Jackson's Story

Jackson was born October 20, 2016. Within days, his newborn screening came back positive for the possibility of CAH and by October 25th, he was seen by the Department of Pediatric Endocrinology at the Mass General Hospital for Children. His first week of life consisted of blood draws daily and stress doses of medication to hopefully prevent a crisis. By October 28th, he was admitted into the NICU because he was in adrenal crisis. He was hospitalized for 4 days while the doctors worked to regulate his medications and monitor his cortisol and aldosterone levels. His official diagnosis of Classical CAH came during his NICU stay.

His blood work is now monitored every 2 months and medications are adjusted as he grows. This condition, and the medications he takes, is going to be lifelong for him, unless we can find a cure.

Jackson is a happy child. He LOVES Mickey Mouse and all things Disney. He loves his doggies and he fills our days with joy. One day, he hopes to find a cure!



CARES Foundation research, education and support for congenital adrenal hyperplasia

What is CARES Foundation?

What is Congenital Adrenal Hyperplasia?

CARES Foundation is a 501(c)3 nonprofit organization that leads in the effort to improve the lives of Congenital Adrenal Hyperplasia (CAH) patients, and seeks to advance quality health care through support, advocacy, education and research. They represent affected individuals, families, and health care professionals in all 50 states and more than 70 nations.

They are the only U.S. Organization solely dedicated to the CAH community. Your contribution will help us continue to offer programs and services to CAH and other Adrenal Insufficiency patients, as well as the medical community. Some of these programs include:

- Comprehensive Care Centers for CAH
- Research grants and participant recruiting for qualifying researchers studying treatments and searching for a cure
- Advocacy for life-saving EMS response for adrenal insufficiency and other important issues facing the CAH community
- Support for affected individuals and their families

Congenital Adrenal Hyperplasia (CAH) is a family of genetic disorders affecting the adrenal glands. Over 90% of those diagnosed with CAH are affected by the 21-hydroxylase deficiency. Inherited in severe, moderate and mild forms, the major types of CAH are Classical CAH and Non-Classical CAH.

Classical CAH is the severe form of CAH that can result in life-threatening imbalances in salt and hormone levels. If undetected at birth, it can lead to adrenal crisis and death. Frequently, newborn babies show no outward signs of the disorder and they are sent home only to present a few weeks later for urgent medical attention. Classical CAH also is the most common cause of urogenital birth defects in affected females due to the overproduction of testosterone. The adrenal glands of those with CAH make little or no cortisol. The lack of production of cortisol causes the overproduction of testosterone. Cortisol is a stress hormone and must be available to the body during times of injury, illness or other stressors on the body. CAH patients must increase their steroid medications during these times of stress or illness because the body is unable to make sufficient cortisol.

Non-Classical CAH is the mild form of CAH. It may cause symptoms at anytime from infancy through adulthood. Common symptoms include premature development of body hair, rapid growth spurt but ultimately short stature as adult, early puberty, severe acne, mood swings, migraines, and infertility.

For more information, please visit <u>www.caresfoundation.org</u> or call their office at (908) 364-0272 or (866) 227-3737