

John Michael Connell born 03/20/2005

John was born 6 weeks early and diagnosed with Down Syndrome. Although he did not have heart problems or breathing issues, he was somewhat low-tone and had significant difficulties with drinking/feeding. He had occupational therapy in the hospital and immediately thereafter. OT and oral motor therapy were initially required to assist with the feeding issues and building strength. His veteran physical therapist (beginning at 3 months) was very concerned about his lack of core muscle tone.

I happened to mention to our church children's ministry director about John and she said that I must meet a Dr. Teresa Cody. Dr. Cody's friend, Jamie Martin Currie, went on to explain that Teresa's son, Neal, had Down Syndrome and that Teresa was very involved with Stanford, research and fundraising for DS treatments. What a blessing and in our own town! Who would even imagine such a coincidence (which I like to call "God-incidence")? Of course, I could not wait to meet Teresa and her family.

John and I went to her home in the Summer of 2005. Dr. Cody was highly energetic, amazingly intelligent, resourceful and motivated by the best motivator in the world...her son. At that time (summer of 2005), Neal was 8 (?) and she had done everything (supplements, therapy, etc.) to help Neal learn and communicate/interact with the world around him. Speech and remembering (remembering anything) was very hard for Neal, if not impossible. This is a woman who loved her child more than anything and wanted him to have some of the same experiences and relationships that we have. She knew that without a certain level of cognition, that would not be possible for Neal. Not only that, she knew that Alzheimer is a brutal reality that many people with Down Syndrome face at a young age. She had started trying Ginkgo Biloba with Neal approximately 3-6 months earlier and had noticed improvement. She encouraged me to try Ginkgo with John.

GINKGO

In December 2005, John was 9 months old and took his first Ginkgo. I decided not to tell anyone, as became my pattern with new treatments, just to see if anyone noticed a difference. That day in December, I remember thinking, “his eyes look different, there is something more, he is making more sounds, more emotional connection with people”. That night, my husband said, “John had a great day today, seemed like a lot more going on”. Later in the week, his therapist noticed a difference. She said, “John is much more verbal, are you doing anything different?” Another therapist made a similar comment. My parents noticed a change...The ginkgo was working and I felt that the multiple 3rd party verification (although not scientific) was more than good enough to continue.

PROZAC

In the meantime, Dr. Cody continued her research about Alzheimer, massive cell death, and Down Syndrome. Prozac came into the picture. Prozac (not just for depression) had the ability to generate neurons. For a population of folks (Down Syndrome) that had trouble with a lack of neurons, this seemed intuitively to be a good thing to me. Add to this information some research I did on my own and a pediatrician who was fully supportive of the protocol and its safety...John started on Prozac at about 1 ½ years old. Sorry to be so vague about the dates...looks like I'm the one who need the protocol. The results with Prozac were amazing. The verbal ability and connection to others was very much enhanced. He was able to communicate better and you could feel more of a connection between him and others around him. The multiple 3rd party verification was also there with Prozac. The therapists and family members noticed the change but had not been told what I was doing.

BODY BIO PC & BALANCED OIL

Somehow Dr. Cody's research led her to Dr. Patricia Kane and Phosphatidylcholine PC. This is arguably the gem of the protocol and brings it all together beautifully as if master-planned. John started PC and

the Balanced oil at approximately 2 years old. He immediately started doing things that typical children do. And we all know, that is not always good but definitely welcomed with a special needs child. I recall John trying to get out of his car seat and calling Dr. Cody while in transit. She asked, "How is he doing on the PC?" I said, "Great, but he won't stay in his car seat and wants to get out". She thought that was so funny and said very delighted..."isn't that great? That is what the typical kids try to do...who would want to be tied in a car seat?" She had mentioned that she felt the protocol worked together and was exponentially enhanced by the oils. I tend to agree, so much that the entire family takes these oils. They are anti-inflammatory which helps all disease states and particularly Down Syndrome and Autism Spectrum. They just seem to make the whole body work better.

ADHD MEDS

The final component of the protocol, and maybe one of the more discussed is Focalin or ADHD medication. There is no doubt that my son is hyperactive and would benefit from medication. This diagnosis has been confirmed on at least 3 occasions by medical practitioners. We tried the Focalin and noticed a positive difference. He went off the focalin for a period of time and is now on Vyvannse (a very small dose < 5mg). This seems to work better than the Focalin for him, but I know this is a difficult area to manage and need to be open to changes.

THE ALL – IN PROTOCOL

Today, John is doing very well. Why? A few reasons... protocol, teaching/therapy and he is highly motivated. His speech, vocabulary and sentence structure are very good. He is able to learn letters, words and numbers. He enjoys almost everything: books, puzzles, athletics, singing, swimming, you name it, but especially being with people. Therapy is wonderful, but therapy won't work by itself without cognition...that is where the protocol comes in. As Dr. Cody says...The protocol is great, but it does not work by itself, you must have interaction/teaching/therapy. Joanne Mothes, special education teacher, has know John since he was 2 weeks

old. She has been a tremendous help to John (and us) during her tutoring visits to Houston and consultations over the phone.

LEAKY GUT – FOOD SENSITIVITIES

Unrelated to the protocol, John had a 'leaky gut' problem from birth. He is on a gluten-free / casein-free /soy-free diet. With the help of the Thoughtful House in Austin Texas, he no longer suffers with diarrhea. I only mention this because a number of people with DS also have food allergies and leaky gut issues that can further complicate lack of cognition and learning difficulties. This has also improved his quality of life.

MY THOUGHTS ON JOHN

I adore my son, John Michael Connell. I fell in love with him the day he was born and bonded with him immediately. I love him forever and always, I love him for who he is and not for what he does. Of course, I'd rather not give him any medication. He must take thyroid medication everyday also. Bottom line, it is not about me...it is about JOHN and what JOHN would want. John is an important person, a child of God, who will one day be an adult.

Susan Connell

