March 20, 2010

from "DJ Victoria"
[redacted]

MCS Report
NICNAS
PO Box 58
Sydney NSW 2001

Dear Sir,

Thank you for the chance to comment on the revised draft MCS report. I am pleased to see significant changes, and also appreciate the Revisions document.

2 UNDERSTANDING MULTIPLE CHEMICAL SENSITIVITY

Discussion of **initiation** should be followed by **triggering** of symptoms. (Section 2.3)

Ashford and Miller (1998), when grouping problematic substances wrote

"Outdoor Air Pollutants. Among the most hazardous ...seem to be pesticides... Other outdoor exposures ... include vapours from solvents and fuels" and continuing with the list currently in the draft report of the MCS Review. (page 11, para.1) Include the phrase " most hazardous seem to be pesticides".

"Indoor Air Pollutants... paints" has been omitted, and was listed after perfumes by Ashford and Miller.

"Drugs and Consumer Products ...cornstarch or lactose" excipients "in tablets" is important to include, as did Ashford and Miller.

2.5 DOES MCS HAVE A DISEASE CLASSIFICATION?

In Austria, the Department of Health is classifying Chemical Sensitivity/ MCS as a physical disease under the code T78.4 of the ICD-10.

References: Bundesministerium fur Gesundheit, Chemikalien-Sensitivitat (ICD-10 T78.4), 24.06.2008, Wien, Osterreich. DIMDI Schreiben an CSN,MCS ICD-10, 04.09.2008 DIMDI Schreiben, 04.09.2008 www.csn-deutschland.de/icd-10_austria.pdf

3.1.3 LIMBIC KINDLING / NEURAL SENSITISATION

Brain imaging studies are discussed, looking for abnormalities.

These descriptions could be included:

PET scans indicate energy metabolism.

SPECT scans show the pattern of oxidative stress, which will deplete reduced glutathione (a most important antioxidant in the body).

The reference to SPECT brain imaging is already listed from Ross, Rea, Johnson, Hickey and Simon, 1999. Other references should be listed:

Heuser, Mena And Alamos, 1994.

Simon, Hickey, Fincher, Johnson, Ross and Rea, 1994.

Oxidative stress has been shown in MCS with increased levels of markers in the Ionescu, Merck and Bradford, 1999 research. This testing of blood and serum is less harmful to the MCS patient.

2.4 CAN MCS BE CLINICALLY DEFINED?

Pall, 2009, talks of specific biomarker tests that are possible for low-level chemical exposure, and these should be included:

Millqvist et al, 2005 (elevated cough responses in MCS from capsaicin); Schwarz et al, 1994 (EEG changes, neural sensitisation): Joffres et al (2005) reflecting neural sensitisation influencing skin conductivity; Elberling et al (2007) re basophils and elevated histamine; Peden (1996) and studies by Koren et al (1990, 1992) studied nasal lavage in MCS.

2.7 IS MCS RELATED TO OTHER SYNDROMES OR DISORDERS?

Pall, 2009 discusses "recently remodeled sick buildings"
... solvents were compared to organophosphorous pesticides by Miller & Mitzel, 1995.
The "Brigham and Women's Hospital" case suggested "a causal relationship between chemical exposure and illness initiation". Kawamoto et al, 1997.

3.1.4 Research Challenge. It is good to see animal studies mentioned.

The MCS Review describes the fifth principle of the NO/ONOO theory by Pall:

"Therapy for MCS and other multisystem illnesses should focus on down-regulating NO/ONOO cycle biochemistry."

Add: "including antioxidant therapy, sometimes known as nutritional supplements".

The last paragraph of the research challenge is confusing and would be better rewritten, especially this section: The MCS Review says,

"the chemicals implicated in MCS are diverse and often include hydrophilic solvents such as alcohol(i.e. perfumes). Interestingly, in the context of this theory, psychological stress is acknowledged as a potential stressor ... but not in MCS itself"

In discussing Pall's work, perhaps this section needs to distinguish between those chemicals that initiate cases of MCS, or trigger (subsequent reactions) in MCS.

3.1.4

Pall, 2009, wrote about the apparent initiators of cases of MCS:

"In addition to organic solvents and related compounds and the
organophosphorous and
carbamate pesticides, there are (additionally)
organochlorine pesticides ...
pyrethroid pesticides ...
hydrogen sulfide ...
carbon monoxide and
mercurial compounds"

3.2.2 Challenge studies for determing causation.

Did Hippocrates say something like, "first, do no harm"?

I expect that convincing animal studies will be done, before challenging Australians with MCS with low level chemical challenges.

Only the mild to moderate sufferers of multiple chemical sensitivity would be able to tolerate low level challenge studies. (See Rea, 1997, page 2496)

Masking and unmasking need further discussion. (Also see section 4.5). When Ashford and Miller, 1991, described patients avoiding specific foods for 4 to 6 days to 'unmask' reactions prior to test-feeding them, it was Rinkel's technique (published in 1944 and 1951), and used by Randolph. (page 18). Many products in our daily life contain corn (sugar, starch, oil) or milk (lactose etc), and Randolph reported that many of his patients reacted adversely to these. They're in many tablets and drugs.

Provocation / neutralisation needs a full investigation.

Amongst sufferers of multiple chemical sensitivity, if a medical practioner can provoke any symptom at all (if only an increase or change in pulse or blood pressure), then I think the practioner needs to be highly trained in neutralising that reaction with that same chemical (leaving no adverse after-effects the next day or week).

Rea, 1997, in Volume 4 of Chemical Sensitivity, says that "Heine, (1986) has shown that there is a high concentration of vitamin C in the ... epidermis, which scavenges free radicals ... intradermal neutralization works better with higher levels of vitamin C, probably resulting from its free radical scavenging

3.2.2 Challenge studies

ability. We have often observed that a patient could not be neutralized until vitamin C was administered intravenously." Page 2496.

Regarding "chemicals and other provoking substances ...Only moderately sensitive patients (i.e. those who tolerate the testing easily and are not made ill for over one night) can tolerate treatment with chemicals ... we do not use formaldehyde and phenol for treatment ... we have seen 5000 patients who were made extremely ill when phenol or alcohol was used as a preservative in their vaccines" page 2512.

4 DIAGNOSIS, TREATMENT AND MANAGEMENT OF MULTIPLE CHEMICAL SENSITIVITY

4.1.1 Studies ... of MCS in Australia

The 4th paragraph should be removed, as it's simply repeating a statement.

4.1.2 Studies ... of MCS in other countries.

I believe it's very difficult to get an accurate picture. A number of the studies are not including those people too ill to work or study, or who are receiving a Disability Support Pension, or those in a worse situation.

I expect the prevalance of MCS is underestimated overseas and in Australia.

Patients with MCS cannot always find the energy or money to consult a practioner whose treatment helps their MCS.
How would patients with MCS find a helpful practioner?

4.3 TREATMENT FACILITIES

Paragraph 2 could give a more accurate picture of the evidence provided to the Inquiry into MCS by the South Australian Parliament (2005).
From page 38 of the report of the Social Development Committee, 2005:

> "Dr Donohoe ... opened an environmental clinic (in) Manly (Sydney, NSW) ... An audit ... was conducted after three and a half years ... Dr Donohoe told the committee: 'One of the reasons for closing down the unit was that the ... drug therapies, the psychological and dietary counselling ... had not been effective in modifying their illness ... However, the education, support and acknowledgement of the illness did make a significant difference".

In the Gibson et al, 2003, survey, the drug therapies helped less than 26.3% and harmed 33% to 68% of those who tried them.

Since the late 1980's in Melbourne there have been 2 doctors specialising:
A day clinic named an Environmental (centre), another doctor had a hospital named an Environmental Control Unit. Both have been very successful.

4.4 TREATMENT / MANAGEMENT STRATEGIES

Dr W Rea (1997) stated that "continuous monitoring of 10,000 patients ... over the last 8 years (showed) that patients do well if they practice total load reduction, including avoidance of air, food and water pollutants; injection therapy, food rotation; and nutrient supplementation ... the majority of these patients were working at jobs, traveling throughout the world, and living their lives with vigor". Page 2862.

Rea shows that similar diagnostic and therapeutic regimes were used (in 1995) in Canada and in Germany at the Institute for Environmental Diseases with improvement of health long-term.

Rea's case studies of 3 working doctors who overcame MCS symptoms is inspiring, never missing a day's work due to illness in 15 years, or in another case in 50 years. Pages 2854, 2858, 2860.

Regarding malabsorption of nutrients: Rea wrote that "our patients observed that they could feel more of the adverse effects of pollutants if they did not take their vitamin, mineral and amino acid supplements" p2858. Figure 42.10 showed that 86% of the patients took vitamin, mineral and amino acid supplements. "They were clearly absorbing nutrients far better during follow-up than when initially seen. Malabsorption had been overcome" p2861.

Paragraph 8:
Speaking of the Australian support groups:
some also present information
and news of local and overseas research

Paragraph 10: re the guideline, Access to Buildings ... (HEREOC 2007).
please extend the quote (beyond information about early notification)
"For more information on ways to eliminate or minimise chemical and fragrance sensitivity reactions look at http://www.jan.wvu.edu/media/MCS.html and http://www.jan.wvu.edu/media/fragrance.html "

4.5 CLINICAL APPROACHES TO MCS IN AUSTRALIA

The last 2 paragraphs about the MCS Clinical Management Principles seem inadequate to me.

Paragraph 6.
For a better understanding of symptoms that fluctuate over time, I believe that Ashford and Miller, and also Rea, 2007 contribute a great deal.

4.5 CLINICAL APPROACHES (continued)

Paragraph 6 continued

Rea, 2007, states that a "demonstration of unmasking (deadaption)" is apparent even though "the patients were vigorous" "As they reduced their total pollutant load and could then recognise specific pollutant and food triggers (they) experienced increased ... transient symptoms (and) as their total load decreased, they became symptom-free". Page 2862.

4.6 CLINICAL RESEARCH NEEDS

Paragraph 4 Overall, a number of primary clinical research needs are evident:

point 3, insert: Blood tests of some toxic chemicals will determine if a chemical overload has occurred, as these levels should be below detection limit in the normal healthy population. Rea, 2007, quoted with permission a study by Pan, Johnson & Rea 1987/88 of Aliphatic hydrocarbon solvents. Another study by Rea et al, 1987, was quoted for toxic volatile organic hydrocarbons. "Pesticide levels. ... for organophosphates can be obtained, although positive results register for only 48 hours after exposure ... Metabolic breakdown products can also be detected from the blood and urine, and these may remain in the body for an extended time (maybe) 1 month. However, tests for either organophosphates or their breakdown products do not always reveal levels, even though a patient has been exposed and remains sensitive."

"Organochlorines...(more) are present in the chemically sensitive individual ... than in control populations." pages 2105 - 2109.

"It is apparent that there is a group of people who are at greater risk from organophosphate pesticides than the general population."

4.6.2 Education / Training.

A longitudinal investigation would be worthwhile if it did not adversely affect the health of people already suffering with multiple chemical sensitivity, meaning to simply document the treatments/ therapies found to be worthwhile, record non-invasive tests of blood, temperature, air volume, blood pressure, pulse.

Australian evidence of clinical research, and clinical management suggested by Australian clinicians who did this clinical review would be quite harmful.

Education about the clinical management of people with MCS comes from those specialists who have a success rate of over 75% with their MCS patients, that is Rea in USA, Canada, Germany, the UK, Japan

5 APPENDIX 1.

Paragraph 4. The survey was conducted by BMP Healthcare Consulting Pty Ltd. I'm wondering who the directors were at the time.

5.2 PROBLEMS ENCOUNTERED

This first heading could be rephrased, to mean that little evidence for biological markers has been found in peer reviewed journals.

5.4.1 Common MCS treatments

Websites of support groups and the experience of clinicians are the source of information for this section.

Surely, with patients sensitive to many chemicals, total or partial avoidance of chemicals is the **first** thing on the list of treatments.

Even if avoidance of pest-killers and weed-killers were not on the list, which is hard to believe.

If those with MCS have found they've improved on quiet camping trips by the seaside or in remote parks, or that the laundry powder aisle in the supermarket affects them, they may be fortunate enough to stumble across the conclusion that the chemicals make the difference.

The survey of Gibson et al, 2003, showed that 95% of the MCS interviewed found it helpful to avoid chemicals, most helpful of 101 treatments.

6 VIEWS OF ...GOVERNMENTS AND ...MEDICAL ORGANISATIONS

6.3 Paragraph 4: re the study of Kassirer et al., 2004. "prohibits ..fertilizers" I presume the "fertilizers" containing banned ingredients would be fertilizer/pesticide combinations, so this should be stated.
This discussion is about restricting non-essential use of pesticides in Canada.

6.5.2 British Society for Allergy, Environmental and Nutritional Medicine (BSAENM) The Working Draft (Nov 2008) was more informative regarding the lengthy report issued by BSAENM, in many respects.

Retain the first introductory paragraph of the November 2008 version draft of the MCS Review, with reference to Eaton et al,2000, as it appears to present a clearer overview of their statements.
In dot-point 3: Is this exactly what the BSAENM stated or implied?
"to avoid extreme avoidance behaviours by those with MCS"

ABBREVIATIONS

Correction:

ME/CFS Myalgic Encephalopathy / Chronic Fatigue Syndrome

ME/CFS Soc SA ME/CFS Society (SA) Inc.

In addition:

CFS Chronic Fatigue Syndrome

FM Fibromyalgia

Again, thankyou for the opportunity to comment. References follow.

Yours sincerely,

[redacted]

REFERENCES

I'd prefer to see the full reference for Ross, 1999. ie.

Ross GH, Rea WJ, Johnson AR, Hickey DC, Simon TR. (1999) Neurotoxicity in single photon emission computed tomography brain scans of patients reporting chemical sensitivities. Toxicol Ind Health; 15:415-420.

ADDITIONAL

Bundesministerium fur Gesundheit, Chemikalien-Sensitivitat (ICD-10 T78.4), 24.06.2008, Wien, Osterreich.

DIMDI Schreiben an CSN,MCS ICD-10, 04.09.2008.

DIMDI Schreiben, 04.09.2008 www.csn-deutschland.de/icd-10_austria.pdf

ElberlingJ, Skov PS, Mosbech H, Holst H, Dirksen A, Johansen JD. (2007) Increased release of histamine in patients with respiratory symptoms related to perfume. Clin Exp Allergy 37, 1676-1680.

Heuser G, Mena I, Alamos F. Neurospect findings in patients exposed to neurotoxic chemicals. Toxicol Ind Health 1994;10:561-572.

Ionescu G Merck M, Bradford R. (1999) Simple chemiluminescence assays for free radicals in venous blood and serum samples: results in atopic dermatitis, psoriasis, MCS and cancer patients. Forsch Komplementarmed6:294-300.

Joffres MR, Sampalli T, Fox RA. (2005) Physiologic and symptomatic responses to low-level substances in individuals with and without chemical sensitivities: a randomozed controlled blinded pilot booth study. Environ Health Perspect 113, 1178-1183.

Kawamoto MM, Esswein EJ, Wallingford KM, Wothington KA. (1997) Health Hazard Evaluation Report 96-0012-2652 Brigham and Women's Hospital Boston, MA, September 1997. United States Government (NIOSH). Washington DC.

Koren HS, Hatch GE, Graham DE. (1990) Nasal lavage as a tool in assessing acute inflammation in response to inhaled pollutants. Toxicology 60, 15-25.

Millqvist E, Ternesten-Hasseus E, Stahl A, Bende M. (2005) Changes in levels of nerve growth factor in nasal secretions after capsaicin inhalation in patients with airway symptoms from scents and chemicals. Environ Health Perspect 113,849-852.

Rea WJ, (1997) Chemical Sensitivity Volume 4: Tools of Diagnosis and Methods of Treatment, CRC Press, Boca Raton, Florida.

Simon TR, Hickey DC, Fincher CE, Johnson AR, Ross GH, Rea WJ. (1994) Single photon emission computed tomography of the brain in patients with chemical sensitivities. Toxicol Ind Health 10,573-577.