

Mary Romaniec

GFCF in 10 EASY weeks.

A Streets-Smart Approach to Negotiating your Child's IEP.

Her experiences with IVIG.

Recently she completed an article on relationship challenges.

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Her son is recovered from autism (article in Mothering magazine a year ago).

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Q: My daughter is starting IVIG next week. She has very high ASO titers. How did you determine that you needed IVIG for your son, and what benefits did you see?

A: My son went to see Dr Gupta. My son's immune system was suppressed. But because my son's immune system was not suppressed enough, insurance would not pay. We went ahead and did the IVIG. Without this my son would not be recovered. We're so happy we did it.

Q: How long did this take to recover?

A: Saw progress after the first infusion. We saw jumps for 19 months that we did this. All major jumps. After a few months went from non-verbal to verbal. When he plateaued we stopped. It is expensive. My son was recovered by age 4.

Q: can you please explain what IVIG is?

A: IV immunoglobulin – human blood. Comes from thousands of donors. You're taking antibodies from donors. It helps with autoimmune issues.

Q: How long, and what did you see?

A: We did the treatment (IVIG) for 19 months. We saw significant improvements every month. The school district saw remarkable changes. They'd never seen anything like this before. We were witnessing miracle events every day.

Q: What is the test to determine if your child qualifies?

A: There are a series of tests to be done by an immunologist. Dr Gupta is at UC Irvine in California. He did tests to tell where the immune system was struggling. He also did an antibody titer. My son was missing the antibody titer to polio even though he had the vaccine.

Q: Is it blood?

A: yes. We asked about the blood resources. We were comfortable

Q: Do you know if IVIG works as well for kids that are older? My son is now 11.

A: It does work, at what age I don't know. The best way to determine if appropriate, do the tests, find out if his immune system is severely suppressed. If it is, that's actually good news, because insurance might cover. For a child that age, could be \$5000/treatment.

Q: can you talk about types of carnitine vs carnitor?

A: sorry, I'm not familiar

Q: you consider your son cured from ivig, not diet?

A: Actually, he's recovered, not cured. I'm always looking out to make sure he stays well. Without gf/cf we don't think IVIG would have worked as well. We're still on the diet. For us, all 3 things worked together, gf/cf, IVIG and behavior therapy. My son is very well trained to keep himself on the diet. Daniel is 6 years old now.

Q: Is IVIG considered a "mainstream" therapy for immune suppression? In my wonderful home state of FL insurance companies are exempted from anything considered experimental-never mind for autism.

A: yes, for immune suppression, this is the treatment. FL is one of those interesting states. If you have a physician ordering IVIG, they will be looked at closely. Dr Bradstreet and Kartzinel got nailed on that. Insurance would need to see immune-suppression, or something other than autism.

Dr Bradstreet is a fan of IVIG...but now has to use it as a last resort. He has to show due diligence now.

Q: We will be going thru the IEP process for the first time for my almost 3 yo son for preschool in the next couple of weeks... any advice?

A: Yes, lots. There is a great book The Complete IEP Guide by Lauren Siegal www.tacanow.com has an IEP checklist that I wrote. I also wrote an article on this.

Go in prepared, bring a tape recorder, notify them in writing about everything.

Q: What is your view on soy products?

A: Soy can cause erosion of the esophagus and large intestine. Many of our kids get OD'ed on soy because we put them on gf/cf. But it's a very common allergen. My son had to have an endoscopy because I OD'ed him on soy. Please use it very rarely, or not at all if you're child has a sensitivity. It's very common to have IgG allergy to soy, more common than not.

Q: what do you think of electrodermal screening?

A: Sorry, don't know about this

Q: You are GFCF, what are your thoughts on SCD?

A: I'm a big fan. I encourage folks to start with gf/cf though, it's easier to start with. The SCD has casein, and I think casein removal is important. (Rick N adds that casein is bad for MB12, interferes with methionine synthase pathway)

Q: My daughter tested negative on hep B titers and tetanus titers. Did you mention that your son was negative for polio?

A: If your daughter was immune suppressed on two or more tests, insurance will cover IVIG.

Q: are you familiar with kefir and if so what are your thoughts on this as far as casein and - do you have experience with non-dairy kefir

A: I haven't heard of a non-dairy kefir, and I'm not a fan of casein. A little bit is not a good idea for our kiddos. If you need probiotics, rather than kefir go to acidophilus.

Q: there is young green coconut kefir from body ecology diet

A: I'm a fan of Body Ecology Diet. You have to determine if it's right for your particular child.

Q: How can you determine if your child is having an intolerance to a food if your child's behavior is typically erratic anyway? My DAN doc wants me to remove soy/egg and reintroduce it to see if there is any rxn...

A: Did your DAN dr not run an IgG? He should run a full IgG. This is the best way to find what your child is sensitive to. We had to remove 21 allergens for my son.

Q: Can you recommend a bread mix that taste like "real" bread. We tried several (this was a couple of years ago) and they just tasted weird. If you know of something that will make good pancakes and biscuits that would be great.

A: favorite bag mixes causeyourespecial.com
Creationsbykristin.com
Glutenfreepanty.com

Q: 2 questions - We are starting the 3rd year of preschool and I've requested a full day program because he is progressing nicely. This will be a battle with our school which things "progressing means less is needed." So I'm trying to figure out if I should be satisfied with a full a.m. program and a unstructured p.m. play setting.

A: If he hasn't achieved the goal, you don't dial back services. You as the parent need to lead the charge, and get the school to follow. We got a shadowed aide in a private preschool, with 5 hours speech, all paid for by the school district. I clearly demonstrated that the proposal for my son was not appropriate. I needed him to emulate normal children by kindergarten.

Q: 2nd question - we are seeing better communication after b12 shots - but LOTS more frustration. HELP! It looks like terrible two's but I don't know how to help him since his communication skills progress so slowly!

If anyone wants the article, go to tacanow.com

Q: I'm really apprehensive to send my 3 year old to preschool because we are strictly following GFCE diet. Wherever there are young children, there are contra-band foods. I don't think an EA or teachers assistant would be able to police my child's grabby hands... any suggestions

A: If your child is grabby, you need to get a shadow aide. Meet with the teacher at the beginning of school year, explain that a little bit of gluten or casein will turn your child into a demon. Make sure there is no regular playdough, the teacher should get gluten-free playdough. I've never had a problem getting teachers on board.

Q: Can you take us through the 10 easy weeks to GFCE? It seems like we cannot get started because we are afraid our son won't eat anything.

A: The 10 week calendar is on the tacanow.com website.
Remove dairy for the first 2 weeks.
Go slow with the rest of the diet.
Stock up on ready to eat and package mixes at first.
Third week, breakfast.
Fourth week, tack on lunch.
Fifth week, dinner.
Etc. (see [tacanow](http://tacanow.com))

There are usually 5 foods a child will eat because of the opioid high. When you remove these foods (gluten/casein), they'll over time get used to eating other foods, the craving will go away after a week or so.

Q: does anyone know how to get a shadow aide?

A: These are aides well-trained in autism, will not overwhelm the child, but is there to help.

Q: what do you do for cheese?

A: Almost all of them have casein, there is only one brand (Chreese) that is similar, but it has soy. We go without it.

Q: What is the thing(s) in the diet that most effects tantruming

A: There are a variety. Gluten and casein. Artificial colors, preservatives, phenolics, sugars. Yeast overgrowth.

Q: What is it about french fries that kids-or at least my 8yo- go nuts about? (McDonalds)

A: We use Cascadian farms and bake the fries.
McDonalds is fried in soy oil.
We eat McD's once in a while.

Q: What are some GFCF toothpastes you recommend? I live in Canada...

A: Toms of Maine non-fluoride, or Kirkmans non-fluoride

I want to tell you about another article I wrote. We all grieve at different levels. The article is coming out, I'd be happy to forward it when it comes out. In the meantime I'd like to share some tips in getting through this Autism diagnosis. You commiserate with friends, but there are various levels.

- 1) you're struck with fear, overwhelming, all-consuming. One or both of the spouses get stuck in that mode.
- 2) You're angry. You can also get stuck here.
- 3) Denial. Can get stuck here too.
- 4) Bargaining/guilt. If I do a little of this, the rest will go away.
- 5) Acceptance. This is something I need to deal with. What do I need to do to go forward.
- 6) Resolve to overcome. Create family normalacy; or overcome your child's health issue.

If one spouse is stuck and another is at 6, that's where the conflict starts. You start to see real dissent in a family.

I have some hints for how to get through these stages a little quicker.

I mentored a friend. Dad wasn't getting the gf/cf thing, he fed the child the wrong foods, the child's behaviors were horrible and the mom had to deal with them. She wanted to make the dad's night miserable.

Mary suggested giving dad a night he couldn't forget instead; then the next morning bring up the gf/cf thing and get him on board.

That worked!

Mary suggested that when the lady and her husband go away on vacation together, they again have a night to remember. Friday and Saturday...then Sunday morning bring up the biomedical stuff, and get him on board.

That worked!

From the other viewpoint, the husband trying to get the wife on board, give lots of TLC

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Q: Will my child ever be able to eat fruit with a serious yeast issue at present?

A: Fruit is not a problem unless it's eaten in really large quantities. To help the yeast, control sugars, use antifungal, probiotic

Q: My son also loves bananas. You were mentioning them in regards to the salicylates. Is there something about bananas that would not be good for him? BTW, what's a vacation!

A: They're not really a salicylate. They do set off behaviors though. Like demonic laughing, that's usually caused by bananas. It's not that the bananas are not good for him...but might cause behaviors.

Q: Did you use Benadryl and/or fever reducers immediately prior to each IVIG infusion? Any tips on how I can make the IVIG comfortable for her? What are signs of a bad reaction to the IVIG?

A: One hour prior to IVIG, we got to the appointment. The nurse applied the EMLA cream. Then benadryl and motrin were both given. Then he was hydrated heavily. Hopefully the facility where you are going is well acclimated to dealing with children – tvs, video games, etc. With the benadryl your child will most likely sleep.

Bad reaction – headache and nausea. That can be mitigated with benadryl and motrin for next 24 hours. Also a chicken pox type rash is a less common reaction.

Q: I have two diff questions one would be have you ever met a couple where the father blames the mom

A: yes, many couples, especially Asian and Hispanic families, the father blames the mom. Father thinks it's the mom's fault for not disciplining enough, or thinking about the behaviors too much, or whatever.

If you can get your husband to go to the conferences, and be more involved, maybe that will work, but in many cases you can't get the husband on board. He's stuck between anger and denial.

Q: How long is the IVIG infusion? I have heard it is something like 6 hours. How do you get a kid to stay put that long?

A: 6 hours is about right. I never saw a child

Q: Does the low dose naltrexone address some of the same immune issues as IVIG?

A: Nothing is the same as IVIG, not even oral immunoglobulin. LDN won't do the same thing.

Q: is IVIG permanent or is it a temporary thing that is done periodically - how many infusions typically. How do you know if your child qualifies for this treatment

A: IVIG is temporary, in that it lasts 4-6 weeks before you need another infusion. You want to get to the point where the body can heal itself. It detoxes the body – heavy metals were coming out like crazy, because the body started doing what it was supposed to do. IVIG does exacerbate yeast – stay on antifungals and probiotics.

How many depends on the child, we ended up with 19. Others have more, less. Depends on the child.

You need to have an immunologist run tests to see if your child qualifies.

Q: Will this test tell if the child has an immune deficiency?

A: Yes, Dr Gupta is very careful about the patients he takes. He turns down many who he feels would not benefit.

Again, it's very expensive, priced by the gram.

Q: Any IVIG clinics in Canada - Ontario - Greater Toronto Area??

A: Canada is not real up on IVIG, because they have to pay for it. The folks I've talked to had to fly to the states for the infusions.

Q: What about baygam as a "cheap" alternative to IVIG?

A: Anything we do to improve the immune system is a good thought. I do try to caution parents that there is a difference between IVIG and any other treatment. It's up to each parent to decide what's best for their child.

Q: Where will your article on relationship challenges be posted?

A: As soon as it gets fully edited I'll let you know.

Q: First, is yeast-free diet a must as long there is a gut-yeast issue? Next, how do you know that after some number of IVIG sessions, treatment is enough and can be ended?

A: That was my number one question to Dr Gupta – your child will either plateau or regress. My child did plateau. At his 18th infusion, the pediatrician saw no more autism in my son. After that we did one more, then decided we were done. On yeast free diet, you're dealing with total dysbiosis of the gut, so clean the gut as much as possible, but don't go nutty about being totally sugar-free and carb-free, stay sane along the way.

Q: Did your son have any gut issues?

A: The gut issues were so bad. His poops (20 a day) were like barnyard animals in the way they looked and smelled. We went to Krigsman in NY, he diagnosed 2 autoimmune issues in his gut. We started IVIG because of all the gut issues, but they didn't clear up all the gut issues, he had to be on meds.

Q: Did you use any chelation therapy prior to the IVIG?

A: We didn't do chelation. It was on my list of things to do..but when we tested heavy metals, they were all gone. I give credit to the IVIG.

Q: Do you know how the divorce rate of autistic children affects the kids?

A: I've seen so much of that, a lot of families struggling. It can really complicate a child's recovery. I try to encourage parents to work it out.

Q: Do you think IVIG is comparable to MB 12 treatment for detox/immune function? Which is better?

A: They're different. Detoxing immune is totally different than MB-12. They can be used in conjunction with each other. You can also use antioxidants, like glutathione.

Q: did your son have metals when tested before ivig? What is the approximate cost for a single IVIG session for approx 40lb kid? Could you explain the source of IG that is infused into the kid?

A: He had both blood and hair tests, and was off the charts on quite a few metals. We had to address gut issues before chelation, and along the way went into IVIG instead of chelation. The IVIG is put through quite a purification process, it's donations of droplets of gamma globulin from thousands of donors.

Q: every how often would one do ivig

A: We did every 4 weeks, some go longer.

Q: If you have a child that's a responder to MB-12, does that mean he's a responder to IVIG?

A: He might benefit. He also might benefit from Tomatis sound therapy. We did that, and it helped my son's auditory processing delay.

Q: AIT?

A: yes, you need to choose which version of the sound therapy, AIT, Tomatis, etc. You need to decide which is best for your child.

Q: If I'm going through a divorce, what was it you said about biomed?

A: If the husband gets a court order, you might be stopped from doing a biomed treatment that's beneficial. It might also be hard to get the money from the husband to do the biomed.

Q: Should there be any concern of impurities or issues coming from others' blood sourced IG? Does insurance pay a part of it?

A: There is a 1 in 1,000,000 chance of a blood borne disease from IVIG. My sister is a cancer researcher, she asked Dr Gupta about the process, she felt it was a good process, safe enough for her nephew.

The insurance might pay, especially if autoimmune is suppressed enough, like missing two antibodies when having titers tested, even though child was vaxed.

Q: do you have your experience on ivig anywhere on website?

A: We were published, but the magazine sold out of 250,000 copies! There was so much interest. It was Sept/Oct 2004 Mothering. You can go on tacanow.com and search Daniel's Story, you should find it. Or email me and I'll send you the pdf.

Q: did you say if the child did not have 2 titers for vaccines they received they could qualify for insurance - does this mean the immune system is not functioning properly when they don't have the antibodies?

A: Yes, that's what it means, missing 2 means the child is immune suppressed.

Q: Would a regular pediatrician run that titer test?

A: No, an immunologist.

Q: will Canadian insurance pay for U.S treatment??

A: If you can get Canada to pay for it, let me know. All the families I mentor are fighting with the bureaucracy, they have not succeeded in getting it paid for.

Q: How many titers are there to test for?

A: I think there are about a dozen.

Q: How many children recover from this therapy.. And from the dozen titers if two are missing the therapy is covered.

A: I'm hearing from Dr Gupta it's about 30% recovery rate. He has narrowed who he accepts as patients.

Yes, if 2 are missing, I'm hearing insurance will pay.