Organizational Support

From *Multiple Chemical Sensitivity: A Survival Guide* (2006). Published by Earthrive Books. This version updated April 2007.

It can be tremendously helpful to belong to several of the MCS advocacy/support organizations. They publish excellent newsletters that include vital information for those confronting MCS. It can also be invaluable to belong to environmental organizations that deal with either general or specific environmental concerns, such as groups that focus on pesticides. Both types of organizations are listed below.

Groups Offering Information, Support, and Advocacy

<u>Canaries Foundation, Inc.</u>, PO Box 3253, San Luis Obispo, CA 93403-3253. Phone: 805-547-1568; email: <u>mcelver@noacceptablerisk.com</u>; Website: <u>www.noacceptablerisk.com</u>

<u>Chemical Injury Information Network</u> (CIIN), P.O. Box 301, White Sulphur Springs, MT 59645. Phone: 406-547-2255; email: <u>ciin@ciin.org</u>; Website: <u>http://ciin.org</u>

CIIN is a "charitable support and advocacy organization run by the chemically injured for the benefit of the chemically injured. It focuses primarily on education, credible research into Multiple Chemical Sensitivities (MCS), and the empowerment of the chemically injured." The newsletter Our Toxic Times is published monthly by editor and director Cynthia Wilson. Special features of each issue include summaries of recent relevant research. (Suggested membership donations are: Fixed income - \$15; Employed individuals - \$30; Professionals - \$50)

<u>Chemical Sensitivity Disorders Association (CSDA)</u>, 5374 Echols Avenue, Alexandria, VA 22311. Phone: 410-335-7499; Phone/Fax: 301-897-9614; Website: <u>www.chemsense.com</u>
Newsletter: The Chemical Sensitivity Connection. Support line. "CSDA was established to provide information and support to chemically sensitive people . . . to disseminate information to physicians, scientists and other interested persons: and to encourage research on chemical sensitivity disorders and minimizing hazards to human health. Larry Plumlee, M.D., president. Send \$10 yearly to join and receive newsletter and meeting schedule.

<u>Chemical Sensitivity Foundation</u>, 3 Larrabee Farm Road, Brunswick, ME 04011. Phone: 207-725-8570; email: <u>info@chemicalsensitivityfoundation.org</u>;

Website: http://www.chemicalsensitivityfoundation.org/

"Our mission is to engage in scientific, charitable, and educational activities on behalf of people with multiple chemical sensitivity (MCS), with goals of funding research to validate the existence of MCS, pilot projects for MCS housing, and raising public awareness." Alison Johnson president.

<u>Chemsense</u> (associated with Chemical Sensitivity Disorders Association), 5374 Echols Avenue, Alexandria, VA 22311. Phone: 301-725-5482, 301-897-9614; email: laplumlee@pol.net;

Website: http://members.aol.com/ljavins/chemreact.html

There are two locations for this group, in Northern Virginia and Maryland. Meetings are occasional and offer advice, support, as well as information on toxic substances in the area.

Chronic Fatigue Syndrome, Fibromyalgia, and Chemical Sensitivity Coalition of Chicago (CFCCC). CFCCC, PO Box 277, Wilmette, IL 60091.

Phone: 312-409-5363; Website: www.cfccc.net

This group is a merger of the Chicago Chronic Fatigue Syndrome Association and MCS: Health and Environment, and is "organized for support, education, and advocacy for persons with chronic fatigue syndrome, fibromyalgia, and chemical sensitivity." Offers support, information, and newsletter "The Canary Times."

The Chronic Syndrome Support Association, 801 Riverside Drive,

Lumberton, NC 28358-4625. Website: www.cssa-inc.org

This organization is geared towards education of various invisible chronic illnesses like MCS. Also on the website is a person who seeks to give advice to those who are having problems with intimacy as they relate to having a chronic illness. A newsletter is available "The Syndrome Sentinel," as well as books and videos.

Circuit, PO Box 1UZ, Newcastle Upon Tyne, NE 99 IUZ, UK.

Website: http://www.ukselfhelp.info/circuit/

This group is based out of the United Kingdom and is geared towards people who have been made sensitive by electromagnetic fields. They research and offer information about the hazards of electricity. Send a self addressed, stamped envelope to receive their newsletter.

<u>Ecological Health Organization</u> (ECHO), P.O. Box 8232, Berlin, CT 06037. Phone: 570-472-0374; e-mail: <u>echomcsct@aol.com</u>;

Website: http://homestead.com/echomcsct

ECHO is a statewide nonprofit advocacy, support, and referral organization for people disabled with Multiple Chemical Sensitivity (MCS) and others who care about its prevention. Founded in 1992, ECHO is one of the first organizations in Connecticut linking environmental issues and public health. A donation in any amount will make the donor eligible for membership in ECHO for one year. Membership includes a very helpful 30-page Resource Guide and a newsletter published jointly three times per year with MACI – Massachusetts Association for the Chemically Injured.

Environmental Health Network (EHN), P.O. Box 1155, Larkspur, CA 94977. Phone: 415-541-5075; Support and Information Line (SAIL) 415-541-5075; email: www.ehnca.org. Website: www.ehnca.org.

EHN focuses on "the issues and developments relating to the health and welfare of the environmentally sensitive." The newsletter is The New Reactor. Organization has put particular energy into documenting the problems with fragrances. Large, informational website.

<u>Fibromyalgia Coalition International</u>, P.O. Box 9509, Mission, KS 66201. Phone: 913-384-4673; Fax: 913-384-2462; e-mail: <u>fmcfsgwsg@aol.com</u>; Website: http://www.fibrocoalition.org

Massachusetts Association for the Chemically Injured (MACI), Inc., P.O. Box 754, Andover, MA 01810. Phone: 978-681-5117; Fax: 978-686 0745;

email: macimcs@aol.com; Website: http://www.angelfire.com/ma3/maci

MACI is a statewide support, education, resource, and referral organization that began as a local support group and grew into statewide recognition. Services now extend to other New England states. They now hold support meetings in Boston, on the Cape and in Central MA.

<u>MCS – Danmark</u>, Bonsvigvej 35, 4720 Prasto, Denmark. Phone: +04570201646 Website: www.mcs-danmark.dk

MCS – Danmark is a Danish patients' organization. We aim at campaigning for proper medical recognition of MCS, offering the latest news and essential information on this illness, helping individuals with MCS, and arranging social activities for members.

ME/CFS Society (SA) Inc. GPO Box 383, Adelaide South Australia, 5001. Information and Support Line (MWTh 10am – 4pm) (08) 8410 8930, Administration (08) 8410 8929; Website: http://sacfs.asn.au/welcome.htm

This organization is primarily in South Australia. They are dependent on support from members and other individuals. Their services include promoting government recognition of the issue as well as education on ME/CFS. They also promote research and provide support to individuals. Regular membership is \$32 but there is a reduced amount for those who are unemployed or students (\$22) or after the first half of the financial year (which begins in July). A subscription to their magazine "Talking Point," is a benefit of membership.

<u>Multiple Chemical Sensitivities Task Force of New Mexico</u>, P.O. Box 23079. Santa Fe, NM 87502. Phone: 505-983-9208, 505-466-3622

Volunteer advocacy organization comprised of chemically sensitive New Mexicans. Dedicated to raising awareness of MCS and educating others about the hazards of high and low level chemical exposures, especially to pesticides. Provides information and referrals regarding resources in New Mexico.

National Center for Environmental Health Strategies (NCEHS), 1100 Rural Avenue,

Voorhees, NJ 08043. Phone: 856-429-5358;

email: ncehs@ncehn.org; Website: www.ncehs.org

Mary Lamielle, director. NCEHS is a nonprofit organization committed to education, research, support, and advocacy services on environmental and public health issues including environmentally and occupationally induced illnesses.

North Carolina Chemical Injury Network, 6442 Hwy 42, Bear Creek, N.C. 27207. Phone: 336-581-3471; Website: http://www.ncchem.com

This site contains a vast amount of information on various topics related to chemical injuries as well as links to other groups. They offer an email list for the planning of MCS Awareness Day. Membership is available to those who have some form of connection to the state.

Ohio Network for the Chemically Injured (ONFCI). P.O. Box 29290, Parma, OH 44129.

Phone: 440-845-1888; Website: http://www.ohionetwork.org

Educational and advocacy group that is very active. Has initiated a large number of projects, including the "Healthier Hospitals" book.

IN CANADA:

Allergy And Environmental Health Association Canada, Branches:

EHA/AEHA BC -Ecological Health Alliance, Box 30033 Saanich Centre PO, Victoria, BC,

Canada V8X 5E1. Phone: 250-658-2027;

email: info@ehabc.org; Website: www.ehabc.org

Newsletter: "Ecological Health Alliance Support News"

AEHA - Kitchener Branch, 2 - 513 Quiet Place, Waterloo, Ontario, Canada N2L 5L6,

Canada. Phone: 519-885-2803

AEHA - Nova Scotia (AEHA-NS). E-mail: aeha-ns@geocities.com;

Website: http://www.geocities.com/RainForest/6847/aeha.html

This is a group that is geared towards people with MCS and related illnesses so that they can share information. Membership is not limited to Canadians. Use of the message board requires membership. To become a member, a Yahoo! Account (which is free) is necessary as well gaining the approval from the group. The website has a list of other support groups, pamphlets, accommodations, and other resources.

AEHA - Ottawa Branch, Ottawa RPO Shopp/West Box 33023, Nepean, Ontario K2C 3Y9,

Canada. Phone: 613-860-2342; email: info@aeha.ca;

Website: www.aeha.ca Newsletter: "Eco-Sense"

AEHA - Prince Edward Island, Sandra Boswell, P.O. Box 1482, Charlottetown, PE

C1A 7N1. Phone: 902-368-2730

Environmental Health Association of Nova Scotia (EHANS), (formerly Nova Scotia Allergy and Environmental Health Association), PO Box 31323, Halifax, Nova Scotia, B3K 5Y5.

Phone: 800-449-1995

"EHANS is a non-profit, province wide education, advocacy and action organization established in 1985. The EHANS mandate is to increase knowledge and awareness of environmental health issues stressing prevention, recognition and treatment; and to advocate for fair and equitable treatment of persons with environmental illnesses."

Website: http://www.environmentalhealth.ca

Website on less toxic products: http://www.lesstoxicguide.ca

Membership \$25 per year; Pay What You Can Membership - \$5 or more Canada, \$10.00 or more U.S. Membership includes semi-annual newsletter and e-mail bulletins of general interest.

Environmental Illness Society of Canada,

Website: http://www.eisc.ca

Online support and information

Chemical Injury Relief Foundation (CIRF)

Website: http://www.cirf-hub.ca

Founded by Brian Hack, CIRF seeks to educate people on the issue of injuries due to chemical exposure. Available on the website is a library of research on MCS, CFS, and Fibromyalgia.

Dr. Rapp

Website: http://www.drrapp.com/

Website of Dr. Doris Rapp, a physician of environmental medicine. Author of a number of books, particularly on children and sensitivities. *Is This Your Child?* and *Is This Your Child's World?*

Environmental Illness Resource (EIR)

Website: http://www.ei-resource.org

This site has a compendium of resources, including articles, forums, and details regarding the latest illness research. The site covers chronic fatigue syndrome, fibromyalgia, and MCS, including many links, and some petitions. Also included is a store that offers filters, vacuums, supplements, cleaning and personal care products, and other products.

Health and Environment Resource Center

Website: http://www.herc.org

"The non-profit Health & Environment Resource Center was created in 1997 by Earth Angels Association, Inc. as a source of information for people seeking to learn more about the relationship between the environment and human health." Webmaster Andrea DesJardins. Site has message board, newsgroups, articles, the Earthweb Project, newsletters including Sharon Wachsler's "The Clarion" (see below).

Jacki's Web Site (Our Little Place)

Website: http://www.ourlittleplace.com/

A personal Web site, includes a range of topics including MCS, Chronic Fatigue Syndrome, Fibromyalgia, health risks of perfume & other scented products, "Guidelines for Non-Toxic Living," information on detox baths, resources, links, and on-line ordering of MCS books. One of the pages has a decent list of no-toxic products/substitutes including cleaning, pesticides, personal care. See http://www.ourlittleplace.com/nontoxic.html

JMU MCS Research Team Website

Website: http://mcs.research.net

Has Pam Gibson's research papers, other MCS resources, and links.

Mary Kempf's Website http://www.ctaz.com/~bhima/

Extensive and broad coverage of MCS issues and resources. The following link focuses on EMF issues.

http://www.ctaz.com/~bhima/emf.htm

MCS: A Survival Guide

Website: http://www.earthrivebooks.com

This is the website for *Multiple Chemical Sensitivity: A Survival Guide*, 2^{nd} *Edition*. It allows you to read excerpts from and/or order this book.

MCS-Global

Website: http://www.mcs-global.org

Global Recognition Campaign for Multiple Chemical Sensitivity, Chemical Injury, Chemical Hypersensitivity, Environmental Illness and other chemically induced illnesses and diseases affecting Civilians and Military personnel. This is a comprehensive educational and activist site dedicated to recognizing environmentally-induced illnesses and identifying and reducing the toxics that cause them. Included are articles, people's stories, public health alerts, petitions, many links, and other information. Diana Buckland established this campaign after she and her son were harmed by pesticides.

MCS Guide (from Ability Maine)

Website:http://www.abilitymaine.org/guides/mcs.html

Developed by Sharon Wachsler.

Extensive resource list sorted out by type. Type of websites range from those housing materials to individually owned pages and medical information.

MCS Heightened Senses Network

Website: http://p217.ezboard.com/bmcsheightenedsensesnetwork

The MCS Heightened Senses Network is a purely online discussion. Here there are member journals where you can, once a member, record your responses to your form of treatment. A listing of environmental doctors by state is also available. Membership is free.

Online Newsletters:

"The Clarion." "the newsletter of information, resources, and activism for people with MCS (multiple chemical sensitivity), CFIDS, (chronic fatigue immune dysfunction), related disorders, and our allies." Has exhaustive information and resources, and activist opportunities. Excellent way to stay current. To receive "The Clarion" by e-mail, contact Sharon at Swachsler@aol.com

Planet Thrive

Website: http://www.PlanetThrive.com

"A grassroots community for personal wellness with a focus on the health-environment connection." Offers discussion forums, blogs, resources, recipes, videos, Ask An Expert advice columns featuring Dr. William J. Rea (founder and director of the Environmental Health Center-Dallas), Dr. Jacob Teitelbaum (CFS and Fibromyalgia expert and author of From Fatigued to Fantastic!), master herbalists Stephen Harrod Buhner (author of Healing Lyme) and Susun Weed, and others, plus much more. Membership base includes those recovering from Lyme Disease, Chronic Fatigue Syndrome, Fibromyalgia, Chemical Sensitivity, Mold Illness and other chronic environmental illnesses. Julie Genser, founder and director

Find an MCS support group in your area. Website: http://mcs.meetu.com/

Groups Offering Primarily Information and Support

The American Academy of Environmental Medicine (AAEM), 7701 East Kellogg, Suite 625, Wichita, Kansas 67207. Phone: 316-684-5500; Fax 316-684-5709;

email: administrator@aaem.com; Website: http://www.aaem.com

AAEM is a professional organization of practitioners of environmental medicine (previously

referred to as Clinical Ecology). It offers education and training to physicians and sells tapes from their educational conferences. Website offers links to member physicians' websites.

Human Ecology Action League, Inc. (HEAL), P.O. Box 29629, Atlanta, GA 30359-0629.

Phone: 404-248-1898; Fax: 404-248-0162; e-mail: HEALNatnl@aol.com; website:

http://members.aol.com/HEALNatnl

A longstanding informational resource for those whose health has been adversely affected by the environment. Emphasis is on support rather than advocacy. They publish The Human Ecologist quarterly. Membership is \$26. HEAL can inform you of local HEAL support groups in your area.

Atlanta H.E.A.L.

Website: http://www.atlantaheal.org

Phone: (770) 787-1249; e-mail: info@atlantaheal.org

Atlanta HEAL is a part of one of the oldest organizations in the world concerned about the health effects of environmental exposures. The Atlanta HEAL Chapter has monthly meetings with presentations from alternative healers, environmental practitioners and other related people.

<u>The Jeremiah Project</u>, HC 1 222 Soft Wind, Canyon Lake, TX 78133. Phone: 830-935-4618; e-mail: jeremiah@texannet.net.

The Jeremiah Project provided education and interdenominational ministry for people with MCS/EI. The newsletter, "I Am Jeremiah," is published bimonthly by Rev. Linda Reinhardt and includes discussions of faith and coping, book reviews, and updates. Donations are appreciated to cover costs.

MCS Referral & Resources, 508 Westgate Road, Baltimore, MD 21207-6631. Phone: 410-362-6400; Fax: 410-362-6401;

Website: http://www.mcsrr.org

Albert Donnay, Executive Director. This organization, founded by Grace Ziem, M.D., Dr.PH, and Albert Donnay, MHS, focuses on "professional outreach, patient support, and public advocacy devoted to the prevention, diagnosis, treatment, and accommodation of Multiple Chemical Sensitivity Disorders" by collecting and disseminating information and resources to "further the diagnosis, treatment, accommodation and prevention of multiple chemical sensitivity disorders."

Share Care & Prayer, P.O. Box 2080, Frazier Park, CA 93225. Fax: 661-245-6614; Website: www.sharecareprayer.org.

Founder and contact is Janet Dauble. This is a Christian organization that attempts to serve the needs of those with MCS, CFS, and FM through a variety of resources. Offered are an E.I. answer line, newcomer packet, twice yearly newsletter, tape and book libraries, a church packet to share with your church on how to help E.I.s, pen pals, and books and tapes for sale. Answer line is available 8 hours per week via phone or e-mail and offers practical information regarding all areas of living with chemical and food sensitivity through expert Carolyn Gorman, M.A., author of Less Toxic Alternatives. There is no charge; however, contributions are needed and appreciated. Answer line contacts are: Phone: 972-964-8333 Tuesday 9:00 am to 1:00 pm Central Standard Time (Texas) or email: eianswerline@sharecareprayer.org. You may e-mail questions at any time to be answered during the above hours.

Groups Focusing On Environmental Quality

Beyond Pesticides, 701 E Street S.E., Suite 200, Washington, DC 20003. Phone: 202-543-

5450; Fax: 202-543-4791; email: info@beyondpesticides.org;

Website: http://www.beyondpesticides.org.

Has the goals of educating communities and individuals on the use and misuse of pesticides, and promoting non-chemical and least toxic methods of pest control. Publishes a variety of publications including "Pesticides and You."

<u>Center for Health Environment and Justice</u> (Formerly, Citizens Clearing House for Hazardous Waste), P.O. Box 6806, Fall's Church, VA, 22040. Phone: 703-237-2249; email: chej@chej.org; Website: http://www.chej.org.

Lois Marie Gibbs, executive director. This organization has provided technical assistance to more than 10,000 community groups threatened by toxics. It aims to empower people to fight for their rights to environmental justice. They have written a wide variety of publications, including Gibbs' book "Dying from Dioxin: Reclaiming Our Health and Rebuilding Democracy," and offer training in community organizing. Subscription to quarterly magazine, "Everyone's Backyard" is \$35.

Environment and Human Health, Inc., 1191 Ridge Road, North Haven, CT 06473. Phone: 203-248-6582; Fax: 203-288-7571; email: info@ehhi.org; Website: http://www.ehhi.org
Nonprofit organization founded by Nancy Alderman, MES, "dedicated to protecting human health from environmental harms through research, education and the promotion of sound public policy. Environment and Human Health, Inc. is made up of doctors, public health professionals and policy experts committed to the reduction of environmental health risks to individuals."

Environmental Research Foundation, P.O. Box 160, New Brunswick, NJ 08903-0160. Phone: 732-828-9995, 888-272-2435; Fax: (732) 791-4603; email: erf@rachel.org; Website: http://www.rachel.org.

Strives to "strengthen democracy by helping people find the information they need to fight for environmental justice in their own communities" and "specialize[s] in information on hazardous substances and hazardous technologies, including landfills, incinerators, pesticides, organochlorine compounds, risk assessments, and their effects on human and environmental health." Newsletter, "Rachel's Environment & Health News" is available free by email. To subscribe, email the words SUBSCRIBE RACHEL-NEWS (YOUR FULL NAME) to: listserv@lists.rachel.org

<u>Greenpeace USA</u>, Greenpeace, Inc. 702 H St NW, Suite 300, Washington, DC 20001. Phone: 202-462-1177, 800-326-0959; <u>email: info@wdc.greenpeace.org</u>;

Website: http://www.greenpeace.org/international.

Well-known, environmental activist group that addresses toxics, nuclear waste, and a host of serious issues relating to contaminants. Annual donation of \$30 for membership and newsletter Greenpeace Quarterly.

<u>National Pesticide Information Center,</u> Phone: 800-858-7378; Fax: 541-737-0761; email: nptn.@ace.orst.edu; Website: http://npic.orst.edu.

NPTN is a cooperative effort of Oregon State University and the U.S. EPA and offers free information on pesticides including what to do in a spill or emergency, proper use/cleanup, etc. Can also take reports of poisonings. Small fee for faxed or mailed information.

Natural Resources Defense Council, 40 West 20th Street, New York, NY 10011. Phone: 212-727-2700; Fax: 212-727-1773; email: nrdcinfo@nrdc.org; website: http://www.nrdc.org
Powerhouse environmental organization whose mission statement begins: The "Natural Resources Defense Council's purpose is to safeguard the Earth: its people, its plants and animals and the natural systems on which all life depends." Fights in court to save the earth and often wins. As of April 2007 is pursuing an 18-year battle with Texaco over pollution of the Delaware River. Desperately needs contributions to finish this fight.

New York Coalition for Alternatives to Pesticides (NYCAP), 353 Hamilton St., Albany, NY 12210-1709. Phone: 518-426-8246 or 518-426-9331; email: nycap@crisny.org; Website: http://www.altpest.org

NYCAP is a "citizens' organization committed to public education and advocacy to reduce the pesticide hazards."

Northwest Coalition for Alternatives to Pesticides (NCAP), P.O. Box 1393, Eugene, OR 97440. Phone: 541-344-5044; Fax 541-344-6923;

email: info@pesticide.org; Website: http://www.pesticide.org;

NCAP has a twenty-year history of providing information and assistance regarding prevention, policy, and victim assistance in relation to pesticides. Basic membership is \$25. Members receive the *Journal of Pesticide Reform*. Caroline Cox, editor.

<u>Pesticide Action Network North America</u> (PANNA), 49 Powell St., Suite 500, San Francisco, CA 94102. Phone: 415-981-1771; Fax: 415-981-1991.

email: panna@panna.org; Website: http://www.panna.org

"PANNA (Pesticide Action Network North America) works to replace pesticide use with ecologically sound and socially just alternatives. As one of five PAN regional centers worldwide, we link local and international consumer, labor, health, environment and agriculture groups into an international citizens' action network."

<u>Pesticide Education Center</u>, P.O. Box 225279, San Francisco, CA 94122-5279. Phone: 415-665-4722; Fax: 415-665-2693; email: pec@igc.org;

Website: http://www.pesticides.org

Non-profit organization founded in 1988 to educate workers and the public about the hazards of pesticides to human health and the environment.

Public Citizen, 1600 20th Street, N.W., Washington, DC 20009. Phone: 202-588-1000.

Website: http://www.citizen.org

Founder, Ralph Nader. Very well-known consumer advocacy group.

Rachel Carson Council Inc., PO Box 10779, Silver Spring, Maryland 20914. Phone: 301-593-7507; Fax: 301-593-6251; email: rccouncil@aol.com;

Website: http://members.aol.com/rccouncil/ourpage

Clearinghouse and library with information at both scientific and layperson levels on pesticide-related issues. Provides resources including pamphlets and books on pesticides.

Work and Disability Advocacy

<u>Independent Living Resource Center</u>, 70 10th St. #409, San Francisco, CA 94103. Phone: 415-863-0851. Offers legal advocacy for employment, housing, and access to public service for the disabled. Also provides information, referrals, and a newsletter.

Working Fragrance Free, P.O. Box 460461, San Francisco, CA 94146-0461. This group, founded by Amy Marsh, helps the fragrance-sensitive worker achieve effective accommodation through workplace education, information, events, and a newletter. Amy has now joined the Environmental Health Network of California.

Online MCS Recycling of Items

A Yahoo Group called MCSRecyle has been formed to share with each other items that are chemical free and have been used in a non-toxic environment. This group is planet-wide. Membership is restricted to those with chemical sensitivities. You may post for items wanted, items you can donate, and items you want to sell. Parties involved in a transaction will have to determine who pays shipping and handling costs.

Rosie Lloyd, List Owner. http://groups.yahoo.com/group/MCSRecycle

MCSRecycle-subscribe@yahoogroups.com

MCSRecycle-owner@yahoogroups.