Our unexpected ride

Life was on track just as we had planned: two university jobs, with tenure for Andrew and a clear path toward a tenure-track position for Yssa (check); the purchase of our first home (check); and three beautiful daughters (check). But 3 months after our youngest daughter Marie was born, she started to have seizures. After a terrifying ambulance ride and a nerve-wracking week in a children’s hospital, Marie was diagnosed with ring chromosome 14 syndrome, an exceedingly rare and debilitating condition caused when the 14th chromosome is fused into a ring. Life for our family was about to switch tracks, and we were along for the ride but no longer in control.

Marie’s seizures had no regard for class schedules or family time. We tried to keep up with our teaching duties, but it was difficult to lecture knowing that our young daughter could have a life-threatening seizure at any moment. Neither of us wanted to give up our academic career—and we didn’t want the other to have to, either. But rigid teaching schedules proved untenable, especially when coupled with the other stresses of academic life, and we needed more flexibility.

The reality was that Andrew was tenured, with the associated job security, and Yssa had applied mathematics expertise that made her more marketable outside academia. After discussing our options, we decided that Yssa would forgo her academic appointment. She obtained a part-time research position in industry, which required fewer hours for equivalent pay and allowed her to work from home when needed. She also started a nonprofit organization for families and researchers interested in ring 14. Our lives were still complicated—including multiple therapy sessions each week plus specialized, expensive child care—but it seemed we had found a way forward.

We made this arrangement work for many years. But as our older daughters approached college age, we needed to re-evaluate our situation again. They had matured into fantastic caregivers, and their departure would have a huge impact on their sister and on us. Marie’s seizures continued unabated, she was hospitalized regularly, and new concerns were looming as she approached adolescence. Facing numerous surgeries and complex long-term care, we struggled to achieve the elusive work-life balance and needed more support than well-meaning friends could offer.

So, 5 years ago, we moved from Indiana to our native Texas, where most of our extended family resides. We developed a plan to sell the move to Andrew’s department head and dean: He’d take a 1-year sabbatical at 50% pay while spending the other half of his time working in an unrelated family business. That way we could give an in absentia appointment a try.

The administrators were understandably skeptical at first, but they agreed to a trial run. The first year of Andrew’s “sabbatical” ultimately proved successful, so he resigned from the family business and returned full-time to his faculty role—buoyed by the support of empathetic students, colleagues, and administrators. He spends about 1 week per month on campus and continues to teach, maintain a research lab, and serve on myriad committees. It’s often difficult, as Andrew sometimes struggles to arrange online access to meetings and he misses having colleagues down the hall. But so far it has been tenable.

By helping us find a better work-life balance, the arrangement has also allowed Yssa to continue her work, which is now fully focused on running national and international ring 14 nonprofits. Yssa misses many aspects of her prior professional life, most of all the students. However, she finds intellectual stimulation and reward in working with parents and physicians to push medicine forward and help families become their own advocates.

When Marie was born our smooth, straight ride unexpectedly turned into a roller coaster, with many joys but also with some poignant regrets. Ultimately, though, we are fortunate in many ways: wonderful children, a strong marriage, and rewarding work aided by a university that accommodates our whole family’s needs.

J. Andrew DeWoody is a professor at Purdue University in West Lafayette, Indiana. Yssa D. DeWoody is president and CEO of Ring14 USA and Ring14 International.
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