



TSGA RESEARCH

Changing the Future







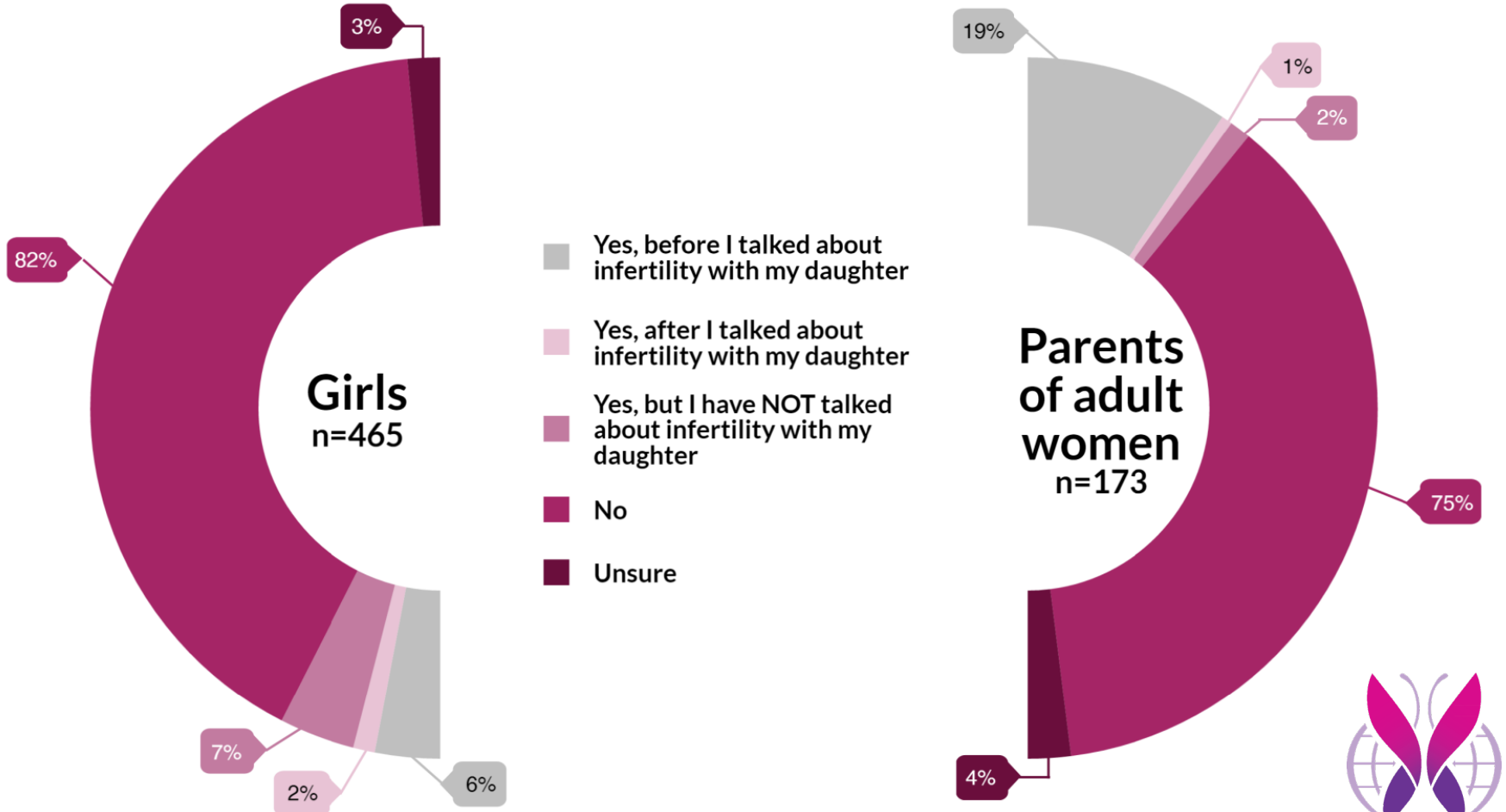
- *“I cried as I read this bc out of everything I knew when she was diagnosed this (infertility) was what hurt me the most. She has since a baby been very attracted to other babies and still today even when she was not interested in us at all , she always has a couple with her. Live babies, in tummy ,dollies, it doesn’t matter, she is obsessed with them all. She is 4 now and I had just mentioned to my hubby that we need to start introducing adoption as something normal and OK as another option,. We don’t know anyone who has adopted so it makes it harder. Most everyone I know has a couple kids and she has started to say that when she gets older she wants to have lots of babies.*

We do hope that when the time comes she is comfortable with either choice she makes and perhaps her sisters can donate an egg if that’s what they decide. For now, we watch adoption stories and explain about it...Not sure when the time will come to explain all this to her, we just pray that science will continue to evolve and provide her options that we don’t know about today. “

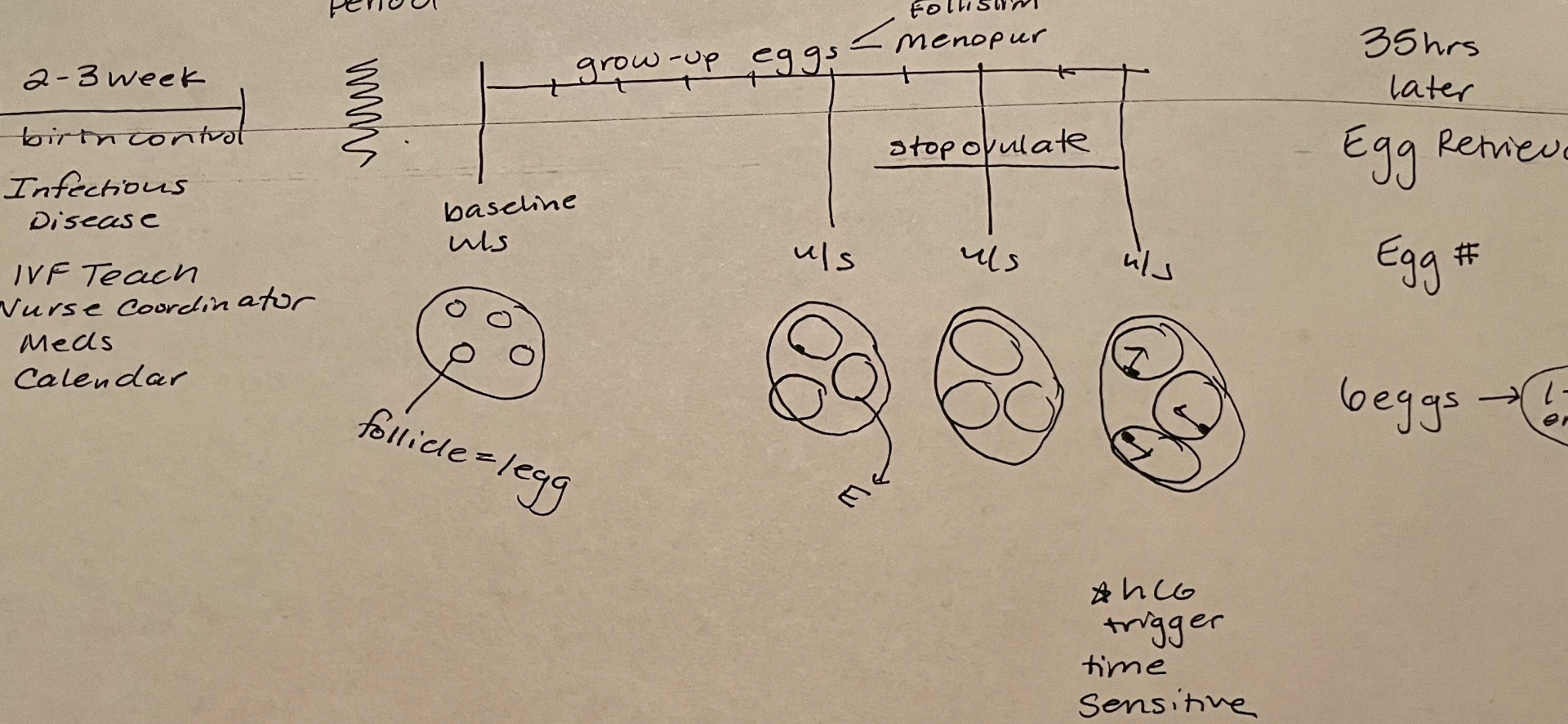


Infertility

Received Specific recommendations from health care provider about how to talk about infertility

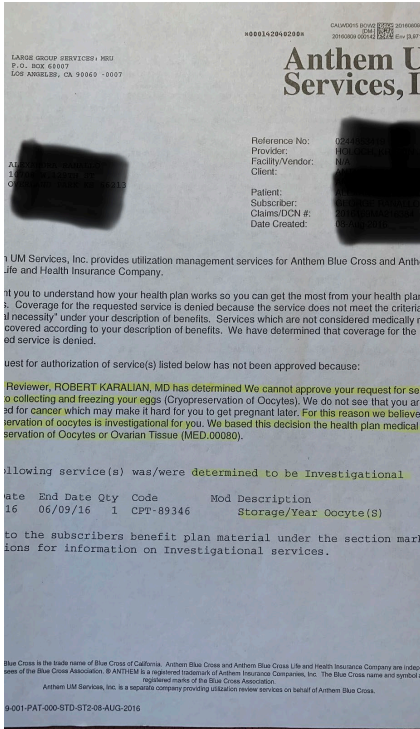






The Unexpected News





- Meghan Sucheski**

We tried a surrogate, and for that we took out a home equity loan.

2y Like Reply
- Vanessa Isabella**

I sold my car and we had savings. we also paid lots of tests, scans and medication from our monthly wages.

2y Like Reply
- [REDACTED]**

I used inheritance money to harvest my eggs. Starting saving now so that in 4 or 5 years I can try IVF

2y Like Reply 1
- [REDACTED]**

Also, my province gives a 40% rebate up to 10,000

2y Like Reply
- [REDACTED]**

I got funding through charities. A lot of work but never had to take a cent out of pocket

2y Like Reply 1

She did beautifully during her 2 week stimulation session. By the end, the sonographers were seeing at least 18 measurable follicles, and her labs supported that she was exactly where they wanted her to be to order the final trigger shot (combo of Lupron and Pregnyl - HCG.) We went in the next morning for post-trigger labs and her doc called yesterday afternoon and told us she wasn't satisfied with Alaina's labs and wanted me to add another HCG injection right away, 3x 20 minute procedure with the devastating news...she retrieved 14 good sized follicles...but they contained no eggs. She did take possible ownership of the problem, surmising that she didn't order enough of the HCG to use as part of the trigger, and that if she was willing to go through it again (we are self-pay...the whole program set us back at least \$8K plus \$15/day for parking in the city, \$5/day bridge tolls, plus gas) she would give her more than double the amount of HCG she ordered for this trigger. Her other speculation is that it may be her TS causing the EFS (Empty follicle Syndrome). I also wonder if at some point between the initial trigger, second trigger, and today's procedure, that she ovulated. Has anyone's daughters gone through this process? I can't believe my strong as a rock daughter said she'd be willing to try it again next summer. She doesn't believe it's her TS causing the problem, as her period is so

2001 & 2007 I had 2 stillbirths and 3miscarriages. In 2010 @40yo I was pregnant with my rainbow baby terrified that I would lose him too. I went to the best of the best to see if they could help keep my baby's heart beating. They did all the test and that's when I received my diagnosis of Mosaic Turners Syndrome. It was then and yrs later I would realize how fortunate I was. I sometimes wonder if I had been diagnosed earlier and be told that there was a large chance I would not have children if I would

Ongoing Challenges



Partnership in Research

- 2006 – Bondy Clinical guidelines
- 2014 – Turner Syndrome Global Alliance (TSGA) founded
- 2014 – Patient-Family Survey – Jacksonville, FL
- 2015 – Pediatric Clinic Network
- 2016 – International Clinical Guidelines – Cincinnati, OH
- 2018 – TS international Research Meeting – Washington, DC
- 2020 – Adult Clinic Network
- 2020 – InsignTS Registry Created
- 2022 – International Guideline Update – (Proposed) Copenhagen, Denmark

Practice
Guidelines for
Parents of Girls
with
Turner Syndrome

Brief Synopsis for
Turner Syndrome Girls
and Women and for the
Parents/Caregivers/Families





INSIGHTS REGISTRY

Inspiring New Science in Guiding Healthcare in **Turner Syndrome**

- https://www.youtube.com/watch?v=YUDgpa_w24b8



Thank you

Because **EVERY** woman
deserves a chance

