



Complex Child E-Magazine

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Vaccinating Children with Neurological, Metabolic, and Neuromuscular Issues: A Call for Research

by Susan Agrawal

I want to say upfront that I am neither pro-vaccine nor anti-vaccine, and this commentary is not just another position paper on what has become a very contentious issue recently. Instead, this is a series of reflections on the very difficult decisions that need to be made by parents of children with neurological, metabolic, or neuromuscular disorders about vaccinating their children.

When talking about healthy and typically-developing children, parents have the luxury of choosing whether or not to vaccinate. In most cases, a healthy child will be unlikely to acquire any of the vaccine-preventable serious diseases such as diphtheria or meningitis. The vaccine-preventable illnesses that are more likely, such as chicken pox, flu, or rotavirus, are also probably not going to be particularly harmful in the long run to most healthy children.

It is an entirely different scenario when it comes to children with neurological, metabolic, or neuromuscular conditions. Many of these children could easily die from something as simple as the flu or chicken pox. Diseases that are rare in most children, such as sepsis or meningitis, may be much more frequent in this population due to impaired immune systems, central line use, or organ damage. Even a basic case of rotavirus can be life-threatening for some children with complex medical issues.

On the other hand, certain vaccinations have a history of causing neurological symptoms or exacerbations in a very small number of children. Some children with immune system issues may also respond to vaccines in unusual and unexpected ways. Children who are chronically ill in general may also have their underlying conditions exacerbated by the stress of vaccination.

How do you decide whether to vaccinate your child with complex medical issues, and which vaccines do you choose?

Our Story

We recently faced a very difficult decision regarding vaccines and my daughter, Karuna, who has cerebral palsy, an undiagnosed condition, and multiple complex medical issues. After a case of life-threatening sepsis caused by the bacterium *Strep. Pneumoniae*, we

had to make the choice whether or not to give her the Pneumovax vaccine, a vaccine that protects against sepsis and meningitis from this bacterium. Sepsis or meningitis from *Strep. Pneumoniae* is fatal in 20-30% of children who get it, and in a child who is as medically fragile as my daughter, the risks are even higher. In addition, the vaccine was also being used to test her immune system's ability to make antibodies since she had no immunity from her series of Prevnar vaccines, another vaccine against the same bacterium that is administered in infancy.

Karuna has not had any vaccines since she was a toddler due to ongoing illnesses and medical complications. But we had now entered a new realm, since she was actually getting extremely serious illnesses that are usually preventable by vaccines.

Which was the greater risk, allowing her to get this and other vaccines, or risking her life if she developed sepsis, meningitis, or other serious illnesses?

In her case, we were not sure. She has had complicated sepsis three times in the past two years and has a central line, so the risks of acquiring a severe infection are quite high. Her respiratory status is also very fragile, and a simple cold typically leads to weeks of serious illness, increased oxygen needs, and multiple episodes of respiratory distress. Diseases such as the flu or pertussis could easily be deadly for her. Because of a history of pancreatitis, other viruses, including varicella, could also be incredibly risky for her.

At the same time, however, her autonomic nervous system and immune functioning is clearly atypical, and every little stress on her body has the potential to cause grievous harm, ranging from a life-threatening autonomic crisis to a greater risk of infection.

Moreover, we were concerned about several past incidents that involved introducing novel substances to her immune system. She got very sick after receiving her last two rounds of Botox injections, and while Botox is not a vaccine, it is a toxin that can produce an immune response within the body. The other incident involved her becoming very ill after her brother received his varicella vaccine. This is a live vaccine, and her brother reacted to it by getting a slight varicella rash several weeks after his vaccine, a known and common side effect of this vaccine. At the same time his rash blossomed, Karuna developed pancreatitis and became very sick. While the two events may just be coincidence, the varicella virus is known to cause pancreatitis in some individuals.

It seemed to me that we had both very good reasons to vaccinate, and very good reasons not to vaccinate. In an attempt to help make our decision, I turned to research on vaccines and guidelines established by the Centers for Disease Control (CDC).

CDC and Red Book Vaccine Precautions and Contraindications

The CDC publishes a document, revised every few months, that outlines the guidelines and contraindications for all current childhood vaccines.¹ It is available at <http://www.cdc.gov/vaccines/recs/vac-admin/downloads/contraindications-guide-508.pdf>

Another source, the American Academy of Pediatrics' *Red Book*, a frequently-revised guide to infectious diseases, also lists precautions and guidelines by population, mostly echoing the CDC guidelines.²

Some of the CDC information is quite straightforward, such as the listings on allergy and anaphylaxis, that detail which vaccines should and should not be given for children with certain allergic responses. But the information on conditions such as seizures or other neurological disorders is much more vague.

The guidelines for children with seizures, for example, state that all vaccines other than the DTaP (diphtheria, tetanus, and pertussis) vaccine should be given according to the normal schedule. They suggest administering Acetaminophen four hours before DTaP vaccination, and every four hours thereafter for 24 hours to prevent seizures. *Red Book* goes a little bit further, suggesting deferring the vaccine to a later date for children with seizures that are uncontrolled or of indeterminate origin.

For children with neurological, metabolic, or neuromuscular disorders, all vaccines other than DTaP and Tdap (another version of the same vaccine) are recommended. The CDC states that, "Whether and when to administer DTaP to children with proven or suspected underlying neurologic disorders should be decided individually," and goes on to say that those who are neurologically stable, with controlled seizures, cerebral palsy, and static encephalopathy, should be vaccinated.³ Similarly, Tdap is not recommended for children with progressive neurologic conditions until the condition stabilizes. Children who experienced encephalopathy after a previous dose of DTaP or Tdap should not receive additional doses.

Red Book, in its section on children with chronic medical conditions, emphasizes the importance of vaccinating this high-risk population. At the same time, they are carefully to note that, "Documented experience with immunization of children with some of these [rare neuromuscular, neurological, and metabolic] disorders is minimal or nonexistent, and the physician should seek guidance from a specialist before administering the vaccine(s)."⁴

Those are the complete recommendations for children with neurological, metabolic, and neuromuscular conditions. No further information is given regarding other specific vaccines or children with specific medical issues.

Research on Vaccines and Children with Neurological, Metabolic, and Neuromuscular Issues

If you found the CDC and *Red Book* recommendations as unsatisfying as I did, you probably would want to get much more information before making your decision. I turned to PubMed, the search engine for the medical literature, to try to get more concrete research material.

My first search was for cerebral palsy and vaccines or vaccinations. Apart from a handful of articles written during the 1960s, 70s, and 80s on older vaccine formulations, there were no articles at all on vaccines and children with cerebral palsy. Not one.

Searches for seizure or epilepsy and vaccine/vaccination brought up a lot more results, but almost all of them dealt with febrile or non-febrile seizures after vaccination, and not with vaccinating children with underlying seizure disorders or epilepsy. The one exception is infantile spasms, which has a few articles dedicated to the subject.

Searches for encephalopathy and vaccine/vaccination again brought up lots of information about post-vaccine reactions. I did find it interesting to learn that almost all cases of post-pertussis vaccine encephalopathy are actually caused by an inherited genetic defect of the SCN1A gene. But apart from that, no information was given on children with underlying encephalopathy and vaccines.

There are, of course, many articles focusing on autism and vaccines, but once again, these articles do not focus on children with underlying disorders, but rather the aftereffects of vaccines. There have been several recent articles written on vaccines, autism, and mitochondrial diseases in response to the case of Hannah Poling, a child with a mitochondrial disorder that was exacerbated after vaccination.

Searches for other neurological and neuromuscular diseases led again to very little material. One fine article, on vaccines and metabolic disorders, is available, though it mostly points out the paltry amount of information available.⁵ Articles on immune compromise and vaccines, as well as premature infants and vaccines, are widely available. Some unpublished material, such as this article on Mitochondrial disease and vaccines [<http://www.mitoaction.org/blog/autism-mitochondrial-disorders-how-much-do-we-really-know>] is available, but unpublished articles vary widely in accuracy and reliability.

Why has so little research ever been done on this issue? The only articles that do exist on chronic medical conditions and vaccines have simply cataloged vaccine compliance in children with special needs, and have not even scratched the surface regarding safety and administration guidelines.

A Call for Research

It seems clear that more research needs to be performed in this area. Most likely, research will show it is just fine for children with stable neurological conditions to be vaccinated. But so little information is known on unstable neurological conditions, neuromuscular diseases, and individual metabolic disorders, that it is really difficult for parents and even doctors to make the decision whether or not to vaccinate.

Children with neurological, neuromuscular, and metabolic disorders are some of the children at greatest risk for acquiring many of these vaccine-preventable illnesses.

Moreover, these children are some of the most likely to suffer severe complications from these diseases.

If anything, these are the children who most need these vaccinations, because in many cases, vaccination will prevent serious illness or death from diseases like flu, RSV, varicella, sepsis, and meningitis. More research must be done, so that the most susceptible children can be vaccinated safely when it is appropriate to do so.

In the meantime, parents and doctors must continue to make tough choices on vaccines with very little information. It is currently a lose/lose situation for many families: don't vaccinate and risk severe illness, or vaccinate and risk severe reaction. The risks and benefits must be weighed individually for each child, based on risks and past responses to vaccines or stresses on the immune system.

In our case, we decided to try to administer two vaccines targeted to illnesses Karuna was getting or was very likely to acquire. Unfortunately, she suffered extreme fatigue and a significant respiratory decline within a few days of administration. It appears that in her case, vaccination is simply too stressful for her immune system. Now we are left with little more than crossing our fingers, hoping that she will not be exposed to or acquire any vaccine-preventable diseases.

A little bit of research could go a long way and make a huge difference in the lives of many children. Here's hoping medical science will take a much closer look at our children and develop safe vaccine guidelines and protocols for them.

¹ Centers for Disease Control, *Guide to Vaccine Contraindications and Precautions*. Revised April, 2009. Available at <http://www.cdc.gov/vaccines/recs/vac-admin/downloads/contraindications-guide-508.pdf> Hereafter CDC.

² Larry K. Pickering, *et al.*, editors. *Red Book: 2006 Report of the Committee on Infectious Diseases*. Elk Grove Village, IL: American Academy of Pediatrics, 2006.

³ CDC, 11.

⁴ Pickering, 85-6.

⁵ Jeffrey D. Kingsley, *et al.* "Immunizations for Patients With Metabolic Disorders." *Pediatrics* 2006;118(2): e460-70.