ME/CFS Society (SA) Inc
Annual General Meeting 8 November 2008
President’s Report

I begin by acknowledging the powerful spirit of all those who endure ME/CFS and live life to its depths despite it.

A glass half full report

This is my sixth report as Society president. In all the others I have been able to report in generally optimistic tones about how we’ve done over the past year. This time I feel obligated to report more soberly. This has not been a great year for us. It’s not been bad. But it could have been better. The committee and key volunteers merely happen to be the elected or coopted willing workers from amongst a membership of 250 or so people. So it does neither them nor the general membership much good to gloss over things and hope that it’ll all turn out right in the end (as it has so often in the past).

There were some terrific highlights during the year, and I will come to good news later, but I want to start with the issues.

First, the bad news…

- **Staffing the office.** We had real problems this year keeping the office open each Wednesday. Key volunteers were taken off line by health, family and work pressures. One outcome was that occasional volunteers came by from time to time only to find no one there to let them in. We need a core or people in the office to deal with phone calls and basic administration. We just don’t have enough of a team at present. And without a reliable team of experienced people we actually can’t build further when other people volunteer.

- **Budget.** We logged our biggest deficit in years – around $18 000. We had anticipated a tough outcome given the loss of our long-term donor Ms Miller and her generous annual gift of $12 000. And we anticipate getting a cheque for $5000 from her estate some time soon, helping us to a better result in 2008/09. But the deficit was more than expected. Simply put, memberships cover only a quarter of our costs. We have to raise the rest through sponsorships and donations. We have the reserves to cover us for a while. But we can’t keep on going with the red ink so red for too many years more.

- **Finances.** We have struggled in recent years to manage our book-keeping –everything from processing cheques and paying bills to the general paperwork required by the authorities. We have to get a handle on this and that will be something the committee will look at carefully in the next month or so.

- **Tired leaders.** This was a year when a number of veteran workers for the Society have not been able to put in anywhere near their former level of effort. I include myself in that. You wear out after a while. It’s not true of all our committee or other key volunteers, I hasten to add. But the truth is, as some old hands have reminded me from time to time, the Society comes to rely on a few people for too long. We need a few more fresh faces and need to gear up for this time next year when several of the committee will, they have told us, step down.

The truth is that one’s energy runs down over time anyway. But it runs down more quickly when there’s a constant background noise of little administrative issues going awry. So if we can expand that cadre of volunteers who run the administrative basics of the Society, that would re-reenergise those of us charged with the more strategic end of the business.
There. I feel better now for sharing that with you. And…

**It does get better**

There were some really positive aspects to the year. One was the development of a new support group in the Riverland –about which more below.

Another was the effort put in by Jayne Warwick to greatly improve our database of health practitioners. Our big FAQ is: where can I find a good doctor or other health professional? Our old list had become outdated and Jayne has worked on a project basically akin to painting the Sydney Harbour Bridge. We now have a much better list from which to offer advice to enquirers. Thanks Jayne.

And another highlight was having a highly competent and reliable person step forward to take on the role of Membership Officer. We were being driven mad by constant problems with our membership database and with complaints from people who had not received Talking Point and so on. It was very dispiriting and of course it’s not pleasant to think that formerly faithful members are getting cross enough to threaten not renewing their membership.

Well, a few months ago Lorenzo Pizza took on the job. And he’s done it splendidly. We now have our databases sorted and Lorenzo is taking seriously his brief to be our members’ advocate – ensuring that we offer the right range of benefits to members and so on. Thanks Lorenzo.

**Seminar program**

Lorenzo again organised a very good seminar program for the year.

The year kicked off in February with a very practical lecture by physiotherapist Julie Peacock. Julie had us all up and about doing exercises. As luck would have it we didn’t have a videorecorder there on the day. This was one of those lectures which can’t be easily taped or noted down –you had to see it! Psychologist Liana Taylor addressed us in April. Liana had been booked for a gig in 2007 but fell sick. We were glad to book her in again. Our focus on allied health professions continued with occupational therapist Edwina Shannon in June. Dr Anne-Marie Southcott, president of the Sleep Disorders Association of SA, spoke on sleep disorders in August. And we had naturopath Katie Behlau in October. The year is to be capped off by a lecture at this AGM by our great supporter endocrinologist Dr Richard Burnet speaking on his latest research.

Thanks to all our speakers, to Lorenzo and to Colin Northey who has taken on the task of filming the lectures. We are not producing DVDs generally but have the recording on hold for copying when people ask –although again this is one of those areas where we run into labour shortages from time to time.

**The website and our communications program**

I always spark up when I come to this item. Peter Scott for yet another year has diligently and cheerfully kept the website running smoothly. In fact I did a quick count of news items from 8 November 2007 till today and came up with 280 or so. That is, we posted a new item almost daily over the past year. It’s an amazing achievement. Peter was helped by a small band of suppliers of content. Jenni Gay assisted him with this and Talking Point content for much of the year till pressure of other work compelled her to take a step back. Judy Rhodes from Yorke Peninsula has since taken on those roles capably. And Michael Ritter ably supplies photographic content.
For much of the year we hosted content for the Victorian Society while it was re-jigging its site. This seems to have boosted our readership and at peak in May 641 people a day were visiting the site. The annual totals are over 170 000 visitors and over 2 million hits. So we continue to serve a big market and meet the needs of many people hungry for information on ME/CFS. We also targeted the specific interests of people with MCS and Fibromyalgia by creating special sections on those topics.

We continued our weekly e-bulletins. I am particularly grateful to Peter Mitchell who has shared that task with me this year. His jokes section has gone down well. I’m a terrible jokester myself but appreciate the importance of maintaining good humour in the face of adversity. Thanks Peter.

Talking Point

We produced four issues of Talking Point this year. As noted above, Peter Scott, Jenni Gay and Judy Rhodes made that possible. So also did Emma Wing who has covered backroom logistics such as getting it to printers and from there to the mailroom.

The Schools Brochure

At last I am able to report that the glossy brochure for young people with CFS and one for their school staff have been completed. During the year, we got copies into schools in all three systems: government, Catholic and independent. They are there available to parents who come to the school with a child diagnosed, or to staff who work with students with ME/CFS. All three systems were supportive of our aim to get the information where it was needed. We would particularly like to thank the Catholic Education office for couriering copies into every Catholic school at their own cost. Tiffany Linke designed the brochure, and she gave us enormous value for our money in the task. We now have lots of copies available to respond to requests from parents/caregivers and schools. We even had a request from Dublin for some copies recently. Thanks also to the parents, young people and Open Access College staff who assisted greatly along the way.

ME/CFS Australia Ltd

ME/CFS Australia is our national peak body. I’m the Society’s nominated director with Peter Mitchell as my alternate director. And the company secretary this year was member Jenni Gay. We’ve had a busy year in those capacities as the Society has moved into higher gear under the driving leadership of President Paul Leverenz – our previous State president. So South Australian input to the board’s activities was pretty considerable-especially when Peter Scott’s input to a working party on a national website is added to the list. At times indeed we were spending more time on national business than on the Society’s own affairs – which made for an interesting balancing act.

The board met by teleconference monthly. Key issues included working on a policy for the national website and on developing the agenda for a two-day meeting in Canberra in late November. This will be only the second such meeting ever held, the first having been held in Melbourne in late 2006. Trying to forge a stronger national body for ME/CFS is a slow and difficult process given distance and the utter lack of resources available to the board. But it has to be done and it is being done and I pay tribute to Paul Leverenz for his energetic leadership.
**The Multiple Chemical Sensitivity Campaign**

It’s been slow but hopefully steady enough going in the struggle to get a better deal for people with chemical sensitivities this last year. It was the second full year of activity for the Minister of Health’s Interagency Reference Group on MCS. Peter Evans and I are both consumer advocates on it and are joined by Cathie Powell and by Drs Ian Buttfeld and Bruce Wauchope. The other members represent a range of agencies.

The meetings have been irregular and at times little seems to be happening. But overall there has been a pleasing outcome in terms of a draft hospital protocols document; a policy for government agencies booking venues – they have to take chemical sensitivities into account; a draft policy on controlling spraying for local government; and several other items.

Peter Evans and I also attended a summit for MCS lobby groups in Canberra convened by the Office of Chemical Safety. The purpose was to consider a draft report on MCS issues before the Office released it for public comment. It was a most interesting day for me, introducing me to a number of highly-talented and dedicated persons from all over Australia who are fighting for a better deal.

I do have to say that too much falls on the shoulders of too few in this regard. Peter Evans has been remarkable but he, even with me helping a bit, can only do so much. We both feel that too many opportunities have passed us by this year to push harder – even on the Reference Group itself – because we’ve been too stretched. One example is the work we and Deb Paier did with the Catholic Education Office. After meeting with the CEO over several years we have not secured a concrete outcome in terms of a policy on chemical safety and health for Catholic schools. The key CEO officer retired and we lacked the time and energy to keep pushing. So I take this chance to urge our members who have a direct interest in the MCS campaign to come forward and take on bite-sized parts of the struggle.

**Support groups, the support line and Facebook**

Our one metro support group based at Glenelg folded its tents during the year. Our thanks to Marion Hansen who did so much to keep it going. On the other side of the ledger the newly-formed Riverland Support Group has had a great year under the enthusiastic leadership of Simon and Raelene Jackson. The new Clare Valley group has likewise met quarterly and so has the older-established Northern Yorke Peninsula group. David Shepherd convenes both with assistance from his wife Glenda. These are vital links in our chain of support to people with ME/CFS and we thank these leaders for their great contribution.

One of our greatest other assets is our long-running support line. It once fielded a team of volunteers but the group has shrunk over the years. This year our veteran fount of knowledge at the end of a phone, Elaine Balfort, retired from the work. This left only Alex Harris and Vicki Foote in the team and they have adopted a lower profile for the moment. We thank them all sincerely for their work and can only hope that we can continue to provide a support line service.

Meanwhile, new opportunities arise for helping people to get information and mentoring about the condition. Committee member James Hackett has set up a Facebook group, ME/CFS Australia, which as I write has 64 members. It’s not highly active at present but is building a presence and has several discussion threads going on topics such as helpful medications and good doctors. James’ project is a great addition to our overall campaign to make the fullest use of new technologies to create a stronger community of ME/CFS persons in South Australia and beyond.
Thanks

Once again I want to thank the small band of people who do the work that aims to benefit South Australia’s 7000 or so ME/CFS sufferers and their families. Some I have mentioned already. The others include:

- **The committee.** Lynda Brett, Spen Langman, Emma Wing, Adrian Hill, Richard Cocker and Peter Mitchell continued serving the Society this year. Mel Cocker resigned during the year but the gap was filled by James Hackett who, as a Quorn resident, is our only country-based member. The committee has continued its tradition of meeting at the Wing family home which provides a relaxed setting and contributes to the pleasant way in which our business is conducted.

- **The office team.** Lynda Brett, Emma Wing and Mike Ritter have been mainstays of the office this year. Jacquie Smith has been the other most regular volunteer. Together they have struggled to keep up with the paperwork and phone calls and we thank them for their work. Without them we would be, to use the vernacular, stuffed.

- **Fundraising.** Once again we have cause to thank Carole Carroll for organising a successful badge day. It goes without saying that without other forms of income generating we are in the mire and it’s great that she takes on this task each year. We had one particularly nice surprise this year when the Daimler Interest Group of SA wrote to us out of the blue with two cheques of $1250 each for us and the Alison Hunter Memorial Foundation. The money came our way through the efforts of members Harold and Rosalie Parslow who pointed the Group in our direction and we thank them for that. Finally, we continued to gain support from the Bank SA Staff and Charitable Fund.

Future directions

We have one over-riding task in 2009. That is to build our base of reliable volunteers to staff the office and handle our administrative and financial affairs steadily. Without a firm base there we cannot direct our energies easily to the higher affairs and larger issues which you need your Society addressing: promoting research, encouraging medical education, lobbying on disability and other issues, continuing the MCS campaign and so on.

Until we do that it’s a case of hanging in there. Please join with me in wishing us all luck on the journey.

Peter Cahalan