaction between everyone.
- In May, we had an impressive performance from Emeritus Professor Barrie Marmion AO, one of those people better known internationally than in his own city. Prof Marmion is a world authority on Q Fever and national moves are in train to attempt to maintain the momentum of his research into a virus which can trigger ME/CFS.
- In July, we heard about two alternative therapies used by a number of our members. Tim White spoke on kinesiology and Dr Andrew Barrie discussed bioresonance therapy.
- In August, psychologist Liz Vaskin stepped forward after our scheduled speaker fell ill. Liz, herself a member of the Society, spoke on the value of using psychology in coping with ME/CFS.
- In September, dietitian Melanie Reid spoke to a large gathering on the role of diet in helping to deal with the condition. Diet had been noted at the Experts Forum as a key factor in treatment in these times when more fundamental 'silver bullet' cures are not available.

Several of these presentations and associated material are available on our website. We thank all the speakers for giving us such a great series.

To have delivered a planned and coherent series of seminars was a real fillip after the previous years of drought. Most hearteningly, Lorenzo had by August already prepared the 2008 seminar series. In fact, we now face a potential surfeit of riches and might delay several sessions until 2009. It's a nice place to be in and undoubtedly it's been one of our best achievements for 2007.

### **3. Political campaigning**

Dr Dan Peterson made a very interesting comment during the Experts Forum. He remarked that ME/CFS societies around the world had made the mistake of focusing overwhelmingly on providing support to people with the condition and ignored politics. If we are to get more funding for research and improved health, education, welfare and employment conditions for people with ME/CFS, then we

have to get out and lobby. The trick of course is to work out how to both support members and also do this political work.

We took heed of Dan Peterson's comment. We spent much effort this year encouraging members to take on the task of lobbying candidates in the Federal election. We decided that in the long run it is better to mobilise collective effort than to rely on the Society's hard-pressed official representatives to do all the political work. We have also found that the political lobbying process allows many of our members to make a contribution to the society, even while house-bound. A single letter or email from a member can help enormously, especially if it is repeated ten- or twenty-fold across the membership.

We used our website as our key campaigning tool. Member James Hackett pulled together data on all eleven electorates in South Australia. We encouraged members to tackle local candidates and furnished them with material from the ME/CFS Association of Australia and the Western Australian Society. A number of members responded and in fact we had enquiries from people in other States seeking advice on how to approach their candidates. The overall number of members who took up the challenge was small, but nevertheless a good start. But we believe that we have learned a lot from the exercise and have helped to encourage a number of people to learn how to play the political game more effectively. Hopefully we can keep building momentum in this crucial area of collective advocacy. Our ultimate target will be a really strong showing in the next State elections, to be held in two years' time. Thanks to all who put the effort in this time.

#### **4. Communications**

We have continued to build our reputation for excellence in communicating with members and other people with ME/CFS.

- **Talking Point.**

At the end of last year, member Jenni Gay volunteered to assist our Editor, Peter Scott, with the magazine as well as with sourcing items for the website. Peter heroically combines both tasks. The move has been a great success. Talking Point has come out regularly and at a high level of quality – helped by Emma Wing's good work in sourcing a new printing house and hard work from Peter on improving the layout. Despite the IT revolution, members still hang out for the printed word and so being able to strengthen our magazine has been a real plus for the year. Thanks again to both Peter and Jenni.

- **The website.**

We have fed a constant stream of items to the website and as a result its audience has continued to build. I first looked at the statistics for the site in September 2004 and was impressed that 30 000 visitors used it a year. The statistics now stand at 160 000 visitors and over 1.5 million hits. This puts us in the international A-League for ME/CFS sites, as far as we can tell. We made a start towards the site becoming the basis for a national site when the Victorian Society closed its site for maintenance and directed anyone accessing it to our site. We now have a Victorian segment and the flow of Victorian news to it has increased steadily.

- **E-bulletins.**

These have continued for most weeks of the year except for a break over the main summer holiday period. Keeping them going has at times been demanding and our Honorary Secretary Peter Mitchell now shares the task with me. I thank him and also Michael Ritter, our IT Coordinator, who manages all the backroom side of this and other communications work for us.

We also keep in touch with members via SMS text messages and phone calls. The latter work has rather dropped off this year and we hope that if we can recruit some additional volunteers we can once again renew stronger contacts with members – especially those not accessible by email.

As a result of the continuing efforts to keep in touch and also as an outcome of our increased seminar activity, we gained a whole swag of new members this year. There has not been a great net increase in membership – as a few people always drop by the wayside – but we have stabilised at the 300 mark.

## **5. National Association**

The ME/CFS Association of Australia Ltd is our national peak body. I'm the SA Society's nominated director and Peter Mitchell is my alternate director and sits in on our teleconferences. The Association ended last year strongly with an excellent two-day meeting of Directors in Melbourne. We decided on a series of achievable projects to get on with and left each other in positive spirits. This year unfortunately saw the energy sag. I'll comment on why.

We had intended to concentrate on doing the few simple tasks we had agreed on. We have no real funding and the directors are mostly people already flat chat running State societies and other groups. So keeping it simple and steady made sense. Instead, we found ourselves embroiled in what the SA delegates from the beginning saw as an unproductive debate over what name to use for the condition. Several members decided that we ought to revisit the name ME/CFS and wanted to get rid of the 'CFS' tag altogether. A flurry of long emails followed and in the end we were left still without a consensus on that matter and feeling less cohesive than when we had left Melbourne.

So we hit a rather low spot for a while. It coincided with the decision of our eminent president, Simon Molesworth QC AM, to resign because of the pressure of work and other business. Our able company secretary Nola Miles also resigned to deal with an increased flow of work for the Victorian society, which has been very successful in securing a range of grants for projects. Another director also resigned leaving us at present without a Western Australian representative. But we have pulled through and our former SA president Paul Leverenz has been voted in as our new National president and we believe we have found an able new company secretary.

The moral of this is that working as we do with so few resources and so many challenges, those of us in the ME/CFS movement need to be pragmatic and mutually tolerant. This Society has copped occasional flak from people who think we ought to get rid of the words 'chronic fatigue syndrome' from our title, for

instance. Frankly, your committee is not going to spend its scarce time struggling with medical terminology or looking at changing our name. Developing an international consensus on nomenclature and definitions is a job which we will leave to international forums and better-resourced movements.

Meanwhile we have recommitted to a high level of support for the National Association. We will get nowhere without one and have agreed that we will boost our funding support to it and continue to help in every way we can.

## **6. The Multiple Chemical Sensitivity campaign**

The campaign to extract the maximum benefit from the 2005 parliamentary report on MCS entered a new phase this year. Last year we had been frustrated at government inaction and highlighted this by running an MCS Clock on our website. Partly in response to our pressure, the Department of Health finally in December 2006 convened a Reference Group and in 2007 that committee slowly cranked into action. The committee includes representatives of the Department of Primary Industry and Resources SA, the Environment Protection Authority, Safework SA, the Department of Families and Community and the Department of Health. There are also two representatives of the Local Government Association. “Consumers” are represented by Peter Evans, the indefatigable convenor of the SA Task Force on MCS (and a member of the Society), Cathie Powell of the Bridges and Pathways Institute and myself representing the Society. In addition Drs Bruce Wauchope and Ian Buttfield are members and both are good allies.

After a slow start as we got to know one another, the committee gathered momentum over the last few months. PIRSA has drafted a set of guidelines on the use of pesticides and herbicides for use by local government authorities especially. The Department of Health has committed itself to shaping protocols for hospitals regarding the treatment of people with MCS. The Department of Families and Communities has also committed itself to improving its policies and procedures on MCS and to disseminating them throughout the public sector. There is still much water to flow under the bridge before these various policies are fully shaped, endorsed and implemented. But for the veteran lonely campaigners, they represent a decided increase in the momentum of the campaign.

We have also renewed late in the year our discussions with the Catholic Education Office about MCS policies for Catholic schools. The CEO hopes to have a policy endorsed by March 2008 and has already moved to improve its approach to building and refurbishing facilities.

It has been nice to move beyond huffing and puffing noisily – and perhaps thereby stirring some members to ask whether we were too focused on MCS issues – to a quieter and more focused phase of the campaign.

## **7. SAYME**

SAYME again had a quiet year. Coordinator Emma Wing has been heavily burdened with her general work on the Society’s committee and in the office and yet has managed to hold one gathering at her home, along with telephone and email contact with members of the group. The Committee has tried to give some time to working out how to give more support to SAYME as we regard it as fulfilling a crucial role in a number of areas. We have not been able to find a

solution yet but will keep looking.

One long-term project relating to the needs of young people with ME/CFS almost came to fruition this year. Peter Mitchell took on the role of reviving a long-dormant project – for which we had a grant – and we are ready to go to print with two brochures for schools and students about how schools can assist young people to gain the best possible education despite the challenges which ME/CFS poses. The brochures will make some impact once disseminated widely for the 2008 school year.

## **8. Support groups and the support line**

It was a year of some growth in this area, although our Adelaide Support Group folded early in the year. But that loss was offset by the establishment of a new Riverland Support Group. I attended an excellent meeting in Berri in October and we thank Simon and Raelene Jackson for their work. We also thank David and Glenda Shepherd for attending on behalf of the excellent Northern Yorke Peninsula Support Group. That group has had a good year. It held its usual meetings and also staffed a booth at the Paskeville Field Days. David Shepherd is also helping to launch a Clare Valley support group within a few weeks. The three country groups together cover the middle belt of regional SA from Renmark to Wallaroo. They are joined by the one continuing city group based at Glenelg and capably led by Marion Hansen.

It would be great if we could see one or two more regional support groups established in the next year. In all cases we rely on the leadership of committed members such as those mentioned above. That country members – especially if not on the Internet – can feel particularly isolated is a matter of continuing concern to the Society.

Meanwhile our wonderful trio of support line workers continue to answer telephone enquiries from all parts of the State. Elaine Balfort, Vicki Foote and Alex Harris have stayed at this task for years now. The committee gets regular reports from them and is always struck by the range of issues about which they are called up on to provide advice. We gather that the internet revolution has changed their work in two ways. At one level there is somewhat less demand than some years ago as more people use the web to find answers and information. At another level the high profile of our own website has meant more enquiries from interstate.

## **9. Thanks**

Once again the effort to support people with ME/CFS and get a better deal for them has fallen largely upon a few people. Almost all have ME/CFS or are close family and supporters of people with the condition. Once again it is my pleasure to thank them.

*The committee.* Lynda Brett, Spencer Langman, Emma Wing, Adrian Hill, Mel Cocker, Richard Cocker and Peter Mitchell, have continued to work in close harmony and with good humour. Those are qualities never to be taken for granted in a committee! It makes volunteering for the Society a pleasure to have such nice people to work with. The achievements of 2007 are in no small measure due to their commitment and wise stewardship.

*The office team.* Lynda Brett took on the role of office coordinator this year and has handled this absolutely pivotal role with great competence. Our thanks go too to Emma Wing, Mike Ritter, Jacquie Smith and Spen Langman for their regular attendance to handle the basic administration of the Society. They were augmented on occasions by a number of other volunteers who assisted with particular events or projects and to all of those people we send our grateful thanks. Mind you, we are always in need of more help and we really struggled to keep up with membership related work especially – processing applications, sending out renewals, packing and sending every member a free copy of the South Australian and Canadian guidelines. We really do need more help to take the pressure off the few hard workers.

*Fundraising.* Thanks to Carole Carroll for organising this year's Badge Day. We're delighted that she's willing to do it again in 2008. We rely on it as we have few sources of fundraising otherwise. Once again, though, we can express our delighted thanks to the anonymous donor who has for five years now sent us an annual cheque for \$12 000. We also gained our first bequest in years – for \$1560. And we received continuing sponsorship from the Adelaide Bank and the Bank SA Staff and Charitable Fund as well as sponsorship from Eco Pest Control for our public meeting with the international experts.

## **10. Reflections and future directions**

There are some **key trends and issues** for us. They include:

- Improving our capacity to advise people with ME/CFS about expert and empathetic health practitioners. This has been a vexed problem for us with out of date and partial lists to work from. We have made a start by asking all members to provide us with their own recommendations and hope to systematise the results.
- Doing what we can to improve the supply of health practitioners with a knowledge of and commitment to treating ME/CFS. There is a real concern that not enough new medical practitioners are entering the profession as older members with expertise and accrued wisdom leave the scene. This was the focus of a meeting of four interested doctors and myself as the Society's representative in October. This is a complex issue which will not be easy to address but we hope to do more in 2008.
- Supporting the National Association in its efforts to create a more concerted and mutually supportive national movement of people with ME/CFS.
- Supporting the National Association in its efforts to create a more concerted and mutually supportive national movement of people with ME/CFS.
- Reviewing our efforts to encourage members to become self-confident and well-armed political lobbyists on the many issues of concern to people with ME/CFS.



- Keeping up the pressure on the State and Federal governments to do more for people with chemical sensitivities. I believe that one of the most important of these is getting a better deal for them with regard to safe housing. It's an issue which comes before us several times a year and the needs of the most seriously ill and chemically sensitive people are dire.
- Finding ways to enable more members to contribute from home rather than having to come into the office – whilst rebuilding our office team from its present too-fragile size.
- Continuing to stay open to possibilities for working more closely with other disability groups and in time coming to share accommodation and resources with them.

I want to conclude this annual report with greetings and respectful best wishes to all the courageous and talented people who share in the work of our Society – which, incidentally, celebrated its twentieth birthday this year.”

Discussion with members present led to the suggestion that, when we ask members to agitate politically, we need to be clear about what we are asking them to do. Peter suggested that what we would like is

- awareness raising: that members keep raising the name of ME/CFS.
- people to write papers on political issues
- people to gather stories on medical case studies to use as a political “weapon”

Other discussion led to the suggestion that we need to have all the information on the renewal form so it can be filled in and sent back immediately without the need to search addresses etc, Peter mentioned that Jayne Warwick is working on a database of medical practitioners as of last fortnight. Further to this, there was discussion about the issue of us impacting on the training new younger groups of doctors, to overcome prejudice/ignorance. There was acclamation for the role of the support groups and support line.

*Motion: That the President's report for 2006/7 be accepted:*

*Moved: J Tosolini, Seconded J Clarke*

**Carried**

## **8. Any Other Business:**

- Nil

**Meeting ended 2:15 pm approx.**

**Signed: ..... (President)**

**Date:** .....

| 2007 AGM Attendee | Member | Representing another Org.? |
|-------------------|--------|----------------------------|
| B Campbell        | Y      |                            |
| R Cocker          | Y      |                            |
| J Tosolini        | Y      |                            |
| J Clarke          | Y      |                            |
| M Cocker          | Y      |                            |
| J Hackett         | Y      |                            |
| E Balfort         | Y      |                            |
| D Staudenmann     | N      |                            |
| S Langman         | Y      |                            |
| J Warwick         | Y      |                            |
| X Pankar          | Y      |                            |
| L Pizza           | Y      |                            |
| D Liestecht       | N      |                            |
| G Langman         | N      |                            |
| B Corbett         | Y      |                            |
| P Mitchell        | Y      |                            |
| P Cahalan         | Y      |                            |
| S Lawless         | Y      |                            |
| M Ritter          | Y      |                            |

| PROXY inc apology | Apologies, inc proxy |
|-------------------|----------------------|
| W Begg            | V McKeown            |
| C Penglase        | G McKeown            |
| L Brett           | E McElroy            |
| G Wilson          | M Quick              |
| A Ballard         | G Tiver              |
| G Lear            | N Radvic             |
| I Pudsey          | C Siddall            |
| P Scott           | L Brett              |
| R Arikawe         | R Crocker            |
| G Brown           | D Jefferys           |
| D Carty           | A Rooney             |
| J Gay             | A Harris             |
| S Jackson         | V Lomax              |
|                   |                      |
|                   |                      |