

SPOTLIGHT

on Leigh syndrome

Special Edition 2020

QUARANTINED WITH LEIGH SYNDROME

Houston residents and co-founders of People Against Leigh Syndrome, Lori and Neil Martin, are the proud parents of Will, who has been living with Leigh syndrome for 11 years, and Quinn, 6. We reached out to Lori to see how the Martin family has fared during the pandemic.

Q: What have the past four months looked like for the Martin family?

A: Like the majority of the country, our kids left for spring break and never returned to school. While we held out hope they would go back, spring break eventually stretched into summer and here we are. During these last four months, we've spent all our time together and we've thoroughly enjoyed it. While there have been challenging times, we realize we may never again experience this much quality time with Will and Quinn, and we've worked hard to make the most of it.

Q: What are some activities you've done together during quarantine?

A: Having an immunocompromised child has forced us to hunker down and limit our exposure to anyone outside our immediate family, so we've spent a lot of time swimming (thankfully we have a pool), playing games, and trying not to go crazy. And, let's be honest, playing on devices. We also have used quarantine to explore and expand our cooking skills beyond taco night. Fresh salmon and grilled chicken has become a key staple. Additionally, the kids have discovered a love of home makeover and cooking shows, so you might find us on the couch watching HGTV or the Food Network in the evening.

Q: Do you guys have a routine and, if so, what does it look like?

A: All four of us thrive on routine. Until summer officially started, our mornings were filled with online learning, followed by a long lunch break and then as much physical activity as possible, usually swimming. In the evening, we cooked dinner and ate together. We still stick pretty close to this routine these days, minus the online learning. We also follow a regular bedtime schedule because like most Americans, Neil and I have been binge watching a variety of shows.

Q: What is something positive that has come from quarantine?

A: In addition to the together time I've already mentioned, I would say one of the most positive things to come out of this is an improvement in Will's physical health. Leigh syndrome greatly limits Will's ability to effectively move his body, which can result in weight gain and muscle atrophy. However, because we've had more free time, we have had an opportunity for more physical activity. When it was cooler, we would take a short morning walk. Now, in the heat of Houston summer, we mostly exercise in the pool by wrestling a ball or kicking with the support of pool noodles. An unexpected, but beneficial result has been Will's increase in stamina and decrease in weight! He seems to be more alert, better rested and displays increased core and leg strength.

Q: What are some challenges you've faced and how have you overcome them?

A: Quarantine has been emotionally challenging for Will and re-entering world has been extremely hard. When we are outside the house, Will's autonomic nervous system is in constant "flight" mode. However, if he gets adequate physical activity during the day, it seems to help his anxiety and overall mental state.

Boredom also has been an issue - no sport games, no friends, no school. Will is a BIG sports fan. He enjoys watching everything from badminton to football, but baseball is by far his favorite. Plus, he's not into Legos, toys, or art, and he's limited in what he can do physically.

To battle boredom, we plan little milestones we can look forward to. It can be as simple as picking up food from a favorite restaurant or Facetimeing with a family member. We also are fortunate to have grandparents with a lake house. So, we've taken quite a few "coronacations" there. I had a major "YOLO" moment on the way to the lake one day and spontaneously pulled off the freeway to stop and walk up to the Sam Houston statue in Huntsville, TX. We've passed by it a million times throughout the years but were always in "too big of a hurry" and never stopped. Coronavirus brought the world to a screeching halt, but occasionally there is an upside.

Q: What are your thoughts moving forward? What will be your new normal?

A: Call us crazy, but we actually believe that the world might just be a safer place for kids like Will. People are washing their hands and staying home when sick. Most people wear masks. In reality, any illness can put Will in the hospital - flu, common cold, GI issues and yes, Coronavirus. We have spent 10 years creating a bubble. We aggressively take the proper safety precautions to keep Will and our family safe. The new normal will actually be similar to the old normal. The amount of thought, preparation and planning is more complex now because of Coronavirus, but it's a familiar process. We just hope that people who haven't had a life with a medically complex person continue to make it safer for all to enjoy.



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