Although the symptoms they create are treatable, these biotoxins can exacerbate autism traits and wreak havoc on health...

By Keith Berndtson

In a 2009 study, Jack Thrasher and colleagues compared neuropsychological abnormalities in eight autism spectrum disorder (ASD) boys to six ASD boys who were also exposed to mold toxins. The ASD boys averaged 6.8 abnormalities. The ASD boys who were also mold toxin-exposed averaged 12.2 abnormalities.

While not a scientific investigation, this simple observation suggests that boys on the spectrum with toxic mold exposure may average nearly twice the neuropsychiatric abnormalities as ASD boys without exposure to mold toxin. Should this matter to parents of children with autism? The answer is yes because mold toxicity is treatable.

Subtracting mold toxicity from an already complex illness equation like ASD holds potential to improve function and quality of life for people with autism and their families.

A Newly Discovered Form of Chronic Illness

For the past 15 years, a steady stream of research by Ritchie Shoemaker and colleagues of the Maryland-based Center for Research on Biotxin-Associated Illness have documented the causes, diagnosis, and treatment of a new chronic medical condition called Chronic Inflammatory Response Syndrome, also known as CIRS. A biotoxin is a toxin made by a living thing as opposed to a man-made chemical process. Of all patients with CIRS,
an estimated 80 percent suffer multiple symptoms caused by biotoxins produced by certain molds known to grow in water-damaged buildings (WDB).

When CIRS markers are present and the suspected source of toxin exposure is, or was, a water-damaged building, the condition is called CIRS-WDB, also known as mold toxicity syndrome. Part of the problem for such patients is that they do not clear mold toxins from their bodies as well as most of the population. For this reason, when making the diagnosis of CIRS-WDB, it doesn’t matter whether the exposure to mold toxins occurred in the present or in the past. Since the toxins are so poorly cleared, the toxic burden accumulates with each exposure.

When it comes to treatment, however, it matters very much whether the exposure(s) occurred in the past or in the present. This is because the treatment that removes the toxins from the body requires the absence of ongoing exposure. In other words, the success of treatment designed to produce an egress of mold toxins from the body depends on conditions that prevent an ongoing ingress of mold toxins into the body. Before turning to the details on how to diagnose and treat mold toxicity, it may help to know what Dr. Shoemaker and his team have learned about the criteria needed to make the diagnosis.

### Diagnostic Criteria for Mold Toxicity Syndrome (CIRS-WDB)

#### A Multi-Symptom, Multi-System Illness

In an early study by Shoemaker, CIRS sufferers averaged 22 of 37 symptoms, whereas controls averaged only 3 of 37 symptoms. Many of these symptoms suggest neuropsychiatric or neurocognitive problems.

#### Visual Contrast Sensitivity

Many mold toxins are documented neurotoxins, some of which also act as mitochondrial poisons. Shoemaker and Ked Hudnell documented that over 90% of patients with CIRS fail visual contrast sensitivity (VCS) testing in one or both eyes. Studies conducted through the Department of Defense have shown that the visual function for edge detection, also known as contrast sensitivity, is reduced by exposure to neurotoxins. Shoemaker and Hudnell showed that treatment lowers the neurotoxic burden enough for visual contrast sensitivity to become normal again.

#### Genetic Susceptibilities

Shoemaker also found that up to one in four people inherit HLA genes that predict poor clearance of biotoxins. If blood testing detects one of these genes, that person would be prone to retain mold toxins if exposed. Genes merely load the gun--environment pulls the trigger. Shoemaker and his team have identified a characteristic pattern of abnormalities affecting vision, immune system regulation, and blood flow.

#### Immune System Abnormalities

Most patients with mold toxicity syndrome have high C4a levels. This marker indicates activation of a toxin-handling protein produced by the innate immune system—the part of the immune system that comes factory installed and ready to operate at birth. It doesn’t have to be trained—it already knows to react to molecular patterns that signal danger. Another immune marker called transforming growth factor beta-1 (or TGF beta-1) runs high as well.

#### Neuropeptide Hormone Abnormalities

Certain neuropeptide hormones are adversely affected by the chronic inflammation that results when mold toxins are not effectively cleared from the body. These include anti-diuretic hormone (ADH), alpha melanocyte stimulating hormone (MSH) and vasoactive intestinal peptide (VIP). ADH tells the kidneys to conserve water. When ADH reserves fail, the patient is always thirsty but stays dehydrated despite drinking lots of water because the kidneys let the water escape. MSH acts like a field general coordinating immune responses in the mucous membranes of the body. A low MSH level can perpetuate a leaky gut. Both chronic inflammation and certain staph bacteria that colonize the deep nasal space are associated with low MSH levels. VIP is a master regulator of immune responses, circadian rhythm, cell secretions, and blood flow distribution in various body tissues. Low VIP levels can disrupt a range of key bodily functions. Low VIP levels are not uncommon in CIRS-WDB cases.

#### Lab Interpretation

The key to interpreting CIRS panel lab results is to use Shoemaker’s reference ranges for these markers as opposed to ranges determined by a hospital or by a national lab such as Quest Diagnostics or LabCorp. Each lab is responsible for setting its own reference range. Most do so based on specimens obtained from 100 to 200 consecutive patients regardless of health status. Shoemaker’s reference ranges are based on cases (sick patients) and controls (healthy patients) for thousands of people. Very few physicians are certified in the methods of lab interpretation required by the Shoemaker protocol.
In the fall of 2005, our son Rob, then 13 years old, changed schools and entered an excellent self-contained classroom at Greenwood Middle School in Goldsboro, NC. At the time, he was in excellent health, able to perform all the activities of daily living independently, and putting together 500 piece puzzles with little assistance. During the first few months of school, he was enjoying reading out loud, learning some geometry, and in general doing very well.

Then, he started having a serious—and unprecedented—problem with drooling and next started falling out of his chair, first at school and then at home. We worked with his doctor trying to figure out what was going on, adjusting the seizure medication he had taken for several years for petit mal seizures.

Throughout 2006, Rob had dozens of blood draws and was tested for everything imaginable. In the fall of that year, Rob had both an MRI and a 24-hour EEG looking for either a brain tumor or seizures. No trace of either was found, but Rob continued to get worse each month. He stopped talking, lost the ability to walk without assistance, and was unable to even feed himself. He slept a lot, became somewhat incontinent, started choking on food, lost about 25 pounds, and finally became unresponsive.

Waking him up each morning was becoming increasingly difficult—I literally had to open his eyelids since he could no longer do it himself. Rob’s doctor, after ruling out everything he could think of, decided it looked like some type of poisoning and sent us to the Environmental Health Center in Dallas, Texas.

Two weeks later, Rob was diagnosed with mold and pesticide toxicity. We’d already had our house tested for mold (negative), so as soon as we got back I insisted that the school be tested. Aspergillus, penicillium and stachybotrys were found in his classroom. When we received the results of Rob’s lab tests, he, of course, had mycotoxins in his system from those exact molds! Rob never had any respiratory symptoms, only neurological symptoms. I think if he had, we would have caught on much sooner to what was making him so sick.

There were only small patches of mold on some ceiling tiles, and Rob came home from school each day at lunchtime (due to his GF/CF diet) so he wasn’t exposed as much as others in his class. However, after extensive research, I came to the conclusion that the seizure medication he was taking made him more susceptible. Seizure medications (and certain other meds) can make the blood-brain barrier (that protects the brain from toxins) more porous, allowing mycotoxins to go directly to the brain.

Most physicians don’t know how to diagnose and treat mold toxicity. If we hadn’t gotten to the right doctor when we did, Rob would have died. On a happier note, he is 21 years old now and only has minor residual side effects from this episode. We lost almost two years of his life dealing with this, but are so grateful he is still here. I urge parents to be aware of mold exposure and to be active in making sure their children are not exposed at home, in school, or in the community. Additionally, parents need to research any medications and supplements taken and be aware of those which may affect the integrity of the blood-brain barrier.

I had the opportunity recently to sit down with Rob’s physician during this period, one of the top experts in the world on autism, and we were talking about how mold was not on either of our radars prior to Rob’s exposure. Since then, he’s had several patients with similar issues. Now that he knows what he’s looking at, he’s able to turn them around quickly, before they regress to the point Rob did.

I thank God that Rob lived and pray that no other family has to go through what we did. If you start seeing serious regression with no apparent cause, get your child to a physician who has experience in mold and other environmental issues. It may just save your child’s life!
Treatment of Mold Toxicity Syndrome (CIRS-WDB)

Fortunately, it is possible to pull various toxins, including mold toxins, out of the body using binding agents. Such agents act like US Marshals—they handcuff the toxins and escort them out via the bowel. This prevents the endless recirculation and retention of these damaging toxins. As these toxins make their egress from the body via the bowel, toxins lodged in cells and tissues mobilize more easily into the bloodstream. This can cause a temporary increase in symptoms that is controllable to some degree with regular doses of high quality fish oil.

If testing shows genetic susceptibility and lab evidence of exposure to mold toxins, then treatment is indicated. The mainstay of treatment for children is a prescription medication called Welchol (colesevelam), which came on the market many years ago as a way to lower cholesterol levels. Welchol is available in both tablet and powder forms. It is gentle and can be taken with meals but it needs to be taken at least an hour after drugs and supplements to avoid having their absorption blocked by the Welchol.

Another cholesterol lowering agent known as Questran (cholestyramine) is also available in powder form. It is three times stronger than Welchol and is typically reserved for adults who can adhere to its more demanding directions. It must be taken at least an hour after drugs and supplements and half and hour before meals, three times a day and again at bedtime. Questran also contains several additives. Pure forms are available through compounding pharmacies.

Questran is a very strong toxin binder. It removes more toxins per dose than other binders, which makes it more prone to aggravate underlying symptoms. It is also more likely to cause constipation. Dosing can be modified to fewer times per day and less powder per dose. Other binders such as charcoal or bentonite clay are sometimes used but they have not been proven to work as well as Questran or Welchol.

Pandora's Box

If this all sounds too easy, you're right. Here's the catch: if the patient lives in a home that contains mold toxins, the treatment won't work well at all. The same is true if the patient is continually exposed at school or in the workplace. This is because for every batch of toxins pulled out of the body with binding agents, a new batch enters the body from breathing air that still contains mold toxins. If toxin ingress equals toxin egress, nothing changes, or worse—symptoms may amplify from the increased mobilization of toxins in the system.

There is a way to test whether the home, school, or workplace is a source of toxin-producing molds. It's called the ERMI test. ERMI stands for Environmental Relative Moldiness Index. Using vacuum canisters for carpeted areas or swiffer cloths for wood or tiled areas, dust samples are obtained. These dust samples also contain mold spores that have settled on floors and surfaces. The lab amplifies any DNA sequences present in the samples. The result is a listing of the relative amounts of specific mold species found in the sample. Detected species are divided into common molds and toxin-producing molds and the results reported as an index that ranges from minus 10 (least toxin producing molds) to plus 20 (most toxin producing molds). Shoemaker's research indicates that to recover from CIRS-WDB, people with mold toxicity syndrome must live, work, or go to school in an environment with ERMI scores less than 2.

You won't get better with continued exposure to toxic molds, so if the ERMI score at home, work, or school is greater than two, you have just opened Pandora's Box and
now the air is also contaminated with difficult questions. Should you hire a mold inspector to find areas of water intrusion or plumbing leaks? Should you hire a mold remediator to clean everything up? Will this be money well spent? What are the chances that remediation will fail to produce an ERMI score of less than two, thus impeding recovery? How will a landlord, employer, or school administrator respond to a request to perform ERMI testing on-site? If I find toxic mold in my home, do I have to report it? You get the idea.

When the health of your loved ones is at stake, it can help to find the right guidance for navigating the obstacles between you and recovery from toxic mold illness. Before running the obstacle course of mold toxicity diagnosis and treatment, seek out a physician with certified expertise in the Shoemaker protocol. This will maximize your chances of getting the answers you need.

**The Upshot of It All**

A preliminary observation suggests that children with ASD and toxic mold exposure may have nearly twice as many neuropsychological abnormalities as children with ASD alone. While more research is needed to better clarify the functional differences between people with ASD and people with ASD plus toxic mold exposure, this simple observation takes on great potential meaning. This is because mold toxicity syndrome, also known as CIRS-WDB, is treatable. Shoemaker and colleagues at the Center for Research on Biotoxin-Associated Illnesses have developed a well-documented protocol for recovery from mold toxicity syndrome.

To obtain proper help sorting out whether a loved one with ASD also suffers from mold toxicity, you must locate a physician with experience in this area. At the time of this writing, only five physicians nationwide are Shoemaker-certified to diagnose and treat mold toxicity syndrome. Non-certified physicians with adequate experience are also hard to find. For help locating a physician, contact Dr. Shoemaker’s Center via www.survivingmold.com.

To be clear, no research to date implicates mold toxicity syndrome as a cause of ASD. Rather, mold toxicity syndrome is a multi-symptom, multi-system illness in its own right that can complicate efforts to treat people with ASD. If you have two tacks in your behind and we pull one out, you’re not likely to report feeling 50 percent better. CIRS-WDB needs to be treated in its own way. Successful treatment won’t erase ASD, but it is likely to remove a few of the invisible sandbags on the backs of people with ASD and move them closer to their goals for a more functional life.
In 2000, my family moved into what we thought was our dream home. One of the first houses built in the small community where we lived. Built in 1835, it had been a family home until it was entered into a trust with a bank and became a rental property, owned by my in-laws. After the birth of our third child, our home had become too small and we were looking for a larger, country home just as this one became available. We jumped at the chance to move our family to the country and fell in love with the historic brick two-story on seven acres.

Soon after, I became pregnant with our fourth child and all was fine until we had a roof leak in the fall of 2002. We fixed the leak and within a month, the children and I started having respiratory issues: ear infections, sinus infections, pneumonia and flu-like symptoms that lasted the entire winter. No amount of antibiotics helped. Once spring arrived, we could open the windows and the symptoms would subside. We often visited my parent’s home for the weekend and always felt better when away from our home. Upon returning, however, the symptoms would return.

Our fourth child, Kaden, began presenting “autistic like symptoms” after getting the “catch-up” vaccination schedule in September of 2003. Kaden and our third child, Kassidy, had both gotten behind in their vaccines due to recurrent infections and the doctor wanted to get them “up-to-date” after a three month stretch without illness.

No one would answer my questions: Why are my children always sick? Why aren’t the antibiotics working? Even after they both had tubes placed in their ears, they still continued to have ear infections, but at no time was what was in their ears cultured. I researched hundreds of hours on dial-up internet late at night while they slept and finally came upon a mold help forum. This is where my mold education began.

It took a whole year of seeing doctor after doctor, calling health departments, asking experts to include an infectious disease doctor for help to finally get some answers. I was sick, really sick—and no one believed me. Even family members would say, “It is all in your head.”

My family doctor finally told me to move out of the home following a cat scan showing nodules in my lungs. I saw a trusted heart/lung doctor who had the head of radiology view my cat scan frame by frame. I had an active fungal infection in my chest, leading to an eight-hour surgery to remove one-fourth of my left lung due to the extent of the infection. I was hospitalized for a month and on antifungal medication for six months to clear up “one of the worst fungal infections” they had ever seen. The pictures of the inside of my chest are now used to teach infectious disease doctors in the Midwest. Because of my case, two more infectious disease doctors are now employed at the same practice that, in 2002, told me, “There is nothing wrong with you. Stop going to see doctors—it’s all in your head.”

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Red Flags for Toxic Mold Exposure

- If you feel better and symptoms subside when you are away from the home you may have a mold problem.
- Is there a musty smell or do you or your children smell like yeast?
- Pets show symptoms normally before humans.
- Are you or your family having a lot of recurrent respiratory symptoms?
- Does anyone in the family have athlete’s foot or other fungal infections? Not everyone reacts to mold the same way.
- Does anyone have a constant cough or flu-like symptoms?

Tips if you believe your home is mold-infested:

- **Have the Home Tested.** Upon having our home tested we found 17 different types of mold inside the home that were different or at elevated levels compared to outside of the home. There was additional mold found in the ground surrounding the home and in the well.

- **When There Is a Leak of Any Kind, Remove the Wet Materials Within 12 Hours.** While wet, the mold spores don’t spread. Once the area dried out, the mold reproduces, releasing the spores to go and find other wet areas in order to live.

- **Check Your Home Insurance for Mold Exclusions** (our insurance had an exclusion). After receiving the results from the mold testing, my husband started investigating. He ripped out the ceiling in our children’s bedroom and found it was full of black mold following years of roof leaks that were covered up by a drop ceiling.

- **Do Your Research.** Mold can only be killed by sunlight, and bleach only changes its color. If you need find a new place to live, only take items from the home that can be cleaned with Borax and set in the sun for at least 8 hours. Do not take a mattress or anything else that cannot be cleaned. You don’t want to infect your new home.