

Recovering from Autism

And Why Recovery is not the same thing as Cured.

Our story into the world of autism began like many of yours. . .

- Difficult pregnancy
- Difficult labor/delivery/oxygen deprivation
- MMR just prior to conception
- Flu vaccine while pregnant
- Hep B at birth, plus two weeks later a second dose
- Systemic reactions to vaccines

Where our story is different

- Son was born with limb deformity
- Sensory issues at birth
- Loud, cat-like cries at birth
- Hypotonia at birth
- Difficulty lifting his head
- Assigned a physical therapist by the age of 7 months.

Then he had his 1 year vaccines

- MMR, Varivax and Polio on the same day.
- By the next day he had a 105 fever, non-stop diarrhea and began to lose what few milestones he had gained.
- Stopped speaking, stopped walking, stopped waving goodbye.
- Retreated into his own world while continuing to cry in obvious pain.

Our pediatrician's advice

- For non-stop diarrhea – give him crackers.
- For head banging, biting, pinching – ensure firm discipline.
- For possible vaccine reaction – keep vaccinating.
- He was a nice pediatrician but even he admitted he knew very little about autism. He had two on the spectrum himself.

Receiving the diagnosis

- By 16 months his physical therapist told me that she suspected autism spectrum disorder because of his overt sensory overload. She then demonstrated his aversion to various textures and sounds.
- By 18 months he had received his initial diagnosis from a developmental specialist.
- Within four months he received two more diagnoses by two separate neurologists.

Now what?

- One neurologist suggested that our son might just “snap out of it”.
- Another neurologist just recommended we not feed him any sea water.
- Early intervention started him on a 13 hour a week program.
- BUT. . .we still had diarrhea!!

Finding GFCF Diet, then SF too

- Googled dietary intervention for autism and stumbled on Lisa Lewis book “Special Diets for Special Kids” and understood that diet helps our kids.
- Read Karyn Serossi’s book “Unraveling the Mystery of Autism and PDD. . .” and understood that kids can recover from autism.

Started GFCE right away

- Implemented dairy removal and my son stopped waking up in pain after his naps.
- Better eye contact
- Better attendance during therapy
- However. . .
 - I replaced milk with soy (lots of it)
 - I could not figure out how to implement gluten removal fully

And then the unthinkable happened

- My son got worse because I reintroduced gluten.
 - Head banging, biting, pinching, screaming, chipping his tooth because he slammed his face into the floor.
 - Diarrhea worsened
 - ER visit in the middle of the night because he was writhing in agony with gut pain.
- Never again!!

I got good at GFCF but still had not removed soy

- Needed an endoscopy to address constant GERD.
- Scope discovered he had chronic erosion of the esophagus, stomach and upper intestine.
- Did further research and discovered soy was a big culprit in this kind of erosion. Removed it and saw immediate improvement.
- Diarrhea still persisted.

IVIG

- We were referred to Dr. Sudhir Gupta our of University of California, Irvine when it was determined my son might be a candidate for IVIG – I.V. Immunoglobulin
- Testing involved checking his Ig immune system levels as well as his vaccine titers.
- Turned out Daniel was an excellent candidate for IVIG.

What is IVIG?

- **Intravenous immunoglobulin (IVIG)** is a [blood product](#) administered [intravenously](#). It contains the pooled, [polyvalent](#), [IgG \(immunoglobulin \(antibody\) G\)](#) extracted from the [plasma](#) of over one thousand blood donors. IVIG's effects last between 2 weeks and 3 months. It is mainly used as treatment in three major disease categories:
- [Immune deficiencies](#) such as [X-linked agammaglobulinemia](#), [hypogammaglobulinemia](#) (primary immune deficiencies), and acquired compromised immunity conditions (secondary immune deficiencies) featuring low [antibody](#) levels.
- [Autoimmune diseases](#), e.g. [immune thrombocytopenia](#), and [inflammatory diseases](#), e.g. [Kawasaki disease](#).
- Acute infections

General source: Wikipedia Encyclopedia.

What happened?

- Daniel started IVIG at 2-1/2 years old.
- After the first infusion we saw positive behaviors.
- By the 4th infusion he was speaking full sentences for the first time.
- By the 8th infusion his DAN doctor declared he was winning the autism lottery.
- By the 12th infusion Dr. Gupta declared Daniel to be one of his recovery kids.
- By the 18th infusion his pediatrician declared he no longer saw any symptoms of autism. He was astounded!

What else were we doing?

- DTT through school
- PT/OT/Speech
- Private preschool in a typical classroom
- Gymnastics for hypotonia
- Yeast control therapy
- Supplements
- BUT, we still had diarrhea after 2-1/2 years.

Gut issues revisited

- Flew to New York to have Daniel scoped by Dr. Krigsman
- Found out he still had lots of gut inflammation in spite of diet, supplement and IVIG.
- Started him on two medications that did the trick and he had his first normal BM within a month.
- Then he got his first cold after not being sick for over two years and that caused a bit of regression. Eventually he ended up on a round of antibiotics and then was fine after that.

Why do I use the word recovered and not cured?

- Daniel went from a 27 hour a week program down to 2 hours a week for just speech by the time he entered kindergarten. His diagnosis with the school district changed from ASD to just speech delay.
- But there is a lingering sense that you must be ever watchful for anything new that might pop up. And it did in his kindergarten year.

What's next?

- Began Tomatis therapy to address auditory processing delay issues.
- Stopped G.I. meds when he began to have reactions.
- Started hypotherapy (horseback) to address chronic hypotonia.
- Added accommodations to the IEP.
- Worked with teachers to ensure they understood GFCFSF and Daniel's