

MS Strategic Plan

Summary

Although Multiple Sclerosis has been a recognised medical condition for a long time, the recent MRI scan has improved the rate of diagnosis. It is logical that this will mean an increase if the number of people being diagnosed, acknowledging some previous diagnosed might now be found not to have MS. Until the results of the prevalence study come out it is hard to estimate whether there is a growing number of people with MS or whether any increase in numbers is the result of better diagnostic tools.

Whatever the outcome of the prevalence study it is likely there will be a growing number of people diagnosed with MS and the means more potential clients for the MS Society. It also means the Society must always revisits its “relevance” and “effectiveness”.

The Society has come a long way in the last few years and now there is a need to focus on structure and increasing professionalism to take it to the next level.

Recommendations:

The following recommendations are made, but in no particular order. The numbering system is for ease of discussion purposes instead of priority ranking and I intend to speak to them at our forthcoming meeting and provide my own view of the priorities that the committee needs to consider.

Client Services

	Recommendation	Rating TBA
1	The Committee appoints a sub committee to explore the range of options for facilities for respite care and office accommodation and report back.	
2	The Committee asks the General Manager to explore the range of options for a counsellor or appropriate counselling service and report back.	
3	The Committee asks the General Manager to organize a plan for the development of a “dummies guide to MS” and report back.	
4	The Committee asks the General Manager to facilitate a meeting for those interested in an “employment collective”. The meeting is to occur and once set up staff leave the collective to self manage.	
5	The Committee asks the General Manager to include in reports to the committee on the face to face visits, telephone visits etc of Field Workers. This report should not be about a single Field Worker but the collective figure so the committee has confidence that face to face visits are happening for all clients.	
6	The Committee asks the General Manager to explore the possibility of Field Workers being accredited to assess for DHB and report on this possibility.	
7	The Committee asks the General Manager for an exercise schedule plan for the next twelve months. The plan to include exploration of new exercise classes and area	

Operations

	Recommendation	Rating
8	The Committee asks the General Manager to report back on the range of options and cost effectiveness of those options for a more integrated data base system.	
9	The Committee asks the General Manager for a plan on raising the profile of MS and MS Auckland Region. This plan to be presented to the committee.	
10	The Committee asks the General Manager to present a business case for a Public Relations employee.	

Finance

	Recommendation	Rating
11	The Committee set up a separate finance sub-committee to look at fundraising, a separate research fund and a policy on “reserves”. This committee should have the power to second others with appropriate expertise and present a report at every committee meeting.	

Governance

12	The Committee changes to a Board of Trustees.	
13	The Committee set up a regional committee structure with defined guidelines.	
14	The Committee set up a social and training programme for themselves.	
15	The Committee publishes this report on the web site and markets it through the newsletter.	
16	The Committee makes the commitment that six monthly progress reports are given to clients on the outcome of the strategic review.	

The report will now look at each recommendation and why it needs consideration.

1. Respite care
 - a. All people interviewed talked about the need for improved respite care. We average about 3-5 people in respite care at any given time. Some of the current facilities are not appropriate.
 - b. There is the potential to gear such a model so that it becomes an income stream for the society.
2. Counsellor
 - a. At the time of being newly diagnosed there is the need for counselling, along grief lines to help clients and families adjust to MS invading their lives.
3. “Dummies guide to MS”
 - a. An overwhelming case for accurate and timely information for clients, not just in medical matters, but benefits, managing WINZ, alternative therapies etc.
 - b. Knowledge is power and MS has already disempowered. This is a mechanism for giving power back to the clients.
4. Employment collective
 - a. A number of clients have lost their employment through MS and yet still have much to contribute. They want/need an MS friendly work environment. Getting clients to form their own company/companies under the MS umbrella creates employment and hope.
 - b. A possible extra income stream for the society. The profits from the company can come to the society. The clients working for the “company” would receive remuneration. The clients would need to establish what their product, market etc are.
5. Field worker visits

- a. A governance reporting system to ensure field worker visits are happening and not just visits to field workers “holy huddles”.
 - b. A consistency of approach and higher professional standard required from the field workers. They are the front line of the society and their training and performance needs to reflect this.
6. Field workers accreditation
 - a. Clients trying to get wheelchairs and other equipment to assist them are struggling with the level of service currently provided through the DHB’s. There is the possibility the field workers could get accreditation as assessors and thus speed up the process.
 - b. If (a) is successful this would become a minor income stream.
7. Exercise schedule
 - a. Exercise is important to clients and their well being. A strong desire from the client base for more exercise type programmes.
 - b. Programmes could consider the possibility of being available outside work hours so those currently employed could use these services.
8. Integrated database system
 - a. Efficiency and effectiveness could be improved with an integrated database system. There are cost effective options available in the market place.
 - b. A good database would have information of skills sets available from clients and their families. This would lead to greater engagement with the society if volunteer’s particular skills were used.
9. Raising the profile
 - a. Clients want the profile raised so there is more understanding of MS on “the street”.
 - b. A higher profile raises the chances of getting more generous sponsors and hence more income.
10. Public relations employee
 - a. A head count dedicated to raising the profile through quality press releases helps raise the profile and generate more income.
 - b. The public relations employee can be a good government lobbyist for more funding from government. Many clients felt this is an area where the society is noticeably weak.
11. Governance finance committee
 - a. A number of committee members commented on how meetings focused on fundraising and other governance matters were not raised. A separate committee who dealt with this area and reported back would make committee meetings more efficient.
 - b. There was a feeling among some committee members that meetings were not as productive as they would like and they are giving up valuable time. They want to be involved and feel their skill set is used to the maximum. Committees are a tool for accomplishing productivity.
12. Change to a Board
 - a. The overwhelming response from both clients and current committee members was to change to a Board of Trustees. This creates a more professional feel and stops the feeling of being a “cup of tea” brigade.
 - b. A Board would attract more professional people and hence give access to increase funding.
13. Regional Committee structure
 - a. Local regional committees can utilise volunteers more and create a stronger sense of “community”.
 - b. Local committees can organise local events, but care must be taken that they do not “take ownership” of employed staff.
14. Committee training
 - a. Some members of the committee requested training so they understand the role of governance better.
 - b. Social events as a committee would create a stronger team culture.
15. Strategy report
 - a. This report should be sent to members and put on web site so that everyone knows the outcome of their input.

- b. There is a desire for transparency and accountability from the clients. They feel they are often asked for their opinions but do not often see it followed through. Publication creates a sense of trust.
16. Progress Reports
- a. The committee commits to giving regular progress reports to clients to show that as a result of this process, things are changing.
 - b. Progress reports create a sense of forward movement and energy which will only be positive.

General report

The overall attendance at the focus groups was 6.05% of those invited. This turn out was very low, but the feeling from most of the focus groups is that they are overall satisfied with the state of the society and this could have had an impact on attendance, if this attitude reflects the society as a whole.

The Auckland focus groups, staff and committee all commented on how much the society had improved under the leadership of Gary. The North Shore had been feeling left out and now are excited to be part of the bigger group and hope to get some of the benefits of the amalgamation. There is still a lot of work to be done at staff levels to get the North Shore to feel part of the greater team, but Gary is aware of this and working hard to remedy this dynamic.

The lasting impression I am left with at the end of this exercise is that everyone is poised to take the society to the next level and there is a strong desire for that to happen.

During the focus groups, the clients were asked to express one positive thing that had happened in their lives that would not have happened if they had not got MS. This was a revealing question as many broke into tears and struggled to answer the question. The common theme was that through the society they met a lot of new friends who encouraged them and supported them in positive ways. If they hadn't belonged some described how their depression could have taken them anywhere. Others talked about how MS had made them stop in their tracks and take a new meaning out of life. Many described how they no longer took their health for granted.

When talking about being newly diagnosed they referred to the fear put into them of joining the society because they would see people at advanced stages and this would upset them. This dynamic does happen for most, but they quickly get past this point because of the new people they meet.

The question about what positive thing MS has given demonstrates the important role the society is playing in the lives of MS and also shows there is a lot more to do.

Mission/Vision

35.29% agree with the mission/vision statement with 29.41% strongly agreeing with it. I believe this is a strong mandate to leave it alone. There were comments made about it needing an action verb, but I believe this is semantics that will not advance the society at this point in time.

Client Relations

Respite care and newly diagnosed issues were very high on everyone's agenda. The desire for the society to have its own respite centre, designed along the lines of a holiday lodge or similar was raised by far the most of any issue. Not only were clients concerned about the current system, they are worried about if/when they need respite care and became very emotional when describing their fears.

When newly diagnosed the need for a counsellor for the client and family was the next biggest issue. Some clients described how they were going to a counsellor years down the track, at their own expense because of the unresolved (emotional) issues. Those going to counselling and paying for it are currently on sickness benefits and this is adding to their financial struggle.

This led into the desire for accurate, consistent, structured information. There is huge inconsistency as to what clients are told and I suspect large gaps in individual field officers knowledge of what is available. This led to the desire for a “Dummies guide to MS” that covers everything from medical, how to deal with WINZ, what entitlements are available under what circumstances to alternative forms of treatment. The most sensible place to put such a document is on the website so it can be cost effectively altered as new information comes to hand. Separate mechanisms can be put in place for those who don’t have internet or whose eye sight has deteriorated to such an extent that reading is not possible.

Employment issues and problems were at the fore front of mind for many of the under 60’s attending the focus groups. Those currently employed live in fear of losing their jobs and are uncertain where to turn for help. Those who have stopped work because of MS are frustrated in that they still want to be contributing members of society and feel if they could work in an MS friendly environment they would lead more satisfied lives.

Field Officers are seen as central and there is a strong desire with 47.22% strongly and 36.11% agreeing with more resources for Field Officers. From the focus group discussions, clients are wanting more face to face visits and don’t deem a Field Officer turning up to their exercise or support group as counting as a visit. In the focus groups most stated that they would not tell a Field Officer what was happening in their lives – they would only do this face to face.

Exercise classes are seen as important with 42.86% agreeing and 31.43% strongly agreeing that more resources should be put in this area.

There is a strong sense that everyone should take more ownership of the society with 58.33% agreeing and 30.56% strongly agreeing in the need for others to get involved. When the question was put about personal involvement, 61.11% agree and 11.11% strongly agree that they should personally get more involved. These figures are very encouraging and vary from the general public attitude about public transport where they want it for everyone else but not for them. These figures indicate a strong sense of ownership of the organization.

Venue event had 45.71% agreeing and 14.29% strongly agreeing that events should happen close to their local suburb.

The following are the suggestions, most of which came up many times from the staff, committee and focus groups. They are reported in priority order, based in the frequency they were raised.

1. **Facilities**

- a. Need own “wellness facilities” – to include gymnasium and swimming pool – admin training rooms.
- b. Respite care – need for own facilities – maybe with offices attached?

2. **Counsellors**

- a. Need for counselling service – especially grief counselling at time of being diagnosed
- b. Need our own psychologist – this is based around the needs of the newly diagnosed

3. **Quality information**

- a. Dummies guide to MS – the A-Z of MS in Auckland – not just medical information – questions such as how to get on a benefit – what are your entitlements – who to turn to for support. In the medical area they want more understanding about the drugs and under what circumstances who gets what – this came up many times.
- b. Database came up a number of times – better information sharing about skills not just with clients but amongst carers. Also many asked for contact details of someone nearby with MS and told privacy act prevents this. (Privacy Act does not prevent sharing of information, just means certain rules must be applied. Could be beneficial for staff to get formal training on the Privacy Act).
- c. Monthly newsletters – North Shore want joke page – Aucklanders not fussed about it – they wanted more medical information, chat room type column where they have their input. Many were quiet vocal about wanting up to date research information and more information about alternative approaches to health management.
- d. More follow up – connection after events – feels like everything is stand alone. Example – those who go to Mana come back and left on their own – don't have cooking classes any more or meditation classes as part of the follow up. Many expressed strong desire to follow Jelinek diet system but didn't know where to start or where to turn.
- e. Many of the clients raised the issue of wanting to see an annual plan and for this to be reported against so that they know where “their” society is going and why. Also many come from professional backgrounds and like that sense of “knowing” what is happening.
- f. Online forums – chat groups
- g. Encourage phone networks – set up MS buddy type system where the clients take responsibility to communicate with at least one other MS person

4. **Employment for those with MS**

- a. Employment collective – this suggestion from one person caused a lot of interest throughout the focus groups. The suggestion is that there are a lot of people with MS who have had to stop work, but have still got a lot to contribute. All the office need to do is facilitate a meeting of those wanting to form a collective and it could form its own business. At this stage a product etc is unknown, but could operate conceptually like the IHC one. The profits from the collective company can go towards helping fund the society.
- b. Clients wanted event sessions on employment law and discrimination – raised a lot and is a big concern.

5. **Field Officers**

- a. Need more field workers with lighter loads.
- b. Work with DHB to get Field Officers as accredited disability assessors – this would speed up the current process of people getting access to wheelchairs and other such essential tools.
- c. Integrated approach to assessment with MS Nurses and MS Staff being more proactively involved.
- d. Standardisation of performance and role of Field Officers. There was a lot of confusion as to what the Field Officers are supposed to be doing and the differences in the information they share. Strong feeling from the focus groups they would like a F/O who has a social work background.
- e. Field Officers to pay face to face visits and giving them consistent information came up at every group. Some got irate when they found others had received information they hadn't.
- f. Integrated approach to assessment with MS Nurses and MS Staff being more proactively involved.

6. Events

- a. More wellness classes – especially North Shore region
- b. Classes on Cognitive behavioural therapy to give better understanding of fatigue and its management
- c. More regular “regional” events that allow those with MS to “mingle”.
- d. Support group for young people with MS and for young mums who are struggling – the later was raised a number of times at focus groups.
- e. MS Creche – mothers with young one’s who came to sessions had very painful stories to share of the difficulties they encounter daily. They are not asking for a weekly crèche but one whereby they meet other young mothers with MS and the children can play while they share their stories. Perhaps this could be done in conjunction with an existing playschool or similar.

7. General matters

- a. Desire to be normalized, rather than isolated
- b. Family support – needs formal organization, more structure
- c. Be more flexible – especially with volunteers – young people operate differently to use – they like to do evening and weekend work. Suggestion of improved database that held information about volunteers.
- d. Assist clients to get political over disparity between what they suffer and someone on ACC
- e. North Shore keen to become part of Auckland “taxi” system – many currently feel disadvantaged through not being able to get to “events”.
- f. System to encourage those with MS to take a carer or support person to Doctor visits – many get flustered and forgetful and don’t always hear what the Doctor is saying.

Locality – Field Officers – overall strong desire for Field Officers to operate a territory model and has a regular client base that they know well. In saying that concern was expressed about the management of personality clashes and how does a client request a change of Field Officer without it being too painful or difficult.

Offices – most areas saw no reason for more offices – they preferred the model that the Field Officers come to them – especially true for those with greater levels of disability or personal circumstances like young children.

Stakeholder Relations

The overall feeling was that staff enjoyed working under Gary’s leadership and many members (from both old regions) commented on how dramatically things had improved under Gary’s leadership.

The membership varied from locality to locality on whether they thought the staff are doing a good job. This is obviously personality driven and Gary is aware of there issues and is addressing them. Overall, 57.14% agree and 5.71% strongly agree that the staff are doing a good job. There is room for improvement in this area.

The strategic issues going forward, listing in no particular order, but numbered for ease of discussion are:

1. Technology

- a. Lap tops with remote access for Field Officers – means less time in the office and more time available for face to face visits.

- b. New office facilities – many staff commented how they don't like the open plan and none can see how to change the current Sandringham office to make it a more effective work place and one that can accommodate the needs of those with MS. Everyone (staff, committee, focus groups) commented on how impractical the current Sandringham office is. Regular comments about the lack of confidentiality caused by office lay out.
- c. Database came up – it needs to be explored for a more efficient, cost effective one that will meet the long term needs of the society.
- d. Reliable computer system that has sufficient power to cope with workload and not crash frequently. It might be worthwhile exploring external leasing arrangements.

2. Communication

- a. Consistent information to give to all clients.
- b. Planned and structured meeting schedule. It needs to be stated no one wanted a meeting culture, but a regular formal meeting structure would improve a lot of the little niggles that have a risk of growing.
 - 1. Regular admin meetings
 - 2. Regular Field Officers meetings
 - 3. Regular meetings with MS Nurses.
- c. Role reversal – MS Nurses and Field Officers – spend a day per year with the person in the other role. In other words, a Field Officer spends one day per year at the hospital with the MS Nurse to get some understanding of their role and vice versa.
- d. Need for praise culture – clients to staff (this was raised by clients who acknowledge they don't say thanks enough).

3. Sponsors

- a. Not a lot contributed in this area, but the exercise did raise awareness.
- b. Suggestion to look to those companies who use NZ Business Excellence Foundation as potential sponsors. They require philanthropic acts to raise their scores.

4. Health Professionals

- a. See above 2.c as a method of building better relations

Market Awareness

Overall the comments from all who spoke was along the lines that the market awareness isn't as good as it should be and that this makes sponsorship difficult as sponsors want their profile raised through the sponsorship.

There is a strong sense that this is an area that needs a lot of work. 57.58% disagree with the statement that MS Auckland Region is well known. Most of the reaction was based on awareness of MS itself. The overall comments were along the line that if we were better known it would be easier to get sponsorship and overall public support. Many comments were made by clients of being accused of being drunk because of their physical instability and the emotional pain that these comments created for them. They believe greater public awareness can remove a lot of the current stigma they feel and get more appropriate reactions to their difficulties.

1. Raising the profile.

- 1. Get JK Rowling over for an MS Awareness week and perhaps she would agree to do book signing sessions and a % of sales get donated. Her presence and why she was here would raise the profile significantly. The cost of getting her here would be off-set against the extra revenue she generated. Seen as an investment.

2. TV campaign – get a group of sponsors to get in behind something of this nature – example was given of the Salvation Army and how they did extremely well out of television campaigns.
3. Campaigning over abuse of disability car parks
4. There are 2500 members of the Foundation for the blind and yet they raise \$25 million through fundraising per annum. Their profile is large – we need to be up there and normalize MS.
5. MS also stands for Microsoft – maybe we should have a partnership
6. Do a big public launch of the merger and new brand.
7. Employ a Public Relations person to raise the profile and take on a lobbying role.

Research

The general feeling was that large scale medical research should be conducted by National Office; however social research was viewed differently. The question – “MS Auckland should have its own research fund” 39.39% agreed while 12.12% strongly agreed with the caveat this was focused on social research and did not become a distraction from the societies core business. This would be a governance issue to monitor this situation.

There were a large number of queries/questions around the prevalence study; when are the results coming out? Will the results come out? Many felt it was too big and over powering for them to manage the prevalence study requirements. Also many comments were made about the need for structure around the quantity and frequency of research.

1. MS Auckland region to develop research fund for “social research” issues.

Financial Results

There was a strong feeling amongst all parties interviewed that Government should play a bigger role in funding the society. There is a concern that the society is going through a good period because of a few bequests and concern was expressed about the long term strategic approach to finances. The research question – “MS Auckland Region should put a small percentage of funds aside each year, in reserve” 68.5% agreed while 17.14% strongly agreed. This is a powerful message. The consensus was that it is a governance issue as to what was appropriate amount but figures varied around the 5 -10% of the annual income being put aside.

There were a number of negative comments made about the quality of lobbying being conducted by National Office and they are perceived as very weak in this area and that Auckland should play a significant role in this area. The research question – “currently MS National Office does all the government lobbying for all regions. MS Auckland Region should be going this role for our region” 39.9% agreed and 21.21% strongly agreed – 27.27% were neutral. In other words only 18% disagreed with MS Auckland Region being involved in lobbying. Comment was also made about lobbying local councils.

Many comments were made about having someone dedicated to lobbying on behalf of the Society.

Financial ideas

1. Engage the services of a lobbyist – this could be a volunteer in a governance role.
2. Set up a proactive system for getting clients to get a “circle of influence” in other words averages of 10 people per client to go onto an automatic monthly payment system of say \$10. Engage a sponsor to donate time of their call centre to make calls and have easy access to forms for automatic payments. With 600 members and a circle of 10 each (average) this would bring in a cash flow situation of \$60,000 per month.
3. Be more proactive about bequests – put some case studies into newsletters about the advantages of bequests.

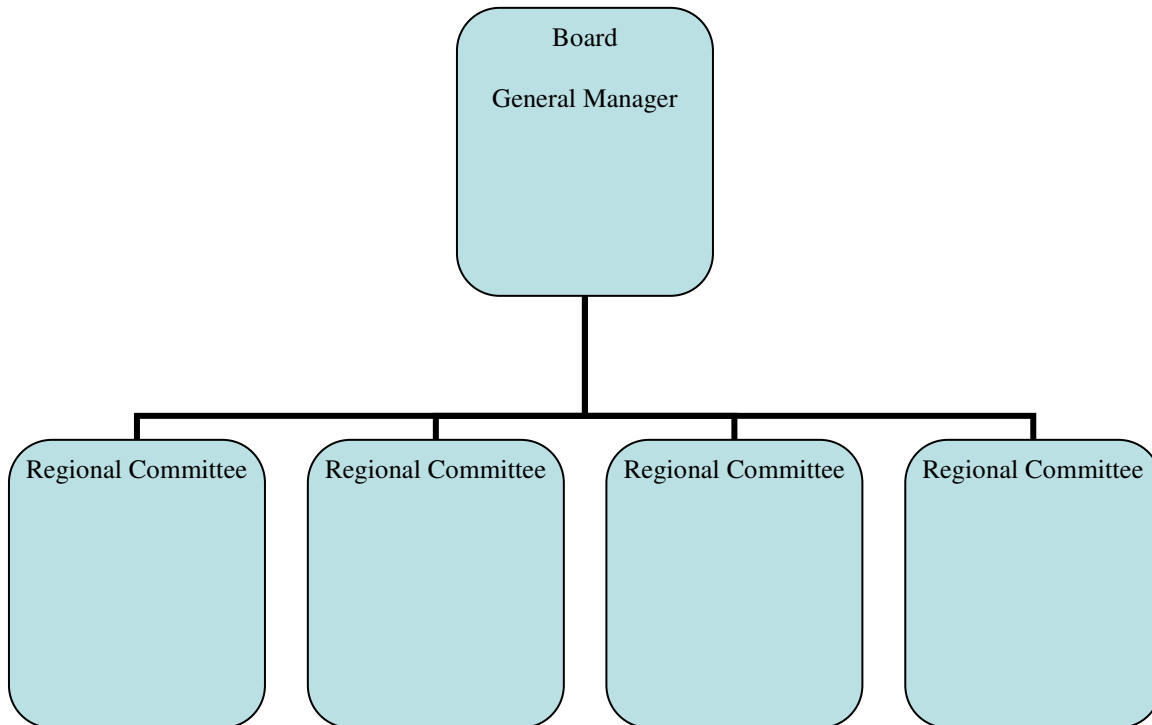
Governance

There was a strong feeling among the clients for a change to a Board structure with a regional committee structure underneath.

The reasons for the shift to board were:

1. Can attract professional people onto a Board easier than a committee
2. Professional people are likely to encourage their employers to take on a sponsorship role.
3. Board is more likely to operate at a governance level – some of the current committee feel they spend too much time on fundraising issues at the expense of governance across the whole organization. Perhaps the Committee/Board should appoint a separate fundraising steering committee who report to the Board and thereby reduce the amount of time in this area.
4. It is considered important that if the change to a Board happens there are Client representatives on the Board.

The model proposed early in the piece by the clients and supported by other clients is:



The suggestion is that Regional Committees take on activities for their area – it was felt important that they were separated from the Field Workers so there was and is no crossing of employment roles. The committees report to and work alongside the General Manager who may delegate the responsibility to a staff member if appropriate. When questioned about the number of committees feedback was we had 10 focus groups for a logical reason perhaps they should be the natural areas. This concept needs a lot of thought and governance debate.

There was also a lot of comment about the desire to watch the progress of this strategic review and that they are kept up to date with changes. In the interests of transparency a communication plan should be implemented.

Feedback from Committee members is a need for their own social and training programme. This might include a 1 day retreat or equivalent to build a strong team and learn about each others strengths and weaknesses.

Social Awareness

The research question – “MS Auckland Region is there for the sole purpose of its members and not for any other role within in the greater society” – 39.39% agreed and 21.21% strongly agreed. The general feeling the greater good role of the society is to look after its members rather than focus externally. The only “trend” suggestion was that staff be given one “charity of choice” day off per year whereby they can do voluntary work for another charity. This would help develop links to other charities and goodwill.

Conclusion

The Society is in good heart and has come a long way in the last few years. The merger is perceived as a positive thing for all parties. As the Society has raised the standard of its performance so have the expectations risen accordingly.

As a sweeping (and perhaps dangerous) generalization, many MS clients are of above average intelligence and from commercial or similar backgrounds. In their working lives they have been used to structure and direction and expect this from their Society. They have enjoyed the “entrepreneurial” phase and recognize the need for this to continue, but also want to see more structure and planning. For the staff this is a very important issue.

The difficulty facing not for profits is the struggle to address is the need for funds versus service. If the focus is on fund raising, service slips and vice versa. The service cannot be delivered without funds, but while focusing on service funding slips. The need to invest for the long term to get the balance is critical. A public relations person who raises the profile through the media, does government lobbying often brings in a significant amount of funding. This person is not a fundraising manager, as that is a separate skill set, but the PR person creates the baseline for the success of the fundraiser.

The two words that come across as the focus for the next five years came from Ernie Willoughby: structure and professionalism. The need for more shape, accomplished through sound and rigorous processes and the need to take the standard of professionalism up a couple of steps are critical. Part of the professional stance is to have everyone within the MS team giving the same standard of advice.

The Society is in good heart and the committee and staff should feel proud of what has been accomplished in the last years. There is a lot of goodwill towards the society.