

FAQ: Adopting Children who are HIV Positive (HIV+)

Created by Erin Henderson and Merrily Ripley, and reviewed by Dr. Jane Aronson, Jan. 2010

Over the past few years it has become possible for US families to adopt children from Ethiopia who are HIV positive (HIV+). AAI now has over 100 HIV+ children from Ethiopia either home with new families or in process of being adopted, and we have started being able to place HIV+ children from Thailand, Ghana and possibly China. This FAQ provides some information for families interested in this possibility.

Please note that international adoption of HIV+ children is still relatively new. In the past there was no hope for these children to ever be adopted, and so the children who have been in the orphanages for more than the last year or two may not have the paperwork that is necessary for an adoption ready, and if the child has been in care for some time it can take extra time for this paperwork to be completed correctly.

Also, it is important for the adoptive parents to understand that it is the responsibility of the orphanage that has custody of the child to prepare the paperwork for court, and AAI can only assist with that as the orphanages are willing to allow. In the past, some of the HIV+ cases have taken longer to get through court in Ethiopia than other cases because of this. However, AAI staff worked with the orphanages and trained them on how to get the paperwork done correctly the first time and the importance of doing so, and the court process for HIV+ kids has smoothed out as more children have been adopted, and we are doing all that we can to ensure that continues to be the case.

The courts in Ethiopia used to expedite our cases for HIV+ children, but now they do not give expedited court dates unless a child is very ill and treatment is not available in Ethiopia, which only happens very, very rarely.

Erin Henderson is the HIV+ Adoption Coordinator for AAI, and she can be reached at Erin@adoptionadvocates.org Erin keeps track of the waiting HIV+ children who are available for adoption through AAI, obtains medical updates on the waiting children, answers questions about parenting HIV+ children and HIV adoption for prospective adoptive parents, helps find resources for parents adopting HIV+ children, helps parents with the waiver paperwork and is a support to AAI families adopting HIV+ children.

How do we find out about HIV+ children?

Children are tested for HIV when they are referred to AAI. Children in Ethiopia who are HIV+ generally do not stay at Layla House, but are referred to an appropriate agency in Addis, usually AHOPE-Ethiopia, where they receive medical care. In other cases, orphanages who work cooperatively with AAI may be aware of children with HIV in their care and may refer them to AAI for possible adoptive placement. Currently, most of the HIV+ children AAI has placed and has waiting are from either AHOPE or Kidane Mihret. AAI has the same basic Intake Medical information on these children as for those children accepted into AAI care. Some of the children with HIV have siblings who are negative and may be in AAI's care or in the care of another orphanage AAI works with.

Some of the children who are HIV+ are included on the AAI Ethiopia Waiting Child DVD. There is also a complete list of all of the waiting HIV+ children that are available. If a family is interested in a child of a certain gender or age they may make a request and a child meeting those parameters can be identified. A complete file of medical and social information is sometimes not gathered on

children who are HIV+ until a potential family expresses interest. Thus, there may be a short wait while that information is obtained.

We typically now have a short waiting list for parents wanting to adopt young (under two years old) HIV+ children. The wait for a referral for HIV+ infants and young toddlers is hard to predict and can vary.

Prospective parents can contact Erin to discuss available waiting children that are HIV+. Please note that information on waiting kids cannot be shared until a family has submitted an approved homestudy to AAI and a referral can not be official until a completed dossier has been submitted to and approved by AAI.

What kind of care are these children receiving?

Thanks to Dr. Jane Aronson www.orphandoctor.com/ and her Worldwide Orphans Foundation (WWO) www.orphandoctor.com/wwo/ program, the children at AHOPE have had access to life-saving Anti-retroviral (ARV) medications since September 2005. Children are thriving and enjoying good health. <http://www.ahopeforchildren.org/> Children at Kidene Mihiret receive ARV's through the Black Lion Hospital.

The children at AHOPE have regular doctor appointments, quarterly blood tests to monitor their health status, and medications are administered according to the clinical standards used in Ethiopia. There is a nurse on staff to monitor their day-to-day health issues. They enjoy nutritious meals to help keep their bodies strong, counseling, and a very high quality of care by African standards. They have a daily routine similar to that of other orphanages, including basic schooling. (See "FAQ: Where do the children come from?" and the AHOPE website for more information)

How does the adoption process vary for HIV positive children?

The process is generally as described in the Process FAQ's, with an additional component in the homestudy and a required TB test. Please note that as of Jan. 4, 2010, the I601 waiver is NO LONGER required for HIV+ children being adopted to receive a visa. With this no longer being required, the visa process for HIV+ children is the same as other adoptions and parents can expect typical timeframes and travel times.

How is the homestudy different?

The homestudy must specifically address the HIV issue and how the family is prepared to handle related matters. The homestudy must have a statement that the family is open to and approved to adopt a child who is HIV+. Typical questions a family should be prepared to answer include:

Why do you want to adopt a child who is HIV+?

How have you prepared yourselves for adding a child with a chronic disease to your family?

What type of health insurance do you have? Will it cover an adopted child without considering "pre-existing conditions?" What sort of co-pays do you have for medications? Do you have the resources to pay the cost of daily medication for a chronic, lifelong disease?

What appropriate medical care is available in your community for a child who is HIV+?

Have you made contact with a doctor who is willing to monitor your child's health?

How do your extended family and your friends feel about the possibility of you adopting a child who is HIV+?

How do you plan to address negative responses towards your family and your new child?

TB Test

A TB test comprising of three consecutive days of sputum samples is required for all HIV+ children being adopted to the United States. Three consecutive days of sputum samples will be collected and then tested. A positive result (showing active TB) can come back as quickly as two weeks, and a negative result typically takes about nine weeks to confirm that there is no active TB. If a child was to have active TB, they would require six months of treatment before they would be able to travel, however most children will have a negative result to the sputum sample tests.

There is now a process in place which allows us to take our HIV+ children to have this test started around the time that the child's case is submitted to court so that there is no delay to travel caused by waiting on the results. The embassy appointment can not happen until the test results are back and sent to the embassy, as these results are now a required part of the embassy medical for all HIV+ children.

Once the TB test results are sent to the embassy, the embassy appointment can happen and the waiver will be submitted.

How do I find a doctor for the child I want to adopt?

Parents who are considering adopting a child with HIV can get more information from local, county or state public health offices. They typically have an HIV specialist that can help with a variety of resources, including finding a doctor. Parents can also contact the Pediatric Infectious Disease clinic or HIV team in the Immunology department at the closest children's hospital. Because parents adopting a child who is HIV+ need a doctor to sign the waiver paperwork, it is important that a doctor is chosen fairly soon in the adoption process. It is also very helpful to speak to a doctor who can answer questions about caring for a child with HIV. Here is a website that lists Pediatric Infectious Disease doctors by state: www.healthgrades.com/local-doctors-directory/by-specialty/pediatric-infectious-disease-medicine

Dr. Jane Aronson, as the Executive Medical Director of Worldwide Orphans Foundation, <http://www.orphandoctor.com/wwo/> is a medical resource for Ethiopia. WWO provides treatment for hundreds of children at many Ethiopian orphanages (including Artists for Charity, Hope for Children, Atetegeb, African Services Committee referrals, etc.) and the WWO Family Health Center in Addis treats all comers including parents and children off the streets of Addis. WWO can facilitate the collection of the medical information for children being adopted so that the parents will receive an up-to-date health report that can be transferred to a Pediatric Infectious Diseases doctor in the U.S. She is available to review the medical records of children with HIV who are receiving treatment from WWO in Ethiopia.

How is a parenting a child who is HIV+ different from parenting a child who is HIV negative?

Generally speaking, parenting a child with HIV is not substantially different from parenting any other child. Children with HIV can eat, drink, kiss, hug, bath, swim, sleep, etc. without risk to their family members and friends. Much scientific evidence proves that HIV is not spread through normal household contact. HIV is spread only through sexual contact, birth, breast feeding and blood-to-blood contact. (See "What are typical safety precautions" below) Most children live day to day without any effects or complications from their HIV. In the U.S., HIV is considered to be a chronic, yet manageable disease, and is not a death sentence. Children are expected to live long and full lives with the medications now available, and medications have been consistently improving.

There are no guarantees on the long-term health of a child that is HIV+, but things are very optimistic.

The primary parenting differences include tracking medications, care for blood-to-blood contacts, and handling the social aspects of living with HIV.

What are typical safety precautions?

Blood-to-blood contact is the biggest concern. With an HIV person in the home, any blood spills should be handled with care: use gloves, hard surfaces should be cleaned with bleach. Any open wounds should be covered with a bandage or clothing. Some toiletries should not be shared -- tooth brushes because mouths tend to bleed easily, razor blades due to the high incidence of bleeding with shaving. Following these general precautions is good practice and is recommended, however it is also good to keep in mind that there has never been a case reported of someone getting HIV from a skinned knee or a bloody nose, and the possibility of HIV being transmitted in such a way is extremely miniscule.

What is the expected medical treatment?

Children with HIV typically visit a Pediatric Infectious Disease (or similar) specialist about four times a year to be monitored. Once medications are started, they must be taken daily at regular times without missing any doses to reduce the risk of building resistance to the medications.

After taking medications for a short period of time, the HIV infection in most children becomes “undetectable.” (The “Viral Loads” are checked a couple of times a year and commonly children have undetectable viral loads on proper Anti-retroviral medications) This does not mean the child is cured. It does mean that there is not enough HIV in the child’s system to register on a blood test. This also means that transmitting the HIV is exceedingly difficult, even without precautions. *However, precautions should always be taken.*

What should I look for in our health insurance coverage?

Thanks to federal legislation, insurance companies are supposed to treat adopted children the same as biological children, and adopted children are supposed to be covered from the date of adoption or date of placement without any “pre-existing conditions” being considered. Thus, your adopted child should be covered in full, regardless of their HIV status. However, there are some insurance plans that have found ways around this legislation, such as private insurance policies (ones that are not through an employer or part of a group).

Before choosing to adopt an HIV+ child, you must know exactly what your insurance company and plan’s policies are regarding covering an adopted child, as well as what prescription coverage is included and what would be your financial responsibility towards your child’s medications. Also consider what might happen if you change jobs and, therefore, health insurance policies. It is also helpful to know what state or federal insurance legislation is in effect, in case you run into any difficulties. You might consult with an insurance professional or insurance lawyer, in addition to background research on the Internet.

All states have HIV programs to assist children and adults who are HIV+ with medication costs and other costs related to their health status. However, these programs and eligibility vary greatly by state. Keep in mind that you must be able to show on the HIV Waiver (Form I601) that you have insurance (without any state or government programs) that will cover your child’s medical care.

How are families handling issues of Disclosure?

Unfortunately, there are many people who are uneducated about HIV and people who are HIV+ are still often treated badly and discriminated against. While a little education can go a long way, parents will also need to be prepared to deal with the stigmas that exist against HIV, and will need to find ways to help their child build a strong self esteem and positive outlook and to protect their privacy. Who to tell and when that your child is HIV+ are very important issues.

Disclosure is a difficult topic and one that all families handle differently. There are confidentiality laws in place to protect HIV+ individuals. Some people feel strongly about not telling anyone about their child's HIV status to protect their privacy completely, while others feel just as strongly that they do not want it to be a big secret that their child has to keep and want their child to know that the people in their life love and accept them as they are. There is no one right way to handle disclosure, and every family has to decide what is the right way for them.

Would we have to notify our child's school, day care center, or other programs?

Telling schools and day care centers is a personal decision. Most states do not require that parents tell schools if their child is HIV+. Some states do have the public health office notify the school district that there is an HIV+ child in the schools, but will not disclose which child. HIV is not a communicable disease in a school setting – precautions are already part of state health code in schools. School nurses maintain health records for students in which health issues – including daily medications -- are recorded confidentially. Schools and day care centers are supposed to take universal precautions when handling blood spills with all children. Volunteer leaders with other programs (Scouts, athletic clubs, playgroups) may or may not have specialized training in this area.

Because children with HIV who are taking medications and are “undetectable” pose such a minimal risk to others, many parents feel comfortable not disclosing their child's HIV status. . It is also good to know that there has never been a documented case of HIV being transmitted in a school, day care or sports setting. Disclosing to a school, day care center, etc. is a decision each family must make for themselves.

Selected Resources (websites checked Feb. 09)

AAI Positive is a Yahoo group just for parents adopting or who have adopted children who are HIV+ through AAI. Contact AAI for more information.

hivadoption is a Yahoo group for parents who have adopted HIV+ children, or who are in process or are considering adopting an HIV+ child. The list includes members adopting from Ethiopia, Guatemala, Vietnam and Haiti. There is lots of good information available. For “parents only,” no agency representatives are on this list: <http://groups.yahoo.com/group/hivadoption/>

From HIV to Home - <http://fromhivtohome.blogspot.com/>

Positively Orphaned - <http://www.positivelyorphaned.com/>

Article on HIV Forum regarding a family adopting an HIV+ child from Africa.
<http://www.thebody.com/Forums/AIDS/Mental/Archive/Family/Q171200.html>

Transracial Adoption Blog Posts under Belane's Adoption category chronicle the adoption of a three year old girl from AHOPE and her family's experiences during her adoption and parenting her once she is home. <http://transracial.adoptionblogs.com/?cat=717>

** A great book that we recommend to families is "**100 Questions and Answers on HIV and AIDS**" by Joel E. Gallant, MD