

Special Article:

Litigation and the Child With a Metabolic Disorder

I have been actively handling cases involving kids with metabolic disorders for roughly seven years now, and I've found that parents of these children sometimes aren't sure how legal cases work in several important ways. That's not surprising, and it's not their fault. The legal system is confusing, and the law is not always the same depending on what state you live in. So let me take a shot at explaining some basics. I think it may be helpful to any parent whose child has an inborn error of metabolism and was injured.

First, let me tell you how I got involved in the "metabolic world." One of my law school friends, Dean Jerrehian, has a son, Matt, with PKU. In the 1990's, Dean lobbied hard for expanded newborn screening. Dean told me that Matt is an honors student – but that his success was only possible because Bob Guthrie fought to screen PKU kids in the 60's and 70's. Dean said he wanted to give back and fight for today's babies who could benefit from the next generation of screening.

Quickly, however, Dean became frustrated with bureaucratic delays. He became convinced that state governments and hospitals would not move faster to expand screening unless they were forced. Dean approached me with a newborn-screening case in Pennsylvania involving a family he knew and asked me to take it. I did, and our firm litigated it for over five years, all the way to the Pennsylvania Supreme Court.

Since that time, we have taken cases involving children with metabolic disorders in Pennsylvania and in other states like California, Colorado, Georgia, Illinois, New Hampshire, New Jersey, Texas, etc.

Two Types of Claims: (1) Screening and (2) Delay In Diagnosis and Treatment

There are two types of claims I see, and sometimes one case will have both claims.

The first claim type is a "screening case." This is where a child was not offered screening that is broad enough, or perhaps screening was performed, but it was done improperly.

We have brought several lawsuits against hospitals for not offering or disclosing supplemental newborn metabolic screening. Typically, a state will have mandated screening for between two and ten disorders, but will not offer supplemental screening. We have claimed successfully that, at a certain point, birth hospitals have a duty to offer or disclose expanded screening – even if their state does not mandate it.

Unfortunately, and this is important, in almost all such instances one cannot sue a state for failing to uphold its duty to timely add new disorders to the state's mandatory panel. The law is very clear on this. So, typically, we are left with suing hospitals and pediatricians in instances where the hospitals/doctors knew about the screening, knew the state was delaying unreasonably, and still did nothing. These cases – to be successful – usually will involve children born after 2003, but each case is so fact dependent that it's hard to generalize. In Pennsylvania, for example, expanded screening has been around since the mid-90's, so earlier cases are viable here.

The other kind of screening case usually involves mistakes in screening. Examples: Blood is drawn too early, before feeding; a positive result is not reported; or the lab used the wrong cut-off to define a positive result. In these cases, if the mistake is made by a state laboratory, some states insulate or severely limit suits against government entities, but it still is important to have the case analyzed carefully.

For example, in Illinois, the state itself is insulated from suit but its employees are not. In a case there, where a lab worker failed to report a positive that resulted in brain damage to a child, the employee was sued individually because it was clear that the state would pay any judgment against its employees – even though it didn't have to. The settlement negotiated with the state in that matter provided money to pay for the child's large life-care and medical expenses, costs the parents could not afford.

The second claim type that I see is delay in diagnosis and treatment. This is very common in metabolic cases because doctors in the United States generally have poor training in recognizing inborn errors and sometimes believe that metabolic disease is not treatable.

By far the most common diagnostic error involves children brought to a hospital/doctor with a history of poor feeding and lethargy, frequently with spitting up or vomiting. If the child is not too sick, the parents (often first-time parents) will be told that they are "overreacting." On the other hand, if the child is critically ill, doctors will do a workup for infection and perhaps other potential problems but will not order simple screening tests to check for inborn errors until days later – after an infection is "ruled out."

The truth is, in a newborn who appears healthy at birth but deteriorates shortly after feeding, metabolic disease is just as common as infection. There is simply no reason to delay the workup for inborn errors. In these cases, days, often even hours, can mean the difference between an unaffected child and a child with special needs.

Another common scenario is the GA-1 child who is sent to a specialist because of a large head. Despite, a wildly abnormal head CT or MRI, the baby is diagnosed with "benign extra-axial fluid collections of infancy" or "external hydrocephalus" without any thought about an alternate diagnosis.

I also have seen several examples of children with urea cycle disorders who have not been promptly treated with dialysis and instead are given so-called "ammonia scavenger drugs" such as sodium benzoate or sodium phenylacetate, which are not generally effective when ammonia is high enough to cause neurological impairment.

Children with galactosemia often develop e-coli infections even before screening results are returned. Ironically, we see infection worked up *first* in cases of other misdiagnosed metabolic disorders, but galactosemia kids sometimes are treated for jaundice only – without any appreciation that they also have a life-threatening infection.

The Statute of Limitations

A statute of limitations is a deadline that courts impose on a claimant. The rule is, if you don't bring your case within a certain time, it is too stale, and it won't be permitted. For adults, most states impose a two-year statute of limitations, although it varies. There also is an exception in

many states called “the discovery rule.” In that instance, a state that has a two-year statute of limitations would permit a claim if made within two years of the date that malpractice is “discovered.”

What parents need to know is that almost all states extend the statute of limitations dramatically for kids. In Pennsylvania, for example, a claim may be brought on behalf of a child until the child is 20 (i.e., 18 years of age, plus the two year statute of limitations). Courts don’t want to penalize children if their parents, for whatever reason, don’t bring a timely claim.

The exception is a case where a child dies. Even though it is a lawsuit about a child, courts consider that a parental claim and will apply the parental statute of limitations.

Retaliation

Many parents are afraid to investigate a claim because they are afraid that the medical system will retaliate against their child in some way, perhaps by denying treatment.

Although I understand this concern, and of course we can make no promises, our experience has been that this almost never happens. Particularly in the case of a child with special needs, most providers understand that a lawsuit is the only real chance parents have at getting enough money for their son or daughter to receive the very best care. Often our clients already have switched their child’s care anyway. A move from the hospital or doctor whose omissions caused injury usually solves any potential problem.

Special Needs Trusts and Medical Assistance

I frequently hear concerns that any settlement in a case will disqualify a child for Medicaid and/or social security. By law, money that a child receives in a lawsuit must be put into trust, typically called a “special needs trust.” The special needs trust is specifically designed not to disqualify a child from receiving medical assistance. We never have had a child’s assistance status change as the result of receiving money through litigation.

These are some issues that come up in metabolic cases. I hope my short descriptions are helpful.

Charles P. Hehmeyer, Esquire
Raynes McCarty
1845 Walnut Street, 20th Floor
Philadelphia, PA 19103
Telephone No.: 215 - 568 - 6190
Facsimile No.: 215 - 988 - 0618
E-mail: cphehmeyer@raynesmccarty.com