

**Ms. S. Pepall
President
MS Society of Canada
First Letter**

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President
MS Society of Canada
Toronto, Ontario

Dear Ms. Pepall:

I am writing to you to express my thoughts on the need for our Society to fund research on alternative therapies at a reasonable level. The petition which was recently presented to our National Board asks for 25% of collected research funds to be allotted to alternative therapies. To me this is a bare minimum if our Society wants to achieve a reasonable balance between research which will help our current members and basic, long term research which may help persons with MS in the distant future.

Currently our Society spends about 25% of the funds collected on research with the remaining 75% on administration, fund raising and programs. Almost all of the research money is granted to very basic, long term research studies on such subjects as genetics, molecular biology and immunology. As I am sure you are aware, such as research effort offers essentially nothing to those currently with MS and is directed at the hope that the research will some day allow new drugs to be developed to offset the immune attack on the central nervous system. At best it will be decades before the research effort of today translates into practical, positive therapies for persons with MS. In this regard it is worth noting that, although the research effort of the Society over the past 25years has increased our understanding of MS, it has produced few, if any, practical results in terms of symptom relief or slowing disease progression. It is reasonable to assume that the current research program of our Society will have no applications for at least 15 years or longer.

I strongly agree that our Society must continue to support such a long term, basic research effort. I myself am involved in such a research effort in my discipline (geology). However, at our research institute there is a balance between such long term research which will be of use to clients in 15+ years, and more practical, short term research which will benefit our clients in the next two to five years. I can assure you if we only did short term research or only long term research our clients would be most dissatisfied.

The obvious flaw in our Society's research program is the lack of practical, short term research. This is, of course, where research into alternative therapies comes into play. The required research in this field is mainly of a practical and short term nature. Most importantly it has the potential to provide, in the short term, persons with MS with reliable information and point them towards positive therapies which will both relieve symptoms and possibly even significantly slow the progression of MS.

Diet revision provides a good example of an alternative therapy which is begging for some proper scientific research in regard to the efficacy of such a therapy. As I have documented in my referenced essay, there is a great deal of scientific evidence linking dietary factors to MS. I have summarized this evidence in another recent letter to you. Thus it is not surprising that many of our members, including my son, are using diet revision to combat MS. Such a therapy demands considerable sacrifice and thus many members do not want to try it until there is solid proof it works. Furthermore, those currently on it would be most pleased to abandon such a strict regimen if it was shown to have no efficacy. Only our Society has the resources to properly test the efficacy of diet revision and to free our members from the frustrating dilemma of "to diet or not to diet".

Another example of alternative therapies which may well be of value are the therapies used by Anne Belohorec. You may know of Anne who spent 11 years in a wheelchair and who contributed substantially to our Society as a volunteer during this time. I believe she won a major international award for this work. A few years ago Anne went outside conventional medical practice and started to use a number of alternative therapies including cranio-sacral manipulation and therapeutic touch. These therapies proved extremely successful and Anne has recovered to a very large extent. I am sure that none of the neurologists on the Medical Advisory Committee advise their patients to use such therapies. If Anne had continued to follow such advice she would still be severely disabled. Of course the question remains of how applicable are these therapies. Only a proper research effort can answer this. I have no doubt that the members of the Medical Advisory Committee have no interest in such therapies but I can assure you that many members of our Society have a great deal of interest, especially now as Anne's impressive recovery becomes known.

There are numerous other alternative therapies which are being touted as being of value for persons with MS but, once again, there are no scientific data to decide if such therapies truly have value or not. Many of our members are trying various therapies in desperation and in ignorance. I believe our Society has the responsibility to undertake research to determine which of these therapies have value and which do not. Such information will be of tremendous value to our members and will allow them to make intelligent, informed choices. The present situation in which our members are given no reliable information on alternative therapies is a very undesirable one and must be remedied.

I have little doubt that some alternative therapies will prove to have substantial benefit for persons with MS and some will undoubtedly prove to be useless. However our members will have no idea which are useful and which are not until proper research is done. I do not think it is unreasonable for our members to look to our Society for providing funds to decide these questions and for making sure such reliable information is widely distributed. This would represent a MAJOR contribution to all persons with MS by our Society.

To me our current situation can be summed up by that classic analogy of the crocodiles in the swamp. About 50,000 Canadians are being mercilessly attacked by the MS crocodiles. All the money which is being donated by a concerned public to stop these attacks is being spent on research to figure out how to drain the swamp 15-20 years from now. What those who are being consumed by the crocodiles could really use right now is reliable information regarding which weapons (therapies) can be effectively used to fight off the crocodiles so that they are still relatively healthy when the swamp finally gets drained. This of course will require a reasonable amount of donated money being shifted from swamp-draining (long term) research to crocodile-fighting (short term) research.

In summary I hope our Society will significantly change its research policy and will set aside at least 25% of designated research funds for research into alternative therapies. Such an initiative will be welcomed by many thousands of our members who are currently groping in the dark and wondering if they should spend their money and time on such and such a therapy. In conjunction with such an initiative the Board will have to substantially change the composition of the Medical Advisory and Grants committees so that expertise on alternative therapies is well represented. I have addressed this need in another letter which you should receive either shortly after or concurrently with this one. I and many others are hoping that our Board will "do the right thing" when it comes to providing adequate funding for research on alternative therapies.

Thank you for considering this very important matter and I look forward to your response.

Yours truly,

Ashton F. Embry