CHERUBS

The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support

The Silver Lining

Spring 2001

CHERUBS
P.O. Box 1150
Creedmoor, NC 27522

Dear Members,

Usually this is the place where I write a short paragraph, stating all that's going on with CHERUBS since the last newsletter. This time, I want to talk about issues, some personal, but all about our cherubs. I thought long and hard before deciding to write this, afraid of insulting some of our members, worried about CHERUBS' reputation. But after thinking and soul-searching, I decided that this needs to be said, and if we lose a few members in order to save hundreds of lives, then so be it. I have written this as diplomatically as I possibly could, but please accept my apologies if this articles does offend you.

I want to start out confiding to you, my friends, the wonderful members of CHERUBS. You see, all these years I have told Shane's story but there were parts I left out, parts that I thought were better left unsaid because of possible judging and legal issues. But now, I need to tell you, in hopes that what my family went through will help others of you.

For the past 6 years, Jeremy and I have been involved in 2 medical malpractice suits. Yes, I said "medical malpractice"- read no further if that phrase terrifies you. Last week, our lawyers informed us that they couldn't find any medical professionals willing to testify for our suit and that with the statute of limitations running out in September, our case has no future. I hung up the phone crying, thankful for all the years our kind lawyers had invested in our case, for all their emotional and financial support of CHERUBS, but mostly crying because I felt so helpless in stopping 2 hospitals from hurting more babies. Money was never the issue-- any settlement that was filed before Shane died was going towards his medical bills; any settlement since we lost Shane was going to CHERUBS. It wasn't the money; it wasn't some sort of revenge to show the doctors they were wrong. It was bigger than our case, bigger than Shane. It was our chance to stop some injustices and to appeal as high as we could go until laws were changed and babies of the future could be saved. Hanging up that phone, I felt like I had failed Shane, had failed those families who had taken their children to see those same doctors and had come home to make funeral plans. I had failed all of you, and most importantly, I had failed our cherubs. But I realized there are other ways to correct these problems with our medical system and other ways to save our children.

By now you're probably asking, "What happened? Why were you suing, Dawn?" Well, I'll tell you our story, a story so familiar to so many of you. The first suit involves the hospital where I received pre-natal treatment. I had an ultrasound during the first trimester because of bleeding. I had had 2 miscarriages before Shane, but somehow Shane hung on. The ultrasound showed nothing abnormal and the bleeding stopped and the rest of the pregnancy was uneventful until the last trimester. As most of you have probably already read in Shane's story, I had premonitions that something was wrong- the same nightmare, every night, for 9 months. After begging and begging for another ultrasound, my doctor finally gave in when I was 8 months pregnant. The ultrasound was performed, and they said everything was OK but wouldn't give us any pictures until they gave in to my begging a few weeks later- only to give a picture of Shane's backside. An ultrasound at 8 months gestation on a baby who had virtually no left diaphragm, the majority of his abdominal organs in his chest, 2 heart murmurs, and a displaced heart, and they claimed they saw nothing. When we requested Shane's medical records a few years later, there it was in black and white on the technician's note- "Stomach missing." They knew something was wrong and never told us, never did more testing, never referred us to a specialist. If we had known, had time to research, we never would have allowed Shane to be treated at the facility that he was transferred to after birth, a hospital with an extremely low CDH survival rate. If we had known, Shane wouldn't have been subjected to the trauma of a transfer and wouldn't have been delivered at a hospital that didn't even have a pediatrician in the building because it was after 5:00 p.m.

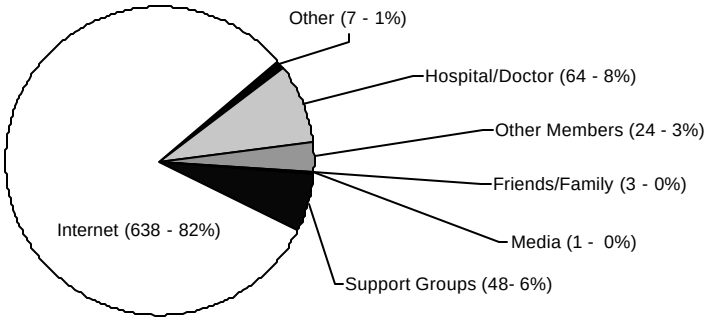
My point is, the doctors knew and did nothing. Maybe they thought they were protecting us from knowing our child would be sick; maybe they didn't do their research and learn that there was treatment for CDH, but they took away our rights to have the best medical care for our child. Our story is not rare-- over the years, I have heard dozens of stories from our members whose obstetricians did the same thing. And the stories of so many of you having ultrasounds just days before delivering and not having severe cases of CDH diagnosed. In a country that is supposed to be the leader in medical technology, medical technology is advancing, but our legal system is falling behind. In the United States, there are no laws governing that ultrasound technicians must be certified. How many of you had ultrasounds given by nurses, residents, and medical students with little or no training other than how to operate the machine? And in the United States, there are no laws governing that patients, and in our cases, parents, are given full disclosure of all medical information. We pay so much money for medical care, and yet we do not have the right to

trained medical professionals and all of our medical information. Thankfully, there are thousands of wonderful, trained, and caring obstetricians who are diagnosing CDH in utero, who are disclosing information to parents, and who are, in turn, giving our cherubs the best chance at life. I realize those of you who were diagnosed pre-natally must have gone through hell during the rest of your pregnancies, and I can't even begin to imagine what that is like, and I know you can't relate to my story and the stories of hundreds of other members who weren't diagnosed, but please read on.

The second lawsuit was against the hospital and surgeon who performed Shane's first 2 repairs. When Shane arrived at this hospital, he was doing so well he wasn't even intubated, amazing for a kid that had only 1 lung, but oxygen alone seemed to stabilize him enough for transfer, and he was wide awake, and his eyes were focused when they wheeled him in to say good-bye before he boarded the helicopter. By the next day, he was paralyzed on Pavulon and ventilated-- standard procedure to rest his lungs and truly stabilize before his repair. During the 3 days before his repair, the surgeons explained to us that gore-tex would be used but we never saw them the morning before Shane's surgery, and we were never even asked to sign a consent form. After 6 hours in surgery, the surgeon came out and told us that he had used part of Shane's lung sequestration to repair his diaphragm. The lung sequestration was the bottom portion of Shane's lung that hadn't fully formed or inflated and looked like a deflated balloon. He had an extra blood vessel going from his heart to this "squished" portion of lung, which was not removed during the repair and which caused congestive heart failure. This was an extremely experimental procedure, never documented in medical journals, never even tried on lab animals, and it just didn't even make common sense to use damaged tissue with no elasticity. Our consent for this procedure was never asked or given. For 4 months, Shane couldn't be stabilized. His blood gases were so out of whack that an ECMO machine was parked beside him for weeks, but it was never used. He endured pneumonia 4 times, dozens of blood infections, a tracheostomy, and by the time his 2nd repair was done, he had suffered severe brain damage leaving him blind and deaf and in the intensive care unit for a total of 10 months.

During this time, I searched for a support group, spent countless hours in the university library reading medical journals, learning and asking so many questions that the surgeons avoided me at all costs except when I demanded care conferences, and then they sent their residents if they could. If not for the time spent in the library, the amazing surgeon we took Shane to after we got him out of that hospital, the PICU staff, the wonderful nurses, some great residents, and other parents that had children in the hospital, I would have had no information on CDH or Shane's progress (or lack thereof). The bedside manner of the surgeon and his partner were so horrible that they even bet money on how long Shane would live, and we had to go in front of the ethics committee to prevent them from "unplugging" him and to finally get Shane home. This hospital is still experimenting on cherubs, and I know of 2 other cases where similar procedures (though not lung tissue) were done and both babies died. Medical research is needed and someone has to be the first to try something new, but our rights to decide whether or not our children should be that first person should not be taken away from us. Over the past 6 years, my lawyers have contacted dozens of pediatric surgeons, but my reputation as being that "crazy woman running CHERUBS and educating parents (gasp!)" has not helped. Many doctors said, "Yes, they screwed up, but I can't testify because I work with them, I work with you, the pediatric surgical community is close knit, etc." I've even been told that Shane's care was "standard CDH care." CHERUBS has the largest CDH database in the world, and I can tell you, that was not standard. It appears that once you sign an admission form, you are giving the hospital and the doctors cart blanche on your child. This shouldn't have happened-- not to my family, not to any family.

Yes, Shane's case is rare, thank God, but cases like his are still happening. This is by no means meant to retaliate against Shane's first surgeon and hospital (have you noticed I listed no names?), and this is by no means meant to insult all pediatric surgeons. Over the years, I have met hundreds of wonderful, caring, amazing surgeons who look at our children like children and not just patients. Pediatric surgeons who cry along with the parents, who take time out to attend birthday parties and funerals, who stay up all night to answer questions on e-mail and phone calls, who are so wonderful and dedicated that they give up much of their personal lives to be there when we need them. Many of you are thinking, "This didn't happen to my child; why does it concern me?" Because most of you encountered the same problem that I did-- lack of information, no referrals for a support group, no one to turn to who could answer your questions. How many of you didn't find CHERUBS until years later? How many of us stayed up until 3 a.m. searching the internet for information? How much difference would it have made in your child's care and outcome if you had that information and support? How much difference would it have made to your sanity if you knew that you weren't the only one going through all that CDH has put you and your family and your cherub through? Take a look below and see how our parent members are finding us. It is quite disturbing that only 8% of hospitals and doctors feel it necessary to give us access to the support and information that we need.



So what can we do? I have asked myself that question a thousand times since last week. Lawsuits are not the answer. Yes, they may stop a few hospitals and doctors from making mistakes, but what good will a lawsuit do if there are no laws to base them on? Lawsuits will not restore our children's health; they will not bring back our cherubs lost; they are not the answer. The answer is to change the law, to gather together and make a stand, to join in with the hundreds of other small groups like our own, to take the knowledge that we have learned, the friendships we have made, and the strength we have gained to make life better, and in many cases, make it possible, for future cherubs. We can roll around in the grief and self-pity of all that we have lost, all that life has cheated us of, or we can turn it around and honor our children and make a difference. We can change the laws, petition our senators and congressmen; we can stand on the front steps of the Capitol and demand better healthcare for not just our children, but every child born with a birth defect. What we are asking for is:

1. Standard Certification Of All Ultrasound Technicians
2. Disclosure Of All Diagnoses At The Time Of Diagnosis
3. Restructuring Of The Patient Protection Act Requiring Patient Permission For EVERY Experimental Procedure
4. Standard Referral To Local And/Or National Support Group At Time Of Diagnosis For All Diagnoses

By now you're probably saying, "Well Dawn, that sounds all patriotic and good, but I have a family; I have a life; and I don't have the time. And how can I make a difference? I'm just a mom from a small town who doesn't even know where to start on something like this." Well, I'm just a mom from a small town. I didn't have a clue what to do when I started CHERUBS, and one person can change the world if he/she tries hard enough. Now, don't think, "Oh, someone else will help." We have over 850 members in CHERUBS, including 785 families. Do you all know how many volunteers we have? 93. Do you know how many actually are volunteering? About ¼ . That means that approximately 23 of you are really digging in and helping, and we can't make a difference without ALL of you! How much time will it take to get 100 people to sign a petition? How much time will it take to sit down and look up your Senator and State Representative in the phone book and write a letter? A few hours out of our lives to honor our cherubs. A small inconvenience to try to save babies of the future. Now, you all have known me long enough and well enough to know that when I beg (yes, I am actually begging) for your help, that it is truly needed. CHERUBS doesn't beg for donations (but they are ALWAYS needed), we don't subject you to membership fees, we don't guilt you into volunteering, we don't demand your time, and we allow each member to be as involved or as uninvolved in CHERUBS as is convenient to you, but this time, we are begging.

Now, it's up to you. If each of you will write a letter, if each of you will get at least 100 signatures, we can have a wonderful start on getting 1 million signatures and finding a Congressman or Representative to sponsor our causes. If you are interested, you can contact me or you can visit our web site to download a petition form.

Dawn M. Torrence
President and Founder

New Arrivals

(*siblings of Cherubs)

Ashley Kaitlyn Abel
Kaitlyn Michelle Bradburn
Madison Faith Broward
Anneliese Mae Browning
Emily Nicole Clark
Trinity Faith Crump
Jaxon Eli Culwell
Nathan Andrew Dewberry
Joshua L.S. Eck
Jamison Lee Ellis
Ryan Williams Fox
Taylor Paige Gartman*
Daniel O. Gates
Joseph Michael Hales
Samantha D. Johnson
Joseph Mackenzie Kelley
Brandon Scott Kryk
Morgan Anne Lee
Chloe Christina Lewis*
Joshua Scott Low
Mallory Ellen Murphy*
Hannah Sarah Pieterse
Jared Kenneth Pongo
Joseph Isaiah Reed
Alexis Angelynn Riggs
Charles Ryan Roberts
Hayley Elizabeth Sum
Hannah Elizabeth Svoboda
Tegan James Walls
Emma Margaret West
Iakona Kaleikaumaka White-Fleming
Dyllan M. Wiggington
Michael Tyler Wolfe
Dorothy Sariah Woods

We Would Like To Thank The Following People For Their Gracious Help:

Bill Beaudett
Matt Daniels
Faith Evangelical Methodist Church
Glory Road Internet Services
Danielle Kessner
Cynthia Powell, MD
Christy Stevenson
Rev. and Mrs. Howard Torrence
Jeremy Torrence
Barbara Wagner
Jay M. Wilson, MD

This Newsletter Is Dedicated To the Memories of:

Kaitlyn Michelle Bradburn
Madison Faith Broward
Anneliese Mae Browning
Starr Castronova
Emily Nicole Clark
Kelsey Brooke Cunningham
Nathan Andrew Dewberry
Mikayla Marie Duscher
Jamison Lee Ellis
Ryan Williams Fox
Christopher L. Gaff
Daniel O. Gates
Rori Dyan Guerrero
Joseph Michael Hales
Lucas Danial Huether
Brandon Scott Kryk
John W. Livingston
Jack M. Moriarty
Brandon James Meulebroeck
Jared Kenneth Pongo
Alexis Angelynn Riggs
Charles Ryan Roberts
Hope Natasha Scott
Kolton Grayson Seibert
Hayley Elizabeth Sum
Hannah Elizabeth Svoboda
James Garry Townsend
Tegan James Walls
Emma Margaret West
Kimberly White-Perez*
Michael Tyler Wolfe
Dorothy Sariah Woods

We Would Like To Welcome The Families Of The Following New Members:

Ashley Kaitlyn Abel
Mitchel Abraham
Jacob Rodger Amlin
Kaya Taylor Azzopardi
Lacey Alyson Baugh
William Gerald Bock
Ricky James Brock
Madison Faith Broward
Anneliese Mae Browning
Logan Devyn Carty
Starr Castronova
Baby Cheney
Emily Nicole Clark
Peter Compa
Darrien Jeffrey Cook
Kelsey Brooke Cunningham
Maria Jean Dahl
Joseph M. Domizio
Kellien Doody
Baby D'Ulisse
Mikayla Marie Duscher
Joshua L.S. Eck
Jamison Lee Ellis
Sofia Louise Fiorillo
Clinton W. Foster
Ryan Williams Fox
Christopher L. Gaff
Emma Gallagher
Daniel O. Gates
Rori Dyan Guerrero
Joseph Michael Hales
Daniel James Haughian
Bethany Michelle Jenkins
Kyle Benjamin Jenkins
Samantha D. Johnson
Michael Monroe Davis Jones
Cody Walker Keeton
Joseph Mackenzie Kelley
Caroline E. King
Brandon Scott Kryk
Christine Gloria Kutka
Steve Larkin
Morgan Anne Lee
John W. Livingston
Kerryn Noelle MacBride
Brandon James Meulebroeck
Chloe Maree Lysaght
Sandra Anne McCune
Ryder D. G. Moorhead
Jack M. Moriarty
Baby Morrell
Paul Leslie Noble
Baby Palamarczuk
Caleb Partin
Daniel Patrick James Pearson
Baby Penney
Hannah Sarah Pieterse
Jared Kenneth Pongo
Samantha Paige Porter
Riley R. Purcell, Jr.
Joseph Isaiah Reed
Ryan J. Richard
Charles Ryan Roberts
Jacova B. Rogers
Baby Schafer
Baby Schmidt
Madison Lillian Schultz
Hope Natasha Scott
Kolton Grayson Seibert
Ilaria Signorini
Hayley Elizabeth Sum
Hannah Elizabeth Svoboda
James Garry Townsend
Thomas J. Tyler
Lilliann Marie Walder
Tegan James Walls
T.J. Wanshon
Heather Weisenfels
Iakona Kaleikaumaka White-Fleming
Dyllan M. Wiggington
Georgia Helen Willis
Michael Tyler Wolfe
Dorothy Sariah Woods
Nicole Kaylynn Wright

We Would Like To Thank The Following People For Their Generous Donations:

- Alex and Angela Abel- in honor of their daughter, Ashley Kaitlyn Abel
- Iris Adame- in memory of her daughter, Aileen Iris Adame
- Lisa Alamillo- in memory of Kolton Grayson Siebert
- Jane Amesse- in memory of Christopher Michael Toth
- Arcana Lodge # 246- in memory of Maximillian Gerard Kastner
- Keith and Catherine Archambault- in honor of their daughter Emily G. Archambault
- Bank of America, North Maricopa Team- in memory of Kolton Grayson Seibert
- Minnie Berglass- in memory of Maximillian Gerard Kastner
- Cheryl Berry- in memory of Kolton Grayson Seibert
- Danny and Janie Best- in memory of Jamison Lee Ellis
- Robert and Harriet Brinkerhoff- in memory of Daniel Owen Gates
- Dolores M. Brown- in memory of Maximillian Gerard Kastner
- Robert and Heather Brown- in memory of Daniel Owen Gates
- Scott and Kathleen Browning- in memory of their daughter, Anneliese Mae Browning
- Michelle and Greg Burgess- in memory of Maximillian Gerard Kastner
- Burkeville Body Shop, Inc.- in memory of Jamison Lee Ellis
- Andrea Castilla- in memory of Kolton Grayson Seibert
- CMH Education Department- in memory of Jamison Lee Ellis
- The Cormany Family- in memory of Kolton Grayson Siebert
- Lisa Cowen- in memory of Kolton Grayson Siebert
- Diana Cox- in honor of her son, Dallas Cox
- Chuck and Patti Crist- in memory of Haley Elizabeth Sum
- Jimmie and Becky Crowder- in memory of Jamison Lee Ellis
- CSP Information Group/CSP Magazine- in memory of Kolton Grayson Seibert
- Camille M. Cuciti- in memory of Maximillian Gerard Kastner
- Steven and Laura D'Ulisse- in honor of their child, Baby D'Ulisse
- Pablo Dominguez- in memory of Kolton Grayson Seibert
- Elsie Dugger- in memory of Jamison Lee Ellis
- C.B. and Jimmie Elam- in memory of Jamison Lee Ellis
- Timothy and Sandra Elfrink- in memory of Lucas Daniel Huether
- FFCA Funding Corporation- in memory of Kolton Grayson Siebert
- FFCA Research & Underwriting Department- in memory of Kolton Grayson Seibert
- Jeffrey M. Fleischer- in memory of Kolton Grayson Seibert
- The Fleischer Foundation- in memory of Kolton Grayson Seibert
- The Fortson Family- in memory of Shane Torrence
- Paula and JR France- in memory of Haley Elizabeth Sum
- Franchise Finance Corporation of America- in memory of Kolton Grayson Seibert
- Verna Gearey- in memory of Kolton Grayson Siebert
- Dorothy M. Gilford- in memory of Kimberly White-Perez
- Stephen and Cathy Giovanisci- in honor of Raquel Stockwell
- Paul and Lenore Goldstein- in memory of Maximillian Gerard Kastner
- Heather Haughian- in honor of her son Daniel James Haughian
- Laurie Hawkes and Paul Grand Pre- in memory of Kolton Grayson Siebert
- Ken, Paula, and Cortni Hawkins- in memory of Kimberly White-Perez
- R. Patricia Hoemke- in memory of her great-grandson, Cade Andrew Turner
- Geraldine Holbert- in memory of Kolton Grayson Seibert
- Mabel Hollrah- in memory of Kolton Grayson Seibert
- Anita and Joe Homer- in memory of Maximillian Gerard Kastner
- Lawrence and Marian Horman- in memory of Kolton Grayson Seibert
- Michelle and David Huber- in memory of Kolton Grayson Seibert
- Robert and Michelle Huether- in memory of their son, Lucas Daniel Huether
- Julie Hutchins and Dave Clark- in memory of Maximillian Gerard Kastner
- Imperial Capital Bank- in memory of Kolton Grayson Siebert
- Katy Jacobs- in memory of her grandson, Kolton Grayson Seibert
- Jason and Kristin Jasper- in memory of Haley Elizabeth Sum
- Thea Johns- in memory of Kolton Grayson Seibert
- Jane Jordan- in memory of Maximillian Gerard Kastner

- Andrew Kent- in memory of Kolton Grayson Seibert
- Kim, Dan, Dennis, Dawn, Sean, Gregory, Brandon, and Anita- in memory of Maximillian Gerard Kastner
- Kloth Termite and Pest Control- in memory of Lucas Daniel Huether
- Timothy and Laura Knapp- in memory of Kolton Grayson Siebert
- Elizabeth Knopp- in memory of Daniel Owen Gates
- Janice Krause- in memory of Kolton Grayson Seibert
- Kutak Rock, LLP- in memory of Kolton Grayson Siebert
- Russell and Anne Kutka- in honor of their daughter, Christine Gloria Kutka
- Brenda S. Lewis- in memory of Jamison Lee Ellis
- Wanda Livak- in memory of Haley Elizabeth Sum
- Catherine Long- in memory of Kolton Grayson Siebert
- Robin Maddux- in memory of Maximillian Gerard Kastner
- Anthony and Amanda Manos- in honor of Raquel Stockwell
- Mary Martin- in memory of Kolton Grayson Seibert
- Paula Masiulewicz- in memory of Kolton Grayson Siebert
- Kate Matthews- in memory of Kolton Grayson Siebert
- Mr. and Mrs. Nolan Modica- in memory of Maximillian Gerard Kastner
- Peter and Grace Modica- in memory of Maximillian Gerard Kastner
- Dorothy Melies- in memory of Kolton Grayson Siebert
- Joe and Annette Melies and Family- in memory of Kolton Grayson Siebert
- Ricardo Gomez & Cindy McKernan Gomez- in honor of Raquel Stockwell
- Beth McNally- in memory of Maximillian Gerard Kastner
- Sheryl McNichol- in memory of Maximillian Gerard Kastner
- Joy L. Nash- in memory of Maximillian Gerard Kastner
- Russadean and Gary Nies- in memory of Kolton Grayson Seibert
- North Star Systems, Inc- in memory of Kolton Grayson Seibert
- Elizabeth Noyd- in memory of Kolton Grayson Seibert
- Edward and Deborah Parham- in memory of Jamison Lee Ellis
- Charles and Margaret Parlato- in memory of Kolton Grayson Siebert
- Park Avenue Hair Company- in memory of Maximillian Gerard Kastner
- Bruce and Daphne Parker- in honor of their daughter, Alison Joanne Parker
- Roger and Carolyn Pendergrass- in memory of Jamison Lee Ellis
- Dennis and Mary Pepperd- in memory of Kolton Grayson Seibert
- Polly K. Piercey- in memory of Jamison Lee Ellis
- Donna and Michael Pizzulli- in memory of Maximillian Gerard Kastner
- Jean Potts- in memory of Kolton Grayson Seibert
- Nina Presto- in memory of Kolton Grayson Seibert
- The Product and Design Engineering Teams from Motorola AMPO- in memory of Morgan Avery McClintock
- Brian Propst and Elizabeth Doyle Propst- in memory of Jamison Lee Ellis
- Brian Propst and Elizabeth Doyle Propst- in memory of their daughter, Cecilia Winn Propst
- Providence United Methodist Church- in memory of Jamison Lee Ellis
- J. U. Reeves- in memory of Maximillian Gerard Kastner
- Thomas and Donna Richards- in memory of Maximillian Gerard Kastner
- Mr. and Mrs. Hugh Ripton- in memory of Maximillian Gerard Kastner
- James and Susan Robb- in memory of Maximillian Gerard Kastner
- Roxbury Press Inc. Research Department- in memory of Kolton Grayson Siebert
- Gregg and Angela Seibert- in memory of their son, Kolton Grayson Seibert
- Virginia Seibert- in memory of Kolton Grayson Seibert
- Shell Capital- in memory of Kolton Grayson Siebert
- Shoe Show Employees- in memory of Jamison Lee Ellis
- Shoney's Restaurant- in memory of Kolton Grayson Seibert
- Silvia Signorini- in honor of Ilaria Signorini
- Grandpa Steve and "Bubbe" Ilene Skoorka- in memory of Maximillian Gerard Kastner
- Gregg Skoorka- in memory of Maximillian Gerard Kastner
- Jeremy Skoorka- in memory of Maximillian Gerard Kastner
- Thelma J. Smelley- in memory of Jamison Lee Ellis
- Daniel and Rosalyn Steck- in memory of Kolton Grayson Siebert
- Ivy Stein and Laura White- in memory of Kimberly White-Perez
- Ailene Steinberg- in memory of Maximillian Gerard Kastner
- Cynthia Stockwell- in honor of Raquel Stockwell

- Jane Stockwell- in memory of Kylee Freedom Green
- Kale and Mary Stockwell- in honor of Raquel Stockwell
- Charles and Elise Stratton- in memory of Maximillian Gerard Kastner
- George and Ann Elizabeth Susich- in memory of Maximillian Gerard Kastner
- Michele Tegels-Giegling- in memory of Kolton Grayson Siebert
- Arzella Thornton and Family- in memory of Kolton Grayson Seibert
- Dorothy Thornton- in memory of Kolton Grayson Seibert
- Marilyn and Richard Tillotson- in memory of Maximillian Gerard Kastner
- Lisa Tisor- in memory of Kolton Grayson Siebert
- Dawn M. Torrence- in memory of Kimberly White-Perez
- Jeremy and Dawn Torrence- in memory of their son, Shane Torrence
- Judith Toth- in memory of her son, Christopher Micahel Toth
- Troy and Michelle Underwood- in memory of Kolton Grayson Siebert
- Carol A. Viola- in memory of Maximillian Gerard Kastner
- Barbara Y. Vosburg- in honor of Dr. J. Anjou N. German
- Karl Warner- in memory of Maximillian Gerard Kastner
- Washington Mutual Bank Commercial Financial Department- in memory of Kolton Grayson Seibert
- Dennis and Janet Weckenborg- in memory of Kolton Grayson Siebert
- John and Amy Weldon- in honor of their daughter, Allison Brooke Weldon
- Lisa M. Jenkins Wells and Elgin Wells, Jr- in memory of Kolton Grayson Seibert
- Inez White- in memory of Maximillian Gerard Kastner
- Rene B. White- in memory of Kimberly White-Perez
- Virginia White and Family- in memory of Kimberly White-Perez
- Robert and Karen Widbin- in memory of Daniel Owen Gates
- Pamela Williams- in memory of Kolton Grayson Seibert
- Esther Wolpers- in memory of Kolton Grayson Seibert
- Wanda Young- in honor of her daughter, Courtney Young
- Seth Zolot- in memory of Maximillian Gerard Kastner

Volunteering at CHERUBS

CHERUBS always has the need for more volunteers, especially because soon we will be losing quite a few volunteers. If you have just a few minutes or a few hours a week and want to help other CDH parents, please contact one of our Volunteer Coordinators: Barbara Wagner at 810-249-5279 or PURPHAZE19@aol.com or Danielle Kessner at 03 5135 6999 (Australia) kessam@bigfoot.com.

On-Call Volunteers for Non-Survivors

On-Call Volunteer	Phone Number	E-Mail Address
Kate Rogula	313-565-8722	Alugor@worldnet.att.net
Danielle Kessner	(03) 5135 6999	kessam@bigfoot.com
Michelle Huether	618-853-4157	mchbob92@midwest.net
Marian Lansdon	360-882-5502	MnML0895@aol.com
Laurelle Lehmann	250-838-2250	tlm-mathias@telus.net
Amy Rademaker	616-844-4156	rademakeramypete@novagate.com

On-Call Volunteers for Survivors

On-Call Volunteer	Phone Number	E-Mail Address
Lea Donahue	603-425-2639	leamd@mail.com
Ann Peterson	509-735-7208	petersonzoo@msn.com
Jeff & Sandy Vanesko	570-388-6113	vaneskoj@aol.com
Deeshia Partin	770-919-2162	dpartin@mindspring.com
Grace Ore	814-833-6421	-
Heidi Forney	208-584-3708	hforney@bigskytel.com
Tara Hall	614-777-4906	TARAJEFF@aol.com
Jeannette Davis	405-670-9937	Daviswe3@aol.com
Jill Coon	530-582-1261	JLC835@aol.com
Elaine Moats	406-232-5038	bmoats@midrivers.com

On-Call For Families Considering In Utero Procedures

On-Call Volunteer	Phone Number	E-Mail Address
Kimberly Doades	503-625-7343	k_doades@hotmail.com

CHERUBS State and International Representatives

Our members are encouraged to contact our Representatives. For your Representative's e-mail address, please visit our web site. Our Representatives are helping members, encouraging new families to join, contacting local hospitals and medical professionals, and conducting such activities as get-togethers, newsletters, parent matching, web sites, on-line chats, and more. We still need volunteers for states that are not listed, states that have "*" by them (we have temporary Representatives for those states), and the following countries; Belgium, Chile, Denmark, France, Greece, Hong Kong, India, Israel, Italy, Japan, Mexico, The Netherlands, Oman, Pakistan, Papau New Guinea, Romania, Scotland, Spain, South Africa,Turkey, United Arab Emirates. If your state or country does not have a representative (or even if they already do), please consider volunteering. You do not have to be on-line to be a Representative. If you are interested, please contact one of our Volunteer Coordinators for more details.

STATE/COUNTRY	REPRESENTATIVE	PHONE#	E-MAIL ADDRESS
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CHERUBS' 2001 Conference

Due to lack of funds, interest, and volunteer help, we had to cancel this 2001's annual member conference in Minneapolis. A huge thank you goes out to all our conference volunteers who tried their hardest to make it work. Your dedication and perseverance has not gone unnoticed and is deeply appreciated.

Please make plans to join us in May 2002 in Phoenix, Arizona. To pull next year's conference off, we need many volunteers and also need to raise at least $10,000 in conference funds (regular donations do not go to the conference fund). If you can help or are interested in attending, please contact our Conference Coordinator, Lea Donahue, at 603-425-2639 or leaerind@mediaone.net.

North Carolina Get-Together

Saturday, June 2, 2001
12:00 - 7:00 pm
Faith Evangelical Methodist Church
1945 Dale Earnhart Blvd
Kannapolis, NC 28083

Cherubs and Siblings are welcome. Out-of-State Members are welcome. Please feel free to bring a covered dish or drinks for our potluck dinner. If you are planning to attend, please call or email our North Carolina State Representative as soon as possible, so we will know an approximate number to expect. You can reach Jeremy Torrence at 919-693-8158 or jeremy@cherubs-cdh.org. For more information and driving directions, you can visit the NC CHERUBS' web site at www.cherubs-cdh.org/nc.

New England Get-Together

Our New England State Representatives are planning an informal regional get-together for July 28, 2001. For more information, please contact your State Representative or Lea Donahue at 603-425-2639 or leaerind@mediaone.net.

Ohio Get-Together

Our Ohio Representative is planning a state get-together for September 15, 2001. For more information, please contact Tara Hall at 614-777-4906 or TARAJEFF@aol.com.

Ebay Auction

Our next on-line Ebay Auction will take place September 9-15th. This time we are going to strive for a celebrity auction. In order to do this, we need a massive group of volunteers to contact celebrities and ask them to donate autographed items to CHERUBS. Many of you have wanted to volunteer but need a short-term volunteer position that won't take up too much time- this is your chance! We have an enormous list of celebrity addresses that will be divided among volunteers. We also need a coordinator to get the ball rolling. We will also be auctioning off other items, so please send in your items or contact if you would like to hold an auction. If you would like to help, have autographed items to donate, or any items to donate, please contact Dawn at 919-693-8158 or dawntorrence@cherubs-cdh.org.

Letters to CHERUBS

Hello. I am a 27-year-old mother of two, and my one child had a diaphragmatic hernia on his right side. It was repaired November of 2000. His liver was pushed up his right side, and his lung had collapsed. He has had pneumonia a few times. Also, I know you said that is all related to these types of hernias, but he has also had other hernias: hiatal hernia, ingiunal hernia, and umbilical hernia. All have been repaired, except the umbilical hernia. Is it normal for someone to have had this many hernias? And what are the odds of them coming back?

He does have delays in speech and did not walk until the age of 23 months. He was not diagnosed with the diaphragmatic hernia until October of 2000; he was born in December of 1998. He began having breathing problems as soon as he was born, which they said was a laryngomalacia mild case through stridor sounds. Could this have been related to this diaphragmatic hernia? He still has this breathing problem.

Even after surgery for the diaphragmatic hernia, he acts like he is in pain. He has a feeding tube (g-tube) placed in his stomach on the left side that was placed in 1999, when they repaired his hiatal hernia and did the nissen fundoplication for the reflux. He acts like he is in pain when he comes off his feeds. Sometimes he won't even walk, and he is very stiff. Is this all normal or one of the side effects to this diaphragmatic hernia? I am lost for words sometimes. This has been a very long road for my whole family. I just want to know what my son's outcome is going to be? Will he survive this? He has come a very long way, and I am very of proud of him. He has been such a strong little boy. One and last final question, when they pushed his liver back down into his stomach, his stomach has been distended and very hard; is this normal? I know this is a long email, but I have not had any luck with doctors and specialists for answers to my questions, and I figured I have nothing to lose by sending you this email. Thank you for your time and may God bless you and your family.

Michelle Thatcher

I don't know really how to start this letter, as I have often thought about writing it so many times. I guess the best way would be to just share my thoughts the best I can. I was young, right out of high school, married to my boyfriend who was five years older than myself. We decided to start a family, and with very little timing, I became pregnant. My due date was in January of 1985. My pregnancy was not ideal at all. I was sick all the time; I couldn't hold anything down. Doctors didn't seem alarmed, as in my last month all of a sudden, I gained a lot of weight.

On Christmas night, a little before midnight, my water broke. I was so excited all the waiting was over. I went into labor shortly after midnight. I believe it was about 12:15 a.m. or so, and my labor lasted only 20 minutes. It was really chaotic from the beginning. My doctor and the baby's doctor didn't show up, as it was Christmas night and a skeleton crew was on. The minute my baby was born, I knew something was wrong. I kept waiting to hear the baby cry, and I never heard it. Everyone was running around and screaming for this and that, while I lay there. Finally, after what seemed to be forever, they told me it was a baby boy and that he didn't make it. I later found out it was a diaphragmatic hernia, and I went to genetic counseling where they did some testing and told me that it is a rare birth defect that they didn't know much about, but it was like being hit by lightning, and I should have no worries for the future. Time went by, and I did the best I could by trying to just go on; I divorced a couple years later with no children.

I later went on with my life and got remarried to my childhood sweetheart. We were married for about five months, bought a house, and decided to start a family. I again became pregnant very quickly. It was in February 2000. I was so happy. I was much older than before and much more financially secure, and everything just seemed so perfect. I kept trying to block out the past and kept remembering the genetic counselor from many years before telling me the chances of this happening to someone is like being hit by lightning. I was actually more concerned about being too old to have children, as I was going to be 35 years old by the time my baby was born.

I went to my doctor and gave her all the history. I started taking my vitamins and thinking about names. I had the blood work done to rule out Down syndrome and other complications, and because of the past, my son Christopher, they sent me to a high risk doctor, which immediately made me very uncomfortable. I met with another genetic counselor who went over my history, and it didn't seem like it was something to worry about. They said it was just a precaution, that it would seem very unlikely to happen again, and that also the father was a different person. I was so positive everything was going to be so different. I felt great, not even one day of morning sickness.

Because of the high risk, they scheduled me for an ultrasound at 14 weeks, which I went to, and they seemed to think everything was OK. I was so relieved. I had names picked out that my husband and I had been going back and forth with and finally decided on Dillon for a boy, and Tori for a girl. Then they scheduled me for another ultrasound a couple of weeks later. I believe I was at almost 18 weeks. I remember lying there while the nurse kept rolling the thing over my belly, and I kept asking, "Can you see if it's a girl or boy?" I was so impatient. She kept politely saying, "I can't tell yet," then all of a sudden, she asked if she could be excused; she would be right back.

I knew at that moment everything was going to change. I wanted to disappear, to just run and never come back. Then the door opened, and a man walked in and introduced himself as a doctor. He was accompanied by the same girl who had been doing the ultrasound. I got enough courage to ask, "Is there something wrong?" And I remember so clearly him saying, "Just wait until we are finished," in such a tone that just sent chills up and down my spine. He took some more pictures, and all of a sudden, with no warning, me still lying there with gel on my belly, he blurted out, "This baby has a diaphragmatic hernia." I went numb. The room started spinning, and I wished my husband had been there, (he had wanted me to reschedule as he could not get out of work.)

I was more than devastated; tears still come from my eyes when I think about it. I remember being so mad. I wanted the doctor to be lying; I wanted it to be a sick joke; I begged him to tell me he was wrong. I was determined that he was wrong. I made another appointment with another doctor to get a second opinion, only to find out more about this birth defect and the options and procedures and that fetal surgery was not an option for me, that my daughter Tori had a very bad hernia where her heart was on the wrong side, and that it was best to terminate my pregnancy. I didn't want to believe it; I couldn't believe it; they told me it was like being struck by lightning. How could it happen twice?

In the end, I made a decision to terminate my pregnancy. By this time I was 21 weeks, and I actually had to deliver the baby. It was a decision to this very moment that I still doubt myself, wondering if I did the right thing. I had come to this web site and read and read and read and decided in the end because of the severity of the hernia it was probably best. It devastated me, and I thought up until today that it had made me stronger and that I had gotten past it, not over it, just past it. My husband and I had many talks and decided to adopt an older child/siblings, as we knew we had lots of love to give to children, and we both wanted a family. So we started the adoption procedure. I had gotten the shot for the method of birth control, as I was told because it happened to me two times, there is a 50/50 chance that it will again. I knew I could not go through this a third time, so adoption was our answer.

Well today, I found out I am pregnant. I am so scared, upset, and happy all at the same time, if you can believe that. I have not stopped crying all day, and figured this was the best way to express myself, as everyone here knows about this terrible birth defect that can have such harsh memories. I guess I was wondering if anyone else has had multiple children with this same birth defect, and I am looking for some kind of assurance that this cannot happen to me again, knowing no one can answer that for me. I am strong, and I want children more than anything else. Since I was little, I dreamed about having at least four or five children and always wanted twins. At this point, I would be more than grateful to have one happy, healthy baby boy or baby girl. To all the survivors of this birth defect, I wish you the best, and to all the lil'cherubs who didn't make it, I wish you the best, and to all the parents, grandparents, family of all these children with diaphragmatic hernias or any birth defect, to just say a prayer that someday all these defects will be curable, as children are our future.

God Bless, Kerry.....Christopher and Tori's mom

My baby was born on March 6, 2001, around 9:27 a.m. He weighed 6 pounds and 11 oz and measured 19 and one-half inches long. I learned about this condition when I was watching a program on T.V. At that time, I was two months pregnant. I didn't find out that my baby had this condition until I was four months pregnant, and when the doctor told me, she scared me a little because she was talking about how her friend's baby died because of this condition, and she told me that I had to go to Gainesville, FL. So I was treated as a high-risk pregnancy at that time. I was sad because I remember the program that I saw earlier, but it was very hard to tell my husband that our baby had CDH.

During my pregnancy, I found more information about this condition, and I knew it was serious, but how serious, I didn't know for my child; I had to wait and see. By the time I was 7 months, I had had 12 ultrasounds, and I had been to Gainesville twice just to see which side it was on. The doctors confirmed that it was the right side but couldn't tell how much of a lung he had on that side. Then we met the doctor named Dr. David Kays, whose specialty is taking care of babies with this condition. My husband and I met him, and basically, he explained everything to us, including about ECMO. He said he usually takes the baby around 37 weeks, so he wanted me to come back on March 5th of 2001. My husband and I had mixed feelings because we didn't know what to expect, but we were happy that we found someone who was devoted to his work, and we could tell that once a CDH baby is born, those were his children.

On March 4th, I went in to labor, and I went to St. Luke's Hospital at 3:30 in the morning. The doctor checked me, and I was an inch dilated, so he told us to go ahead and go to Gainesville, which we did. Once there, they checked my contractions and as luck would have it, I wasn't dilating. So we checked in a hotel free because it didn't make sense to go home, and the next day change our lives forever.

On March 5th, I checked in around 3:00 in the afternoon, nervous since this was my first child. I didn't know what to expect. They had to induce me in order for me to contract, which was painful. Then the next morning, the baby was in distress, and they went in, and I had a c-section. Tara'mais John Lamkin Brown was born at 9:27 a.m. I remember when he came out, he had that face like he was mad, and he made a little noise. That sounded good because I knew he had life, but that was just the beginning of his life. Within a few hours, they told me he had to be on ECMO.

When I saw my baby, I started to cry because he was so small and fragile, but yet I couldn't hold him. The machine he was on was so big, and the tubes -- it was very overwhelming for me. I was mad because he shouldn't have had to go through this, and it

wasn't fair. My husband and I cried like children, we couldn't stand to see Tara'mais like that. He was on ECMO for a few days before they could repair him. They repaired him on March 12th. The surgery usually took two hours, we were told, but to repair Tara'mais's took 3 hours. He came back and said that our baby almost didn't have a diaphragm at all and his liver was far in his chest, smashing the right lung. He said that he might not live, and the next two hours were critical.

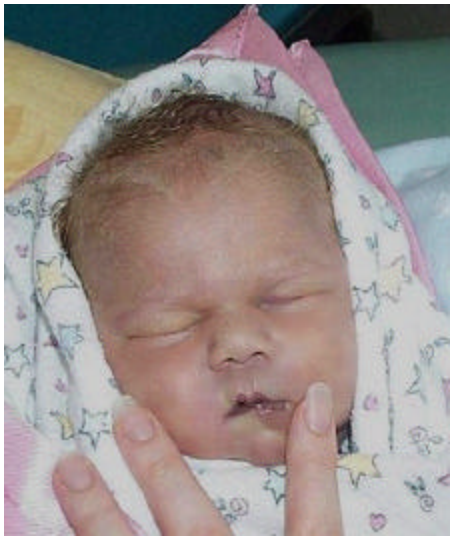
The next morning, he was awake and squeezing my hand very hard; that let me know he was strong. He was on VV ECMO up until March 22nd; then they switched him to VA ECMO. I didn't know which was worse. I was hoping for the best recovery because I couldn't wait to take him home with me. The nurses there took good care of him. I remember him trying to pull the tube out of his mouth, and they had to watch him. Everyday my baby was getting stronger. He kept on fighting with the nurses; he wouldn't be still, plus he didn't like to be touched when he was sleeping. I remember one morning, he had his eyes open, and he stared at me and had those little hands in the air, like he wanted me to pick him up. I told him, "Not yet, little man, but soon."

Then one day, on April 1st, he coughed really hard and split his diaphragm open again. They called me that night and told me that his stomach was hanging out, and they had to call Dr. Kays, and once again, they had to do another surgery. I was up all night long with the nurses; he scared everyone that day.

Tara'mais was on ECMO for a month, and he was improving a little, but the doctors had a different story. They took him off ECMO on April 11th, and they gave him 50 percent chance of living, 50 percent of dying, which was hard for us. But the next day, he was awake and squeezing my hand hard, letting me know that he was not done. On April 27th, he was off the ventilator and on a c-pap, which he was doing really well on. The only condition they are concerned about is his heart because it is slightly enlarged due to the fact that he was on ECMO for so long. Now he is on a nasal canulus and still gets upset when the nurses give him his vitals. Those hands ball up in a fist with his hand in the air; the only difference now is that he cries, and it is so cute. He still is not out of the woods, and we know he won't be home for some months now.

Tarcara Brown

Stories of CHERUBS



What a crazy year 1999 was. On January 10th, Simon & I were married in Melbourne, Australia. The following day, we jetted off to Hamilton Island for a glorious 7-day honeymoon. On the last day of our holiday, the weather had turned nasty, & we decided to sit in the lounge area of the hotel & have a drink & laze around. I had noticed that my period was late but thought maybe it was due to the whirlwind nature of the previous months. However, just to be sure, I bought a pregnancy test & since we had little to do because of the weather, I decided to take the test. To my absolute delight, it was positive, & Simon & I were ecstatic. What a wonderful start to our married life. We celebrated with a glass of champagne. I sipped at mine, immediately mindful of the delicate cargo I was now carrying.

Just because we didn't feel we already had enough on our plates, we decided to accept a posting up in Papua, New Guinea for Simon's work, commencing 10 days after we returned from our honeymoon. In this time, we had to pack up our house, store all our furniture, farewell family & friends, & get to an obstetrician. It was hectic but exciting.

I managed to fit in an appointment with an Ob-gyn two days before we departed, & fortunately, I really liked him. We had decided that I would return to Melbourne to have the baby, as the medical facilities in PNG are not fabulous. We hadn't told anyone of our news, as we wanted to wait until after 3 months to make sure everything was fine.

We arrived in PNG on Australia day 1999 & settled into our new lifestyle. I had organised to see an obstetrician in Cairns for checkups until it was time to go to Melbourne. I felt great throughout the pregnancy; I experienced no morning sickness or any other discomforts that so many other women are afflicted with.

In March, Simon & I traveled down to Cairns for our first appointment. We were terribly excited & were thrilled when we saw our baby for the first time on the small monitor in the doctor's office. From what he could see, our baby looked fine. I couldn't tell which way was up, the screen was so small. Added to which, it resembled an untuned TV, the picture was so fuzzy. We spent the next few days in Cairns celebrating, & upon our return to PNG, we made our announcement.

I spent most of my time at home decorating the nursery. I remember being in there one day pottering around when suddenly a voice rang out as clear as a bell. It was eerie, & I'll never forget it. I was looking at the cot at the time, & the voice said to me, "Your baby will never sleep in this cot." I was horrified with myself for thinking such a thing & put it down to first mum's nerves. It sounds ridiculous when I mention this incident, but having spoken to other mothers who have lost children, they say they have experienced a similar thing.

May came around, & it was time for another checkup. I was 22 weeks pregnant. I had had very strong feelings that we were going to have a girl, & sure enough this was confirmed after our scan at Cairns Diagnostics. This time the scan was far more in-depth, & all throughout the appointment, I asked the technician if all was alright & if everything was where it should be. I never received a definitive answer. The scan seemed to take a long time, but having never been through it before, I knew no better. Now I know what the delay was. I felt uneasy for the rest of the day, but Simon & I went out to dinner that night to celebrate the news of our little Princess.

We had an appointment the following morning with our doctor, & he took us through to his office & sat us down. He looked solemn, & he asked if the technician had spoken to us yesterday. I replied hurriedly, "No, what's wrong?" Then the craziness began. Alien words such as "diaphragmatic hernia" were bandied around. It was a blur to me, & I just burst into tears without really comprehending what was being said. I'd heard of Down syndrome & spina bifida, but what the hell was this? All I knew was that it was not good. Our little girl was going to be in for a battle.

It took me a couple of days to be able to even pronounce "diaphragmatic hernia," & now it rolls off the tongue. I was struggling to understand just what we were dealing with. I needed knowledge; I needed information; and I needed to understand. We called our obstetrician in Melbourne, & he did not sound optimistic. However, we arranged to fly down to Melbourne the following week to commence tests & decide what our plan of attack would be. All I took from our meeting with our doctor was that our girl had a defect, & she would require an operation as soon as she was born. Death was never mentioned.

We arrived back in PNG in a stupor. I had called my parents whilst in Cairns & babbled at them about a condition that I had no idea about. Mum tried to pacify my hysteria, but how can anyone pacify a situation that can't be controlled. Now that I had access to my computer again, I spent the next week looking through different sites, gathering all I could on CDH. Simon & I spent hours researching, & we were horrified with the results. To this day, I don't know if it was a good thing or not to have ingested so much information. I was in tears most days; it was heartbreaking to read the tragic outcomes, but then hope would filter through in a case of a survivor. I had had no idea that the condition was so hateful.

We searched in vain for reasons for the condition-- what had I eaten, had I taken a medication, was it something in the environment that I was in contact with? Simon asked himself questions right down to the type of deodorant he was using. We needed answers, but none were forthcoming.

Simon & I left for the long flight to Melbourne with a sense of desperate hope. Perhaps we'd arrive at the scan, & they'd tell us it was all a horrible mistake & that our girl was fine. They'd slap us on the back & laugh at the misunderstanding. As it turned out, there was no mistake, & there was no backslapping. We stayed with my mum & dad, & as the extent of this drastic situation unraveled, I was destined to remain with them until Rhian (we'd decided upon her name) was born.

I had an amniocentesis also to make sure that there weren't any other problems we had to deal with. Fortunately, there weren't, but then what we were coping with already was more than enough. The hernia was confirmed. It appeared that Rhian's intestines had worked their way up into her chest cavity, she had a left-sided CDH, & the tip of her liver was also protruding into the chest area. Her heart had been pushed over to the right side, but at least it was functioning normally. Just how well her lungs had developed was a mystery & would remain so until she was born. I hated everything about this condition-- its uncertainty, its secrecy, its indiscriminating nature.

Simon had to return to Lae, PNG for work. He had stayed down in Melbourne for two weeks with me, but unfortunately, just because we had a situation didn't mean he could shirk his work responsibilities indefinitely. The separation was hard, as we had clung onto each other for dear life since we'd received the news of Rhian's CDH. Sim did manage to come down to visit periodically, but it wasn't ideal, & we missed each other terribly.

There are two sides to finding out early in your pregnancy about CDH. The first is that you have an amazing opportunity to try everything you can, no matter how desperate, to increase your child's chances of survival. I had steroid injections to try & increase her lung capacity; I took vitamin E, as I had heard that it could help with immature lungs. I was a desperate mother, desperate to save her daughter. The other side to knowing your child has CDH early is the worry & waiting . . .

I had to fill in time without going insane. I realised to my disgust that I had hardly bought a thing for Rhian. I had lost my appetite for children's stores once we learned of the hernia, but now I was determined to remain positive, as it was my only choice. How could I give up on Rhian when I was all she had? I went straight to the nearest kids store, & I bought up big. I went on a shopping frenzy, buying everything pink & beautiful I could lay my hands on. I was determined to keep her, & that meant if I bought things for Rhian, then she'd have to stick around to use them.

Time crept by, & each week I went to my obstetrician for checkups that did not alter. I was also going into the hospital to have Rhian's heart monitored every Tuesday, & all was proceeding as normally as it could under the circumstances. Rhian was due around the 16th of September 1999, but when I visited my obstetrician one week, he stated that he believed she would be ready to come out in the next 6-8 days. Simon was still in PNG, so I called him immediately & got him to change his flights to come down earlier. He organised to fly down on the 6th of September. Saturday the 4th, I decided to gather together all of my girlfriends & have a dinner at a local restaurant. I knew that once Rhian was born that things would never be the same, so I gathered everyone around as a kind of "last supper." Rhian was always a good kicker, & she let herself be known to me daily, which I loved. I read her stories & chatted to her constantly, & she would respond with a tirade of thumps. I kept thinking, "How could a little girl that is so strong possibly have anything wrong with her?"

Sunday morning came, & she was very quiet. In fact, for the remainder of the day, I barely felt her. I prodded her to try & gain a reaction, but she was not playing that day. I was growing increasingly concerned so that by Monday morning, the 6th of September, I called my obstetrician & explained my fears. He told me to go into the hospital, & they would check Rhian's heart through fetal monitoring.

My mum had been to every appointment with me when Simon couldn't be there with us, & together we drove into the hospital. Usually the monitoring took between 20-30 minutes; this time I was there for over an hour with different nurses & doctors coming in to check the read- outs. Finally, they contacted my obstetrician, & he came down & stated very matter-of-factly that her heart rate had increased & her activity had decreased, so they were going to whip her out by c-section.

"When?" I questioned, a little dumbstruck by it all. "Right now," was the response. I burst into tears immediately. "Can't we wait for Simon?" I pleaded, but I was met with a negative response. I begged them to leave her where she was, knowing that whilst she was still inside me, I could protect her, but the ramblings of a terrified mother were not enough to convince the medical staff that that was the best option.

They prepped me for theatre, & my heart was in my mouth. I wasn't frightened for myself; I was absolutely beside myself with fear for my little girl. I cried most of the way into theatre, & in there my mum met me, all gowned up. She held my hand as the doctors started, & a few minutes later, the most stunning little girl was held up, & I couldn't believe she had come from inside me. There was no cry, just a scrunched up little face that did not look impressed.

Rhian was whisked away immediately to the corner of the room where a hoard of doctors started to work on her. There were so many people in the room, & yet I only had eyes for my girl. A nurse kept me informed as to what they were doing to Rhian. I was later told that she fought like a trooper the entire time the doctors were attempting to insert the tube into her nose to put her on the respirator. They had so much trouble with her that they ended up having to insert it down her throat instead. She apparently thrashed around, & that made me feel proud.

Next thing I knew, they had brought her over to me bundled up. Her little face was tightly screwed up, letting me know that she was not happy about being taken from her warm home. I gave her a quick kiss on her forehead, & then she was gone, raced down to ICU.

I lay in recovery in a state of shock. My baby was born, & yet I wasn't holding her; she was now in the hands of strangers that I had to literally trust with her life. I felt alone & useless. I couldn't help my daughter anymore; she was in the hands of others. No information was available the half hour I was in recovery, & when I was finally wheeled back to my room, my mum was waiting for me with some Polaroid pictures of Rhian the doctors had taken for me. Rhian had a little pink woolen beanie on & what seemed like dozens of tubes emerging from every inch of her body. But what I noticed most about her was how beautiful she was. I could see past the medical paraphernalia, & all I saw was a perfect little girl.

As soon as my anesthetic wore off, I popped some painkillers & got the nurses to wheel me down to ICU. There I saw Rhian properly for the first time, & I was in love. I was also confused. She didn't look sick. She was a reasonably good size at 6 lbs 1 ounce. Especially since the ICU had several premie babies there, Rhian looked a picture of robust health in comparison, & yet she was so much sicker than they all were. No other babies were hooked up to respirators; no other babies had tubes coming from each foot, wrist, & belly button. No other baby had machines that beeped & whirred. It wasn't fair.

Rhian was quite a looker & would have been a heartbreaker for sure. She had the most wonderfully shaped lips; the top lip was a perfect M shape. Her hair was a glorious strawberry blonde, & she had masses of it. I studied her for the next two days. 48 hours is not a long time, certainly not long enough to live a life, but that's all our girl was given.

Simon arrived that night at 10.45 p.m. after a day's journey from PNG. He was devastated that he'd missed Rhian's birth, but we went down immediately to ICU so that he could see his beautiful daughter. We clung to hope for the first 24 hours, but on Tuesday night, the doctor came into my room with the worst news imaginable. I can't remember what he said to us because I didn't want to hear him. I whaled, I cried, I screamed, "No, No, No," as though by this outburst I could change things. My heart was being ripped out. What I do recall being told was that we should spend as much time as we could with her now, not that we weren't doing that already. We went down that night , & I got to hold her for the first time. I finally got to hold my baby, attached to all of the instruments that were keeping her alive. We stayed with Rhian until the early hours of the morning, then got a few hours rest & went back to her at 7 a.m. that morning.

I nursed Rhian for 7 short hours. I took in every inch of her body. I noticed that she had my big feet & that she had a pixie ear just like her daddy. I talked to her & told her how much we loved & adored her, how sorry we were that she had to be put through all of this. I rambled on, & Rhian patiently listened – I know that she heard me. The doctors had taken her off the sedatives, & she had begun to move around. It was a wonderful sight to see our girl kick out with her legs. We spent a couple of hours helping her open her eyes, & I like to think that she saw us. I was in denial right up to the last minute when they took her off the life support machines. I kept believing she would make a miraculous recovery & prove them all wrong. It never happened.

Simon had to bring me back to reality when he gently told me it was time to let her go. We didn't want her to pass away hooked up to the machines, so before that could happen we had to release her ourselves. I couldn't bear to see them take away her life support, so I waddled into the designated room they had kept for us & sat & waited. Simon stayed with Rhian, & then he carried his daughter in to me. She was so quiet, but she was alive. For the first time, I got to see her face clearly, & she was even more beautiful than I had thought. I held her free from the tubes & machines, & for a brief moment I could pretend we were a normal happy family. That

moment soon passed as Rhian took two quick gasps, & then she slipped away from us there in my arms. Devastation.

There we were, the three of us alone at last. Nurses, doctors, & machines had always accompanied us, but now it was just we three. We stayed & held Rhian for hours after she left. We bathed her & dressed her in a little outfit that we were one day hoping to bring her home in. It had three sheep on the front of it with the numbers 1,2,3 – like counting sheep, which I thought was appropriate, as our girl had gone to sleep, but she was just going to sleep a little longer. After what seemed only minutes, a nurse came in to take Rhian from us. It was the hardest thing to hand over my daughter. Our hearts were broken; we were nothing but empty shells. Our future had been ripped from us, & we missed our brave baby.

I have never known a pain like it. To lose a child is the ultimate agony. We buried Rhian a week later in a quiet little cemetery by the ocean. At her funeral we had brightly coloured tulips with bows on them that people could either keep or give to Rhian. We also had 40 multicoloured balloons, which we released – it was a very uplifting experience. Little hearts were handed out to everyone & on the hearts they could write a note to Rhian & express their feelings. The tulips & the hearts went into her grave before she was buried. My sister had written a poem to her niece, & it was also buried with her.

I know a lot of people choose to cremate their children, but personally, Simon & I thought that Rhian had been through enough, & now we wanted to lay her to rest. We got to say a final farewell to her at the funeral home the day before her burial. There we dressed her again in a warmer little suit, placed a pink teddy in her tiny coffin along with her daddy's hanky, which we had used to wipe away our tears, & a photo of the three of us together. We then wrapped Rhian in a pink bunny rug, tucked her in, & kissed her goodnight.

At the time of writing this, Rhian would now have been 17 months old. I often look at other little girls around her age & wonder what my precious little baby would have looked like. She will always be perfect in her Daddy's & my eyes. I miss her every single day & wish I could change it all. Rhian now has a little brother, & when he is old enough he will know all about his big sister Rhian. I am often asked how many children I have or if Caden is our first, & I always reply, "No, he's our second. We have two children, our first is our beautiful daughter Rhian." And that's the way it will always be.

Caitlin and Simon Robilliard (parents of Rhian Robilliard, 9/6/99-9/8/99, P.O. Box 569, LAE 411, Papau New Guinea, 0011 675 475 1129, csrobilliard@global.net.pg)

Our son was born on June 9, 1972, after a very routine pregnancy. This was before ultrasound was used, so we were not aware that anything was wrong with our son. After a long labor, Peter was born early in the morning of June 9, 1972. There was activity in the delivery room, but since Peter was my fourth baby, I realized there was always some hustle after the birth. They showed me the baby and quickly took him away without a word. After a short time, I was taken to my room, and my husband came in with my OB/GYN, Dr. David Landers. He had started to speak to my husband in the waiting room but then brought him in to me where he was joined by our baby's pediatrician, Dr. Vincent McAuliffe. They also had a pediatric surgeon, Dr. Anthony Barbara, from Hackensak Hospital. At this point, Dr. Barbara proceeded to tell us that Peter had been born with a diaphragmatic hernia and that he needed immediate surgery to save his life. I remember saying to him to do his best. I truly don't think I realized the severity of this problem. I was to find out later that Dr. Landers had noticed the baby had difficulty breathing when he was going to perform the circumcision. They inserted a tube to help Peter breath until they could perform the surgery. Luckily for us, Dr. Barbara was available and performed the surgery when Peter was four hours old.

We have been truly blessed, and I have often called Peter our miracle baby. We were told after the fact that his chances were about one in ten. But he came through the surgery beautifully. After a couple of days, he kicked one of the tubes out, and they told us that if he was that strong, they would not replace it. He went home after 11 days without any complications at all. Over that year, he had pneumonia four times and was hospitalized each time. He was also tested for cystic fibrosis twice, but each time that was negative. We were sent to Columbia Presbyterian Hospital in New York for further testing and were told that one side of his diaphragm was smaller than the other. But other than that, he was fine. At 11 months, we were told that Peter needed another surgery to make a permanent correction of the hole. The first surgery was to save his life and now a piece of material called cyloplast would be used to repair the hole permanently. That surgery also went well, and on Mother's Day of that year, I took him home. He has been fine ever since.

He was a little small for his size initially, but he definitely caught up over the years. He has played soccer since he was eight years old, Little League, and even wrestled for a short time. When he needed a physical for the wrestling, we had to return to the surgeon and have x-rays taken. After he looked at them, he said no one would ever be able to tell that Peter had ever had a problem.

After reading so many of the stories on this site, I am so thankful for my Peter. He could have had so many other complications that I never was aware of until now. I guess very little was known about this condition almost 29 years ago. I do know that I have a living miracle in my life, and I thank God every day for him. I had another son four years later, and he was fine. And my three daughters born before Peter were also perfect.

I hope all of you parents have the strength to endure the struggles you seem to be faced with and pray that each of you turns out to be as fortunate as I am.

Kathy Compa (mother of Peter Compa, 6/9/72, COMPA@WORLDNET.ATT.NET)

Although my pregnancy was nothing to brag about, I did have my problems. I felt like even though this was my fifth child (all of whom have had no problems either with the pregnancy or birth and all have been healthy children), I did have problems. I felt huge, and they said the baby was normal size. I went into labor early twice; both times they stopped it. I had 2 sonograms, one at about 2 months and another at 5 months and both looked normal. Even so, at 37 weeks, Joey was born. At first they said he was just having problems breathing, and after a few hours in NICU, he would be back with me. That sounded OK to me since 7 years ago, my daughter was born after a great pregnancy and had problems breathing and was fine after a few hours.

Four or five hours later, the neonatologist came in and said they had to talk to me about Joey. They said he had CDH and possibly had to be flown to Phoenix (two hours away) to be put on ECMO. I had honestly never heard of this, even though I had been a surgical tech for a few years! I wasn't sure what this was, and the doctor explained it to me, but it still made no sense. All I wanted was to hold my baby and go home.

After two days, the doctors said Joey was doing better and probably wouldn't have to go to Phoenix. I was so thankful. I left that day (two days after he was born) thinking he would be OK. Three days later, after going to the hospital everyday in between taking and picking up my other three children to and from school, the doctor called and said they did have to fly Joey to Phoenix that afternoon. I was so upset that I could hardly drive back to the hospital.

Later that day, Joey left on the helicopter (with his three sisters and brother and me and his grandma saying goodbye) to go to Phoenix. His oldest sister Sky (18 years old) and I went up later that day. When we got there, he was already on ECMO.

Joey stayed on ECMO for 10 days. On his littlest sister's 7th birthday, they told me that the next day they were going to do his surgery. I was so happy, but at the same time scared. I just hoped he made it through the surgery. His sister said that was the best present she got for her birthday, to tell her baby brother he was having surgery and maybe coming home soon. I wanted to cry. She was so hopeful; so was his brother CJ (age 5). CJ never once thought anything bad would happen to his brother.

Well, we were one of the few truly blessed families. After surgery, Joey came home to Tucson two days later, and after another seven days he came home to us.

Other than the fact that he nurses every two hours, he is absolutely perfect and is his mommy's little miracle baby. We all love him and pray for any other family with a baby born with this defect. We were lucky, and we know that most of the babies and their families aren't this lucky.

Thank you for this great website, and we will keep you updated on Joey and our family as we keep reading about our extended family on this website.

Laura Edmiston (mother of Joseph Mackenzie Kelley, 3/8/01, 4675 S. Harrison Rd #197, Tucson, AZ 85730, 520-296-2657, lbluesmom@aol.com)

When I was 27 weeks pregnant, I went in for a routine checkup, and my doctor was alarmed at the size of my belly. I was measuring around 32-33 weeks, so she sent me to the hospital to have a level 2 ultrasound done, (hoping to find out the sex), and we found out that our baby "girl" had a congenital diaphragmatic hernia. I was hysterical! They immediately sent us to a high-risk doctor, and he explained to us our options. His first suggestion was to terminate the pregnancy. To me and my husband, that was not even an option, so instead he wanted to do an amnio to find out if it was a genetic problem. So we did the amnio, and from there, we were sent to the ECMO coordinator in the NICU. She explained to us what was going to happen when our baby was born and then gave us a tour of the NICU.

I began doctor visits twice a week for ultrasounds to measure the amniotic fluid index and have non-stress tests. In that first week, I was contracting at a regular rate, so my high-risk doctor said we needed to do an amniotic reduction to help stop the contractions. During the reduction, I went into labor, so I was put on meds, and it was eventually stopped, and I was allowed to go home with orders of strict bed rest (not an easy task with a 2 1/2 yr-old at home). My son and I spent our days in my air conditioned bedroom watching Disney movies and taking naps.

I was still having the contractions off and on, so they decided to induce at 37 weeks so that the team of doctors would be prepared for her arrival. Well, Bethany had other plans! She came at 36 weeks. I went into labor at 2:00 A.M. Monday morning and completely denied I was in labor because it wasn't very strong, and I just didn't want to believe it. I felt that as long as my baby was inside of me, then she was alive and with me. At 5:30, my husband woke up to get ready for work, and I was wide awake and in the middle of a contraction. I told him to go ahead and go to work, and I would call him if anything happened. By 7:30 A.M., I knew it was the real thing. So I called my husband and then called my sister to watch my son.

We got to the hospital at 10:00 A.M., and the contractions were definitely there but still nothing compared to what it was like with my first. They hooked me up to a monitor and were convinced it was false labor, that is, until they did an exam. They found that my water was literally bulging and about ready to burst at any moment. I was completely effaced and had begun dilation. They told me to walk around for an hour and then come back. They were afraid my water would break, so they instructed us not to leave the hospital.

We came back at 1:00 P.M., and the nurse examined me again. I had dilated even more, and my water was even closer to being a waterfall. The nurse got my records and knew that our baby was sick, so they cleared out what they call the "Cadillac room" and put me in there. It was like a luxury suite! They treated me like I was so fragile.

They gave me an epidural at 2:30 because they wanted to be prepared for an emergency c-section. At 4:00 P.M., my doctor arrived, and I apologized for not waiting until the induction date. She laughed at me. My labor was now very hard when I had a contraction, but the contractions were still very slow, and Bethany was showing signs of distress. So my doctor gave me pitocin to speed it up. At that point, my mom and hubby were in scrubs ready to go to the OR for delivery, and they had made a bet on what time Bethany would be born. My hubby guessed 6:45, and my mom guessed 6:55. Well, at exactly 6:55 P.M., Bethany Michelle Jenkins was born. I only caught a glimpse of her as they cut the cord and rushed her off into the resuscitation room. She was very gray and didn't even look alive at all. My husband was allowed to go with her, and my mom stayed with me to keep me calm.

I had some problems with hemorrhaging and lost a great deal of blood, but they were finally able to get that under control and stitched me all up. Because of the hemorrhaging, I wasn't allowed out of my bed, even to go see my daughter. So I relied on updates from my husband and the neonatologist.

About 10:00 P.M., the neonatologist came into my room with a solemn face and told me that we needed to start thinking about funeral arrangements because he didn't feel that Bethany would survive the night. I was devastated! I hadn't even seen her yet! My husband stayed at her bedside most of the night and kept me posted on her condition. The next morning her condition had improved somewhat, and she was still with us. They allowed my husband to wheel me in to see her. I thought I was prepared for what I was about to see because I had toured the NICU twice before she was born. But it turned out that it was very different because it was my own child hooked up to all those machines. I think what bothered me the most was the high frequency ventilator making her chest vibrate so violently. I was only allowed to stay for a short time, and when I got back to my room, I bawled and prayed!

Bethany had her ups and downs through that second day and through the night. But by 10:00 P.M. the following night, they decided that she was stable enough for her life-saving surgery. Before her surgery, we had her baptized and then off she went. After her surgery, the doctor came in and told us that she probably wouldn't be awake until the following morning and that they had given her some paralyzing medicine so she wouldn't be moving at all until at least then. Ten minutes after we talked to him, we went in to see her. (They had closed the NICU and did the surgery right there in her bed). When I talked to her, she opened her eyes and stared at me! And when I held her little hand, she squeezed my finger! She was such a little fighter!

The remainder of her hospital stay was touch and go. The first time they tried to extubate her, we were there. They waited for what seemed like an eternity for her to start breathing on her own, but it wasn't flying, so they bagged her and reintubated her. It broke my heart. About a week after that, I was at home resting with my son, (they made me go home to sleep), when I got a call from the neonatologist. He called to tell me that Bethany was off the vent and doing well! She was on a nasal cannul but pretty much holding her own! What an achievement! I was so excited! I went to the hospital, and for the very first time, was able to hear my baby cry. What a sweet, sweet sound!

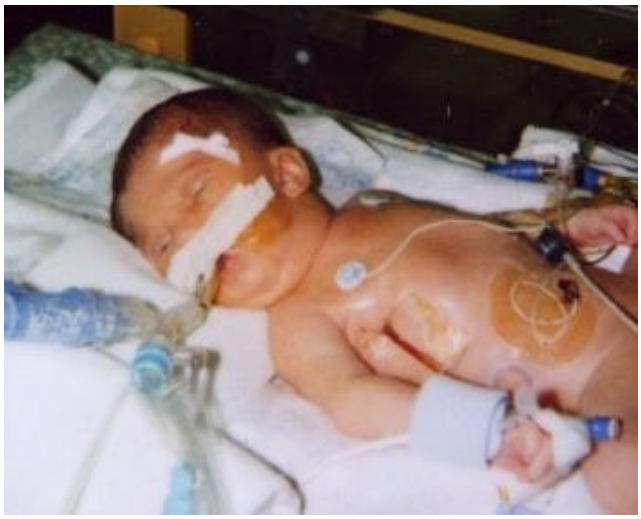
A few days after that, she swelled up like a big balloon, and her blood pressure went sky high. So her BP meds were upped, and she was put on diuretics to get rid of the fluid that she was retaining and causing her to swell. They got that under control, and then they cut her narcotics off cold turkey! That didn't go well at all! She cried and cried from withdrawals. So they ended up putting her back on them to slowly wean her off. To make a really long story short, Bethy was eventually put on feeds through a Gavauge and then was able to nurse. Then one day when I came in to visit her, the doctor came in and asked me how I would like to take my baby home! He said that he wanted me to "room in" with her that night in a special room, and the next day they would release her. Ohhh, what a happy day!

Bethany is now 3 1/2 years old and doing fairly well. She has some bowel problems, reflux, and if she gets too active, she has some breathing problems. But those are so small compared to what she went through just to be here today! Her development has not suffered at all. She is in pre-school and absolutely loves it! She's writing her name and starting to spell words, and she is the sweetest child, always thinking of other people before herself. My little angel! Anyway, that is Bethy's story in a nutshell. Feel free to e-mail me for anything.

Jennifer Jenkins (mother of Bethany Michelle Jenkins, 8/18/97, 4915 SE Ina Ave., Milwaukie, OR 97267, 503-353-1610, Jjenn316979@aol.com)

Did You Know?

- There are estimated 78 million babies born worldwide each year; 31,200 born with CDH (based on 1:2500 odds).



I had a happy, uneventful pregnancy until week 28, when my local OB doctor mentioned the he was concerned that I was measuring small. I wasn't too worried because small babies run in our family. At 31 weeks we went to the local hospital for an ultrasound so that my doctor could make sure that everything was okay, since he was worried about IUGR. Our lives seemed to fall apart that day when we were told that her heart was on the right side, that they couldn't find a diaphragm, and that her stomach and intestines were up in her chest cavity. A few days later, we were in Salt Lake City seeing a perinatologist that did another series of ultrasounds and other tests. It was on that day, January 5th, that we learned that she had a diaphragmatic hernia. Our doctor did an amniocentesis that day, and we were so relieved, 18 days later, to find out that her birth defect was not chromosomal related. The perinatologist was realistic but also optimistic, and we were convinced that after Anneliese was born, she would have surgery and be home in a few weeks. To us, there was no other outcome.

The local OB continued to care for me during my pregnancy, and I was supposed to move to Salt Lake City and stay at the Ronald McDonald house when my pregnancy progressed to a certain point. (Our local hospital here in Wyoming is not set up to deal with high- risk pregnancies.) At 34 1/2 weeks, I went in for a checkup and found out that I was 80% effaced-- time for us to head to Salt Lake City. We got home from the doctor's office and packed up, then drove the 2 1/2 hours to the University of Utah Hospital. I didn't even think I was in labor yet, but 2 hours after we got to the hospital, my water broke. I was in a panic, thinking it was too early. They gave me one shot to help her lungs develop. They didn't want to stop the labor for fear of infection, and the following night, Anneliese was born. She was only 3 lbs. 5 oz., but she had these cute little chubby thighs, and to us looked perfect. They told us that the umbilical cord was short, but I still don't know why or if that is related to her low birth weight.

Prior to her birth, the NICU doctor had asked us if we wanted to hold her until she died or try to save her. There was no option for us-- we had to give her a chance! She made it through the delivery, and they were able to stabilize her. The next hurdle was to transport her down a long hallway to the NICU at Primary Children's Hospital. The doctor said she may not make it through the trip, but she did. She continued to be stable that night, and we visited her at about 2 a.m. after they had gotten her situated there. It was overwhelming, seeing our dear, sweet baby girl hooked up to IV's, life support, and a chest tube. The second night after she was born, she went downhill, and they told us she would probably not live through the night. That night, we (including my mom and dad) stood at her bedside while she was baptized. She surprised the medical staff again by getting better.

She had some more, smaller ups and downs, and a little over a week after she was born, her surgery was done. The surgeon had warned us that her defect was very large and because she was so small, she might not make it through the surgery. Her vitals went haywire whenever she was moved that they had to perform her surgery right there in the NICU. To everyone's surprise, she "sailed" through the surgery, and for four wonderful days afterwards, she did very well. The defect wasn't as large as they thought, and they were able to repair it without the use of a gortex patch, a very good sign! At that point, they were talking of starting to wean her off the ventilator. We were so happy, sitting next to her for hours, telling her of all the things we would do when we all came home together.

On days when she was doing well, we were able to cup our hand on her small head, and it was so comforting to her I think, since we couldn't hold her. It was definitely a comfort to us to be able to touch her like that. She was paralyzed with a drug called Pavulon the whole time, but sometimes she would try to open her eyes when I talked to her or move her head a little when the drug started to wear off. It would break my heart to see her making sucking motions with her mouth. I know she wanted to move so badly. I was constantly worried about her every second of every day, asking the nurses if she had been given her sedatives recently, was she being given enough painkiller, etc. I cherished the times I got to help change her diaper or put Vaseline on her little lips. One night, when she was doing really well, the nurse let me put baby lotion on her feet, legs, arms, and part of her back. Normally, she couldn't tolerate that much stimulation, but that night she did so well, and it was one of the happiest moments I had with her, being able to caress my baby girl that I loved so very much.

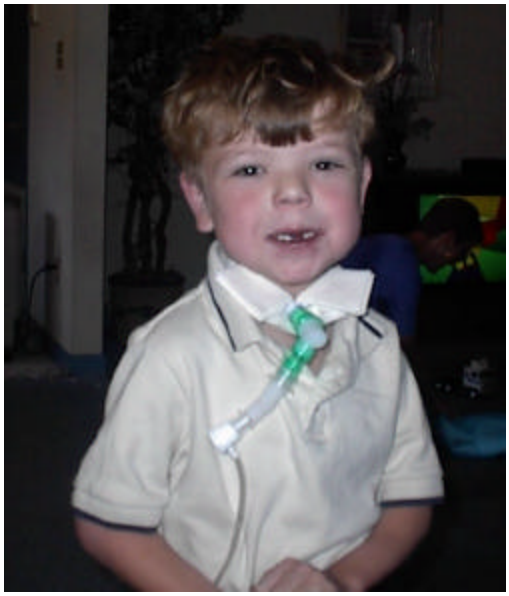
On the fifth morning after her surgery at 5 a.m., we received a call from the hospital that her oxygen saturations had fallen, and nothing they were doing was working to bring them back up again. We rushed to the hospital, and slowly she improved when they turned up the mean on her ventilator. (Turning up her support was a risk since it put so much pressure on her lungs, and could blow a hole in them, which is what happened a few days later.) Then she started having some major ups and downs, and they ended up putting a chest tube back in that they had taken out and an additional one because of the pnemothorax that had developed in both lungs. We were devastated when we found out that there were holes in both of her lungs, but we were still trying to be positive because we had been told that the lungs heal very well, that it was just a matter of time. One night her oxygen levels fell to 30% for just a few minutes, then came right back up to 95% when they repositioned her chest tube.

Her last day with us, she did excellently; all her vitals looked very good, but that night after the shift change, she went downhill. I knew in my heart, just by looking at her, that she didn't feel good and that it might be time. The doctors that were caring for her that night were wonderful, doing everything they could, but they also told us that it might be time for us to say goodbye. We sat with her all night, off and on, while they tried to make her better. At 3:00 a.m., I had her primary doctor paged, and he came in to be with us while she was taken off ventilator support. I held her while they took her off the support, the first time I was able to hold her in the 18 1/2 days of her life. My husband Scott and I took turns holding her in a quiet room while she died. Those were the happiest, the saddest, and most difficult moments of my entire life. My arms now feel so empty.

I just couldn't consent to an autopsy. I felt like her little body had already been through too much. We had a public funeral service and family and friends over to our house afterwards. We wanted everyone to celebrate with us the birth of our beautiful daughter Anneliese. We showed everyone pictures of her and continue to do so because we are so proud to have had her and wouldn't trade those 18 1/2 days with her for anything.

Anneliese was a blessing and a gift from God. We love her and miss her so much.

Kathy & Scott Browning (parents of Anneliese Mae Browning, 1/31/01-2/19/01, 300 Hoover Drive, Green River, WY 82935, kbrowning@wyoming.com)



OK, where do I begin? It was during my 23rd week of pregnancy that I had a freak accident and fell on vacation. My mother urged me to go to the hospital, but I refused because I wasn't in pain at that time. A few hours passed, and I had unbearable pain like nothing I've ever felt before, so I went to a strange hospital with strange doctors, and by fluke, the midwife decided to give me an ultrasound at the very last minute. I felt very robbed by this ultrasound because the tech knew a problem was there and played it off well. The midwife gave me a dressed up story about CDH and made it sound like no big deal, and so did my OB when I went the next day. (We drove back early from our vacation.)

So then my Ob-gyn decided to have a perinatologist as a consultant during my pregnancy. From then on, I saw both the regular OB and the perinatologist every week after it was confirmed. Since I was only 17 years old when I delivered him and was pregnant at 16, I could not get a research grant for intrauterine surgery, and insurance wouldn't pay for experimental surgery. So the only thing left was betamethasone weekly until the end of the treatment course. Then they started weekly amniocenteses to test for lung development. I gained 83 lbs. on this drug, and the baby barely showed any lung development until 38.3 weeks. The doctors decided to induce that night for oligohydramosis, and he was born into the arms of the neonatal transport team, with Apgars of 2 and 8, weighing 8 lbs. 14 oz. He was whisked away, never crying at all.

A few hours after I delivered, I got more good news: the neonatologist came over from the Children's Hospital to the delivering hospital (through an underground tunnel) and whipped on me that my son also had a deadly heart defect and to come a soon as possible because they thought he would not make it. They called everywhere in our state; four hospitals rejected him. He was not a candidate for ECMO because of the heart defect he had. He needed the oxygenated blood and deoxygenated blood to mix, and ECMO wouldn't allow this, so four hours later, he was on a flight from Tampa to Miami, where his diaphragmatic hernia was immediately repaired.

Then 24 hours after that, he had to have an emergency illiostomy for a bowel blockage. I was not even discharged from the hospital yet and had to give verbal consent over the phone for surgery 2 times in 24 hours. Both went well. After six weeks there, he was flown back to Tampa and transferred to Children's where he then underwent open-heart surgery. By this time he was 3 months old. I had never held him and he'd lost a lot of weight, down to 6 lbs. He did not come off bypass well at all, 3 defibs before he came back and another month before they closed the sternum. Plus, he got a blood infection, which was a setback. After that, we finally went home at 6 months of age with 24-hour home nursing, which we still have, and we recently were evaluated and rejected for heart lung transplantation. In March of 2000, they told me to take him home, that he would live longer with me. So I did. I could have done a better job writing this, but to tell you everything would take 10 pages and there's a 3 page or less limit. I haven't met anyone whose child has the same two defects as mine or as bad as his that's still living, so that's a miracle in itself. But they have limited his life expectancy; we just play it by ear. What else can we do besides pray?

Vicki Holloway (mother of Dominick Aaron Beach, 8/1/95, 5240 13th Ave N, St Petersburg, FL 33710, 727-321-9317, WEEDIEBIRD@AOL.COM)

My name is Angie. I am the mother of two beautiful little girls. I gave birth to my second daughter, Ashley Kaitlyn Abel, on January 10, 2001, by repeat c-section at Central Carolina Hospital in Sanford, NC. We were the first case that morning. We knew we were having a little girl. We knew the day and time she was going to be born. What we didn't know was that our little girl would be born with a diaphragmatic hernia.

I had a very smooth pregnancy. I had an ultrasound in my first trimester to confirm the due date and then another one at 18 weeks. The hernia did not show up on the 18-week ultrasound. At that time, the abdominal organs were still in their correct anatomical position. Since I had a healthy baby the first time and was not considered high risk, a third ultrasound was not done.

My husband and I arrived at the hospital at 5:30 a.m. I was taken into the OR around 7:00 a.m. I was given a spinal block and had the final preparations for surgery. My husband was in the operating room with me. I had a rough delivery because my daughter was stuck. The doctor used the vacuum to free her, and for the second time in my life, I heard the most beautiful sound, the cries of my newborn baby girl. But those cries were followed by a deafening silence. At first I thought that the doctors were suctioning her nose and mouth. Still no sounds. I watched them take her to the corner of the room. When I asked what was wrong, I was told that she was just having a little trouble breathing on her own; some newborn babies do. My baby was brought over to me twice, only to be whisked away to the corner of the room each time. They took Ashley out of the OR, and my husband went with her. I didn't know what was going on, but I didn't want her to be alone.

After my incision was closed, I was taken downstairs to recovery by the anesthesiologist. He called the newborn nursery to find out what was going on and let me talk to my husband. I still was being told that she was just having a little trouble breathing. The anesthesiologist instructed the nurse to get me up to my room ASAP, and he went back to the nursery to check on her (I found this out later). I was taken up to my room, where my parents and my 19-month-old little girl were waiting. When I asked them what was going on, they really didn't know any more than I did. We called and asked my Aunt Susie to come to the hospital, and she was there within a few minutes. Shortly after that, my husband came in and was followed by the doctors. The pediatrician told us that Ashley had a diaphragmatic hernia and explained what it was. She wasn't sure if Ashley had a left lung; her heart was pushed over a little to one side; and she was not sure which abdominal organs were involved. They told me that the helicopter from UNC Hospitals at Chapel Hill, NC was on the way to transport her. I asked the doctor what Ashley's chances of recovery from this were, and she told me 50/50. My doctor had arranged for me to be transported by ambulance to UNC Hospital. My husband and family were going to follow in the car.

We waited for the paramedics to bring Ashley in. She had been intubated and placed in an isolete. They pushed her over to my bed and let me reach inside and touch her. I told her that I loved her and would see her soon. They left with her, and my husband and aunt followed. I waited for the ambulance crew to come get me. It was about a 45-minute ride to the hospital we were being transferred to. My parents and daughter left after I did. We were all reunited in the ER of UNC Hospital with the exception of my baby. She had been admitted to the Newborn Critical Care Unit and was being evaluated by the doctors and nurses. The NCCU doctor came to the ER to talk to us. She told us that they would have to wait for 3 days before they could do surgery on Ashley. She would have to be monitored and evaluated for that period of time and the survival rate was about 60%. I was then taken to my room on the same floor as the NCCU. The nurse brought in a wheelchair, and I went to see Ashley. I visited with her as much as I could over those three days. She was doing well. They kept cutting back on the ventilator. The surgeon came and talked to us when Ashley was one day old and told us that she was doing very well and that if she continued to make such progress that he would perform the surgical repair when she was 3 days old, which he did.

The day for surgery came. The nurse called my room around lunch and said it was time for Ashley to go. We went to the NCCU to see her, and they allowed us to go with her to the surgical area. My husband stayed across the hall in the waiting area, and I went back to my room where my daughter and parents were waiting. Halfway through the surgery, the anesthesiologist came out and said the repair was complete and Ashley was doing great. She was going to have to stay in surgery a little while longer so that a Broviac could be inserted into her thigh and a chest tube put in. My husband was allowed to walk along side as Ashley was brought back to the NCCU, but they asked us not to visit until they called us. They needed to get her hooked up to all of the monitors and assess her. About 30 minutes went by, and they called us to come see her. Ashley was doing just fine. The surgeon told us that her stomach, spleen and intestines had migrated through the hole in her diaphragm and compressed the left lung. The heart was not involved. She did have lung tissue on the left side and it would be fully developed by the time she was a year old.

I was discharged the day after her surgery. My husband and I visited Ashley every day until she was able to come home. I even spent the night with her in the family room once. It was hard to leave her, but we knew that our little girl had to be there.

Ashley came off of the ventilator 3 days after her surgery. She was extubated and given oxygen by nasal cannula for 4 days. Her chest and stomach tube came out when she was 8 days old. She was also taken off of the medications she had been given and moved from a warmer to a crib. They began feeding her breast milk through an NG tube. I finally got to hold Ashley and it was great. I didn't want to put her down. She continued to make great progress. She only had to learn to suck, swallow, breathe.

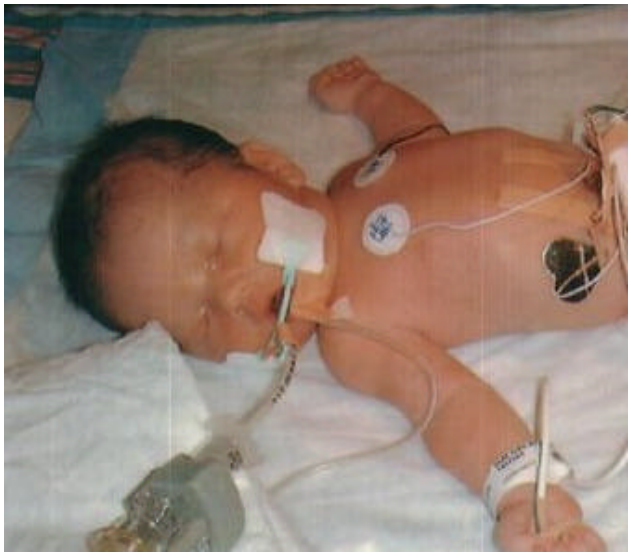
She was moved to the newborn intermediate care unit when she was 17 days old. She seemed to do better at breastfeeding rather than bottle. One of the nurses also tried finger feeds. My breast milk was supplemented with high calorie formula to help her gain weight. She was on Reglan and Zantac for reflux. She finally started to tolerate the bottle feeds well enough to come home. The NG tube and Broviac were removed and Ashley was discharged at 25 days old. Five days after she was released, we had to take her back to the ER at UNC. She had picked up a stomach bug and had become dehydrated from the vomiting. She drank several ounces of Pedialyte without vomiting, so they let her come back home. She has done well ever since.

Through trial and error, I discovered that she didn't really have reflux; she was lactose intolerant. I switched her formula about 3 weeks after she came home, and her meds were discontinued. She had episodes of rapid heart rate (SVT) and breathing (tachypnia) while she was in the NCCU. She also had a small PDA (opening between heart and lungs that usually closes after birth). She was put on digoxin, which stopped the SVT and tachypnia. The doctors continue to monitor the PDA. Half of the children with this condition require surgery to close the opening and in the half of the cases it closes on its own. The cardiologist has said that he will do surgery if it does not close by the time she is 3. She continues to gain weight and is not at all behind developmentally. Ashley is truly a miracle baby.

I would like to thank all of my friends (especially Tanya, Carrie, Angella, Karen, Susie, Linda and Ann) and my family (especially my daughter Alyssa-she has been such a sweetheart through all of this, my husband Alex, my mom and dad, my brother Murph and my Aunt Susie) for their love, support and prayers. I would also like to thank the staff at Central Carolina Hospital in Sanford for diagnosing her condition and getting her the help she needed so quickly and the staff at UNC Hospitals at Chapel Hill for saving her life and taking such good care of her. I would like to thank Dr. Shelley McClure and Dr. Jim Crowgey for going the extra mile for our family. Thanks to Dr. Tim Weiner, our little girl is here with us today because of him and we are eternally grateful. Last but not least, I want to thank God for answering our prayers and working His miracle through these doctors and nurses. We are very blessed to have both of our daughters with us today.

God Bless all of the CDH children everywhere and their families.

Angela Abel (mother of Ashley Kaitlyn Abel, 1/10/01, 2121 Oriole Circle, Sanford, NC 27330, 919-777-6794, abelab@att.net)



The Lord lives. The Lord is good all the time. My faith and hope are in God. He knows what is best for us if we let Him work in us. I thank God for the wonderful daughter that was given to us. Her name was Haley Elizabeth. She was a beautiful baby who came into this world on March 1, 2001, at 5:06 P.M., weighing 6 lbs. 12 oz. at Northside Hospital in Atlanta, Georgia. She came into this world "crying" just as any other newborn. She looked perfectly normal on the outside. However, the inside of her was not right. She had a condition called a congenital diaphragmatic hernia (CDH), which caused her stomach and part of her intestines to move up into her chest. This did not allow her left lung to fully develop. We had found out about this condition two weeks earlier, but the doctors (pediatric surgeon, OB, and perinatologist) were all very hopeful that they would be able to correct this problem.

Almost immediately after Haley was born, the neonatology team went to work on her to help her breathe with the one good lung (right lung) that she had by putting her on a respirator. The team then took Haley upstairs to the NICU to "stabilize" her.

At around 7:30 P.M., Joan Maples, the nurse who had been with us since 8:00 A.M. that morning to help deliver Haley, contacted the NICU. Joan indicated to us that Haley would have to be transported by ambulance to Egleston Children's Hospital, which is about 30 minutes south of Northside Hospital. However, Joan did tell us that they would bring Haley to Robin's room to see us before she was transported to this other hospital. We waited with eager anticipation to see her, and I was hopeful that her condition was good because the neonatologist explained to me earlier in the day that it could have taken a long time (24 hours or more) for her to be "stabilized" before she could be moved so that she could survive the trip. At that time, I thought this was "good" because she was to be moved so soon after her birth.

Finally at around 8:30 P.M., Haley was brought down to Robin's hospital room and then taken afterwards to Egelston by ambulance. I followed her to the hospital to ensure that she made it there safely. Once I made it to the hospital, I found my way to the NICU. One of the nurses directed me down to the admissions office, where I had to complete the obligatory insurance paperwork. After this, I went back upstairs to the NICU. The nurse told me that the doctors were not finished evaluating Haley, so I went into the waiting room at around 10:00 P.M.

At 11:00 P.M. or so that night, the doctors came to me and asked if I wanted to see Haley. I was somewhat nervous but excited and went to see her. She was connected to a respirator and a bunch of other tubes. One of the nurses told me at that time that Haley was "very, very sick.." This sort of surprised me, because I knew there was a problem and thought that she was referring to the CDH. However, the tone of her voice made it sound much more serious. The doctor (Dr. Anthony Piazza) who examined Haley then came to me and wanted to talk to me and Robin immediately. I explained to him that Robin was still at Northside Hospital recuperating. Because Robin was in no condition to travel, I asked him if this could wait until the morning, and he said, "No." I think at that time, I went into a state of "shock," because I sort of sensed that the things he was going to tell us were not positive. Dr. Piazza and the nurses then led me into a private consultation room where we called Robin. The first thing that Dr. Piazza asked us was, "What did the other doctors tell you?" At first, I didn't really understand why he was asking this and didn't know how to answer. I thought to myself, "The perinatologist said that Haley would be fine; don't you already know this?" Dr. Piazza then went on to explain to us that not only did Haley have the CDH, but she also had a problem with her heart. When I heard this, I don't think that I wanted to believe it. "No one told us this before…," I thought. The doctor then explained that because Haley had both conditions (the problem with the diaphragmatic hernia and heart) there was nothing more that they could do. Haley would not be able to survive on her own, and it was only a matter of time…

I then asked Dr. Piazza if Haley would make it through the night so that Robin could see her. Dr. Piazza indicated that she probably would be OK. Naively, I thought to myself, "Maybe things will turn around, and she will be better in the morning." I didn't really know what to do. I felt helpless because I couldn't fix it or change the situation. After this, I went back to Haley and prayed with her and dedicated her to the Lord. I told her that Mommy, Emily and Daddy loved her. I then drove back to Northside Hospital around 1:00 A.M. to be with Robin. On the way back to Northside Hospital, I listened to a song called "Enchanted," which I dedicated to Haley.

Haley had taken a turn for the worse early in the morning, and the NICU team had to revive her. Robin and I went to the hospital to be with Haley at around 6:30 A.M. but did not know what to expect. When we got there, even though she was connected to the respirator, she looked very good. I asked Dr. Piazza again if there was anything that could be done, and again he told me that it was "inevitable" and only a matter of time. The doctor then asked if we wanted to hold Haley. At the time, I didn't want to, because I didn't want to hurt her… But I did end up holding her for several hours and was so glad that I did. Even though it was very hard, I was grateful that I could be with my daughter at that time. We were able to pray, sing, and read some children's books to her. I really believe that little Haley knew that her mommy and daddy were there and that we loved her.

At around 11:00 A.M., Friday March 2, 2001, Haley went to be with the Lord. At that moment even though the sorrow Robin and I felt was insurmountable, I felt somewhat at peace and very grateful that I was able to spend the time that I did with her and to be able to hold her.

To Haley Elizabeth:

God was very gracious to bless me with a precious little girl like you. When you were born, you reminded me of your big sister because you looked a lot like her. I wanted to hold you close to me so that I could protect you. I wanted you to live, but it was not meant to be… Life is so precious and when I was with you and praying for you, I realized that everything else that crosses our path in life seems so trivial…

I will never again get to read to you, sing or pray with you. I will never again get to hold you in my arms or kiss you. I will never get to take you to school, send you off to college, or see you get married. But know this, I love you and always will. You will never stop being my daughter. You were a beautiful baby. After you were born, the pediatric surgeon called you a "survivor." You are a "survivor" in my mind because you will always "survive" in my heart. Words cannot express how much your touch felt to me, and I long to see you again one day in heaven. You were surrounded by so much love during your time here on earth. Lots of people loved you and were praying for you. But you are now in very good hands with the King of Kings. I will always believe that. I will miss you very, very much.

I love you, Daddy

"And He shall wipe away every tear from their eyes; and there shall no longer be any death; there shall no longer be any mourning, or crying, or pain; the first things have passed away" (Revelation 21:4).

Jay Sum (father of Haley Elizabeth Sum, 3/1/01-3/2/01, 3903 Edith Drive, Albany, GA 31707, jresum@netzero.net)

Did You Know?

- 3,965,000 babies were born in the United States in 1999; 1586 with CDH (based on 1:2500 odds).

I would like to share my story with CHERUBS, as this support group is wonderful and has helped many of us, including myself, in answering so many questions to this birth defect.

Our story begins in June of 1999, when my husband and I went in for a routine 20-week ultrasound. We expected to walk out with a picture in our hands and smiles on our faces, naturally. We already had a very healthy beautiful 2 year-old girl at home and couldn't have been more excited to have our second child. After the ultrasound tech informed us there was a problem and went to get a doctor who immediately did a level 2 ultrasound, we were told right there of our daughter's CDH diagnosis. After going to see my regular OB, he had informed us that there was a nuchal thickening (thicker neck tissue), which increased our chances of Down syndrome to a 20% chance. So a few days following I had an amnio done. We asked for FISH results, which gave the results back in 3 days for the major chromosomal defects. Needless to say, it was the longest weekend of our lives waiting for these results. And to top it off, I was a bridesmaid in my sister's wedding that weekend, so we didn't want to tell the rest of the family, or they would have been too upset at the wedding. So we just told our parents and hid it from all 7 of my siblings! (Although now they say they knew something was wrong that weekend-- I guess you can't hide sleepless nights from those who know you best.)

After receiving the phone call from the genetic counselor at Northwestern Hospital in Chicago that everything with the chromosomes was fine, we then just had to wait out the next 20 weeks until my due date in October. We were referred to the best pediatric surgeon at Children's Memorial Hospital in Chicago who would do the surgery. After meeting with her and several of the other specialists at the hospital, we were terrified to have our baby, as she was so safe inside of me since she didn't need her lungs then.

I was scheduled to be induced on October 20th, but was already having contractions before even getting there that morning, so I needed very little pitocin to get going. After a very easy labor and delivery, 5 hours total and only 7 pushes, out came our beautiful 7 lb 2 oz baby girl. I was barely able to get a look at her before they took her to another area in my room to work on her right away. There were so many specialists in the room when she was born that it was very overwhelming. But they all knew exactly what they were doing, and I thank God that we knew ahead of time, or it would have been even scarier. They immediately intubated her and paralyzed her. I kept asking if she was going to make it, and they just kept telling us they would do everything they could for her.

After taking her to the NICU, I was then given a room on another floor instead of the maternity ward. This really meant a lot to me that I wouldn't have to see or hear the other babies when I was in such a state of shock and scared to know whether our baby was going to live or not. After stabilizing her as best they could, they transported her by ambulance to Children's Memorial Hospital neo-natal intensive care unit. My husband Peter followed her there while I had to stay at Northwestern to recover for the night. Luckily, one of my best friends, Heidi, came to stay with me and bring me dinner, so I wouldn't be all alone there. I received phone calls about every 15 minutes from Peter with updates on Clare's condition, as it was changing constantly those first few hours and days. I was released from the hospital the following morning and was never prepared for what I saw-- my tiny little angel lying there with tubes coming out everywhere, hanging on for dear life. The doctor had informed us that she was not yet stable enough for surgery, and she could "crash" at any moment. So we spent the next five days with lots of ups and downs-- blood gas readings, nitric oxide, etc.-- but luckily she just escaped having to go on ECMO.

On day five, she had her repair surgery, and after about 3 and 1/2 hours we received word that she was doing fine. The surgeon did say her hole was so large that nearly the entire diaphragm was missing, and they had to use a large piece of Gortex to patch it up. Her recovery actually went very smoothly after that, as she was home from the hospital in 21 days! The nurses, who were absolutely wonderful in the NICU, couldn't believe how well she responded to everything. They said she truly was a fighter, and that made a difference in her recovery. After pumping breast milk every 3 hours for 21 days, I was finally able to nurse her, and it went very well. She did come home from the hospital with a feeding tube in, just to make sure she was getting enough, but it was out in three days, and she ate much better after getting it out. I did rent a baby scale from a lactation consultant's office near our house, as I wanted to make sure she was gaining enough weight every day. We were lucky that there had been absolutely no complications at all, including reflux for the first 8 months. Then they couldn't figure out why she wasn't gaining weight and was only 12 lbs at 8 months.

It turned out, after getting an x-ray, that her Gortex patch had come loose, and her stomach and intestines were back up in her chest cavity. We didn't expect this to happen, as it only happens in 20% of babies within the year after their first surgery, so we were very nervous and shocked. We had to go back to Children's for her second repair surgery. Since there was more muscle now to sew

the patch to, this one should hold longer, we are told, but they can't predict how long unfortunately. We just have to take it one day at a time. They will give her an annual x-ray to make sure it's still in place, since her patch is so large.

We have been so blessed by God to have such a beautiful, happy baby. Looking at her now, you would never know she had anything wrong with her when she was born. Her weight is even on the charts in the 25% for her age. And her scar is healing very nicely. She has such an incredible personality-- I can't even imagine not having her in our lives. The only other surgery she may need some day is to have her pectus repaired. She got this as a result of her CDH. But that would be years down the road and is not life-threatening like her first surgery was. For anyone out there reading this who is going through this, I would be happy to answer any questions you may have. Thank you, Cherubs, for listening and for informing people via the internet about this terrible birth defect. Without you, we would have felt very alone, but after reading your letters we realized how many people in this world are also going through this same situation.

Lori O'Connor (mother of Clare O'Connor, 10/20/99, 8160 Hess St, La Grange, IL 60525, 708-246-9375, peteandlorio@msn.com)

Tips For Grandparents of Surviving Cherubs

by Suzy Keeler

Grandmother of Amanda Slavin (11/6-93-11/1/94) & Nicholas Slavin (11/6/95-11/6/95)

- If you know the baby will be born with CDH or other problems try to visit the NICU before the birth. It's a little less scary that way and you'll know what to expect.
- Offer to spend the night at the hospital so at least one parent can go home, work, run errands etc...
- If possible be there for the doctor's consultations. It's hard to absorb all the facts you're receiving when you're upset. Another pair of ears often helps.
- Don't be afraid to ask questions to doctors or nurses.
- Be prepared for crisis phone calls. Have a bag packed, inform your boss of what is going on in advance in case you need time off. Have your other children (if at home) & your mate prepared to be without you for a period of time.
- Help clean your daughter's/son's home, prepare casseroles and easy-to-heat meals for them.
- Learn to G-tube feed & how to take care of the baby to give the parents a break.
- Don't forget to give son/daughter-in-law time and a listening ear; they are hurting too. Offer your opinion, but remember all decisions are up to the parents.
- Don't be afraid to touch, talk to, hold, and love the baby, even if they are hooked up to monitors, etc.
- Listen to your son/daughter. If you can't be there and let them talk, AT&T has a great calling plan if it's long distance. It is good for them, as well as it is for you.
- Don't be afraid to cry, show your fears & frustrations.
- Hug often. This bonds families.
- Pray and know God will be there and let his will be done. Remember as grandparents you are a great support for your son/daughter, always be there for them; they will need you.

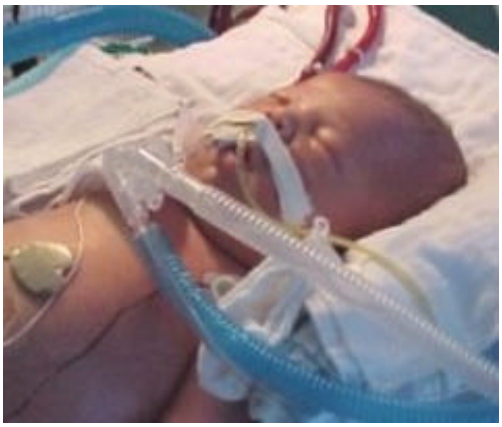
Did You Know?

- Every 15 minutes, a baby is born with CDH

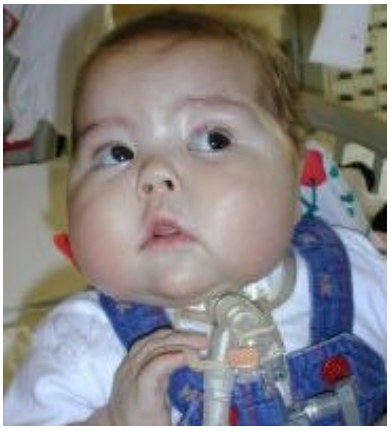
*statistics from the Center For Disease Control and World Overpopulation Awareness Organization

Pictures of Cherubs

Jessica Kate Holt
3/9/95



Jacob Anthony Friske
9/22/99 – 10/16/99



Luke Joseph Thomas
12/1/99 - 7/4/00

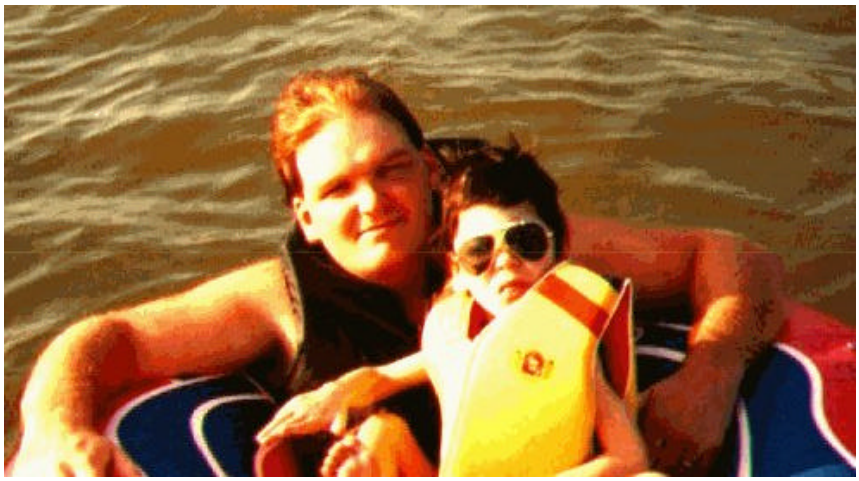
Robert Haines
2/7/98

Millicent Jane Golding
2/17/97

Madeline Sentner
6/25/99 - 6/25/99

Dad's Corner

By Jeremy Torrence



In this newsletter I wanted to write about feelings-- feelings on Mother's Day, Father's Day and feelings when other people who don't have a sick child talk about their kids.

To me, when you lose a child, Mother's Day and Father's Day are just as painful as the child's birthday. It's that one day that's specially marked just for mothers and fathers. But when you don't have your child to spend it with, what do you do? You feel empty, lost, sad, and hurt. This will be my second Father's Day since Shane died. Last year I was still in shock over what had happened. This year I'm already wondering how I am going to react on Father's Day. Am I dreading it? I don't think so. I think I am dreading the pain of not having him with me (I miss him everyday, but being Father's Day, I think it's going to be worse). This year I am a lot more emotional than I was last year. Shane is on my mind all the time. I can just think about missing him, and I start crying. It doesn't matter where I am, it could be at work or just driving down the road. I can't imagine what it's like being a mother on Mother's Day. They have that really special bond with the child, carrying the baby for nine months and breastfeeding. Don't get me wrong, dads have a bond with their kids also, but the moms have that special connection.

Have you ever listened to other people talk about their kids like they were a burden instead of a joy? I hear that a lot, in the workplace, in stores, and listening to some family members. I hear some people tell their kids they love them whenever they are leaving them to go to work or to bed. Then I see some kids that don't even know what the phrase "I Love You" means. To me, that's sad. We made sure that Shane knew he was loved, and even though he couldn't say it, you could see it in his eyes and his smile that he loved us back. I always told him I loved him when I left for work, or if I was just going to the store, I wanted to make sure he knew that. I see so many people who take their kids for granted, and it upsets me very much. We just don't know how much time we have left, so let your kids know you love them; spend as much time as you can with them. Shane loved for us to read Sesame Street books to him, but I would get kind of short with him because if we spent too much time on one page, he wanted to turn it. Well, I would try and finish reading the page, and he would be turning it, so I finally gave up. Now I realize that he didn't care if I finished reading or not; he was enjoying the time I was spending with him just looking at the pictures. We had a toy box for him in the living room, and at least once a day he would point at the toy box for us to get something out. He wouldn't stop at one toy; we had to empty the box and show him it was empty. Then he didn't want any of those toys. I think it was just the time we spent with him was what he wanted, not some specific toy.

I often wonder how other dads who have lost a child feel when their co-workers or friends talk about their kids. I like to hear my friends talk about their kids to a point, then it's like this pain starts hitting me. Then I start thinking and wishing I could do that kind of activity with Shane. I envy those dads who get to take their kids to the park or wagon rides through the woods. I do have one friend who is a good Daddy to his son. He's always taking him places and doing things with him. He's one of the few friends I have who doesn't mind listening to me talk about Shane, and it doesn't make him feel uncomfortable. Before he asks questions about Shane, he always tells me that if it's going to make me uncomfortable, I don't have to answer. When I go over to his house, his son likes playing with me, and he always asks if I am OK. You don't find too many friends that are like that. We do have some family members that are sensitive about what they say when we are around, and some are not. Some I commend on being good parents, and some I wonder why they had kids. Some of them I can really talk to about my feelings, and some I just don't hardly say anything because I know that even though they hear me, they are not really listening. If you don't know what to say to someone who has lost a child, just be willing to listen. To me that means more than anything.

In closing, I once heard a story of a woman in the workplace where the lunch conversation led to someone needing a mother figure, and one of the guys spoke up and said, "There aren't any moms in this building." They all knew that this woman had lost a child. I can't imagine how she must have felt. The point I am trying to make is, even though there are many of us who have lost our children, that doesn't mean that we aren't their moms and dads anymore. I will always be Shane's Daddy no matter what.

I wish you all the best on Mother's Day and Father's Day.

Advice From Other Members

(taken from our Parent Worksheets)

"Be positive, ask a lot of questions and always make sure you are enjoying every day with your child. You don't know how many there will be at first. Make sure the staff does everything the way you want it. Your child deserves the best care"- Jeannie Seery (mom of Parker Seery, 4/24/99)

"Ask the doctors any questions you may have, no matter how silly you may think they are. Write down all things you are told, because you won't remember everything in years to come" - Alice Jurkowski (mom of Thomas Robert Jurkowski, 6/1/88)

"Make sure your doctor has dealt with a lot of cases of CDH. Don't be caught like a deer in the headlights as your doctor tells you things that are scaring you to death and just stay with him because he seems like he knows some things, even if he knows a lot. You have to be in the right place with the right people around you when you deliver and that means finding the doctor with the most experience with this. We found such a doctor and he saved my beautiful son's life"- Paul Norris (dad of Cooper Gerald Norris, 9/19/94)

"Make sure you ask for a written plan regarding your child and STAY on top of the doctors...You may have to ask about every square inch of your baby to find out everything" - Theresa Connelly (mom of Michael Patrick Lee, 7/21/98)

"Love your baby as much as you can and ask thier nurses what you can do for them - and remember to take care of yourself, so you can take care of the baby!" - Elizabeth Doyle Propst (mom of Cecilia Winn Propst, 11/2/99 - 12/10/99)

"Put together a plan with your doctor and review it daily, write everything down, understand the goals your child needs to reach, talk to, and touch and sing to and be there with your child every moment you can, it helps!! Take care of yourself" - Linda and Michael Clarke (parents of Jamie Michael Clarke, 6/18/96)

"Read, read, read, become informed about all treatments/options. Ask questions, lots of them. Spend as much time with your baby as possible, get involved in your babies care as soon as possible" - Deb Gabites (mom of Emma Doreen Gabites, 5/6/97)

"Take an active role even if it is not promoted by the professionals. Take many pictures don't assume you will get them later. Tell people exactly how you feel, be specific. Let people know when they do not say the right things" - Tammy and Kenn Niebrugge (parents of Brighton James Niebrugge, 2/27/00 – 3/8/00)

"Remain as strong as possible, ask questions anytime you don't understand, keep asking until you do understand, state your feelings when you feel strongly, seek help and emotional support"- Susan Grubb (mom of Tyler James Grubb, 1/7/94)

"Stay informed and educated on local services and opportunities to learn how to handle problem areas for you and your child, and don't be afraid to always ask, ask, ask until you feel your child's needs are being met!!!" - Rene Fields (mom of Bethany Nicole Fields, 3/11/97)

"Take lots of photos and videos. We kept a disposable camera at our son's bed side, because of this we were able to get our last pictures of our son" - Linda and Richard Kryk (parents of Brandon Scott Kryk, 3/8/01 - 4/9/01)

"Try to get in touch with another parent who has gone through this as soon as possible after diagnosis even if prenatal diagnosis was made" - Wendy Barkley (mom of Jack Barkley, 4/25/95)

"When you stop comparing your child to other "normal" children you are then free to enjoy your child for what they are and what they can accomplish. They are a gift from God put here to teach us about unconditional love" - Lisa Higginbotham (mom of Sydney Cecilia Higginbotham, 1/17/98)