

PKIDS' News

"Life's tragedy is that we get old too soon and wise too late."

Benjamin Franklin

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Telling Our Children They're Infected

If hearing your child is infected with HIV or hepatitis B or C is the worst that can happen to a parent, telling your child about the infection runs a close second.

When should a parent disclose? How should they tell them? What will a child ask? Will they ever forgive the parents who infected them? Are silence and secrecy justified to protect a child from a painful diagnosis?

Two pioneers who have peered into the disclosure cauldron are Lori W. Wiener, coordinator of the Pediatric HIV Psycho-Social Support and Research Program at the National Institutes of Health, and Heidi Haiken, coordinator of social work at the Francois Xavier Bagnoud Center in Newark, N.J., an innovative program that works with parents and children with HIV.

For more than 10 years, Haiken and Wiener have worked with hundreds of families infected and affected by HIV on the emotional and social issues related to the disease. Wiener, who has a PhD, has researched and written about the impact of disclosure on family members.

Their combined experiences have produced two cardinal rules for parents of children infected with chronic, viral infectious diseases:

◆ Never lie. You don't have to name the disease if children are very young, but never, never lie. The damage to the parent-child relationship will surpass any short-lived benefits gained by deceit.

◆ Disclose as early as you can, especially once kids start asking questions. The longer you wait, the harder it gets and the greater your chance of undermining your child's trust in you.

"We even tell parents who come to the center that if they don't tell the kids by the time they reach sexual maturity, we will," Haiken said. "But of course it's much, much healthier to have this information come from the parents."

Both women acknowledge that disclosing is very traumatic for parents. "For some parents, it's just devastating," said Haiken. "They feel guilt because they infected the child because of their past sexual behavior or drug use. They feel guilt that the child has to suffer. Even for parents of children who contracted it from transfusions or are adopted, disclosure is extremely difficult."

Wiener, who has written several research papers on this topic, found the longer parents withheld the diagnosis, the more embedded the lies became and the harder it became to disclose the truth. "Parents often fear that once they disclose new and different information, that their child will no longer trust them," she said. "Following disclosure, many of these children feel embarrassed that other people in their family have been aware of the diagnosis before they had been informed. Once disclosure takes place, these issues and feelings can be

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successfully dealt with in individual and group counseling sessions with parents and children.”

Haiken and other social workers at the center work hard to help parents work through their guilt, or at least face it without flinching, before they disclose.

“I tell them ‘you didn’t mean for this to happen, it’s clear you never wanted to hurt your child, look at all the wonderful things you’ve done for your child,’” said Haiken. “After a while they get there, they see it, but it’s still very difficult. No parent ever wants to infect her child. It’s something they felt they had no control over.”

In terms of disclosure, parents who are themselves living with HIV have additional challenges to face. They fear disclosing their own life-threatening disease to their children. But generally, says Wiener, by the time children reach ages 6 to 10, they realize the consequence and finality of death. It is useless to shield children this age from the knowledge that their parents have a serious or terminal illness.

The disclosure process, timetable and style are often dictated by the parents’ health. Can they focus on their kids and execute disclosure, or are their own health problems overwhelming? Are they getting the support and time they need or are their own medications, insurance forms and other factors too overwhelming?

“Foster or adoptive parents have the luxury of not having to worry about their own illnesses, so the emotional and financial stress on the entire family may not be as intense,” noted Haiken.

The journey to disclosure begins early, says Wiener. “The child and parent should first have a sense of trust - that is the highest priority.” Disclosure occurs little by little in age-appropriate ways as soon as a child can communicate. Just like talking about adoption, it’s always on the table, though not all the details or medical terms may be exposed just yet.

Ideally, suggests Wiener, when the parent discloses, the conversation should go something like this:

“Do you remember when I told you that you had a germ in your blood? That’s why we have blood work done every year. (And) Do you remember I told you that you got the germ from blood? Well, that germ is a virus that is called HIV or hepatitis....”

“You see, the disclosure dialogue is a constant building process,” she said. “If the child asks why the parent didn’t tell them earlier, the parent needs to be able to say, ‘I never lied to you, I told you what was wrong, I just hadn’t told you the name of the virus.’”

It may take a child weeks, months or years to absorb the diagnosis. “Try to be where the child is at when they ask questions,” wrote Wiener. “Let the child know that no matter how difficult the subject matter, he or she can always ask questions or share feelings. Be careful, however, not to provide more information than the child wants or is prepared for. They may not be ready for a virology discussion.

“You never want to be in the position of telling a 12 year-old about his or her disease that you have never even referred to before,” she added. “That is my main concern in the disclosure process. We’ve interviewed a lot of children who have been disclosed to. Most felt they had been told at the right age and by the right person except those whose parents had a doctor tell them. Those were the only kids who remained upset about the disclosure process.”

At NIH, counselors work intensely with parents of HIV-infected children to prepare them for the disclosure discussion. Social workers even have parents write out what they will tell their children and then play the part of the child in role-play situations. Generally, parents should be prepared to answer the following questions, depending on the child’s age and development. (Some questions apply if the parent is infected also.)

Why did this happen to you?
Are you going to die?
Who else in the family has it?
Why don’t (siblings) have it?
Will this hurt?
Who can I tell?
Can I get married?

Where did you get it from?
Am I the reason you got sick?
Why do I have it?
Am I going to die?
Who else knows I have this?
What will happen to me and (siblings)?
Can I have children?

Here are some general guidelines Wiener has identified for parents to consider as they prepare for the disclosure discussion:

- ◆ Where do you want to make the disclosure and who should be part of the discussion?

“You don’t want to have a ton of people there, just those whom the child trusts and feels most comfortable with,” cautioned Wiener. “Try to anticipate the child’s response based on his or her emotional age and maturity. Be careful never to disclose when you’re angry, or during an argument. Have the discussion in a safe, comfortable environment.”

- ◆ What is the most important message you want your child to walk away with from this discussion?

Possibilities include: Nothing is going to change... I am just now giving you the name of the virus... We will always be there for you... I will never lie to you... Nothing you did caused this disease.

- ◆ How exactly will you disclose the actual diagnosis?

“We have parents write out how they’d like it to happen, and they always start out with, ‘Do you remember?’ Weave in pertinent aspects of the child’s life and pick up the threads of your past discussions about infections,” suggested Wiener. “Rehearse the questions and answers, including ‘How did I get it? Can I get married? Can I have kids? Who else knows about it?’”

- ◆ If the diagnosis is to be kept secret, who else can the child talk to?

“If parents tell a child not to tell anyone, the first thing a child will do is go tell someone,” said Wiener. “They’ll feel resentful if they have no one to talk to. Parents need to find others in the community for the child to talk to. If there isn’t anyone nearby and the child wants to tell his or her best friend, I would tell them to talk with me, the parent, first. I would explain that not everyone is as educated as we are, and it’s important that we make a plan and educate the friend about this infection first. After all, we don’t want anyone to treat us badly.”

- ◆ Give child a journal or diary or a way to express their feelings about the infection.

Encourage the child to use art or writing to express feelings. “If HIV had a face, what would it look like? Or start a discussion with, ‘If I had a million dollars, I would get rid of this virus. What would you do with a million dollars?’ Keep those discussions going,” Wiener suggested.

“It is usually not until days or weeks after disclosure that the child has the courage to ask more questions,” she added. However, after finally making the disclosure, some parents feel so relieved and so exhausted from the ordeal that they may not have the emotional energy to talk about it again. This blocks open

communication at a time when sharing concerns about the disease and its impact on the family is most important.

- ◆ Red flags to look for in a child following disclosure.

These include difficulty sleeping, changes in appetite, withdrawal, ticks, new fears, mood changes, difficulty concentrating or hoarding things. If you see any such problems, talk to your child and if necessary, seek help from a social worker or psychotherapist. Remember, disclosure is not a one-time event and a child needs constant reassurance that they did not cause the disease.

- ◆ Don’t forget siblings in the disclosure process.

Whether or not a sibling is told depends on age, said Wiener. “If the sibling is close in age, I don’t make it a choice, the sibling must be told. But, I do give them a choice of whether the infected child tells the sibling or if the parents tell the sibling. You need to give the child a sense of control. Living with secrets in the home does not promote a healthy emotional climate. I try to minimize the amount of secrets or lying that’s going on. However, if there’s a medical procedure or if they’re on interferon which makes them grouchy, it’s important that siblings know why.”

Even after disclosure is made, the full reality of the diagnosis may not come about for years. “It may not be until someone dies, or they get sick for the first time or they can’t go to a party and drink like everyone else that the reality really sinks in,” said Wiener. “At that point, it becomes an emotional reality, not just an intellectual reality.”

Wiener finds most parents do feel relief after making disclosure. The burden of secrecy is lifted, and children who already intuitively know something is wrong often feel better after they are told of their diagnosis. Siblings, especially if they are older, are also relieved when the veil of secrecy is lifted.



“The demands of keeping the family secret is a heavy burden for a young sibling and may threaten healthy development,” Wiener wrote in a study of siblings of HIV-infected children. “As inquisitive peers begin asking siblings why their brother or sister is sick, it becomes increasingly difficult not to tell the secret. One 9-year-old girl describes: ‘I want to tell people. Right when I almost say it, I remember in my head I’m not allowed to.’”

(cont. page 4)

Helping Kids

"There is no use
trying," said
Alice. "One can't
believe
impossible
things."
"I dare
say you haven't
had much
practice," said
the Queen.
"When I was
your age, I
always did it for
half an hour a
day. Why,
sometimes I've
believed as
many as six
impossible
things before
breakfast."

Lewis Carroll

The Songs of Love Foundation. This fabulous group will create a one-of-a-kind song just for your child.

They believe that "there is no stronger way to bring smiles to the faces of sick children than to honor them in their very own song. Children typically tend to play the tapes over and over again. They cannot believe they hear their names and all the things they like mentioned in the songs. The enthusiasm, beauty, and spirit reflected in each song also touches the lives of family members, friends, hospital staff, and soon everyone finds themselves singing along with the music. A recent article in *In Touch*, a health magazine, stated that 'young patients endure invasive procedures thanks to the comfort their songs provide.' The ongoing therapeutic value of each composition deeply affects not only the child, but everyone else who has been affected by the patient's struggle with illness. The songs move beyond one event, and capture the beauty and spirit of each child as they provide lasting joy and encouragement."

To learn how to get a song for your child at no cost to you, go to:
<http://www.songsoflove.org>.

KIDSAFE ID. This company, based in San Diego, California, offered us the opportunity to provide parents and other caregivers free access to child IDs. If a child is lost or taken, the parent or caregiver carrying this ID can show it to police and other emergency personnel. It has important information that will be needed to help find the child.

KIDSAFE is a for-profit business. You may print out free IDs for yourself and others who watch over your child from our website or you may pay KIDSAFE to print them on credit card-type paper. You're under no obligation to order anything from KIDSAFE.

If you print out IDs yourself, just take them to a business store and have them laminated, they'll last longer. We hope you find this opportunity useful. Please let us know if you have any questions. You'll find everything you need at: <http://www.pkids.org/childid.htm>. We receive no compensation from KIDSAFE and are not liable for their actions. You may contact KIDSAFE directly at: 619-427-8686

Make-A-Wish Foundation. Most people have heard of this organization. You or your physician (or your child) may refer your child for a wish. The Foundation confers with your child's doctor to see if your child is medically eligible

for a wish. Your child does not have to be terminally ill to qualify. All wish expenses are covered by the foundation - the families pay nothing. For more information and to refer a child, go to:
<http://www.makeawish.org>.

(Disclosing cont. from page 3)

Resentment of the special treatment given to the sick sibling may cause the healthy sibling to feel less loved, Wiener explained, particularly if no explanation for the preferential treatment is provided.

Heidi Haiken, who has worked with more than 400 HIV-infected kids, has found disclosure to be beneficial to parents and kids alike. "By and large, the kids do well and are glad they've been told," she said.

But disclosure is just a step in the journey. Parents must be prepared to ask, probe and continue the dialogue about health safety, standard precautions, medical treatments, good nutrition and the fundamentals of safer sex with their infected children.

"In our program, we start teaching safer sex at age 10 to 13," said Haiken. "We give out condoms, talk about masturbation and how to keep yourself and your partner safe. We don't deny they're sexual beings, we focus on how to be safe with it, how drugs and alcohol can make you do things that aren't safe."

That safer sex discussion is just one more elaboration on the discussion that began when parents tell their infected toddlers never to touch anyone's "boo-boos."

Most parents of infected children and teens don't have a Heidi Haiken or Lori Wiener in their hometowns. And, they can't count on local schools to teach standard precautions or to delve into the nitty gritty of safer sex procedures. Most parents must be open and honest as they continue these discussions, no matter how painful or awkward, throughout their children's lives.

Katherine's Corner

Fever Phobia

Few symptoms cause as much confusion and concern as fevers do.

Why do Fevers Occur?

A fever is a resetting of the body's thermostat to a higher temperature. This usually occurs in response to an infection, although other conditions can cause fever as well. Fever is an indicator that the immune system is working.

What is a Fever?

We all tend to think of 98.6 as a "normal" temperature, and anything above as a fever. In fact, temperature varies from person to person, and will also fluctuate by about a degree in any given person over the course of a day. We typically run about a degree lower in the morning compared to the evening. A temperature of over 100.4 is considered a fever.

How should a Temperature Be Taken?

Rectal temperature is considered the "gold standard", and it's most important to obtain in this way in an infant under 3 months of age. An axillary or ear (tympanic) temperature can be obtained in older infants and children. Forehead and pacifier thermometers are not as reliable a measure of temperature.

When Do I Worry About a Fever?

Always notify your doctor if an infant 3 months of age or younger has a rectal temp of over 100.4. The fever itself isn't harmful, but babies this age can be quite ill without showing other signs, and will likely need to be seen.

For children over 3 months of age, it's less likely they will be seriously ill and not have other signs and symptoms. A child's behavior and activity level are more important clues to the severity of illness. A 6 month-old who is playing and happy with a temperature of 103 would be less concerning than a 9 month-old with a 101 temp who is listless and lethargic. A fever has to be quite high (generally felt to be greater than 106) for the fever itself to be harmful.

Other symptoms, such as rash, trouble breathing, lethargy, or other indications of a sick-looking child should prompt a call to your physician or visit to the ER. Fevers over 104 degrees, or any fever lasting more than 3 days, should prompt a call to your physician to help assess for the need for a visit.

When Should a Fever Be Treated?

The main reason to treat a fever is for comfort. A happy child with a fever does not have to be treated. However, as temperatures rise over 101, many children become uncomfortable, with headache, body aches, increased heart rate, etc.

Treatment can be with acetaminophen or ibuprofen at the appropriate doses. **Never give your child aspirin for fever.** It has been linked to a condition called Reyes' syndrome.

Lukewarm sponge baths can also be used, as well as offering plenty of fluids. Don't worry if your child doesn't want to eat much for a few days, as long as they're drinking.

Avoid alcohol sponging (it will raise the temperature) or cold water baths (increases discomfort).

Fever Myths and What Ifs

1. "The temperature came down a few degrees and my child feels better, but the temperature still isn't normal. My child must be really sick." A child's response to acetaminophen or ibuprofen (in terms of degrees a fever decreases) is not an indicator of severity of illness. We don't expect the temperature to come down to normal. Remember, treating the fever is done mainly for the child's comfort, but it doesn't make the illness get better any sooner.
2. "Fever can cause brain damage." A temperature probably has to be over 106 to cause problems like this, and in a normally healthy person, that doesn't happen.
3. "What about febrile (fever) seizures? They can occur at temperatures less than 106." True. Febrile seizures are frightening. They occur in 3-4 percent of children, usually between 6 months and 5 years of age. They are typically brief and don't cause any lasting problems. Always notify your child's doctor if they have a febrile seizure.

Take Home Message

Fevers are rarely harmful.

In a child under 3 months of age, call your doctor for any temperature over 100.4. In older children, you can feel more comfortable evaluating the child, giving medicine to bring the fever down if they are uncomfortable, and calling the doctor if you're concerned about how they are looking or acting.

Dr. Katherine Vaughn is a board-certified pediatrician and PKIDs' Chief Medical Advisor.

"If you
want to
make an
apple pie
from
scratch,
you must
first
create the
universe."

Carl Sagan

The Hepatitis B Foundation

We asked Joan Block, one of the founders of the Hepatitis B Foundation, to tell us about their wonderful work. Here is what she had to say:

About the Hepatitis B Foundation

The Hepatitis B Foundation is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide. Our commitment includes funding focused research, promoting disease awareness, supporting immunization and treatment initiatives, and serving as the primary source of information for patients and their families, the medical and scientific community and the general public.

Our Story

In 1991, Paul & Janine Witte and Timothy & Joan Block were deeply moved by the plight of a family affected by hepatitis B. To their dismay, they discovered there was no place to turn to for information and support, nor was there any organization devoted to finding a cure for hepatitis B. With the help of friends and the personal support of Dr. Baruch Blumberg, who won the Nobel Prize for his discovery of the hepatitis B virus, the Wittes and Blocks responded to this unmet need by working tirelessly to establish the Hepatitis B Foundation (HBF).

The journey has been an incredibly exciting one as we have successfully grown from a kitchen grassroots effort into a professional organization with a global reach. Currently, the HBF's offices and labs are located in a state-of-the-art research facility in Doylestown, Pa. However, our work is not done. There are 400 million reasons why our mission remains so urgent - a cure must be found for the 400 million people who still suffer from chronic hepatitis B.

Promoting Excellent Science Rooted in Human Compassion

Over the past 11 years, the HBF has developed a comprehensive research, education and patient advocacy program to achieve its mission of helping those affected by hepatitis B. We are committed to providing information and support to all those affected and to finding a cure by funding excellent science rooted in human compassion.

By phone, mail and the internet, we touch thousands of lives each year. The importance of our mission is affirmed every day as we listen and respond to the personal stories of those contacting us for help. We provide information and support to individuals and families through our dedicated website (www.hepb.org) that includes language chapters of translated information, email and telephone help-lines, free *B Informed* newsletter and educational literature, national directory of liver specialists, community events and an annual patient conference.

We bring hope through research by funding the HBF Lab's search for a cure; hosting the prestigious annual Princeton Workshop where the nation's top clinicians and researchers are invited for intense discussions about hepatitis B therapeutics; awarding the "Bruce Witte Research Fellowship" that is a three-year grant to encourage a beginning scientist to study hepatitis B; and sponsoring a student internship program to introduce college students to the problem of hepatitis B in the HBF labs.

Partnering for Patient Advocacy

As the only organization solely dedicated to those affected by hepatitis B, the HBF serves as an important voice for the hepatitis B community. Our experts are often invited to provide testimony to state and federal legislators. We have successfully advocated for funds to support hepatitis B prevention, education and research programs as well. Last year we sponsored the first-ever national conference for those living with chronic hepatitis B and their loved ones. Almost 50 people traveled across the country to meet and share

"The best way to predict the future is to invent it."

Alan Kay

"Not
everything
that can
be
counted
counts,
and not
everything
that
counts can
be
counted."

Albert Einstein

their stories during our "B Informed - A Gathering of Friends". This conference is an exciting activity that has resulted from the strong partnership we have formed with the Internet Hepatitis B Information and Support List (HB-L), which is the only online support group for "hepBers". Due to popular demand, a second B Informed conference is scheduled this year June 28 - 30 at the HBF, so please be sure to contact us for more information.

In addition, we are proud to actively support PKIDs' call for a Presidential Advisory Council for Viral Hepatitis. The HBF strongly believes an advisory council would do tremendous good in raising the national profile (and increase federal funding) of viral hepatitis in general, and hepatitis B in specific. We are very committed to working with PKIDs, the ALF, HFI and the Children's Vaccine Program at PATH to make this happen. It's not only exciting to have all of these organizations working together for a common cause, but by combining our resources and talents, we also have a much greater chance of succeeding.

A Cure is on the Horizon

Only ten years ago, there were no effective treatments for those living with chronic hepatitis B. Today, there is a lot of hope with exciting new advances in hepatitis B therapeutics. The good news is that as researchers have begun to zero in on how the hepatitis B virus operates, more promising drugs are becoming available. We now have two FDA approved drugs, and at least three drugs in phase III clinical trials, eight in phase II clinical trials, and twelve in the research pipeline! HBF scientists are also contributing to the progress of hepatitis B research through their discovery of a promising compound that is currently in development. Be sure to check the "Drug Watch" on our website or subscribe to our free *B Informed* newsletter for regular updates.

Although the initial hope was that there would be a magic bullet to cure hepatitis B, none of the individual drugs to date offer a complete cure, except in rare cases. Experts agree the most effective therapy will probably include a combination of several drugs. The best way to halt the hepatitis B virus may be to employ two strategies - one aimed to attack the viral replication factory, the other to beef up the immune system. The two-pronged approach, however, raises a slew of questions such as what will be the most effective combination, should the drugs be given together or staggered, and which patients are the best candidates for these therapies? Despite the many unanswered questions, it is encouraging to remember that the strides made in the past ten years represent a huge step forward toward turning the tide against this insidious virus. There is certainly good reason to hope that a cure is on the near horizon.

The Future is Today

The Hepatitis B Foundation can help increase disease awareness, keep the hepatitis B community up-to-date about therapeutic advances and continue to serve as vocal patient advocates. But to achieve our ambitious goal of finding a cure for hepatitis B will require a major team effort. Government grants, biotech investment, and major pharmaceutical research and development programs are all needed to fund the cure. We also need those who are affected to become active members of this team. Individuals and families can share their stories to help remove the social stigma, participate in the HBF's annual "Gathering of Friends" patient conference, volunteer for clinical trials if it's medically appropriate, and urge industry and government leaders to increase research dollars for hepatitis B. A cure is too close for the 400 million people worldwide who live with chronic hepatitis B to be forgotten. Raising our voices together about this silent disease is an important step towards eliminating it!

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Parents of children infected with HIV or viral hepatitis wrestle constantly over whether to tell a child's teacher or a daycare provider about a child's infection. I'm no exception.

Both the American Academy of Pediatrics and the Centers for Disease Control and Prevention (CDC) say disclosing to teachers or daycare providers is not necessary because all school staff, coaches or camp counselors should be practicing standard precautions with everyone. They're supposed to assume everyone is infectious.

But I have doubts about how well my children's teachers and daycare providers are trained in standard precautions, and I have even more doubts about whether they follow them.

I live in Northern New England where no one has even heard of hepatitis B. Most residents here probably figure no one they know has HIV or AIDS. And if they do, it's because they moved here from out of state.

While I know it's my responsibility to encourage my community to follow standard precautions, I suspect the more I grill a teacher or coach about her adherence to standard precautions, the more questions I stir up about why I am so obsessed.

I often feel in a no-win situation. While school nurses may practice standard precautions, in all likelihood it will be a teacher who will tend to my child's bruise on the playground or bloody nose in the classroom. I'm back to the old debate of protecting my child's privacy vs. protecting public health.



While the Academy and CDC say I don't have to tell, my child's school health forms still ask about notable medical conditions. To date, there has not been any clear federal legal precedent or case that definitely establishes that parents do or do not have to disclose to educators and daycare providers.

If I lived in New Jersey, I wouldn't have to hold this daily debate. The Garden State made it easy for parents like me. As a result of its close experience with HIV and AIDS, New Jersey mandated that parents don't have to tell teachers about a child's chronic, viral infectious disease.

"Here in New Jersey, some parents tell teachers and some do not," said Heidi Haiken, coordinator of social work at the Francois Xavier Bagnoud Center in Newark, N.J., an innovative program that works with families touched by HIV.

"My issue with telling a teacher is that next year the child will have a new teacher. Will you end up essentially telling every teacher in the school?" asked Haiken. "School nurses tend not to change that much. School nurses are not supposed to tell teachers that they have a child with HIV in their class. If a school nurse is doing her job, she will be educating the staff so everyone in the school follows standard precautions."

But if and when a parent develops a close, personal relationship with the teacher, they may still decide to disclose, she explained. "However, we've had some cases where teachers don't realize the laws and have disclosed to others, but less so as the years go by and people become more educated," she added.

Teachers in Newark, because of the area's HIV infection rate, have received extensive education about HIV and standard precautions. Not so in other parts of the country, including my home town.

Four years ago, I didn't know enough to stop my child's pediatrician from noting her hepatitis B infection in her school health record. Today, I ponder how to get that information removed without inadvertently drawing more attention to her infection.

Last fall, because that information was already there, I decided to tell my child's new teacher. I figured the new teacher would eventually hear about it anyway. I wanted to be the one to tell her, and to take the opportunity to reinforce the need for standard precautions.

I had another motive. If the teacher reacted badly, I wanted to deal with that immediately and get my daughter transferred to another classroom if necessary. Her teacher responded well, but this chessboard maneuvering is exhausting. Haiken is right, the more teachers I inform, the higher the risk of exposing my daughter's infection status to the greater community.

A privacy mandate, like New Jersey's, would prevent this gamesmanship, and accomplish something far more valuable. When HIV and hepatitis are not topics for disclosure, they move a step closer to what childhood cancer or other illnesses are - terrible diseases that could happen to anyone. Nothing more needs to be said.

Christine Kukka is PKIDS' Director of Communications.

Travis: A Young Man's Life

Parents of children with viral hepatitis and HIV struggle with the prickly issues of disclosure, whom to tell, teaching safer sex practices and other issues. In this feature, Travis, a 19-year-old college student who has hepatitis C, offers parents some insights into what it is like growing up and coping with a chronic, viral infectious disease.

I contracted hepatitis C at a very young age, maybe 1 or 2. I was told I had it a few years later. I also have hemophilia A, and during the early 1980s, before blood was screened, the national blood supply was contaminated with all sorts of major diseases.

I got hepatitis, but considered this almost as a blessing. At the time a very large number of hemophiliacs my age and older got AIDS, hepatitis B or C or combinations thereof. I really didn't understand the implications of having the disease at the time, but I was scared to death of AIDS and figured if I was going to get a disease, better nearly anything but that.

So I guess I took the news of having hepatitis C pretty well. It was also facilitated by already having hemophilia. My life was already dominated and defined for the most part by having one major disease so I had always known that I was different than the average child and that my lifestyle would have to be different as well. It was not as if I had gone from being a perfectly healthy individual to one with a major viral disease - having to drastically change my conception of self or lifestyle.

Not a lot was known about hepatitis C and I really was not aware of how it could be transmitted during my early adolescent years, so I tried to be really careful. I tried not to let people drink after me, etc. This was common enough that I really did not stick out as being different. Besides such little things, hepatitis C really did not impact my life that much. I was always a little drained of energy and had to get more sleep than the average kid. I got teased some about the sleeping but no one would say anything about my not being super-active or anything because a severe hemophiliac has no business playing football anyway.

Later in my teen years, having hepatitis C did have a little more impact. However, I could cover most things with my hemophilia. I had no trouble telling my closest friends that I had hepatitis C, but thought it unwise to spread that knowledge around as most people are uncomfortable with such things and it might hurt my chances of getting girls, etc., which would have been tragic to a high schooler, of course.

I grew up in a small town and everyone knew that I had hemophilia, which, of course, is not contagious. Having had hepatitis C for close to 20 years and hemophilia on top of it, I try to baby my liver and avoid the alcohol, tobacco, pot, etc. that would only make it work even harder.

At social events where such things come up (in small towns, alcohol comes up weekly), I would tell everyone that I had a bad liver and shouldn't do any of that. They knew I had hemophilia and put two and two together and had no problem with me not drinking. In such a way, I did not have to tell everyone that I had hepatitis C, but I could still be completely socially accepted in an environment where, sadly, alcohol is a mark of acceptance.

As far as sex goes, I grew up in a very religious Christian family that was very conservative about the topic. I never expected to be a "playa," and my goal was and is to try to wait until marriage. I believe that at the very least I should really love a girl to have sex with her. Giving her a major disease doesn't exactly fit the "love" criteria. This is where it gets complicated. A condom is, of course, a must. However, using it when married not only helps prevent me giving the woman whom I love a nasty little bug, but it also keeps us from having a child. I don't really want to adopt, and, for that matter, don't really want to have to use a condom for my entire sex life ...

"When you do the common things in life in an uncommon way, you will command the attention of the world."

George Washington Carver

Hopefully, by the time I am married, a cure for this disease will be available. If not, I guess I will have some hard decisions to make as I go.

As far as sex in high school or college goes, I am not exactly a lady's man so the situation really has not come up all that often. I believe that, besides the moral issue, hepatitis C or any other major disease makes things very complicated. Not only is there the possibility of getting the girl pregnant, you could also give her a serious disease, neither of which can be very pleasant, especially for someone unprepared for it. Also, if you really liked the girl - good luck continuing the relationship if you accidentally give her those two presents...

My advice to parents raising children with hepatitis or any other transmittable disease is to encourage abstinence, even if just for practical purposes. Besides the messes of unwanted pregnancies or giving the partner the disease, there is always the chance that another disease might be given back, which only makes matters much more complicated.



On the medical treatment front, I have had the interferon/ribavirin treatment for my hepatitis C. It was a doozy. The treatment has many, many serious side effects that can vary a considerable amount in intensity, among different people. I highly recommend taking it at a time when there is little stress in your life. I also recommend not taking it at too early an age. One must be very self-aware and watch every action to get through it, as some side effects can be quite insidious.

In my case, I had some depression and slight aggression sneak up on me. It was making me miserable and really hurting my relationships with family, friends and teachers. It took me a while to realize that it was the medicine that was doing this to me, and only then could I deal with it.

I had to tell people that I was on some serious medication and that I was very sorry about my attitude and that I hoped they could forgive me for any offense or rudeness on my part. I feel that if I had been much younger, I would have never realized that and could have seriously hurt a lot of relationships and perhaps done some damage to people I really cared about that could never be repaired.

Still, I recommend giving interferon a try if possible. While it did not cure me, it initially had great suc-

cess. Another member of my family went on the treatment as well and in that case the treatment was immensely successful. It is very much an individual treatment and its harshness and success or lack thereof can never be predicted. Still, it is very much worth it if it does succeed!

Now that I'm in college, I am much more closed about having hepatitis C. Most people I meet I will not know for a long time, so there is really no need to tell them. I have not known them for many years and really cannot predict how they might react. College students tend to be aware that everyone has personal business that they don't need to share to still get along. It is not at all the small town environment where one will know the same people all their lives and know how they will react to things.

Hepatitis C continues to impact my life now much as it did earlier. I try to lead a healthy lifestyle and avoid anything that has too much impact on my liver. I try to avoid fast foods, alcohol, drugs, exercise and contracting other diseases, of course. People with such diseases can lead fairly normal, healthy lifestyles without too much trouble. It just takes a little self-discipline, which can beneficially impact your life in other positive ways as well. One should always do what you have to do, and not do what you shouldn't do, not just dealing with diseases but in everyday living.

As far as advice to parents: Look out for the health of your children! I did not get AIDS because my mom had the foresight to heat my hemophilia factor VIII medicine before administering it to me. I did not get hepatitis A or B because I was vaccinated for them nearly immediately. I don't even want to imagine what it would be like to have more than one type of virus!

I highly recommend vaccinations. There is always the chance that a person can go without ever getting a disease, but there is also the chance that that person will. Having a major disease can be a minor hassle requiring only a disciplined lifestyle, vigilance, and some treatment, or it can be a huge hassle with huge medical bills, constant hospitalization, and living in a state of permanent illness. Or, it can just kill a person outright.

None of these options are that great, and they are all a much greater hassle than going to the trouble to take your child to have a shot or two.



Pediatric Hepatitis Report

We wanted to remind you that the 530-page Pediatric Hepatitis Report is online in English, Spanish, Russian and Simplified Chinese and available for download free-of-charge. The report, the first ever to address hepatitis A-E in children, is designed to help parents, social workers, childcare workers, teachers and healthcare providers better understand these diseases that infect millions of Americans, many of them children.

Today, the Centers for Disease Control and Prevention (CDC) estimate:

- ◆ One in 20 Americans have been infected with the hepatitis B virus
- ◆ About 4 million have been infected with the hepatitis C virus
- ◆ About 85 million have been infected with the short-lived hepatitis A virus, most during childhood. (Unlike hepatitis B and C viruses, hepatitis A is spread through food and water contaminated with the feces of infected people.)

Because children with hepatitis B or C rarely have symptoms, it is not known how many children are infected nationwide. However, CDC, which provided partial funding for this report, estimates that between 20 to 30 percent of the 1.25 million Americans with chronic hepatitis B became infected during childhood.

In addition to examining how hepatitis viruses affect the liver and what the latest medical treatments are, the report also addresses critical non-medical issues that families face, including:

- ◆ How and when to disclose a viral hepatitis diagnosis to an infected child
- ◆ What civil rights protections are available to children with infectious diseases in schools, daycare centers and sports programs
- ◆ How to practice standard precautions in everyday life to prevent disease transmission
- ◆ And how to ease children's anxieties about doctor visits and lab tests, including dreaded "blood tests"

If you prefer a hard copy of the report, please send \$45 to our office. We accept checks, money orders or credit cards.

Infection Protection

Infection protection is always useful to have around the house or car. Should you need such items, we maintain a supply in our office. We don't want our children to accidentally infect someone, but we also don't want our children to become infected with another disease. The most practical way to go about living these days is to assume everyone is infected with something and practice standard precautions.

We have a large list of items on our website (<http://www.pkids.org>), or call the office if you have questions. We carry many things including Red-Z Powder, a First Aid Kit, lots of different kinds of Gloves, Infection Control Kits, Sharps Containers and a Handwashing Video. Any profit made from the sale of these items is plowed back into our programs. If there is something you'd like for your family that we've not listed, please let us know and we'll see if we can find it for you. Give us a call if you'd like to place an order. You may pay by credit card, or just send in a check or money order and tell us what you want and where you'd like it sent.

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Don't forget! If you contribute \$40 or more annually, you will automatically receive our quarterly newsletter. If your contribution is between \$75 and \$149, you will receive a set of posters or a handwashing video as your gift. All those contributing \$150 or more will receive a free Pediatric Hepatitis Report (PHR) as our gift to you.

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