

# Autismus - Forschung in Richtung Umwelt-Toxizität

## Autism Research Slowly Turns Its Focus to Environmental Toxicity

By Brita Belli

Autism cases are on the rise. Or so the most recent data would have us believe. The Centers for Disease Control and Prevention (CDC) found that 1 in 100 children in the U.S. have been diagnosed with autism spectrum disorder (ASD)—up from 1 in 150 in 2007. A study in the journal *Pediatrics* in October 2009 revealed similar numbers—parents of 1 in 90 children reported that their child had ASD. With boys, the rate of ASD was 1 in 58. Without a doubt, autism is the country's fastest-growing developmental disability, affecting more children than cancer, diabetes and AIDS combined. Still, in dealing with a childhood disorder that ranges from “highly functioning” to uncommunicative, and such a long list of potential triggers and treatments, even the numbers themselves are subject to questioning.



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“It irritates me to no end that we still argue over whether there is an increase in incidence,” says Michael Merzenich, Ph.D., a neuroscientist at the University of California San Francisco who has pioneered research in brain plasticity (essentially, retraining brains) and leads the brain-training software company Posit Science. “I think there is lots of evidence for increased incidence,” Merzenich says. “Overwhelmingly it supports that there are things in the environment that are contributing to the rate of incidence. But people still argue.”

Doubters point out that autism is better understood today and more frequently diagnosed. Some have even suggested that an autism diagnosis may be a means to an end—a way for parents to get the immediate speech and physical therapies their children need to prevent long-term delays. Massachusetts-based health writer Lisa Jo Rudy, mother to one autistic child, Tom, 13, as well as to a 10-year-old daughter, Sara, is one such skeptic. “Are we simply calling what used to be called being a ‘dweeb’ autism?” Rudy asks. The National Institute of Mental Health writes: “It is unclear from the report in *Pediatrics* whether the 1 in 90 estimate is measuring a true increase in ASD cases or improvements in our ability to detect it.”

Researchers like Merzenich say the waffling over numbers is beside the point—too many children are living with the disorder, and not enough research is focusing on what's causing it or how best to treat it. The term “autistic” was not even part of the modern lexicon until it was introduced by Hans Asperger and Leo Kanner in the

1940s—the word itself (containing the Greek *autos*) describes the self-absorption that is a hallmark of the disorder. While it takes many forms, autism affects social interaction and communication and leads to the development of intense habitual interests. Often, after a year of seemingly normal interaction, autistic kids will fail to respond to stimuli, make eye contact or turn at the sound of their name. They may not talk readily, or they may repeat themselves incessantly. They are likely to follow compulsive behavior, such as shaking their hands, stacking objects or repeating daily activities the exact same way each day. The treatment is years of intensive—and expensive—therapy.

Richard Lathe, Ph.D., a molecular biologist and former professor at the University of Strasburgh and Edinburgh University who wrote *Autism, Brain, and Environment* (Jessica Kingsley Publishers), calls the latest autism cases “new phase autism.” Explaining the term, Lathe says, “The rate of autism was quite low between the 1940s and 1980s. The beginning of the 1980s saw a marked increase in the incidence and prevalence of autism. Rates have gone up at least tenfold. It indicates that it can’t just be genetic—it must be environmental.”

### **The Chemical Connection**

The debate over the connection between vaccinations—particularly those preserved with mercury-containing thimerosal—and autism has been widely publicized, and is still the subject of controversy. The connection makes sense, says Lathe, because “People who suffer from lead or mercury poisoning appear to be autistic.” Thimerosal is still found in flu vaccines and the most recent H1N1 or “swine flu” vaccine, as well as a few single-dose vaccines. But vaccines are no longer the biggest mercury culprit, though aluminum, which is used as an adjuvant (an agent to stimulate the immune response) in many vaccines remains a concern.

James Adams, Ph.D., the head of the Autism/Asperger’s Research Program at Arizona State University says, “The two major sources of mercury are from dental fillings and mercury from seafood...And that in turn comes from the environment, from coal-burning power plants and other sources [including waste incinerators]. It just happens to concentrate in large fish because they’re pretty high in the food chain.”



Gavin Schultz has been steadily improving from autism since beginning biomedical treatments.

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Cindy Schultz lives in Wisconsin not far from a coal-powered plant. She works with the nonprofit Autism Network through Guidance, Education & Life (ANGEL Inc.), which provides grants for autism treatments. Her oldest son has Asperger’s

syndrome, a milder form of autism; her younger son, Gavin, has a more severe form of autism. Her three daughters have not been affected. Still, Schultz believes that “the air is better than it was 40 years ago,” and blames vaccinations—not pollution—for her sons’ disorders.

One National Health and Nutrition Examination Survey from the CDC that looked at mercury in the bloodstreams of women found that about 3% of women of childbearing age studied from 2003 to 2006 had at least 5.8 parts per billion (ppb) of mercury in their blood. The Environmental Protection Agency (EPA), meanwhile, “has determined that children born to women with blood concentrations of mercury above 5.8 parts per billion are at some increased risk of adverse health effects.” And that’s just one toxic chemical of concern. Others include air pollutants like lead and sulfur dioxide, water pollutants like arsenic and pharmaceuticals, and environmental toxins like phthalates (plasticizers), Bisphenol-A or BPA (used in some plastic water and baby bottles), and flame retardants known as polybrominated diphenyl ethers or PBDEs, which are used in everything from electronics equipment to plastics and furniture.

“The problem is these chemicals are everywhere,” says Merzenich. “They’ve looked at levels of contamination from PBDEs in the polar regions and there are significant airborne levels everywhere. You really can’t escape them.” At the same time, he urges parents to avoid putting old plastic baby furniture, old mattresses and used electronic equipment in a baby’s room, to keep potential PBDEs at bay.

In total, there are 3,000 chemicals that the EPA classifies as “high production volume.” In other words, chemicals that the U.S. imports or produces at a rate of more than one million pounds per year. According to the EPA, 43% of these chemicals have not been tested for basic toxicity. In 2007, *The Oakland Tribune* arranged to test the body burden—or level of chemicals—in the blood of a Bay Area family that was attempting to live a chemical-free life. They found surprisingly high levels of PBDEs, particularly in the children. While the mother had 138 ppb and the father 102 ppb, their four-year-old daughter had 490 ppb and their 20-month-old son, 838 ppb. In the case of lab rats, at 300 ppb the rats exhibit behavioral changes.

“Our current situation is an incredibly backward position that everything is OK until there is an unequivocal scientific demonstration that it ain’t safe,” says Merzenich. “And really the only thing that protects us at all is the threat of lawsuits...The onus should be on the manufacturer and distributor of any new chemical to demonstrate that it’s safe in terms that are acceptable to the public welfare. And certainly that includes that it’s not going to impact the life or development of the fetal child.”

### What the Studies Show

Sudhir Gupta, M.D., Ph.D., Chief of the Division of Basic and Clinical Immunology at the University of California, Irvine, once famously remarked in regards to autism: “Genes load the gun and environment pulls the trigger.”

But the large majority of autism research is focused on genetics, despite the fact that there are known environmental factors that impact the likelihood of the disorder. Living in an urban, as opposed to rural, area increases the incidence of ASD 4 ½ times according to one Texas study. There are other chemicals that are known to increase the likelihood of children born with autism, too, including maternal smoking, drug ingestion—from cocaine to anticonvulsants—and excess alcohol consumption by pregnant women.

Still, says Adams, “Most of the autism research is focused on problems in the brain, on genetics and on behavioral treatments. There is still extremely little money out there for looking into environmental issues. And there’s also extremely little money out there for looking at treatments for autism.”

The nonprofit Environmental Working Group, in a detailed report about the neglect of autism research’s focus on environmental factors, points out that “Hundreds of studies have explored the genetic roots of the autism epidemic, but none has uncovered a single gene or vulnerability to account for more than a fraction of cases.”

But the research that is taking up the environmental challenge is uncovering surprising answers—particularly in relation to the link between heavy metal toxicity and autism. Some of this research focuses on porphyrins: chemicals that increase in the blood in response to heavy metal toxicity. Turns out that autistic kids have more porphyrins in their blood following chelation—a detoxing process done by administering a drug such as dimercaptosuccinic acid (DMSA) used to treat lead poisoning—than do typical kids. The antioxidant glutathione—critical for the body to excrete metals—plays a role, too. Glutathione typically works by binding to heavy metals, which the body then knows to eliminate. In 2004, researcher Jill James, Ph.D., of the Arkansas School of Medicine, led a pioneering study that showed autistic kids had significantly less glutathione than typical kids—which put



Progression & Recovery: Gavin Schultz was most affected by autism between two and five years old. Treatments have helped

their bodies in a state of “constant oxidative stress.” In other words, autistic kids were genetically predisposed to have low glutathione levels, making them particularly susceptible to heavy metal toxicity. That toxicity—whether in the form of vaccines, fish, dental amalgams, air pollution, tainted water or other environmental toxins—might provide the “toxic tipping point” to render a child autistic.

Adams has done several studies looking at the role of toxic metals in children with autism, with similar findings. In one, he used DMSA in 221 kids with autism versus 19 controls, comparing the amount of heavy metals evident in the children following the detoxing process. “That first study showed that kids with autism dumped three times as much mercury as typical children did,” Adams says, “strongly suggesting that mercury was a major issue.” Another study found that the baby teeth of children with autism had twice as much mercury as did the teeth of typical children. It was an especially difficult finding for Adams, who had shifted the focus of his chemical research to autism when his daughter Kim, now 17, was diagnosed with the disorder in the late 1990s. His daughter’s baby teeth were included in the study—and the mercury level in her teeth was the second highest in the study. Even with extensive therapy, she still only functions at a third-grade level. A “Dateline NBC” video from 2006 about Adams’ research and family shows Kim singing along to a Barney kids’ video that she’s seen “thousands of times,” following detailed instructions to brush her teeth, and using a series of pictures pinned to her door to make her bed.

Adams’ findings point to more than just the fact that autistic kids seem less able to excrete mercury and heavy metals, although that’s part of the problem. He also found, looking at the medical history of autistic kids, that they were much more likely to have been given multiple rounds of oral antibiotics as infants, mostly due to increased ear infections. And that impacts mercury excretion, too. “Oral antibiotics in rats have been shown to greatly decrease the rate of excretion of mercury,” says Adams. “So the half-life for excretion goes from 10 days to 100 days in rats on oral antibiotics.” Adams relates that his own daughter was on oral antibiotics for six months continuously as an infant. Dr. Jonathan Finkelstein, a staff physician with Children’s Hospital Boston reports that antibiotic use in children is down 25% to 40% since its peak in the early 1990s (when children took an average of three antibiotics a year in some places), but says the first-line defense for ear infections remains the antibiotic Amoxicillin, despite the fact that the American Academy of Pediatrics encourages the practice of “watchful waiting,” or allowing certain infections to play out for 48 to 72 hours.

Dr. Jerry Kartzinell, who wrote the question-and-answer book *Healing and Preventing Autism* (Dutton) with celebrity and autism treatment advocate Jenny McCarthy, calls the frequent ear infections common in autistic babies and young children a “red flag” that indicates something amiss with the child’s immune system. “The medical community as a whole,” he tells McCarthy in the book, “should have been evaluating this child’s immune system, probably after the third

infection requiring an antibiotic, to see what was not working properly. But that's rarely, if ever, done."

## The Biomedical Approach

Kartizinel, along with Adams, belongs to a network of doctors and researchers under the umbrella Defeat Autism Now! DAN!, as it's known, is a set of practices for looking at autism from a biomedical or whole-body perspective—taking a holistic approach to both underlying factors and treatment. These are medical personnel who speak openly about potential chemical triggers for autism, from vaccines to mercury-tainted fish, who advocate treatments such as chelation therapy, gluten- and casein-free (wheat- and dairy-free) diets and even hyperbaric oxygen therapy, in which oxygen is administered in a pressurized chamber. They tend to be anti-drug and pro-supplement, and they insist that autism is, indeed, a treatable condition.



Shauna M. Layton, founder of Together In Autism, with her son, Hayden Michael.

© c/o Shauna M. Layton

Needless to say, they've sparked a lot of controversy. The autism community tends to fall into two camps—those who believe in a holistic cause and cure for their child's autism and those who trust in the established medical protocol, which includes a mixture of drugs with speech and physical therapies. Amid the accusations of "quackery" on the one side and "money-driven medical industry" on the other, it can be difficult to find a balanced voice.

Shauna M. Layton founded the online support group Together in Autism (T.I.A.) after her son, Hayden Michael, was diagnosed with autism at 2½. While she and her group's followers fall almost exclusively into the DAN! camp, Layton says, "We are not anti-vaccine. There are many vaccines that are necessary to one's protection and health. We are pro-awareness for those injured or who may have an underlying issue that maybe cannot tolerate a shot." She includes her own son as one who she believes was vaccine-intolerant, because he was put into intensive care following birth, but received the normal vaccination schedule, and his condition (first noticeable at six months) became worse with each progressive shot. Hayden was also prone to frequent ear infections and given regular rounds of antibiotics.

DAN! doctors, despite their detractors, tend to focus on one physical attribute common to autistic kids that's scientifically indisputable: As many as 70% of them have something wrong in the gut. Common maladies include what's known as "leaky gut syndrome," in which the intestinal lining is damaged, allowing toxins and waste to enter the bloodstream; bowel inflammation and an overgrowth of harmful bacteria and yeast. These kids can be constipated often, or prone to chronic diarrhea. Stools are often horrible-smelling (well beyond the norm) and the act of

pooping can lead to bleeding. And besides the cramping, pushing-on-their-bellies behaviors, autistic kids with these complications often have outward physical signs: bloated bellies, dark circles under the eyes, pale complexions.

Back in 1999, a study of 36 severely autistic kids by doctors at the University of Maryland School of Medicine found the first link between autism and a series of gastrointestinal disorders. Nearly 70% of the kids had acid reflux and 58% had chronic diarrhea because they could not properly absorb carbohydrates. Many of the kids could not sleep through the night as a result of their constant discomfort, which in turn was thought to contribute to their behaviors of irritability and aggression. Then, in March 2009, researchers found what looks to be a gene variant linking these two conditions. Published in *Pediatrics*, the researchers found that the specific gene variation called the MET C allele affected both brain development and gut processes. After studying 214 families with at least one child with autism, researchers found that only kids with both autism and gastrointestinal problems had the gene in question. In a subsequent article in *U.S. News & World Report*, the author concluded, “This line of research may turn up targets for new drugs.”

## Diets, Not Drugs

But DAN! doctors and their patients aren’t waiting for the next miracle drug—they’re finding sometimes extraordinary results with a combination of strict diets, supplements and other biomedical treatments that heal the underlying gastrointestinal issues. “We always feel that healing the gut is the first step [in treating autistic kids],” says Dr. Kenneth Bock, who runs the Rhinebeck Health Center in Rhinebeck, New York, and wrote the book *Healing the New Childhood Epidemics: Autism, ADHD, Asthma and Allergies* (Ballantine Books). Bock’s treatments range from extensive food allergy testing to chelation, supplements and gluten-free, casein-free (GFCF) diet recommendations (see interview, page 33). The waiting list to be seen there can be six months or more.

The GFCF diet, which involves eliminating all wheat and dairy products, is often the first line of treatment—and it’s daunting. Bock’s book of no-nos includes bread, hot dogs, pizza, pudding, cereal, chicken nuggets, pasta, waffles, cheese, ice cream, yogurt—pretty much all the foods picky toddlers prefer. But parents today have an easier time than in the past—even mainstream grocery stores sell standard items that are GFCF now, and substitutes include rice, buckwheat (for pancakes), soy milk and rice ice cream. Not to mention a healthy infusion of vegetables, disguised if necessary. In fact, the book McCarthy penned with Dr. Kartzinel includes quite a few hot dogs on the GFCF menu (including Ball Park and Kahn’s), Lay’s potato chips, Boar’s Head lunch meat and other readily identifiable, kid-approved items.

Parents of autistic kids rave about the results. “First we removed casein,” says Layton of her autistic son, Hayden Michael. “It was like he was going through detox, he was so addicted to it. After a week he started asking the ‘who, what,

where, when, why' questions and answering them as well. Prior [to the diet] he would only say a few words to express what he wanted or needed and it was pretty much a guessing game." Six months later, she had Hayden on a full GFCF diet, and says another six months in, he was speaking in sentences. After adding fish oil—given to autistic kids undergoing this treatment for their omega-3 essential fatty acids, which boost brain function and reduce inflammation—Layton says she was "blown away." "My son was doing all things now to an extreme in a neurotypical manner," she says. But Layton cautions that her son is still on the path to recovery, and that every child's response to such treatments is individualized.

Among the many supplements recommended to autistic kids, B12 is high on the list. Nearly every cell in the body uses B12, and the vitamin promotes proper functioning of the nervous system and gastrointestinal system. But it's not easily absorbed, so the best way to get it is through a shot. "This form of therapy seems to really allow a bloom in language, concentration and focus in many children," says Dr. Kartzinel in the book. McCarthy's autistic son, Evan, is one who had a marked verbal response following B12 injections.

Chelation therapy, in which DMSA or another drug such as ethylenediaminetetraacetic acid (EDTA) is administered in order to remove lead or heavy metals from the body, is a highly controversial treatment. In several chelation cases, a person was administered the wrong drug (disodium EDTA instead of calcium disodium EDTA) and died as a result, as their bodies were fatally robbed of calcium. The most recent was 5-year-old Abubakar Tariq Nadama, who died in 2005 while receiving chelation therapy in Pennsylvania to treat his autism.

But doctors who support the practice argue that past medicinal mix-ups should not compromise what looks to be a promising treatment. Says Adams: "The fact is that many families have used chelation. According to the Autism Research Institute, which has collected data from over 25,000 families, over 50 treatments, chelation therapy is ranked number one in terms of effectiveness by families."

There was enough positive response in regard to chelation as a treatment for autism that the National Institute of Mental Health decided to conduct a study on its use in 2006. By 2008, the agency changed its mind—saying in a statement that "there was no clear evidence for direct benefit to the children who would participate in the chelation trial and that the study presents more than a minimal risk." Adams calls the agency's change in decision "very sad."

Still, as controversial treatments go, chelation can hardly be considered the fringe. Other parents seek out hyperbaric oxygen therapy—in which a child is administered oxygen inside a submarine-esque pressurized chamber that allows them to take in additional oxygen. It can take 40 treatments or more to realize any improvement in the child's language, so some parents have gone so far as to rent or purchase these chambers for home use. Prices range from \$1,500 per month to

rent a small unit to up to \$20,000 to buy a large one. Says Lathe: “I don’t know about the long-term benefits, but [hyperbaric oxygen therapy] does have short-term benefits in normal people.”

Marty Ann Kelly, a mother from Maine affiliated with T.I.A., bought a mild hyperbaric oxygen chamber for her home to treat her son, Kenneth, now 8 years old. She has also taken him to the Institute of Cellular Medicine in Costa Rica for stem cell injections taken from umbilical cord blood. There, he was injected with 24 million stem cells over four days; and she plans to return. “We believe this will bring him to recovery,” she says, adding: “We are fanatical about understanding autism, what is causing it and how to help combat it better every day, week and month...For the last three years, we have been studying biomedical interventions and using parent-based online-forum analysis to uncover the reasons for his autism.”

### **Finding Answers Online**

Online forums, whether railing for or against such alternative therapies for autism, have become hives of activity, with parents swapping treatment stories, medical fears, offering support and encouraging parents to take matters into their own hands. “People even get aggressive,” says Renate Lindeman, another T.I.A. supporter, and mom to a 6-year-old autistic daughter. “It is a misunderstanding. A misplaced trust in pharmaceutical companies and [believing] authorities have our best interests at heart.”

Moms like Rudy find it all a bit confining. The public forum and medical industry lashing don’t sit well with her. She took her son Tom out of school after fourth grade so that she could teach him at home, and says, “I’m not a good fighter; but I’m a good teacher.” Together, mother and son engage in a different sort of alternative therapy—going on nature walks, following bird tracks, listening to music. She remarks that he’s a great observer, and that she grew tired of trying to mold the school system to his needs. “People become so invested in whatever course they’ve invested in,” she says of certain autism parents, “that they just can’t afford to consider that it may not be accurate.”

Perhaps most frustrating for all these parents is that they’re required to seek out answers on their own, and then defend them, all while trying to provide treatments for their autistic child that—traditional or alternative—are time-consuming, expensive and may or may not bring results. Says Lindeman: “My husband and I do not have a personal or social life anymore since our child started regressing. All our time, money and efforts are spent on getting our child well before it is too late.”

Even if research begins to shift more decisively into studying environmental triggers for autism—which it is only, slowly, beginning to do—the results of those studies will not come soon enough to make a difference for parents of autistic kids today. So researchers suggest, in lieu of definitive proof, that parents take precautions. During pregnancy, women can take proper prenatal vitamins, so that

the fetus is not drawing nutrients from mom's bones and fat tissue where toxins are stored; they can avoid fish such as shark and swordfish and limit albacore tuna to prevent additional mercury; and they can minimize household chemicals and cleaning products. Once the child is born, researchers affiliated with DAN! say parents can better monitor vaccinations—following a more spread-out schedule, making sure the child is healthy prior to vaccinations and certainly not allowing vaccinations to be administered if the child is on antibiotics. And parents, good research shows, should resist antibiotic treatment for infants unless it is unequivocally necessary. Says Adams: “The research shows that roughly three weeks after getting an ear infection if you have used oral antibiotics, you’ll have about a 95% recovery rate; but if you do absolutely nothing and let the child’s immune system fight it out, you have a 90% recovery rate.” And if the child’s immune system fights off an infection, it’s less likely to return. Adams cautions against the use of Tylenol in infants, too. “Tylenol vastly depletes glutathione,” he says, meaning “kids lose their ability to excrete toxic metals.”

Early preventative steps—and early precautions—may be parents’ only defense against the likelihood of autism. It seems the wait for any definitive answers is going to be long.

**BRITA BELLI** *is editor of E.*

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