

# ASEHA Qld Inc

ALLERGY, SENSITIVITY & ENVIRONMENTAL HEALTH ASSOCIATION Qld Inc

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A volunteer community organisation providing support for people with allergy, food and chemical sensitivity

*A participating organisation of National Toxics Network*

23 August 2007

Dr Margaret Hartley  
Director  
Office of Chemical Safety  
GPO Box 9849  
CANBERRA ACT 2601

Dear Dr Hartley

## **Re MCS Clinical Review**

Thank you for your letter of 4 June 2007 in which you have partly responded to my correspondence to Health Minister Abbott. With regard to the MCS Clinical Review the following concerns need to be addressed:

### 1. Openness and accountability.

The MCS Clinical Review should be an open and accountable process in its entirety. Already there are community concerns about the process to date. The consultant's report on the MCS Clinical Review is a secret and yet it is a critical document which all stakeholders should be able to access in order to adequately address all the issues raised. To date, you have not offered any response to the issues of openness and accountability or bias that were raised in previous correspondence.

### 2. The discussion paper and final report should present fairly.

It is important that the MCS Clinical Review adequately and fairly represents the views of sufferers and clinicians. It is not acceptable for clinicians who are not trained in MCS to make decisions for persons with MCS disability (Marshall, L et al. 2002). poorly informed or biased attitudes amongst clinicians must be overcome and satisfactorily addressed both in the review and the final outcome e.g.:

- When MCS sufferers are referred to physicians for validation of their illness for insurance purposes, workers compensation or other benefits, sometimes they are confronted by clinicians who oppose or will not recognise MCS. Persons with MCS disability can then be bullied i.e. subjected to aggressive behaviour, psychological abuse, or disrespect.
- In some cases, patients' allergy and alert sheets on hospital records are not observed which can physically threaten their wellbeing. Generally, persons with MCS disability are not believed due to attitudes by clinicians that the patient has a 'belief system' which is usually based on avoidance as a management strategy. However, avoidance as a treatment strategy is validated in the Worksafe literature and is a normal part of allergy management by allergists and clinical immunologists. Numerous studies have found chemical avoidance to be an essential part of the medical management of MCS.
- A chemical exposure can affect several organ systems at the same time and produce a large range of unrelated symptoms. As this is not taught at medical school, to a clinician it can add up to somatisation disorder and the person with MCS disability erroneously diagnosed with psychiatric problems. However, a presumptive psychiatric diagnosis is prejudicial to a person with MCS disability obtaining an accurate diagnosis and appropriate treatment.

Such issues need to be overcome as this flows on to social problems such as inability to obtain medical reports/certificates necessary to support issues such as compensation for workplace injury; obtaining appropriate (disability) public housing; eligibility for welfare benefits and necessary disability support.

In spite of pointing out a conflict of interests by physicians consulted for the MCS Clinical Review who are paid to appear in court cases by industry, insurance companies, workcover etc to the detriment of persons with MCS disability, there has been no comment from you. It is difficult for the community to have confidence in a fair and equitable outcome of the MCS Clinical Review under such circumstances. Thus far we have not been given equal opportunity and this inequity needs to be urgently addressed.

### 3. Consultation with stakeholders.

In our view, the most relevant stakeholders in the MCS Clinical Review are MCS sufferers and there was initial consultation with a very small number of organisations/individuals who support persons with MCS disability. However, MCS sufferers and their supporters were not involved in the clinical workshop that was undertaken in the initial consultation process. While you have not used the term 'stakeholder' in your correspondence, it is important to the MCS community that you clarify precisely who you consider to be 'stakeholders' who should be invited to contribute to the MCS Clinical Review as a pattern of exclusion is emerging and we do not want to see our input minimised.

4. One discussion paper, one consultation process. Would you please be so kind as to clarify whether the MCS Clinical Review is one process related to the entire community or two processes divided between clinicians and sufferers?

While we can understand that the input will be different for clinicians and consumers because of differing expertise, knowledge base and unique points of view, many consumers are well informed about the modern diseases from which they suffer. They gather studies from government sources in the USA, Canada, the European Union, the World Health Organisation, United Nations, university libraries, including medical schools and peer reviewed journals on issues such as toxicology, the causal roles of acute and chronic chemical exposures, or the role of infections such as EBV or hepatitis in their chronic ill health. Further, within the MCS groups there are professional members such as GPs, dentists, PhDs, medical scientists, environmental toxicologists, nurses, social workers, social scientists etc who represent a large range of interests.

Broad participation in one consultation process is required to ensure flexibility and responsiveness to the needs of all stakeholders in the MCS Clinical Review. Tailoring separate consultations to sufferers and professionals is unacceptable as it divides the community and could indicate a double agenda instead of one equitable outcome. No other government discussion papers separate civil society and professionals

According to the WHO Bangkok Charter for Health Promotion in a Globalised World we should all work together to:

- **advocate** for health based on human rights and solidarity
- **invest** in sustainable policies, actions and infrastructure to address the determinants of health
- **build capacity** for policy development, leadership, health promotion practice, knowledge transfer and research, and health literacy
- **regulate and legislate** to ensure a high level of protection from harm and enable equal opportunity for health and well-being for all people
- **partner and build alliances** with public, private, nongovernmental and international organizations and civil society to create sustainable actions.

If there is to be two discussion papers, we would like to see both discussion papers available for everyone to view and comment on. We would like reassurance that:

1. MCS advocates and sufferers will be given an opportunity to have a significant and valued input into the discussions leading to the development of MCS guidelines
2. That practitioners involved in the professional consultation process fairly represent MCS

5. The establishment of an MCS reference group. In view of our concerns about a fair and equitable outcome from the MCS Clinical Review, we recommend the establishment of an MCS Reference Group to advise the government, oversee the review process and make recommendations. Many other reviews establish reference groups.

The MCS Reference Group should ensure balanced and informed input from individuals with MCS disability, government representatives and clinicians and should be composed of equal representation of MCS sufferers, government representatives, clinicians who support persons with MCS disability and who have upgraded their medical skills to take in MCS. There is no place on such a committee for representation that does not support access to health, allied health care and welfare services for people who are unable to tolerate current levels of chemical pollution in our modern environment. There are sufficient studies in existence for such a view to be regarded as archaic and unproductive.

6. The role of the NICNAS Community Engagement Forum (CEF) in the MCS Clinical Review consultation process. Thank you for the information that the CEF will be consulted in regard to the MCS Clinical Review so that 'an acceptable community based consultative mechanism is utilised'. We would like to be advised of further detail as to their role in the MCS Review process as soon as this is decided. We would also like to know if the CEF will be involved in developing the discussion paper to ensure it presents fairly to the community and whether they will consult with the community re the content of the discussion paper prior to its release. This is essential as the community was not engaged in the earlier process and had only minimal consultation.

7. Will the CEF be adequately funded to engage the community in the consultative process?

NICNAS/OCS needs to ensure that the CEF will have adequately funding to engage the community in the consultative process for the MCS Clinical Review. Many persons with MCS disability also suffer economic disadvantage and require assistance to attend workshops or take part in the consultation process. The budget for community consultation needs to take this into account as the views of persons with MCS disability must be heard and included. There are individuals with MCS disability in other support groups such as Chronic Fatigue/Fibromyalgia Syndrome groups, migraine, respiratory disease groups etc and it is important for CEF to contact these for input as well.

As so many persons with MCS disability in the community are disadvantaged and in very deep personal crisis, it is essential that we get the consultation process right so that equalization of access is addressed and all problems resolved. Both Canada and the USA have established MCS hospital access in many facilities, some Canadian nursing homes have also adopted MCS policies and Australia is seriously lagging.

The Canadian Nova Scotia Environmental Health Center [www.cdha.nshealth.ca/facilities/nsehc](http://www.cdha.nshealth.ca/facilities/nsehc) is a dedicated facility created by the Canadian Government to meet the unique needs of those with environmental sensitivities through research, clinical care and education in close collaboration with affected individuals, health care professionals and research scientists. The centre offers a clean environment to its patients and advises other agencies working to develop policies related to recognising, preventing and treating environmental sensitivities. The South Australian government consulted with the Nova Scotia Environmental Health Center during its review of MCS.

MCS disability has more recently been acknowledged by the US National Institute of Building Sciences in their 2005 Indoor Environmental Quality Report. The project had funding support from the US Access Board which is an independent federal agency devoted to accessibility for persons with disability. MCS and fragrance sensitivity are recognised disabilities in the USA under the Americans with Disabilities Act and in Canada which leads the world with actions to reduce pesticides and fragrances in some provinces. The US Government provides funding support for agencies to address MCS disability [www.nau.edu/idh/aztap](http://www.nau.edu/idh/aztap) [www.jan.wvu.edu/media/atoz.htm](http://www.jan.wvu.edu/media/atoz.htm)

As there was no response to issue of the Health Minister's primary obligation to individuals with MCS disability in my previous correspondence, it is reasonable to assume that government obligation to persons with MCS disability is either nil, has a very low priority and that industry profits are more important than human health and wellbeing. If the MCS Clinical Review is to be a fair and equitable process and our Human Rights respected, this question requires an urgent response from the Minister.

We have enclosed a copy of the ASEHA Qld Inc responses to the BMP Consultants questions. Within this document we have addressed the clinical questions as well as many of the social, financial and health issues unique to persons with MCS disability.

Australia should not be a stagnant backwater in MCS disability access to medical services, aged care, nursing homes, housing, other welfare services and schools. The MCS Clinical Review should proceed at a more rapid rate, be an unbiased process and give a fair and equitable solution for those

long suffering persons with MCS disability in the Australian community. Anything else is totally unacceptable.

I look forward to hearing from you in the near future,

Yours sincerely,

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**CC Marion Healey**

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