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MCS Report
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Dear Sir/Madam

Thank you for the opportunity to comment on the revised draft MCS report.

I confirm I chair a Community Taskforce on Multiple Chemical Sensitivities and on behalf of the Taskforce I commented on the original working draft report. I **enclose** a copy for your ease of reference. The Taskforce had two main concerns about the original working draft report: a. it had a negative bias, and b. the public health nature of MCS was ignored.

I am pleased to see that our first concern has been taken into account and that the revised version of the report is more balanced than its predecessor.

Our second concern does not appear to have been much addressed. I acknowledge NICNAS's stated intention that the report be a technical one for assistance of the medical profession, and the statements in the Summary of Revisions that social policy and chemical regulatory issues are outside the scope of the review.

I respectfully submit that this is an inadequate response that significantly reduces the impact of the report and of the research that will flow from it. There is only so much that medical practitioners can do for MCS patients in the absence of a framework of relevant public health policies and chemical regulation.

MCS is disabling for the people who suffer it. It imposes a heavy burden on patients, on the people who care for them at home and on the people who care for them in a public health context. It is mercurial and therefore a difficult subject for longitudinal research. As the revised report notes, avoidance of agents that trigger symptoms is currently the most effective way of managing MCS. The people who made comment on the original working draft report provided considerable information regarding avoidance of triggers, at both an individual level and at a broader policy and regulatory level. Yet the report neither includes this information nor identifies research into policy and regulatory approaches that would facilitate avoidance of agents that trigger symptoms as a key research need.

I submit that the report ought to be expanded to include these matters, for several reasons.

First, it appears to me that policy makers are waiting to be guided by the final report. For example, I **enclose** copies of:

- My letter of 21 February 2008 to the then new Federal Minister for Health, Hon Nicola Roxon, and the reply, dated 12 May 2008;
- My letter of 28 October 2008 to Minister Roxon, and the reply, dated 9 January 2009, and
- My letter of 24 October 2008 to the then new Western Australian Minister for Health, Dr Kim Hames, and the reply, dated 13 November 2008.

Secondly, "*A little knowledge that acts is worth infinitely more than much knowledge that is idle.*"¹ Here are two examples of what MCS patients are experiencing in the absence of an approach to MCS that encompasses broader policy and regulation:

- A Taskforce member who has MCS has advised me that upon being taken to a Perth hospital for symptoms related to her condition, she was inappropriately referred to a psychiatrist, and also made more ill by chemicals that were present in the hospital environment, and
- The same person has advised me that she has to leave her own home every time the local council sprays for weeds on verges and in public spaces, otherwise she becomes ill.

Thirdly, I submit that expanding the report to encompass identification of key research needs in respect of policy and regulation is consistent with:

- The statement on NICNAS's website that its mission is "the integrated regulation of industrial chemicals for the protection of human health and the environment through scientific excellence and regulatory efficiency to deliver the safe and sustainable use of chemicals", and
- The statement on OCSEH's website that its vision is "safe and sustainable chemical use for all Australians" and that its mission is "to protect and secure human health and the environment through the delivery of evidence based, nationally consistent approaches to managing human health risks and environmental threats, and a rigorous and efficient chemicals regulatory system. The OCSEH will support national environmental health initiatives and safe and sustainable chemical use that will result in positive public health outcomes for all Australians."

I acknowledge and appreciate the work that has been put into the report process and that the report does have value. However, I strongly submit that the report would be of substantially more use to both health consumers and policy makers if it included the public health aspects of MCS and identified a key research need for determining and documenting effective broader health and social policies and chemical regulation for prevention and management of MCS.

¹ Kahlil Gibran (1883 - 1931) Lebanese-American Poet Philosopher & Artist, cited in "Exploring the impact of primary health care research - Final Report Stage 2 Primary Health Care Research Impact project" a February 2009 publication of the Primary Health Care Research and Information Service with the assistance of the Department of Health and Ageing and Flinders University:
http://www.phcris.org.au/phplib/filedownload.php?file=/elib/lib/downloaded_files/publications/pdfs/phcris_pub_8108.pdf

Unless this happens, I submit that the impact of the report on alleviation of the burden of MCS illness will be far less than it could (and should) be.

Yours sincerely

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