

March, 31, 2019

FROM: Rosey Sills (patient of Genetic Counselor at OHSU, Puneet Rai)
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Re: My experience with Genetic Counseling at OHSU, with Puneet Rai, M.S., C.G.C.
To Whom it May Concern:

I would love to share my experience as a patient, working with a Genetic Counselor. I receive Genetic Counseling care & services from OHSU, working with Certified Genetics Counselor, Puneet Rai. If I could sum my experience up in one word, that word is: "priceless." The value of working with a Genetic Counselor is life long and actually can potentially last even longer, for subsequent generations. Here is my story, I hope I am able to express in a coherent manner, just how important my work with Genetic Counselor, Puneet Rai, has been to me. This is an emotional situation for me, as it relates to psychological and psychosocial aspects of my life that I have been dealing with for many years.

As someone with at least one known rare "congenital" condition and several more common conditions, including autoimmune, I feel I bring a lot to the table, when I meet with a doctor. I always have to educate my doctors about my rare condition, as it they have never heard of it before. It seems, it's easier for the doctors to treat what they are familiar with- as a result, my "rare condition" has been "pushed to the side" by most every doctor I have had since I first was diagnosed in 1996, as a teenager. This is absolutely not the case with Genetic Counseling- it has been a completely different experience working with Puneet Rai, a knowledgeable, caring Genetics Counselor at OHSU. Puneet Rai has expertise and is not intimidated by the concept of a rare condition; she is enthusiastic to help me dig deep and delve into the situation and my symptoms. Genetic Counseling with Puneet Rai has been a wonderful experience for me. It has been reassuring to me, that there may actually be some answers to the mystery condition that I have been struggling to understand for over 20 years. I do understand that after investigation, there may not be any more answers. However, I will potentially have ruled out some possibilities and I have established a relationship with a Genetics Counselor. As the world of genetics rapidly changes to reveal new information, I realize the information available to me may also change.

I am very impressed with the way in which genetic counseling service allows for a personalized approach, this is a unique and important part of modern medicine. In order to create a personalized plan of action, Genetic Counseling looks uniquely at an individual and the elements (family history, symptoms, etc.) that combine to create the personalized situation that the patient is experiencing. The more opportunities that patients have to experience Genetic Counseling will allow for holistic, personalized treatment plans. The more health officials that are familiar with Genetic Counseling will allow for patients to receive this thorough, customized approach. I would like to take a moment to acknowledge the RN who was shadowing at my doctor office when I went for a new visit appointment in 2017. When they reviewed my new patient paperwork, as typical, they had never heard of my "rare condition" which had always been described to me as, a "birth defect." The RN took the time to look up my rare condition and saw that there may be a genetic link and offered a referral to OHSU Genetic Counseling.

I had never heard of Genetic Counseling and was not sure what would happen at my appointment. I was asked for a thorough family history prior to my first appointment, this allowed me to prepare by speaking with family members and providing some potential pieces to the genetic puzzle. Over the years working with Doctors on my health, I have become timid to express my long list of symptoms, this was absolutely not at all the case with the Genetics Counselor- In fact, it was the opposite, Ms. Rai wanted to know everything and

asked questions to further inquire. She takes a small piece of information I give her and digs deeper. I was pleasantly surprised to be introduced to a counselor with the specialized expertise of Ms. Rai. I was able to feel comfortable immediately with personal attention and interest in my unique situation. At the initial appointment, with the help of the Genetic Counselor, I was made to feel at ease right away and was able to understand the explanation of what they understood about my condition. The counselor also expressed interest in discovering genetic components to these other symptoms I experience. I felt listened to, with genuine concern for my situation and many symptoms. In the past, many providers have appeared to be overwhelmed at the magnitude of symptoms I experience in a wide range of body systems- they tend to stick with generic diagnoses, concentrating on the most common, least complicated symptoms. This was not the case at Genetic Counseling with Puneet Rai, she listened to all of thoughts, concerns and symptoms- whether or not I knew if they were pertinent. I have not felt before, this much curiosity and genuine concern trying to help me discover the causes of my symptoms- I really appreciate this thorough level of care. I was able to bring my Mother with me to attend the appointment, which was helpful as Ms. Rai was able to inquire for further family history.

As my myriad set of symptoms is rare and I live in a rural, sparsely populated county, it has been difficult to find health care providers who have been able to understand my challenges. The service of a genetics counselor is so helpful and immensely worthwhile, that I was able to reasonably travel to OHSU to attend my appointments. I was able to receive some travel and lodging reimbursement through my insurance, Allcare and the Readyride service they provide. While Portland has very expensive lodging, there are some discounts offered for OHSU patients, as well as a new patient housing opening this year. I also appreciate how Puneet Rai has made herself available to accommodate long distance communications with me. Even though I live far away, I feel like I can phone or email and she will be familiar with and understanding of my unique set of conditions. Ms. Rai has been immediately available through messaging with the Mychart system. I have received immediate response from her when I inquired with additional questions and concerns. Having a rare condition, I often experience anxiety with health care and tend to be hyper-vigilante about exchanging all the possible information that I can think of. Ms. Rai has extremely receptive of receiving this information in any and all forms, whether it is through a message or a link on Mychart. She is able to take the health & family history information that I give her and she translates it into an understandable explanation for me. She explains thoroughly in ways that I can understand and she considers all the information I give her, no matter how slight it seems. Puneet Rai has worked with me for an initial appointment, the process of genetic testing, additional help appealing the preliminary denial for the genetic test with Allcare insurance, subsequently receiving approval for testing, the logistics of where to test (Ms. Rai advocated for me to be able to get this testing done closer to home to save hours/days of travel time and was able to order the test to be sent to my Southern Oregon location), she has provided communication on the results of the test prior to the follow up, as well as new, additional concerns I presented to her for the follow-up appointment, the follow up appointment and plans for the future. She has provided me additional explanations to inquiries I make and explained the processes in ways I can understand.

I will always be grateful for the care and concern expressed by my Genetic Counselor, Puneet Rai. I have been struggling with problems since I was a child. There is a holistic element included in their services that is missing in many systems. This genetic counseling component, is truly the future of healthcare. Thank you for listening to my story,
Sincerely, Rosey Sills

