

"CI" Internet Lists: Diverse Communities - Common Cause

By M M Carson MacRaven

I was acutely poisoned in 1971 with formaldehyde and pesticides--back in the day of platform shoes, 8-track tapes and soundless Super-8 home video cameras. Videophones, where "chatters" could see who was on the other end of the telephone "line" and hand-held devices for sharing information from around the world via what is now known as the "interweb" (a phrase used by curmudgeon television character Dr. Gregory House played by Hugh Laurie) were still in the realm of science fiction. We laughed when Maxwell Smart used the heel of his shoe to communicate--today we see people with small phones clipped to their ears, walking down the street often being mistaken for talking to themselves. It was an interesting time politically and many long overdue social justice issues, finally, reached a turning point as civil rights groups, feminists and environmentalists fought for their rights and the rights of others, individually and collectively. Unfortunately, those battles will continue ad infinitum with the changing of the "guard" as the pendulum swings back and forth between left and right. Power seekers (masquerading as leaders) intent on controlling the lives of others (usually because they have little control over their own impulses--what the musical group Pink Floyd kindly referred to as "momentary lapses of reason") reverse history-making strides forward and the battles begin anew for what were once the future generations.

Many who were activists for various causes back in the 60's and 70's still work for those same values today, though they may have taken on a different frame. Thankfully, many bring what they have learned to the CI community, though toxicants have accelerated their biological clocks shortening their useful years. Marching in the streets has become very dangerous these days (for the chemically injured as well as others) but the true activist heart and soul cannot and will not be quelled. Paul Rogat Loeb in Soul of a

Citizen: Living with Conviction in a Cynical Time quotes Thomas Merton: "Souls are like athletes that need opponents worthy of them if they are to be tried and extended and pushed to the full use of their powers." When times are particularly rough in the CI activist community, I turn to Loeb's book (and many other sage writings) as a reminder that activists do get burned out, but they will bounce back. They need to take time to reach a higher level of clarity to be able to stand firmly in the face of opposition whether from without or from within their own community.

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In my case, I didn't even know there was a "CI community"--that is, other chemically injured/intolerant people like myself--for many years after having

been poisoned. I vividly recall the day I read a small article in a local newspaper about a woman who had deliberately moved to an area with dirt roads and no paved streets. The city had annexed her street and was about to asphalt it--and she had dug in for a fight for her life, literally. I called her and with that phone call, I learned that I was not the only "weird" person who was intolerant of so many toxicants. Later, surveys showed the number to be approximately 35 million in the United States alone. As I have come to know over the last 36 years, there are those who know what causes their health problems and those who do not know--poisons poison everyone and can manifest in various ways. Knowledge is power, particularly in the case of toxicant-induced illnesses where prevention can mean the difference between thriving and struggling to just get through the day. I was so encouraged by that phone call and was driven to learn all I could, knowing that I would spend the rest of my life working for awareness of toxicant-induced intolerances. I felt that a grave injustice was being meted out on the beings of Planet Earth at the hands of an ethic-less industry.

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My quest for knowledge began. It had been my practice to ignore the computers at the university--being a "quasi-Luddite", but I decided to bite the bullet and dragged myself (kicking and screaming) to the computer lab to start doing searches, with what little experience I had. Just about that time the rock group Guns N' Roses had released a song titled "Welcome to the Jungle." Every time I got online I felt as if I had entered a very foreign, fearful technical jungle. This feral

Nature-girl was not what one could call an "early adapter" where technology was concerned. I felt much better outdoors in my beloved Nature and deplored the time I spent indoors given the load of toxicants permeating indoor air, especially facing a computer. But I felt an obligation and was driven to learn all I could. On the computers, I found information about health issues caused by toxicants and in particular those who had become intolerant, though the information was scant. I found the writings of Cindy Duehring, Director of the Environmental Access Research Network, who died as a result of her chemical exposures at the age of 36. I spent as much time in the medical libraries pouring over journals as my health would allow--but came up fairly empty-handed. Then I found articles in Chemical & Engineering Digest and a book by Dr. Claudia Miller and Nicholas Ashford: *Chemical Exposures--Low Levels, High Stakes* and the steady trickle began. During the next decade I collected every publication I could find on CI issues (and continue still). But it wasn't until 1998 when I got a workable personal computer that I found the CI internet lists. That is when my education really expanded and I owe much to those who were on the lists long before I arrived. What a phenomenal resource those lists were and are even more so today. Had that resource been available to me back in 1971, my health would not have deteriorated so quickly. Early intervention is key to avoiding a downward health spiral.

The CI lists were a perfect place for the home-bound future leaders, activists and sufferers to come together. List owners paid for their lists

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early on and some still do today. The doors were opened even wider as the "free" listservs became available, hosted by E-groups (now Yahoogroups), Topica, Geocities, et al. As more and more CI sufferers arrived on the internet, groups with various special interests within the larger community were formed to fill many niches. There are groups that focus on: religion (some exclusive, some inclusive); artists; science; politics; activists; partners of CI sufferers; parents of CI children; housing; disability benefits; accommodations; general support lists and so many more---lists to suit just about everyone's needs. And if there isn't a special interest list, anyone can easily start one--the only cost is their time. Most interested individuals join several lists and the awareness-raising, education and support spread quickly. As important, many people, once feeling powerless, have found and learned to use their own voices.

The list owners, most of whom work long hours for no remuneration--(and I speak from experience--the hours can be quite long) institute guidelines for their members--some are quite rigorous and some are less so. The lists are like real-life "villages" and because the CI community is a cross-section of society, diverse viewpoints should be welcomed and even encouraged. Eruptions are not unheard of, though it would be ridiculous to blame all the members on any given list for the actions of a few errant individuals. Of course, there will always be those who disagree with list policies, but as Yahoogroups' "techies" told me, "a list is like your living room." You can invite or exclude whomever you well please. No one has a "right" to join any particular group and the list owners have discretion to moderate or to remove anyone who seems to have uncontrollable "momentary lapses of reason" or who abuse other members. There are those who find it difficult to engage in or even listen to others debate or to honour opinions different from their own and they may decide to leave a list when a skirmish is taking place. Some are too fragile to read or to take part in threads they may find to be upsetting, but they can just delete the posts they do not want to read and still remain on the lists to stay informed. Others realize that differing opinions are just part of belonging to a group of interacting adults and understand that debate is an opportunity for growth.

The last nearly 10 years on the CI internet lists have been an invaluable learning experience for me. The scientific and other information exchanged is beyond compare. I don't even have time to read all of the information (particularly the wealth of science) that comes to my mailbox these days--and I find that encouraging. But what the lists offer goes much deeper on a personal level. The "newbies" (and we all begin as newbies) in the community learn much from the elders and vice versa. Further, I have watched tight-knit "families" form on certain lists. The amount of love and caring is heart-warming. Many on the lists are lurkers, and fear posting for personal reasons. But, generally, every list has leaders (not just the owners) who help others feel confident enough to participate. Much back channel and on-list hand holding takes place, new members are welcomed and encouraged to take part, computer help is shared (I learned much about computers when I first got on the lists from other listmembers and still do), information is freely exchanged whether about the best soap, shampoo or cleaning products, building materials, referrals to suitable doctors, unrelated medical issues that can prove to be very difficult for the chemically intolerant (recently I wrote asking for help with a spider bite that has bothered me for two years--and my mail box immediately filled with support and help), members have sent money and clothing to those in need, some have offered housing, some have shared science and medical help, information about safe(r) locations, some have shared legal advice, some

help with disability benefit information, some are especially good at offering moral support when others are losing hope, and many have spent hours during the night talking those most desperate out of committing suicide. This help is given willingly and freely to others sharing the same strife with no remuneration expected. We have also collectively grieved for our beloved community members who have lost their lives due to their chemical injuries and intolerances. Compassion abounds. So many have been abandoned by those closest to them--family, friends, co-workers, medical practitioners who refuse to understand that poisons poison people, their churches, schools and places of work to name just a few. Often, the only place many in our community can receive the support they so desperately need comes from those who understand the problems first hand--they have become surrogate families. The CI internet lists are safe, comfortable places for them to discuss their travails and to commiserate. Many of us have also made life-long friends from around the world. We have spent many joyful hours exchanging pictures, personal stories, holiday gifts and telephone calls. Was it all a bed of roses? Of course, not! I, and others, have endured some horrendous attacks, but we have learned to consider the source and just carry on. Our community is, after all, a cross-section of society with all its foibles. On the other hand, when my computer got fried by a lightning strike in 2002 (yes, I did have it protected--or so I thought), my list members donated money for me to get a new computer. It is the one I am still using today! And I have been gifted with books, warm hand-knitted socks, chocolate, sweet endearing friendships and much more! So the positive has far outweighed the negative.

In 2001 I attended the CIIN Conference held in Santa Fe, New Mexico. It was like a "family reunion" for many of us. I recall standing in front of my booth, when I heard a voice asking "is this Maggie MacRaven?" I turned around and there stood Barb Wilkie (as I type this my eyes fill with tears). We engaged in a huge, loving sisterly hug. It was an honour to meet her and many of the other (until then) faceless activists I had come to know on the internet. Many of us still have a very tight bond that will never be broken.

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Personal health issues have caused me to cut back on my participation on the lists and I belong to only a few these days. When Nodi (my co-owner) and I closed the original MCS-CI-Exile list in 2002, we willingly turned that list over to new owners (who gave it a new name), knowing it was in safe hands. There was no need to wait for a next generation of leaders because there were

leaders ready and waiting. There has been a constant flow of new people into our community (quite unfortunately due to ever-present toxicant threat). I am so encouraged to see this influx of new people doing such a marvelous job in picking up the gauntlet. We do not have to wait for the next generation of leaders to come forth, we have plenty working diligently and selflessly right now. Some of the websites they have built are phenomenal. Some are lyrical writers. Some bring major knowledge of catastrophic chemical injury events and stories of how they have coped. They have a wealth of information to share with those in similar tragic situations. They are as driven as any of us were and still are. I am certain they would welcome the support and sage advice of some of those who have retired from "active" activism. I do not see this community being on a path of destruction as some have contended. Quite the contrary, old-timers, newbies and

those in between are involved in diverse and necessary grassroots initiatives--online and in the "real world." Many are working collaboratively. Most do not seek the spotlight, so we seldom hear about their successes, but they are out there striving (even with health problems--some monumental), without compensation, to bring justice to our community. I celebrate their work! Not only have the CI lists been a vital resource for those suffering with CI (even saving lives), they have been a fantastic meeting ground for our advocates and activists. I, personally, cherish the helpmates, friends, surrogate family and fellow activists/advocates I have met over the years online, my life would not have been quite the same without them.

Styles and technology may have changed since 1971, but one thing remains true. Activists will still speak out in the face of injustice. Taoist Lao Tzu said many centuries ago, "a journey of a thousand miles begins with one step." Happening on one small article in a local newspaper about a woman fighting for her right to not be poisoned in her own home was an important serendipitous step for me. The beginning steps for our

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community have been taken, the old-timers will fade away, but our community is in the capable hands of today's upcoming leaders. Though the next steps may continue to be challenging, as Paul Loeb wrote: "The only failure is quitting."

I'd like to end with one example of the community working together---the Celebration Tree Project in 1999. I live near a national forest and the residents began decorating forest trees along the road for the holidays. One tree was for breast cancer awareness, adorned with pink ribbons and ornaments. I asked the lists where I was subscribed if they would like to help decorate a CI awareness tree and the response was exciting and heart warming. I received ornaments from around the world. After much searching, I found a perfect family of 5 little trees huddled together and the time was set for me to decorate them during the rising of the Full Moon. When I got home we all engaged in an unforgettable internet party that night. A Gulf War Illness vet said it was "Moonificent."

Here is a link to the [Celebration Tree Project](#) story and a picture of the 5 little trees adorned with international decorations. I see those trees every time I drive down "Maggie's Mountain." They are much taller today and their branches are still lovingly intertwined. Their growth and connectedness is a symbol of how our community has worked together and will continue to do so far into the future.

Maggie MacRaven--Wishing our community Happy Holidays and a brighter future.
Maith a dhéanamh de ghealltanais (Irish for "to honour a commitment")
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