



# Complex Child E-Magazine

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## Gamma Globulin Treatment for Children Without a Defined Immunodeficiency

by Kelly Weiderman

Groundhog Day. That's what it felt like our lives had been reduced to. Every two weeks or so, we would wake up and find ourselves in an eerily familiar place: tending to a child who was sick with the same old fever and the same old respiratory and sinus junk. But her breath is what always gave it away. The odor behind a festering sinus infection is unmistakable.

### **Ali's Antibiotic Allergies**

Our daughter Ali's run with recurrent infections began when she was an infant discharged from the hospital after her birth with what would quickly develop into a massive staph infection across her skin. At two months old, she was admitted for the first time with a viral respiratory infection. Ear infections, more staph infections, thrush, multiple bouts with pneumonia, and chronic sinusitis followed soon after.

But things didn't start to get really complicated until sometime after her third birthday. This is when she was diagnosed with mitochondrial disease, which left us with no choice but to treat these infections aggressively, because each illness seemed to bring further decline of her overall health. Unfortunately, this was not as easy as it may sound, despite the ubiquitous availability of antibiotics.

The first antibiotic Ali reacted to was erythromycin. Not a problem, her doctors informed us, there are many choices out there. This reaction was quickly followed by reactions to amoxicillin, which was ultimately followed by azithromycin, cephalosporins, clindamycin, sulfas, and fluoroquinolones--a class full of drugs I never could pronounce correctly. Her allergies to all of these antibiotics were confirmed with allergy testing, though she was cleared for Rocephin and another third generation cephalosporin called Cefdinir.

### **Gamma Globulin Treatment**

We got to know her allergist/immunologist very well with the start of kindergarten and Ali's introduction to public education. Despite being in a small class and having an infection control protocol in place, she was always sick. Always. And because of her

antibiotic allergies, we were running out of ways to treat her infections.

Gamma globulin treatment was first brought up in November of 2010. Her immunologist ran a complete immune work-up, and while it was mostly normal--she did show a poor response to the few vaccines she had been able to receive--we knew based on presentation that she wasn't able to mount an appropriate immune response. He indicated that if she could tolerate vaccination (she couldn't), that would be step one. And then step two would involve prophylactic antibiotics, another non-option. Rock, meet hard place.

After further consulting with Ali's otolaryngologist regarding the chronic sinus infections, we were told we essentially had two choices: gamma globulin or sinus surgery. I emailed her immunologist that very day to have him start pushing the paperwork through for insurance.

### **Battling for Approval**

In March, we were told that she was approved to receive gamma globulin either intravenously (IVIG) or subcutaneously (SCIG). We chose SCIG. While she tolerated the treatment well, the physician affiliated with her insurance company called her immunologist to tell him we had been given erroneous information, and that she would not be approved due to a lack of a clear immunodeficiency. We were devastated.

Her immunologist reassured us he would mount an appeal, since Ali's case was unique and we truly did not have other options. In the meantime, Ali got sick. Again. But this time she required a hospital admission. And it was shortly after that the insurance company approved her SCIG on an interim basis.

Starting in April, Ali started receiving SCIG infusions of Hizentra at home. We are able to set them up and administer them ourselves, which greatly reduces her anxiety. She has few side effects other than some localized itching and hives, but nothing that isn't easily controlled with Benadryl. And most importantly, she has been infection free for over a month. We are no longer stuck in the seemingly endless cycle of non-stop infections.

While it is rare to get approval for costly gamma globulin treatment in children without defined immunodeficiencies, it is possible. Children like Ali, who has a long detailed record of chronic infections requiring hospital admissions and no other viable treatment options, can be approved. It is important to remember that the immune system is thus far very poorly understood. Children like Ali, with underlying diseases, complex allergies, and a clearly abnormal immune system, may simply not test as deficient because the tests are currently not able to detect all forms of immunodeficiency.