

ECHO

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**Public Hearing Testimony on H.B. No. 5014 AN ACT MAKING ADJUSTMENTS TO STATE
EXPENDITURES AND REVENUES FOR THE FISCAL YEAR ENDING JUNE 30, 2013**

Subject: Consolidation of the Office of Protection and Advocacy for Persons with Disabilities with CHRO

*Appropriations Committee Co-Chairs - Senator Toni Harp and Representative Toni Walker and
Members of the Appropriations Committee:*

Thank you for this opportunity to speak tonight. My name is Carolyn Wysocki and I am the President of Ecological Health Organization – ECHO. ECHO opposes the consolidation of the *Office of Protection and Advocacy for Persons with Disabilities and the Human Rights and Opportunities Commission*.

ECHO is a statewide nonprofit advocacy, support, education 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. Over the past twenty years, ECHO has worked with state agencies providing them with information on the needs of citizens disabled with MCS.

As you may know, MCS is caused by repeated low level exposures to toxic chemicals, or it can be caused by a single exposure to one chemical. It is a chronic condition usually involving the central nervous system and other organ systems of the body. Symptoms of MCS include chronic fatigue, muscle and joint pain, rashes, asthma, short-term memory loss and lack of concentration, digestive and neurological problems. People with MCS develop an increased reaction to common chemicals such as perfume, fabric softeners, formaldehyde, paints, tobacco and wood smoke, pesticides and petroleum-based products. Because of lack of understanding of this disabling illness, obtaining accommodations in the workplace, healthcare setting or housing situation can be very difficult for the person with MCS.

People with MCS need a separate state agency advocating for the rights of citizens of Connecticut who have this illness. Over the past twenty years, OPA has offered stalwart support for people with MCS and it has helped ECHO advocate for its members disabled by chemicals in the environment. **This is the mission of OPA and others in the disability rights community: to ensure the respect and dignity of the individual – no matter what ability that individual possesses.**

OPA has advocated for people with MCS facing discrimination in housing situations; and it has advocated for those seeking employment accommodations. It has helped students who need access to classes and teachers who can still work and need accommodations in the classroom. It has helped members of ECHO who need access to healthcare in hospitals, doctor's offices or other medical facilities. **The May 2000 Governor's Proclamation of MCS Awareness Week in Connecticut states:** "...reasonable accommodations information about and recognition of MCS can provide opportunities for people with this disability to enjoy access to work, schooling, public facilities, and other settings where they can continue to contribute their skills, ideas, creativity, abilities and knowledge..."

ECHO has a long history working with the Connecticut State Office of Protection and Advocacy for Persons with Disabilities (OPA). In June, 1992, at the request of the director of OPA, ECHO wrote a paper "*How to Accommodate The Worker with Multiple Chemical Sensitivity*" which was distributed to Connecticut State Agencies. The then Executive Director of OPA, Eliot J. Dober wrote: "*MCS, also referred to as environmental illness, can be a serious problem and extremely debilitating for an*

otherwise productive employee. It is not a condition of which we should be afraid of. It just makes good business sense for all of us to learn as much as we can; not only about the illness, but also how we can modify our work environment to allow individuals to remain productive."

ECHO has worked with OPA and other disability rights organizations across the nation since that time. Once again, at the request of OPA in January 1994, ECHO made a presentation to Connecticut State Agency personnel at an ADA Workshop held at the state capitol regarding "**Accommodating the Worker with MCS – An Invisible Disability**". Seeing the need for a concise handout for employers and employees disabled with MCS and in need of workplace accommodations, ECHO President, Carolyn Wysocki, M.A., M.H.S.A followed-up on that presentation with a handout titled "**ADA Title I Accommodations for People with Multiple Sensitivity.**" **OPA encourages people with disabilities to become engaged in the community and enables even those of us who have limited abilities, due to exposure to chemicals in the environment, to educate the larger community about our illness.**

People with disabilities need a state agency whose primary focus is to fight for them and their rights. When a person with MCS need housing or workplace accommodations, ECHO always tells them to call OPA because they understand the illness and can find the correct interpretation of their rights as individuals or workers defined by the Americans with Disabilities Act (ADA).

Stalwart support from the Connecticut State Office of Protection and Advocacy for Persons with Disabilities (OPA) has been continuous and unflinching. When a "mean-spirited" editorial ridiculed people disabled with MCS, then OPA Assistant Director, Stan Kosloski swiftly fired-off a rebuttal in defense of our members.

Kosloski wrote: *"It is indeed unfortunate that we need a law like the ADA, or any other civil rights laws for that matter. But isolation, segregation, discrimination, exclusion, and prejudice are realities of life not just for people with disabilities but for many others who find themselves treated differently, not because of their lack of skills or qualifications but because of their color, national origin, sex, religion, or age. If these weren't legitimate issues there would be no need for the ADA, or any other civil rights law for that matter."*

Kosloski continued, *"With regard to those with chemical sensitivities, it seems clear the editor has never known anyone who has what is often a very disabling condition. I use a wheelchair to get around, but I know many people who have chemical sensitivities who are far more limited than I."*

Kosloski concluded: *"Chemical sensitivities are indeed 'human-made' conditions, due to the explosion in the use of chemicals in our environment over the last thirty to forty years. It is a condition most people know very little about currently, but one which we will hear more and more about in the coming years. For the editor to demean as a group those with this condition is unconscionable."* **(Letter to the editor, dated January 9, 1996 from OPA to The Waterbury Republican.)**

We need a strong state agency to advocate for us in the disability community – an agency committed to the principles that says that people with disabilities should be treated with respect and dignity. In Connecticut, that agency is **The Office of Protection and Advocacy for Persons with Disabilities.** It has been a life-line for so many of us who suddenly find we have an illness after exposure to a common everyday chemical in the environment. Often, this exposure occurred in a classroom, an office or other workplace setting. Accommodations can allow that person to continue to be a productive member of the community to "...enjoy access to work, schooling, public facilities and other settings where they can continue to contribute their skills, ideas, creativity, abilities and knowledge" to society.

The Office of Protection and Advocacy for Persons with Disabilities has been a dynamic supporter for the citizens of Connecticut disabled with MCS. We ask that the status of this state agency remain independent to continue its vital mission dedicated to the community of people in our state who have disabilities.