

President's annual report 2006

Peter Cahalan, President ME/CFS Society (SA) Inc, delivered this annual report for the year 2006 at the Society's Annual General Meeting on Saturday November 4, 2006.

I want to begin 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.

The last year was one of fluctuating fortunes for the Society. There were times when your committee wondered if we were making inroads into the many challenges facing us. But it's nice to report at year's end that things have gone generally in the right direction.

Communications

We continued to focus on strong communications with all members as our 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 our 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 us in some way or another. We're particularly pleased with our German linkages on the one hand whilst Cort Johnston, who runs a wonderful e-report on ME/CFS research, tells us that he has tracked his high proportion of Australian visitors to referrals on from our site. The site got so busy this year that we experimented with ways to separate local, Australian and international items of interest.
- **E-bulletins.** We maintained weekly bulletins to members.
- **Talking Point** appeared three times during the year. A blip in mid-year took us down from the planned four which our members expect. Thanks once again to Peter Scott for handling this job as well. It's great that at year's end Jenni Gay, a trained medical librarian, stepped forward to begin assisting Peter by sourcing articles for the website and magazine.
- **SMS messages.** We found these to be 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 we circulated batches of printouts of e-bulletins on several occasions.

Perhaps the nicest feedback we had on the communications strategy came from Dr Peter Del Fante. He remarked some months ago that there was a distinct trend in patients mentioning to him that the website and bulletins were helping them feel better by linking them to the latest research and to a wider community of PWCs (people with CFS).

Seminars

We had planned to run an increased range of seminars this year but for want of someone to coordinate them and other reasons ended up in fact with a slim program. The highlight was a well-attended meeting where Drs Ian Buttfeld 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. So we're hoping for a stronger program next year – and are off to a great start with the planned workshop with international experts in March.

We did have an interesting variation on the normal meeting format earlier in the year. We planned a meeting for parents of children with ME/CFS. In the event, only one person came along -by telephone. So Marg Wing, my wife Penny and I sat with the phone on loudspeaker at our house and Clytie Siddall from the Riverland had a long and interesting discussion with us. It's interesting that this is the second meeting over the last couple of years where we have tried to target parents – traditionally actively concerned about what to do for their sick children – and yet had a low turnout.

National Association

The ME/CFS Association of Australia Ltd has been hitherto a frail enterprise. With minimal funds of its own and meeting only two or three times a year by teleconference it has struggled to advance our cause nationally. But things changed this year and for the first time the Board met for two days in Melbourne in October. The directors are mainly State presidents although as company directors we are there to take a national perspective.

We agreed unanimously that we had to develop a stronger and more coordinated approach to supporting people with ME/CFS across Australia. Measures agreed to included developing 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. We looked at our basic needs and decided that we 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.

Your committee endorsed these proposals, including the increased levy, at its October meeting. As I write WA has followed suit and so has Queensland with some qualifications.

The development of a stronger national body will put pressure on our budgets and involve some lessening of our capacity to do our own thing. But the State committee is agreed that we have to take this step. I hope that by this time next year you will have begun to see the impact of the decisions taken at the Board meeting.

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. I am taking on that role. But it is frustrating to have to report that the Department has been extremely slow in actually getting the group to the point of holding a first meeting.
- By contrast the Catholic Education Office has been wonderfully cooperative in responding to a suggestion from us that it develop policies and procedures to make Catholic schools chemically safer for all who use them. Debra Paor and Peter Evans and I have served on an informal working party with CEO representatives Greg Simon and Jayne Ryan.
- 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.
- We also lobbied Spotless, which has major cleaning and facilities management contracts with the State government, to incorporate MCS considerations in its operations. We haven't heard back from Spotless but received a cordial response when we met with a senior manager some time ago.
- 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. It was the largest crowd at one of these rallies and the largest number of politicians ever to join us.

Advocacy

Peter Mitchell, Peter Del Fante and I met with the Director of Primary Health Services for the Central Northern Region, drawn by an understanding that we might have some hope of getting a project officer appointed to research the needs of PWCs. We came away disappointed. One thing the meeting underlined was that if we could show that PWCs are clustered in one or more particular areas, we might have a better case. Well in fact we're spread thinly across every part of the State. But we are now developing from our membership list a map showing where our members live to give us some idea whether there are cluster areas. If so we'll use it in further negotiations with the health authorities.

We've also maintained our membership of the Physical and Neurological Council, the umbrella body for several dozen disability societies. The PNC secured a Department of Health grant to investigate whether its member societies could deliver shared services which might – only might – enable it to secure some measure of State government support. The Society has been clear for some time that we can't get government support on our own so this hopefully a step in the right direction. The end result, we'd stress, 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.

We also facilitated research projects undertaken by several graduate students during the year.

SAYME

SAYME had a quiet year. 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. For those of us who have been around the Society for some years, its value is very clear. It has a big impact on the young people and their parents who have participated in it and it has also been a training ground for leaders of the Society generally.

Thanks

The Society runs on the efforts of a fairly small pool of people around the State. Once a year we get to thank them officially. They include:

- **The committee.** Peter Mitchell, Emma Wing, Adrian Hill, Geoff Wilson, Mel Cocker and, in the last month or so, Richard Cocker, have been a terrific group of people to work with. We pay particular tribute to Geoff Wilson as our long- serving Treasurer as he is standing down today. Geoff has religiously attended to the duties of Treasurer and provided sage advice about what the figures really mean – which is the essence of a good Treasurer.
- **The office team.** Mike Ritter is also someone I'd like to thank especially for staying with us for over two years after coming in to join us with no connection with ME/CFS. He keeps the IT side of things well under control and administers our emails, SMS messages and much besides. Lynda Brett regularly gets on the phone to members. Libby Hughes made a great contribution for some months until new work commitments took her away. Emma faithfully held the fort.
- **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. My thanks also to all support group leaders across the State. I always feel that we give them less than their full due in sch reports. That's because we on the committee don't see a lot of them and so their work goes on quietly and effectively but somewhat anonymously. It's nice to have two leaders – Marion Hansen and David Shepherd – with us today representing this great group of people. Thank you all.
- **Fundraising.** Thanks especially to Adrian Hill again for our annual badge day and to Carol Carroll for organising a team of Annesley College girls (and a few others) to badge sell at the Railway Station. David Shepherd of Balaklava also generously organised the production and sale of torches and pens for us.
- Peter Greco of Radio 5RPH has been our best media supporter. He actually pursues us for stories and has interviewed Elizabeth Cahalan on a monthly segment on spirituality and chronic illness.

Reflections and future directions

What did we learn in 2006?

- Our focus on communicating with and between members is working well. Not least, there were heartening signs near year's end that more and more members are taking up the idea of taking on some small advocacy task within their capacities and so increasing our collective political clout. It can't all be done by a few committee members, most of them burdened by the administrative aspects of the Society.

- It's not easy to build our financial reserves and get to a point where we have the resources to employ people to assist with administration and/or undertake specific support and project work. So the support of all members in coming years will be vital as we use all the contacts we can to tap business and philanthropy on the shoulder.
- There's local strength in national unity. I was greatly impressed with the range of skills and experience which the National Association's members have. We'll do better over time to deploy the strength of people from all parts of Australia on delivering services to members and on advocacy for everyone with ME/CFS. To some extent in the short run that could well actually divert State energies from other, more immediate work. But at the least by the end of next year I think our members will be getting a strengthened magazine in their post each quarter. And there'll be more benefits to follow. Meanwhile neither we nor any other State intends to support arrangements which will weaken that sense of local community which our societies offer.
- Lobbying is a slow, hard job. The MCS campaign shows that. If you've got a State health system whose administrators are pursuing priorities which don't include us, it's particularly hard. But the MCS campaign has taught us a lot and got us some wins on the board. We'll continue with it whilst also plugging away at the broader ME/CFS agenda.
- A positive spirit is a great asset. I think we have a positive spirit here in our State society. Goodwill and a certain (often naïve!!) hopefulness gets people going tackling things which would not happen where people feel downhearted and isolated. The grim challenges of ME/CFS affect just about everyone who has joined our Society and you can't will them away. But my hope is that in 2007 our 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.

On behalf of the State committee and all who actively work for our cause, I tender this report to the wider membership.

Peter Cabalan

4 November 2006