Ellen, Paul and Abby: heartwarming story of a challenging but rewarding pregnancy

Ellen and Paul just welcomed their first baby, Abby. Not such unusual news except this baby was the result of 10 years of dreaming, patience and persistence. Ellen and Paul both have pituitary failure. Ellen had pituitary surgery and a bilateral adrenalectomy to treat Cushing’s disease, while Paul had pituitary surgery for Cushing’s disease, as well as radiation therapy for cancer as a teen. These health issues made getting and staying pregnant more challenging. In addition to constant hormone tweaking by Dr. Friedman, they consulted a reproductive endocrinologist but multiple cycles of in vitro fertilization (IVF) failed, as did three separate adoption attempts. Almost out of hope, they made one last return to IVF and little Abby was born. Ellen shares her experience:

Educate yourself ahead of time about pregnancy with endocrine disease. The more you know, the more you can help your medical team to keep you healthy. For my pituitary failure and Addison’s disease I started with this article (Yuen et al, Adrenal insufficiency in pregnancy: challenging issues in diagnosis and management, Endocrine, Feb 2013) and used the references for even more information: https://goo.gl/p489QR

1. I had to learn to listen carefully to my body. It took some experimenting, with the help of my doctors, to find what medication doses felt best.

2. A balanced thyroid is so important for a successful pregnancy! I was surprised at how much thyroid function was affected by pregnancy hormones, even up to my third trimester.

3. I enjoyed the extra boost I got from pregnancy hormones—bonus estrogen, progesterone and growth hormone helped me to feel wonderful. Surprisingly, I slept better and had more energy.

4. Pregnancy with pituitary failure and Addison’s involves a leap of faith. There are no great lab tests to check and see how things are going with regard to hormone status (except thyroid). Doctors may or may not have a complex understanding of your unique needs. Don’t be afraid to advocate for yourself by voicing your concerns or seeking new medical team members. Of course, Dr. Friedman has significant experience in balancing hormones during pregnancy and a visit to him may be worthwhile.

5. Persistence in IVF pays off. A new study (http://goo.gl/JyJxzj) just showed than each additional round of IVF is associated with progressively higher success rates (up to nine cycles). Don’t give up! Look into insurance plans that offer your money back if you don’t have success after a set number of cycles—this may allow you to try again.

6. Research not only success rates with IVF clinics (http://www.sart.org/Find_A_Clinic/) but also clinics that are more affordable. You want high success at a reasonable cost. Consider that traveling for care may ultimately save you money.

7. If you have concerns about the risk of passing on genetic diseases, consider donated embryos, eggs and/or semen.

8. You may be able to nurse your baby even if you have some pituitary damage. Again, medication balance is critical for success. It’s hard enough for Mom and baby to learn how to work together in those first few weeks but hormone fluctuations post pregnancy can make it even tougher.

9. Be patient with your recovery after having a baby. It takes time and tinkering to get those hormones balanced again.

Pregnancy was a miraculous experience for me. Parenting can be exhausting, yes, but I wouldn’t trade it for the universe. I adore our daughter and am so happy I braved the challenges. Feel free to contact me through Dr. Friedman if I can answer any questions you might have about my personal
experience.