# Interview with Kathy Pilolla

## Session 1 (5/28/2020)

## Timed Log

[00:00:00] Background: Born in San Diego, California and moved to Kansas City, Missouri at six months old following dad's job with Trans World Airlines. Lived in Chicago until 1989 and then moved to Oregon, where she has been since 1991. Loved the Midwest growing up—the arts and culture, schools; hot and humid summers and cold and windy winters.

[00:01:44] Mother was a registered nurse, also suffered from chemical sensitivities. The difficulties her mother faced due to the lack of awareness surrounding chemical sensitivities meant she had to quit her job in her forties. At the time, no one knew about chemical sensitivities. Family faced a lot of challenges, especially when Pilolla and her sisters were young, because their mother was always in the hospital, not everyone understood the condition. Looking back, she wished she knew more about the disease so she could help her mother.

[00:04:22] Relationship with family. Growing close with her sisters – all of whom have developed some sort of health issues. Close relationship with their grandparents who often took care of them. Developing empathy for others dealing with related diseases and what people have to do to get proper care.

[00:05:40] The lack of knowledge many family members, including herself and her father, had regarding chemical sensitivities. Difficult for them to really understand, doubted mother's conditions. Received no support from the health field either, especially from doctors; limited medical knowledge.

[00:07:15] Consistently had sinus infections and colds twice a year. Otherwise, relative absence of any symptoms relating to chemical sensitivities during childhood, except for irritation from cigarette smoke and gas fumes. Did not really develop any symptoms that could be associated with MCS until fifty-one.

[00:08:13] Remembering the scent of mold and mildew from the Midwest, associates moldy smell with her Midwestern childhood. Loves the west coast and Oregon, despite the increasing chemical sensitivities over the years making it harder to travel; misses visiting the Midwest.

[00:09:57] Throughout childhood until her move to the west coast, she suffered from bi-annual sinus infections, unaware of its origin or causes. Otherwise, no other significant health issue that could be associated with Multiple Chemical Sensitivity (MCS). Attended the University of Missouri, Kansas City.

[00:11:03] Enjoyed school as a child; she and her sisters were very active and involved with other extracurricular activities. Father would take her and her siblings to senior homes to perform and other fun activities; also played the flute and French horn. No matter how sick her mother was, her parents made sure they could participate in extracurriculars.

[00:12:57] Attended the University of Missouri-Kansas City, graduated with a bachelor's in liberal arts with a focus in journalism. Took a semester off to attend University of Missouri, Columbia but not a good match.

[00:14:13] Following graduation, moved to Chicago where her now-husband lived, worked for an advertising agency and then a nonprofit organization helping researchers and scientists write and publish their literature for three years. Also worked throughout college as well. Always enjoyed writing.

[00:15:31] Worked for an aviation company selling flight lessons and jet fuel during college. Co-worker also had chemical sensitivities; gained more understanding of chemical sensitivities from both her manager as well as her own mother.

[00:17:14] Very social in college. Active during college and post-college years in a fraternity, church group; always on-the-go despite the bi-annual sinus infections. Worked into the late hours and woke up early – typical young adult years.

[00:18:10] Diagnoses. Dislike for cigarettes and gas fumes during her time working in aviation but did not realize it was related to chemical sensitivity. Was not until diagnoses of Ehlers-Danlos, Postural Orthostatic Tachycardia Syndrome (POTS), and Mast Cell Activation Syndrome (MCAS) did she make the connection between chemical sensitivity and mast cells. Initially, did not recognize the impact of MCAS; focused on the Ehlers-Danlos and POTS. Doctor told her that most of the symptoms she was experiencing was due to the mast cells. Symptoms have only increased since her diagnosis, is now at the point of being medicated twenty-four hours a day.

[00:21:02] Since 2015, kept on going to the doctors to talk about her struggles but was only prescribed different medications. Not until she developed a rash did she decide to go to a naturopath and got diagnosed with Lyme disease. Lyme treatment did not address all of her symptoms, geneticist performed more tests and the Mast Cell Test; connected mast cell to most of the symptoms she's experienced. Symptoms are worse now than they were back then – tiredness, passing out, body stiffness.

[00:25:16] Having a type A personality. Had to eventually stop working prior to the Lyme diagnosis as she could not even complete basic tasks. Over the years, have tried to work here and there but for now is unable to continue. Has had to come to accept her limitations but this can be difficult. For her and her husband, it's been a struggle, but learning to be flexible and come to terms with her illness. Maintaining a positive attitude towards her life now, viewing it as a gift.

[00:28:24] Benefitted her to have grown up with a mother who had sensitivities so she would know what to expect. Pilolla's husband never had that exposure, struggles to watch her slowly become a different person, but has also been supportive and stepped up.

[00:29:15] Sisters are very interested in the disease because they are experiencing similar symptoms and are very supportive of her. Doctors she encounters are also very curious about her condition; it's been a learning experience for people unfamiliar with MCS. Her friends have been very supportive of her condition, trying to understand and be more aware and conscious.

[00:31:56] Diagnosis of Lyme in Oregon; however, she suspects that she got it in the Midwest but never tested positive for it. She stopped working because she had to have back surgery and could never fully recover from that.

[00:32:54] Asked for accommodations at her last position and they were very supportive. In her other positions, she did have some irritation with cigarette smoke from co-workers but never asked for anything because she thought it was due to her own dislike. Now, she knows that it was due to the mast cell activation.

[00:34:25] Her advocacy with doctors and other health professionals; how she has helped educate them on her own illnesses and symptoms, connection with chemical sensitivity. Her doctor who performed kidney surgery had to check her mast cell activation in order to prevent reactions; doctor was interested in learning more about MAST because he suspected his sister-in-law had a similar condition. Importance of getting doctors to recognize her standpoint. Otherwise, cannot do other forms of advocacy simply because of her current situation.

[00:37:41] Skepticism she has faced from some traditional MD doctors who either referred her to a psychiatrist instead or fired her, refused to see her. Resorting to naturopaths who are not governed by insurance companies and who are willing to dig into this situation more. Challenging to find the "right person" that can help you.

[00:39:55] Dealing with a Chiari malformation and cranial cervical instability, on top of her illnesses. If her cranial cervical instability is corrected, could relieve some of her symptoms. Otherwise, she is relatively housebound, except to go for intravenous (IV) infusions and an upcoming surgery in Maryland that can hopefully relieve some of her mast cell issues. Her day-to-day life is focused on self-care.

[00:42:53] Prior to 2016, her husband used to work in aviation and hydraulic fuels. Could not tolerate the smell but again, did not know why it was such an issue. Now, he is working from home to support her and her illness. Being cautious about cleaning products or other scents, learning to administer shots and how to use epi-pens.

[00:45:09] Has sought mental health counseling a few years ago because it was suggested to her. Otherwise, she is a positive person so the changes have been easy to accept but believes counseling is helpful.

[00:46:11] No drastic changes from her life before and during COVID-19. Except to go for IV saline infusions to help with her symptoms, she and her husband already social distance as she does not have the stamina to go anywhere. COVID-19 has not really changed her life greatly.

[00:48:59] Always takes her husband to doctor's visits; helpful having her husband support and advocate for her story. As a woman, worries she could be seen as being hysterical or overreacting, lending to the stigma regarding women and chemical sensitivities. Has developed a strong relationship with her doctors so her gender was no longer an issue. Nervous about her upcoming trip to Maryland because of having to advocate for herself, especially during time of COVID.

[00:52:04] Marketing of scented products as a potential way to change society’s contemporary relationship with chemicals and fragrances, although she is not entirely sure.

[00:54:10] Benefit of online communities in helping to deal with these illnesses and understanding the diseases, having access to resources and even getting introduced to projects such as that at CSW. An invaluable resource for people dealing with these obscure diseases; thinking about her mother and how her experience could have been different with social media. Concern about talks regarding censoring or taking down social media.

[00:57:10] Concluding remarks.

[00:57:22] (End of May 28, 2020 interview)