

Boston CME

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Wendy Baruchowitz

DYSAUTONOMIA INTERNATIONAL



AWARENESS



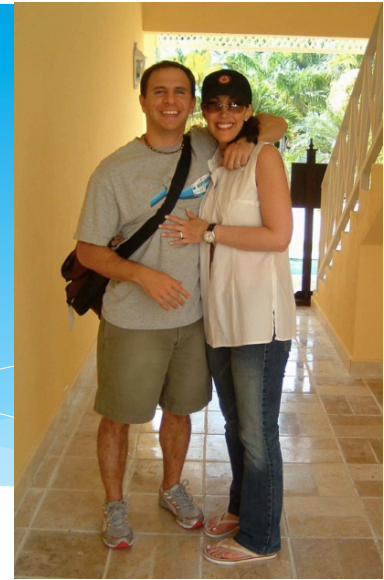
ADVOCACY



ADVANCEMENT

Life Before POTS

- * Family and I moved to Rye, NY in 2010, after stints in NYC and Hoboken
- * Future seemed bright. Married to my husband, Mitch and mother to my five-year old son, Braden.
- * Active woman, working at an ad agency in NYC and just settling in new home when I became pregnant via IVF with my second son, Blake at age 39.



Life Before POTS

Had some health “annoyances” but no real concerns until being diagnosed with Celiac in 2008

- * Trouble waking up in the morning
- * Fatigue feeling all day
- * Never liked to stand for long periods of time
- * Lethargic
- * Instinctively always crossed my legs while seated
- * Stints of anxiety and depression
- * Sometimes felt water dribbling on my legs, but they were dry to the touch

2011 The Year of Major Change

- * Pregnant with my second son, placed on bed rest
- * 1 week before birth, I was given clearance to move
- * Aside from being out of condition, I had severe difficulty moving around
- * I knew something was very wrong
- * One week before giving birth I had done research and read about POTS and a light bulb went off
- * Gave birth to my son



SYMPTOMS – What POTS Felt Like

- * Lost my ability to function overnight
- * Woke up feeling hungover
- * Resting heart rate was 150-160
- * Intense Dizziness
- * Floaters in my vision
- * Headaches
- * Pre-syncope upon standing
- * Nausea and vomiting
- * Debilitating fatigue
- * Gastrointestinal issues
- * Insomnia
- * Anxiety
- * Depression
- * Adrenaline rushes
- * Inability to hold in urine – constant need to urinate

Frustration of Getting Properly Diagnosed

- * Lack of information or medical awareness of POTS deeply affected my mental health, causing fear, anxiety and depression
- * Rejection self diagnosis by medical community was deplorable and insulting - told I had CFS, anxiety, post partum depression but no validation of POTS as a possibility
- * Numerous doctors, numerous incorrect evaluations:
 - * Cardiologists
 - * Neurologists
 - * Primary Care Physician
 - * Psychiatrist
 - * Post-partum specialist

Diagnosis!

- * Repeated misdiagnosis from numerous highly rated NYC medical institutions
- * Doled out anti-anxiety and anti-depressant medications
- * Diagnosis? Post- Partum Depression
- * POTS diagnosis came from a cardiologist in NJ

Day 1 – How To Proceed

- * Exercise prescribed to get my heart rate up
- * Drink copious fluids
- * Add extra salt to diet
- * How to accomplish this in my state?
- * Trial and error – very small increments
- * P90X



**KEEP
CALM
AND
EXERCISE**

6 Months Later

- * Swim everyday as a protocol
- * Still working on daily regime for my health
- * Some symptoms had subsided, others still troubling
- * Experimenting with medications (Zoloft 50mg, Metoprolol, 25mg, Trazadone, 100mg, Xanax, .5 mg)



Year 2 and 3 My Daily Regime

- * 1 teaspoon of warm Celtic salt water every morning
- * 60-80 ounces of water and additionally adding salt to drinks and foods
- * Made trip to Ohio to see Dr. Blair Grubb
- * Began building up to orthostatic, cardiovascular exercise
- * Treadmill – began in small increments



My Life Today

- * Daily cardio exercise for 30 minutes
- * Workout 3 days a week with a trainer doing circuit training, building core strength and weight bearing exercises to build large muscle mass
- * Walk 5+ miles a day
- * Reiki once a week
- * Meditate regularly
- * Went back to school and earned a degree in integrative nutrition and have my own practice



How Can You Help?

- * Awareness! Knowing about POTS and dysautonomia first step to helping patients
- * Early diagnosis is key!
- * Key threshold diagnostic tests in the office
- * POTS is a puzzle: recognizing uncorrelated and multiple symptoms can greatly help patients improve by figuring out the correct protocol early on
- * Can help reduce stress, mental and physical anguish and frustration of going undiagnosed



Knowledge is Power!

- * Having tips to give patients can be impactful-adding salt, fluid intake, proper nutrition, pursuing exercise in a moderate way-can help patients ameliorate some of the more acute symptoms and give hope to someone with a recent diagnosis
- * The medical community wasn't aware
- * I listened to my body
- * There were things I could do to help ameliorate my symptoms



Research and Awareness

- * My goal is bring awareness to the general population and doctors and raise funds for research
- * Incorporating POTS and dysautonomia in the medical schools curriculum
- * Inform patients about lifestyle changes – nutrition, exercise - for example I eliminated gluten from my diet



Life Reclaimed

