

Member Spotlight:

Kathy Houghton



Kathy Houghton is a member of MCS America and also runs the Alaska MCS Association.

How did you learn that you had MCS?

As of today, I am 51 years old and I have been ill for over 15 years. I was first diagnosed by a well known CFS doctor in south Florida. He was the original doctor who also told me about being Chemically Sensitive. I remember his exact words: "Well Kathy, I have good news and I have bad news for you... the good news is... you're probably not going to die from this but that is

also the bad news because there will be times you will wish you would!"

Clearly, that was over 15 years ago and although my doctor was ahead of his time and able to diagnose these thought to be "rare" illnesses, I do not feel he was accurate in the part about not dying from it because I see that many people do, though often under different diagnoses.

What were your symptoms & when did they start?

At the age of 36 which was over fifteen years ago. I lived in south Florida at the time and I was a Pediatric Special Care nurse doing home health for infants and children on life support. My initial and sudden onset of symp-

toms were VERY neurological as well as gastro-intestinal. I called in sick one day because I could not get out of bed and a fellow nurse came to see me and got me to the hospital immediately. Clearly something was very wrong as I could not even follow sentences, recognize familiar things and people or figure out how to spell or do simple arithmetic! Imagine that from someone who used medical equipment and gauges to keep kids alive! I had severe diarrhea and I was very dehydrated. I was placed on an AIDS - Hospice unit until test results came back. Two weeks and after losing 20 pounds, 20 doctors gave me 20 different diagnoses. It wasn't until several months later and on my own that I found my doctor who eventually diagnosed me accurately.

Were you able to get good medical treatment?

I feel I was VERY fortunate to be able to get the best available treatment anywhere in the country at that time. I had great insurance and resources because I was a nurse and I was very connected in the medical community. In those early years I was more "physically portable" so I was able to go to the University of Miami, to New Jersey UMDNJ and see some great doctors. Now, although I had wide access to doctors treating CFS and MCS, I will admit that clearly in the early years of illness, most treatments

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failed as we have now learned so much more about these illnesses. Not to mention, back then we did not have the Internet readily available if at all, and even if we did, I would have been too sick to use a computer. I am no less sick now, but the symptoms that I deal with on a day to day basis are much different than in the early days. I have also developed other illnesses since my initial diagnosis.

What have you done to accommodate MCS in your life?

Most of the accommodations I have made are eliminations in my day to day living. I am also homebound now.

Has this created a major change in your lifestyle?

I think major change would be minimizing the necessary change in lifestyle one with MCS has to make to survive. I have not been able to work for over fifteen years and this in itself is devastating, not only because of financial loss, but also because I loved what I did and it all ended in one day.

How do your family & friends react to your MCS?

Ahhhh... I love this question! Being that I am originally from New Jersey as well as south Florida I do have what some might call an "East Coast At-

titude"! I tell it like it is, I am either black or white, but seldom or never gray and I am living my life the best that I can JUST to make it to tomorrow. I have 2 grown children (in their 30's) both of whom I have missed ALL of their life events over the past fifteen years. Graduations, birthdays, my only daughter's wedding, the birth of my grandson whom I have only seen once, funerals, you name it... I was not there. I think that although they "get it," it is difficult for my family as well as friends, BUT I also think that nobody can quite understand how physically and emotionally painful this cruel illness is. I have anaphylaxis so I must further isolate myself, thus I do not go to other peoples' homes nor can I have any visitors come to my home. Do I care what others think or how they react? Not really... they don't wake up in my shoes!

What words of wisdom do you have for others?

If you DO NOT have MCS: If you think this can't happen to you.... well, you are one chemical away from becoming just like me, you just don't know which one. Read and heed every accurate piece of information you can get your hands on about MCS.

If you DO have MCS: Be involved in MCS advocacy as much as you possibly can when you can!

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Interviewed by Wanda Finney

