

Navigating the Path to Healing

When I joined Arlington Free Clinic as a Nurse Manager last spring in the middle of a global pandemic, I expected that through telehealth software platforms and layers of PPE, my days would be filled with helping patients navigate this frightening new virus. But then I met “Juan,” a patient who was already in the midst of a decade-long journey to find answers about a completely *different* unfamiliar and scary disease.

Juan moved to Arlington from Guatemala 10 years ago. A modest and warm 31-year-old, Juan enjoys spending time with family, playing fútbol, and - in his words - “going on adventures.” He worked in the countryside harvesting vegetables in his home country, and now works as a house painter.

Juan came to AFC through Virginia Hospital Center (VHC) after being seen in their emergency department for the kind of headache that would drive someone to go to the hospital. He was found to have a brain lesion and underwent two craniotomies, and then he developed a seizure disorder. Over the years, he’s been evaluated by just about every specialist at the Clinic, but no one had been able to firmly diagnose his condition.

Our Medical Director, Dr. Joan Ritter, has followed Juan’s case very closely. When a follow-up MRI showed a new lesion last year, we reached out to Dr. Anne Pariser, a longtime volunteer who connected us to colleagues at the National Institutes of Health (NIH). We helped Juan apply to two different research studies at NIH which involved weeks of complex applications and consents; obtaining all of his stored pathology samples from VHC and FedExing multiple packages off to NIH; compiling hundreds of pages of medical records;

and engaging in scores of logistical discussions with the two separate NIH programs.

Of all the patients referred, Juan was one of the very limited number accepted into the Undiagnosed Diseases Program which focuses on the most puzzling medical cases referred to NIH. From there, he began the lengthy admission process involving a litany of tests performed over a week of inpatient care. Finally, he received a diagnosis and treatment plan. While Juan expresses relief at having found his way to NIH, his journey has and continues to be challenging. He describes having brain surgery and developing a seizure disorder as the most difficult parts of his experience. He recalls falling down and not waking up until he was in the hospital, and he continues to worry that he may fall again and not wake up next time. His journey to recovery is not over, and we will continue to stand by him as he navigates it.

While Juan continues to receive cutting edge treatment at NIH, he’s been able to access counseling services through AFC and free hearing aids (he experienced hearing loss after his brain surgeries) through a connection with a program in Rockville, MD. It has been an honor to support Juan over the last year and a half. While I too am relieved that he has landed at NIH, I am also mindful that his journey is not over. It’s comforting to know that Juan is receiving such multifaceted care and support through AFC as he continues navigating his path to healing.



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