

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

Ms. S. Pepall
Chair, National Board of Directors
MS Society of Canada
Toronto, Ontario

Dear Ms. Pepall:

Thank you for taking the time to reply to my letters of January 18th and 20th. I am pleased to hear that our Society is now acknowledging that alternative therapies have a place in MS treatment and that research into these therapies is required. I look forward to our Society turning these words into actions.

I am writing this letter because of some major developments which should impact our Society's research initiatives. The Annual Meeting of the Calgary Branch was held on Saturday, March 7th and the keynote speaker was Dr. Peter Seland, the Chair of the Medical Advisory Committee. In this position Dr. Seland has significant responsibilities regarding the Society's research effort and, appropriately, he spoke on various aspects of the research program including the process by which projects are chosen for funding support. Needless to say I was front row, centre for this talk and enjoyed it thoroughly.

Following the presentation, the floor was open to questions and, after the subject of funding for diet research was breeched, I asked Dr. Seland the following question: "Given all the published theoretical, epidemiological and experimental data which link such foods as dairy, gluten and yeast to MS onset and progression, can you tell all the persons with MS in this audience that such foods are safe to eat and will not affect the progression of their MS?" This is obviously a very important question for all persons with MS and clearly Dr. Seland is the best representative of our Society to answer it.

I am pleased to say that Dr. Seland answered this key question in a direct and forthright manner. He unequivocally stated that NO he could not tell persons with MS that such foods would not affect the progression of their MS because the necessary research had not been done. Given the available data, which I summarized for you in my letter of January 20th, this answer was of course the only responsible answer which an informed scientist with integrity could have given. I was very impressed with how Dr. Seland handled my question and, to me, our Society is fortunate to have an individual like Dr. Seland leading the scientific program.

I hope you and the other National Board members will now carefully consider the rather profound implications of Dr. Seland's public statement that, as Chair of the Medical Advisory Committee, he cannot assure persons with MS that common foods such as dairy, gluten (wheat, rye) and yeast are safe in regard to MS. Without a doubt, our members cannot be left in this incredibly difficult and basically untenable situation. Just imagine if a city official suddenly announced that he could not guarantee the safety of your tap water. I am sure you and the rest of the citizens of Toronto would be demanding that the city determine beyond a doubt if the water was safe or not and in the shortest possible time. "Maybe" is just not an acceptable answer in this situation or, for that matter, in the case of the safety of common foods for persons with MS.

To me our Society now has a major responsibility to resolve this issue as quickly as possible. It is not reasonable or fair that persons with MS be left not knowing if many of the foods they eat are harmful or not. I am hopeful that you and the Board, in conjunction with the Medical Advisory Committee, will take the necessary steps to see to it that persons with MS receive an unambiguous, reliable answer to this critical question in the shortest possible time.

The other significant development, which also has major ramifications for our Society's research effort, took place after the meeting when Dr. Seland kindly met with my wife and I to discuss the need for diet research. I refer you to the letter I sent Dr. Seland on February 13th, a copy of which was faxed to you via Deanna Groetzinger also on February 13th. One of my requests in the letter was for Dr. Seland to provide me with scientific reasons why the diet hypothesis is not plausible. As I emphasized in the letter, he is clearly much better informed on these matters than I am and I have no interest in pursuing an implausible hypothesis. In our meeting Dr. Seland addressed this and said that there are no scientific data which render the hypothesis untenable or unlikely and thus it is plausible given our current data base.

The declaration that the diet hypothesis is plausible has major implications for the future research effort of our Society. As you know the # 1 goal of our Society is "the cause and cure for multiple sclerosis are identified in THE SHORTEST POSSIBLE TIME" (1996 Fact Sheet). The only way the cause(s) of MS will be found is by doing definitive tests of plausible hypotheses. The key points of this equation are identifying plausible causes and designing appropriate tests to evaluate them. Unfortunately plausible, testable hypotheses for MS cause are very rare and this has resulted in the current situation of our Society funding mainly basic research which is at best only indirectly tied to MS cause (e.g. myelin chemistry).

I have no doubt as to the National Board's sincerity and resolve regarding its stated #1 goal. Given this, it seems to me that when the Board and Medical Advisory Committee are presented with the diet hypothesis which relates DIRECTLY to MS cause and which is both PLAUSIBLE and TESTABLE that all concerned should be very interested. In fact one might expect they would be falling over each other to organize a proper research study to test the hypothesis as quickly as possible.

As you know at least 1500 Canadians are given the devastating diagnosis of MS every year and that perhaps another 2000 progress from being ambulatory to needing a wheelchair. Time is definitely of the essence when considering MS cause and cure and I am hopeful the Board and Medical Advisory Committee will act expediently on this matter.

As always I would be pleased to personally address the Board on these issues and to answer any questions that they or anyone else may have on the diet hypothesis and the type of research necessary to properly test it. I would be grateful for a reply by fax to this letter within the next four weeks so that I can gain an appreciation of how the Board is planning to act on this information.

To me, these developments are of the utmost importance and have a good chance to lead to a major breakthrough in understanding MS and developing effective therapies in an reasonable time frame. The initiation of such research would be one appropriate way for our Society to celebrate its golden anniversary.

Yours truly,

Ashton F. Embry