

PHYSICIANS

How to Choose a Pediatrician and a Specialist

Finding the best doctor possible for a child with viral hepatitis is critical for the child's health and for the parent's or caregiver's peace of mind as the child enters daycare, school or summer camp.

A pediatrician and a liver specialist together define the care and treatment a child with viral hepatitis receives and are essential when finding the best drug treatment or clinical trial.

These doctors also wear other hats:

- The pediatrician can serve as a vital advocate and educator when family members or friends, teachers or school nurses have questions about hepatitis.
- A trusted doctor can be an essential ally when disclosing a viral hepatitis diagnosis to an older child.
- Doctors can also be a family's best advocate when insurance companies balk at covering certain tests or treatments.

Selecting the best medical care for a child is a multi-step process. Parents must first select a pediatrician who will serve as a child's overall medical coach. Next, they need a specialist who is either a pediatric gastroenterologist (GI) or a pediatric hepatologist.

Parents may also have the flexibility to select a laboratory that will perform the blood draws on a child if that service is not available at the pediatrician's office.

How to Chose a Pediatrician

The pediatrician should be thought of as a child's health care coach, manager and advocate.

The pediatrician is the generalist who oversees all aspects of a child's health—from colds, coughs and vaccinations to his or her viral hepatitis. When choosing a pediatrician, look for one with a great bedside manner and an efficient and courteous office

staff. Parents must like and trust their child's pediatrician.

A pediatrician should know enough to answer parents' questions about hepatitis and how the liver works as well as help them interpret basic liver tests and viral reports, even if he or she is not extremely familiar with hepatitis-specific tests.

A pediatrician should be flexible and realize his or her limitations. A pediatrician should be willing to say, "I am not an expert in this area. You need an expert to treat your child's hepatitis."

If a pediatrician says he or she can do it all, find another pediatrician. Any child with chronic viral hepatitis should see a specialist.

"My pediatrician proved to be invaluable the first time I enrolled my daughter with hepatitis B in daycare," said a mother. "The daycare teachers were visibly nervous about taking my daughter. I had them call my pediatrician and she spent nearly a half-hour on the phone with them educating them about hepatitis. It made all the difference to have her there for my family at a time when I didn't know enough to answer their questions myself."

A pediatrician must willingly provide parents with the necessary referrals (and maybe even do some networking and informal checks) to find the best specialist for a child. A specialist will know exactly what tests should be ordered and will make sure a child is enrolled in treatment programs or clinical trials that can improve a child's condition.

A good pediatrician never limits parents' education or access to their child's medical records. Parents should collect copies of all lab tests so they can track the results themselves. If a doctor refuses or is unwilling to accommodate parents and make copies of the lab reports, parents should find a new pediatrician.

In addition to hepatitis-specific knowledge, a pediatrician should be someone parents and children genuinely like and who communicates well with child and adult alike.

Parents must also find out with what local hospital the pediatrician is affiliated. It's important they feel comfortable with this hospital in the event a child must be treated for an illness or for an emergency.

It's also important to find out how available the doctor is by phone. Does he or she return calls promptly? Are parents happy with the doctor's nurse who may often answer some of the parents' phone questions?

What about weekend coverage? Are there on-call doctors associated with a pediatrician whom parents feel comfortable with when a doctor is away or unavailable on weekends?

There is another role a pediatrician plays in the community—as an advocate and hepatitis health educator. A pediatrician and his or her office staff must be willing to serve as an advocate when uneducated or fearful daycare center staff, teachers or camp staff express concerns about a child’s hepatitis.

If a child has a good relationship with the pediatrician, and a parent trusts the pediatrician’s knowledge of hepatitis, the doctor can be enlisted as a “safe” person to talk to after parents disclose a hepatitis diagnosis to a child or adolescent. Children know their parents aren’t medical experts and may appreciate time alone with a doctor to ask questions that their parents can’t answer, or have difficulty answering.

How to Find a Specialist

When looking for a specialist for a child, many parents choose one that is either a pediatric gastroenterologist (often called GI for short) or a pediatric hepatologist.

A gastroenterologist is an internist who specializes in the treatment of digestive disorders, including the liver. As a result of that broad focus, a GI’s experience in treating liver disease, such as hepatitis B, C or D, may range from none to extensive, so it’s important to find one who specializes in viral hepatitis.

A hepatologist is a physician who receives comprehensive training, such as a one- to two-year fellowship, in liver disease.

It is important to find a GI or hepatologist who specializes in children (called a pediatric GI or hepatologist). Hepatitis can act quite differently in children than it does in adults. Parents want a specialist who is up-to-date about the latest clinical trials and treatment experience in children, given the limited drug therapies available.

Parents can ask other parents in support groups or e-mail lists about whom they recommend and what their experiences have been. Once they find a pediatric hepatologist or GI, these are some questions to ask ahead of time, if possible:

- How many children with hepatitis B, C etc. has the doctor treated?
- Is the doctor actively involved in any clinical trials? If yes, which ones?
- How many liver biopsies has he/she performed?

Many parents say the most qualified pediatric GI/hepatologists are found in large institutions or teaching hospitals. These specialists are typically involved with the latest clinical trials and are likely to be conducting research projects of their own. They are also experienced in treating children with all stages of liver disease.

Unless a child is quite ill, it is unlikely he or she will see a specialist more than once or twice a year, or even more infrequently. The pediatrician and the local lab will be able to collect blood samples and send the results directly to the specialist. These infrequent visits mean parents can broaden their search geographically in pursuit of the best specialist available.

The only difficulty in working with specialists who are in high demand is that their schedules are extremely demanding. These doctors do not have a great deal of time to spend talking to parents about the basics of hepatitis. Parents must educate themselves as much as possible before these office visits in order to get the most out of their limited time with the specialist.

The family's pediatrician should be able to help parents through the early learning curve. More specialized information can be found in medical journals in a local library, web sites, non-profit organizations that specialize in supporting families with hepatitis and friends who are in similar situations. Parents should have a list of questions in hand when they walk into the specialist's office.

Appointments usually must be scheduled weeks or even months in advance with in-demand specialists. When the appointment is made, make sure to find out what tests (Liver Function Tests or viral reports) must be run ahead of time. Be sure to talk to the right person ahead of time at the specialist's office—either the doctor or a high-level nurse assistant.

Parents will want to make sure they either hand-carry the results into the office with them, or know for sure that the test results have been faxed, e-mailed or sent to the specialist ahead of time.

Some parents say that to be on the safe side, they hand-carry two sets of the reports to the appointment—one set is for themselves and one for the doctor in the event the lab reports don't reach the specialist in time. Patient charts can be misplaced—even in the best hospitals. Specialists like to work with data. Parents will get little feedback without the appropriate data.

Remember the clock is ticking when the doctor walks in the door! Many parents with

young children try to have two adults present during the office visit. One parent needs to be able to focus on the doctor and ask the right questions while the other entertains the child.

Watch for body language or any other signs that might provide additional insight into the health status of a child during discussions with the specialist. Ask how the doctor really feels about a particular treatment protocol. Remember that doctors are people too, and they have their own style and way of handling things. Some doctors prefer to have data to back up their statements while others are willing to extrapolate a bit more.

Parents should weigh doctors' experience in treating viral hepatitis against their bedside manner. In short, a specialist may excel more at research and numbers than a warm and cozy bedside manner. But if parents feel the doctor is belligerent or not answering their questions, then they should find another specialist.

Remember, a child's situation is not unique to the specialist. Many parents, whose children are in the early asymptomatic or immune tolerant stage of hepatitis, find it frustrating when a specialist recommends a "wait and see" approach.

The doctor is not the only valuable resource in his or her office. Typically, specialists have nurse specialists assisting them. Be sure to get to know this person; this assistant is likely to be the source of great information. This person refers back to the doctor whenever parents pose questions either before or after the office visit.

Many parents discuss their post-visit questions—all the ones they forgot to ask during the visit—with the assistant, and he or she forwards them to the doctor. It is important to figure out the best mode of communication with the specialist and his or her assistant. Some doctors work best by phone—others by e-mail.

Also, between visits to the specialist, don't be afraid to get the pediatrician involved. If parents feel their child is exhibiting symptoms, don't wait to see the specialist. A pediatrician knows the signs of liver distress. He or she can help determine whether or not it is necessary to involve the specialist. If a parent isn't comfortable with the pediatrician's input, then it is best to find a new pediatrician!

The Laboratory Experience

Gathering blood samples for the various liver and hepatitis tests can either be conducted at your pediatrician's office, or your specialist may fill out an order for specific tests and send you to a lab that specializes in these tests. This depends on your medical office and

your location.

The doctor can fill out a “lab sheet” that details what tests need to be run and when they take place. This may sound like a trivial function, but mistakes can be made. The forms must be filled in correctly and the lab must be sure to send the results to the appropriate doctor and/or specialist.

A lot can go wrong and parents must be vigilant. Test dates can be accidentally transposed or the wrong tests can be ordered if a lab technician reads the instructions wrong.

One important tip for easing the blood draw process for your child is working with the same phlebotomist or lab technician at the lab or at the doctor’s office. Be sure to have your pediatrician’s office call ahead the first time to ensure that there is someone there who is experienced in drawing blood from children. Get the name of the technician who is a pro and comfortable with children.

When you sign in, place that person’s name by your child’s and tell them you will wait for that person. If your child is very young, work with the lab technician to get everything ready before you enter the room. The anticipation of the blood draw is often worse than the stick itself and can be alleviated by having the child and the technician ready for the draw.

The technician should have the equipment out and gloves and assistants ready.

The child should be well hydrated (give him or her lots to drink ahead of time; it makes blood draws easier) and warm, but quickly bare-armed before entering the technician’s office or cube.

Another alternative is to have all blood drawn at the facility where the hepatitis specialist is seeing the child. But if you are traveling a far distance, you may want the reports in hand ahead of time.

If you are close to your specialist, it’s often quicker and easier to have blood drawn for the lab work. However, make sure your insurance company will cover the cost of tests conducted at another facility.