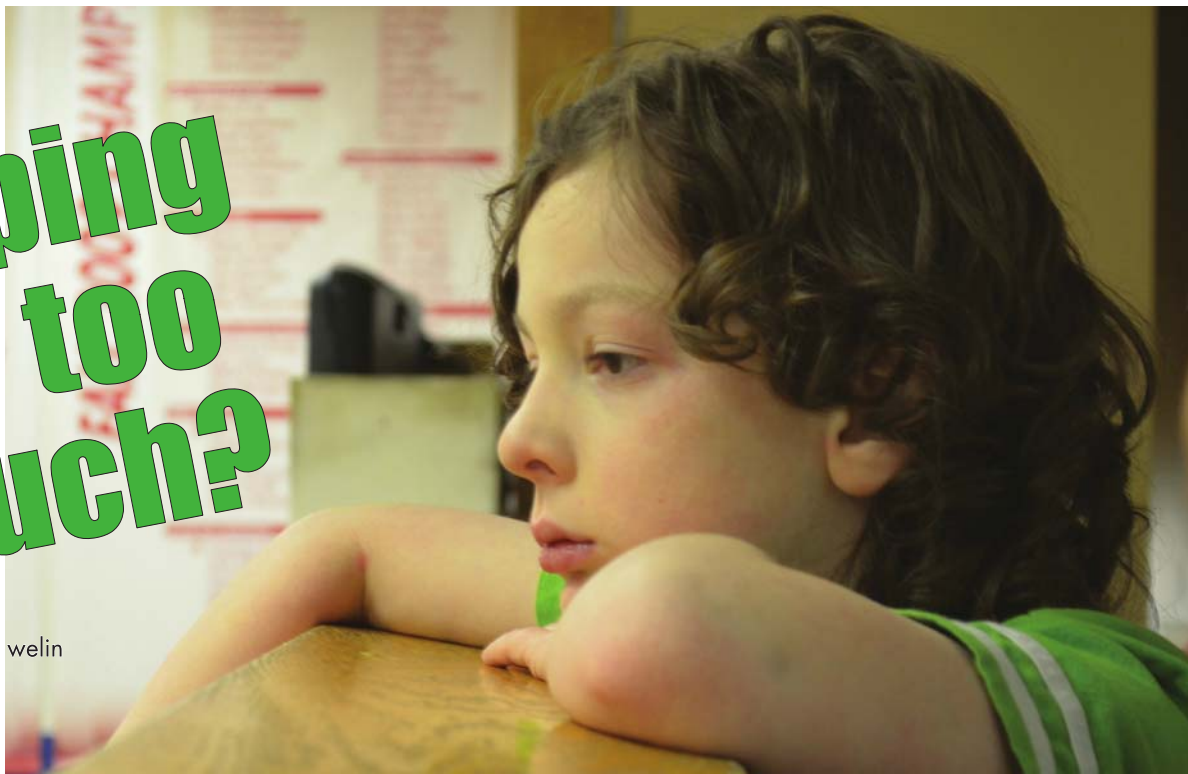


Hoping for too much?

BY

melissa welin



In April of 2006, my son was diagnosed with Fragile X Syndrome. Any words that I use to describe that experience sound clichéd and trite. My husband, Eric, and I were “heartbroken,” “devastated” and “angry.” That was the just the surface though, below the emotions that were running riot through my head day and night was something much worse. It was as if the very heart of me had been ripped away. There was a great, yawning emptiness inside of me that I couldn’t even bear to look at, much less talk about. There were a few unfortunate souls who tried to tell me that having this part of me ripped away would leave room for something else to grow. I assume they survived the conversations, I’ve blocked most of that out.

At some point during those early days I decided that we would have a cure before Caleb turned 8. We had to have a cure by the time he turned 8 or we would forever be stuck in this horrible world of Fragile X. Eight was so far away back then, surely it would happen. There was talk of a cure; there were treatments and exciting research just around the corner. I had no idea back then how slowly medical science moves and how quickly the years pass when you’re busy being the world to the most awesome little man alive.

And then, in a blink of an eye, he was 8. He was 8, and he still had Fragile X. He was 8, he still had Fragile X, and we were happy. Eric and I had a new circle of friends - sisters and brothers really - who love Caleb, who love us, who encourage us when we struggle and who cheer us on when we inevitably succeed. And we return that love, encouragement and pride in their children. We claim them all as family, there’s no other word that fits. These are the people

who I laugh and cry with, the people who know my deepest fears because they share them, the people who know my blazing joy at every inch we gain because they fight for every inch, too.

It seems strange to me that while I was happy, I still had a seed of discontent deep inside. While it’s true that a seed of discontent is a vast improvement over the great, yawning emptiness of the early days, it’s still destructive. It was whispering in my head, “It’s almost too late. We’re never going to get away, we’re never going to wake up from this.” I decided to compromise with this little voice. If we signed Caleb up to participate in the latest drug trial, a Phase III study of Seaside Therapeutic’s STX209, it would just shut up. I can be very bossy.

I was surprised though that making that call to start the drug trial was such torture. In order to take part in this study, which would look at the drug’s potential for treating social withdrawal for kids and adults with Fragile X Syndrome, we had to remove Caleb from his anxiety medication. Starting the anxiety medication had been a huge gift to us; it had allowed Caleb to interact with the world more easily. It had freed up some of his energy that he had been directing solely into surviving his days in our loud, bright, smelly world, for using language. Our non-verbal child was now chatty. And I was going to take away the one thing I knew helped him for months of... who knew.

The study is a double-blind placebo-controlled study, so he would either receive a full dose, a 1/2 dose, a 1/4 dose or... nothing. We didn’t know what he would get, and we would never know what he had been on. The only way I was able to make that decision to go for it was hope. Hope that this would help him more than

the anxiety medication had, that this would help a whole lot of other kids that we love someday.

I try so hard to not let myself hope for too much. I am the ultimate silver lining in a bad situation kind of girl, but I can only maintain that if I am prepared for and expecting the worst. Hoping and wanting good things is torture to me, the anxiety it generates is paralyzing.

I try so hard to not let myself hope for too much. Hoping and wanting good things is torture to me, the anxiety it generates is paralyzing.

This is why when we began the STX209 trial, Eric and I agreed from the outset that Caleb was on the placebo. My heart nearly broke each day as I watched him so closely, despite that agreement, for any sign of improvement.

What if he is on the full dose and it didn’t help him? That to me would be the worst

possible outcome. That would have killed the hope I have held in my heart since the diagnosis that we would find something to fix this, to make this better, to make him happier and more successful.

During the trial we saw glimmers of improvement, increased eye contact, decreased anxiety, but I refused to let myself believe it. It wasn’t until Caleb’s last IEP meeting, when we heard his teachers and specialists confirming that they saw the same at school, that I actually allowed myself to believe he was on something. I still hoped fervently that it wasn’t a full dose because I want to keep that hope, that the glimmers would become so obvious that we couldn’t deny their existence, alive.

Then we titrated down off the trial. It became clear immediately that Caleb had been on something. His anxiety shot through the roof, his emotions fluctuated wildly, and we were left with a child who was just flailing in every aspect of his life. He was out of control which, fortunately enough for us, meant tears and whining, but no aggression.

We had known at the outset that if we completed this double-blind portion we would be allowed to join the open label extension trial in January. It would mean that the wondering would be over. We would know that he was getting the medication, and we would know how much. There was never any doubt in our minds that we were going to participate, this was the reward for taking such a huge risk.

The start of that open label trial wasn’t a very happy process for us. Caleb still seemed to be struggling emotionally, and we didn’t see any improvements. We noticed that for 24 hours after we increased his dosage his emotions fluctuated wildly, his appetite would disappear, and he was incredibly

sleepy. He even fell asleep at school a few times. And still we saw nothing, not even glimmers.

That fear that he wouldn't respond to the medication resurfaced. I began to have doubts that he had really improved during the trial. I began to think we had fallen victim to the placebo effect and imagined it all. I began to think maybe we needed to stop the whole process, he had been so happy before we had taken him off the anxiety medication in the fall, and now we were just playing with his moods. It reignited all of those painful thoughts I had struggled with before agreeing to the trial in the first place. Thoughts of experimenting on my own child. Thoughts that I hadn't truly loved him just as he was, that I was doing all of this for my own selfish benefit because I still couldn't accept that I had a child with Fragile X, that this was our life for now and forever.

Then I noticed a small something, it was the same small something that had let me know that the anxiety medication had been working oh so long ago. Caleb's eye contact returned. He would engage us in play and, no matter how excited we all got, he maintained a consistent level of eye contact. When we ate dinner he would look straight at me when I spoke. Though my worries began to ease, I still wasn't confident enough to voice that.

Then in mid-February, nearly a month into the open label trial, I whispered to Eric as we were all playing on the big bed, "He's looking at us," and Eric agreed that he'd seen it too. I crushed that ridiculous little flutter of hope with the weight of my continued worries over his emotional struggles around medication increases, his loss of weight due to appetite suppression and his exhaustion at the end of each day.

I find though that I can no longer deny that this medication is working. Too much has changed too quickly, too obviously, for me to continue.

He is more independent in our routines, I can ask him to do something and it no longer matters how many steps are involved...he will do it with virtually no prompting. The only prompting I find myself doing involves him getting distracted by what he's watching on TV. It's so very typical for his age that I can't even really consider it prompting in the same sense. If I pause the movie or TV show, he will quickly finish what was asked of him.

He takes initiative - I don't have to ask him to do certain things anymore. If I tell

him it's bedtime I don't have to ask him to put on his pajamas, find Grabbit (his much loved security blanket) and get into bed... he will do all of that...again with the minor distractions that you expect from an 8 year old who isn't quite convinced I meant that it was bedtime right that very minute, he might grab a toy or a book but he'll lay it aside and continue if I remind him that it's bedtime.

He is doing chores, willingly and without being asked. He has helped fold laundry, he loads and unloads the dishwasher, he will run around the house and pick up dirty dishes and put them in the sink. When we go grocery shopping, he will grab a basket and carry it until his arm nearly falls off. We tell him what we need, and he will grab it and put it in his basket. If we forget and grab it, he will choose his own and ignore whatever we picked up.

His social skills are improved, after the last big storm we were outside with a big portion of our neighborhood cleaning up and he greeted everyone, some with handshakes and others with a "Hey 'sup?" Many of those who were out there are virtual strangers to him but he never hid his face, he wandered freely amongst the houses while keeping an eye on Eric and me. At the grocery store the clerk remarked, "He must keep you laughing all the time," based on Caleb's greeting and obvious understanding of the entire process and his eagerness to help us all.

His verbal skills are improved. He has more words, sentences, paragraphs. He tells us about things that happened, not just things they happen. He repeats everything; we have taken to calling him "The Echo" which always earns us a quiet "echo" from him.

He's planning. He found a Christmas catalog somewhere, found a Nerf gun that he wanted and asked for it. He knew where to get it "ToyRUs?" he would tell us what color it was to differentiate it from the others on the page. When Eric took him to ToysRUs to buy it, he wandered up and down the four different Nerf aisles until he found the exact gun that was in the catalog. While Eric scanned box by box looking for it he took a glance and immediately knew those were not it, some were close, but not it, and he kept looking. Oh, and, when he saw the catalog, he read "Nerf" and pointed it out to us.

I could go on and on but what I'm saying is that (except for those 24 hours after a dosage increase) he is calm, focused

and independent. His air of capability is remarkable, he has no doubt about what to do or how to do it. I watch him in awe these days. I'm not sure I can convey what it is like to see a child go from a toddler to a kid almost literally overnight. He is changing so quickly, so drastically, that the biggest risk here is that we will continue to baby him too much when he's really OK on his own. Other than other FX parents who are on this trial, I'm not sure anyone will ever experience watching their child seemingly mature years in just weeks.

And it's not just us. Caleb's teacher reports that he is increasingly independent at school as well. She can send him to the office alone, she waits for him at the top of the stair still but she doesn't need to. When we drop him off at school he walks through the classroom door easily, often

with no prompting. After years of tears over this task, it's magical. And when he's ready to head out with his friends to start his day he's right at the front leading the charge to the next class.

Oh, and he's at less than half the ultimate dosage still. I'm not sure I can even hope for too much at this point. He's changing faster than I can dream new dreams.

Melissa Welin is the mother of one son living in Cambridge. She and her husband, Eric, co-founded the Fragile X LINKS Group of Eastern Massachusetts in 2009 (fragilexma.org). LINKS groups are organized and run by parent volunteers to provide emotional and educational support for families and to support the mission of the National Fragile X Foundation. Melissa also blogs about living with Fragile X Syndrome on basicallyfx.com.

Something for everyone at the JCC!

Big Savings!

Membership Special

*Purchase a 12 month membership now and get 1 extra month for free & save \$50 off the enrollment fee!



Personal Training Special

Purchase 3 hours of personal training for \$99



- Personal training
- Massage therapy
- Indoor and outdoor pools
- Daily group fitness classes
- Aqua aerobics classes
- Small group fitness training
- Gymnasium w/open gym
- Krav Maga self-defense *(New!)*
- Men's & women's spa facilities
- Free babysitting
- Summer camps



Offer good from 3/28/13-4/30/13
Personal training special - 1 per person



Worcester JCC

633 Salisbury Street, Worcester
worcesterjcc.org • 508.756.7109

For more information:
Kelly Whalen x 236 or
kwhalen@worcesterjcc.org

THE JCC IS OPEN TO ALL REGARDLESS OF RACE, COLOR, RELIGION, NATIONAL ORIGIN, GENDER, SEXUAL ORIENTATION, AGE, DISABILITY OR ECONOMIC CONDITION. THE CENTER IS HANDICAPPED-ACCESSIBLE.



Nashoba Montessori School

Visit our website for a "virtual tour" of our classrooms and details on our program offerings

NashobaMontessori.com

Classroom observations by appointment.

Please call 978-368-3555

Now accepting applications for 2013