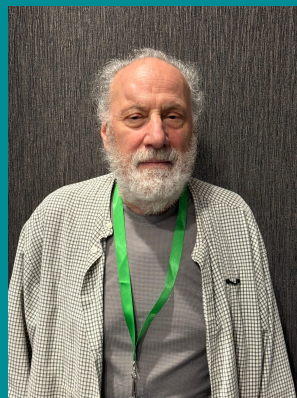


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August spotlight patient:

Saul Wiener
Cincinnati, Ohio



Saul Wiener

I founded and ran an urban farming non-profit in West Philadelphia (Urban Tree Connection), working with kids from the projects, squatting on vacant land, growing vegetables and starting farmers markets. I started the Urban Tree Connection in my early forties and made it thrive for 30 year. My own Board asked me to retire because they felt I was too old to continue, so not having a pension with limited funds we decided to retire to Mexico.

We had a lovely old Hacienda in San Juan Tlayacapan, Lake Chapala south of Guadalajara. I started to settle in, jogging, gardening, helping the local soup kitchen write grants and secure funding to feed the poorer villagers. One day I noticed that I had slight double vision which a visiting physician said was the stress I felt in managing my husband, an amputee who was living on morphine to manage his pain. I dismissed this and carried on. One day while I

was jogging I felt my legs get heavy and before I knew it I was collapsed, lying on the ground immobile in the middle of a busy intersection with cars swishing by.

Dr. Sam, the local doctor, who was managing Robert gave me one of those shots that if your symptoms disappear immediately indicates you have Myasthenia Gravis. My symptoms did disappear and I started to look for a neurologist. It was a dizzying several months, but I finally ended up in the neuro-opthamologist office. She said, after a chest scan, a brain MRI to eliminate a brain tumor and thymus stuff that MG was probable and send me to a neurologist who put me on Mestinon and 5mg prednisone after a blood test in Mexico City diagnosed generalized MG. The clinic in the village did not have specialists, so I had to rely on bimonthly visits and my MG deteriorated with thimble swallowing, eating, breathing and total fatigue.

After several years of trying to regulate my MG, we decided to look for state-side doctors in Texas and scale down our living situation, but with one thing

and another our Hacienda sold in 14 days and without a place to live, we decided to return to Philadelphia. We were priced out of the housing market. What used to be hundreds of thousands was now millions. So Robert researched affordable cities with excellent neurology access and Cincinnati emerged with a condo priced at the selling price of our Hacienda. In a month, we were here. I am not sure how we managed it, but we did.

Finding physicians initially was very difficult, but I did find Rebecca Molitoris, who was running her zoom calls from Cleveland and for two years she kept me sane and focused along with many others who were experiencing the challenge of stabilizing their MG. I was lucky, after being told it would take 8 months to see a UC neurologist that through a cancellation I got an appointment

with Dr Kushlaf, with whom I have been working for close to 4 years. We went from low dose Mestinon to higher doses with prednisone. But my double vision was staggering and my leg fatigue required a two hour naps in the middle of every day. Some of this, of course is the aging body of an 83 year old man. Dr. Kushlaf said that I did not qualify for any infusion drug based on my ADL score, but that we could move to cellcept. It took a year to activate, which means my MG was not regulated for an entire year. During that year, I contracted a bad flu and Covid and was hospitalized a couple of times. It took six months before I returned to the living, and now I am more stable than I have ever been.

So, my journey of about 10 years has been at times exhausting, debilitating and exhilarating. This year Robert and I will celebrate a marriage of 40 years and our blended family of 5 children and 17 grandchildren is a legacy that we can look to and enjoy, hoping the world around us behaves.