Dr. Rosario Trifiletti ("Dr. T")

Autobiographical

"I believe we have the clinical experience, medical and genetic data to truly help children with PANDAS/PANS and autism.
I would cherish the opportunity to help your child."

I was born in 1958 and raised in Whitestone, Queens. I moved to Park Ridge, NJ in 1972. I attended St. Joseph's Regional High School in Montvale, NJ and Seton Hall University in South Orange, NJ, graduating as salutatorian of the 1979 Graduating class, with a B.S. in Chemistry.

I then went to Johns Hopkins University School of Medicine in Baltimore, where I graduated with MD and PhD degrees in 1986. My PhD was in Neuropharmacology and was mentored by Dr. Solomon H. Snyder. My thesis concerned central-type benzodiazepine ("Valium") receptors. During 1985-86, after competing my thesis work, I spent an additional year in Dr. Snyder's lab, during which time I purified the peripheral-type benzodiazepine receptor of the outer mitochondrial membrane and demonstrated its interaction with VDAC aka porin, through which mitochondrial product efflux to the cytosol. Although not fully appreciated at the time, subsequent studies over the next three decades showed this was a key control molecule in metabolism.

From 1986-1991, I completed a internship in Pediatrics, residency in Neurology and fellowship in Child Neurology at Columbia-Presbyterian Medical Center, in NYC. In 1991, I was appointed assistant professor at Columbia and opened my own laboratory. During this time, in collaboration with Dr. Darryl De Vivo and colleagues, described the first cases of GLUT1-deficiency, aka De Vivo disease, where there is deficient transport of glucose across the blood-brain barrier. I devised a method to utilize red blood cell glucose transport as a surrogate marker for blood-brain barrier glucose transport and used it to prove GLUT1 haploinsufficiency in affected patients. I also worked on the role of nitric oxide (NO) in neonatal stroke, and provided the first evidence of in vivo protein tyrosine nitration in animals and humans, now known to be a very important process in the neuron.

I moved to Cornell University Medical College in 1994. In 1998, while at Cornell, I attended a lecture by Dr. John Zabriskie, of nearby Rockefeller University, that would change the course of my career. Dr. Zabriskie mentioned the word "PANDAS", a new disease just described by Dr. Susan Swedo and her colleagues at the NIMH. Dr. Zabriskie needed a pediatric neurologist to assist him in a collaboration I was setting up with Dr. Swedo, and I volunteered. After seeing a few of these utterly fascinating patients in whom mental illness was apparently cured by antibiotics or anti-inflammatory agents, I knew I wanted to spend the remainder of my career figuring out what was going on.

I left Cornell in 2002 to become Chief of Child Neurology at St. Vincent's, Manhattan and then in 2003 was appointed Chief of Child Neurology at UMDNJ-Newark. I focused on PANDAS/PANS at both places. Also, while at UMDNJ-Newark, I ran the Autism Clinic of New Jersey, which provided an opportunity to see many autistic patients, particularly from an inner-city population.

I spent the next 22 years of my life focused on studying PANDAS and the "renamed" version of the condition, PANS. A significant number of developments arose room this:

1. A clinic, called the "PANDAS/PANS Institute" was developed in Ramsey, NJ. This the only clinic in the world that I am aware of, that sees children suspected of having PANDAS/PANS on an everyday basis. **We have now seen over 5,000 patients suspected of having PANDAS/PANS, the largest experience in the world**.

2. I have developed, through years of progressive revision, and optimized workup for PANDAS/PANS. The basic philosophy is find the trigger(s), treat the trigger(s) and evaluate thoroughly for immune system function. **The treatment is based on data, not guesswork.** I am convinced that, at its heart. PANS is an immunopathy characterized by an **"alternative fever response"** (more on that elsewhere in this web site)

3. Development of a large database of over 600 patients, all personally examined of whole exome sequencing data. This currently involves over 6.8 million lines of dataWe have developed protocols to analyze this data and are rapidly closing in on "PANS-risk genes". This is by far the largest genetic database on PANDAS/PANS in the world and continues to grow daily.

4. After studying patients with PANDAS for many years, it became apparent that the incidence of PANDAS/PANS is particularly high in children with Autism. As a result, **I am starting our AUTISM INITIATIVE in 2020**. We perform a fast track medical and genetic evaluation similar to that in the child with PANDAS. Within three months time, we can have a full, multi-disciplinary, evaluation.

In summary, I was trained as a Child Neurologist and a medical scientist, and I remain a Child Neurologist and medical scientist, always using a scientific perspective to evaluate children with PANDAS/PANS and autism. **Humility in the face of the extraordinarily complexity of the body** – there is so much we don't know scientifically- that it gives license to "think out of the box" at all times. In my opinion, this is the best way to establish a firm diagnosis and optimal treatment.