

TMR and IACC SURVEY

Fall 2014

Q1.

Thinking Moms Revolution and TEAM TMR are composing a public comment for an upcoming IACC (Interagency Autism Coordinating Committee) Workshop. We would like to speak for all the Thinking Moms out there who are in the trenches recovering and healing their children. So we are asking for your help. What would you like to tell IACC about "Under-Recognized Co-Occurring Conditions in ASD"

- All the so called under recognized co occurring conditions are extremely common. Most kids I know with Autism have gut issues, encephalopathy, sensory processing issues, heavy metal toxicity, seizures, food allergies, sensitivity to food additives, PANDAS, mitochondrial dysfunction, cerebral folate deficiency, multiple vitamin deficiencies, low tone, and speech delay. These are varifiable by testing. Study this, not genetics.
- Autism is medical.
- My son's thyroid, not just his brain, was derailed. He's gone from 50 percentile in height to 25%, to 10%, to 5% and after twelve years of this nonsense, he now sits at 3%. Improving immune system function, digestive health which includes avoiding processed foods and GMOs, detoxification and exceptional nutrition are key to restoring health - but they do not guarantee it. Recovery, if possible, is very expensive. But, the alternative is even less affordable.
- These babies' bodies are SICK...THAT leads to neurological issues...not the other way around
- They do not represent my family.
- Autism is medical and the result of toxic food, chemicals and a far to aggressive vaccination schedule.
- PANDAS/PANS Autoimmune issues Stomach/gut issues
- Mercury toxicity from mother's amalgam fillings.
- That the gut & brain are intertwined. Co-occurring conditions are real and the government(IACC) should stand up for our children and change the paradigm.
- They are real. They exist. They are not mental disorders but toxin induced brain injuries.
- According to my family and my son's medical records, he was developing typically until 16 months. Something happened to my son.
- These co-occurring conditions should be studied and be treated seriously.
- They are the cause of autism
- We simply must stop promulgating this myth that autism is a behavioral diagnosis. There are neurological and biological differences in individuals with autism, but doctors still very much

treat each condition like it is separate and unrelated to autism.

- I am not sure
- I think its time to stop sweeping this issue under the rug. While I myself am not an autism parent, I do have a child who suffered an adverse reaction to one shot and I know many, many parents with children on the spectrum. Many attribute it to the shots. I believe them. They know their children. They know their child changed in correlation to the shots they received. I also have some dear friends whose son's dr recently gave him the medical exemption he needed and deserved because they know shots make his PANDAS and autism even worse. It has been noted he does react to the adjuvants contained in shots.
- PANDAS/PANS Coinfections-borrelia burgdorferi, bartonella, rickettsia, ehrlichia, anaplasmosis
- pandas/pans as well as mitochondrial disease need to be recognized in our autism community because in some cases, they have caused the autism behaviors/diagnosis.
- I don't know
- There are many
- I don't have a child. I don't know anyone close to me with autism but I would have to be blind and deaf to not recognize the links between the two. I think the public statements concerning population control will always be the crux of the vaccinations. I don't believe I will ever live in a world without vaccinations but I will continue to speak out and with those organizations who promote the truth about the deadly injections. Should I have a say so over what goes into my body and my future child's body? You're damn right. Because to say I don't is to say I'm owned without human rights.
- Behavioral problems in young children are not a psychiatric disorder. All underlying medical issues - family history of autoimmunity, GI, PANS, food allergies/sensitivities, immune - must be investigated. Prescribing a five year old Ritalin (UIC) in 2004 and locking an as yet undiagnosed child with "autism" in a "quiet room" in Chicago's Children's Memorial Hospital in 2006 are inexcusable.
- They need to look at MTHFR, GI diseases like colitis/crohns, and mitochondrial disorders.
- There are no 'legitimate' studies to research vaccination reactions and why number changed from 1:10,000 to 1:69 in 10 yrs
- More research into seizure disorders, anxiety disorders, acid reflux, high instances of copper in blood serum, etc...
- The biology of the child & all the health issues that go along with this is vitally important, it's not "ABA" only that's going to help, need to look at the body.
- They exist! Nervous systems are being affected. Brains are being inflamed. Skin disorders, allergies, gastro problems, all exist thanks to toxins.
- My son was vaccine injured. My doctor at the time said give ibuprofen. Then she said the things that we were seeing were "just him", we took him to get evaluated elsewhere and when I called the Doctor back to say my boy had autism and asked for a return call to discuss treatment options. The pediatrician refuse to return my call. My kiddo was developing properly before the MMR shots. They didn't give me any info for reporting a vaccine injury. Nothing... He was dropped like a hot potato. I asked questions before shots and was told they were safe. I wasn't given any information on any options I had per refuse shots, limit shots.
- If there is a chance that ASD is caused by vaccines, we need to investigate that

- Non verbal children need help. They have so much to say and can't need more help with coverage for services and research to help these kids.
- (Vaccine induced) toxic brain damage in my sons medical chart in 7 places. Following his MMR. RSV after his 6 months shots that lasted 8 months. Being evaked for XLA now. He has Lyme disease, PANDAS, chronic strep over load in his gut that years if antibiotics has not been able to wipe out like MRSA, yeast over growth, had chronic ear infectuons , multipule food allergies, seizers since vaccines, hasnt had solud stools since MMR going on 11 years straight dispute some if the best specialist in the field, pancreatic insuffincy, glucose regulation issues, thyroid auto antibodies, hyper extended joints, low tone, glasses early, skin issues, unless on meds fungal foot infections with peeling toes, lowseritonin, low lithium, can get violent, ODD, OCD, tics, ADD...can no longer attend public school because of his medical damages in packing health and immune system effecting brain function, impulse control and behavior.....stolen future
- Daughter born with simian crease, small left pinky, curved pinkies. Early speech. Began to regress at 18 months. Sensory issues, shyness, anxiety. At age 5 suggested possible ion channel disorder and periodic paralysis after investigating guillaine barre, ms and metabolic disorders. Family history of autoimmune disorders. Diagnosed with fibromyalgia type pain processing disorder, anxiety, adhd. Suffers from chronic fatigue, 80 processing IQ, 130 language IQ.
- Autism involves a great magnitude of health issues such as Mito dysfunction, PANS, PANDAS, Lyme, etc., not just behavioral. It's medical big time.
- Intestinal dysbiosis (constipation, or diarrhea or both), ocd, feces smearing, wandering, self-injurious behavior, tics (motor and vocal), hyperimmunity, allergies, food intolerances - shall I go on?
- GI issues; sensory processing dysfunction
- It is imperative that you recognize ALL Co-Occurring Conditions in ASD!
- We need to quit looking for a genetic cause, because we already know many of the causes or "triggers" for our children. We need others to recognize that there are many conditions that occur along with autism, and start making the treatments available to families without having to fight for help from doctors and insurance companies. We need to realize that treating these conditions can reduce or eliminate the symptoms of autism. We need to stop telling people to "accept" autism. It is medical and it is treatable! Children can be recovered!
- Pathogens, including Lyme (Borellia burgdorferi), parasites (ascaris), mercury, aluminum, food and environmental allergies, brain damage, nerve damage
- Digestive
- Issues with OCDs and GI issues
- You cannot underestimate the influence of vitamin and mineral deficiencies on autism symptoms.
- That diseases like mitochondrial disease,CFD,PANADS/PANS are often more severe than the "autism" itself
- That autism is not a condition. It's a word used to describe the behavioral effects of induced medical issues in children.
- Vaccine toxicity

- Not all autism is alike. The more severe the child the more in need they are of medical treatment for their symptoms. The symptoms are result of the co-occurring infections.
- When I treat my son's Co-Occuring conditions including PIDD and IBS his autistic symptoms fade. It is all connected.
- You should have listened to the parents, especially Lynn Redwood.
- Severe gi pain looks like "classic autism symptoms ". Sib, head banging, diarrhea, hyperactivity , inability to focus or tolerate slightest touch.
- Be honest and productive already.
- They exist. Sensory, allergies, mito, they are all there for so many of our kids.
- The well documented co-occurring conditions in ASD are too often ignored and written off by the medical community instead of being treated.
- Diet, gut, natural interventions
- first, go to hell, second, LOL, you need to come clean now, and third an unvaccinated vaccinated study an insurance updo...that we get full compliment therapies covered like hbot, IvIG, immune therapies.
- Please see my reply to question #8
- take action to stop killing/disabling children around the world
- Just because a child has autism doesn't mean they don't have co-occurring conditions that shouldn't be treated by hospitals and Doctors.
- It is not that the co-morbid conditions are unrecognized by the medical profession as a whole. It is that the co-morbid conditions are not getting treated because the pediatricians say "oh, that's because he/she has autism". And since they feel that autism cannot be treated medically, somehow that makes it OK to ignore the responsibility to investigate the cause of and treat the co-morbid conditions such as GI issues, hypothyroidism, immune dysfunction, general malnutrition, etc.
- Read the paper, "Metabolic Features of the Cell Danger Response" and note all the possible triggers of the cell danger response, along with all of the downstream consequences of the cell danger response. You will understand why there are so many sub-populations, why it is so multi-factorial, and why the same protocol that recovers one child will not recover them all.
- Even though my kids don't have autism, we still struggle with possible PANDAS, vitiligo and outer auto immune. I personally am very concerned about children with autism and getting help for families. My kids were never vaccinated but had several courses antibiotics and Tylenol and I strongly believe had they been vaccinated we would have an autism diagnosis.
- They are missing a key element in their agenda - gastrointestinal dysbiosis. Unless it is covered under the "Metabolic and Immune Disorders" piece - that could be the underlying cause linked to all the key points they are addressing.
- Heavy metal toxicity.
- That they need to recognize them and make them mainstream so that doc's can never again say "he has autism, we aren't going to treat"
- I am the grandmother of 2 boys with autism.....I have legal custody of one....we can not afford to try most of the things that would or could aid in healing.....what will happen to our children who cannot take care of themselves ??
- Our childrens co-occurring conditions are overlooked by mainstream medicine BECAUSE of

their ASD dx. Any typical child can go to a Dr. and receive treatments for bowel pain, food allergies, diet change, DENTAL CARE. But not my child with an ASD. I'm told "Oh well that's just a symptom of Autism" Yeah, fix that.

- Autism is an umbrella term for a number of medical conditions that cause "autistic" behavior in children. Most if not all have a leaky gut and heavy metal toxicity. Leaky gut usually is combined with bad bacteria, yeast overgrowth, biofilm that locks it in and parasites. Treat the gut and detox the metals and slowly the "autistic " behaviors will decrease and eventually disappear.
- Physical symptoms should never be ignored, regardless of a persons behavior. The behaviors that present in autism can be related to physical symptoms such as pain (as they were in my child). Heal the issues that are causing the pain and "magically" the behaviors improve. Also, most of the children I know with autism, have parents with binders full of clinical presentation of illness in their child, followed up with laboratory testing and appropriate medical intervention, that has resulted in numerous "recoveries". Why are our government & medical communities ignoring this? We have the documentation available. It defies logic!
- Chronic infections in ears, throat, sinuses Strep infection Neuropathy Weakened Muscles Allergies & Asthma Digestive problems, constipation, diarrhea Rash Mentally exhausted
- ADHD, over- or under-weight, seizures, are just a few of the co-occurring conditions I have had experience with.
- My son, as do SO MANY OTHERS, has severe GI issues that I have had to fight for 4 years to get someone to help him with. Doctors, Nurses, teachers, school administrators have no idea how to help or that IT ACTUALLY IS AN ISSUE for our kids. Please stop focusing on genetic causes and look into stuff like gut bacteria. ARI - Prof. James Adams is doing fabulous research at ASU that is FDA Approved! Lets spend money where we see results that ACTUALLY HELP people.
- food sensitivities and environmental allergies. Change in intestinal track...she went from normal bowel moments to either having diarrhea or constipation all the time (for about TWENTY YEARS NOW!!). Immune dysfunction that makes them catch EVERYTHING and then they fight it five times longer than other children. O.C.D.; anxiety; visual and auditory dysfunctions and sensitivities; low muscle tone; low to almost nonexistent energy levels.
- Bastards!
- Well I think I would stat out with the poor neglected elephant which caused brain damage and goodness knows what other bodily damage when my daughter received her MMR. Since IACC refuses to acknowledge us parents after all these years and address vaccines. I would also like to tell them that its absurd it took twenty years for the science under their leadership to even admit to gi issues and we still are nowhere with answers regarding diets, probiotics, indentifying/screening, treatments. I would discuss why we can't manage to come up with any plan for doctors to actually test for underlying conditions such as mitochondrial dysfunction or mthfr or lyme. Why we aren't looking at viral loads and vitamin deficiencies still? Basically what the heck have they done in all these years besides waste time and ignored our calls on every single thing for years now!
- Primary immune deficiency, bowel disease, apraxia of speech, antibodies to measles that stop measuring at 5 times normal, encephelopathy, death by wandering, seizures
- GI issues, pancreatitis, ITP, anemia, chronic malnutrition,PANDAS

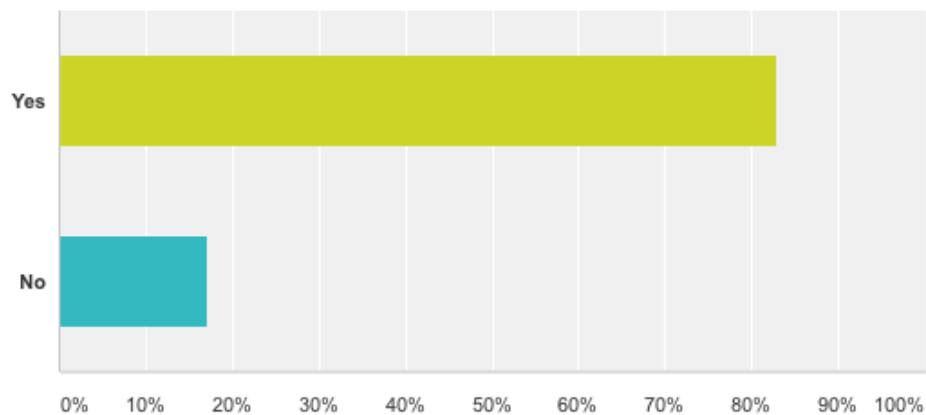
- My daughter has several "medical" condition as a result of her 1 yr old vaccines.
- They are real. Head banging is not 'just autism'. it goes away when brain inflammation is treated.
- 'Seizures'... how could a so called non physical DX have so many physical things going on... Would it not be better to study the GUT that feeds the brain?
- yes
- **THAT THEY ARE REAL, ALL OUR CHILDREN HAVE THEM, AND THEY HAVE THE RIGHT, JUST LIKE A CANCER PATIENT, TO GET THE TREATMENT THEY DESPERATELY NEED!!!**
- The physicians out there are clueless and think this is just some neurological/behavioral disorder. These kids are ill and until these physicians can recognize that these kids really have an auto-immune disorder they will never get better. The parents are the ones recovering these kids not physicians.
- Autism and gastrointestinal disease, and interventions 2. Environmental impacts and regressive autism 3. Autoimmune interventions 4. Food allergies and autism 5. Brian inflammation, and interventions 6. Immunomodulatory therapies 7. BioMed... BioMed... BioMed... 8. Yeast and fungal infection among those with autism 9. Identify environmental risk factors and facilitate prevention 10. Demographics and active surveillance 11. Case management protocols
- My son had diaharrea and yellow, mustard like feces. I was told this was what some kids with autism have. I didn't believe it. We got him scoped, found out he had an inflamed instestine, and gave him an anti-inflammatory. He potty trained himself at six years old, two weeks after we gave him the medicine. Look for the story under the story.
- Mitochondrial dysfunction and or disease
- Need to do something about autism rates and help the families in this situation. get on board with the best doctors and try to come up with a treatment for getting the toxins out of their systems
- Children should be screened before receiving medical interventions, such as vaccines. Autoimmune diseases and mitochondrial dysfunction are more common than originally thought, especially in children/families that are affected by autism. Allergies/intolerances/sensitivities are also much more common now, and organic, GF/CF diets are making huge improvements in overall quality of life for those struggling with them.
- I would just want to say it needs to be recognized our children are sick. I have talked to so many whose children have GI issues, PANDAS, PANS,mitochondrial dysfunction, seizures, ect...the list goes on. We have to address these issues in our children. I have had experiences where because my son has a diagnosis of autism his health issues are not taken seriously. We have been to numerous doctors who have no clue how to help our kids. Parents with children with autism usually go broke trying to help their child. This has to change!!
- No comment
- It is important to listen to the mothers of children on the spectrum. They certainly know their children better than their doctors.
- ASD is not a behavioral disorder. It is a gut/neurological disease. You must treat the disease, not the behavioral symptoms. Autism is a disease, an iatrogenic disease.

- My child is sick. She has many underlying medical conditions due to the toxic assault on her body.
- Please devote study to medical conditions such as IBD, mitochondrial disorder, oxidative stress, food allergies.
- my son is 23 and violent. He is morbidly obese from past medications. He may have another undying disorder such as bipolar but because of lack of language it is not diagnosable. He gets skin allergies in the fall season, no tests have been conclusive on what exactly.
- The environment that the child is in needs to be clutter free with as little an occasion to say "no" as in "don't touch that" "don't do that". If you don't have "that" there it's much easier for the child. Also this emphasis on technology and electronics to "help" our children is not helping them in the long run. One to one is BEST for these kiddos until THEY are ready!!!! Not on our "timeline". Just sayin.
- I would like to tell them to please open their eyes, admit that autism is a full body disorder, immune system, mitochondrial disorder, MTHFR gene mutation, heavy metal toxicity, malabsorption, leaky gut, candida.
- This needs to be an area of research instead of spending millions of dollars on genetic research. There needs to be research done examining unvaccinated vs. vaccinated.
- Autism IS medical
- My child suffers from extreme chemical sensitivities and makes for a limited life on places she can go.

Q2. Tell us a little more about your journey. (optional) Do you have or have had a child with an Autism or ASD diagnosis?

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Answered: 88 Skipped: 12



Answer Choices	Responses
Yes	82.95% 73
No	17.05% 15
Total	88

[Comments \(21\)](#)

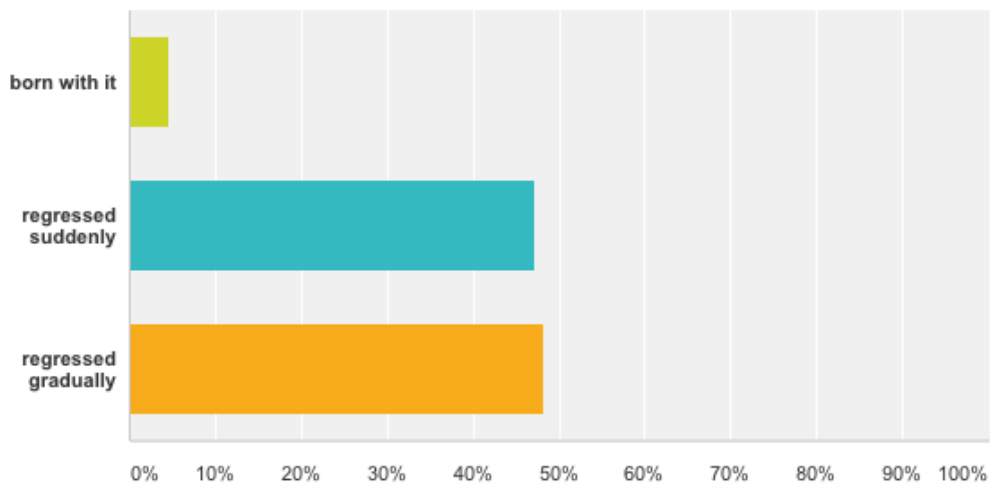
- my child does not have autism but rather autistic like behaviors and suspected acquired mitochondrial disease
- Mine is dxed with ASD and PANS - his NT younger sibling also has been dxed with PANS
- ADHD
- although, after many years....RECOVERED
- PANDAS and now coinfections of lyme
- No specific diagnosis
- My child is unvaccinated
- Atypical presentation
- My son was about 75% of the way to an ASD diagnosis before starting biomedical

interventions.

- ASD adult diagnosed in the last five years,with CFD,mito,and 5,10-MTHF Deficiency
- My son is 15 w/Regressive Autism. My daughter is 12 w/ Moderate to Severe Autism.
- sensory integration disorder
- I have two boys with autism
- PANDAS, auto immune
- DX at 26 months, after chelation and biomedical interventions, at 4, didn't fit criteria
- 2 grandsons
- He is 7 and is on the way to recovery!
- RECOVERED, NO DX ANYMORE
- TWO children... out of my three...
- twin boys with mitochondrial dysfunction and autism
- Both of my children have Autism.

If Yes, Was your child born with "autism" or did they regress or develop "autism" and if so what age?

Answered: 89 Skipped: 11



Answer Choices	Responses
▼ born with it	4.49% 4
▼ regressed suddenly	47.19% 42
▼ regressed gradually	48.31% 43
Total	89

[Comments \(80\)](#)

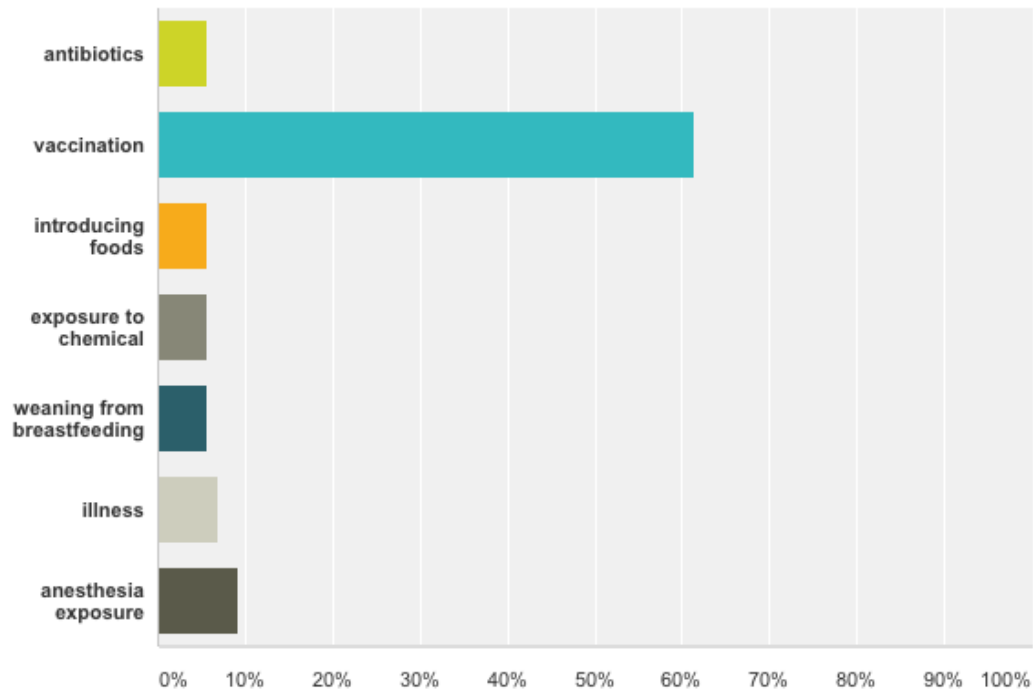
- regressed intermittently.... waxes and wanes
- Around 2.5 we had a huge change in behavior
- 12 months

- A month or two after 4th birthday. Suddenly, without fever or any sign of typical illness following DPTP vaccination. Worsened with antibiotics and general anaesthetic.
- 15 MONTHS.....immediately following vax
- 18 months
- 18 months
- 15-18 months
- 12-18months
- 2 years
- On or after 16 months
- 3 yrs old
- 6 months
- around 3 months old
- 12 months
- 3, even more at 5-6
- 18 mos
- 12-18 months
- 6-7 months
- 6 mos 1 hr after 6mo vax
- 18 months - after MMR
- 2
- 12-13 months
- Right after MMR shots, vaccine injuries.
- 13 months
- 12 months. was tested 2 weeks before shots with developmental score of 18 months development, regressed suddenly with shots at 12 months. retested 2 weeks later scoring sudden development of 2-4 months by same state evaluator through parents as teachers
- 2 yrs old
- 3ish
- 13 months old
- 18 months
- 12-15 months of age
- 1-2
- 12-18 mos
- 18 months
- Gradual decline from age 3 weeks (sleep problems), worse regression after anaesthesia at 2.5 y.o.
- 6 months
- 12 months.
- 15 months
- 12 mos.
- My son approx 18 months & my daughter approx 16 months.
- Post surgery

- stopped growing and regressed after 18 month shots
- I believe he was born with it but also regressed further into it.
- 18 mos
- for son 1, for daughter 2
- 24 months
- 18 months old for both my boys
- ~12 months
- 15 months
- 7
- 15-18 months
- 3y 1mo
- 18 months
- 15mo
- 1
- 18 months
- 1 yr
- between one and two years old
- 15 months
- Between 9 -12 months
- 16 months
- Following MMR vaccine
- 15 months
- 1 year old "well" checkup after MMR
- after 6 month well visit - head went from 3rd percentil to 60th in a few weeks time.
- One child, regressed slowly and has regressed a total of THREE times. The other child regressed suddenly, at age 4.5
- 2 yrs old after 2 mycoplasma infections
- 18 month acute regression
- 14 months
- I think Hep B at birth and flu vaccine plus h1N1 and then MMR damaged everything
- My oldest at 16 months, my youngest at 24 months.
- Let's say birth - she had the Hepatitis vaccine the day she was born!
- with each dtap shot he got worse and worse, until I finally noticed at 15 months what was happening
- 13 months
- day of birth
- 1 year and 8 months.
- 2.5
- 2years old
- 2 months

If your child regressed, what do you believe was the trigger for your child's regression?

Answered: 88 Skipped: 12



Answer Choices	Responses
antibiotics	5.68% 5
vaccination	61.36% 54
introducing foods	5.68% 5
exposure to chemical	5.68% 5
weaning from breastfeeding	5.68% 5
illness	6.82% 6
anesthesia exposure	9.09% 8
Total	88

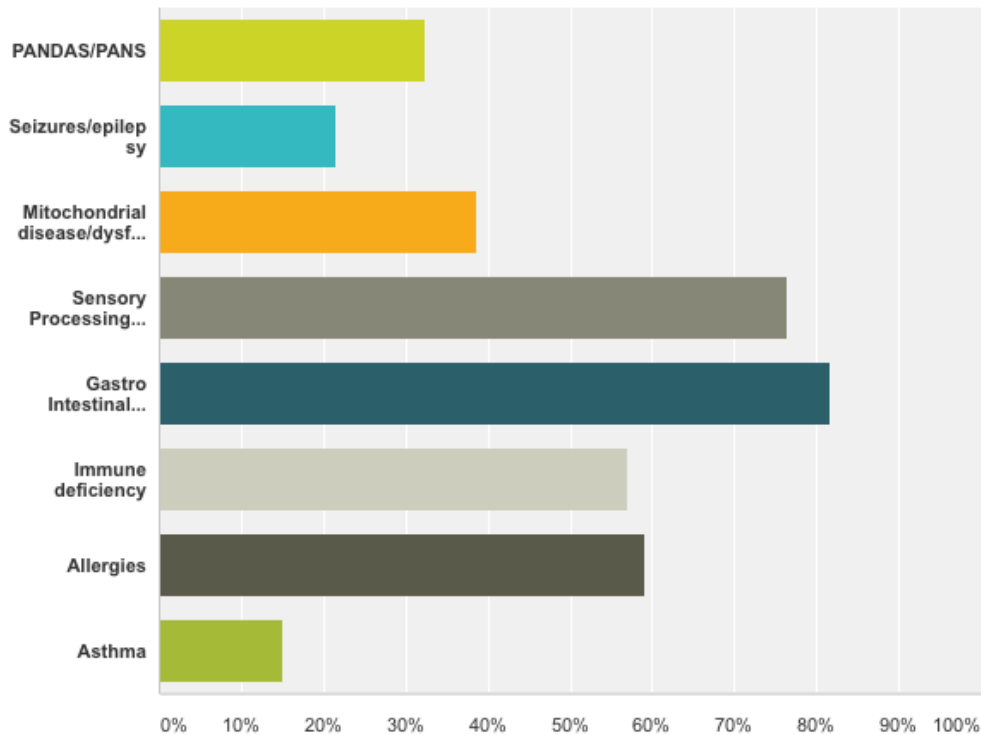
[Comments \(32\)](#)

- colic and food allergies gone south triggered by toxic insult...
- The more I read I think it's vaccinations that triggered PANS and ASD
- possibly exposure to a moldy house
- Mercury exposure from amalgams breaking down when nursing.
- My son had monthly, sometimes more frequent very high fevers (105 degree) disregarded by pediatrician.
- received MMR, spiked fever, seuzersed and rushed to ER. vaccine reaction noted in ER record. we lost everything, eye contact, smiles, playing, communicating and walking

- Exposure to chemicals, antibiotics, pediatrician suggested vaccine injury, then immediately covered his mouth and never referred to this again.
- GMO foods
- Had high fever, rash and terrible diarrhea exactly 14 days after the MMR/Varivax at 12 months of age; developed signs of brain damage--toe walking, vertical nystagmus, petit mal seizures
- poor medical choices during pregnancy and birth
- Regressed after 15 month shots
- my son was injured in utero by the flu vax, RhoGam and antibiotics.
- MMR at 12 mos.
- in utero exposure to mercury
- Antibiotics, vaccines, compromised immune & tylenol
- main hit, vaccines, second weaning, third genetic immune defects
- Combo of stop breast feeding at age 3, antibiotics, Tylenol for UTI some minor symptoms from about 1.5yrs to explosive at age 7
- actually several of the above - MMR + Weaning + bad case of influenza
- Flu vaccines in utero that mother was badgered into getting started the decline
- And vaccines
- vaccinations AND antibiotics, and the birth mother was a drug addict.
- Vaccine was tipping point, but lots of factors above didn't help
- all of the above minus anesthesia
- and anesthesia, along with antibiotics, but the MAIN cause Vaccinations!!
- 9 vaccines: 1 Well visit
- Combination, not one thing more than the other. Antibiotics, vaccination, environmental toxins, autoimmune disease, difficult delivery, Pitocin.
- antibiotics, vaccines and my mercury toxicity from amalgam removal just prior to pregnancy.
- My son reacted to the hepatitis B vaccine at birth. He showed signs of autism from early on, so it cannot be called regressive autism, but I do believe it was due to vaccines.
- not sure, possible vaccinations. he had ear infections and had several rounds of antibiotics.
- Combo of vaccines but being a premie and in the NICU for 3 months and getting many "treatments". Of course they were trying to keep him alive however there was no addressing the damage that was probably done already. No guidance.
- also antibiotics and chemical exposure.
- And later anesthesia exposure

What co-morbid medical conditions does your child with ASD have?

Answered: 93 Skipped: 7



Answer Choices	Responses
▼ PANDAS/PANS	32.26% 30
▼ Seizures/epilepsy	21.51% 20
▼ Mitochondrial disease/dysfunction	38.71% 36
▼ Sensory Processing disorder	76.34% 71
▼ Gastro Intestinal disorders	81.72% 76
▼ Immune deficiency	56.99% 53
▼ Allergies	59.14% 55
▼ Asthma	15.05% 14

Total Respondents: 93

[Comments](#) (34)

- eosinophilic gastritis, immune deficient at one time, suspected acquired mitochondrial disease
- Not sure about mito yet
- CFD, low tone, global developmental delay
- Stopped having growth spurts after DPTP vaccine. Slow, delayed growth. This, as part of a cluster of symptoms, is consistent with hypothyroidism.
- although....after MANY years of biomedical treatments and diet....we consider her recovered

- Tics
- Lyme disease, Parasitosis, Babesia, Bartonella, Erlichia, Strep
- hearing loss, severe oral and verbal apraxia
- Low tone, minimal functional motion
- Originally high copper in blood, suffers from anxiety and stomach pain
- metabolic disfunction, thyroid issues, glucose issues, inability to absorb nutrition so many nutrition insufficiency dispute great diet intake and food choices
- Pain processing disorder, adhd, anxiety, fatigue, numbness, tingling in extremities.
- Inborn errors of metabolism
- Auto immune disease - transverse myelitis
- Lyme/Bartonella
- Sleep disturbances for both.
- heart block requiring pacemaker, liver dysfunction, mthfr homozygous, autoimmune/possible dysautonomia
- Lyme Disease, hypothyroidism
- Behaviour
- parasites
- Behavioral....self injuringtrying to rip their own skin off.....beating their heads on the walls or floor or even with their fist .
- No one in my area recognizes PANDAS, but we seek help for the symptoms
- CFD Apraxia Dyspraxia
- Pandalas/pans, and mito never tested (because nobody actually bothers when you have an asd diagnosis)
- Apraxia
- apraxia
- My oldest has everything except Asthma. My youngest is now recovered... but allergies remain.
- possible mito, no confirmation yet
- Central Auditory Processing Disorder, Eczema, Abnormal Neurotransmitter Function
- Lyme disease
- Anxiety - debilitating
- morbid obesity
- Lyme parasite yeast
- hypotonia

Q6. What treatment has been most important in your child's life?

Answered: 93 Skipped: 7

- Diet change, elimination of toxins and boosting nutrient levels
- Treating pandas got rid of most if his OCD, SPD and tics. Still working on social skills.
- GFCF diet, electromagnetic transcranial stimulation, GCMAF, Folinic and 5-MTHF supplementation, CD, Amantidine, and HBot.
- avoiding allergens, supplementation, homeopathy
- GAPS, exceptional nutrition from natural sources; homeopathy; and now we are trying Coseva ClearTRS to remove heavy metals. If I had been able to afford it, he would have also had HBOT.
- Biomedical and diet, including oral chelation
- GFCFEF
- A good allergy free diet, anti fungals and probiotics
- Diet, Sensory Integration Therapy, Homeopathy, Stem Cells
- Proper methylation, allergen removal, healing the gut, and chelation
- diet & antioxidants
- Chelation, essential oils,
- Dietary change, biomedical treatment
- Anti parasitics
- Methyl B12 injections Gluten/Casein and Dye & Preservative Free Diet Levocarnitine
- IDK? she was just diagnosed 6 months ago
- Healing the immune system via antibiotics-the right ones, after finding the all of the possible infectious triggers that produce ineffective immune response gut healing diet
- biomedical 2. speech
- Gaps diet, craniosacral therapy and chlorine dioxide protocol
- Homeopathy
- Neurofeedback, ABA, diet, supplements, DAN Dr./biomedical, chiropractic/brain balance, counseling, hippotherapy. Least helpful and fully paid for by insurance, Ritalin/antipsychotic drugs, ADHD diagnosis, partial "psychiatric" hospitalization.
- so mb-12 shots were one of the biggies for us
- G-tube and supplements
- Gluten and casein free!
- IVIG
- CD
- Son-rise, clinical nutrition, sensory integration therapy and Kerri Rivera's Protocol with the last being the most Obvious healing.
- Anti microbials to rid bacteria parasites and yeast

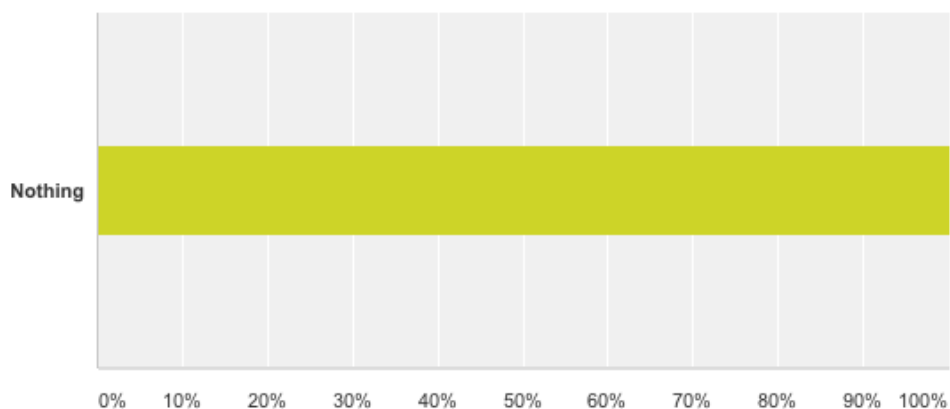
- Gfcsf diet, eliminating allergen and intolerance foods, secretin shots, HBOT, antibiotic and antifungal therapy (azithromycin, clindamycin, fluconazole, flucanazole) compounded, carnitine, vitamin A therapy for measles, addressing Lyme, PANDAS, essential oils, joint compressions, brushing therapy, DAN trained doctors who understood autism and co issues, testing biochemically and addressing what shows.
- Organic, gluten free diet, low stress, homeschooling or alternative schooling, art and drama therapy, supplementation.
- Diet. Detox. HBOT.
- Camel's Milk, MTHFR supplementation, diet (nonGMO, GAPS Diet), CBD, improving his visual processing system (rehabbing the brain after removing toxic/stress exposure)
- Diet, Chelation, Hyperbaric Oxygen.
- Biomedical (diet and supplements), chiropractic care, homeopathy, and auditory integration training.
- Diet, detox, HBOT
- Biomedical
- GF/CF diet for the GI issues
- Vitamin and mineral supplementation, gluten and casein free diet, low oxalate diet and FAILSAFE diet (low salicylates & amines).
- Leucovorin, GF/CF, mito cocktail in that order.
- Diet change De-chemicalized lifestyle De-tox Correction of vitamin and mineral deficiencies
- ABA
- Gf/cf diet and chelation of heavy metals/parasites
- IVIG
- ABA & medication for sleep.
- Immune and GI disorders
- IV chelation
- None yet - resistant to almost everything we've tried bio medically
- Nutritional interventions
- VNS/pacemaker, hbot, IVIG, plasmapheresis, gcmf
- CD, chelation
- Diet and supplements
- Medical treatment for hypothyroidism, immune dysfunction, GI dysfunction, inability to clear viruses.
- Mito cocktail
- Gaps diet, whole organic foods, MTHF supplements, and vitamins
- Restrictive diet
- Chelation therapy.
- CD
- Not much....there is no one within a 70 mile radius that is qualified to work socially or physically with a child who has autism.
- Diet change... all I can really afford.
- Diet. Treating the leaky gut.
- Gf/Cf and biomed

- Diet changes, chelation, low dose allergen therapy (LDA)
- chiropractic support for TMJ, allergies, muscle development drops for allergies As a result of so many infections and strep, my son had 4 surgeries to reconstruct sinuses and remove tonsils, etc. Physical therapy for TMJ, stiff muscles Glasses and vision therapy for convergency issues Exercise for mitochondrial Enzymes for digestion issues Fast ForWord for language development needed after so many ear infections
- ABA
- That's difficult to answer. We made a lot of progress and gained language/communication skills by 4 yrs doing Hab, speech, occupational, feeding, and music therapy. However, his GI health, cognitive awareness and communication went to another level when we began GFCF diet and nutritional supplements such as vitamin D and B12 shots. Diet has been the key to a happier healthier kid.
- change in diet, trying to heal gut
- Diet Chelation HBOT Supplements ABA
- Diet, adjusting vitamin deficiencies, supplements-NOT BEHAVIORAL THERAPIES.
- Diet, hbot, gcmf, detox
- Homeopathic care
- Supplements and GFCFSF diet
- intense detox
- 'Secretin'... Helped my oldest son the most. Ferring Secretin.
- Migraine treatment
- We've done so many, but I think treating his gastro issues first. We've tried many things, they've all helped to some degree.
- CD protocol and homeopathy
- BioMed
- The biomedical treatments we used have helped my son feel better-and therefore he is able to access the curriculum when he isn't in pain..
- GFCF, b12, HBOT, transdermal glutathione
- homotoxicology and mito cocktail
- Our DAN doctor's biomedical protocol and recommended diet.
- Scd diet, supplements for mitochondrial dysfunction(coq10,L car irvine,high dose vitamin c) digestive enzymes, and probiotics.
- Speech therapy, nutritional adjustments
- Biosyntonie - after one treatment she was calm and reasonable, much less anxious.
- son-rise, CD, ABM, diet
- Gluten free casein free diet, detoxification, and yeast fighters
- GFCFSF diet, Houston enzymes, supplements from Kirkman lab. We really should have done more biomedical treatments but we found out about them late (age 10 already), good providers in our area were hard to come by, and it is so hard to know what is best for each individual child. We did try some treatments such as B-12 which did not seem to make a difference for our son.
- constant love and attention. Repetition. But really nothing has worked.
- Son-Rise, Biofilm protocol.

- Biomedical intervention, gfcf organic diet, supplements, chelation, healing his body!
- GFCF diet, supplements, GI treatment.
- CEASE Therapy
- Restricted diet

What has the IACC done that has specifically helped your child

Answered: 86 Skipped: 14



Answer Choices	Responses
Nothing	100.00% 86
Total	86

[Comments \(7\)](#)

- sharing of information
- IDK what IACC is
- Encouragement not to give up
- Just found out about it
- they don't give a rats behind, and never will
- I am unaware of anything the IACC has done to combat autism. It's possible there is something but thus far I have been unimpressed with the direction of research continuing to focus solely on genetics and with the complete lack of a nationwide plan to provide much-needed services to children and adults with autism.
- I can't say that they have helped!

Q8. Name 2 things the IACC should be doing to help our children.

Answered: 93 Skipped: 7

- 1. establishing medical standard of care for autism 2. funding research to investigate the link between environmental toxins (including pharmaceuticals, anesthesia and vaccine ingredients) and autism.
- Stop focusing on genetics and look at environmental triggers
- Studying the link between vaccines and Autism in earnest, and ensure that all Autism therapies and treatments are covered by insurance.
- I will have to learn more about IACC to answer this question.
- Reduce the burden of the vaccination schedule: recognizing that vaccines are designed to provoke an immune response in healthy toxin-free children who are fed real food, and most children already have a compromised immune system, eat over-processed items from the GMO food chain and are exposed to toxins at an unprecedented variety and rate - and STOP GIVING PREGNANT WOMEN VACCINES. 2) Protect access to natural nutrition and health remedies. The loss of Heel in North America is not funny. There is no place for malicious litigation when recovering our children. 3) DEAL WITH CORRUPTION: Investigate corruption, remove conflict of interest from all vaccine, pharmaceutical, chemical and GMO safety studies, and remove any legal immunity for any corporation whose activities may pose a risk for deformities and autism - i.e. fracking; vaccination and other pharmaceutical damage; GMOs/glyphosate and other pesticide/herbicide use.
- Biomedical protocols.....covered ny insurance 2. Research that can "come to light" about vaccines...We NEED to PROVE IT
- Investigating vaccines
- Studies comparing vaccinated vs unvaccinated. Research those who have recovered and study that. Recognize that the majority of our kids are physically sick and that autism is medical
- Advocating for the health of our children period-no politics involved. Stop funding asinine and duplicative genetic studies. Providing direct support to families. Earmarking funding for the care and support of our adult population
- Research the effects of GMOs on the gut, and heavy metal exposure on the developing brain. Research the effects of grains and fortified frolic acid on those under 12 months old.
- changing the perception of autism from mental disorder to whole body disease. adult employment that is self sustaining & meaningful to adult's capabilities, just like anyone else. Autism Rights!
- Force the CDC to stop vaccines Make insurance companies pay for any and all autism treatments
- Pay restitution to our children and help them get better.
- Stop protecting big pharma by abolishing vaccine court, disallowing the CDC/US government from making financial gain from selling vaccines, and putting caps on how much money

corporations can contribute to political campaigns.

- Ensuring that biomedical protocols are being provided to doctors to assist in the recognition and treatment of comorbid conditions with autism. Ensuring that a vaccinated vs unvaccinated study is carried out by a neutral party.
- IDK what IACC is
- Finding the root cause of the symptoms that are commonly known as features of autism or features of PANDAS/PANS--the immune issues are an appropriate place to start for many
- providing adequate medical coverage and access to appropriate care regardless of what our insurance will pay
- I don't know
- The IACC should study this with the ferocity that this epidemic deserves. Find good treatments, find a cure, find a way to prevent it from occurring, find the cause/causes. Study this with the same ferocity that the AIDS epidemic was studied; we're talking little kids here, not risky behaviors associated with IV drug users or adults having unprotected sexual encounters.
- Research the environmental causes of autism. Work with Drs. who treat children with autism on best practices to help the children and/or adults who are suffering.
- researching the same things that the DAN! doctors/MAP doctors have been researching
- Actively help the families by working on health insurance coverage like other disabilities and diseases; getting the AAP to change autism to a medical disease for all the insurance coverage!
- Bio-medical interventions & finally stop this one size fits all mass vaccination program. Please look at family history's of autoimmune disorders & develop testing for who should be vaccinated & who shouldn't as well as doing away with unnecessary vaccines & do not immunize so young and spread them out, as well as recognize adverse reactions.
- Finding cures. Stop saying it's uncureable. Admit that vaccines and other foreign materials are subjecting our children to serious disorders and autism.
- Educate parents on choices of treatments.
- Look at the possibility that ASD could be caused from vaccines
- Study vaccinated vs non vaccinated Pay for alternative doctors whom have been the only doctors to help with his extreme GI pain.
- Research things pharm companies are not going to look at. Diet changes, vitamins therapy, HBOT, stem cell treatment, IVIG, antibiotic therapy. Involve specialists DOING these therapies so the studies done right (right doses, companies, clean products, long enough, looking for changes monitored right) pass money help or services on to families. Research how school baking helps these kids or hurts these kids when needs are ignored, pass laws for families rights with IEP. Standards of care for drs and school, insurance accessibility for respite, personal care aids so parents aren't at breaking point, educating drs better on how they can help and be part of the solution in helping families on spectrum. Heloubg cover family counseling instead of picking between individual for child only Or family, legal aid to families fighting for rights and needs of kids with schools insuring kids get what they NEED to be successful and learn skills yo survive with out parents.... Biggest fear with kids growing up and parents ageing. If independence isn't taught and skills implanted early we're going to have a helpless title wave of adults needing constant life care which will bankrupt our country, and cripple the care systems. Financial support for alternative treatments showing promise and

results. There are many out there ignored by mainstream outlets.

- Talking to parents as part of research, promoting awareness.
- Stop the madness & recognize the full scope of autism. Educate & not ridicule parents & specialists.
- Prevent ONE new case of autism. Research the children that have recovered and lost their diagnosis.
- Find out what are the main risk factors for adverse vaccine reaction 2. Effective treatments for GI problems and we need help in our home; have exhausted financial resources over the past decade trying to get our son the help he needs
- #1 Increase funding for research on alternative treatments that are actually HELPING our children. #2 GET RID OF COLEEN BOYLE!
- Listen to parents--research the vaccine connection! Make all treatments readily available!
- Stop the mandated vaccine program and acknowledge the fraud and give due justice to the affected families.
- Researching causes
- 1) Provide funding for treatments that insurance refuse to cover such as ABA therapy. 2) Do the vac vs. unvac study to figure out the cause to prevent anymore future cases.
- Encouraging nutritional testing for children with autism. Promoting awareness of the role of mitochondrial dysfunction in autism.
- Address the needs of severely disabled and sick autistic adults, like myself.
- Addressing causation immediately Listening to, documenting and acting on the stories of families already effected
- Honestly researching vaccines role Having insurance/govt cover alternative treatments
- Looking at the MEDICAL aspect which causes autism. Vax vs. Unvaxed study done with complete transparency.
- Provide funds for medical treatment and care that they require throughout their lives.
- Go away!
- study recovered kids study iv chelation fairly so insurance will cover it quit lying and wasting time
- Research and funding to help with treatment.
- Investigating the vaccine link. Studying the children who have been recovered and the methods used for that recovery
- Alternative non medical interventions
- fire themselves have a parent committee overtake this committe
- Insist that a long over-due & independent (free of any pharmaceutical industry & CDC ties) study of totally Unvaccinated & vaccinated children begin immediately.
- withdraw the study - expose the truth
- More fitting services for special needs children. Investigating the CDC practices and study's.
- In light of the recent scandal involving researchers at the CDC doctoring data sets, I'd say priority number one should be to obtain ALL data sets for ALL studies proving vaccines are safe so that independent scientists can validate the results since apparently we cannot necessarily trust hte CDC to do so themselves. Subsequently, the IACC needs to be directing research towards the myriad of potential environmental factors that may be contributing to

autism. Directing research towards studying the medical health of children with autism and making sure the American Academy of Pediatrics is well informed as to their responsibility to TREAT the co-morbid conditions associated with autism.

- Funding research into better antibiotics Funding research into better anti-inflammatories
- Family support, financial aid, early childhood intervention, help change the stereotype of not vaccinating
- 1)Work on an altered immune schedule 2) Prioritize nutrition and gastric health outside of GF, CF diets.
- Performing an independent study between vaccinated and unvaccinated children to discover the percentages of autism diagnosis between the two groups. Finding ways to financially support biomedical research for scientists and families who are recovering children. When we recovered our son (10 years now), everything was out of pocket, sending us into a period of debt. We are both highly educated and my husband has always been employed. I do not know how anyone can proceed to recovery without financial assistance.
- Remove insurance discrimination against ASD diagnoses entirely (my son's stopped at age 7)
- 2. Publish a concise list of DAN model treatments for ALL MD's to be required to use for treatment of ASD. 3. Take ASD out of the DSM4 and make it a MEDICAL diagnosis, not mental.
- Therapiesspeech,occupational , ABA ,tomadas, training to be able to work and live on their own....respite for the family....
- Finding and charging those responsible for fraudulent studies. Doing a study of vax vs unvaxxed children by an INDEPENDENT GROUP that has NO TIES to ANY Pharmaceutical co. Services beyond, OT, PT, SP. Survey parents that have lessened or diminished symptoms in their sick children with non- traditional treatments then implement system that allows parents to choose those treatments (that most cannot afford) FOR FREE!!! It is because of government negligence that so many like my son are here; it's only right that the government should put an end to further destruction.
- Educate that autism IS medical and recoverable Insist on insurance coverage for MEDICAL treatment of autism
- Listen /believe parents
- They should be listening to the parents. 2. THEY SHOULD BE LISTENING TO THE PARENTS!
- Target the medical problems instead of assuming the pain is a personality issue Awareness and treatment for toxin overloads
- Pushing health plans to fully cover autism therapies. Any and all of them, including biomedical, HBOT, music and speech therapy, assistive technology.
- Stop solely funding genetic research and redirect funds to research environmental causes and fund studies that assist children already affected with ASD and its many symptoms. Studies like the ones ARI is conducting Fecal Matter Transplant of beneficial bacteria.
- Stop denying the effects of vaccinations so that we can put research money where it belongs...in learning how to UNDO vaccine damage. HELP FAMILIES GET THE HELP THEY NEED IN DOING THIS. I am a broke, sick, single Mom. I need help. By the way, my poor health came after I took an MMR shot to go back to school (law school). I've been sick ever since with auto immune disorders. I was an energetic dance teacher before the shot.

- Medical diagnostics Medical treatment Intervention therapy (ABA, ST, OT) throughout childhood.
- LISTENING TO THE PARENTS. LISTENING TO THE PARENTS.
- Studying the actual environmental causes of autism including the current vaccine schedule. Prevention and treatment and reversal of autism.
- Paying our medical expenses that have driven us to bankruptcy and providing childcare so we can obtain income for our families and ill children
- Investigate vaccines, help pay for recovery!!
- get an independent vax vs unvax study completed. 2. test all children at birth for immune function to determine what toxic load they can handle and customize schedule accordingly.
- Acknowledge that these children need real help and healing other than ABA. Study the GUT, that feeds the brain.
- I dont' know
- STOP VAXING, DO A VAX VERSUS UNVAX STUDY, BUY AN INDEPENDENT AGENCY WITH NO CONNECTIONS WHATSOEVER TO GOV'T BIG PHARMA ETC #2 GETTING US THE INSURANCE ASSISTANCE WE NEED TO COVER ALL OUR CHILDREN'S MEDICAL NEEDS!!!
- Fire Tom Insel and Coleen Boyle Immediately! Get to work on treatment protocols that HELP!
- Listen to parents Consider alternatives to the research you have funded, which has done nothing to help our families. Until there is an identified cause or useful treatment for autism other than ABA, everything should be on the table. Open your minds to other ways of thinking.
- Demanding transparency from the CDC in their study findings. 2. Focusing on toxins with in the environment (pesticides, food additives, & GMOs) that are contributing to the increasing rates
- provide and pay for the therapies our children need to get better and admit the wrongs they have done
- Connecting parents to relief, support, funding, and biomedical doctors that treat the underlying cause for ailments... To start.
- We need to have medical treatments covered by insurance and we need our children's doctors to take insurance. All of our children deserve to afford treatment!
- Enforcing insurance coverage for conventional and alternative treatment. Seek out William W. Thompson, Ph. D., a senior research scientist at the Centers for Disease Control and Prevention and request full disclosure of the fraud that has taken place there.
- admitting the cause. admitting that it is a disease that needs to be treated. teaching doctors how to properly respond to parents who do not want to vaccinate...not a one size fits all scenario. teaching doctors how to treat asd using experts in the field. lobby to get health insurance to pay for alternative therapies besides ABA.
- Admit that vaccines damaged our babies and then figure out a way to reverse the damage!
- Study vaccine injured children. 2) Do a study comparing vaccinated and unvaccinated populations. This could be done as a gold standard double blind study in animals, and as a retrospective or contemporaneous study in humans.
- we need help with the violence. No medications have been constantly successful. They work for a bit and then stop working.

- Helping in some way with the cost of the many therapies. Providing caregivers with updated info instead of antiquated "behavioral" tactics which push the child away even more.
- The need to be listening to the parents of children with autism and admitting that autism is caused by toxins and is treatable if you heal the body. Admit vaccines cause autism.
- Help with financial costs of treatments. Develop services that provide therapies and biomedical treatments that are accessible to more families.
- Funding research that is not run by unethical people who are connected to the pharmaceutical industry and find ways to truly help the struggles of adults with autism aging out of the school system.
- Make medical treatments a priority and open up coverage for alternative treatments such as b12 shots, hyperbaric chambers, gi labs etc