# Children of All Nations
# Waiting Child Program Guide

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# Program Overview

The Waiting Child Program is a very special program that we hold dear to our hearts. *Children of All Nations is* honored to be entrusted by the central governing authorities of the placing countries we work with that oversee adoptions, to find families for "waiting children" – children who, for one reason or another, are not as easily placed with loving families. We care tremendously for these children and recognize that these are the children that are most in need of a home. Our staff feels a strong calling and huge responsibility to positively impact the lives of these children. If we can find a permanent home for them, a home they can call their own, we believe their lives will be forever changed.

**Who is a Waiting Child?**
Waiting Children have been selected for this program because of the following:

- They are healthy older children (usually 6-8 years and older)
- They have special medical needs (please refer to the special needs glossary at the end of this guide for the most common medical conditions of waiting children)
- They are part of a sibling group of two or more*

While we are eager to find homes for these precious children, we place great importance on finding qualified families for each child to ensure that the needs of the child will be properly met.
This program is for those special families that share our calling to help children in the greatest need.

**The classification of waiting children varies country to country.*

If you think the Waiting Child Program may be a good fit for your family, it is necessary to take these important steps.

**Research**
One of the most important steps in the waiting child program is doing your research to determine the special needs that your family has the resources to accommodate. This should be done before submitting a general application. You can start by:

- Reviewing and researching the special needs included in this guide to help your family understand the needs available and all that is involved in parenting such a child.
- Talking with your pediatrician and other specialists that understand the needs you feel you have the resources for so that you have a complete understanding of the best case and worst case scenarios.
- Contacting local facilities that may provide resources for that particular need, including therapists, physicians, surgeons, schools etc.
- Contacting other families who have experience in parenting a child with the special needs you are researching. We are happy to provide you with a reference list upon request.

**Communicate**
Communication with your family members involved in the adoption is a key factor in the process. Talk about all of the scenarios, special needs and resources you have and determine as a family what is best for you and the child you will bring into your home.

Communicating with our staff is also a key factor. Being specific and detailed in your waiting child profile provides us with the vital information to review and hopefully match you with a child.

**Plan Ahead**
Having a plan is important during any adoption process, and may be more so in the Waiting Child process.

- Outline your treatment plans for the special needs you have researched and included in your Waiting Child Profile
- Determine your finances, considering short-term and long-term costs for any medical procedures or treatments your child may need upon joining your family.

**Remain Realistic & Flexible**

- Understand your assets and limitations as you begin and move through the process. Continuing to communicate with your family and our agency can help.
- Know that as with any process, there may be unforeseen changes and bumps in the road.

# Eligibility for Applicants

Ideal candidates for the Waiting Child Program will first need to meet the basic requirements to adopt from the country of interest. Families must be dedicated to the child and the process. It is important to remember that the children placed through this program have special needs that may require more attention, patience and additional resources in terms of both finances and emotional support.

It is also very important to keep in mind that a family should not pursue the Waiting Child Program solely because they want an expedited adoption. In addition to the basic qualifications for the traditional adoption programs, families will also need to meet the following special guidelines for the Waiting Child Program:

- Families who are loving, caring, and mentally prepared to nurture children with special needs. In particular, an optimistic and flexible attitude is required in coping with the journey of caring for a child with special needs.
- Families who have experience and skills to care for children with special needs. If you are first-time parents, you will need to have a minimal level of exposure to children with special needs, through work experience, volunteer experience, caring for extended family members or friends who have special needs. In other words, families adopting children with special needs will need to have some insight into the daily realities of parenting children with special needs.
- Families who have medical rehabilitation and parenting plans specially designed for children with special needs. The goal is to help a child with special needs reach his or her full potential. Families will need to lay out a plan for reaching this goal.
- Families who are in good financial standing with annual income being relatively higher than the general guideline for adoptive families. Due to the extra expenses that may likely occur in caring for a child with medical issues, families with a relatively stronger financial standing will be cushioned from the frustration of meeting the child's financial needs after placement.
- Families who are physically and mentally healthy, free from contagious diseases, cancers, psychosis or other diseases which might affect their ability to nurture children with special needs.
- Families who are of good conduct and meet all criteria related to criminal history.
- Families who are committed and prepared to raise a child with special needs in terms of the persistent care and support needed by the child in different stages of life. With the best interest of the children in mind, we work to find families who are best suited to care for each child.

# Getting Started!

**Research**
Families should first research CANs Adoption Programs and determine the country that best meets your family's needs and adoption desires. It is important to understand the overall program, process, requirements, timeline and cost prior to starting your adoption journey. For a full review of all programs, please read CAN's Outreach Guide,

The next step of the research phase is to review, read and gather resources on the medical, developmental, behavioral conditions of the children available. This will provide you with a good understanding the resources you will need in parenting a child with special needs.

To start your research, please find general descriptions of the medical and developmental needs in the Special Needs Glossary at the end of this Guide.

When you have initiated/completed your research, we ask that you complete a Waiting Child Profile that will provide CAN with information on your family and the needs you are open to so that we may assist you in guiding you through your adoption journey. You may access the Waiting Child Profile here: http://childrenofallnations.com/waiting-child-profile/

The next step of the Waiting Child Program Process is guided by the research stage. Each country's Waiting Child process varies and depending on the country you have chosen that best meets your family's needs, you may either begin reviewing files, or start the process to submit your dossier so you may review files after your paperwork is submitted. Of course for any program, if you are committed to a particular country – you may go ahead and get started on your dossier paperwork.

# Choosing a Country

# Bulgaria

Files of the children in the Waiting Child program are released every 3 months to agencies to advocate for the children and search for their forever family. CAN staff review the list each month to search for potential matches for the children with families in process with CAN or those who have a Free Waiting Child Profile on file with our agency. We are provided two months to advocate and place the child. If we are unsuccessful in placing the child, their file is returned to the Ministry so another agency in turn searches for their family.

A child is identified through a special needs listing either pre or post-dossier submission. Once identified by the family through CAN, an application letter to adopt is submitted to the Ministry of Justice. If approved, and a dossier has not been submitted, you will complete and submit a dossier within 6 months.
If you already have a dossier in place, once a child is identified by the family through CAN, an application to adopt is submitted to the Ministry of Justice. Once your dossier is approved by the Bulgarian government, you will then receive an invitation to come to Bulgaria, meet your child and accept your referral. Once the referral is accepted, the Ministry of Justice will approve the adoption and forward your case to the court.

Parents return for second trip 3-5 months later to pick up child, finish visa and complete the adoption process to return home.

Post adoption reports are required every 6 months for 2 years (4 total).

Children Available

- Boys and girls with no identified special needs 7 - 14 years old
- Boys and girls of all ages with medical conditions ranging from mild or moderate to severe
- Sibling Groups

Eligibility Requirements*

- Citizenship: One adoptive parent must be a U.S. citizen.
- Age: Adoptive Parents must be at least 25 years of age and at least 15 years older than the adoptive child.
- Marriage Status: Married couples are eligible to adopt. There are no prior divorce restrictions. Single women and men are also eligible to adopt children of either gender.
- Previous children: There are no restrictions on the number of children already in the home.
- Medical History: There are some medical restrictions. If you have a chronic medical condition, please contact our adoption consultant to determine your eligibility
- Income: There are no minimum income requirements. However you need to meet the income requirements provided by USCIS for the child to immigrate.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence or domestic violence are not eligible to adopt.

# DRC

Families interested in adopting a child through the Waiting Child Program for the DRC will need to submit a dossier prior to matching. Once a dossier is submitted, CAN program staff will initiate a request for a referral of a child that meets the age, gender and special needs the family is open to adopting. You will then be matched with a child based on your preferences, and will receive photos and information on your child. You then have two options to accept your referral:

1. You may notify CAN staff in Austin of your acceptance of your referral, and CAN's lawyer will submit the consent to adopt act for your child. No travel to the DRC is required.
2. You may choose to travel to DRC to meet your child, and then accept the referral in-country. Then you would submit the consent to adopt letter in person. Time spent in DRC if this option is chosen would be approximately 1 week or less.

You will be required to travel to DRC for a short trip to pick up your child and apply for their visa. First, a hearing will occur after all consent for the adoption has been given at the Tribunal de Paix in the region where the prospective adoptive child resides. Paperwork is submitted to the court. You do not need to be present for the court hearing. They can be represented by Children of All Nation's experienced attorney during all the adoption process in Congo. If a family is adopting two children, we must receive both referrals within 6 months of each to be able to travel at one time to pick up the children. If the referrals come more than 6 months apart, you must travel twice or move forward with one.

Following this hearing an investigation is ordered to make certain that all conditions for final adoption have been met. Once this entire process is completed the judge issues an adoption decree. Parents or CAN's lawyer will then complete paperwork for their child's immigration visa from U.S. Embassy in

Kinshasa. Once the visa appointment is set, parents will appear in person to request their child's visa, and then obtain exit permission from the Congolese government, and accompany their child home. Your stay will be 1-3 weeks in the DRC when you pick up your child.

Congolese law does not require any post-adoption reports, but the orphanage where the child comes from requires two post-adoption reports at 6 and 12 months. These reports demonstrate to the DRC government and the child's orphanage the benefits of international adoption for their children

Children Available

- Boys and girls 6 months to 16 years of age
- Boys and girls 6 months to 16 years of age with medical conditions ranging from mild or moderate to severe
- Two or more siblings or unrelated children at one time

Eligibility Requirements*

- Citizenship: One adoptive parent must be a U.S. citizen.
- Age: Applicants must be at least 25 years old and 15 years older than the child they plan to adopt.
- Marriage Status: Married couples are eligible to adopt. Married couples need to be married at least 5 years. There are no prior divorce restrictions. Single men and women can adopt children of the same sex.
- Previous children: Families cannot have more than three children already in their home and may not adopt more than three children at once. Families who have adopted children previously and have more than three children in the home can contact CAN for an eligibility check.
- Income: There is no minimum income required, but prospective adoptive parents must be able to prove financial stability. You must meet the income requirements provided by USCIS for the child to immigrate.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence, or domestic violence are not eligible to adopt.

# Ghana

Families interested in adopting a child through the Waiting Child Program for Ghana will need to submit a dossier prior to matching. Once a dossier is submitted, CAN program staff will initiate a request for a referral of a child that meets the age, gender and special needs the family is open to adopting. You will then be matched with a child based on your preferences, and will receive photos and information on your child.

After a referral is accepted, there is a 3 month waiting period, and then the case will be registered in court. Both parents should travel to Ghana to attend the court hearing. In special circumstances one parent's requirement to appear in court may be waived. After the court issues an adoption decree, parents will file immigration paperwork with the US Embassy. At this time given unknown visa processing times, it is best if the parents leave Ghana and return to pick up their child. The U.S. Embassy will investigate the child's background, and parents must return to Ghana 3-4 months later to pick the child up take them to the U.S.

CAN requires 2 post-adoption reports to be issued at 6 and 12 months after the adoption is finalized. These reports must be submitted to demonstrate the benefits of international adoption for their children.

Children Available

- Boys and girls 6 years and older. Children under 6 years old may be available; please inquire with CAN about estimated wait time and process
- Boys and girls 6 months to 16 years of age with medical conditions ranging from mild or moderate to severe
- Two or more siblings or unrelated children at one time

Eligibility Requirements*

- Citizenship: One adoptive parent must be a U.S. citizen.
- Age: Applicants must be between 25 and 50 years old and 21 years older than the child they plan to adopt. Parents over 50 years old are considered on a case-by-case basis if one parent meets the requirements.
- Marriage Status: Married couples are eligible to adopt. There are no prior divorce restrictions.
- Previous children: Smaller families with less than 5 children living in the home are preferred.
- Income: There is no minimum income required, but prospective adoptive parents must be able to prove financial stability. You must meet the income requirements provided by USCIS for the child to immigrate.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence, or domestic violence are not eligible to adopt.
- Medical History: If you have a medical condition, you can contact our adoption consultant to determine your eligibility.

# Haiti

Families interested in adopting a child through the Waiting Child Program for Haiti will need to submit a dossier prior to matching. Once the dossier is submitted CAN will review the children currently available and provide potential matches to the family. CAN is provided with a current list of children available each month. If a potential match is located, the family will review the referral information and photo and decide if they would like to pursue the adoption. If a family decides to move forward a referral acceptance letter is submitted to adopt the child and the official adoption process begins.

An adoptive family is required to make 2 trips to Haiti, but has the opportunity to travel more often if they wish to visit the child while the adoption process is finalized. The first trip lasts 3-5 days and is used for the family to bond with their child and to accept their referral. On the second trip, the family picks up their child to bring them home. If the family chooses, they are able to take additional bonding trips to Haiti during the time that they wait for approval to bring their child home.

You will be required to submit a post adoption report completed by your home study agency three months after your international adoption from Haiti is finalized. After the first year, the crèche requests that parents submit a letter and photo of the child directly to them.

Children Available

- Boys and girls infants to 12 years
- Boys and girls infants to 12 years of age with medical conditions ranging from mild or moderate to severe
- Siblings or two unrelated children at one time

Eligibility Requirements *

- Citizenship: One adoptive parent must be a U.S. citizen.

- Age: At least one prospective adoptive parent must be 35- 50 years old. One parent can be slightly younger.
- Marriage Status: Married couples of 10 years are eligible to adopt. Couples who can prove a committed relationship of at least 10 years (five years of commitment and five years of marriage) are eligible. Couples with documented infertility may be able to adopt sooner. Single women can adopt.
- Previous Children: Parents can have no more than four children already in the home (three biological and one adopted).
- Religion: Prospective adoptive parent(s) must be Christian to adopt through our current program.
- Income: Prospective adoptive parent(s) must demonstrate the means to support the physical and education needs of the adoptive child.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence, or domestic violence are not eligible to adopt.

# Latvia

Families interested in adopting a child through the Waiting Child Program for Latvia will need to submit a dossier prior to matching.

Once your dossier is approved by the Latvian government, a child is identified either identified through efforts of CAN and your family reviewing the current Waiting Child Listing or by the Ministry based on your preferences for gender, age and health status. You will receive a description of the child, including the child's history, medical test results and photos with your referral.

The Ministry of Welfare in Latvia issues updated profiles 3 to 4 times a year, allowing us to update our listings according to their schedule. Each child's profile includes two to three paragraphs explaining the type and severity of the child's special needs.
Upon identification of a child, a letter is provided to the Latvian Government requesting permission to travel to meet the child/Children.

Latvian government requires families to make two to three trips to Latvia to complete the adoption. If married, both parents are required to travel for the first trip, with only one being required for the second. An example description is noted below:

1st visit: Family meets child in person, there is a 2 week minimum stay of pre-adoptive care. The Ministry will issue 2 documents: "the Agreement that the adoption may proceed" and "the authorization to adopt", the 2nd is normally issued only in Latvian for the Court. The representative submits the documents in the Court followed by 2 month waiting until the Court takes place. Your child can travel to States with you if the Orphan's Court and US authorities allow but this must be monitored by social services.

2nd visit: The Court decision is held and there is a 20 day waiting period for the decision to come into force. The regional court will then proclaim the full decision about 10 days after this waiting period. This visit can be broken up into 2 shorter visits. If applicable, your child must travel back with you if the child is older than 12 years – the judge can make an exception to this if deemed reasonable.
3rd visit: If parents decide to break up the 2nd visit, 5-8 weeks after the judgment comes into force the family will travel and Immigration documents are finalized.

Latvia requires 2 reports post adoption reports, once a year the 1st two years after adoption.

*** Please note if your child travels with you to the United States prior to finalization additional post-placement reports and requirements must be met.*

Children Available

- Boys and girls 9 years old and older
- Boys and girls of all ages with medical conditions ranging from mild or moderate to severe
- Siblings groups of three or more (all ages)

Eligibility Requirements*

- Citizenship: One adoptive parent must be a U.S. citizen.
- Age: Adoptive parents must be between the ages of 25- 55. Parents over the age of 55 are considered on a case-by-case basis. The ability of the adoptive parents to take care of the child is evaluated during the care and supervision time here in Latvia (first visit) by the Orphan's court and by the Regional court during the last court hearing.
- Marriage Status: Married couples, single women and single men are eligible to adopt. Latvia does not require couples to be married for a specific length of time.
- Previous children: There are no requirements on the number of children already in the home.
- Income: There is no minimum income required; however, you must meet the income requirements provided by USCIS for the child to immigrate.
- Criminal History: Applicants with a criminal history of child abuse, violence or domestic violence are not eligible to adopt.

# Peru

Peru requires dossier submission and approval from Peru's central authority prior to identification and application to adopt a specific child. CAN receives listings of children available on a regular basis and we will review the lists with our families upon approval. Families will receive the child's background information including medical and developmental evaluations and can also place a child's file on hold for one month to make a decision to adopt. It is important to note that the children come from all over the country and the level of information we receive is dependent upon the region.

Once a child is identified and the family decides to move forward, CAN will submit the request to adopt the child or children to the Peruvian government.

Peru requires the adoptive family to make 1 trip, which lasts 1 month. However, 1 parent may return home after 2 weeks, if necessary.

Post adoption reports are required every six months, for four years after completing your adoption. These reports demonstrate to the Peruvian government the benefits of international adoption for their children

Children Available

- Boys and girls 5 to 16 years of age
- Children of all ages with special needs
- Two or more siblings at one time (children younger than 5 may be in sibling sets)

Eligibility Requirements*

- Citizenship: One adoptive parent must be a U.S. citizen.

- Age: Adoptive parents must be between 25 and 55 years of age. Generally, the following age guidelines apply:
    - Prospective Adoptive Parents 25 - 43 qualify to adopt a child up to the age of 3 and older*
    - Prospective Adoptive Parents 44 - 50 qualify to adopt a child 3 - 6 years old and older*
    - Prospective Adoptive Parents 51 - 55 qualify to adopt a child 6 years and older*
    - Singles 35 - 50 may adopt a child 5 years and older*
    - Prospective adoptive parents must be at least 18 years older than the adoptive child.
      *Please note that parent age brackets for Peru can be flexible. Contact CAN for additional information.*
- Marriage Status: Married couples are eligible to adopt. Single men and women are eligible to adopt children five years and older.
- Previous children: There are no restrictions on the number of children already in the home.
- Income: There is no minimum income required. However, you must meet the income requirements provided by USCIS for the child to immigrate.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence, or domestic violence are not eligible to adopt.

# Philippines

The Philippines Central Authority – Inter-Country Adoption Board (ICAB) provides information monthly on children available for adoption. This information is provided to multiple agencies and is what we call a shared listing. What this means is that if you identify a child you would like to request additional information on – that child may or may not be available.

Upon review of the listing, if a child is located that may fit your family, you will either request that file through the online, waiting child listing or CAN will contact you and suggest the match. If it is agreed that this child/children may be a great fit – we will contact ICAB to request the file be placed on hold and the full file be sent to your family for review. The file will include the child's background information, including medical and developmental evaluations. In most cases, additional information is available upon request.

If you have not completed a dossier, you will have four months to submit your dossier to the Philippines' Inter-country Adoption Board (ICAB). Please keep in mind that you must have selected a child to adopt before sending your dossier to the Philippines.

Children Available

- Boys and girls with no identified special needs 6 - 15 years old
- Sibling groups of two or more
- Boys and girls of all ages with medical conditions ranging from mild or moderate to severe

Eligibility Requirements*

- Age: Adoptive parents must be at least 27; there must be a 16 to 45 year difference between the parent(s) and child.
- Marriage Status: Married couples may adopt if they have been married at least three years. No more than two divorces are allowed. Single men and women may adopt children 9 to 15 years old and children 9 to 15 years old with special needs.
- Education: Both parents must have a high school diploma; high school equivalent acceptable.

- Health: Medical and psychological conditions or history that disqualifies a parent from adopting include:
    - diabetes
    - BMI over 35
    - history of cancer
    - major organ transplant
    - stroke, myocardial infarction, having a pacemaker
    - degenerative muscle disorders
    - auto-immune disorders
    - any condition that will impede caring for a child
    - psychiatric disorders
    - mood or major depressive disorders
    - anxiety disorders
    - substance abuse disorders
    - sexual disorders
- Previous children: Families with three or more children in the home are not eligible to adopt a child younger than 6; families must wait one year from the birth or adoption of a child before filing for adoption from the Philippines.
- Income: You must make at least $40,000 annually in order to be eligible to adopt.
- Religious Affiliation: Parent(s) must demonstrate a relationship of at least five years with a religious or spiritual organization.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence, or domestic violence are not eligible to adopt.

# Poland

Poland requires dossier submission and approval from Poland's central authority prior to identification and application to adopt a specific child. Your dossier will be sent to Poland and translated and legalized, which will take 2-4 weeks. Then, it will be submitted for the Custody Center(s) to approve and await a referral or identification of a child through the Waiting Child Listing provided by the Custody Centers.

After you are matched with a child or sibling group, you will plan your first trip to Poland to meet your child and spend 2-3 weeks bonding with them, depending on what amount of time the judge issues. At the end of the bonding period, the court process will take place in the district the child is from. Both parents are required to travel to Poland to attend the court hearing and must be present for at least part of the bonding period. You will then return home for about 2-3 weeks during the adoption finalization period, although you can also stay in Poland if you wish. The second trip should take about one week or less while you are finalizing the visa process and to bring your child home.

Poland requires 3 post-adoption reports at 6, 12, and 18 months after the adoption is finalized. These reports demonstrate to the Polish government and Custody Centers the benefits of international adoption for their children.

Children Available

- Boys and girls 1-16 years old
- Boys and girls of all ages with medical conditions ranging from mild or moderate to severe
- Sibling groups of two or more

Eligibility Requirements*

- Citizenship: One adoptive parent must be a U.S. citizen.
- Age: Adoptive parents must be at least 25 years of age. Parents can be 40 years older than the adoptive child. In special cases, one parent may be more than 40 years older.
- Marriage Status: Single women, as well as married couples are eligible to adopt. Married couples should be married at least three years. There are no prior divorce restrictions.
- Health: If you take prescription medicine or have a medical condition, please contact our adoption consultant to determine your eligibility.
- Previous children: There is no limit to the number of children currently in the home. However, some Custody Centers give preference to families with no other children in the home.
- Income: There is no minimum income required. However, you must meet the income requirements provided by USCIS for the child to immigrate.
- Criminal History: Applicants with a criminal history of drug abuse, child abuse, violence, or domestic violence are not eligible to adopt.

** Eligibility is reviewed on a case-by case basis. If you do not meet the standard eligibility requirements, please contact our staff for a free consultation. We are standing by to help you!*

# Understanding Certain Steps in the Process

## File Review

- In order to review a file and assist CAN staff in matching you with a child through the Waiting Child Program you will need to have a current Waiting Child Profile on file with our agency. Please find the link here for your convenience - http://childrenofallnations.com/waiting-child-profile/
- The Waiting Child Profile will provide you with access to a listing of children available through CAN's Waiting Child Program password protected site and provide us with information to assist in matching you with children available in the program. Please note that this list is not exhaustive and certain countries, such as Peru and Latvia have more extensive listings of children available.
- Review the current listing of children available and if find a child that you feel may fit with your family, you may submit a request to review that file. Again, please note the following countries require a dossier to be submitted prior to reviewing files: DRC, Ghana, Haiti, Latvia, Peru
- A CAN representative will contact you regarding your request by email and by phone. Upon further discussion with your family and all parties agree that this child may be a good fit – CAN will provide you with the information currently available for review. A more detailed description is noted in the considerations by country section of this guide.
- All files will need to be reviewed by a doctor or other specialists if applicable, prior to making a decision to apply to adopt a specific Waiting Child. We highly recommend that the medical files are reviewed by a physician with international adoption experience. Children of All Nations partners with international adoption specialists to assist all families in making the important decisions when it comes to file review and really understanding a child's needs. For more information on this program please visit our Medical Referral Program on our website.
- If you decide to move forward with the adoption of the child we recommend that you discuss your decision with your social worker if applicable. Your family will need to be approved by your social worker to complete the adoption process of this child and bring him or her into your family.

# General Application and Initiation of Dossier Paperwork

Once you have committed to a Country or committed to a child whose file you reviewed with a doctor, you will formally apply to Children of All Nations by submitting our General Application online with the appropriate fee https://www.gwca.org/application/

Once you are approved through the general application process you will receive a contract to submit with the appropriate fees to get started the dossier paperwork phase of your adoption journey.

As noted above – each country has varying processes and procedures as you move through the adoption journey for that program. Upon submitting your contract for a specific program, an Adoption Counselor will be assigned to your family and help you through each stage of the process!

## Considerations as you move forward in your journey to your special child!

- Do you have a full understanding of the medical conditions you are open to? Have you considered the prognosis for best and worst case scenarios?
- Are you aware that other medical conditions beyond those listed in your child's medical report may appear after placement?
- Have you spoken with your family and friends to gauge their feelings about raising a child with special needs?
- If you have children in your home, how will you prepare them for the arrival of your adopted child?
- What other support systems do you have in place?
- Do you have the financial resources to care for a child with special medical needs?
- Does your medical insurance provider cover adopted children with pre-existing medical conditions?
- What resources (schools, rehabilitation centers, support groups, etc.) are available in your area to help provide care to a child with special needs?
- If you are adopting an older child, are you prepared for the issues that may arise during the bonding and attachment process?
- Are you aware of common conditions of children who have been raised in an institution and the methods to care for these conditions?

Welcoming any child into your home is a life changing experience that requires a great amount of forethought and preparation. Bringing home an older child or a child with special medical or developmental needs may also have additional challenges. It is important to consider the financial and emotional investment needed to properly care for a waiting child. After taking all of this into consideration, also picture the unimaginable rewards a child adopted through the Waiting Child Program can bring to your family. So as you consider adopting a Waiting Child ask yourself one last question:

# Special Needs Glossary

Please keep in mind that we provide this glossary only as a reference for families interested in adopting waiting children from around the world. For the most accurate and up-to-date information, we recommend speaking with a physician.

**Blood Conditions**

**Cancer** is the uncontrolled growth of abnormal cells in the body. Cancerous cells are also called malignant cells. Symptoms of cancer depend on the type and location of the tumor. Some cancers may not have any symptoms at all. In certain cancers, symptoms do not start until the disease has reached an advanced stage.
The following symptoms can occur with most cancers: chills, fatigue, fever, loss of appetite, malaise, night sweats, and weight loss. Treatment and prognosis also vary based on the type of cancer and its stage. We have seen cancers of the eyes, brain, and lungs in the waiting children.
**Hemophilia** is a rare inherited disorder in which the blood does not clot normally. Symptoms may include excessive bruising, joint pain, unexplainable bleeding, prolonged bleeding, and nose bleeds. There are three different types of hemophilia; however, children do not typically have a test completed to determine which clotting factor is absent.
Treatment involves clotting-factor medication. Risks include internal bleeding, damage to joints, infections, and adverse reactions to the medication. Although hemophilia is not "curable," most individuals can lead relatively normal and active lives.
**Phenylketonuria (PKU)** is a rare condition in which a baby is born without the ability to properly break down an amino acid called phenylalanine. People with PKU need to follow a diet that limits phenylalanine, which is found mostly in high-protein foods. If PKU is realized early on and the diet monitored, children can lead relatively normal lives.
Children with PKU are at risk for mental retardation, behavior problems, hyperactivity, stunted growth, microcephaly, and eczema.
**Thalassemia (Mediterranean anemia)** is an inherited blood disorder characterized by less hemoglobin and fewer red blood cells in your body than normal. Symptoms include fatigue, weakness, shortness of breath, paleness, jaundice, slow growth, protruding abdomen, dark urine, and facial bone deformities.
There are two major types of Thalassemia: alpha and beta, named for the two protein chains that make up normal hemoglobin. Some children will have a Hemoglobin test in their file, while some orphanages and hospitals do not have the resources to provide the test to determine which type the child has. Both types can range from mild to severe. It is important to note that for children who receive blood transfusions, excessive amounts of iron can build up in the blood and internal organs.
Chelation therapy helps remove the buildup of iron; however, this therapy is not often available in the child's home country. Without chelation therapy, early mortality is inevitable.

- α Thalassemia trait is characterized by mild anemia and typically has no severe effects. This type is rarely diagnosed.
- Hemoglobin H disease is a subtype of α Thalassemia. Children with this disease may require regular blood transfusions.
- β Thalassemia is characterized by mild anemia and typically has no severe effects. This type is rarely diagnosed.
- β Thalassemia intermedia creates mild to severe anemia. These children do not typically require regular blood transfusions, however may need one during illnesses or later in life during pregnancy.
- β Thalassemia major is also referred to as Cooley's anemia. Children with this type will require regular blood transfusions to survive.

**Sickle Cell Anemia** Sickle cell disease causes red blood cells to form into a crescent shape, like a sickle. The sickle-shaped red blood cells break apart easily, causing anemia. Sickle red blood cells live only 10-20 days instead of the normal 120 days. The damaged sickle red blood cells also clump together and stick to the walls of blood vessels, blocking blood flow. This can cause severe pain and permanent damage to the brain, heart, lungs, kidneys, liver, bones, and spleen. Severe pain is an emergency called acute sickle cell crisis. A person may not know what brought on the pain, but infection and dehydration are common triggers.

Sickle cell disease is most common in Africans and African-Americans. It is also found in other ethnic and racial groups, including people from South and Central America, the Caribbean, Mediterranean countries, and India.

Treatment of sickle cell crisis includes:
Opioid pain medications (for example, morphine)
Anti-inflammatory medications (for example, ibuprofen)
Antibiotics for infection
Oxygen
Intravenous or oral fluids

Transfusions of red blood cells are given for severe anemia, to prevent strokes, and before surgery. Sometimes an exchange transfusion is performed with a special machine that removes the abnormal sickle red blood cells and replaces them with normal red blood cells.
Hydroxyurea is the only FDA-approved medication that prevents painful episodes in sickle cell disease. Studies of patients with sickle cell disease show that the regular use of hydroxyurea decreases the frequency and severity of sickle cell crises and reduces the number of blood transfusions and hospitalizations.

Stem cell transplant is the only curative treatment for sickle cell disease. More than 200 patients with sickle cell disease have undergone stem cell transplants from a matched sibling donor. Stem cell transplant has a 5%-10% risk of death, but patients with successful transplants were completely cured of sickle cell disease, with no further episodes of pain.
Stem cell transplant is performed in young patients with severe sickle cell disease who have a matched sibling donor. Stem cell transplant using umbilical cord blood from a related donor has also been curative in a small number of patients.

**G6PD** deficiency is an inherited condition in which the body doesn't have enough of the enzyme glucose-6-phosphate dehydrogenase, or G6PD, which helps red blood cells (RBCs) function normally. This deficiency can cause hemolytic anemia, usually after exposure to certain medications, foods, or even infections. Most people with G6PD deficiency don't have any symptoms, while others develop symptoms of anemia only after RBCs have been destroyed, a condition called hemolysis. In these cases, the symptoms disappear once the cause, or trigger, is removed. In rare cases, G6PD deficiency leads to chronic anemia.

**Central Nervous System**
**Arachoid cysts** are cerebrospinal fluid-filled sacs that may develop between the surface of the brain and the cranial base or on the arachnoid membrane. These cysts can be present at birth or caused by injury
Symptoms may include dizziness, nausea, headaches, problems with vision or hearing, back pain, and weakness. Treatment may or may not be necessary, depending on the symptoms experienced. If treatment is necessary, the two most common treatments are insertion of a shunt or fenestration (opening of the cyst).

**Cerebral Palsy** (CP) is an umbrella term for any group of disorders caused by abnormal development or damage in one or more parts of the brain that control muscle tone and motor activity (movement). The effects of CP can range from mild or subtle to very profound. Some issues linked to CP may include difficulty controlling and coordinating muscles, breathing, vision and hearing issues, seizures, and mental retardation.

There are several different types of CP characterized by how the disorder affects the muscles. It is important to note that CP is typically non-progressive, meaning it will not get worse over time. Most children will not have a defined type of CP, however, they would fall under the mild-moderate categories. For the purposes of the Waiting Child Profile, the severities are defined as follows:

- Mild: The child may have some diminished function of one or more limbs, such as walking with a limp or mildly decreased strength. The child is able to walk and function independently, but may require some therapy to strengthen muscles.
- Moderate: The child may require some levels of assistance to function in daily life (ie: using a walker). The child may have more mild to moderate global delays, such as gross and fine motor and language skills.
- Severe: The child may have significant global delays and would require continual, long-term assistance.

**Epilepsy** is a general term for conditions with recurring seizures. There are many kinds of seizures, but all involve abnormal electrical activity in the brain that causes an involuntary change in body movement or function, sensation, awareness, or behavior. Generally seizure disorders are not curable, but they can be controlled with medication and sometimes surgery. In most cases, individuals with seizure disorders can live relatively normal lives, with only the severest cases requiring restrictions.

**Hydrocephalus** is a condition in which the primary characteristic is excessive accumulation of cerebral spinal fluid (CSF) in the brain. The excessive accumulation of CSF results in an abnormal dilation of the spaces in the brain called ventricles. This dilation causes potentially harmful pressure on the tissues of the brain. Hydrocephalus can be congenital or acquired through injury. In young children, typically the first symptom is an increased head size. In older children, symptoms may include an abnormal gait, nausea, incontinence, vision and balance issues, and changes in cognition. Treatment is most often a shunt, which is placed in the brain to allow the fluid to drain into another part of the body. A third ventriculostomy is also a potential surgery where a hole is made in the brain ventricle to drain the fluid so it can be reabsorbed by the brain. Many children diagnosed with the disorder benefit from rehabilitation therapies and educational interventions, and go on to lead normal lives with few limitations.

**Microcephaly** is a medical condition in which the circumference of the head is smaller than normal because the brain has not developed properly or has stopped growing. Microcephaly can be present at birth or it may develop in the first few years of life. It is most often caused by genetic abnormalities that interfere with the growth of the cerebral cortex during the early months of fetal development.

It is associated with Down syndrome, chromosomal syndromes, and neurometabolic syndromes. Depending on the severity of the accompanying syndrome, children with microcephaly may have mental retardation, delayed motor functions and speech, facial distortions, dwarfism or short stature, hyperactivity, seizures, difficulties with coordination and balance, and other brain or neurological abnormalities. Some children with microcephaly will have normal intelligence and a head that will grow bigger, but they will track below the normal growth curves for head circumference.

**Neurofibromatosis** (NF) is a condition that causes tumors to grow on nerve tissue, producing skin and bone abnormalities. NF is often diagnosed in childhood; occasionally in infancy (in children with severe cases), but usually around 3-16 years of age. Some children live almost unaffected by the condition; rarely, others might be severely disabled. The first notable sign of NF is café au lait spots on the body. Other symptoms include hearing loss, vision loss, and skeletal abnormalities. There's no specific cure for NF, but tumors usually can be removed and related complications treated. Because learning disabilities occur in approximately half the children with NF, some might need extra help in the classroom.

**Spina Bifida** (SB) is a birth defect that involves the incomplete development of the spinal cord or its coverings.

- SB occulta is the most mild form and typically has no long-term effects. It is usually only discovered if the child is being screened for other issues.
- Meningocele occurs when the membranes responsible for covering and protecting the brain and spinal cord (meninges) protrude through a hole in the vertebrae.
- Myelomeningocele is when both the meninges and the spinal cord push through the vertebrae. Children with myelomeningocele also typically have hydrocephalus as well and are at risk for paralysis. All children are at risk for some nerve damage and possible incontinence.

The terms meningocele and myelomeningocele are typically used interchangeably due to translations. However, most of the children will fall under the category of meningocele. Most often, these children are able to recover from surgery and lead full and active lives.

**Congenital Heart Disease**

Congenital Heart Disease (CHD) refers to a problem with the heart's structure and function due to abnormal heart development before birth. While congenital heart disease is present at birth, the symptoms may not be immediately obvious. Defects such as coarctation of the aorta may not cause problems for many years. Other problems, such as a small ventricular septal defect (VSD), may never cause any problems and some people with VSD have normal physical activity and a normal life span.

Some congenital heart diseases can be treated with medication alone, while others require one or more surgeries. All defects could be considered minor or severe, depending on how they affect the individual child. It is important to speak with a physician about each possible diagnosis to gain a good understanding of what your family would be comfortable handling. For the purpose of the Waiting Child Profile, CHD is divided into the categories listed below. The majority of the children referred with CHD would be categorized as having moderate to severe conditions.

- Mild: Mild heart conditions are defined as only one defect being present. This would include defects such as VSD or ASD. It would also include a child who had a significant heart condition that has been surgically corrected, with a positive recovery.
- Moderate: Moderate heart conditions would be defined as either more than one defect (for example: VSD and ASD) or a more severe defect, with a surgery having already been completed (Tetralogy of Fallot, post Glenn shunt surgery).
- Severe: Severe heart conditions would be defined as any defect that would require significant medical intervention and the child has had no corrective surgery completed. Defects that would into this category would be Endocardial Cushion Defect, Transposition of the Great Vessels, and Tetralogy of Fallot with pulmonary atresia.

**Craniofacial**

**Cleft Lip/Cleft Palate** is a congenital defect in the facial tissues of the lips, mouth, and nose where the tissues do not fuse together, leaving a space often caused by a genetic mutation or other developmental effects from drugs or alcohol.

A cleft lip occurs when the tissue of the upper lip does not fuse together. A cleft palate occurs when the tissue on the roof of the mouth (palate) does not fuse together. The clefts can be unilateral (only occurring on one side) or bilateral (occurring on both sides). The severity can range from a small slit or notch to a large gap. Often cleft lip and cleft palate are associated with each other, but this is not always the case. It is possible to have a cleft palate without cleft lip or cleft lip without a cleft palate. The most severe cases generally involve bilateral cleft lip and cleft palate.

There are varying degrees of cleft lip and palate, however, most of the children will have cleft lips that are second degree (cleft is above pink of the lip, but not to the nostril) or third degree (cleft extends into the nostril) and the cleft palate is almost always third degree (cleft in both hard and soft palate and affecting the bone from which teeth grow).

For the most part, individuals with cleft lip only do not experience many issues, especially if surgically corrected. However, individuals with cleft palate have the most issues with eating, speaking, occasionally breathing, and can sometimes sustain hearing loss and other problems. Cleft lips and palates are correctable and surgeries generally begin at a young age. Cleft palates may require multiple surgeries throughout youth and adolescence. After treatment, speech and other therapies are often required. Orthodontics may also be necessary at a later age.

**Eye/Orbital Deformities** involve abnormal growth of the bones of the skull and face which can cause the displacement of the orbit (the bony area surrounding the eyeball). These bony shells of the eye expand for the first two years of life as the eye grows.

Protrusions, herniation, and sunken or wide-set eyes are examples of orbital deformities. Craniofacial surgery is often required to correct eye and orbit deformities.

**Facial Deformities** are often characterized by disproportionate or missing features, and/or abnormal growth. Facial deformities can be caused by congenital defects, injury, or environmental causes. Sometimes we see children who have a facial cleft in conjunction with cleft palate. A facial cleft typically starts at the lip and will extend into the cheek and eye area.

Severe facial deformities can cause complications with vision, hearing, and sometimes, breathing. Most individuals with a facial deformity can live fairly normal lives, with little to no treatment. Mild facial deformities can often be corrected with cosmetic surgery, if necessary. In the most severe cases, extensive cranial-facial surgery is required to prevent complications.

**Microtia** is defined as an incomplete development of the ear. In most cases, it only affects one ear. It can range in severity, from a malformed outer ear, to the absence of the outer ear and ear canal opening. Children may or may not have hearing loss in the affected ear.

**Developmental**

**Autism** is a disorder of neural development that is characterized by impaired social interaction and communication, and by restricted and repetitive behavior. People with autism may be overly sensitive in sight, hearing, touch, smell, or taste, have unusual distress when routines are changed, or perform repeated body movements.

Symptoms can range from moderate to severe. An early, intensive, and appropriate treatment program will greatly improve the outlook for most young children with autism. Most programs will build on the interests of the child in a highly-structured schedule of constructive activities. Visual aids are also often helpful.

**Down Syndrome** is a genetic disorder that causes lifelong mental retardation, developmental delays, and other problems. Down syndrome varies in severity, so developmental problems range from moderate to serious. Children with Down syndrome typically have flattened facial features, a protruding tongue, small head, abnormally shaped eyes for the child's ethnic group, and abnormally shaped ears. They may also have poor muscle tone, short fingers, and abnormal flexibility. These children are also at higher risk for heart defects, leukemia, infectious diseases, dementia, sleep apnea, and obesity. In general, children with Down syndrome usually meet developmental milestones, but it may take them longer than it does a child without Down syndrome. For example, children with Down syndrome may take twice as long to sit, crawl, walk, or talk. However, early intervention programs, started as soon as possible, may give kids with Down syndrome the best chance of success.

**Developmental delays** are diagnosed when a child does not reach developmental milestones at the expected times. Developmental milestones are determined by the average age at which children attain each skill. Statistically, about 3% of children will not meet them on time, but only about 15-20% of these children will actually have abnormal development. The rest will eventually develop normally over time, although a little later than expected. Nearly all children adopted internationally will have some level of developmental delay due to not being raised in a family setting.

If a child is diagnosed with a developmental delay as a special need, this indicates they are delayed in comparison to other children in the orphanage.

**Gross Motor Skill delays**

Delays in gross motor skills involve the large muscles of the body that enable such functions as walking, kicking, sitting upright, lifting, and throwing a ball. A person's gross motor skills depend on both muscle tone and strength. A child with a gross motor delay may not meet milestones on target due to prematurity, heart conditions, or exposure to alcohol and drugs in utero.

**Language Skill delays**

Delays in language skills involve acquisition of day to day language. Children usually begin to babble around the age of six months, creating distinctive words around the age of one year, and able to speak simple sentences around the age of two.

Research has shown that a child who is just beginning to talk must hear a word approximately 500 times before it will become part of his active vocabulary. In an institutionalized setting, the children may not have as much exposure as children in a family setting. Many children are delayed in language acquisition. However, if a child is labeled with a delay in language, there could be many causes. Children with cleft lip and palate or hearing issues are often delayed in language development. It is also possible for a child to have a learning delay that has affected language.

**Cognitive Development** includes the ability to analyze, evaluate, retain information, recall experiences, make comparisons, and determine action. There can be many reasons for a delay in this development (brain injury, lack of stimulation). For the purposes of the application, cognitive delays would be defined as follows:

■Slight delay: A slight delay would be categorized as mildly affecting day-to-day life. Perhaps the child requires extra assistance when learning new tasks or needs more one-on-one attention. The child would be able to complete simple tasks, would be responsive to instructions, and though possibly not meeting developmental milestones at the appropriate time, is meeting the milestones.

■Significant delay: A significant delay would be categorized as affecting day-to-day life and their ability to complete self-care. The child would most likely require significant one-on-one attention and ongoing care.

**Global delays** include delays in all areas of development. It is usually caused by static (does not worsen with time) encephalopathy, occurring before or near the time of birth. Causes of global delays include prematurity, cerebral malformations, chromosomal disorders, infections, and progressive encephalopathies, such as metabolic diseases, hypothyroidism, neurocutaneous syndromes, like neurofibromatosis and tuberous sclerosis, Rett syndrome, and hydrocephalus.

**Fetal Alcohol Syndrome** Fetal alcohol syndrome is growth, mental, and physical problems that may occur in a baby when a mother drinks alcohol during pregnancy. A baby with fetal alcohol syndrome may have the following symptoms:

- Poor growth while the baby is in the womb and after birth
- Decreased muscle tone and poor coordination
- Delayed development and problems in three or more major areas: thinking, speech, movement, or social skills
- Heart defects such as ventricular septal defect (VSD) or atrial septal defect (ASD)
- Problems with the face, including:
    - Narrow, small eyes with large epicanthal folds
    - Small head
    - Small upper jaw
    - Smooth groove in upper lip

- Smooth and thin upper lip

The outcome for infants with fetal alcohol syndrome varies. Almost none of these babies have normal brain development. Infants and children with fetal alcohol syndrome have many different problems and may be challenging for parents. Children do best if they are diagnosed early and referred to a team of health care providers who can work on educational and behavioral strategies that fit the child's needs

**Known History of Physical Abuse/Sexual Abuse or Neglect**

Child abuse is the physical, sexual or emotional mistreatment or neglect of a child or children. There are four major categories of child abuse: neglect, physical abuse, psychological or emotional abuse, and sexual abuse.

Counseling and Therapies are necessary for abused children over age 2. The child will need help dealing with the fear and pain of abuse caused by the abusers who should often be trusted figures. Failing to get this help can lead to significant psychological problems, such as post-traumatic stress disorder (PTSD).

There are a number of treatments are available to victims of child abuse.

- Trauma-focused cognitive behavioral therapy
- Abuse-focused cognitive behavioral therapy
- Rational Cognitive Emotive Behavior therapy
- Other forms of treatment include group therapy, play therapy, and art therapy. Each of these types of treatment can be used to better assist the child, depending on the form of abuse they have experienced. Play therapy and art therapy are ways to get children more comfortable with therapy by working on something that they enjoy (coloring, drawing, painting, etc.).

**ADD/ADHD**

**Childhood ADHD --** attention-deficit/hyperactivity disorder -- is diagnosed after a child has shown six or more specific symptoms of inattention or hyperactivity on a regular basis for more than six months in more than two settings. There is no single test for ADHD. Symptoms of ADHD in children are generally grouped into three categories: inattention, hyperactivity, and impulsiveness.
Symptoms are noted below.
**Inattention -- A child with ADHD:**
Is easily distracted
Does not follow directions or finish tasks
Does not appear to be listening when someone is speaking
Does not pay attention and makes careless mistakes
Is forgetful about daily activities
Has problems organizing daily tasks
Avoids or dislikes activities that require sitting still or a sustained effort
Often loses things, including personal items
Has a tendency to daydream
**Hyperactivity -- A child with ADHD:**
Often squirms, fidgets, or bounces when sitting
Does not stay seated as expected
Has difficulty playing quietly
Is always moving, such as running or climbing on things (In teens and adults, this is more commonly described as a sense of restlessness)

Talks excessively
**Impulsivity -- A child with ADHD:**
Has difficulty waiting for his or her turn
Blurts out answers before the question has been completed
Often interrupts others

**Doctors may diagnose children as:**

- Combined Type (Inattentive/Hyperactive/Impulsive). Children with this type of ADHD show all three symptoms. This is the most common form of ADHD.
- Hyperactive/Impulsive Type. Children show both hyperactive and impulsive behavior, but for the most part, they are able to pay attention.
- Inattentive Type. Formerly known as attention deficit disorder (ADD), these children are not overly active. They do not disrupt the classroom or other activities, so their symptoms might not be noticed.

Education of the child and family about ADHD is an essential component of any treatment plan, which may encompass special education programs, psychological intervention, and drug treatment. Be sure to discuss all options with your child's health care provider to find the best treatment for him or her.

Studies show that long-term treatment with a combination of medications and behavioral therapy is far superior to just medication treatment, or no specific treatments in managing hyperactivity, impulsivity, inattention, and symptoms of anxiety and depression. Those kids treated with both ADHD drugs and therapy also had better social skills.

**Infectious Diseases**

**Encephalitis** is irritation and swelling of the brain, usually due to infections. Treatment depends on the cause of the infection. Encephalitis is not contagious, although the cause of the infection can be. Encephalitis can be caused byWest Nile, Japanese B, Lyme disease, rabies, meningitis, or syphilis. Mild symptoms can include headache, loss of energy, and poor appetite, while severe symptoms can include nausea, vomiting, confusion, personality changes, seizures, memory loss, and coma.
**Hepatitis B** is a disease that affects the liver. When the virus is active, it can cause symptoms similar to that of the flu. Someone that has been exposed to Hepatitis B may have symptoms one to four months later. Some people with Hepatitis B do not notice symptoms until they become quite severe. Some have few or no symptoms, but even someone that doesn't notice any symptoms can still transmit the disease to others. Some people carry the virus and are contagious for the rest of their lives.
Acute Hepatitis needs no treatment, other than careful monitoring of liver function, which involves blood tests. The acute illness usually goes away after two to three weeks. The liver usually returns to normal within four to six months in almost all patients that are infected.
Some people develop chronic Hepatitis. People who have chronic Hepatitis B stay infectious. Patients with chronic hepatitis are treated with antiviral medications. Hepatitis B cannot be cured, but these medications may help lessen the infection. They are considered carriers of the disease, even if they do not have any symptoms. Most children referred with a Hepatitis B diagnosis would be considered carriers, meaning they are infected with the virus, however, have no outward symptoms.
**Human immunodeficiency virus –** HIV is a retrovirus that causes AIDS by infecting helper T cells of the immune system. The most common serotype, HIV-1, is distributed worldwide, while HIV-2 is primarily confined to West Africa. While there is currently no cure for HIV or AIDS, the medications that are now available to treat HIV are highly effective. HIV is now considered a chronic illness, rather than a terminal disease. HIV positive individuals who are receiving treatment can live indefinitely without developing AIDS. Studies show that people who are HIV+ and have access to treatment can have close

to normal life expectancy. HIV+ children can grow up, get married, have healthy babies and can expect to live long enough to meet their grandchildren.

**Syphilis** is an easily spread infection caused by the bacteria Treponema pallidum. The symptoms of syphilis depend on the stage of the disease. Many people do not have symptoms. In general, painless sores and swollen lymph nodes are symptoms of primary syphilis.

Those with secondary syphilis may also have fever, fatigue, aches and pains, and loss of appetite, among other symptoms. Tertiary syphilis causes heart, brain, and nervous system problems. With prompt treatment and follow-up care, syphilis can be cured. Late-stage syphilis can lead to long-term health problems despite therapy. Most of the children referred from will have congenital syphilis and will have received treatment.

**Tuberculosis** (TB) is caused by a bacterium called Mycobacterium tuberculosis. The bacteria usually attack the lungs, but TB bacteria can attack any part of the body, such as the kidney, spine, or brain. Symptoms include a cough that lasts longer than three weeks, weakness and fatigue, weight loss, and fever or chills.

**Nephrological**

**Hydronephrosis** is the swelling of one kidney due to a backup of urine. Symptoms include abdominal pain, nausea, fever, urinary tract infections, and increased frequency of urination. Hydronephrosis is a condition that occurs with a disease. It is not a disease itself. Conditions that are often associated with unilateral hydronephrosis include: acute unilateral obstructive uropathy, chronic unilateral obstructive uropathy, vesicoureteric reflux (backflow of urine from bladder to kidney), or nephrolithiasis (kidney stones). Treatment and prognosis for unilateral hydronephrosis depend on what is causing the swelling of the kidney. Treatment may include: a ureteral stent (tube that allows the ureter to drain into the bladder), a nephrostomy tube (allows the blocked urine to drain through the back), or antibiotics for infections.

**Polycystic Kidney Disease (PKD)** is a kidney disorder passed down through families, in which multiple cysts form on the kidneys causing them to become enlarged. People with PKD have multiple clusters of cysts on the kidneys. The exact action that triggers cyst formation is unknown.

In early stages of the disease, the cysts cause the kidney to swell, disrupting kidney function and leading to chronic high blood pressure and kidney infections. The cysts may cause the kidneys to increase production of erythropoietin, a hormone that stimulates production of red blood cells. This leads to too many red blood cells, rather than the anemia seen in chronic kidney disease. Symptoms include pain and swelling, blood in the urine, and excessive urination. It can also be associated with drowsiness, joint pain, and high blood pressure. The disease gets worse slowly, eventually resulting in end-stage kidney failure. It is also associated with liver disease, including infection of liver cysts. Medical treatment may provide relief of symptoms for many years. The absence of systemic disease or autoimmune disease makes people with polycystic kidney disease good candidates for kidney transplantation.

**Orthopedic**

**Arthrogryposis** is the name given to a group of disorders characterized by multiple joint contractures throughout the body present at birth. It is usually caused by decreased fetal movement in utero.

Decreased movement can be caused by central nervous system malformations, such as spina bifida, brain malformations, neuromuscular disorders, maternal infections or fever, or too little amniotic fluid. The particular joint contractures vary in each child, however, there are several common characteristics: the legs and arms are affected, with wrists and ankles being the most deformed, the joints in the legs and arms may not be able to move at all, muscles in the legs and arms are thin and weak or even absent, and/or the hips may be dislocated. Some infants with arthrogryposis have facial deformities, curvature of the spine, genital deformities, cardiac and respiratory problems, and skin defects. There is no cure for arthrogryposis, but early vigorous physical therapy can help stretch out the contracted joints and develop

the weak muscles. Splints can also help stretch joints, especially at night. Orthopedic surgery may also be able to relieve or correct joint problems.

**Clubbed Feet** refers to an inversion of the foot at the ankle. The foot is twisted inward and downward so that the child cannot place the sole flat on the ground but must walk on the ball, the side, or even the top of the foot. During development, the posterior and medial tendons and ligaments (in the back and inside) of the foot fail to keep pace with the development of the rest of the foot. As a result, these tendons and ligaments tether the posterior and medial parts of the foot down, causing the foot to point downward and twist inward. The bones of the feet are therefore held in that abnormal position. Over time, if uncorrected, the bones will become misshapen. Treatment can involve serial casting, splits or braces and/or surgery. Children can have either a unilateral clubbed foot, which means only one foot is affected, or bilateral clubbed feet, which means both feet are affected.

**Clubbed Hands** are also referred to as radial clubbed hands. This can affect one or both hands. In radial clubbed hands, a baby's radius was not formed properly in the womb, which in turn causes the wrist to be in a fixed bent position toward the thumb side of the hand. In most forms of radial clubbed hands, not only is the bone abnormal, but the soft tissues and flesh of the forearm are also abnormal. The arrangement of muscles and nerves may be unbalanced and some muscles and nerves may even be absent. The most severe cases lead to significant problems in the function of the hand, fingers, and elbow. The entire arm will be shorter, with marked curving of the forearm, stiffness of the elbow and fingers. In these situations, the thumb will either be very small or absent. The long-term outlook is dependent on the severity of the deformity. In mild cases, intermittent therapy throughout growth is required to maintain alignment and strength. These children will have minor limitations of motion, function, and strength. In the more severe cases, there will be marked limitation of motion, strength, and function. In these situations, growth will also be limited in that forearm.

**Complete absence of a limb (or more than one limb)** This indicates that either no bones of the limb developed at all, where a prosthetic would not be able to be used, or the limb is significantly underdeveloped.

**Deformity of fingers and/or toes** This may take on many forms. The types of deformities are defined below. Each deformity may affect one or multiple fingers or toes. Most often, digital deformities are caused by amniotic band syndrome, which occurs in utero. Damage to the amnion (part of the placenta) may produce fiber-like bands that can trap the arms, legs, fingers, or toes of the fetus. These bands reduce blood supply to the areas and cause them to develop abnormally. These children may also have deformed or missing limbs, clubbed feet or permanent "band" or indentation around a limb.

- Adactayly refers to missing digits.
- Brachydactyly refers to shortened or underdeveloped digits.
- Polydactyly refers to one or more extra digits.
- Syndactyly refers to fused or combined digits. This may be surgically correctable, or the bones may be permanently fused or absent.

**Dwarfism** is a condition characterized by short stature. Technically, that means an adult height of 4 feet 10 inches or under and can be caused by any one of more than 200 conditions, most of which are genetic.

As a child with dwarfism grows, they may have delayed development of some motor skills, such as sitting up and walking, a greater susceptibility to ear infections and hearing loss, breathing problems caused by small chests, weight problems, curvature of the spine (scoliosis), bowed legs, trouble with joint flexibility and early arthritis, lower back pain or leg numbness, and crowding of teeth in the jaw. At times a child may need surgery to help alleviate some of these symptoms. Most children referred that are diagnosed with dwarfism will have achondroplasia, which is characterized by disproportionately short arms and legs compared to the head and trunk.

**Hip Dysplasia** is the medical name used to describe a problem with formation of the hip joint in children. The location of the problem can either be the ball of the hip joint (femoral head), the socket of the hip joint (the acetabulum), or both. The treatment of hip dysplasia depends on the age of the child. The goal of treatment is to properly position the hip joint ("reduce" the hip). Once an adequate reduction is

obtained, the doctor will hold the hip in that reduced position and allow the body to adapt to the new position. The younger the child, the better capacity to adapt the hip, and the better chance of full recovery. Over time, the body becomes less accommodating to repositioning of the hip joint. If the hip dysplasia is significant, the children are often treated with braces or surgery. The success of treatment depends on the age of the child, and the adequacy of the reduction. In a newborn infant with a good reduction, there is a very good chance of full recovery. When treatment begins at older ages, the chance of full recovery decreases. Children who have persistent hip dysplasia have a chance of developing pain and early hip arthritis later in life. Surgery to cut and realign the bones (hip osteotomy), or a hip replacement, may be needed later in life.

**Paraplegia** is an impairment in motor and/or sensory function of the lower extremities. It is usually the result of spinal cord injury or a congenital condition, such as spina bifida, which affects the neural elements of the spinal canal. The area of the spinal canal which is affected in paraplegia is either the thoracic, lumbar, or sacral regions. Most often, children with paraplegia will use a wheelchair.

**Requiring assistance to walk** Children who require assistance to walk cannot stand or walk solely on their own, but are not confined to a wheelchair. Their need for assistance may be caused by cerebral palsy, spina bifida, or other limb issues. Most often the children will use a walker or crutches.

**Rheumatoid Arthritis** is a general term for the most common types of arthritis in children. It is a long-term (chronic) disease resulting in joint pain and inflammation, which may lead to joint damage. The first signs of arthritis can be subtle or obvious. Signs may include limping or a sore wrist, finger, or knee. Joints may suddenly swell and remain enlarged. Stiffness in the neck, hips, or other joints can also occur. Rashes may suddenly appear and disappear, developing in one area and then another. High fevers that tend to spike in the evenings and suddenly disappear are characteristic of systemic juvenile rheumatoid arthritis. In many cases, it may be treated with a combination of medication, physical therapy, and exercise. In specific situations, a child may require injection of corticosteroids into the joint or possibly surgery. The goals of treatment are to relieve pain and inflammation, slow down or prevent the destruction of joints, and restore use and function of the joints to promote optimal growth, physical activity, and social and emotional development.

**Rickets** is the softening and weakening of bones in children, usually because of an extreme and prolonged vitamin D deficiency. Rickets can cause skeletal deformities, fragile bones, impaired growth, dental problems, bone pain, and muscle weakness. If a vitamin D or calcium deficiency causes rickets, adding vitamin D or calcium to the diet generally corrects any resulting bone problems for a child. Rickets due to a genetic condition may require additional medications or other treatment. Some skeletal deformities caused by rickets may need corrective surgery. Children who are referred with a diagnosis of rickets, though occasionally treated, will most often have significant skeletal deformities.

**Scoliosis** is an abnormal curvature of the spine. In scoliosis, the spine curves to the side when viewed from the front, and each vertebra also twists on the next one in a corkscrew fashion. Scoliosis can be caused by a non-structural issue where the spin is normal, but is caused by another issue such as one leg being shorter than the other. It can also be structural where the curvature is caused by another disease process, such as a birth defect, muscular dystrophy, metabolic diseases, connective tissue disorders, or Marfan syndrome. Some instances of scoliosis require no treatment, while some may require braces or surgery.

- A slight curvature is defined as a defect that does not appear to affect the child's spinal structure. From a visual standpoint, the curvature is not evident through the child's clothing.
- A significant curvature is defined as being apparent that the child will most likely require surgery and the spine and thorax are significantly deformed. For these children, the curvature is apparent when the child is dressed.

**Short/Webbed Neck**, or pterygium colli deformity, is a congenital fold that runs along the sides of the neck down to the shoulders. On babies, webbed neck may look like loose folds of skin on the neck. As the child grows, the skin may stretch out to look like there is little or no neck. It can be a feature of Turner syndrome and Noonan syndrome, as well as the rarer Klippel-Feil syndrome.

**Underdevelopment/Maldevelopment of a limb** This indicates any level of limb difference aside from complete absence. Most often these children will have at least half of the limb that is underdeveloped. It can be characterized as missing the lower portion of an arm or leg or underdevelopment or absence of a hand or foot.

**Sensory**

**Hearing Loss** refers to all hearing issues, including deafness. Hearing impairment can be caused by a variety of reasons, including:

- Congenital defect
- Disease
- Environmental causes

Depending on the underlying cause, some types of hearing impairment can be corrected with hearing aids, surgery, or other therapies. If the individual suffers from complete deafness, many therapies and learning techniques such as Sign Language, lip reading, and animal assistance programs, are available to help the individual to be independent. Often with only minor aid, individuals with hearing impairment can live full and successful lives.

**Vision Impairment** is a very broad category that covers any vision issue which has not caused vision loss in the child. Typical vision impairments include:

- Mild or corrected cataracts
- Ptosis (drooping eyelids)
- Strabismus (crossed-eyes)
- Ambylopia (lazy-eye)

These conditions would be considered correctable or manageable with minimal intervention.

**Vision Loss** includes any level of explained or unexplained vision loss. Typical diagnoses seen would include:

- Glaucoma (increased eye pressure)
- Severe cataracts
- Microphthalmia (abnormally small eyeball)
- Atrophy of the eye (one or both)

If the individual has complete blindness, many therapies and learning techniques, such as Braille and animal assistance programs, are available to help the individual to be independent. Often with only minor aid, individuals with vision impairment can live full and successful lives.

**Skin Conditions**

**Albinism** is a recessive genetic condition characterized by reduction or complete lack of pigment in the skin, hair, or eyes. There are several types of albinism that have different characteristics, but the most common characteristics are very light skin, white to light blonde hair, and light eye color ranging from light blue to purple. Physical characteristics may vary depending on the individual and type of albinism. Individuals with albinism lack protection from UV rays and are susceptible to sun burns, skin cancer, and other skin problems. The eyes are also greatly affected by albinism. Individuals with albinism usually suffer from eye conditions ranging from mild nearsightedness to complete blindness.

Albinism itself is incurable, but sometimes eye and skin issues associated with albinism can be corrected with UV protection, corrective lenses, or surgery. With proper care, this condition is generally not life threatening, and individuals with albinism can live long, productive lives.

**Ichthyosis** is an inherited skin disorder that causes dead skin cells to accumulate in thick, dry scales on the skin's surface. It occurs when the production of skin cells is too fast or the skin's natural shedding process is too slow. These scales can be present at birth, but usually first appear in early childhood.

Though most cases are mild, some cases of ichthyosis can be severe. No cure has been found and treatments are directed at controlling the signs and symptoms. Treatment can include prescription creams and ointments that contain alpha hydroxyl acids, such as lactic acids and glycolic acids. These chemicals help control the scaling and increase skin moisture. In severe cases, the doctor may prescribe retinoids—medications derived from vitamin A. They reduce the production of skin cells. It is best for individuals with ichthyosis to live in warmer climates.

**Nevus/Hairy Nevus** is an overgrowth of skin pigment on the skin surface. A large nevus is typically classified as anything over 20cm. If a child is diagnosed with a nevus/hairy nevus as their only special need, these children are likely to have a large nevus. While some nevi can be treated with laser treatment or simple outpatient surgery, larger nevi can require all layers of skin to be removed where the nevus is located. Removal can involve a grafting and/or stretching. Skin stretching involves balloons being inserted under the skin that are gradually filled to stretch the "good skin." The nevus is removed, and the stretched skin is put in its place. The lifetime risk for malignant degeneration in a large congenital nevus is approximately 6 percent.

**Urogenital**

**Anorchism** is the absence of one or both testes. Generally, if one testicle is absent, the other can be found in the abdominal cavity. Although the testes are absent, the male genitalia are otherwise normal. This suggests that there was normal testicular function in early fetal life and normal male differentiation took place. The testes are presumed, therefore, to have regressed for some reason. Torsion of the testes (twisting) in fetal life has been suggested as a cause. In the long term, the boys will need male sex hormone replacement. The introduction of testosterone pre-pubertally would need some age limitations. The defined onset of puberty in males occurs around the age of 11.5 years old.

As a result, a very low dose of testosterone could be given at around 10 years of age, gradually increasing the dosage schedule. This would, in part, mimic the changes that occur in normal boys. In adulthood, testosterone preparations can be used as capsules, intramuscular injections, skin patches, subcutaneous pellets, gel, or cream. Testicular prostheses should be considered pre-pubertally to overcome psychological problems related to anorchia.

**Cryptorchidism** refers to one or both of the testes being undescended. This occurs when one or both testicles fail to move into the scrotum before birth. Usually, the testicle will descend into the scrotum without any intervention during the first year of life. If this does not occur, the child may receive hormone injections (B-HCG or testosterone) to try to bring the testicle into the scrotum. Surgery (orchiopexy) is the main treatment. Earlier surgery may prevent irreversible damage to the testicles. This damage can cause infertility. Most cases improve on their own, without any treatment. Medical or surgical correction of the condition is usually successful.

**Funicular Hydrocele** is a collection of fluid along the spermatic cord. This is usually treated surgically and poses no long-term issues for the child.

**Hermaphroditism** This is defined as a group of conditions where there is a discrepancy between the external genitals and the internal genitals (testes and ovaries). In general, this will refer to a child who has a chromosomal abnormality. Often, we see children who have malformed genitalia mislabeled as hermaphrodites.

**Hypospadias** is a somewhat common birth (congenital) defect in which the opening of the urethra is on the underside, rather than at the end, of the penis. The condition varies in severity. In most cases, the opening of the urethra is located near the tip of the penis on the underside. More severe forms of hypospadias occur when the opening is at the midshaft or base of the penis. Occasionally, the opening is located in or behind the scrotum. For the purposes of the application, the severity is defined as follows:

- Mild: Mild hypospadias is defined as typical appearance of genitalia and mild misplacement of the urethra. In some occasions, the scrotum will be split, however the overall structure of the penis appears normal.

- Severe: Severe hypospadias may include significant misplacement of the urethra causing further structural deformities of the penis and scrotum. These children may also be classified as having more ambiguous genitalia.

**Imperforate Anus** is a congenital (present from birth) defect in which the opening to the anus is missing or blocked. The rectum may end in a blind pouch that does not connect with the colon. Or, it may have openings to the urethra, bladder, base of penis or scrotum in boys, or vagina in girls. A condition of stenosis (narrowing) of the anus or absence of the anus may be present. With treatment, the outcome is usually good. However, it depends on the exact problem. Some infants may never develop adequate bowel control.

**Incontinence** is the inability to control the bladder, bowels, or both. It can be caused by spinal injury (spina bifida), nerve disorders, prolapse or any other urogenital disorders. It may be treatable with therapy, depending on the cause.

**Rectovaginal Fistula** is an abnormal connection between the lower portion of the large intestine, the rectum, and the vagina. This can be associated with imperforate anus in girls, as well as complications from other surgeries, cancer, or Chron's disease. Symptoms include the passing of gas or stool from the vagina, irritation, urinary tract infections, and a foul smelling discharge. Treatment for a rectovaginal fistula depends on its cause, size, location and effect on surrounding tissues. Sometimes fistulas heal on their own, but most people need surgery to close or repair the abnormal connection.

**Ambiguous/Underdeveloped Genitalia** refers to any genital malformation that does not include a chromosomal abnormality. Ambiguous genitalia may include an enlarged clitoris or concealment of the vagina in girls and severe hypospadias or an abnormally small penis in boys. Treatment may include reconstructive surgery or hormone replacement.

**Vascular**

**Capillary Malformation (Port Wine Stain)** (CM) is a flat, sharply demarcated, red-pink vascular stain of the skin. These can be located anywhere on the body. If the CM is located on the child's face, especially near the eyes or forehead, the child could have vascular abnormalities of the eye and brain, called Sturge-Weber syndrome. Sturge-Weber is characterized by possible seizures, glaucoma or other vision issues, and sometimes cognitive delays. CMs overlying the spinal column can be associated with a spinal vascular abnormality (Cobb syndrome). CMs can overlie a deeper vascular abnormality involving arteries, veins, or lymphatics, and often there is overgrowth of the involved tissues.

Treatment is typically laser therapy.

**Hemangioma** is an abnormal buildup of blood vessels in the skin or internal organs. Most hemangiomas do not require treatment. However, if the hemangioma is on the face, it may interfere with vision, in which case efforts would be made to remove it. Complications could include difficulty breathing, bleeding, vision issues, or infections, depending on the location of the hemangioma. If a child has a diagnosis of hemangioma, it is likely the hemangioma will be and/or interfering. If the hemangioma is smaller or fairly insignificant, it is unlikely the child would be referred through the Waiting Child program, unless the child also had a secondary diagnosis.

**Lymphangioma** is a rare, benign, congenital disorder in which a blockage in the lymphatic system causes fluid to accumulate in bubbles beneath the skin. Lymphangiomas can occur anywhere in the skin and the mucous membranes. The most common sites are the head and the neck, followed by the proximal extremities, the buttocks, and the trunk. However, they sometimes can be found in the intestines, the pancreas, and the mesentery.