



PATIENT STORY

Anisha Gangotra

Finding Hope Through the Pandemic

Shift to home healthcare becomes a lifeline through long, difficult journey with Autoimmune disease



»» Her Journey ««

With calm strength and a sense of humor still intact, Anisha Gangotra speaks about life with an autoimmune disorder. In 2008, at 24 years of age and with a flourishing career, she began experiencing debilitating medical symptoms. Two years later she was diagnosed with Ulcerative Colitis, one of the two main forms of Inflammatory Bowel Disease (IBD). It took 10 years to find the right medication to achieve remission — a difficult and frustrating journey.

Creating further complications, in 2008 Anisha's sister was diagnosed with Multiple Sclerosis and another sister with MS just three years later. In that same year Anisha was involved in a high-speed car accident leading to Post-Traumatic Stress Disorder and anxiety/depression. Trying to find the right treatments while managing her mental health, physical injuries and IBD was a real challenge.

In 2019, Anisha had achieved remission so she came off her medication but in July of that same year she had a flare-up. She needed to stay on medication and ended up evaluating two clinical trials as alternatives to her previous biologic treatment, with its known side effects and also concern over its effectiveness having previously come off it. Ultimately she decided to stick with her previous regimen and scheduled infusion treatments to resume in January 2020.

And then the pandemic hit. Traveling 90 miles round-trip to a London specialist hospital, Anisha was able to get three loading doses of infusions before life went on lock-down. She is in the clinically extremely vulnerable category and her family members are all in the vulnerable category, and she had to shield throughout the pandemic. "My biggest concern was how to continue receiving treatment safely in a pandemic while managing my mental health and all of the stress," Anisha said.



"I had a huge amount of anxiety as I felt I had to make a decision between managing my symptoms and keeping my family safe."



Anisha learned an injectable formulation of her biologic was waiting for approval. Home care and treatment now seemed a possibility, but it was difficult to find out if she had access to the injectable as a viable option or if would she still need to face trips to London every eight weeks during a pandemic. Finally, she learned the injection was available on a very limited basis through the specialist hospital in London. After providing her medical history and reasons why she wanted to switch to injections, the clinical review team approved Anisha based on her medical history.



She was one of only five people approved for injections versus infusions at that time. "This option felt like a lifeline," she noted.



While the transition to home healthcare came with bumps in the road, overall Anisha says having care virtually has been very positive. She saves money and time with what now has become a half-hour phone call with a consultant versus a full-day out when going to the hospital. She is able to manage exposure during a pandemic and related stress through virtual care. Even her monitoring is now managed locally, with sample kits sent to her home that she returns by post. Given her busy remote work schedule, there have been challenges from a clinical perspective as scheduled meetings with busy medical staff may shift during the day and cause Anisha to worry that she is going to miss the call.

While Anisha remains very cautious in this pandemic, she sees positive change coming out of it. She believes the pandemic has "pushed the health and social care sector to look at how it is providing care and is making it more accessible by doing it virtually — saving patients time, money, fatigue and stress from work-related absences."



"Care on the whole has not been accessible in the past. The pandemic has created the push forward to address these things, informing change now and for the future. I think it's a very positive thing."



»»» Her Insights «««

Removing barriers, improving access

Through her journey, Anisha has gained some valuable insights into removing barriers to medical care and improving access and diversity:



- Include diverse patient perspectives from the beginning. Anisha believes “If you have the patient voice from the start, they can tell you if the protocol will work.”
- Train healthcare professionals to give patients the right information at the right time and inform them of services, patient support groups and specialist care. In Anisha’s experience, “If you are not given that choice, if you are not given that information, the choice is already taken away from you.”
- Holistic care that factors in treatment options while supporting your mental health in coping with the diagnosis, including continued dialogue with healthcare and medical professionals and trusted information from disease groups and medical websites, is essential.
- Provide information relevant to underrepresented groups (both ethnic and gender related) to bring them into clinical trials. Acknowledge historic mistrust of the medical community to build trust.

In reflecting on her journey Anisha closed by saying,



“It’s nice to vocalize my experience and be heard knowing that it actually might make a difference.”



We go through this journey and sometimes it feels like hitting your head against a brick wall. I’m just one voice out of all these people living around the world with all these conditions. As a patient and a carer and everything else, it’s really positive to share my thoughts and see progress. It feels really hopeful!”

Thank you Anisha and family for focusing on the opportunities toward progress that exist through the toughest of times and inspiring hope. You are a truly remarkable!

Parexel is committed to continuing these Discussions on Diversity.
For the latest updates please visit parexel.com/diversity-inclusion

For more information on Parexel and our Discussion on Diversity efforts please contact
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