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→ Mr Boseski
copy to our consultants MCS file pls and copy to Dr Harvey at Nicnas for inclusion on their website etc. as a submission
M L Hartley 3/11/08

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Dr Margaret Hartley
Principal Scientific Advisory
Office of Chemical Safety
Office of Health Protection
Department of Health and Ageing
GPO Box 9848
CANBERRA ACT 2601

Dear Dr Hartley

I refer to the Multiple Chemical Sensitivity Interest Group Consultation Meeting scheduled for 30 October 2008.

I confirm that Ms Michele Kosky will be attending as my representative, on behalf of all members of our Taskforce.

In relation to the draft report, I thank you for the opportunity to comment and advise that the feedback from our Taskforce is as follows.

The Taskforce has a concern that the report lacks a clear and unambiguous focus on the personal and public health nature of MCS. The issue of MCS has arisen from the suffering and disability experienced by individuals and groups. Understanding the clinical problem of MCS as experienced in the daily lives of those affected is essential to a responsible interpretation of the situation. A report without a substantial examination of the burden of illness due to the condition and the meaning of MCS to those affected is unquestionably incomplete.

Irrespective of the level of scientific understanding, prevention is a very high priority, yet the report does not promote the precautionary principle or primary preventive public health intervention. Given the chronicity of MCS, secondary prevention and care of those affected is particularly important. These practical measures to protect the community fail to receive the priority they deserve.

The report is heavily weighted towards inadequacies in the scientific understanding of MCS. Emphasis has been placed on the unknowns of science, the divergence of opinion and the uncertainty surrounding causation, pathology and diagnosis. This presents a skewed view as the presentation of the unknowns is not balanced with examination of the available evidence of what is known about MCS. In Public Health it is the available evidence that provides the basis for action, whereas scientific uncertainty, when considered alone, provides a case for inaction. This negative bias is most unwanted and its presence is disquieting.

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There is a strong undercurrent of statements which confuse rather than clarify. Some examples make the point:

- The claim in the draft report that *lack of agreement over pathogenesis is a hindrance to research* is certainly no more valid than saying that lack of understanding of pathogenesis is a stimulus to research. Such a one-sided statement is irresponsible and incorrect;
- The claim that *MCS patients cannot be distinguished from individuals with other conditions* is to flirt with the idea that there is no such entity as MCS. This position is extreme, and runs counter to the premise on which this report was commissioned. What is such a statement doing in this report without a comprehensive, systematic and balanced substantiation of both sides of the questions and doubts it raises?
- Reference is made to there being *no unequivocal epidemiological evidence* regarding MCS. Behind the use of this statement is the intimation that it is reasonable to expect epidemiological evidence to be unequivocal; and therefore the absence of such unequivocal evidence implies there is a significant impediment. This is to unreasonably inflate the power of science as epidemiological research is hardly ever unequivocal. This statement has the effect of diminishing the credibility of MCS. Is this the intention?

MCS is a new condition. It has arisen during unprecedented changes in the environment from man-made chemicals. When new diseases appear medical science lags behind in generating a scientific understanding of these new diseases. In many instances in medical history effective Public Health measures have been introduced well in advance of there being scientific understanding of the cause and mechanism of an as yet poorly understood disease. During this lag time in scientific knowledge and for a period after, there is skepticism and opposition to acknowledgement of a new disease and of its causation. Vested interests usually play a major part in opposing preventive action on the grounds of scientific uncertainty. These considerations are all highly pertinent to the case of MCS, yet they do not appear in the draft report.

In the draft report there appears to be a trend towards invalidating MCS rather than responding to the problem. The disability as experienced in the community has not been presented. Public Health priorities do not form part of the draft report. A balanced approach to the condition is lacking. I would not be able to claim that the draft report demonstrates a scientific and unbiased appraisal of the overall subject.

For these reasons I am not able to endorse the draft report. A more straightforward approach to the report is required with adherence to principles based on protection, prevention and precautionary action.

Yours sincerely

Giz Watson MLC
Member for North Metropolitan Region

October 24 2008

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