

A group of doctors and scientists at MassGeneral Hospital *for* Children and Children's Hospital Boston are working together to identify genes that cause Congenital Diaphragmatic Hernia (CDH) and abnormal lung development.

PROJECT UPDATE

From Drs. Patricia Donahoe, Program Project Director and Principal Investigator, MassGeneral Hospital *for* Children and Jay Wilson, Principal Investigator, Children's Hospital Boston

Although doctors and researchers have long suspected that CDH would have genetic causes, only recently have we been able to apply new highly sophisticated technologies that can examine the genetic patterns in all of a person's DNA. The funding to do this cutting-edge work comes from the National Institutes of Child Health and Human Development (NICHD) grant, "Gene Mutations and Rescue in Human Congenital Diaphragmatic Hernia," that was recently renewed (2006-2011). In addition, we have also been recently funded (2007-2008) by the Broad Institute for Genetics and Genomics, a Harvard Medical School and Massachusetts Institute of Technology collaboration.

Let us first update you about "you", the remarkable individuals who make our study possible. We have enrolled 330 CDH patients and carefully collected information about them. We have established "immortal" cell lines on 538 patients and families from which DNA can be extracted & used for genetic studies. CDH patients from the two Boston centers and from around the world are steadily continuing to add to these numbers.

In Issues 1 and 2 of *CDH News*, we reported several important findings from using new genetic technologies. We identified the gene responsible for a rare syndrome associated

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with CDH (Donnai-Barrow syndrome due to a mutation in a gene called "megalin") and also reported on the importance of a pathway involving the gene "Fog2" working with our colleague Dr Kate Ackerman. These discoveries prompted us to look at megalin, Fog2, and related genes, in all our CDH patients. Although this effort, called "resequencing", is prohibitively expensive, additional funding from the Broad Institute is supporting this work which is currently underway.

The NICHD grant and the Children's Hospital Boston (CHB) Surgical Foundation are supporting another exciting project which uses the new technology, Comparative Genomic Hybridization (CGH). CGH can pick up tiny bits of missing or extra DNA that cannot be detected by a standard chromosome study. Fifty children with CDH associated with major congenital anomalies are currently undergoing this analysis (at the cost of \$1,000/patient). Results so far show a few new genetic changes in children with CDH (not carried by either parent) and suggest new genetic regions not previously known to be associated with CDH.

Details about the exciting work in the CHB laboratory of Dr. Dario Fauza (who is creating a diaphragm patch from a baby's own cells) will be highlighted in the next newsletter, Until then, we continue to thank you, the patients with CDH and their families for your faith that findings from genetic studies and application of these new technologies will ultimately help children with CDH.

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CONGENITAL DIAPHRAGMATIC HERNIA AWARENESS DAY™

MARCH 31, 2008

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Breath of Hope, a CDH parent support network, initiated an important campaign leading to March 31, 2008 being proclaimed as Congenital Diaphragmatic Hernia Awareness Day by many states and even one country. People were encouraged to wear turquoise to raise awareness of CDH. The ultimate goal is heightened national awareness of CDH to stimulate and encourage further research about the causes of CDH and gain knowledge about treatments.

As of March 15, 2008, twenty-five states had proclaimed the day as CDH Awareness Day. These states included:

Alabama	Louisiana	Nevada
Connecticut	Maine	New Hampshire
Georgia	Maryland	Oklahoma
Illinois	Massachusetts	Ohio
Indiana	Michigan	Pennsylvania
Iowa	Mississippi	Rhode Island
Kansas	Missouri	South Carolina
Kentucky	Nebraska	Tennessee
		Wisconsin

The entire country of Mexico also proclaimed the day for CDH Awareness!

Since proclamations need to be renewed annually, efforts are ongoing to re-enlist the states from 2008 as well as add more states for next year. If your state isn't listed and you would like to send a letter to your mayor or governor, please contact cdhawareness@breathofhopeinc.com for a sample letter.

Please provide us with feedback on the current issue of the newsletter. Tell us what you would like to see in future issues of the newsletter. Share your ideas by emailing anne.furey@childrens.harvard.edu or calling 617-355-2555. Please let us know if you would like to be taken off our mailing list and NOT receive any future issues of *CDH News*.

RESEARCH UPDATE FOR CDH STUDY GROUP

A baby newly diagnosed with CDH prompts many urgent questions that are directed to the pediatric surgeon. Every family asks questions like “Should the baby be delivered by cesarean section?” and “Can you predict how will my baby do?” These questions remain difficult to answer because of many different factors. For example, all diaphragmatic hernias are not alike (both in terms of the location of the defect in the diaphragm and the degree of associated lung hypoplasia). Likewise, some babies have additional birth defects above and beyond CDH, whereas others do not. Finally, it is difficult for doctors to carry out rigorous studies to answer these questions, because too few CDH babies are delivered at, or cared for, at any one hospital.

The Congenital Diaphragmatic Hernia Study Group, co-led by Dr. Jay Wilson (Children’s Hospital Boston), was formed in 1995 to address key questions pertaining to CDH. Enough data are now available to start answering some of these difficult questions.

The Study Group has collected information on over 3000 liveborn babies delivering between 1995 - 2004 at 51 medical centers from around the world. Most of the medical centers are located in the United States, and all the centers have special expertise providing care for CDH babies. Almost 20% of the babies were **not** offered surgery either because they had additional birth defects or such poor lung function they probably would not have survived surgery; all these infants died.

Among the 2500 babies who were offered surgery to repair their CDH, an overall high survival rate of 83% was noted. Further study of this group found that the size of the diaphragm defect was one of the most important predictors of survival. Babies with: 1) larger defects requiring a patch repair (as opposed to those

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with a smaller defect not needing a patch, a so-called primary repair) and 2) babies with agenesis (defined as virtually no diaphragm tissue) were far more likely not to survive. On the other hand, survival was equally good in cases with left- or right-sided CDH.

In terms of method of delivery, overall outcome was about the same among full-term CDH babies whether they were born by vaginal delivery or by cesarean section. Those delivered by elective cesarian section who did not receive ECMO had the highest survival rate, but further studies are needed to sort out whether cesarian section contributes to the better outcome or whether the babies delivered by cesarian section happened to be healthier babies and might have done well no matter how they were delivered.

Findings from **The Congenital Diaphragmatic Hernia Study Group** about size of the diaphragm defect (in all likelihood correlating with the amount of pulmonary hypoplasia) and the method of delivery are important. In addition to providing information about best care practices for babies with CDH, they also illuminate new questions that need to be answered either in the Clinic or in the laboratory that hopefully will lead to better outcomes for all babies with CDH.

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FEEDING IN CHILDREN WITH CDH: WHAT TO EXPECT

Anne Furey, MPH; Kristen Leavitt, RD LDN;
Barbara Pober, MD, MPH; Jay Wilson, MD

Children with CDH often experience feeding difficulties that can continue into early childhood. Early on, poor feeding may cause substantial growth problems but fortunately, children with CDH usually catch up to their peers, sometimes with help from feeding devices or surgeries. Following is an overview of the growth and feeding issues faced by many children with CDH. Be sure to read the tips at the end of this article about how you can help maximize your child's eating and subsequent growth.

Growth Problems

As most of you already know, infants and children are supposed to grow along a well-established trajectory (or line) and pediatricians monitor this by plotting height and weight on standard growth curves. Use of these curves can show if a child is not growing as expected. Medical professionals describe this using different terms such as growth failure, growth retardation or failure-to-thrive and while their exact definitions may differ, the common theme is either "falling off" a standardized growth curve or having weight for height below the 25th or 5th percentile. We will use "growth problems" as a summary term in this article.

Growth problems in CDH patients can be considerable. In one study, more than half of all CDH patients measured under the 25th percentile for height and weight throughout the first year of life (1). Children treated with ECMO grow even more slowly than those who did not require ECMO (2). (See Newsletter II for a description of ECMO).

Combining information from several sources, it is clear that growth problems in children with CDH are related, at least in part, to gastroesophageal reflux (GER) and to oral aversion (3).

Feeding Tubes

To increase the calories a child takes in each day to help them grow, many children require the use of one of several types of feeding tubes. While in the hospital, babies who need a respirator machine to help them breathe may be fed through a Nasogastric Tube (NG Tube), a tiny tube inserted in the baby's nose and then into the stomach. Sometimes a Nasojejun tube (NJ Tube) is used which continues from the stomach into the small intestines. For some children who continue to have slow growth, a gastrostomy tube (g-tube) is required; this is a tube which is surgically inserted into the stomach. Food generally in the form of formulas or special calorie-fortified formulas can be placed directly into the stomach via the g-tube to supplement whatever food the child takes by mouth. It can be hard to decide whether or not to insert a g-tube since there are competing needs of increasing calories for growth versus minimizing oral aversion and reluctance to eat (3), but as many as one-third of CDH patients showing growth problems end up with a g-tube for adequate calories (1). Most children no longer depend on their g-tube by mid-to-late childhood.

Gastroesophageal Reflux (GER)

One common contributor to poor feeding in children with CDH is gastroesophageal reflux (GER). This refers to the abnormal movement of acids and fluids from the stomach back up into the esophagus, the body's pipe connecting the mouth to the stomach (see **Diagram**). GER can lead to feeding or lung problems, heartburn or vomiting.

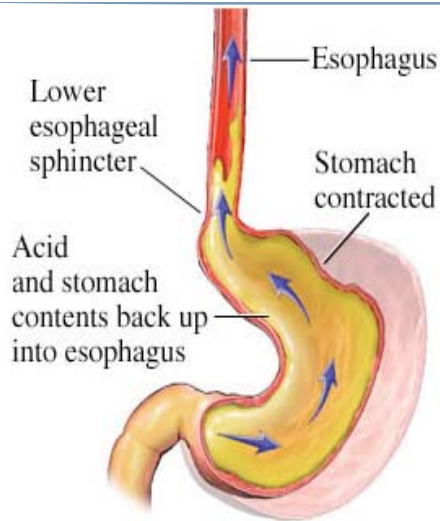


Diagram courtesy of living with reflux.org

It is hard to pinpoint how often GER occurs among children with CDH. Combining data from over two dozen studies, GER is diagnosed in approximately 25%-50% of individuals with CDH. Part of the difficulty in knowing the precise frequency of GER is due to the fact that GER can be diagnosed in different ways; furthermore, the results from these different ways do not always provide the same information about the presence or absence of reflux (3-5). One way to diagnose GER is with a pH probe which analyzes how frequently acid from the stomach gets into and stays in the esophagus (6). Another way to diagnose GER is to perform an upper gastrointestinal contrast study. This type of study follows the movement of contrast through the esophagus, stomach and small intestine on a video screen (7). Yet another test is called an endoscopy by which the interior lining of the esophagus, stomach, and small intestine is seen through a thin and flexible viewing instrument called an endoscope (8). Finally, in some cases, a patient is considered to have GER simply because of certain symptoms (such as vomiting, regurgitation of food, or evidence of heartburn) without performing any of the tests described above.

Treatment options for GER most often consist of medication to block acid and a surgical procedure known as a Nissen fundoplication. This surgery, which involves wrapping a part of the upper stomach around the lower

esophagus to strengthen the natural sphincter (valve) between the stomach and esophagus, prevents the flow of acids from the stomach back into the esophagus.

Oral Aversion

Oral aversion, or the reluctance to eat, is another factor contributing to growth problems that can continue beyond the first years of life (1,3). A quarter of children with CDH have severe oral aversion (1,3). While the reasons for oral aversion are not fully understood, more severe oral aversion is associated with longer time on a respirator and longer use of oxygen at-home (1). Children with oral aversion can benefit from oromotor therapy (provided by an occupational therapist, speech therapist or a feeding team). Oral aversion can last at least through the first few years of life.

Long-term Follow-up

Long-term follow-up studies of feeding issues are few, focus mostly on GER, and study only a small number of patients. One study found GER in 20% of adults with diaphragm abnormalities versus 2% of healthy adults in the general population (9). Although GER was more common in the CDH group, a minority felt that GI problems had a major negative impact on their quality of life. Another small study found that 20-40% of young adults, successfully repaired for CDH, had GER (10). Although this seemed high, it was lower than the 33-58% frequency of GER in children who were repaired for CDH, indicating that GER becomes less frequent over time. This study also showed that "dys-motility" (poorly coordinated movement of food and liquid from the stomach into the intestines) was common in both children and adults

who've undergone CDH repair. Although the frequency and symptoms may lessen over time, individuals with CDH should be monitored and treated for GER as needed throughout their lifetime.

Tips to Help Your Child Grow

Ideas to help your child increase calories:

- Eat small frequent meals throughout the day.
- Try 5-6 meals/snacks per day.
- Keep snacks handy. People eat more when food is available.
- Try eating a snack before bedtime.
- Drink high calorie drinks, e.g chocolate milk, whole milk, shakes/frappes, full fat soy milk, pediasure.
- Notice the time of day when your appetite is best. Eat more at that time.

Here are some snack ideas

- English muffin or bagel with melted cheese or cream cheese.
- Cheese, meat, poultry, or tuna sandwich (add mayonnaise, butter or margarine).
- Bowl of cereal with milk, cream and sugar.
- Yogurt with granola cereal and fruit. Try whole milk yogurt.
- Granola bar with peanut butter.
- Banana or apple dipped in yogurt or spread with peanut butter.
- Milk shake/frappe.
- Cold vegetables with salad dressing or cottage cheese.
- Hot muffin, spread with butter or cream cheese.
- Slice of pizza.
- Full fat ice cream. Try toppings.
- Crackers with cheese, peanut butter or hummus.

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List of Useful CDH Websites & Support Groups

The Association of Congenital Diaphragmatic Research, Advocacy and Support (CHERUBS) (a support group for families of children with CDH):

<http://www.cherubs-cdh.org>

CHERUBS Australia: <http://au.geocities.com/ozcherubs/>

CHERUBS United Kingdom: <http://www.uk-cherubs.org.uk/>

Yahoo Listserv for CDH Families:

<http://health.groups.yahoo.com/group/BreathofHope/>

SHARE Pregnancy and Infant Loss Support, Inc. (early pregnancy loss, stillbirth, or infant death support):

<http://www.nationalshareoffice.com/>

The Compassionate Friends (non-profit organization providing resources and support for grief resolution):

<http://www.compassionatefriends.com/>

MUMS National Parent to Parent Network:

<http://www.netnet.net/mums>

The International Birth Defects Information Systems website:

<http://ibis-birthdefects.org/start/diaphern.htm>

The Parker Reese Foundation:

<http://www.theparkerreesefoundation.com/>

PARENTS' CORNER

In the second issue of CDH News, we unveiled the Parents' Corner, a section dedicated to stories written by parents about their experiences having a child with CDH. Thank you to Nancy and Rick Bryant as well as Anne and Scott Shannon for sharing your stories which appear in this issue! Parents interested in submitting a story are welcome to contact us at anne.furey@childrens.harvard.edu.

PATRICK BRYANT'S STORY

BY NANCY & RICK BRYANT



We were very excited when we found out we were expecting our first child. Everything was going pretty smoothly and we had a relatively uneventful pregnancy. On September 21, 2001, our fifth wedding anniversary, I had a routine obstetrical appointment. Imagine our surprise when we were told that I was well into labor and 5 cm dilated! We rushed home for our bags and headed for the hospital.

We checked in about 11:00 AM. I asked for and

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received my epidural. Shortly thereafter, my water was broken, and I was given pitocin to help things along. About 3:00 PM the pain started to kick in, and I soon felt the urge to push. After 54 minutes of pushing, our angel was born at 5:13 PM. Our baby was a boy. He weighed 8 lbs, 9 oz, and was 21 inches long.

As soon as he was born, we knew something was wrong. He was placed on my belly for my husband to cut the cord, but then instead of leaving him with us to cuddle, he was immediately taken over to a bed in the corner of the room where nurses huddled by. He didn't cry, and when he would try to breathe, his whole little belly would cave in. His Apgar scores were low. We later learned that he was being bagged right there in the delivery room so that he did not try to breathe on his own. A doctor was conveniently blocking my line of sight, but my husband later told me he thought CPR was being done.

The neonatology team took our baby to the nursery before my obstetrician was done with me. We kept asking if our baby was OK, and everyone kept telling us he was fine, but we knew deep down that something was wrong. We wanted to believe the doctors, but there was a part of us that just knew.

The obstetrical team finished with me and started to move me to the maternity ward. We were told "someone from the nursery needs to come and talk to you." We thought he was dead. A nurse came in and gently explained that our baby had something called a Congenital Diaphragmatic Hernia (CDH). He had to be intubated because the more he breathed, the more damage he could do. He would be life-flighted to Children's

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Hospital in Pittsburgh. A helicopter was called. We could see our baby before he was taken. They wanted us to name him, but crazy me, I wanted to see him first. Throughout his entire hospital stay, all his tags said "Unknown Bryant" because of that!

He was hooked up to the machine, and we were brought in to say hello and goodbye to our newborn son. He was lying there, motionless, seemingly asleep. We got to touch his little hand, but he could not squeeze back. Saying goodbye to him was the hardest thing we have ever had to do. We didn't know whether we would see him alive again. We named our lovely son Patrick Neil, and sent him in the care of the kind transport team. I even remember telling the pilot to Fly Safely with our little guy. He must have thought I was crazy! The next day we headed for Pittsburgh.

The neonatology doctors try so hard to prepare you for what you are going to see when you go into the NICU, but nothing can prepare you for the sight of your child hooked up to all of those tubes and wires. You are told all the things that can go wrong and the potential consequences. Mind you, you have no choice but to proceed with surgery. It was mind-numbing to hear it all at once, while still trying to comprehend that your SON is under all those tubes and wires.

Patrick's stats had to stabilize before surgery could be done. The plan was to operate on Monday, but the doctors didn't like the look of the pressure in his lungs (pulmonary hypertension). So, surgery was planned for Wednesday. Well, on Tuesday, he looked so good and stable that our surgeon, who was off that day, came in and performed the surgery at 5 PM. Surgery was done right there



The Bryant Family L-R: Nancy, Stephen, Meredith, Rick and Patrick

in the NICU because of concern that Patrick would destabilize if he was moved. Just past 7 PM, our surgeon came out to tell us the surgery had been a success. The hole was small enough to repair without needing a patch. His small intestines, spleen, and part of his large intestines were in the chest cavity. Fortunately, his abdomen was large enough to hold all of them, so everything was repositioned, the hole was closed, and the healing could begin. But now the hard part would start.

For days the neonatologists and nursing staff worked on getting the respirator settings down. Patrick was slowly allowed to wake up enough to take some breaths, but there was concern because he was breathing at a fast rate. One day he tried to pull out his ventilator tube, so he was taken off the machine, but he wasn't quite ready and had to be reintubated. Two days later, Patrick was taken off the ventilator for good. Due to worry about how Patrick's digestive system would process food through his stomach, as all of those organs were out of his body during the surgery, IV feeds were very slowly turned down and the amount in the feeding tube increased. A feeding tube was used because he couldn't tolerate oral feeds since his breathing rate was so high and he might end up aspirating milk into his lungs. Finally, he was allowed to start bottle-feeding. I had been pumping and pumping, so he was started on my milk. He took to the bottle really

SHANE SHANNON'S "MAYBE SOMEDAY" MOMENT

BY ANNE & SCOTT SHANNON



Every CDH parent, caregiver, or relative has done it, said it and has tried to stop themselves from thinking it. That is looking at another "normal" child doing something rather ordinary and finding ourselves thinking, hoping and praying "MAYBE SOMEDAY." "MAYBE SOMEDAY" our child will be able to do what this child is doing, "MAYBE SOMEDAY." We recently had one of those moments. It is remarkable to be a part of and witness the special moments of a child who had CDH.

Our son Shane, now 5 years old, was diagnosed prenatally with a left sided Congenital Diaphragmatic Hernia. The day after he was born he had a gortex patch repair, and at 7 weeks he had fundoplication surgery and a G-tube placed. Shane was in the ICU on a

well, and after a few days, we were allowed to start nursing. He was soon eating really well and gaining weight. As long as he continued to gain weight, we could finally think about going home.

Finally, on October 15, 2001, Patrick was able to come home from the hospital. Of course, we also brought home lots of equipment - monitors and oxygen tanks. He also came home on two reflux medications. But, Patrick continued to improve at a fantastic rate. He was off the monitors by Thanksgiving, and off the medications soon after. We were housebound for that first winter, though, with instructions to stay away from crowds and children, and he had a Synagis shot every month for RSV protection.

Patrick is a happy little boy who continues to grow well. He is six years old now, and started Kindergarten this year. He likes to play soccer, go to the pool, and play board and card games. He especially loves his Thomas trains. He can build tracks that amaze us with their intricacy.

Patrick does continue to struggle somewhat with some lingering issues. When he was three years old, he was diagnosed with something called PDD-NOS. It is on the Autism Spectrum, but he functions on the high end. He has home-based therapy, and attends an evening socialization program 2 days a week. His progress has been tremendous and we are very proud of him.

To see Patrick now, you would never know that he had these problems. To us, he will always be a miracle. We continue to monitor his development to be sure we are doing all we can to give him the tools he needs to be successful in life.

We know it is the love and prayers of our family and friends, and the skill and talent of the doctors at Children's Hospital in Pittsburgh, that have allowed Patrick to be with us today. We will never forget the support we received, and continue to receive, from so many different places. We are so blessed in so many ways. Our thanks go out to all of you. ■

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respirator to help him breath for 6 weeks, close to ECMO twice, and has had a total of 10 hospital stays. Shane has struggled with a litany of issues including reflux, severe gagging/retching for two and a half years, sporadic oxygen use for two years, oral aversion, fine and gross motor skill delays, speech and feeding delays, cognitive delays, sensory issues, and pulmonary issues. We have had Shane in all different programs and therapies including OT, PT, Feeding Group, Speech Therapy, Behavioral Therapy, and Nutritional Therapy.

We live in a town outside of Boston where almost every summer on Wednesday night there is a free outdoor concert at a town-owned estate. Each week a different type of music is presented and it is always a nice way to spend a summer evening. There is a big field where people set up blankets and lawn chairs, the ladies auxiliary sells hot dogs, lemon-aid, and home-made strawberry short-cake. There is plenty of room for kids to dance, run, play, roll down hills, yell and scream. It is a wonderful place where a family can slow-down, spend time together, and where a kid can be a kid in a Norman Rockwell sort of way.

Each year, these summer concerts at Endicott Estates have been our measuring stick for our "MAYBE SOMEDAY". Each year we would see all the kids running around with ear to ear grins having fun playing and being kids. All the time we would experience that heart-ache, thinking and wondering if these things that were so effortless for others would ever be possible for our beautiful Cherub.

The first year in 2003 when Shane was six months old we said "MAYBE SOMEDAY" Shane will be strong enough where we

can bring him to a concert. That year he was too frail to bring out on a hot night as he had recently been discharged from the hospital.

The second year in 2004 we hoped that Shane could go to a concert without oxygen and would not have issues with retching. Our hope was that Shane would crawl around on the grass and enjoy the new world he was starting to discover. This year thankfully Shane was strong enough to go to a few concerts, and some without being hooked up to oxygen. At the beginning of the summer, Shane did not like the feel of grass so he was happy staying on the blanket and watching the world. Then, at one concert, Shane darted off the blanket - a baby on a mission. He took off from the blanket and crawled passed two groups of people right up the leg of a woman who was about 20+ feet away from our blanket. Stunned, shocked, and not quite sure what had just happened, we ran over to Shane. Half-laughing we picked him up and apologized. The smiling woman said that it was OK and then asked how Shane was doing; this took Mom and Dad by surprise quite a bit. Her face was vaguely familiar, but not someone we could place. She explained that she works at Children's Hospital; it turned out she was one of Shane's ICU nurse coordinators. Everyone was in shock, all except Shane who was smiling at his found friend.

The third year in 2005 we hoped to be able to bring Shane, who was 2-½ years old, to the concerts, but he had a recent series of hospitalizations and we thought it best not to stress him with any late, hot nights. No concerts for Shane that summer, but we still hoped and prayed that "MAYBE SOMEDAY"

The fourth year Shane was completely off oxygen, had limited bouts with retching, and was even venturing into eating hot dogs. He was able to run around, but would only do so with one of his parents in tow. His speech delays made him uncomfortable around other kids, so he liked having one of his parents around to be his interpreter.

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with tears when they see their little one do something amazing, ours filled with the joy of knowing that “MAYBE SOMEDAY” was TODAY!

For each CDH parent our “MAYBE SOMEDAY” wishes are different, as different as is each CDH child. It is a long journey, one filled with twists, turns, setbacks and amazing advancements and victories. Shane has taught us many things during this 5 year journey. One of the most important lessons is to celebrate each victory because those are the building blocks to your “MAYBE SOMEDAY” wish. Keep focused, have faith in yourself and especially your child, and enjoy each victory no matter how small it may feel at the time. For you it might be a reduction in the ventilator setting, or elimination of another medication, or getting off oxygen for yet another time, or getting to leave the ICU and getting to the non-ICU floor for the first time, or having the first significant cold or illness without being hospitalized, or finding a food that your child will eat, or graduating from a therapy group, and the list goes on and on. As your child grows and changes so does your “MAYBE SOMEDAY” list. Piece by piece, miracle by miracle the foundation is being laid. Take pleasure and celebrate your child’s accomplishments. All of you have worked hard for each and every small step made, for these are huge steps for our little Cherubs.

We are eternally thankful to the dedicated team at Children’s Hospital Boston for making our “MAYBE SOMEDAY” moments into realities. If it were not for all of them, Shane would not be where he is today. ■

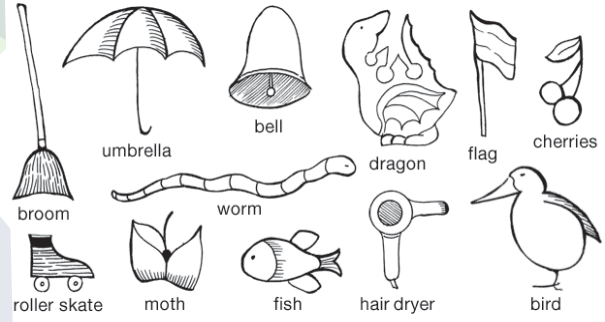
This past summer Shane was 4-½ years old and our fifth year of hoping “MAYBE SOMEDAY.” At the beginning of the year we were hoping Shane would venture off the blanket on his own, and that he might start playing with some of the other kids. He had been working on kicking a stationary ball, but was having difficulty with this and other gross motor skills. But, by mid-July, Shane actually ventured out on his own and what a time he had! He was running and playing with some kids he knew and some he didn’t. He wanted one of the free blow-up beach balls and he went over to the gentleman handing them out and asked politely if he could have one. Shane was thrilled he could finally say what he wanted, and someone understood him other than Mom or Dad!

For about 2 hours Shane played, ran around, danced to the music, cavorted with other kids, and rolled down the hill - G-tube and all!! He even ran down the hill kicking TWO beach balls all the time he was sporting an ear to ear grin that we had been hoping and praying that someday we might see as he played like every other kid there! All parents’ eyes fill

CDH NEWS

Kids Corner: Mr. Frog

In this big picture find the fish, moth, roller skate, worm, bell, flag, dragon, broom, umbrella, bird, cherries, and hair dryer.



Picture courtesy of www.HighlightsKids.com

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