



Meet Chase



I am the mother of six wonderful little boys, one whom passed away May 1, 2008 due to mitochondrial disease. Two of my five remaining children also have mitochondrial disease. Shane, age 6, is healthy at the present time and Chase, 14 months old, whose health is failing very quickly. Mitochondrial disease is a multi-system neuro-metabolic disease. It can affect multiple organs and cause numerous health conditions as a result of mitochondrial failure. This disease is just one of the many that cause life-shortening and complex care needs in children.

Chase and his twin brother Trevor were born January 1, 2009, and by October 2009, Chase had spent nearly 167 days in and out of the hospital. Chase's medical team believed he would not survive past Christmas 2009, but my husband Kevin and I disagreed with this, and felt that a different approach was needed. We knew that while there was no cure for mitochondrial disease, living in a hospital away from his family did not give him the quality of life he deserved to have. This is when Connor's House took an active role in our life. Because comfort and quality of life was, and is, our main priority for Chase, Connor's House provided us with the resources we needed to connect us with a Palliative Care team to benefit our entire family.

Connor's House spoke with us and helped us stop and think about what we really wanted for Chase regarding certain medical procedures. They helped us think "outside" the box in terms of, "would this improve his quality of life or cause him pain and just prolong his life".

Connor's House also helped us learn how to navigate the medical system more efficiently. Chase's hospital admissions are generally very difficult. There are many doctors with different specialties, and all with different ideas. It can be very challenging when my husband and I, who are Chase's primary caregivers and an active part of our son's medical team, are not included in discussions, are not made aware of changes, or are not part of decisions made about our son's care. Connor's House is there to listen about our frustrations, fears and anger so we can maintain a certain level of composure while handling his admission and maintain a more positive relationship with the medical staff caring for Chase. They also help us find ways to advocate for Chase in a difficult setting.

Chase has three continuous IV medications that run 24hrs a day 7 days a week. These run through a central IV in his chest. Chase has a gastrostomy tube for draining his stomach, he has a tracheotomy and is ventilator and oxygen dependent 24 hours a day. Chase has a lot of medical equipment, and Connor's House has helped us find the right equipment and supplies to help Chase live a more typical, comfortable life even with tubes and machines. We can talk through issues and come up with ideas to better manage Chase's needs, deal with new symptoms, or help with medication problems. We have Connor's House to "bounce" ideas off of and brainstorm together as a team with the doctors.



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Due to many issues, Chase is developmentally delayed and functions around the age of a 3-4 month old. Early intervention for occupational therapy and cognition is very important. Unfortunately, at this time due to the lack of therapists in the area there are no therapists available to provide services for Chase. Connor's House helped by giving me some names of outside agencies to call but again no therapist was available at this time so I had to make a difficult decision. Connor's House gave me the support and confidence to be Chase's temporary therapist and proceed with therapy by doing it on my own. They provided contacts for toys, equipment, and realistic therapy goals while he is on the waiting list.

Connor's House works with us to figure out the best way to work within the systems in place. For example they suggested things to help make things work better such as: once a week "check-in calls" to our Palliative Care Team, protocols for specific symptoms so everyone involved in Chase's care knows how to handle a certain situation regardless of personal opinion, calling team meetings to discuss things when Chase's status changes or my husband and I are uncomfortable with what is going on. They helped us, along with our hospice agency and palliative care team, to talk through end of life options and develop a care plan so when the time comes we can be prepared and allow Chase to be as pain-free and comfortable as possible.

It never stops there. Although Connor's House was not here when our son Ryan passed away in 2008, they still help my husband and I through the grief process. Just to be able to connect with someone whose had the same experience. To talk about our children who have passed away is of great comfort. We share our happy memories, and our sadness, we laugh and cry. Connor's House has opened the lines of communication to make sure our other children are handling life ok. It is not easy to live life with sick siblings. They have helped with ideas for activities for all the children to do so we have some great memories with Chase for years to come. I have even received help with Shane and his special education IEP at school. Making sure he is receiving everything he needs from his school.



For our family it is so important for our son to be home regardless of his medical status. We want him to enjoy his short time here being a child, playing with his brothers, dogs and us, creating memories. In order to do that, a large support system is vital. A support system that goes beyond the doctors and nurses. Connor's House is that support system.

Danielle (Danni)

Editor's note: Chase passed away in July 2010, at 18 months of age, from mitochondrial disease. During the first 10 months of his life, Chase spent 208 days in the hospital. As a result of the palliative care plan put into place by Connor's House, St. Christopher's Hospital for Children and Vitas, over the last 8 months of his life Chase spent only 16 days in the hospital. Connor's House currently offers family support services including peer support, resource referrals, advocacy training and sibling support. Once the house is completed we will also offer short break respite care and community based alternatives for end of life care. Please help us attain these goals by donating at www.mysimplegive.com/connorshouse. To learn more about Connor's House visit us at www.connorshouse.org.