



Resources & Referral Request Overview Packet

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Resources

As you begin researching medical needs you are open to considering, please review the resources, information & websites below.

- **American Cleft Palate-Craniofacial Association / Cleft Palate Foundation**
1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514-2820
Phone: (919) 933-9044
Email: info@cleftline.org
Website: www.cleftline.org
- **American Heart Association**
7272 Greenville Avenue
Dallas, TX 75231
Phone: 1-800-AHA-USA-1
Phone: 1-800-242-8721
Email: American Heart Association
Website: www.americanheart.org
- **Hepatitis B Foundation**
700 East Butler Avenue
Doylestown, PA 18901-3691
Phone: (315)489-4900
Fax: (215)489-4920
Email: info@hepb.org
- **Shriners Hospitals for Children**
Shriners Hospitals for Children is a network of 22 hospitals that provide expert, no-cost orthopedic and burn care to children under 18. If you know a child Shriners Hospitals might be able to help, call us toll free at 1-800-237-5055 (in the U.S.) We invite you to explore our Web site to find out more about this special organization.
Phone: (800) 237-5055
Website: www.shrinershq.org
- **Noah**
P0 Box 959
East Hampstead, NH 03826-0959
Phone: (800)473-2310 (US & Canada)
Phone: (603)887-2310
- **Little People of America INC**
5289 NE Elam Young Parkway, Suite F-700
Hillsboro, or 97124
Toll-free: (888) Lpa-2001 (English & Spanish)
Direct: (503) 846- 1562
Fax: (503) 846-1590
Email: info@lpanonline.org
Website: www.lpaonline.org

- **Spina Bifida Association**
4590 MacArthur Boulevard, NW Suite 250
Washington, DC 20007
Phone: 202-944-3285
Toll Free: (800)621-3141
Fax: 202-944-3295
Email: sbaa@sbaa.org
Website: www.spinabifidaassociation.org

- **Signs For Hope (hearing impaired)**
PO Box 460
Fairview, NC 28730
www.signsforhope.org
www.signs4hope.blogspot.com

- **Anal Atresia(AA)/ Imperforate Anus (IA)/Anorectal Malformations(ARM)**

Leading Colorectal Centers

- **Cincinnati Children’s Hospital –**
- <http://www.cincinnatichildrens.org/service/c/colorectal/default/>
- **Nationwide Children’s Hospital – Dr. Marc Levitt**
- <http://www.nationwidechildrens.org/colorectal-pelvic-reconstruction-center>
- **Seattle Children’s Hospital – Dr. Avansino**
- <http://www.seattlechildrens.org/clinics-programs/reconstructive-pelvic-medicine/>
- **DuPont Nemours – Dr. Charles Vinocur**
- <http://www.nemours.org/service/medical/anorectal-malformations.html?tab=about>

Facebook Group:

“Imperforate Anus/Adoptive Mamas” –name of the group

- **Love without Boundaries (LWB):** www.adoptspecialneeds.org
- **No Hands But Ours (NHBO):** <http://www.nohandsbutours.com/resources/>

LWB & NHBO both provide adoption stories, wonderful adoption resources for parents, explanations of medical needs, etc.

Important Factors to Consider

Gender

Both boys and girls are available for adoption. Wait times for boys with commonly seen medical needs are generally always shorter than wait times for most girls.

Age Ranges

Orphan Registration- Due to the length of time it takes to complete orphan registration paperwork in China, the youngest referral typically seen is 6 months, but most commonly seen ages are 12 months and older. Due to Chinese adoption law a child has to be adopted prior to their 14th birthday. (finalized in China)

The CCCWA continues to educate orphanages on how to register children at a younger age to increase their chances of being adopted, but at this time we see referrals of all ages being registered and waiting for families.

Children in the Home- If you have children in the home, you must discuss the birth order with your social worker and any potential issues with your age requests and breaking birth order or artificial twinning. To avoid artificial twinning, AWAA recommends at least a 9 month age gap between children in the home.

Healthy Older Referrals- For unknown reasons, there are generally no healthy referrals ages 3-6 referred in either the healthy or waiting children program. The youngest healthy referral seen in the waiting children program is age 5.5 years, but that is not typical. Most healthy referrals are ages 10 and above, with most being age 11-13 and a very small amount ages 6-10 years.

Varying Degrees of Medical Needs

To learn more about each medical need listed below, please consult with your doctor or the Love Without Boundaries medical manual as listed under "Waiting Children Application: Family Education." For each condition, it can be considered minor, moderate, or severe depending on the amount of medical care or therapy needed. Each family and doctor will define "minor, moderate, or severe" in a different way. For the overview listed below, "minor" is defined as a condition that will not require surgery.

Commonly Seen Medical Needs

Unrepaired cleft lip or palate, repaired cleft lip/unrepaired palate, hand, arm, foot or leg differences, moderate/severe heart conditions (minor heart conditions are seen but in smaller numbers each month), spine conditions, cerebral palsy, developmental delays (motor, mental, growth), brain/neurological conditions, repaired spina bifida to name some of the many various needs seen.

Medical Needs Not Commonly Seen Each Month As a "Stand Alone" Condition

Heart murmur, missing finger or toes or other deformities of appendages, hernia, hemangioma or birthmark. minor burns/scars or other minor skin conditions, minor vision or hearing impairments, minor ear deformity, strabismus, Asthma, Allergies, Jaundice, HIV (this is very rare)

Other Medical Conditions

There are many other medical conditions seen in the program, as listed in the request overview below.

Medical Needs Notes & Disclaimers

Review these notes and disclaimers for an understanding of common referral patterns, though AWA cannot guarantee or predict future referral patterns.

Ear deformity/Partial Hearing Loss

Most of the ear deformities are not minor and they involve the entire ear or both ears and often involve hearing loss. Most hearing loss we see is associated with the ear deformity and could be total hearing loss in one ear.

Multiple Special Needs

There are many referrals with multiple special needs. This could vary such as having a cleft lip/palate and growth developmental delay, to having a finger deformity and heart condition. These are just two examples and it is important to note if you strongly prefer not reviewing a child with multiple special needs.

Developmental Delays

A developmental delay can be undiagnosed in any referral. It is commonly seen as an additional special need with children who have cleft or heart conditions, oftentimes it can be inferred that the developmental delay is due to the special need and the child needing additional nutrition, in the case of cleft conditions. These possibilities should be reviewed with your doctor. All children in an orphanage setting, regardless of diagnosis, tend to have developmental delays due to institutionalization.

Undiagnosed Medical Conditions

As you have discussed with your social worker in the home study report, any referral can have additional or unknown medical needs. It is important for you to continue these discussions during this application process as these are all possibilities during the adoption and referral process.

Heart Defects

Many families research and request a heart defect such as VSD or ASD. These are not as commonly seen each month. There are a variety of heart conditions, such as TOF and PDA and many times a child can have a multiple heart defect diagnosis. We encourage families to research heart conditions and list what types they feel comfortable with.

Cleft Conditions

It is rare to see a child with both repaired under the age of 2 or 3, sometimes a 3 year old may have both repaired, as it depends on the orphanage's access to surgeries. Even with both repaired you should be prepared for future surgeries, speech therapy, and dental work. Rarely is just a cleft lip seen as approximately 98% of the time there is also a cleft palate.

Vision Impairments

It is rare to see referrals for minor vision impairments. Most vision conditions seen are congenital and usually cannot be corrected just by prescribing glasses. Quite often, vision impairments will require surgery(ies) or may not be fully correctible.

Unrepaired vs. Repaired Conditions

Typically, younger referrals are waiting for surgeries in China or will need the surgery when they are adopted. It is also quite common to see a child with more than one special need, where one is repaired and an additional medical need that is unrepaired. Families who are

requesting a child with repaired conditions should also be aware that some conditions that are repaired may still require future surgeries.

Hepatitis B

It may not always be confirmed in the referral information whether this condition is active or if the child is a carrier. A doctor would be able to review the referral information more closely to help your family understand the specifics of a child's condition.

Referral Request Overview & Medical Needs List

Review the following referral request options and then type in your requests in the "Referral Request and Notes" section of the WC application word document.

Gender Request

Male, Female

Age Range Request

List the age range you are open to between 6 months-13 ½ yrs (as children must be adopted before the 14th birthday in China). Please note that requesting a child age 0-2 years means that AWAA will look at referrals up to age 3. If you prefer, you can list the age range more specifically, such as 0-24 months, to ensure we are matching you as closely as possible within the age range you prefer.

Medical Conditions Requests Examples

List the medical needs that you are open to reviewing and possibly the ones you might consider.

Examples of medical requests:

Ear, Eye & Head Conditions

- Apraxia/Mute
- Blindness
- Cataracts
- Cleft Lip
- Cleft Palate
- Deafness
- Ear Malformation-Microtia/Atresia / other
- Facial Malformation
- Glaucoma
- Hemifacial Microsomia
- Eye Malformations-Microphthalmia
- Nystagmus
- Hearing Loss-Partial
- Vision Loss- Partial
- Ptosis*
- Retinoblastoma
- Strabismus*

Heart/Blood Conditions

- Dextrocardia
- Diabetes
- Heart Condition-Moderate/Major //
+please note these examples below are **not** comprehensive of all types in this category
- i.e.- TOF, TGA, Single Ventricle, etc.
- Heart Condition-Minor *
- i.e. -VSD, ASD, PFO, PDA, etc.
- Hemophilia
- Phenylketonuria
- Turner's Syndrome
- Thalassemia

Bone, Muscle and Joint Conditions

- Arthrogyposis
- Club Foot/Feet
- Brachial Plexus Injury
- Cerebral Palsy
- Dwarfism/Short Stature
- Ectrodactyly

Bone, Muscle and Joint Conditions, cont...

- Fibular/Tibular Hemimelia
- Funnel Chest/ Pigeon Breast
- Hernia
- Hip Dysplasia
- Missing/Malformed Feet/Legs
- Missing/Malformed Fingers/Toes*
- Missing/Malformed Hands/Arms
- Osteogenesis Imperfecta
- Radial Club Hand
- Rickets
- Scoliosis
- Syndactyly
- Teratoma
- Torticollis

Infectious Diseases

- Hepatitis B
- Hepatitis C
- HIV
- Syphilis
- Tuberculosis

Neurologic Conditions

- Abnormal Brain CT
- Arachnoid Cyst
- Brain Damage
- Central Coordination Disorder
- Cerebral Hemorrhage
- Corpus Callosum Agenesis
- Epilepsy
- Hemiplegia
- Hydrocephalus
- Hypoxic Ischemic Encephalopathy (HIE)
- Paralysis
- Sacral Tumor
- Seizure Disorder
- Spine Bifida (Occulta, closed neural tube defects, Meningocele/Myelomeningocele)
- Tethered Spinal Cord

Feeding/Colon Conditions

- Anal Atresia
- Biliary Atresia
- Esophageal Atresia
- Failure to Thrive
- Feeding/Swallowing Issues
- Gastroschisis
- Hiatal Hernia
- Intestinal Atresia
- Megacolon/Hirschsprung's Disease
- Pyloric Stenosis

Reproductive/Urologic & Kidney Conditions

- Ambiguous Genitalia
- Hermaphroditism
- Bladder Exstrophy
- Genital Malformation
- Hydrocele
- Hydronephrosis
- Hypospadias
- Kidney Condition
- Undescended Testes

Skin/Vascular Conditions

- Albinism (also includes various level vision impairments)
- Burns
- Ectodermal Dysplasia
- Eczema*
- Epidermolysis Bullosa
- Hairy Nevus
- Hemangioma
- Hematoma
- Ichthyosis
- Lymphangioma
- Lymphoderma
- Port Wine Birthmark
- Vitiligo

Developmental Conditions

- Autism
- Growth Delay
- Mental Development Delay
- Motor Development Delay
- Down Syndrome
- Poor Brain Development
- Premature

Note: Items with * indicate a medical need unlikely to appear as a singular condition; a Waiting Child with this condition would generally have another (possibly more significant) medical need as well.

Referral Request Notes

You are encouraged to be specific in your referral requests, but can also keep your request general. In some cases families are too specific and so their matching is limited, and in others they are too general, so they decline referrals as they were not really open to the special needs they listed. AWAA understands it can be challenging to complete the application and discern God's plan for your family. We respect your feelings and decisions and your Family Coordinator can answer any questions or concerns you may have, and will review all your application requests with you.