Like many families with HHT, Allan & Gwen Olitsky learned to manage his chronic nosebleeds. They worried about their children's nosebleeds. It wasn't until Allan got older and his epistaxis became uncontrollable did they seek out an answer. This is their story...

Our Story

Couple Seeking Answers Finds Hope

By Allan & Gwen Olitsky
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Allan: I've had nosebleeds since I was a little kid. I remember seeing my father and grandfather having really bad nosebleeds. Mine didn't get bad until I was in my twenties. When I got my driver's license, I used to take my grandfather 'for a fill-up,' which is how we referred to his blood transfusions. The last time I saw my grandfather, he was yellow, because he had hepatitis from the transfusions. My father also died from the disease, of an aneurism, which could have been discovered and treated today. At a young age, I learned that the disease was called "Osler-Weber-Rendu Syndrome," and I was told that there was nothing that could be done about it, other than occasional cautery, which didn't help much at all. My father and grandfather had consulted many specialists, and they offered no hope and little help.

Allan & Gwen Olitsky with their children and grandchildren

Gwen: I was only 15 when I met Allan, and he was having some nosebleeds then. I knew that it was something that 'ran in the family,' but didn't think much about it. He took care of them quickly when he was a teenager and young adult. The bleeding never held him back from anything; he was a competitive swimmer and loved to go hunting and fishing. I remember seeing his father have some really bad nosebleeds, but thought that his 'condition' was just worse than Allan's. Shortly after we got married, his grandfather died and I was told that it was from getting a bad blood transfusion. I later found out that Allan's aunt was also affected with really bad nosebleeds, but I never saw that happen; I think she was pretty secretive about them. Other than family members, I didn't know anyone else with the disease, and it was pretty much 'a fact of life' for us to deal with Allan's and the kids' occasional nosebleeds. It was my responsibility to be sure to always have lots of cotton and tissue in my purse and I got to be pretty good at treating bloodstains in the laundry.

Allan: Two of our three children had nosebleeds from the time they were little. By the time our daughter was planning her wedding, I knew that she had to be tested to be sure that if she got pregnant, she would not have HHT-associated problems, and was relieved when she tested 'okay.' We still didn't know anything about a genetic defect, just that Osler-Weber-Rendu could be passed from parent to child. When she got pregnant with twins, her nosebleeds became worse, and she had to go on bed-rest due to very low hemoglobin, both before and after delivery. My wife closed her private therapy practice and went to live with our daughter to help for 7 months. I would travel every weekend to be with them and help out during that time.

Gwen: We knew our daughter had low hemoglobin from the disease, but still didn't know much about HHT and the implications other than nosebleeds and low hemoglobin. Her hemoglobin stayed around 7 throughout her pregnancy, and the doctors wanted it to go up to at least 9 by delivery, which didn't happen. Now we understand that her problem was bad nosebleeds during the pregnancy when she just didn't have good iron stores that would allow her to increase her hemoglobin. Blood loss during the delivery made things worse, and she was so weak that she couldn't get up from bed without feeling dizzy. She had suffered two miscarriages before having her twins, and I now wonder if it was what my mother used to call "nature taking care of things." When I read about HHT infants with strokes and other major complications, I can't help but wonder if perhaps her two miscarried babies were positive for HHT. Thankfully, her twin boys are negative – we even asked the HHT Center to test them twice when we learned about testing! Two of our three children and three of our seven grandchildren have HHT.

Allan: As I got older, my nosebleeds got worse. As a dentist, I often had to stop treating a patient and go into my private office to try to stop a nosebleed, or to just wait until it subsided. I lived with extra clothing in the office, at home, in my car to deal with the messes. I never went anywhere without cotton or tissue and various medications to try to stop the bleeding. By now I had seen many specialists and had multiple procedures, including cautery, laser, and embolization. My kids' nosebleeds got worse, too and I had to live with the guilt I felt about 'giving' them the problem.

Gwen: I tried not to make any fuss over the nosebleeds, but would ask "why not find another doctor? Maybe someone else can help" and usually got the answer, "There is nothing that can be done." By the time we had seven grandchildren, I realized that the bleeding was getting worse and it often interfered with vacation planning, dinners out with friends, watching TV, and Allan's work. In retrospect, I know that we both just figured, "this is the way it is," and never even dreamed the problem would get better let alone go away.

Olitsky Family Reunion 2010

Allan: We learned that the disease is now known as HHT, and found the HHT Foundation and got a lot of information and connected with specialists who got us involved with testing, diagnosis and new treatments. My nosebleeds kept getting worse; I always wore dark red shirts, carried tissues and a change of clothing, and often had to leave places to try to stop a nosebleed or to go home. I retired from private practice and today I am an administrator at the University of Pennsylvania's School for Dental Medicine. It was a relief to not have to interrupt patient treatment to stop a nosebleed, but the bleeding was getting worse as I got older. A few years ago, I had hemoglobin so low that I could not walk from the parking garage to my office without resting. I would come home and just go to sleep on the sofa. I was too weak to do any of the activities I had enjoyed for so long, including hunting with my son and grandsons. I was so depressed that I couldn't see any kind of quality of life for my future, and considered quitting my job and going out on disability. My fear was that I would become transfusion-dependent and unable to leave home.

Gwen: Allan would come home and fall asleep on the sofa every night. He was weak and tired. I was worried, and felt frustrated and helpless to do anything. Allan was beginning to get projectile nosebleeds, with the blood spurting across the room sometimes. He'd go upstairs to 'just bleed in the shower.' I got really good at cleaning blood out of our carpets and furniture, as well as off the walls and hardwood floors. You name the cleaning agent; I had it in my kitchen. When Allan would tell me he wished he would just bleed to death so it would be over, I had to remind myself to not panic and to tell him that I didn't want to live without him, that we had to have hope. The words felt hollow.

Allan: The bleeding was becoming uncontrollable. After one horrible night of bleeding all night on a Friday, I called the specialist who had been treating me, waiting until 9 a.m. on Saturday morning, and he told me to come right into the emergency room. The hospital is about an hour from home, and it was a rare occasion for me to ask Gwen to drive. I actually put a bucket between my legs on the seat to catch the blood. The nurse who came into the room was wonderful; she said she had never heard of HHT and went to her computer to read all about it. In the midst of an emergency, another healthcare professional made aware of HHT! My treating physician wasn't so kind: he said, "You HHT people are all the same, coming in with emergencies." If I could have walked out, I would have done it immediately. His resident was very interested in my HHT history, and suggested trying a new treatment that they were using over at the Children's Hospital. It stopped the bleeding enough for me to go home, but I vowed to never go back to the specialist who found HHT to be so annoyingly inconvenient.

Gwen: After Allan's visit to the ER, we made an appointment with the HHT Center's hematologist, who did some tests and then took a lot of time to talk to us. He explained "how it works" to me (admitting that I have a very non-scientific mind), in easy-to-understand terms. I learned that Allan was making red blood cells, but didn't have enough iron stores to get and keep his hemoglobin up. We went for a new treatment – a series of iron infusions. Now we were going to the office of a local oncologist/hematologist, and most of the patients there were on chemotherapy. The staff was wonderful, and Allan loved to joke with them while he sat through his infusions. It was during this course of treatment that Allan left for work one morning, turned around and came back into the house and interrupted an important teleconference I was chairing. "I thought you'd be mad if I didn't tell you, I have to go to the hospital for blood transfusions." I told myself not to panic, to gracefully exit the meeting, and pack a bag for him to take to the hospital. This was the beginning of a new phase for us. This was probably the first time I realized that he was really, really sick. They kept him in the hospital for a few days and I remember talking to my son, Scott, crying, and I said the scariest words to him, "My husband might be dying."

Allan: I went to work one morning and a colleague said, "You look horrible. You are pale gray. You need to get over to the hospital." Call it denial, but I walked the 6 blocks from my office to the hospital, stopping every half block to rest. I got a blood test and went back to work. The next day, they faxed the results to my office and to my hematologist. My hemoglobin was down to 6.4 and I needed to start blood transfusions immediately. The iron infusions couldn't get ahead of the daily projectile nosebleeds. The hardest part was telling Gwen because this meant actually giving voice to my fear of becoming transfusion dependent. While in the hospital, I had to argue with the nursing staff to get them to understand that HHT patients need a filter for IV procedures. Without a filter, the lifesaving blood could actually kill me! Luckily, my son Stephen was there and stayed all night to be sure I got the filter.

Gwen: My life had moved from 'this is the way it is' to having a feeling of impending doom, with a husband who was very sick and who made it clear that he did not want a life that included being stuck in the house and dependent on blood transfusions. I started reading everything I could find on the HHT website. It was horrible to read about infants dying, toddlers and teenagers having strokes, young adults living on disability and unable to get treatment because they didn't have insurance coverage and had run through family savings. I knew that what I saw was only the tiniest tip of the HHT iceberg: about 90% of people with HHT aren't diagnosed and those who are often only learn about the disease after some catastrophic medical emergency – or death. But the worst part was coming to terms with the reality that there was no hope for things to get better, short of a miracle.

Allan: My son Scott, an ophthalmologist in Kansas, talked to a colleague in San Diego who told him about a doctor using a new drug approved for chemotherapy patients (that they use in ophthalmology) experimentally for HHT-related nosebleeds. Scott called him, then I talked to him and within a month I flew cross-country for treatment with Avastin. I've been nosebleed free since then; I go hunting, walk and jog, stay awake too late, go out with

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