

Thymus Tissue Donation

Congenital athymia is a condition in which a child is born without a functioning thymus. Your decision to donate thymus tissue may help save a child's life.



Gabe, a child with congenital athymia.

Your choice may dramatically change a child's life

Your child is on a challenging journey, but during this time, you have the opportunity to help another child with a rare disease.



How can you help?

In children undergoing heart surgery, a portion of the thymus—an organ located above the heart—is routinely removed and typically discarded as medical waste following the procedure.

If this is likely to happen during your child's heart surgery, the care team will ask for your permission to donate the thymus tissue that will be removed, instead of discarding it.



How will your donation be used?

The donation of your child's thymus tissue may allow for the manufacturing of an FDA-approved treatment for congenital athymia. Availability of this treatment is only possible through donations of pediatric thymus tissue from families like yours.

Without this treatment, a child with congenital athymia receiving supportive care alone typically does not survive beyond 2 to 3 years of age.

What to know about congenital athymia

Congenital athymia is a rare immune condition in which children are born without a functioning thymus, an organ that plays an important role in how the immune system works.

Without a functioning thymus, these children can face life-threatening infections because they are unable to produce enough naive T cells—white blood cells that help fight off infections.

The condition requires children, and often their families, to live in strict isolation. Protecting a child with congenital athymia requires constant care and attention, but a thymus tissue donation from your child could potentially make a significant difference.



What does this mean for you and your child?

To check that the donated thymus can be used as part of a treatment, medical histories will be reviewed for the mother and child, and a physical exam will be performed. A blood draw—no additional needle sticks for your child and potentially one needle stick for the mother depending on your child's age—is also required.

Consenting to donate does not in any way affect the amount of thymus tissue that is removed during your child's surgery. There is no cost to you for donating.



Why is donor consent needed?

If you choose to donate your child's thymus tissue, it may be used to manufacture a treatment that may be implanted into another child with congenital athymia. Your consent is needed to move forward with the donor screening process, which includes screening your blood and your child's blood for infectious diseases that could be transmitted through blood or tissues. If any results affect your child's health, you will be informed by your hospital medical team. The use of your child's donated thymus tissue may result in revenue for a for-profit therapeutics company that produces an FDA-approved medication for congenital athymia. You and your child will not be compensated for the use or sale of the donated thymus tissue.



"My child has a life—a beautiful one at that—because a family said, 'Yes.' **It was life-changing**, and I thank that family every single day."

— Chelsy, a caregiver of a child with congenital athymia

Your donation may be life-changing

To donate, contact your child's healthcare team:

Phone:

Fax:

Email:

See the difference your donation could potentially make

Scan the QR code or visit congenital-athymia.com/autumns-story to learn about a family whose lives were changed by a donation.



Scan the QR code or visit congenital-athymia.com/manufacturing to learn how donated thymus tissue is used to manufacture an FDA-approved treatment for children with congenital athymia.



Learn more about the thymus tissue donation process by speaking to your child’s healthcare team today.

Contact
Phone:
Fax:
Email:



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