



Orsini
Specialty Pharmacy

Dennis, Living with hATTR Amyloidosis

**This is a story about faith, perseverance and finding
new friends at Orsini.**

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About Hereditary ATTR (hATTR) amyloidosis

Hereditary ATTR (hATTR) amyloidosis is a rare, debilitating genetic condition that affects some 50,000 people worldwide. It is characterized by the buildup of abnormal deposits of protein fibers called amyloid in the body's organs and tissues, interfering with their normal functioning. These protein deposits most frequently occur in the peripheral nervous system, which can result in a loss of sensation, pain, or immobility in the arms, legs, hands and feet. Amyloid deposits can also affect the functioning of the heart, kidneys, eyes and gastrointestinal tract.

Dennis' Patient Story:



Dennis was 60 when he found out the rumblings in his chest and fatigue were being caused by atrial fibrillation (AFIB). An EKG in the emergency room (ED) showed the culprit and Dennis was referred to a cardiologist for the first time in his life. In addition to having AFIB, Dennis was diagnosed with cardiovascular disease and this came as a complete surprise. He was a strong walker and never smoked. He had no history of high cholesterol or heart issues, no family history, exercised daily, and had yearly physicals with his primary care physician. Dennis sought a second opinion and this diagnosis was once more confirmed by a new cardiologist. He was prescribed the routine protocol of low dose aspirin and atorvastatin and was told that AFIB was very common and people just learned to live with it. A stress test was also done but Dennis had to stop before the test was

completed because he had difficulty breathing and became lightheaded. *"I knew something was terribly wrong when I was told the results were normal,"* said Dennis.

A few weeks later Dennis was at the ED again when his lower extremities began to swell. *"I was in AFIB and spent the night in the hospital where I lost 35 lbs. of fluid with the help of IV Lasik,"* recalled Dennis. *"The hospitalist that evening recommended I get a catherization ASAP. When my cardiologist came into my room that morning and I told him about the recommendation he firmly said, 'you do not need a catherization.' I went ahead with the cardioversion and that was the last time I saw him. My wife and I decided I needed another cardiologist."*

Dennis was referred to a new physician who scheduled a cardiac catherization immediately. He determined that Dennis' issues were being caused by a leaky valve in his heart. Dennis underwent open heart surgery and had a pacemaker installed when his heart would not go back in rhythm. The surgery to repair the valve was a success but Dennis' health continued to deteriorate. *"Tragically, my cardiologist suddenly passed away and I was left in limbo,"* remembered Dennis. *"I had an upgraded pacemaker put in and I went to two more cardiologists. Neither offered any new answers and one told me the reason I was retaining so much fluid in my legs was because I was drinking too much water. He scolded me to work harder and to exercise more frequently. At the time I had difficulty just getting out of bed by myself."*

Dennis reached out to his cardiac electrophysiologist and asked for a personal referral to a new cardiologist. This was his sixth cardiologist in the past two years and this doctor changed his life. He took the time and listened to Dennis' story, took detailed notes and did a timeline of the

progression of his symptoms. After a lengthy consultation he suspected that it was the rare disease hATTR amyloidosis that was the root of Dennis' heart issues. He referred Dennis to a cardiologist at Yale New Haven Health's Heart Failure Program. Dennis was diagnosed with hATTR amyloidosis after going through a series of tests. Dennis, and his wife, Darlene, were relieved to finally have an answer but devastated to find out this disease had no known cure. *"Somebody was watching over me because this cardiologist at Yale was the Director of their Comprehensive Heart Failure Program and also specialized in amyloid cardiomyopathy. His entire team at Yale made it their mission to keep me alive,"* said Dennis.

It was determined that Dennis would need a heart transplant and was approved by Yale New Haven Hospital as a candidate. Unfortunately, at that time the diagnosis of hATTR amyloidosis was extremely rare and was not yet recognized as a priority disease by the United Network for Organ Sharing (UNOS). Dennis was in stable condition and would need to be critical in order to be able to receive the new organ. His next turn of fortune occurred in November 2018 when UNOS changed its guidelines and upgraded hATTR amyloidosis to a higher status for potential heart transplants. *"We were ecstatic,"* says Dennis. *"My goal now was to stay at home and not be hospitalized while waiting for the heart. I knew I would be in much better spirits and able to stay positive if I could remain at home with my support system. My cardiologist and his extraordinary physician assistant made that happen. They were my guardian angels. They kept me stable and checked in with me daily to monitor my vitals and adjust my medications. I was able to stay home until I received the call from UNOS."* Dennis was considered an ideal candidate for a heart transplant because he had no other health issues. He had normal blood pressure, no history of cholesterol or diabetes and the disease had not attacked any other organs. He was also lean and had exercised all his life. His body was strong. Up until his heart issues he was only taking supplemental vitamins and no prescription medications.

After transplant Dennis was out of bed in 72 hours and went home in 13 days. *"I had a successful outcome due to a wonderful surgeon, an outstanding transplant team, dedicated Cardiac Intensive Care Unit (CICU) nurses and a medical staff that was always supportive."* His lifelines: A spouse who is a true partner and determined to focus on solutions and a devoted collie, Dani, trained as a therapy dog who watched over him like she would her own puppy.



Today, Dennis describes his life as “blessed.” As he sees it, his mission moving forward is threefold. First, is alerting others to the signs and symptoms of hATTR amyloidosis, a debilitating condition affecting some 50,000 people worldwide that is frequently misdiagnosed by cardiologists due to lack of awareness and understanding of this disease. *“By telling my story, maybe patients and their physicians will recognize that the signs and symptoms of congestive heart failure (CHF) may be indicators of a bigger issue,”* said Dennis. *“As my cardiologist at Yale Medicine has said to me many times, do not just treat the symptoms, find the cause. My hero is Matt Millen, former NFL pro football player, who had the courage to share his own struggles with getting his amyloidosis diagnosed. He brought this disease into the spotlight with a sports special titled All Heart. Matt received his heart transplant six months before mine and his positive attitude and determination encouraged me to keep fighting and believing that I would receive my heart soon.”*

Dennis’ second goal is to raise awareness of the compassionate, patient-first culture of Orsini Specialty Pharmacy. After transplant, a drug administered by infusion was FDA-approved and recommended by his cardiologist, neurologist and transplant team at Yale New Haven Hospital (YNHH). He started treatments onsite at YNHH but by March had shifted to infusions at home. *“COVID-19 was spreading and my cardiologist wanted to keep me safe.”* Six months later the specialty pharmacy provider he was working with put new protocols in place. Dennis was informed he may be held responsible for the entire cost of his home infusions, which was not affordable for him.

Dennis stayed calm and focused with the help of Darlene, his pharmaceutical company case manager and Yale’s Transplant Team. Together they worked on a solution and in Dennis’ words, *“Orsini came to the rescue. The pharmacist at Orsini called me at home the same day she received the request for assistance from my case manager. She shipped the medication to me that week and their team arranged to let me keep the same home nursing service. Orsini’s focus*

was always about making sure the medication was available to me, not how they will get reimbursed for it. They treated me like a human being and not just a case number.” Dennis has since recommended Orsini to his cardiologist and transplant team at YNHH. *“Patients deserve a positive therapy experience and that starts with finding the right specialty pharmacy,”* said Dennis.

Goal number three is to encourage people to sign up to become organ donors. Dennis hopes his story inspires others to donate an organ and change the life of someone who desperately needs a transplant. *“I am blessed and very grateful. Receiving an organ is thrilling and a gift from God but there is a feeling of guilt knowing that another person’s heart is living in my body,”* he reveals. *“Someone had to pass away for me to live. I don’t go through a day without saying a prayer for my donor and his family thanking them for their kindness and courage.”*

His infusions are helping Dennis feel less fatigued and a leveling off of the neuropathy and stomach issues caused by hATTR amyloidosis. *“After transplant, when I was recovering at Yale, I focused on getting better and living a normal life again. I dreamed of the little things like working in the yard, enjoying the taste of food and being able to take a walk with Darlene and Dani. My dreams have come true.”*

How Can Orsini Specialty Pharmacy Support hATTR Amyloidosis Patients?

The team at Orsini Specialty Pharmacy is here to listen, provide counseling on treatment, help with side-effect management, and assist with sourcing third-party financial assistance. As part of the patient's treatment, Orsini provides the following:

DEDICATED hATTR AMYLOIDOSIS CARE TEAM: Patients will have access to a primary pharmacy contact, clinical education, and scheduled refill calls. In addition, we provide patients and prescribers with 24/7 access to a clinician.

IN-HOME PATIENT AND FAMILY-CENTRIC CARE: Orsini Specialty Pharmacy utilizes a nationwide nursing network, enabling patients and their families to receive care at home. With the ability to individually match our nurses with the skill and care level required by each patient, we create a unique, high-touch opportunity to optimize their care plans and clinical outcomes.

SHIPPING & COORDINATION OF CARE: Patients receive free priority overnight delivery of medications and necessary medical supplies. Orsini manages care coordination between prescribers, sites of care, nurses, and patients.

FINANCIAL ASSISTANCE: Orsini identifies and assists patients looking to enroll in manufacturer co-pay and foundation support programs.

If you are a prescriber, visit our website to access hATTR amyloidosis enrollment forms. In addition, you can always connect with your Orsini rep to schedule a call and answer any questions. If you are a patient, you can also visit our website to start your patient enrollment form.