

Chapter 4

Diet, Biomedical Treatments, Immunizations, and Autism

I returned Julie Grant's call the next day. She mentioned in her message that beside starting the PLAY Project and wanting to talk about the biomedical treatments, she had to 'make a decision right away'.

Biomedical Treatment. I knew what it was about. The celebrity Jenny McCarthy, who publicly proclaimed that her son 'recovered' from his autism by consuming a gluten-free/casein free diet and using a number of biomedical treatments, was speaking in the Detroit area as part of her national book tour. Everyone in the autism community was buzzing about her. A forceful, compelling, and charismatic speaker, McCarthy was also *against* immunizations, claiming they contributed to autism's increase.

Biomedical Treatments

- Vitamin/mineral Supplements
- Gluten Free/Casein Free Diet
- B12 Shots
- Chelation Therapy
- Yeast Free Diet and Anti-fungal treatment
- Hyperbaric Oxygen
- Secretin
- DAN (Defeat Autism Now) Protocol

Mom (hopefully): "Should I go to see her?"

Me: "Who am I to tell you what you should or shouldn't do?"

Mom: "I don't think we mentioned it but we had an appointment to see a 'DAN doctor' to help with Jacob's diet and supplements. Anyway, he thought I should go to see Jenny McCarthy but I wanted your professional opinion."

Me: "I've been following the 'DAN Protocol' with great interest ever since it was developed several years ago now and I must say I'm very disappointed. The

protocol was designed to do research and evaluate whether the various biomedical

treatments work. To date there has been no evidence that their protocol of vitamins, diet, enzymes, etc. works. It's very discouraging."

Mom: "But it seems to work for lots of kids. There are all kinds of reports on the Internet."

Me: "Well, I consider myself to be a very open minded doctor who is always looking for ways to help the children but, after following hundreds of children with autism whose parents have tried various diets and biomedical treatments, I can honestly say that the vast majority of my patients have had no benefit."

Mom: "That's disappointing."

Me: "I'm disappointed too. Wouldn't it be great? Change the diet or give a supplement and your child gets better from his autism? I'm afraid it's mostly wishful thinking. After all, autism is largely a genetic disorder. I remember the megavitamin craze for treating kids with Down Syndrome. With rare exceptions it makes no sense to treat a genetic condition with diet or vitamins. Don't get me wrong, Julie, I truly wish for a 'silver bullet' too. I wish, along with all of my parents, that I could give a B12 shot, do chelation therapy, use hyperbaric oxygen, or a gluten free/casein free (GF/CF) diet and help my patients with their autism. But in scientific language wishful thinking is called 'the placebo effect' which has been scientifically shown to be very powerful. The placebo effect means because we expect to see a change, we see it.

But the only thing I've seen work consistently are the intensive developmental and/or behavioral

interventions which we talked about during the last visit.”

Mom (not convinced): “Isn’t there *any* benefit? I mean why should so many parents report that their kid got better with a GF/CF diet? I found lots of evidence on the Internet that it helps.”

Autism and the Internet. It’s true that when you type ‘*Treatment of Autism*’ into your Internet browser, hundreds of thousands of links are listed. On the first webpage most of the links—even the *Autism Speaks* link!—mention dietary approaches to autism. Other sites recommend vitamins, B12 shots, supplements, anti-yeast treatments, hyperbaric oxygen. . .the alternative treatment list goes on and on. Another group of websites describes the dangers of immunizations as *the* cause of autism.

How are parents supposed to sort through all this information to arrive at the truth of what works and what doesn’t?

Me: “Watch out for so called ‘evidence’ and don’t believe everything you read on the Internet. The worst form of science is a case study: “I tried it and it worked!” I would challenge you to give me one, just one, scientific article with a good study design, which shows that diet helps autism. In fact there are none.”

Mom: “None?”

Me: “None. In fact there are studies that show diet doesn’t help. But to be completely fair, I’ve seen *some* benefit to overall health from changing the child’s diet.”

Mom (hopeful again): “You have?”

Me: “Children with autism tend to have very unhealthy diets anyway and they are often very sensitive to their internal states. When they don’t feel well, they don’t function as well.

I have seen children who are truly allergic to wheat (gluten) or milk (casein)

get better in their attention and engagement when the offending allergens are taken out of their diets. I have seen children’s sleep improve with dietary changes. I have even seen a decrease in ‘stimming’ behavior (hand flapping, toe walking, etc.) when their tummies don’t hurt. But I have never seen a child ‘recover’ from autism with alternative therapies alone.”

Mom: “Jacob’s been on the diet for a couple of months now.

Me: “I remember you telling me that.” (see *Appendix 2: Jacob’s Evaluation*)

Mom: “And I haven’t seen anything dramatic. And, it’s really been a pain. That’s all he likes is gluten. Pretzels, cereal, crackers.”

Me: “It is a hassle. Did I miss something during our evaluation? Does Jacob have allergic symptoms?”

Mom: “Not really. He’s been healthy as a horse but our DAN doctor thought that he might have hidden allergies.”

Me: “If you’re worried about allergies, I recommend going to a bona fide, board certified, pediatric allergist.”

Mom: “But how will we know if any of this stuff works?”

Me: “That’s another problem. After you invest time and money in treatments you tend to see differences even if they’re not there. First there’s the ‘placebo effect’. Then there’s something called the ‘Hawthorne Effect’—just by being vigilant and looking for any change at all, you attribute the change to the treatment you’re giving at the time.

Mom: “That’s so true! We are hawking Jacob. Every little thing that happens we think maybe it’s because of the diet.”

Me: “You might have to do an *elimination trial*—get rid of gluten and casein for a month or two and then re-introduce it. And see what happens.”

Mom: “Sounds complicated.”

Me: “Unless the improvement is dramatic it’s not worth it.”

Mom: “But I was so excited that I could help Jacob by changing his diet. It was something I could really do.”

The Harm of Biomedical Treatment.

Me: “If it sounds too good to be true, it usually is. People are always looking for a simple solution to a complex problem. I just don’t want you to act on false hope, Julie, and go off in the wrong direction.”

Mom: “But what’s the harm in doing biomedical treatments?”

Me: “Well, you can spend a lot of *money*.”

Mom: “That’s true. These vitamins and supplements are adding up. The doctor is sending me for lab studies and that’s costing a bundle.”

Me: “Yep. It’s big business. Many of these people are well intentioned but there are also unethical people out there who prey on desperate families. Another harm is that you can waste a lot of *time* which can distract you from doing what we know works. And perhaps the most serious harm is that it *drives families crazy*.”

Mom: “What do you mean?”

Me: “Aren’t you worried that you’re missing something?”

Mom: “Absolutely and it’s driving me crazy.”

One Cost of Biomedical Treatment:

Anxiety. We both laughed but it’s not funny. *A deep sadness for me is seeing the consuming anxiety that false hope engenders.* Families are running from this therapy to that therapy and constantly looking over their shoulders wondering ‘What else do I need to do to ensure the best for my child.’ This anxiety will never go away completely because families *should* keep their eyes open for anything that will help the children but I have seen too often what this anxiety of ‘wishing for the cure’ does to a family. . It costs them money. . It robs them of time. But perhaps most importantly, it saps their energy.

Me: “You worry constantly that there is something more to do.”

Mom: “But we don’t want to leave any stone unturned if it will help our Jacob.”

Me: “Exactly. If you believe that any one of these treatments might even have a remote chance of working, then you’ll feel guilty if you haven’t tried all of them.”

Mom: “Exactly how Jim and I feel!”

Me: “I have several families whose lives have become consumed by trying every biomedical treatment.”

Mom: “Everybody is saying ‘You *have* to try this, you *have* to try that. I read about this, I read about that. It’s driving me. . .it makes me feel like I’m not doing enough.’”

Me: “I really understand. Believe me I would tell you if I saw an alternative intervention that was helpful. I’m not a science snob who needs final proof before I recommend a treatment. There are several interventions that have little to no evidence that I refer to all the time.”

Mom: “Like what?”

Me: “Speech and language or occupational therapy. They don’t have much scientific evidence behind them but I think they’re very helpful and they make sense. I trust my clinical judgment. I just haven’t seen the benefits of the biomedical treatments.”

Mom: “I’m disappointed but I feel better about what I’m doing. I think we’ll still keep experimenting but you really helped take some of the pressure off.”

Me: “It’s good to try things or you’ll have doubts. Just don’t expect miracles.”

Mom: “What about B12 shots?”

Me: “I’m comfortable with whatever your DAN doctor suggests. Just don’t spend too much money . . .”

Mom: “. . .or too much time. I get it.”

Me: “Stay focused on what we know works—intensive intervention. And watch out for the predators and the true believers. It’s a dangerous world out there on the Internet.”

The Danger of True Believers.

Mom: “You’re not saying that Jenny McCarthy is preying on families?”

Me: “Not at all. She is a true believer but for that reason she may be even more dangerous than a predator. The predators knowingly go after your money. True believers go after your heart’s deepest desire: to help your child get better dramatically and quickly. Predators and true believers have one thing in common—they both rely on your desperation to help your child. The problem with true believers is that, if they are wrong (and they often are), they can rally whole communities to do the wrong thing. They can unintentionally do harm to lots of families and children.”

Mom: “You think she’s wrong about diet and shots?”

Why Parents Believe In Biomedical Treatments

- We all wish our children would ‘recover’ from ASD
- True believers and predators rely on this wish to promote/sell simple solutions to a complex problem.
- Testimonials are a poor form of evidence.
- It’s natural to confuse ‘coincidence’ with ‘cause’.
- Wishing leads to positive expectations: The Placebo Effect
- Watching intently for change leads to seeing change: The Hawthorne Effect
- Science shows no benefit from a GF/CF diet, etc.
- Science proves that shots do not cause autism.

Me: “I can tell you from following many, many families that diets did not work for them; going to a DAN doctor and doing all the biomedical approaches did not work. But you won’t read about them. I could fill an auditorium with families who had no benefit from diet and alternative treatments but you won’t read their testimonials online. We need more science not more testimonials.”

Mom: “So you think Jenny McCarthy is doing harm to families and children?”

Me: “If a family does a gluten free/casein free diet *instead* of intensive intervention

because of someone like a Jenny McCarthy then she has hurt that family’s chances of doing the best thing for their child. If people, for fear of their child getting autism, don’t get immunizations and their child gets whooping cough or measles and, God forbid, dies from complications then the greatest harm has been done. Almost 40% of families skip some immunizations because they believe that the shots or mercury cause autism and the rate of childhood illnesses is going up. It’s a real concern in the pediatric community.”

Immunizations and Autism

Mom: “So, I take it that you don’t believe that immunizations or the mercury in the shots cause autism.”

Me: “It’s not a matter of belief. The scientific evidence is overwhelming that *immunizations with or without mercury don’t cause autism*. What’s more interesting to me is why people believe that the two are connected.”

Mom: “There’s dozens of stories on the Internet about kids who got autism right after they got their shots. How could parents be so wrong?”

Me: “I’ll tell you how. When two events coincide it is human nature to link them together. Immunizations are given at 15 months, 18 months and 2 years. Guess when the onset of autism is?”

Mom: “Same time.”

Me: “Right. Autism’s onset is typically between 15 months and 2 years. A family brings their child in for a shot and within the month the child loses language milestones. Such ‘regressive’ autism occurs in up to 30% of children with autism. The parents connect the shot with their child’s autism and blame the shot. (see *Thompson et al, 2007 in references*). But there is no link between autism and immunizations. There are 24 studies (see *References*) that show no relationship

between autism and immunizations and *no* studies that link the two.

Besides, pediatricians don't want to hurt children. When the rotavirus vaccine was shown to cause problems they took it off the market right away. When the DPT caused neurological damage they created the vaccine insurance bill. And who do you think found that there was too much mercury in vaccinations? A pediatrician! Why would they keep giving immunizations if they caused autism?"

Mom: "What about Andrew Wakefield who had that big article on the measles shot causing autism."

Me: "Haven't you read? His study was just debunked. It turns out that he was a fraud! He fudged his data to make it come out the way he wanted! The most esteemed British scientific journal, the *Lancet*, for the first time in their long history, retracted his article with profuse apologies to the public. Wakefield lost his medical license."

Mom: "I did not know that."

Me: "And when Jenny McCarthy, who had been using Wakefield's study to support her view, was told about his fraudulent research she continued to maintain that immunizations caused autism because 'it happened to my son'. This is the fate of true believers. They don't want to be confused by the facts."

Cause or Coincidence: The Danger of Anecdotal Evidence.

Mom: "OK. I'm thinking I might not go to see her after all but I have one last question."

Me: "Shoot."

Mom: "Don't you believe that Jenny McCarthy's son got better and is no longer autistic?"

Me: "I don't doubt that her son got better. I just think she's wrong about *why* he got better. Besides the money she spent on diet and alternative therapies, she also spent tens of thousands of dollars a

month on intensive therapies including ABA, and multiple speech and language therapy and occupational therapy sessions. Plus she had Jim Carey, the comedian, to play with her son."

Mom: "Very funny. I hear what you're saying but I don't know Dr. Rick. I still can't quite believe that so many parents could be wrong."

A Case of 'Cure'.

Me: "OK Julie, let me explain how this works. First of all, did you know that between 10-20% of children with autism get better with no intervention?"

Mom: "Really?"

Me: "Really. I have many children who just simple improve over time. Let me give you just one case study from my practice so you can see the problem with the "I tried it and my child got better." approach to scientific evidence."

The Boy Who Got Better. So I told her about my patient, 3-year-old Johnny Smith (not his real name). It was not long after Jenny McCarthy was on the Oprah show (talk about coincidence!) that Johnny and his parents came into my office after 6 months of doing intensive play-based intervention (i.e. The PLAY Project). He was coming back to see me for a follow up visit.

From the time it took him to walk from the waiting room to the playroom I knew something dramatic had happened. He actually greeted me! He looked me in the eyes and said, 'Hi Docker Rick.' A three-word, very social sentence! Before, at age 2 1/2, he had been withdrawn in an autistic shell and had only a few single words.

As I took the history of gains over the last 6 months, I was stunned. Johnny had gone from not talking to non-stop talking; from not being social to not leaving his parents alone and wanting to play all the time; and from having lots of repetitive

and rigid interests to having much more flexibility in his interests. My heart was so happy for this family.

I paused from taking the history and, with obvious amazement said, ‘Johnny’s developmental gains have been tremendous! What in the world did you do?’

“We just did what you told us to.” Mom said matter of factly. “We turned off the TV, we’ve been engaging him for hours a day playing; we started speech and language and occupational therapy every week; and he’s in pre-school—the works.”

“Any special diets? Gluten free/casein free? Vitamins? B12 shots?”

“Nope.”

“I would love to take credit for Johnny’s amazing progress,” I said, “but really it was *him*. I have several children who *spontaneously* make a giant leap forward like this. And if it’s going to happen it usually happens between 2 and 3 ½ years of age. Congratulations!! I am *so* pleased.”

I had to add an editorial comment. “It’s a good thing you *didn’t* start a gluten free/casein free diet or you would have been running down the street shouting ‘Hallelujah!’ to everyone you met. ‘I put my Johnny on a special diet and it cured him of his autism!’

Me: “They would have had the perfect testimonial.”

Mom: “I see what you’re saying. If they *had* changed the diet, they would truly have believed that the diet made the difference!”

Me: “Right. And they would have put it out there on the Internet and then others would have believed it and on and on. The real reason Johnny got better was that he improved *on his own* (with some help from intensive intervention.)”

Mom: “So really this DAN stuff doesn’t work?”

Me: “It might help the child feel better.”

Mom: “This is very discouraging.”

Me: “As long as there are desperate, vulnerable people (which all parents with children with autism are) there will be those who take advantage. I’m just giving you advice based on my experience.”

Mom (discouraged): “I don’t think I’m going to go to Jenny McCarthy’s talk.”

Me: “I didn’t mean to rain on your parade.”

Mom: “That’s OK. I actually feel relieved. I’m tired enough doing what I have to do for Jacob and Charlie. I was getting exhausted just thinking about a gluten free diet. We might give the B12 shots a go.”

Me: “Hey, if it doesn’t cost too much money or take up too much time, you can experiment with various alternative treatments but just don’t get stuck in the wishful thinking rut. It’ll drive you nuts. The key is *time of engagement*. Jacob has tremendous potential. We’re going to get this boy going!

Summary

- Julie Grant is planning on attending a talk by a national celebrity who believes autism is caused by immunizations and can be treated effectively with supplements and a gluten free/casein free (GF/CF) diet.
- I share my observation that, over my 25-year career, I have never seen a child with ASD improve dramatically from diet, vitamins, supplements, or alternative treatments alone.
- Julie wants to know why there is so much ‘evidence’ on the internet supporting a GF/CF diet if it doesn’t really work.
- We discuss why parents believe in the ‘silver bullet’ approaches to ASD.
- We discuss the difference between ‘anecdotal evidence’ and real science.
- There is a lot of scientific evidence that immunizations do not cause ASD.

- There is no scientific evidence that diet effectively treats ASD.

Links:

- Andrew Wakefield debunked:
(<http://www.newscientist.com/article/dn4743-controversial-mmr-and-autism-study-retracted.html>)

References

Elder JH. Shankar M. Shuster J. Theriaque D. Burns S. Sherrill L., The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial. *Journal of Autism & Developmental Disorders*. 36(3):413-20, 2006 Apr.

Minschew NJ and Williams DL, The new neurobiology of autism: cortex, connectivity, and neuronal organization. [Review] [30 refs], *Archives of Neurology*. 64(7):945-50, 2007 Jul.

Thompson WW. et al, Early thimerosal exposure and neuropsychological outcomes at 7 to 10 years, *New England Journal of Medicine*. 357(13):1281-92, 2007 Sep 27.

Coming Up Next

- Jacob's parents are sending him to an early intervention (EI) program.
- I talk to them about the importance of:
 - understanding the education laws
 - how to navigate the education system and
 - how to help Jacob to get the most appropriate services in the school.