



# Complex Child E-Magazine

[www.ComplexChild.com](http://www.ComplexChild.com)

## Temperature Instability: Isaac's Story by Tiffany Acuff

Our son Isaac turned 27 months old this last week and what a roller coaster of a ride he's been on! When we informed his neurologist of one simple fact, that his central sleep apnea is far more exaggerated when his body temperature is higher than 98 degrees Fahrenheit, we entered both the world of temperature instability and a possible mitochondrial disorder.



The relationship between his temperature and apnea initially puzzled our neurologist, because until this piece of information came sneaking up on us, temperature instability had not even been an issue. A grand experiment began! Every time we changed his diaper, planned an outing, or came back from an outing, we were to check his temperature to see if we noticed a trend. Guess what? We did.

Copyright 2008 by Complex Child E-Magazine. All Rights Reserved. This document may be distributed for educational use only with proper citation.

Upon waking in the morning, Isaac had a normal temperature in the 97s and 98s. As long as he was pretty inactive, sitting still or just walking, his temperature would remain close to 98 or 99. However, at the slightest exertion of energy, his body temperature would soar to 100-102. Fevers developed from things as simple as eating a large meal, running around the house, going down a slide once or twice, or even just driving his trucks on our balcony.

The only surefire way to get his temperature back down to some sort of normal is to make him sleep or sit completely still for at least three to four hours, and even then it is still in the high 99s and low 100s. Obviously, this is next to impossible with an active two-year-old. Our other magic trick for bringing his temperature down is to let him go swimming or play in the bathtub for at least 30-45 minutes. This seems to help tremendously.

What does this mean for our lives? Let me tell you.

Even in the spring, when the temperatures in Michigan are in the 60s, we have to monitor his activity level and try to keep him as hydrated as possible. He appears fine as long as he is active, but as soon as he tires out or we have brought him in, he is cranky and very difficult. As mentioned earlier, his apnea also increases dramatically when his temperature rises. He often refuses anything to drink or eat when he is feverish, which is also an issue. He does not sweat unless he has a hat on, and even then he only sweats where the rim on the hat touches his head.

I have been paying attention to other parents talking about temperature issues, and think a cooling vest is a great idea and one we will probably look into come the spring. I also try and minimize his time outside, although it doesn't seem to matter what his surroundings are since he overheats during any kind of exertion.

In the grand scheme of things, we try to let him enjoy life with his friends as much as possible. He doesn't see them too often, unfortunately, since we tend to keep him indoors and reasonably calm. We are hopeful to have some answers soon as to what causes this and if there is a solution. He does seem to do a little better with certain vitamins, although the neurological side effects of these are a bear.

Temperature instability and heat intolerance seem to be a pretty big deal for mito families, as well as families of other special needs kids. I love that we are able to learn from one another's experiences and in the grand scheme of things we are able to help each other's children enjoy life as kids!

*My name is Tiffany Acuff. I am married to a wonderful man, Zeb, and am the doting mother of Isaac (and little brother to come!). We have been on an interesting journey with Isaac since he was about two weeks old and put on an apnea monitor. He has never been without a small contingent of specialists until this year when they gave up trying to figure out his quirks. Fortunately, his neurologist continues to seek whatever help for*

*Isaac we can reasonably get with minimal risk to him. That being said, we are on a journey to either confirm or rule out mitochondrial disease as the source of his issues, as none of them seem to correlate. We live in Southeast Michigan and love it here! We have an amazing church family, who cares for each other like none I have ever seen. God has been faithful to put air in our son's lungs each day, and we pray every night that we get one more!*