

A young girl with dark skin and her hair styled in many small braids. She is wearing light blue-rimmed glasses and a pink sleeveless top. She is looking upwards and to the right with a slight smile. The background is a blurred indoor setting with colorful circular decorations on the wall.

# CARING FOR A CHILD WITH CONGENITAL ATHYMIA

A GUIDE FOR FAMILIES

This guide provides helpful “best practices” on how to limit the risk of germs in your home as well as suggestions for protecting your family outside your home.

### WAYS TO MINIMIZE THE CHANCE OF INFECTION

One of the most important aspects of caring for your child with congenital athymia is limiting their exposure to infectious germs.<sup>1</sup> Children with congenital athymia are managed with supportive care, which means they need to be isolated to avoid contact with germs that can cause infections, so everyone who comes into contact with your child needs to understand the limits and concerns that go along with this life-threatening immune disorder.

Talk to your doctor to find out what is right for you and your family, which may include some of these potential guidelines:

- Restrict visitors in the home<sup>1</sup>
- Encourage frequent handwashing in the home<sup>1</sup>
- Wipe down any items coming into the home
- Remind family members that they should shower and change clothes upon re-entry to the home from work or school<sup>1</sup>
- If possible, work with your doctor to obtain masks, gowns, and gloves for family members and visitors to wear
- Homeschool other children in the family and work from home, if possible<sup>2</sup>
  - If siblings must attend school, ask the school to notify you of any outbreaks or illnesses that siblings might bring home
- Work with doctors to prevent exposure to sick children at medical appointments<sup>3</sup>

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**Establish a sanitation station at the home entrance: You should restrict visitors to the home; however, if you do have visitors, ensure anyone coming into the home disinfects with hand sanitizer, removes shoes, and if available, puts on masks, gowns, and gloves.**

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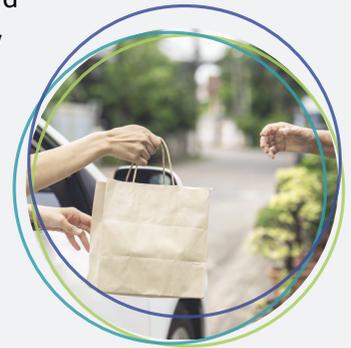
### WAYS TO PROTECT YOUR CHILD OUTSIDE THE HOME

Here are some ways you can address situations outside the home that may help to manage your child's condition.

**Have a “sick plan” in place:** When another member of your household feels ill or becomes sick, make sure they have a destination (such as staying with a friend or another family member) to go to until they are well enough to come home.

**Educate everyone you know:** It is important to educate siblings, other family members, friends, and teachers about congenital athymia soon after you receive the diagnosis. Make sure they understand what special precautions are needed because supportive care for a child with congenital athymia focuses on isolation for the child's protection from germs.<sup>1</sup>

- While friends and relatives are likely not seeing your child in-person, remind them to avoid contact with other family members in your household if they become ill. It's important to avoid exposing anyone in your immediate family to germs, since even a simple cold can be fatal.
- Request that the school notify you of any illness outbreaks that a sibling could potentially bring home and that they regularly sanitize the surrounding school environment.



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**Accept any offers of help from friends and family that you think won't expose your child to germs. This may include running errands or picking up meals for the family so that you can get some time to take care of yourself.**

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#### References:

1. Collins C, Sharpe E, Silber A, Kulke S, Hsieh EWY. Congenital athymia: genetic etiologies, clinical manifestations, diagnosis, and treatment. *J Clin Immunol*. 2021;41(5):881-895. doi.org/10.1007/s10875-021-01059-7.
2. Gupton SE, McCarthy EA, Markert ML. Care of children with DiGeorge before and after cultured thymus tissue implantation. *J Clin Immunol*. 2021;41(5):896-905. doi.org/10.1007/s10875-021-01044-0.
3. Markert ML, McCarthy EA, Gupton SE, Lim A. Cultured thymus tissue transplantation. In: Sullivan KE, Stiehm ER, eds. *Stiehm's Immune Deficiencies: Inborn Errors of Immunity*. 2nd ed. New York, NY: Elsevier; 2020:1229-1239.



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