

Mr. Reid Nicholson
C/o MS Society of Canada

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Mr Reid Nicholson
C/o MS Society of Canada
250 Bloor St E
Suite 1000
Toronto, Ontario, M4W 3P9

Dear Mr. Nicholson:

I noted in the last MS newsletter that you are leading a task force to review the level of funding for MS research. In the past I have been openly critical of MSSC in this regard and thus I am hopeful that your task force will improve a rather unfortunate situation.

On the basis of recent Annual Reports, which provide only very rudimentary financial information, it is readily apparent that MSSC spends considerably less on research than it does on "services". Given that charities are allowed to spend only a maximum of 20% of revenue on "administration", one would hope that at the very least 40% would be spent on research. However it is apparent that MSSC spends only 25% on research with 55% going to "services". I am sure you are aware that most people donate to MSSC on the premise that the Society will "find the cause and a cure for MS". The reason why MSSC is so well funded is because MS is such a feared disease and the general population would be much relieved to see the cause and cure found. I expect most donors would be very surprised to learn that the lion's share of the money goes to administration and "services" and that research only receives only a small slice of the pie.

I am very hopeful that your task force will recommend a much greater percentage of collected revenues be earmarked for research. To me 40% would be the minimal acceptable percentage with 50-60% more in keeping with why MSSC exists and why people donate so generously.

A second, more important, topic is the type of research which is being funded by MSSC. Currently 100% of the research money is being spent on curiosity-driven, laboratory research. Such research funding is preferred by researchers because it allows them to pursue their favourite topics regardless if it is the type of research which is currently needed or not. To me this is not in the best interests of the tens of thousands of Canadians who are affected by MS.

I work in a research environment and such an approach to research funding is entirely unacceptable in our organization as it is in most funding agencies. In our federal government research institution the science managers and scientists hold annual meetings with our various clients to decide on research direction and specific initiatives. If we left it up to the scientists to formulate the research plan I hate to think of what a disjointed and directionless research effort would result. The current research program of MSSC is a fine example of such an unfocussed, scientist-driven program. Currently there are few dozen research efforts which do not relate to each other except in general terms. The most problematic aspect of the MSSC system is the scientific directions which get ignored because they are just not a primary interest of the rather small collection of MS researchers in Canada. Notably the members of this research clique take turns applying for grants and deciding on who gets a grant. Thus it is not surprising that a rather myopic and uninspiring research effort results.

Diet research for MS provides an excellent example of an ignored research area. The head of research for MSSC, Dr. Seland, agrees that the diet hypothesis for MS is plausible. However he has emphasized no research will be done in this area unless a researcher decides to submit a proposal in this area. Of course because diet research for MS is completely new no researcher has any experience in it and it is unlikely a

proposal will be forthcoming. Thus despite the existence of a plausible cause for MS no research will probably be done on it because of MSSC's research funding methods. The same fate will befall any other innovative research area which is not already part of a researcher's program.

To me MSSC needs to overhaul its research funding mechanism to make sure all areas of major interest to the clients of the research effort are at least examined as to feasibility and need. Almost every funding agency I know of has strategic grants for specific areas of research the agency wants investigated. Such a strategic granting policy is badly needed by MSSC if it truly wants to serve the needs of its clients and to have a broader, more innovative research effort.

In summary I hope your task force recommends that substantially more of MSSC's annual revenues be directed toward research rather than salaries (services) and overhead. Furthermore I hope MSSC will overhaul its current scientist-driven research program such that it is much more responsive to client needs and new innovative research fields. Curiosity-driven laboratory work is fine to an extent but to direct the entire research effort in such a fashion is not an very effective way to "determine the cause and a cure for MS in the shortest possible time".

If you have any question or comments on any of the points I have raised please feel free to contact me by letter, phone(403 2927125), fax(403 2924961) or email (info@Direct-MS.org). Because you are one of the few persons affected by MS with any power in MSSC, I am hopeful something more substantial than the usual cosmetic action and rhetorical statements will result from your committee. The widespread dissatisfaction with MSSC among those affected by MS is not without good cause.

Yours truly,

Ashton Embry