

CHERUBS

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



The Silver Lining

Fall 2002

CHERUBS

1109 Williamsboro St
Oxford, NC 27565



Dear Members,
I apologize for the tardiness of this newsletter, there just doesn't seem to be enough hours in the day. We have been so busy here at CHERUBS this year! Planning is underway for our 2003 CHERUBS' International Member Conference, we're working on a research article, tabulating the CDH Survey results, currently have over 1200 members in all 50 states and 37 countries, working on sponsorship and grants, and we now have an "official" office instead of working out of my home. Our new office has allowed us to have a more professional business presence and to be more active locally. We got a great deal on the rent we couldn't pass up and have received a ton of local publicity since we moved in. These are just a few photos of our new office. It took quite a while to pack, move, and unpack so I've gotten far behind on my newsletter duties.

Our mailing address will not change again. Please make note of our mailing address, it has changed since last year and the old post box address is about to expire. Please make sure to send mail only to CHERUBS, 1109 Williamsboro St, Oxford, NC 27565.

Because the summer newsletter never made it to printing, those who purchased

Tributes will be have their tributes printed in both this issue and the next issue.

We have TONS of cookbooks and t-shirts left so we will be selling them again as this year's Holiday Fundraiser. They make great gifts and it's a wonderful way to support CHERUBS. Holiday orders must be received by December 15th. You will find an insert in this newsletter with details on our cookbooks and t-shirts, as well as a form for making your annual voluntary Membership Fee Donation. We still have less than 10% of members making this donation. If you can afford to do so, please do make a tax-deductible donation to CHERUBS.

Happy Holidays to you all,
Dawn M. Torrence, President and Founder

Local Get-Togethers



Texas State Get-Together



Ohio State Get-Together



Alabama State Get-Together

No Local Get-Togethers are planned for this quarter, spring Get-Togethers will be posted in our next newsletter issue.



New Arrivals

(*siblings of Cherubs)

Logan Andrew Alexander
 Nathan Presley Bacon
 Ava Bagherian
 Brendan Jeffrey Beck
 Kyan Andrew Meer Bolin
 Benjamin Joseph Broom
 Tony Callejas
 Victoria M. Calligaris
 Tyrell James Campbell
 Jenna Rachel Cody*
 Garrett Lee Cole
 Atticus Baer Counce
 Ashley John Davies
 Hannah Leigh DiMaria*
 Shelbie Marie Donald
 Ashley Hope Footit
 Taylor-Lynn Faith Halter
 Zarek Ryan Halterman
 Hannah Alysabeth Hamby
 Blake Hanlon
 Madalyn Alizabeth Hensley
 David Hunter
 Lewis David Kelly

Dain Terence Kingston
 Aidan Lewis*
 Daniel Vinicius Hisi Link
 Gage Jonathan Manes
 Jacob Aaron Matulevich
 Margret Faith McSwain
 Justin D. Meredith
 Spencer Andrew Morton
 Kaleigh Marie Myers
 Alexander Joseph Nazareth
 Christian James Payne
 Garrett Luke Prince
 Noah Stephen Propst*
 Rebecca Jade Reid
 Madeline Jo Rutheford
 Leah Catherine Satelle
 Owen Timothy Schultz*
 Seth M. Suyama
 Joshua Carl Swanson*
 Anthony Charles Thomas
 Adam Alexander Tibeau
 Crystal Rose Tweeten
 Matthew Alexander Westpy

Logan Andrew Alexander
 Nathan Presley Bacon
 Kyan Andrew Meer Bolin
 Benjamin Joseph Broom
 Tony Callejas
 Victoria M. Calligaris
 Ashley Hope Footit
 Zarek Ryan Halterman
 Hannah Alysabeth Hamby
 Blake Hanlon
 Baby Boy Hayward
 Madalyn Alizabeth Hensley
 David Hunter
 Nicholas Lee Johnson
 Gage Jonathan Manes
 Margret Faith McSwain
 Baby Morrell
 Spencer Andrew Morton
 Kaleigh Marie Myers
 Alexander Joseph Nazareth
 Joshua T. Portner
 Leah Catherine Satelle
 Brittany Cathleen Shilts
 Harry Brian Tabbernal
 Matthew Alexander Westpy

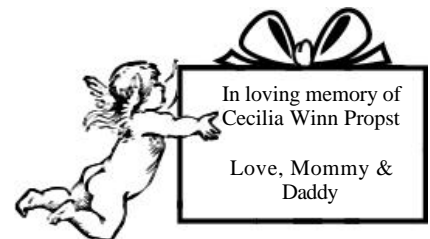
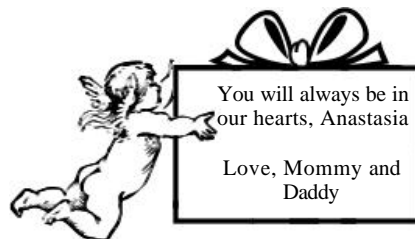
This Newsletter Is Dedicated To the Memories of:

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

Siobhan Barrett
 Rev. Fiona Bergstrom
 Brenda Dickerson-Daniels
 Joanne Dunlea
 Stan Fox
 Ramona Gallegos
 Freedom Green
 Tara Hall
 Joe Haskins

Patricia Jones
 Jason Kerley
 Danielle Kessner
 Laura Lewis
 Julia McEaney
 Mary McEaney
 Roisin McEaney
 Alicia O'Malley
 Julia Overton

Daphne Parker
 Thomas and Holly Pittard
 Elizabeth Doyle Propst
 Malini Rao
 Barbara Stovall
 Robin Sum
 Lesli A. Taylor, MD
 Judi Toth
 Jay Wilson, MD

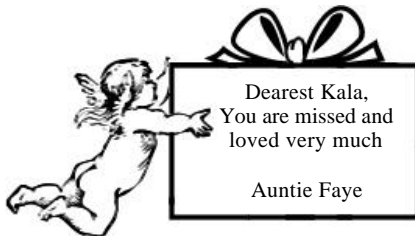


We Would Like To Welcome The Families Of The Following New Members:

Logan Andrew Alexander
 Reilly Caleb Ayers
 Nathan Presley Bacon
 Baby Boy Bauer
 Brendan Jeffrey Beck
 John Brody Bell
 Chella Jane Bell
 Melanie Marie Berge
 Kyan Andrew Meer Bolin
 Peter Lee Briggs
 Andrew Gage Burgeson
 Tony Callejas
 Victoria M. Calligaris
 Tyrell James Campbell
 Brandon Michael Carpenter
 Cassandra Leigh Carter
 Michael P. Chambers
 Baby Chapman
 Nathan Theo Clarke
 Garrett Lee Cole
 Atticus Baer Counce
 Marina E. Coury
 Hope A. Dangerfield
 Ashley John Davies
 Baby Devney
 Georgia Elizabeth Dickinson
 Shelbie Marie Donald
 Jack David Doy
 Tabitha C. Dybas
 Ashlynn Lee Elliott
 Ashley Hope Footit
 Valerie O. Funk
 Steven Gera

Kelsey Ray Glindeman/Smith
 Mani L. Gmelin
 Kaleb Matthew Groce
 Aimee M. Haas
 Taylor-Lynn Faith Halter
 Zarek Ryan Halterman
 Hannah Alysabeth Hamby
 Baby Hart
 Baby Boy Hayward
 Madalyn Alizabeth Hensley
 Owen Jude Heras
 John D. Holeman
 David Hunter
 Ian Cedric Io
 Kaleb Richard Job
 Nicholas Lee Johnson
 Khalil Malik Jones
 Lucy Katherine Key
 Baby Boy King
 Dain Terence Kingston
 Daniel Vinicius Hisi Link
 Baby Maddox
 Allyse N. Marinaro
 Alyssa Marinelli
 Grace Elizabeth Marriott
 Kyra De' Jonye Naycole Maurice
 Hart McConnell
 Margret Faith McSwain
 David Eliseo Medina
 Justin D. Meredith
 Taylor Lee Miles
 Alex Ryan Montanez

Amari Bless Moore
 Spencer Andrew Morton
 Megan G. Myers
 Alexander Joseph Nazareth
 Jacob Quinn Paynter
 Cole Walker Pittman
 Alexander John Pope
 Joshua T. Portner
 Michael Anthony Ramos
 Mary Gray Reames
 Rebecca Jade Reid
 Madeline Jo Rutheford
 Leah Catherine Satelle
 Molly Scott
 Steven Daniel Senesky
 Brittany Cathleen Shilts
 Dylan Joel Smith
 Hailey Elizabeth Steiner
 Abigail Faith Stovall
 Laura K. Stratton
 Seth M. Suyama
 Harry Brian Tabbernal
 Monte R. Taylor
 Anthony Charles Thomas
 Adam Alexander Tibeau
 Joshua Colton Walker
 Matthew Alexander Westpy
 Jordan McKay Wolbert
 Aaron G. Younce
 Zachary Douglas Young
 Christina Anne Zeitler
 Baby Boy Zundel



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

Gary and Dolores Allen - in memory of Benjamin Joseph Broom
 Alireza Bagherian - in honor of his daughter, Ava Bagherian
 Lowell Barker - in memory of Daniel John Wright
 Siobhan Barrett - in honor of her niece, Mia Blake
 Frank and Thelma Bartolf
 Hector and Juanita Becerra - in memory of Benjamin Joseph Broom
 George and Marilyn Becker - in memory of Daniel John Wright
 Devon and Christy Bell - in honor of their son, John Brody Bell
 Gina and Kevin Berta - in memory of Ryan Patrick Morrison
 Deborah Boyt - in memory of Margret Faith McSwain
 Wendy Ann Briehof - in memory of Ashley Hope Footit
 Ron and Pam Briggs - in honor of their grandson, Peter Lee Briggs
 Robert and Denise Broom - in memory of their son, Benjamin Joseph Broom
 Scott and Kathy Browning - in memory of Colton Reiger
 Kim Bylveveld - in honor of her daughter, Jordanna Liberty Bylveveld

Philip and Lisa Carter - in honor of their daughter, Cassandra Leigh Carter
Barry and Elizabeth Christen - in memory of Benjamin Joseph Broom
Donna and Dennis Clark - in memory of Elizabeth Marie Sanders
Melissa and Jason Clark - in memory of their daughter, Emily Nicole Clark
Patrick and Clare Conway - in memory of their granddaughter, Ashley Hope Footit
Jason, Victoria, Nick, & Joshua Dill - pennies from Heaven in memory of their sister, Grace Caroline Dill
Mark and Lise Dill - in memory of Sydney Olivia Matthews
Nancy and Michael Downey - in memory of Daniel John Wright
Joanne Dunlea - in honor of Mia Blake
Alan and Sheri Ely - in memory of Gage Jonathan Manes
Albert and Claudia Faraldi - in memory of their son, Christopher Faraldi
Joe and Cathy Federer & Family - in memory of Daniel John Wright
Mark and Beth Fogelgren - in honor of their son, Michael Christian Fogelgren
John and Paulette Forster - in memory of Margret Faith McSwain
Bill and Betty Gadberry - in honor of their granddaughter, Baby Girl Kirby
Jan and Toby Garza & Family - in honor of Sean Mitchell Benson
Mindy Geis - in memory of Zachary Hooegeveen
Amy Good - in memory of Daniel John Wright
Hartwell Presbyterian Church Bible Study Group - in honor of Baby Girl Kirby
Doretha O. Hawkins - in honor of her granddaughter, Allison Lane Pruitt
Betty Hegwood - in memory of her great neice, Emily Nicole Clark
Betty Hegwood - in memory of Pamela Whitworth and Helen Wertz
Mike and Debra Helfferich & Family - in memory of Daniel John Wright
Vickie Henze - in honor of her son, Jacob Henze
Thomas and Janet Hibbs - in memory of Daniel John Wright
Charles and Kathy Hogan - in honor of Anna Grace Burns
Thomas A. Holt - in memory of his granddaughter, Sarah Ann McMerriman
Mrs. Marion Horne - in honor of Baby Girl Kirby
Frank E. Howe - in memory of Daniel John Wright
Carol Howe & Susan Johansen - in memory of Daniel John Wright
Jeffrey Jones - in memory of Daniel John Wright
Muriel Van Koevering - in honor of her granddaughter, Mariah Hope Haveman
Nick, Aidan, and Sam Kouskolekas - in memory of their brother, William Anthony Kouskolekas
Tony and Leah Kouskolekas - in memory of their son, William Anthony Kouskolekas
Donald and Cathy Leesman - in memory of Daniel John Wright
Vincent Leonardis - in memory of Daniel John Wright
Rosalyn Liston - in memory of Daniel John Wright
George and Vicki Longfellow - in honor of the Carson/Longfellow Wedding Guests
Craig and Jennifer Longstreet - in memory of Olivia Raine Richards
Nancy Matheny - in memory of Olivia Raine Richards
Dawnn and Glen Matthews - in memory of their daughter, Sydney Olivia Matthews
Dawnn and Glen Matthews - in memory of Connor Ellis McLuckie
Dawnn and Glen Matthews - in memory of Grace Caroline Dill
Joyce McCarthy - in memory of Daniel John Wright
Julia McEaney - in honor of her granddaughter, Mia Blake
Mary McEaney - in honor of her daughter, Mia Blake
Roisin McEaney - in honor of her niece, Mia Blake
Matt, Amanda, and Emma McLuckie - in memory of their son and brother, Connor Ellis McLuckie
Matt, Amanda, and Emma McLuckie - in memory of Jane Olivia Lignana
Brett and Elaine Moats - in honor of the their daughter, Kristin Marie Moats
John and Deanna Motts - in memory of their daughter, Mary Elizabeth Motts
Tara Murphy - in honor of her daughter, Taylor Theresa Marie Murphy
Will and Karen Myers - in memory of their daughter, Kaleigh Marie Myers
Darek Newby - in memory of Connor Ellis McLuckie
James and Barbara Noel & Family - in memory of their nephew and cousin, Daniel John Wright
Pamela O'Bryant - in honor of Baby Girl Kirby
Mary Ann and Derek Parker - in honor of Mattson Edward Houghton
Jeremy Perrault - in memory of Olivia Raine Richards
Thomas and Holly Pittard - for their unborn son, Kenneth Edward Pittard
Gary and Beverly Popovits - in memory of Olivia Raine Richards
Leigh Prince - in honor of her son, Garrett Luke Prince
Pete and Amy Rademaker - in memory of in memory of their son's, Jonathan Luke Rademaker's 5th birthday
David and Cristal Rembowski - in memory of Olivia Raine Richards
Matthew and Kendra Roney-Grady - in memory of Olivia Raine Richards
Kimberly Schultz - in memory of her daughter, Madison Lillian Schultz
Mrs. Rosemary Schwarzwaldner - in honor of Baby Girl Kirby
St Matthew Lutheran Church Mothers of Pre-Schoolers - in memory of Benjamin Joseph Broom
Jennifer Stark - in honor of Jonah Alexander Carrier
John and Robin Sum - in memory of their daughter, Haley Elizabeth Sum
Matthew and Meg Swan - in memory of Margret Faith McSwain
Terzian Family - in memory of Daniel John Wright

Jerry and Linda Thornsberry - in memory of Benjamin Joseph Broom
 Dawn Torrence - in memory of her son, Jeremy Shane Torrence
 Judith Toth - in memory of her son, Christopher Toth
 Judith Toth - in memory of Jeremy Shane Torrence
 Louis and Toni Travelent - in memory of Benjamin Broom
 United Way of National Capital
 Stephanie Warnock - in memory of her nephew, Gabriel Kolacia
 Thomas and Donna Waugh - in memory of Gage Jonathan Manes
 Kyle Weissenberger - in honor of his brother, Travis Weissenberger
 David Wojciechowski - in memory of Olivia Raine Richards
 Dean and Linda Wright - in memory of Daniel John Wright
 Jack and Rosalie Wright - in memory of Daniel John Wright
 Connie and Jim Zengel - in memory of Daniel John Wright
 The Ziegler Family - in honor of Sean Mitchell Benson



CHERUBS State and International Representatives

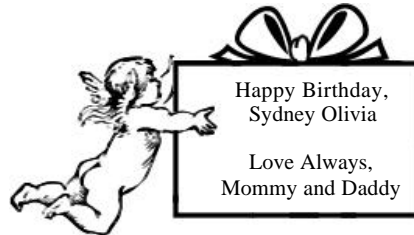
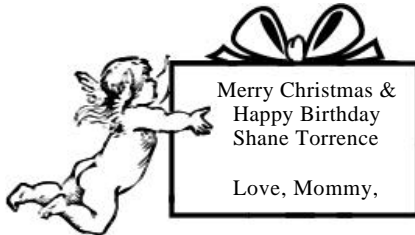
Our members are encouraged to contact our Representatives. For your Representative's e-mail address, please visit our web site. Our Representatives are helping members, encouraging new families to join, contacting local hospitals and medical professionals, and conducting such activities as get-togethers, 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, Columbia, Denmark, France, Greece, Hong Kong, Israel, Italy, Japan, Lithuania, Mexico, The Netherlands, Northern Ireland, Norway, Oman, Pakistan, Papau New Guinea, Peru, Romania, Saudi Arabia, Singapore, Scotland, Turkey, United Arab Emirates, and Venezuela. If your state does not have a representative (or even if they already do), please consider volunteering. If you are interested, please contact Dawn for more details.

<u>REGION</u>	<u>REPRESENTATIVE</u>	<u>PHONE#</u>	<u>REGION</u>	<u>REPRESENTATIVE</u>	<u>PHONE#</u>
Australia	Danielle Kessner	(03) 5135 6999	LA	Sheila Ezernack	318-645-9361
Canada	Laurelle Lehmann	(250) 838-2250	MA	Heidi Cadwell	603-465-3311
Canada	Karen Jenkins	905-852-9410	MD	Brenda Slavin	410-956-4406
Germany*	Renata Hoskins	907-245-8817	MI	Barbara Wagner	810-249-5279
Great Britain	Kevin & Brenda Lane	01553 762884	MO	Jody Hill	913-859-0389
Great Britain	Rachel Wyatt	01908 565574	MS	Melissa Clark	228-432-8942
India	Shankari Murali	6164934	MT	Elaine Moats	406-232-5038
India	Malini Rao	972-423-1871	ND*	Elaine Moats	406-232-5038
Ireland	Mick & Mary Blake	01 4921595	NE	Kristen Stiner	402-502-9310
New Zealand	Nikki Hodson	04 9724841	NH	Heidi Cadwell	603-465-3311
South Africa	Karen Howard	082 850 0851	OH	Tara Hall	614-275-0858
South Africa	Amanda Dean	+2712 5474207	OK	Scott Lenhart	918-371-3020
Spain	Sonia Winkels	34-91-3004029	OK	Jeannette Davis	405-670-9937
AK	Suellen Nelles	907-452-1769	OR	Kimberly Doades	503-625-7343
AK	Renata Hoskins	907-245-8817	OR	Marion Lansdon	360-882-5502
AL	Alicia O'Malley	256-389-8110	PA	Tammy Sincavage	610-796-7324
AZ	Anne Marie Kastner	480-837-1895	RI	John & Charlene Cassese	401-884-0269
CA	Sherry Franklin Amlin	916-428-2738	SD*	Elaine Moats	406-232-5038
CO	Dave & Clare Retterer	720-570-4022	TX	Shelly Evans	254-793-3039
CT	Toni Fiorillo	203-467-2222	TX	Monica Nedrow	817-329-2402
GA	Annette Lichtenstein	404-325-2368	TX	Malini Rao	972-423-1871
HI	Tamara Mueller	808-485-2712	VA	Elizabeth Doyle-Propst	804-293-4602
IA	Tami Logsdon	515-277-6316	WA	Marion Lansdon	360-882-5502
IL	Rachele Alessandrini	708-283-9006	WA	Grace Massie	360-933-0411
KS	Jody Hill	913-859-0389	WV	Sharon Munson	304-947-7162
KY	Lori Welsh	859-239-8970	WY	Kathy Browning	307-332-4759

On-Call Volunteers

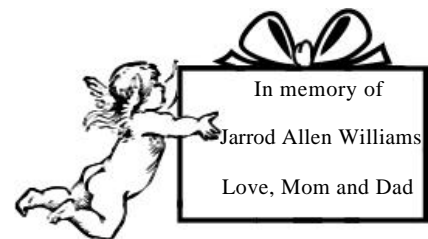
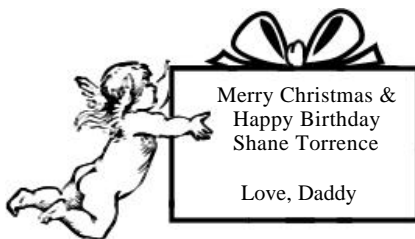
Need someone to talk to? These parents are on-call day and night to listen for any members who need to talk.

For Parents of Survivors	For Grieving Parents	For Expectant Parents
Jeannette Davis - 405-670-9937 Jolene Halbeisen - 419-333-8384 Tara Hall - 614-275-0858 Elaine Moats - 406-232-5038 Daphne Parker - 918-298-8652 Deeshia Partin - 770-919-2162 Ann Peterson - 509-735-7208 Pamela Pruitt - 864-814-7880 Amanda Dean - +2712 5474207 (South Africa)	Melissa Clark - 228-432-8942 Shelly Evans - 254-793-3039 Freedom Green - 770-479-0378 Michelle Huether - 618-853-4157 Tracy Keckler - 419-423-7422 Marion Lansdon - 360-882-5502 Dawnn Matthews - 732-458-5960 Amanda McLuckie - 214-821-7128 Karen Myers - 228-396-9647 Niki Naus - 757-887-3742 Suellen Nelles - 907-452-1769 Amy Rademaker - 616-844-4156 Malini Rao - 972-423-1871 Danielle Kessner - (03) 5135 6999 (Australia) Laurelle Lehmann - (250) 838-2250 (Canada)	Kerrie Chamberlain - 541-855-2370 Kimberly Doades - 503-625-7343 Jody Hill - 913-859-0389 Linda West - 07 3263 4203 (Australia) Sonia Winkels - 34-91-3004029 (Spain) Rachel Wyatt - 01908 565574 (Great Britain)



2002 Ebay Auction

Our next Ebay Auction will begin on January 25, 2003. Thanks to many wonderful volunteers, we have tons of autographed celebrity items arriving daily. Please visit our web site on January 25th and see what great items we are auctioning! If you would like to donate items or hold an auction to benefit CHERUBS, please contact Dawn. A huge thanks goes out to our Ebay volunteers; Daphne Parker, Robin Sum, Freedom Green, Elizabeth Doyle Propst, Laura Lewis, and Ramona Gallegos.



CHERUBS Sponsorship

We are still in need of sponsors. We drastically fell short of meeting our goal of \$100,000 by the end of this year, please help us to reach his goal by next summer. Sponsorship donations start at \$5000.00 a year and sponsors will be noted in special sections on our web site and newsletter. Our goal is to raise \$100,000 to fund 2 full-time employees, our conferences, medical research, and emergency funds for families. Please contact Dawn if you would like to sponsor CHERUBS many events and projects or if you would like to volunteer to help us seek out sponsorship.

CHERUBS' 2003 Conference

Our next International Member Conference will be held in Boston, Massachusetts on July 18-20, 2003. We need many volunteers and sponsors to help pull this off. If you would like help or are interested in attending, please contact Dawn at (919) 693-8158 or dawntorrence@cherubs-cdh.org

Thoughts of a Mom

By Maureen K. Higgins

Many of you I have never even met face to face, but I've searched you out every day. I've looked for you on the Internet, on playgrounds and in grocery stores. I've become an expert at identifying you. You are well-worn. You are stronger than you ever wanted to be. Your words ring experience, experience you culled with your very heart and soul. You are compassionate beyond the expectations of this world.

You are my "sisters." Yes, you and I, my friend, are sisters in a sorority. A very elite sorority. We are special. Just like any other sorority, we were chosen to be members. Some of us were invited to join immediately, some not for months or even years. Some of us even tried to refuse membership, but to no avail. We were initiated in neurologist's offices and NICU units, in obstetrician's offices, in emergency rooms, and during ultrasounds. We were initiated with somber telephone calls, consultations, evaluations, blood tests, x-rays, MRI films, and heart surgeries.

All of us have one thing in common. One day things were fine. We were pregnant, or we had just given birth, or we were nursing our newborn, or we were playing with our toddler. Yes, one minute everything was fine. Then, whether it happened in an instant, as it often does, or over the course of a few weeks or months, our entire lives changed. Something wasn't quite right. Then we found ourselves mothers of children with special needs.

We are united, we sisters, regardless of the diversity of our children's special needs. Some of our children undergo chemotherapy. Some need respirators and ventilators. Some are unable to talk, some are unable to walk. Some eat through feeding tubes. Some live in a different world. We do not discriminate against those mothers whose children's needs are not as "special" as our child's. We have mutual respect and empathy for all the women who walk in our shoes.

We are knowledgeable. We have educated ourselves with whatever materials we could find. We know "the" specialists in the field. We know "the" neurologists, "the" hospitals, "the" wonder drugs, "the" treatments. We know "the" tests that need to be done, we know "the" degenerative and progressive diseases and we hold our breath while our children are tested for them. Without formal education, we could become board certified in neurology, endocrinology, and psychiatry.

We have taken on our insurance companies and school boards to get what our children need to survive, and to flourish. We have prevailed upon the State to include augmentative communication devices in special education classes and mainstream schools for our children with cerebral palsy. We have labored to prove to insurance companies the medical necessity of gait trainers and other adaptive equipment for our children with spinal cord defects. We have sued municipalities to have our children properly classified so they could receive education and evaluation commensurate with their diagnosis.

We have learned to deal with the rest of the world, even if that means walking away from it. We have tolerated scorn in supermarkets during "tantrums" and gritted our teeth while discipline was advocated by the person behind us on line. We have tolerated inane suggestions and home remedies from well-meaning strangers.

We have tolerated mothers of children without special needs complaining about chicken pox and ear infections. We have learned that many of our closest friends can't understand what it's like to be in our sorority, and don't even want to try.

We have our own personal copies of Emily Perl Kingsley's "A Trip To Holland" and Erma Bombeck's "The Special Mother." We keep them by our bedside and read and reread them during our toughest hours.

We have coped with holidays. We have found ways to get our physically handicapped children to the neighbors' front doors on Halloween, and we have found ways to help our deaf children form the words, "trick or treat." We have accepted that our children with sensory dysfunction will never wear velvet or lace on Christmas. We have painted a canvas of lights and a blazing Yule log with our words for our blind children. We have pureed turkey on Thanksgiving. We have bought white chocolate bunnies for Easter. And all the while, we have tried to create a festive atmosphere for the rest of our family.

We've gotten up every morning since our journey began wondering how we'd make it through another day, and gone to bed every evening not sure how we did it.

We've mourned the fact that we never got to relax and sip red wine in Italy. We've mourned the fact that our trip to Holland has required much more baggage than we ever imagined when we first visited the travel agent. And we've mourned because we left for the airport without most of the things we needed for the trip.

But we, sisters, we keep the faith always. We never stop believing. Our love for our special children and our belief in all that they will achieve in life knows no bounds. We dream of them scoring touchdowns and extra points and home runs. We visualize them running sprints and marathons. We dream of them planting vegetable seeds, riding horses, and chopping down trees. We hear their angelic voices singing Christmas carols. We see their palettes smeared with watercolors, and their fingers flying over ivory keys in a concert hall. We are amazed at the grace of their pirouettes. We never, never stop believing in all they will accomplish as they pass through this world.

But in the meantime, my sisters, the most important thing we do, is hold tight to their little hands as together, we special mothers and our special children, reach for the stars.

Stories of CHERUBS

Fourteen years ago, I was told I would never get pregnant-- you can imagine our surprise when I discovered on July 16, 2001 that I was eight weeks pregnant. My 20-week ultrasound was perfectly normal, as was all the other testing done (I am 37 yrs old). My pregnancy was uneventful until I went into preterm labor at 32 weeks. I was measuring about three weeks ahead for my dates, and my blood tests for glucose showed borderline gestational diabetes. So they did an ultrasound to see how big the baby was. It was at that time that they discovered he had a left-sided hernia. I was alone at the hospital when they gave me the devastating news, and I had to break it to my husband.

The next couple of days were a blur as we talked to several different doctors who felt that things would be fine as all other tests on the baby were normal. We continued the pregnancy until 39 weeks when I had to have a C-section due to breech presentation, and I went into labor. Spencer was born Feb 21, 2002 at 10:30 a.m.-- we heard him cry as they whisked him away to NICU. He was initially on a ventilator but was quickly put on an oscillator with 100% oxygen. He was doing okay until the next morning. He developed a hole in his right lung (his left lung was under developed). Again with the help of a chest tube, he stabilized, and then three hours later he had a massive pulmonary hemorrhage, which eventually took his life. The doctors and nurses tried everything, but we had to make that horrible decision to turn off the machines. He died Feb 22, 2002 at 2:30 p.m.

Three months later I still struggle everyday-- why my son? We waited so long for this little miracle, and now he is gone. I spend a lot of time with the pictures we have of him, but what I would give to have him in my arms again.

I live in Canada and would love to hear from other parents who have experienced this devastating blow. I welcome mail from anyone-- just to know I'm not alone would be great.

Carrie Morton (mom of Spencer Andrew Morton, 2/21/02-2/22/02, 54 Oriole Cres, Woodstock, ONT N4T 1T1, Canada, 519-537-6473, carrie.morton@sympatico.ca)



I was pregnant by surprise with our fourth son. He was due on May 5, 2002, but I had planned a repeat C-section on April 30, 2002. I went in for my check-up at 38 weeks on April 15th, and the ultrasound technician told me my baby looked underweight, so I was made an appointment at another office for a level 3 ultrasound on Thursday the 18th of April. It was just a routine check but that's when it was found that we were having a child with CDH. We had no idea what this meant; we had never heard of it before. I guess ignorance is bliss sometimes, for had we known what we were about to get into, we would have been more frightened than we already were.

The doctor told us to be prepared for the baby to be taken straight from the delivery room because he would most likely be in respiratory distress. I was rushed over for an emergency C-section and at 7:30 p.m. on April 18th, Logan Andrew was brought into this world. He came out, and we heard him being suctioned, and then the most beautiful and strong cry came from behind the curtain. The neonatologist

brought Logan around, and we saw him for about 30 seconds, and he was rushed to the NICU. It was later that we learned that he gave them all a run for their money; he was crying so loudly and fighting, the nurses who had been called over to assist said, "Well, he seems okay," but he wasn't. His X ray showed a left-sided hernia with most of the intestines and part of the stomach in his chest cavity. He also had one multicystic kidney that was full of fluid-filled cysts and did not function at all.

He was immediately put on the vent and nitric oxide. The doctor wanted to wait a few days to see what the bowel would do on its own; he said sometimes it would come down on its own as the lung on that side is inflated. Two days later the doctor showed us Logan's X rays, and the bowel had slipped down half way and was showing a good sized lung. We were very hopeful.

On his seventh day of life, Logan was stable enough for surgery, and all went well. This was the first CDH surgery that had ever been performed at this hospital. He remained on the ventilator for five more days and was strong enough to be taken off of it. His lungs were still not strong enough, so he was put on C-pap for three days and then taken off and put on oxygen. He did well for a few days, but we were battling fluid because his one kidney was having a hard time. He was on lasix every day. Finally he was well enough to be taken off of oxygen, and it was Mother's Day. It was such a great gift, but only two days later, he was put back on because he got pneumonia.

He was being fed and was getting sicker and more yellow. They told us he was jaundiced, and it wasn't that bad so he wouldn't go under the light. After a few more days, he was more yellow and sicker than before. He was eating well, but now he was throwing up. The doctor met with us and told us that he possibly had a condition called galactosemia, where his liver was missing the right enzymes to break down galactose, which comes from lactose, so he was immediately put on soy milk. His bilirubin went down. The milk had something to do with it, but DNA tests were taken and sent off. It took over a month to come back, but it all came back negative. He did not have galactosemia. That was great.

Today is June 19, 2002, and Logan is still in the hospital and on oxygen because he has a small amount of fluid around his heart. Because of his one kidney, he has high blood pressure, but his CDH is not mentioned now. He survived, and we were told at first it was 50/50 because of his size of hernia. Logan is our little miracle. We are waiting on Logan's kidney to continue to improve, and when he reaches 70 cc's of formula by mouth, he can come home. I will send more updates when he comes home and let you know about his kidney.

I am so thankful to God for Logan. He has such a story to tell when he is older. I love him so much and thank God every day for the progress he has shown. These little CDH babies are fighters. I have also learned so much from this, but patience most of all. Wellness does not happen overnight-- it takes time. Our babies are fighting a hard fight. Could we be as strong? God bless you all and remember us in your prayers. We will remember you!

Andy & Carla Alexander (parents of Logan Andrew Alexander, 4/18/02, 1062 Laurel Glen Circle #15, Spartanburg, SC 29301, carlabel30@aol.com)

My name is Jamie-Lane Campbell. I am sixteen years old and going into grade eleven in September. My boyfriend is Troy Noseworthy; he is nineteen years old and working full-time at our local mill. We are from a small town called Fort Nelson, British Columbia. There are only about 5,000 people that live here, so when a teenager becomes pregnant, everyone knows about it.

We found out I was pregnant, and I thought my world was over. My parents were EXTREMELY angry with me and Troy because we were so young and not ready to be parents. I, personally, do not believe in abortion, so we kept the baby. I got an ultrasound done, and my doctor called me that night and informed me there was something wrong in the ultrasound. We don't have a great hospital here, so he sent me to Edmonton to the Royal Alexandra Hospital to get a better ultrasound done there.

The same day I had my ultrasound in Edmonton, the doctor informed me my baby had a diaphragmatic hernia. I was terrified. It was bad enough being 16 years old and pregnant, but now there was something seriously wrong with my baby. My parents went to Edmonton with me for support. The neonatologists explained what could happen with the baby, all the complications there could be, and what might happen when it was born.

I came home to Fort Nelson, but had to return to Edmonton once a month for check-ups and ultrasounds. For my last month of pregnancy, the doctors wanted me in Edmonton to deliver, so I had to finish school via fax for the last two months of school. On June 4, 2002, I went to the hospital to be induced because the doctor said the baby was losing weight. At 3:23 a.m. on June 5, 2002, I delivered a baby boy by a C-section. He was 20 1/2 inches long and weighed 7 lbs. 10 oz.

He was on the ventilator for the first three weeks of his life, the oscillator for the first five days. The hole was on the left side of his diaphragm, so his heart was being squished along with his lungs. His stomach and intestines were in his chest cavity. They transferred him to the University of Alberta Hospital when he was a week old. He had his surgery when he was about two weeks old, but they could not close the incision right away because he had retained so much fluid that he swelled up like a balloon. Nine days later they closed the incision. He was in the NICU for the first month and a half of his life before he was transferred to a pediatric ward.

He will be three months old on August 5th, and he is still in the hospital, but doing well. He is now 9 lbs. 14oz., and still getting bigger. The flap over the bottom of his esophagus did not form, so he cannot eat without throwing up. They inserted two tubes into his abdomen. One tube goes into his stomach to drain, preventing him from throwing up bile, the other bypasses the stomach and goes into the first part of his small intestine to feed him-- it's called a J-tube. When he gets bigger, they will do another surgery where they pull part of his stomach across the bottom of his esophagus and make a flap so he can eat orally.

Tyrell is the joy of my life, and even though he has problems, he is still my son. Troy and I are still together, and we're planning to move in together when I graduate. Ty is the most important thing to me, I would not give him up for the world. I was terrified when the doctors explained the ECMO machine, and all the problems he could have when he was born. I just kept my head up and told myself, "This is my baby; he will be strong when he's born, and I know he's going to make it."

Jamie-Lane Campbell (mom of Tyrell James Campbell, 6/5/02, P.O. Box 671, Fort Nelson, BC V0C 1R0, Canada, troysgirl__01@hotmail.com)



I was pregnant with my second child in the summer of 1985. The movie *ET* had just been released to video and there was a resurgence of E.T. dolls and toys, much like this year with the movie's release. My husband and I were on the boardwalk at the Jersey Shore, and he won one of those E.T. dolls on a chance wheel and gave it to me. Suddenly, the strangest feeling came over me, and I could not look at or hold that doll. My husband laughed, but I said it made me think of a deformed fetus, and being pregnant, I found that very disturbing.

My son, William, was born in November of 1985, with a congenital diaphragmatic hernia. It was not diagnosed during the pregnancy. In 1985, ultrasounds were not done routinely on healthy low risk 27-year-olds. I still believe that on some subconscious, sixth sense kind of level, I knew something was not quite right with this baby that summer.

I found the CHERUBS web site only this year, while searching for some information on scoliosis in kids who had this CDH defect. I found little, but as I read the stories of all the parents and children here, tears filled my eyes and still do, even as I recall sixteen years later the birth of my son.

William was born by Cesarean section at a community hospital in Northern N.J., where we live. The obstetrician did the C-section for fetal distress, as they were having difficulty with the fetal heartbeat on the monitor. Because it was a C-section, my pediatrician was

present. As the baby was removed, there was no cry, and the pediatrician took him to the table to examine him. He was able to get air into my son, but my son would not breathe on his own. Minutes later, an X ray was done. As I was in recovery, the obstetrician came to tell me that my son had a congenital diaphragmatic hernia. He briefly described this defect to me. I, as a pediatric nurse, had a good understanding of medical problems but had never heard of this. I asked if he was going to be okay. The doctor said he did not know. My pediatrician had called in a pediatric surgeon. The pediatrician was with my son the entire time, making sure he was getting air and oxygen to his brain.

The pediatric surgeon came to talk to me and my husband while I was still in the recovery room, and told me a team from Columbia Presbyterian in NYC was coming for my baby. The team from the NICU at Columbia arrived about an hour, maybe two, after my son was born. They brought him by so I could see him, and then whisked him away. My husband also left to go to Columbia with our son. I was given lots of medication and was quite snowed. I heard later that there was a traffic jam on the George Washington Bridge as they were crossing it.

Late that night, I got a phone call from my husband, Jim. He told me that Bill had made it through the surgery, but was still in critical condition. He had been talking with many of the team from Columbia and tried to fill me in on all the information, but we were both still numb with shock. I tried as hard as I could to talk in my medicated state, and I recall my mouth being so dry I could hardly form any words. We would talk again in the morning.

At that time, ECMO was considered still “experimental.” Dr. Charlie Stolar, one of the pioneers of ECMO, explained it all to us, and we had to sign a consent form that was about ten pages long in case of respiratory failure for which ECMO would be used. We did, but our son was not in need of it.

Of course, our story is very long, because our son is now sixteen years old, and we have had to face many obstacles along the way. We brought our son home in time for Christmas that year. He has had reflux and has not been a great eater. He has not required any feeding tubes but does still eat slowly, needs smaller more frequent meals (lots of snacks) and is smaller than his peers. He has had a total of five surgeries for things related to the CDH – once for adhesions, once for a rip in the original repair, once for a gallstone which was probably due to the TPN feedings, and for a pectus excavatum (concave chest) repair. Now we are facing scoliosis surgery, to take place this summer.

His most serious problem is the pulmonary hypoplasia. His lung function is at times poor, and he also has asthma, although the asthma has improved a lot over the past year or so. I still listen for his cough at night and still check him more often than I do my older daughter. We still see the pediatric pulmonologist at Columbia regularly. I asked him recently if he could just transplant one of my lungs to Bill. He said it could be done, but that Bill is not even close to needing that.

I remember the day we brought Billy home, in December 1985. The Director of Pediatrics sat down with us and asked us to talk about all we’d been through. Then he told us to take him home and love him just like any other kid. I also remember the morning after he was born, when I learned that he had lived through that first night, I decided that if he could go through all that then I had to do everything possible to give him the absolute best that I could. I started using the breast pump so that I could breastfeed, and I did for nine months.

We have been so very, very lucky to have Bill but also have had some very difficult mountains to climb. Somehow I thought that when I brought him home that first time, it was all okay and would be from then on. Of course, I was wrong. Over the past years I have come to accept that there will always be higher mountains with Bill, harder times, more worry and heartache. And, of course, he is so worth all of it.

I should say that Bill has a very typical teenage life. He is a sophomore in high school, an honor student, and wants to go into biomedical engineering. He is in the band, tried out for the fencing team but got cut. He bowls, builds things, plays video games with his buddies, and takes his little boat out on the lake in the summer. He argues with me all the time, especially about his independence, and tells me that I hold him back. He knows I worry about him. I know when he sleeps over at his friend’s house, the next day we will be using the nebulizer, and he’ll probably be coughing. I wake up in a near panic still when he coughs at night. I take him out for driving lessons. I worry about everything.

Of course, as all mothers of cherubs must know, every bit of heartache is so much more than worth it. Bill and I share a sense of humor and we watch movies together and his smile and laugh just make my life worth living.

I found this site as I was looking for information on scoliosis and CDH. Although my cherub is much older than most, I remember when he was a baby, it was so difficult for me to imagine the future – him as a teenager, going to high school, learning how to drive. I was always somehow afraid we might not see it. So I hope that my story gives hope to those parents, who like me, are a little fearful of the future.

Nancy Kowalski (mom of William James Kowalski, 11/8/85, 409 Riverview Rd., Pompton Lakes, NJ 07442, 973-831-1951, nk2118@aol.com)



Hi, I am Heather Fuhr. My fiancé, Troy Halter, and I had our third baby on August 25, 2002, at 1:00 a.m. in Madras, Oregon. My pregnancy was normal, except for the fact that I have a heart problem. When our daughter, Taylor-Lynn Faith Halter, was born we didn't know there was anything wrong with her. She wouldn't breathe on her own, so the doctors took her away. My doctor came and told us that they thought her heart was on the wrong side. They intubated her and took X rays to make sure they got the tube in the right spot. When they did, they found her congenital diaphragmatic hernia. It was on her left side. The doctors decided to call in life flight since where she was born wasn't equipped to handle her hernia. They picked her up at 2:00 a.m. and flew her to Portland, Oregon to Legacy Emanuel Hospital. There they put her on a ventilator, nitric oxide, versed, fentanyl and dopamine.

When she arrived at the hospital, they had her on a normal ventilator, but a few days later had to be put on a high frequency ventilator. She had pulmonary hypertension, systemic hypotension, pulmonary hypoplasia, and respiratory failure. This whole time all we got to do was look at her. We didn't get to hold her, not even after she was born. On August 28th, she had

surgery to repair the hernia. It was supposed to last two hours -- it lasted four hours. Troy and I sat on pins and needles the whole time. When they finished, the surgeon came and told us that they got everything back, and they did not have to use gortex to patch it. There was enough skin to fix it. But they did tell us that her left lung was the size of a half dollar and her right was much smaller than it should be, but not as small as the other. We were told that she was fine otherwise. She had to have one blood transfusion and one dose of exogenous surfactant. She was able to come off the nitric oxide on September 7th. She was then taken off the ventilator on September 10th.

We finally got to hold her two days later. She had a nasal cannula, but other than that she looked okay to us, and we thought we could take her home soon. Boy, were we wrong. We had no idea what was to come. Taylor-Lynn was started on bottle feedings right after she came off of the ventilator. At first she did okay, but she slowly stopped nipping. We were so frustrated. The doctors decided to put a g-tube in. We weren't too sure about that idea at first. I was afraid it would hurt her or that it would get pulled out. The doctors assured me that they had done this a hundred times and that she would be okay.

She had her first g-tube surgery on October 1st. It went well, and they planned on discharging her on the 8th. When we went to take her home, she had green and yellow stuff coming up her tube. The doctor decided not to let her come home. They took X rays and found that they had put a hole in her small intestine and that it was her stomach acids that were coming up her tube. They took Taylor-Lynn in for emergency surgery. The surgery took five hours, and they had to remove a two inch section of her small intestine. Once they did that, she was fine with her g-tube.

Taylor-Lynn finally came completely off oxygen on October 12th. She still had problems with nipple and reflux, so they put her on Prilosec and Reglan. The surgeons and NICU doctors decided she could come home on October 24th, one day shy of two full months in the NICU. I was in Walla Walla, Washington with our two other kids and did not have a way to Portland to get her. A wonderful program called Angel Flight flew to Walla Walla to get me and then flew us home from Portland. Taylor-Lynn is now home and happy. She has her big brother, Chance, and big sister, Jasmine, to play with her. We are still having problems with her g-tube-- she got a staph infection around it, and she is still on Reglan and Prilosec. But other than that she is doing wonderfully. We go back to Portland in December to get a button feeding tube put in, and she has to be seen by OT/PT. But for now we are trying to take things one day at a time. It has been a hard road to travel and will continue to be one. But we love our girl and finally have her home where she belongs.

Heather Fuhr (mom of Taylor-Lynn Faith Halter, 8/25/02, 711 S 3rd Ave., Walla Walla, WA 99362, 509-526-3606, booboo993622002@yahoo.com)



This is a picture of my daughter Chella Jane Bell. She was diagnosed as having a diaphragmatic hernia when I was 37 weeks pregnant after a routine scan.

I was complaining of having really bad backaches and was sent for an ultrasound. I sensed there was something wrong as the radiologist spent quite a lot of time looking at the ultrasound. He fetched a colleague in to come and have a look at the ultrasound. All I kept saying was, "Is anything wrong?" I was on my own and got quite anxious. They fetched a consultant who told me that the baby had shadows around the heart, and they weren't sure what was wrong. It was a week before Christmas day. They made me an appointment for Christmas Eve for a detailed ultrasound. I came away from the hospital in tears. In a daze I rang my husband at work, crying, thinking there was something wrong with our baby's heart. The week went by very slowly not knowing what was wrong.

The day finally came around for my ultrasound where they found that our baby had a diaphragmatic hernia. I asked if they would be giving me a Caesarian, but they said no. While the baby was still inside my womb, it would be OK; the problem would be when it was born.

I was shown around the neonatal unit, all the Christmas decorations were up, the tiny babies in their incubators. I was due to deliver on the 4th of January 1988. I went into labour on Wednesday 6th of January 1988 at 9.30 at night. I didn't have a difficult labour-- just pethidine for the pain-- and Chella was born the following morning at 8.10, weighing 7 lbs 8 oz. I had a quick glance at her, and they took her away. The paediatrician came to see me sometime after to tell me that she had been taken to the ICU. I eventually saw her when she was two and a half hours old. That same night at 7.30 she was operated on. We saw her again before she went down for surgery, then again around 11.00. She looked so sweet, even with the ventilator and all the tubes around her. She spent six days on the ICU, then came back up to the maternity ward with me. Everything was a success. She's now a 14-year-old with a very delicate scar on her left side of her tummy. She has one sister, age 12, and a brother, age 9.

Jane Bell (mom of Chella Jane Bell, 1/7/88, 111 Querneby Road, Mapperly, Nottingham NG3 5HW, Great Britain, 0115 9522783, leggyjane@hotmail.com)



My daughter's name is Shana Hagood. She was born with a congenital diaphragmatic hernia on June 20th, 1983. We had no idea she even had a hernia until October of the same year. We were in California visiting my mother-in-law when Shana became very ill on a Saturday, mid-October. She had symptoms of vomiting bile and being very listless. We called the doctor and were told to keep an eye on her-- it was possibly the flu. About two hours later, her lips were becoming discolored, and we knew it was time to take her to the hospital. They ended up transporting her to a children's hospital. After four days of going from the diagnosis pneumonia, then cancer, even diaphragmatic hernia (this was the first diagnosis but we were never informed of that because it was never agreed upon by the residents), they finally decided to do exploratory surgery. They found a very small hernia, the size of the eraser end of a pencil. Her small bowel had become lodged in the hernia and had no circulation during the past four days. The majority of her small bowel had died, but they left 30 centimeters to see if they could save as much as possible. After two more surgeries, she ended up with ten centimeters. This was a blessing for us, because we had been told she would need at least 10 centimeters to even be able to survive, and if she did not, we needed to make a decision on whether to prolong her life.

Shana now was an infant with what they called extreme short bowel syndrome. She was in the hospital for three months straight, during which time she had two bowel obstructions from scar tissue (two more surgeries), a fistula and a fever off and on. The longest I was able to take her home was for about ten hours on Christmas Day. Shana continued to have problems with getting the flu and fevers for the next two years. Her first central line lasted for five years (infection free), which was probably too long; the surgeon said it was stuck, and he couldn't get it out, so he cut the tip off and left it in there with a few extra stitches to keep it in place.

There have been so many trials, triumphs, tears, and yes, joy through the years, one would need to write a book. I have to tell you the funniest story was when we were at the grocery store, and Shana was in the child seat in the cart. I was lifting her out of the seat and happened to look down and saw this tube looking thing sticking out of one of the bars on the seat. I had to look real close (wondering what the heck it was) and realized that her gas trostomy tube had gotten wedged, and when I had lifted her, I had yanked it out. She hadn't made a peep, and it turned out we never told the doctors for three days.

They were tube-feeding her progestimal, and she would wake up every morning and throw it up, and it was actually causing her to lose weight. Come to find out she was one of those few that have a reaction to that formula. We never did get another one. Shana has been through a broviac, hickman, two ports, a cathlink, and I don't know if I remember all of them. She eats like a horse-- loves big juicy steaks (with lots of fat), potatoes, veggies, pastas, some fruit, potato chips, popcorn with lots of butter, and pretty much everything and anything. Her favorite two things are eggs and dill pickles. She does not care for sweets or peanut butter.

She is now a beautiful young lady of 19, is 5' 7" tall and is definitely on the slim side. Everyone tells her she should be a model. She graduated from high school this year (she was held back in the 2nd grade) and is excited and nervous about going out on her own. She is currently TPN-free due to a line infection (recurring). She is having her line removed next week. We are praying for her independence from TPN, but time will tell. I guess she will need to take one day at a time; isn't that all any of us can do? I remember when we started this journey, not knowing whether Shana would even survive, and now I look forward to watching her fulfill her dreams and hopes in life. When you go through such a trial in life, you want to just embrace each day. My advice – be your child's best advocate at all times, be persistent, never be afraid to ask questions and make decisions on your own, and lastly, have a nurse for a good friend!

Vonda Hagood (mom of Shana Kay Hagood, 7/29/83, 35656 Fern Forest, Soldotna, AK 99669, 907-260-3168, vhagood@ideafamilies.org)

My name is Denise. My daughter Aimee just turned sixteen years old this past April. The day after Mother's Day this year, she started to complain of severe abdominal pain. We took her to the doctors, who became suspicious when they heard no bowel sounds and didn't hear her breathing on the left side.

They ran many tests that night, the most important a chest x-ray, where they could see only about 30% of her left lung. They ordered a CT Scan and that's when they saw that her large and small intestines, her bowels, and her spleen were in her left chest cavity under her lung.

The following morning a surgeon, Dr. Katlic, looked over her tests and rushed her into surgery. He was worried about blood supply being cut off to her organs. After two hours in surgery, Dr. Katlic came out and said she had done wonderfully. He made only one incision from her diaphragm bone to her belly button. He said all her organs were fine and were back in her abdomen. He did say there was barely enough room in there for them to fit. Until this point we had been under the impression that this was caused by a trauma, but we didn't have a trauma. During surgery, Dr Katlic found out differently. Since her left lung never fully matured, he is certain that she was born this way.

She spent two and a half days in ICU, with wonderful care and another seven days in the hospital. She had a very hard time eating and drinking and lost 12 lbs. But she has been home now two weeks and is doing great-- eating, walking around, feeling fine. She had a chest X ray two days ago, and it looks as though her left lung has expanded a little more. Everyone seemed so amazed by her surgery and her recovery, and we didn't know why until I read your site. I am so amazed that she lived this way for 16 years. I had never heard of CDH until a few weeks ago, and I can't believe how much worse this could have been.

Denise Haas (mom of Aimee Haas, 4/7/86, 534 Delaware Ave, West Pittston, PA 18643, 570-603-9643, dee362000@msn.com)



My husband, Brad, and I were married on June 30, 2001. We weren't trying to get pregnant, but at the same time, we weren't preventing it either, so we made the decision that whenever it happens it happens. We found out I was pregnant in August, and we were both very excited along with our family.

I didn't have any morning sickness or normal symptoms. At 19 weeks, I went in for a routine ultrasound and was diagnosed with having a large right ovarian cyst. It was about the size of a cantaloupe that had to be removed right away. The baby survived that surgery and was kicking all over the place with all the room it had now. We went in for another ultrasound at 24 weeks – we thought everything was normal because the technician can't tell you anything. We had an appointment with the regular Ob/gyn to go over the results, and we were told that there was fluid around the baby's lungs, and he wanted us to be referred to a specialist to have a level 2 ultrasound done to see if everything was OK. Our doctor thought that it would be normal and not to worry.

We went to Arnold Palmer Children's Hospital in Orlando, and we were told that we were having a girl, but that she had a right-sided CDH and that her chances for survival were not good. With the fluid in the chest, the lungs were collapsed and would not be able to expand. He said that the only thing to do is wait, and at the birth, they would put in a chest tube and drain the fluid, then hopefully the lungs would expand. She was given a 30% chance of survival. We saw that doctor on a Monday, January 21, 2002. We called family and friends and asked everyone to pray.

I worked in a daycare with a parent who used to work with my mother-in-law in a pediatrician's office. Dr. Whele was told of the baby's condition, and he knew of a doctor in Tampa that helped CDH babies. He called my mother-in-law and gave her the website; she then contacted Mary Allen by email on a Friday night, and on Sunday she got the email saying I could be a candidate for surgery. Monday morning Dr. Quintero called me at work to tell me about the surgery and our other options. We were given an appointment for an extensive ultrasound to be done the next day. This ultrasound was to see if there was any lung growth to work with.

That night, Brad and I made the decision that if this was the only possible chance for her to survive then we had to do it. The ultrasound lasted four hours, with a different diagnosis. Dr. Quintero said that she didn't have a true CDH but had an eventration, that is a very weak diaphragm without any organs in the chest cavity but with severe pleural effusion. He told us that rather than put in the tracheal ligation, he would put in a

shunt into her chest to drain the fluid and allow the lungs to expand. There was a 40% chance of the baby pulling out the shunt that could mean another surgery to replace it. This was the best news we could have hoped for, so we scheduled the surgery for January 30, 2002. The surgery went well, and Friday the 31st, we went down for an ultrasound and saw that instead of little slivers of lungs her chest was filled with lung tissue. Her lungs expanded overnight with very little fluid left in the chest.

Every week we had to go to Tampa for ultrasounds-- each time it kept getting better and better. Three weeks after having the shunt put in, they realized that she pulled it out. Since there wasn't much fluid left, they decided to wait and see if it came back before they decided to do surgery again. We were thankful for that. Luckily, the fluid never came back, and each week she got better, and her chances of survival went up. It was then time to schedule the date of the C-section, and the best time for Dr. Quintero was on April 9, 2002. Her chances of surviving were excellent, and we were told that once she was born, she would be ventilated, and after she was stable, she would have surgery to repair the diaphragm 24-48 hours later, with a possible hospital stay of two weeks. We were prepared and had family and friends waiting for her birth. April 9th came and at 8:02, Faith Marie was born. She started crying right away, which surprised everyone. They tried twice to ventilate her, but she refused, so they decided to give her a chance to breathe on her own. Her Apgar scores were a 7 and an 8. She was taken up to the NICU where she was weighed and measured. She was 6 pounds 7 ounces and 19 3/4 inches long.

After many ultrasounds and a chest X ray, the neonatologist and pediatric surgeon came in the room and told us that she had a small hole in the diaphragm that was allowing the liver and part of the intestines to come thorough. To stop more from coming through, they decided to put her on a vent but still allow her to take her own breathes, but the vent would only allow the air to go into the lungs and no where else. She was stable all through the night, and at 2:30 p.m. April 10th, went into surgery to have the hole repaired. That was a success, and we were told that she would still be on the vent and paralyzed for at least 12 hours.

Once again she refused and started moving around and breathing normally after a few hours. She was taken off then and never had to go back on. April 11th, we finally got to hold her and on the 12th, she started feeding. We were given the best news on Sunday, April 14th, that the next day she would be coming home.

She proved everyone wrong and came home within six days of being born and thriving. She is a little slow at gaining weight but is doing well other than that. Since Dr. Whele found Dr. Quintero for us, we decided to have him be her pediatrician. If not for him, who knows where we would be right now. We love everyone who took care of Faith at St. Joseph's Women's Hospital and Tampa Children's NICU nurses and doctors. They are the best, very caring, and many of the nurses had children in their family who had to be in NICU, so they knew how it felt. Cherubs have also helped as a wonderful support system, and it helped seeing other children who had it and survived.

Brad and Amy Atkins (parents of Faith Marie Atkins, 4/9/02, 31 Forest Dr, Davenport, FL 33837, 863-420-4294, acatkins2001@aol.com)



It is so wonderful that there is a place we can go and be with those that suffer in the same way that we do. Our son, Nathan Presley, was born on May 5, 2002. We were ready to have a healthy baby, and that is what we were told at all of the check-ups—"He looks great." Well, his health was far from great. We had never even heard of CDH before Nathan, and we have been around a whole lot of babies. Our eyes are opened now.

Just after Nathan was born, there was a team working on him of about nine people. They tell you not to be alarmed, but when you have been in infertility process for nine years, and you see a baby born to you that you never thought you would have, it does not take much to become alarmed. It did not take them long to tell us that we would be losing our son to a defect called a diaphragmatic hernia. "What is that?" we wondered. After we told each other, "They can fix him," Nathan passed away and went back to the Lord in about two hours. We were left to try and understand what happened to our so perfect baby boy. We may never understand, but we held our miracle baby and he taught us about life.

We love you Baby Nathan, so much it hurts-- Mommy and Daddy

Thank you for doing all you do for this cause. When we are strong we will find a way to help.

Jeff and Nicole Bacon (parents of Nathan Presley Bacon, 5/5/02-5/5/02, 7708 59th Avenue North, Crystal, MN 55428, NPB5502@aol.com)

At between eight and nine weeks gestation, I started bleeding and was sent to the emergency room. They saw the baby's heartbeat and could find no explanation for the bleeding. A few days later, earlier than when it was supposed to be, I had my first appointment with the OB. She saw debris in the uterus, but could also offer no explanation for the bleeding except the possibility of a non-viable twin. At around sixteen weeks, I went for a routine sonogram that my provider requires. He immediately showed us that he was a he. The sonographer was acting funny and called in the radiologist who also behaved strangely. Neither would tell me anything. My doctor called the next day to tell me that they thought they saw fluid around the baby's heart and that they would be sending me to a perinatologist.

It took several weeks to get an appointment with the perinatologist because the area only has two, and one was out due to a car accident. So, I spent several weeks thinking my baby was going to die of fetal hydrops. When I finally saw the perinatologist, he was rude, but did a sonogram and indicated that he did not see fluid around the heart, but that the heart was moved over towards the center. He recommended that I get a better sonogram done at the local Genetic Center and that I see a doctor within the network who specialized in fetal echo technology. I was able to go to the Genetics Center that same day. They spent hours doing the sonogram and even called in a doctor from Johns Hopkins to look at the results. She indicated that there was either a malformation on the lung or, and she thought this was unlikely, a diaphragmatic hernia. She recommended

amniocentesis to rule out any chromosomal problems, even though I was only twenty-seven years old. My provider and the perinatologist agreed, and they performed it that same day. They also had me meet with a genetic counselor, which I resented, as she was barely older than some of my students, and I didn't feel she was mature enough to be counseling me on anything. They said it would take ten days to get the results back from the amnio and that they would call me when they were in.

Ten days later I got a call saying the results were normal with no chromosomal problems. When I saw the fetal-echo doctor, he said that from what he saw, the heart was normal and fine, but that it was right-oriented. The Genetic Center recommended a fetal MRI at Johns Hopkins and my provider agreed. By this time, the baby was to be named Jacob Aaron. On the day of the MRI, Jacob was moving like crazy, which he did for every sonogram, or every time they wanted him to be still. Several days after the MRI, the perinatologist called to tell me that Jacob had a diaphragmatic hernia, that his chances for survival weren't good, and that he wanted me to set up appointments with both the Children's Hospital in DC and with the Children's Hospital of Philadelphia because they did in-utero surgery. After setting up the appointment with Philadelphia, we found out that they no longer did the in-utero surgery, so my provider cancelled that appointment but assured me that we would have a head to lung ratio done somewhere else.

I met with the surgeon from Children's hospital, and we discussed possible outcomes. He said that with no other problems and the fact that lung tissue had been seen in previous sonograms, the baby's chances looked good. Before he could give me a better prognosis, though, he wanted the radiologist there to look at the sonograms and the MRI. He called me later that week to tell me that all the radiologist saw in the chest cavity were the intestines and that they had the tenacity to move in and out which should allow the lungs to develop, therefore he felt the prognosis was very good. A few weeks before Christmas, I had another sonogram with the radiology department at my provider's office. They acted very strangely again, despite the fact that they already knew that I knew something was wrong. When I got home, I called the nurse assigned to me through my provider's high risk program and told her what had happened. I was assured that I would have an answer the next day. I did not. By this time I had weekly appointments, which alternated between the perinatologist and a regular OB doctor. At my appointment with the regular OB doctor, I indicated what had happened at the sonogram and that the perinatologist had not chosen to get back to me after promising to do so. So she pulled the results. They simply indicated that there was additional fluid, which is normal in babies with this malformation. The next day that perinatologist called to tell me what I already knew.

The following week I had a sonogram with him that was supposed to be sent with me to my appointment at Children's the week of Christmas for my final consultation with the surgeon before the baby's birth, and for a head to lung ratio to be calculated by the radiologist at Children's. During this sonogram, the perinatologist had another doctor in the room with him. I felt as if I was their science experiment, as apparently neither had seen a diaphragmatic hernia in about twelve years. Also during the sonogram he began to use medical terms that I am sure he thought I did not understand, and at one point he indicated that the stomach was also in the chest cavity. I asked him about this, and he seemed shocked that I understood what he was talking about. I'm not stupid; I had been conducting my own research even before they made the final diagnosis. He indicated that he did see the stomach there. I got upset and started to cry. After the sonogram was over, I went into the adjacent bathroom to wash my face. When I came out, he looked at me and said, "Well, you know only about a third of these babies live." I was appalled. That may have been the case when he graduated medical school back around the time I was born, but from everything I had read, fifty percent was about average and even that wasn't entirely accurate because they should be evaluated on a case by case basis. Then, the day before my appointment at Children's, the high risk nurse called to tell me that the perinatologist had accidentally taken my sonogram films with him on vacation. I was irate. He indicated to her that I didn't really need them and that he would be sending a written report to the surgeon and speaking with him the morning of my appointment. Needless to say, I was not very fond of this man by this point. While I appreciated the fact that he saw his own shortcomings and sent me out for consultations that he couldn't have possibly evaluated himself, he still managed to be infuriating in his lack of bedside manner and organization.

At the appointment with the surgeon, he told me that even without the sonograms, the radiologist indicated that the head to lung ratio as per the MRIs looked good. He also recommended steroid treatments for the baby's lungs and an induction, so that the transport team and he would be ready. I had to give birth at Washington Hospital Center, which is next door to Children's, and then he would be transported. He still indicated that he believed that Jacob's prognosis was good. That afternoon I had an appointment with the regular OB. She gave me a betamethazone shot and indicated that I needed to have another twenty-four hours later. She also scheduled the induction for January 22nd. I would be admitted the night before so they could ripen the cervix before starting the pitocin. Plus, by this time I was having twice-weekly non-stress tests, which Jacob was passing with flying colors. After the steroids, my weight had dropped, but they weren't concerned as I had plenty of it. In addition, my edema all but went away. But at my last (thank God) appointment with the perinatologist he ordered a preeclampsia test because he thought my blood pressure was high. All of those tests came back normal, but he put me on bed rest anyhow. I still think that my blood pressure came up high at appointments with him because I had to see him.

At my next appointment, only a few days later, with the regular OB, my pressure had dropped ten points. I went in to the hospital at 12 A.M. on January 22nd for the induction. Jacob was born at 6:10 that evening. Although we had been told he would not cry and that he would be blue upon arrival, he did cry and his color was good. In fact his Apgar scores were that of a normal baby. He was intubated at two minutes of life. The neonatologist placed him on my chest long enough for me to kiss him four times before they took him to their NICU to prepare him for transport to CNMC. After he was loaded into the transport incubator, the transport team came by my room so that I could say goodbye to him. I was allowed to reach in and touch him. He was not moving, as he had already been sedated. I cried for the rest of that evening. I wanted to be with Jacob. I wanted everything to be normal. My mom was allowed into the NICU to spend some time with Jacob after he arrived there.

At about 2 A.M. on the twenty-third, CNMC called and requested my consent to put Jacob on ECMO. I gave it, knowing that I would do anything if it meant Jacob would make it through this. The next morning I told the hospital where I gave birth that if they didn't release me, I would release myself. They released me, and I went with my mom and her husband to the NICU at Children's. When I saw Jacob lying on that warmer, I couldn't control my tears. I was allowed to touch him although I thought I wouldn't be able to. Even though I had prepared for this, there is no preparation in the world enough to see your baby lying there with tubes coming out of his neck—knowing that a machine is responsible for his life. I went to the Ronald McDonald House to check in. I knew I would not return to my home without Jacob.

Then I returned to Jacob's bedside where I stayed. I would leave at night to go home and sleep, and I would leave when parents were not allowed in because of rounds. I also would leave for about a half an hour for lunch. Aside from that, I never left Jacob's bedside. He was on ECMO for eleven days. I stroked his hair and held his hand the whole time. I also put lotion on his body to combat the dry skin. It was incredibly hard watching the

nurses do what I should have been doing as Jacob's mother. I also went to the chapel every day and prayed. I pleaded with God at Jacob's bedside to save Jacob. I also allowed visits from the hospital chaplain, and we prayed together at Jacob's bedside. I went home every night and prayed as well.

When he came off of ECMO, I was finally allowed to change his diaper and give him his sponge baths. I can tell you I will never complain about changing a diaper ever. It is a privilege when you are not allowed to do it. After coming off of ECMO on the third, Jacob was supposed to have his surgery on the fifth, but his blood was acidotic. They treated it with sodium bicarbs, and on the sixth one of the surgical residents came to me and asked if it was okay if they did the surgery that same day. I consented. I called my mom, and she got there before they took him for his surgery. I cried as they packed him in the transport incubator yet again. He was almost too big for it. I was so scared-partially because that incubator looks something like a small coffin when it is open. I was allowed to walk with him down to the OR, and they let me touch him one last time before they took him in for his surgery. I spent the whole time in the waiting room crying and praying.

After a couple of hours Dr. Newman came to the waiting room and told us everything had gone well and that Jacob had done great. He also told us that Jacob had enough of his own healthy diaphragm to sew back together as opposed to using a gortex patch. In addition, they saw a small, but healthy, left lung. I had been warned that Jacob would probably get sicker before he got better after his surgery and to not be surprised if he had to go back on ECMO or if he had to receive nitric oxide. They said the first seventy-two hours would be the most critical. He made it through that time with no complications and without getting sicker. He was on the ventilator for another eight days after his surgery, for a total of twenty-four days of intubation. Hearing him cry was amazing. Just two days before he was extubated, I got to hold him for the first time. He spent a total of seven weeks in the NICU. The last week was spent figuring out the severity of the reflux.

The day he was discharged, the doctors told me that the day before they had found a ventricular septal defect (a small hole in the heart) and a tricuspid valve aneurysm. He came home on reglan and zantac for the reflux as well as on oxygen (1/8 of a liter) and an apnea monitor. He came off of the oxygen on April 19, 2002. He is still on medications for the reflux and is not always fun to feed, but he is growing as he should and developing as he should. He sees a cardiologist regularly who believes that the hole in his heart will close on its own eventually. Jacob is happy and healthy with no developmental problems thanks to Children's Hospital, the NICU team, my mom, and God. I love Jacob more than anything in the world, and he was worth every moment of sorrow.

Jessica Matulevich (mom of Jacob Aaron Matulevich, 1/22/02, 8904 Footed Ridge, Columbia, MD 21045, 410-715-6840, JAM0201@aol.com)



[Please note: To all the dads out there... this story is told from a mother's point of view. My husband had his own experience with Riley's CDH that is very different from mine. He was the one who delivered him to the wonderful doctors at Children's Hospital. He was the one who barely slept for three days because he was afraid to leave our son alone. He talked to him, sang to him, and held his little hand. He was the one that kissed him before he was taken into surgery. I often wonder what he was feeling at Children's Hospital, late at night, exhausted and worried. I'll never know for sure – all I do know is that the experience has touched both our lives forever.]

Our pregnancy was pretty uneventful. The only drama was that I failed the triple-screen blood test and had to go to Denver for an amnio and a high-level ultrasound. It was a big shock – in my ignorance, I never thought that I would have anything but a perfectly healthy baby. We worried and panicked for ten days until the results came back from the amnio – and luckily, everything was normal. At 36 weeks, we had an unscheduled ultrasound because my blood pressure was high, and they wanted to check the size of the baby and the amount of amniotic fluid. Again, everything looked terrific.

My water broke the day before my due date, and we rushed to the hospital at 3:00 in the morning. After a lot of pushing and some help from forceps, Riley was born on Sunday, August 12 at 4:33 in the afternoon. We were so surprised and happy to have a boy. My husband, Devin, was so excited to have a son that he

immediately started announcing his full name to everyone – even though we hadn't formally agreed on it!

Riley scored two 9's on his Apgars. I didn't get to see him right away because it had been a stressful delivery, and they whisked him away as soon as he came out. They brought him to me for about 30 seconds after they'd cleaned him up, and I got to see him, but his eyes were closed, and he had an oxygen mask over his mouth (we live at high altitude). Devin went with Riley and the doctors to do some routine tests. They came back a little while later, and our pediatrician, Dr. Fahy, told us Riley was breathing very rapidly. He said that it was extremely common in the altitude and not to worry. The doctor said Riley would have to be on oxygen for at least 12 hours, and that he was sorry we wouldn't be able to have him with us the first night. We assured him that it was okay; we just wanted what was best for Riley. As he was leaving the room, Dr. Fahy said, "Before I go home, I think I'll do a chest X ray just to make sure his lungs are fully inflated."

Some time later, maybe 45 minutes, doctors and nurses started hovering around us and acting a little funny. My OB-GYN was still there, and he looked upset. Devin was anxious because they had asked him to leave the nursery. Finally, Dr. Fahy came into the room and said, "Well, we found something on the X ray we weren't expecting." Then, he held the X ray up to the window and said (and I'll never forget these confusing and horrifying words), "Now... see here, how the heart is on the wrong side of the chest?" WHAT?!

The rest of the day was just a blur, and I only remember bits and pieces. There was lots of talk about how they (the doctors) never would have guessed it – Riley was so pink and healthy looking when he came out. There was talk about the Flight-For-Life helicopter that was coming from Denver. There wasn't going to be enough room on the helicopter for Devin so he started making plans to drive to Denver (four hours away) on the two hours sleep we'd had the night before. He finally agreed to let a friend drive him. We were waiting for our friend to show up when we got the news that the helicopter had turned around and gone back to Denver. It ran into bad weather over the mountains. They were going to have to wait for their airplane to return from Wyoming. It was very stressful because we didn't know how stable Riley was, and we wanted him to get to TCH as soon as possible. The good news was that the plane was big enough that Devin could go with Riley.

There was talk about how wonderful the doctors are at Children's Hospital in Denver. There was talk about how the Flight-For-Life people would put Riley in his own safe "space capsule" for the flight, and how they would take amazing care of him. There was lots of talk about diaphragmatic hernias – and it was so weird because, I mean, who had ever even heard of CDH? We were definitely in shock those first few hours.

Finally, five hours after Riley was born, the plane arrived. I was wheeled into the room to say goodbye to Riley – he was under an oxygen tent and again, his eyes were closed. I sang him a little song that we had listened to every day during my pregnancy and then that was it... they left. I had a Polaroid of him that I kept by my bed.

Devin was with Riley for the first three days of his life almost every single minute – I wasn't able to leave the hospital until the day he was scheduled for evening surgery. Devin called me while I was en route and said there had been an opening in the O.R. and that they decided it was best to take him early. I was so relieved because I was anxious for him to have the surgery, but I was also panicked because I was afraid I might never get the chance to see my baby with his eyes open. When I got to the hospital, I found Devin in the waiting room, and about 15 minutes later, someone came out to tell him the surgery had gone well. A half hour later, we were both with Riley in the ICU.

They rest of the story is remarkable. We moved into the Ronald McDonald house for what we thought was going to be a long stay. But in a week, we were on our way home with Riley. They kicked him out of the hospital for being so healthy. We took him home on oxygen because we were traveling to a higher altitude, but he came off of that in six days. His doctor has referred to him as a "normal baby who had some stuff in the wrong place." Although our time at Children's Hospital was brief, I don't think we'll ever forget how it felt to be there – the sounds, the smells, everything.

I don't know why or how we got so lucky. Riley had a sizable hole in his diaphragm. But for some reason his organs didn't decide to move up into his chest cavity until very late in the pregnancy. His lungs were fully developed, and he didn't suffer from any serious complications. He is now taking part in a study at TCH on the effects of nitric oxide – he is one of the few babies that didn't receive it, and so they are using him as the control patient.

We are full of gratitude every day to have Riley in our lives. It doesn't seem fair that some of the little angels don't make it through this ordeal. I cry sometimes when I see a helicopter, wondering if it's Flight-For-Life, and my husband and I both cry when we stop and think about how things could have been different. I look at the pictures of the cherubs on the website and read their stories in the newsletter, and I feel devastated for the families who lost a child. What a brave battle so many of them fight to stay alive. They are all truly angels.

Nicole Padgett (mom of Riley Tucker Padgett, 8/12/01, 630 Evans Court, Basalt, CO 81621, 970-927-0287, nnpadgett@mindspring.com)

This is the story of Luke. He was diagnosed in utero at 20 weeks with a left-sided diaphragmatic hernia and multi-cystic right kidney. Luke is our second son – Jordan, our first son, had no birth defects whatsoever. We went to our local hospital for a routine 20-week scan. "Something" was detected, but they couldn't establish what! The consultant was called, and although he examined the ultrasound scan, he was also unsure and referred us to Dr. Twinning at Queen's Medical Centre Nottingham for the following day – a Friday. I can remember sitting in the scan room for what seemed like an eternity. My husband and I staring at each other in disbelief – what should have been a routine scan was turning into a nightmare!

We were due to leave for a family holiday on the Saturday, following our Friday consultation at Nottingham. We collected Jordan and went to tell our families, still not quite believing what was happening to us. We waited to see Dr. Twinning with deep apprehension. He diagnosed a large left-sided diaphragmatic hernia and rs cystic kidney. He explained that the surgeons could repair the hernia, but the chance of survival was slim, due to the fact that Luke's lungs would not have the opportunity to develop. What a bomb-shell! The geneticist advised us to go on holiday the following day, which we did with heavy hearts, but which in hindsight was the best tonic we could have had. It was preparation for the trials that lay ahead.

It was a good pregnancy, interrupted every four weeks with the trip to Nottingham for scans and counselling from Miss Kapila OBE, who explained everything in a most truthful way. Luke had a 20% chance....and that was probably optimistic. I think that that was when the reality hit me. I just sat there with tears rolling down my face, head spinning, and feeling sick and dizzy. My baby boy, who I could feel every day would probably die – how on earth could we get through this?

We were shown the neonatal intensive care unit where the battle for Luke would be played out. This would be our goldfish bowl world for the foreseeable future. Jordan, our eldest son was not yet three years old, but pretty grown up in most things. Trying to explain this potential disaster to him was a real trial, but he accepted that Mummy & Daddy were going to go into hospital for a while, because his baby brother was poorly. He was going to stay with Nana and Grandad.

The day arrived and we traveled to Nottingham, only to find that there wasn't a neonatal incubator for Luke.....come back in two days. Can you imagine? I was eventually induced on my 29th birthday, hoping that he would join this world on that day. He was born at 08.10 am on the following day, and I saw him for a fleeting moment. He had masses of dark hair and big blue eyes – I thought I heard him cry. I counted the doctors....1,2,3,4,5,6,7, and nurses....1,2,3, all waiting to take my baby away. He was whisked off, and I was left alone, staring at the ceiling. I vaguely remember the medical consultant arriving and mouthing words-- "Very worried about Luke", "Expect the worst".

I was wheeled to the postnatal ward. Long corridors with pictures of smiling babies on the wall – I closed my eyes, crying silent tears and prayed. Mum, Dad and Jordan arrived, and after an agonising nine-hour wait, I was asked if I wanted to see my baby! The neonatal ward was an alien world. Bells and beeps and alarms sounded constantly, and when I eventually met Luke for the first time, I could hardly see him for lines, pipes, tubes and wires. He was surrounded by six or more pumps, the ventilator, o2 SATS monitor, upper and lower body o2 SATS, ECG monitor, BP monitor and another machine. The doctors explained that this was blowing nitric oxide through the ventilator, which was in oscillation mode, due to Luke's small friable lungs. The doctors explained that Luke was in a critical condition, but stable.

We were at Luke's side all of that weekend. Miss Kapila, the consultant surgeon, visited us and explained that we had a window of opportunity to operate on Luke, and that subject to him remaining stable, she would operate in three days time. The operation was booked and a plethora of professors were gathered, supported by an army of nurses, nursing assistants and medical students. Seven people took Luke away for his appointment with destiny. We waited, encouraged by the photographs of babies who had survived CDM. The air was heavy and time stood still – what should we do, what could we say?

Two hours later the surgeon appeared and explained that it was no wonder that Luke was so poorly, as every organ except his kidney was in his chest cavity – one lung being half normal size and the other was a quarter the size it should be. We went to see Luke. His wound was covered by a gortex patch, where his skin couldn't be stretched to meet. The operation had been a success-- now it was up to Luke and divine intervention!

The sedative and paralyzing drugs were to be maintained for at least five days, and then he would re-join this world, and we would see what was to be! On D Day + 5, the drugs were stopped, and Luke came back to us. What a handful! He fought the tubes and pipes and constantly sought to pull his ventilator tubes out!

After three weeks by his side, I had to let go and return home – Jordan needed me as well. A routine became established –on the phone every four hours, travel to Nottingham every other afternoon to spend two precious hours with Luke and bringing new clothes and toys as well as gifts for the ICU team. I spent weekends with Luke, and really time stood still. On one particular day I phoned, and nobody could talk to me. The doctor would call me back. Panic stations...what was happening? The old feelings came flooding back, pacing the floor until the phone rang. Luke had pulled his tubes out and... “We are going to try him without the ventilator, and he is having a trickle of oxygen through nasal canulas.” What progress! Feelings of jubilation, excitement and relief. We went to see Luke, and I breastfed and held him for the first time...what a feeling.

Things went forward in leaps and bounds, and over the course of the next few weeks, he was weaned off more drugs. After eight weeks, he was moved to the low dependency unit, and after a further three, going home was in sight! My dream was to bring Luke home for Christmas, and we did. He was the best Christmas present I could have wished for.

Luke is now a real tinker. He brightens up the room when he walks in. His brother is very protective, but Luke runs and climbs and gets into scrapes with the best of them! Footballs are the love of his life, and he scores goals with a passion.....none more than the greatest goal he will ever have to score! The doctors gave him a 20% chance of seeing this time and kicking his goals, and now he is almost two years old. In Cyprus “Luke” means “fighter.”

Becky Shooter (mom of Luke Stephen Shooter, 9/15/00, 37 Abbey Road, Swineshead, Boston, Lincs PE20 3EN, Great Britain, 01205 820033)



My OB sent us to a specialist in Birmingham when she saw Abby's problems. I was 4 months pregnant. Abby had the diaphragmatic hernia and also a hole in her abdominal wall, allowing her intestines to float outside of her body (omphalocele). The specialist gave her a 5% chance. They told us the problems Abby had were connected with other defects and led us to believe that if she survived, she could have mental problems. They wanted to do a test to see if she had a “terminal chromosome.” If she did, he said she would be born at our local hospital, and nothing would be done to help her survive after birth. But we knew that God could give life to babies, even if they had terminal chromosomes. We refused the test. They also strongly suggested abortion, which we didn't even consider an option.

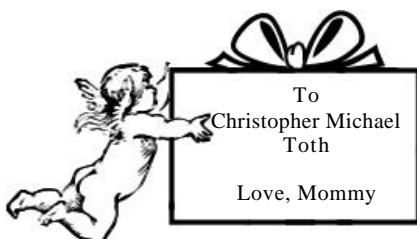
A lot of people were praying. Our church prayed over a prayer cloth, which I pinned to my slip and wore every day. It was God who gave Abby life, and I knew that she wouldn't die until God wanted her to. Still, it was a terrible battle on my mind.

At my 8-month ultrasound, her intestines had gone back inside of her, and the hole (omphalocele) in her abdominal wall had closed up to only two cm. Jesus had done “in-the-womb” surgery and although He did not fix her other problem, the diaphragmatic hernia, it gave me confidence that He would take care of her.

While in labor, the doctor told me that Abby probably would not breathe. But when she was born, she cried. She was sent to Children's Hospital the same day and was put on the ventilator and all the IV's and wires that we all know too well. Dr. Harmon did her repair when she was 11 days old. She got off the vent, and we held her for the first time at three weeks old. At six weeks, she came home with an apnea monitor and a feeding tube through her nose.

She had severe reflux and could keep nothing down. A month and a half later, we were back at Children's for a fundoplication surgery, and they put in a feeding tube button. We still face feeding issues. She takes her formula some, but not enough. She will not drink juice and won't eat much baby food. We are encouraged that in the past couple of weeks, we discovered that she loves table food. Crackers, cheese, and baked beans are her favorites. She is not behind in any other area. She is nine months old now and crawls around the house chasing her older brother, Josiah, who is three. We love you and thank God for you, Josiah and Abby!

Gerald and Amy Curtis (parents of Abigail Faith Curtis, 9/7/01, 170 Fox Trap Road, Tuscumbia, AL 35674, 256-331-0793)





My husband and I got married in April 1995. He already had two children from a previous marriage, but we knew we wanted to have at least one together. We decided to have a year for us before we started trying. In May 1996, we found out we were expecting. We were so excited and never dreamed it would happen so quickly. At about seven weeks, I spotted. I immediately called the doctor and was told to come in. They did some blood work and examined me. They did a vaginal ultrasound and confirmed that there was a heartbeat and that there didn't appear to be any problem. My doctor did notice that I had a couple of fibroid tumors, and he told me they would just watch those closely to make sure they didn't grow too much. He said this would be checked through ultrasounds.

After this small scare, things moved along smoothly. At my second ultrasound at 18 weeks, we decided to find out the sex. A boy – we were thrilled. We decided to name him Jacob. At my third ultrasound at 26 weeks, the doctor did indicate that I appeared to have a little bit higher than normal amniotic fluid, but it wasn't high enough to worry about at that point – they would just keep an eye on it. Now I know that was an indication that there might be a problem – then I had no idea and totally trusted what the doctor said. Throughout my pregnancy, I had a total of four ultrasounds, with the last one at 34 weeks. Each time I was assured that everything looked fine.

My due date was January 19, 1997. The week after Christmas, my legs, ankles, and feet started swelling extremely badly, so much so that the doctor decided I needed to quit work and stay home. So my maternity leave from work started about two weeks earlier than expected. Jacob was also still in the breech position at this time (again, now I know that this is another indication that there might be a problem). The doctor talked

to me about trying to get him to turn by doing a procedure where they push on him, but I decided against this and was then told I would need to have a C-section if he didn't turn on his own. Jacob never did turn, so we scheduled a C-section for January 20, 1997. I could not wait for this day to arrive. I was so big and miserable by this time, but I just thought that's how all women who were nine-months-pregnant felt.

Jacob Nelson Henze was delivered by C-section at 8:03 a.m. on January 20, 1997. He weighed 8 lbs 4 oz. – a full term, good sized baby. Immediately, I knew something was wrong when he didn't cry. We heard a whimper but no cry. I kept asking my husband why he wasn't crying, and he just kept saying they were working on him. The OR got extremely busy with doctors and nurses. They put him in an incubator, stopped him by my head for one second and whisked him away. I had no idea what was happening.

They asked my husband to stay with me while they finished working on me. They then took us to the recovery room. The nurse that was with me was so sweet and kept telling me that a lot of C-section babies have some fluid in their lungs and not to worry, everything would be OK. The next thing I remember is one doctor standing beside me and two standing at the foot of my bed telling me that Jacob was a very sick little boy. They explained he had a right-sided congenital diaphragmatic hernia. His liver and intestines were up in his right chest cavity, and they didn't know how much lung, if any, was on the right side. He needed surgery immediately to repair the hernia and move everything back into place. Glenn, my husband, and I were numb. They had gotten him stabilized, and they wanted our consent to do the surgery. So two hours after he was born, Jacob was in surgery having his hernia repaired. The surgery went great. They moved everything back to where it was supposed to be and used a Gore-Tex patch to close the hernia. He was on a ventilator and was still in critical condition. Then they started talking to us about ECMO. If they couldn't control the pulmonary hypertension, then ECMO would be our next step. I was still flat on my back from the C-section and only had pictures that the NICU nurses had sent up to me by my husband. I could never have imagined that a baby could have that many tubes and wires attached to him.

The day turned into night and Jacob was holding his own. Our other family members went home, and Glenn and I settled in to try and get some rest. Glenn had spent most of the day down in the NICU, and he was exhausted. At 1:30 a.m., the phone rang, and to this day I can still hear the NICU doctor say, "Jacob has taken a turn for the worse. I need your husband to come to the NICU immediately." Glenn ran to the NICU. I was hysterical and called the nurse. The nurse that was on duty was an angel. I know God placed her there that night to be with me. She came in and told me she would get me down to the NICU no matter what it took. She gave me a shot of morphine, and put me in a wheelchair. At that point, I couldn't feel any of my own pain, other than my heart breaking. I just wanted to get to Jacob. She stayed right with me the whole time.

When we got down to the NICU, and I saw Jacob for the first time, all I could see was a beautiful little boy who was my child and was so sick. So many wires and tubes and blinking lights and beeping monitors – it was so overwhelming. They told me it was OK to touch his arm and hand. I touched him, talked to him and told him that his daddy and I were with him. After a few minutes, the doctor said he had to talk to us. Jacob was very ill and needed ECMO. Our local Children's Hospital in Birmingham didn't have an available ECMO bed. They were contacting hospitals in Georgia, Tennessee, Arkansas and Louisiana. He would have to be life-flighted by jet to the closest hospital that had an available ECMO bed. But he wasn't even sure if Jacob would survive the flight. He suggested that we might want to have Jacob baptized before he left. I called my parents and asked them to contact our preacher. At 2:30 a.m. on January 21, 1997, Jacob was baptized in the NICU of St. Vincent's Hospital, and I was trying to prepare myself for the worst.

The doctor advised us that they had found an available ECMO bed at Vanderbilt Children's Hospital in Nashville, Tennessee, and they were waiting on Jacob. The South Carolina Transport team arrived to fly him to Nashville. They were extremely sympathetic and supportive. They assured us they would take good care of Jacob and gave me several pictures of him before they left. I said my goodbyes to Jacob and told him I would see him in Nashville in a couple of days – his daddy would be up the next day. Watching them wheel Jacob away was the hardest thing I've ever been through because I didn't know if I would ever see him alive again.

We received the call from the doctor at Vanderbilt that Jacob had arrived and was stable. He discussed ECMO with us again, and we gave our consent to place Jacob on ECMO. After this had been done successfully, they called us back to let us know. My husband took off for Nashville to be with Jacob. Jacob's nurse called me to let me know she was caring for Jacob and would take good care of him and for me to call her anytime. Glenn arrived in Nashville on Tuesday night – Jacob remained stable. I was finally able to leave the hospital on Thursday morning and my parents, my sister, brother-in-law and I headed for Nashville. I was still extremely sore and not able to get around very well, but at this point that was the least of my worries.

Due to another child being on ECMO in the PICU, Jacob was placed in the PICU instead of the NICU. When I saw him for the first time I was overcome with a variety of emotions. I was so thankful that he was alive, but my first look at him on ECMO scared me to death. There were so many machines and wires and tubes hooked to him, plus there was no sign that he was breathing. His nurse was wonderful and explained everything to me – what all the machines were doing – what all the tubes and monitors were for – that the ECMO was giving his lungs a rest and was oxygenating his blood – it was all truly overwhelming.

Jacob did well on ECMO. They did the first trial off after six days, but he wasn't quite ready. They tried again on the 7th day, and he was able to come off. So we had surpassed our first hurdle. He was still on a ventilator but still doing well. We were able to touch and talk to him more. He was aware of his surroundings, and I know he knew that we were there. About three days off ECMO, I walked into the PICU, and there was a rocking chair next to Jacob's bed. The nurse told me to sit down – she had a surprise. She started gathering up all the wires and bundling up Jacob – next thing I knew he was in my arms – I was finally holding my son after ten days. It was wonderful! – a little scary with all the wires and tubes – but wonderful!

Also during the second week, Jacob came off the ventilator. When I first heard him cry, it was the sweetest sound I had ever heard, and I cried along with him. What a miracle to hear that sweet voice. Jacob was able to stay off the ventilator for two days, but his blood gases didn't stay at acceptable levels and after two days he had to go back on the ventilator. I felt like we had made a huge step backwards. But the doctors and nurses were very comforting and reassuring and helped us see that Jacob just needed to get stronger. I must say he is definitely a fighter.

The next day, Jacob decided to extubate himself. I guess he was tired of that tube down his throat. So the doctor advised they would try C-PAP. Jacob did well on C-PAP for four days. So well, that it was decided that Jacob was at a point that he could be transferred back to St. Vincent's Hospital in Birmingham. They had a NICU and were well-equipped to handle his care from that point on – they had saved his life when he was born. We were thrilled – it would be so nice to be back home. We were scheduled to make the transport on Friday, February 14 – what a wonderful Valentine's present. That morning I was holding Jacob – his nurse was preparing all the paperwork, and we were waiting for the transport team to arrive – it was an exciting day. As I was holding Jacob, he stopped breathing. The monitors started wailing, and the nurse came running. After a couple of shakes, Jacob started breathing again – we thought one episode – nothing serious – well, not so. Over the next hour, Jacob had three more of these episodes. The transport team arrived and they were told about the situation. We were asked to leave while the doctor examined Jacob, and they all reviewed the situation. I was in shock. After about another hour, we were called in to meet with the doctor. They weren't sure what was causing the apnea spells – but because of them, they had to put Jacob back on the ventilator, and they felt he wasn't stable enough at this point to transport. We were staying at Vanderbilt. Again, we had suffered another setback.

Over the next week, Jacob stayed somewhat stable on the ventilator, but he continued to have a few episodes of stopping breathing even while on the ventilator. A week and two days after the first apnea spell, they took him off the ventilator. But after about 12 hours, he went back on. After running a variety of tests, the doctor met with us and said he felt like they had determined the cause of the apnea spells. He was being fed breast milk through an NG tube – during these feedings or shortly after, he was refluxing so bad that it was causing him to stop breathing. They felt that the only way to stop this was through surgery. They wanted to do a fundoplication and put in a G-tube (feeding tube directly into his stomach). Again, this was all so overwhelming but we trusted them to do what was best for Jacob. The surgery was scheduled and done the next day. Jacob came through the surgery fine. I'll never forget what the doctor said to me when he came to talk to us after surgery – he told us what they had done and that Jacob did well – then he looked straight into my eyes and said, "I truly believe Jacob is going to come through all of this fine and be OK." It was the first time anyone had said they thought Jacob would make it.

Two days after surgery, Jacob came off the ventilator for good. He was put on oxygen – nasal canulas. Six days after the surgery, Jacob was transported back to Birmingham to St. Vincent's Hospital. Finally after six weeks in Nashville, we were back in Birmingham.

Back in Birmingham, we settled into a routine. My husband went back to work, and my mom and I spent the days at the hospital with Jacob. Glenn would come to the hospital after work, and we'd stay with Jacob until we had to leave. It was nice to be back home. Our next step was to get Jacob home.

Jacob stayed in St. Vincent's NICU for 4 ½ weeks. During this time, he remained on oxygen, but we worked at slowly lowering the amount he needed. A button was put in on his g-tube – we learned how to feed him through this. Due to his rapid breathing and continuing need for oxygen, they didn't feel that I should attempt to breastfeed him. That's really the only issue I wish I had pushed a little harder, but I trusted the doctor's judgment. I was still pumping breast milk for him, and he was getting it through his g-tube. Regular attempts were made to get him to take a bottle, but he wanted nothing to do with it. We knew this was something we would have to continue to work on for a while. While at St. Vincent's he also had inguinal hernia surgery, and his circumcision was done with this surgery. This surgery was tough because we knew he would have to be placed back on the ventilator, and we weren't sure how he would react when removed. Jacob did wonderfully with the surgery and had no problem at all coming off the ventilator.

One week and five days after this last surgery, Jacob was able to come home. Eleven weeks after his birth, we were finally bringing our son home. We knew Jacob was truly a miracle from God.

Granted, Jacob's homecoming was far from a normal homecoming. We went home with an apnea monitor, a pulse oximeter, oxygen and with a feeding tube in. St. Vincent's did a wonderful job of training us how to use and read all of these machines. A week prior to leaving St. Vincent's, we were placed in a private room so that we could learn how to care for Jacob. We knew we had a long road ahead of us, but we were willing to do whatever it took, and we were so thankful to have the blessing of Jacob as our son.

A week and a half after we got home, we were back in Children's Hospital – Jacob had pneumonia. Luckily they were able to treat it with intravenous antibiotics, and we were back home after a week's stay.

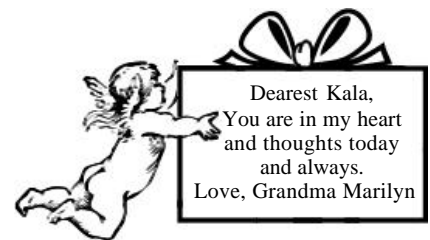
For the next few months, we continued to try to get Jacob to eat by mouth. We worked with physical therapists and occupational therapists. Due to his time in the hospital, he had developmental delays. We were able to get Jacob into our county's Early Intervention Program, which is supported by the United Way. I cannot even begin to say enough good things about this program. We were able to work with a physical therapist and an occupational therapist on a weekly basis and a nutritionist on a monthly basis. Not only did they work with Jacob, but they provided tremendous emotional support to our whole family. Jacob was able to make tremendous strides in this program. Slowly, he started taking more food by mouth, and we were able to cut back on the tube feedings.

In October 1997, Jacob was able to come off the oxygen during the day – he still remained on it at night. On December 22, 1997, Jacob came off oxygen completely. What a perfect Christmas present! Jacob continued to make strides with leaps and bounds. We had our setbacks, but we also had major victories. He was able to overcome all of his delays and is a very bright and smart child. In August 1998, his g-tube button was removed. He has been in the hospital twice with stomach problems. Whenever he gets a cold or cough, we jump on it quickly to be on the safe side. Jacob has a wonderful pediatrician who is very in tune with what he has been through. Jacob has endured respegam treatments and synagis shots. In March 1999, his diaphragm re-herniated, and he had to have repair surgery again. The same surgeon who did his first repair surgery at two hours old also performed the second surgery. This time he was able to use Jacob’s own tissue to repair the hernia, so we’re hoping that will be the last repair he needs.

As of this writing, Jacob is five years old and is a normal, happy, healthy kid. His is still a little smaller than the other kids in his class, but this doesn’t stop him one bit. He is very smart and has the memory of an elephant – his favorite animal. The only doctor we visit on a regular basis is his pulmonologist – about every four months. He has no breathing problems, and she has placed no limitations on Jacob at all. We know he has a small right lung, but he leads a normal life. Jacob has been attending a daycare/pre-kindergarten program at our church for the past two years and will begin kindergarten in the fall of 2002.

What a miracle and a true blessing from God we have in our son Jacob. I look at him now and it’s hard to believe he had such a rough start in life. Sometimes I think back to that first year and wonder how we ever made it through. I know I could have never made it without the support of my husband and my parents and the rest of our family. My parents have been there with us every step of the way and stepped in and took care of Jacob when I had to return to work. I sincerely don’t know how we would have made it through this without them. Jacob also had wonderful care from the moment he was born. St. Vincent’s Hospital and Vanderbilt Children’s Hospital took excellent care of Jacob. His doctors, surgeons, and nurses were all wonderful, caring professionals. I also know that Jacob is a miracle given to us by God. Jacob has had so many people praying for him. From the moment he was born, prayer chains were started that reached across the country. Without our faith and trust in the Lord, we would have never made it through this and we are so cognizant and thankful every day for the miracle that He has given us in Jacob.

Vickie Henze (mom of Jacob Nelson Henze, 1/20/97, 104 Ashford Way, Alabaster, AL 35007, 205-916-6566, GHenze4614@aol.com)



On-Going Research

Massachusetts General Hospital and The National Institute of Health is currently conducting a study to identify genetic markers associated with the occurrence of congenital diaphragmatic hernia. For more information or to volunteer to participate in this study, please contact Patricia Donahoe, M.D. at 617-726-8839 or donahoe.patricia@mgh.harvard.edu

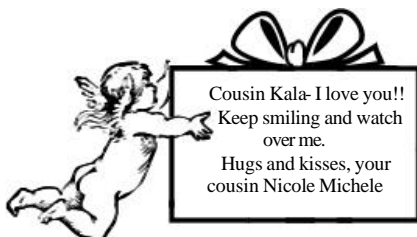
Emergen Labs in Salt Lake City, Utah is also conducting a study to identify genetic markers associated with the occurrence of congenital diaphragmatic hernia. For more information or to volunteer to participate in this study, please contact Becky L. Reimer at breimer@emergen.com

Fundraisers

As well as our sponsorship drive, we have many fundraisers going on. Not only our Ebay action and t-shirt, cookbook, and Tribute sales, but some members have volunteered to raise money through corporate fundraisers. Please contact them if you would like to purchase items or help sell them:

Pampered Chef – Barbara Wagner (PURPHAZE19@aol.com or 810-249-5279)

Avon – Michele Childress (michele_c2002@yahoo.com or 661-393-4616)



Pictures of Cherubs



Thomas Sawyer
3/4/98



Cherylynn Renee' Smith
9/5/01 - 9/5/01



Darren A. W. Honsinger
7/11/01 - 7/17/01



Taylor Nicole Jarecki
2/12/91

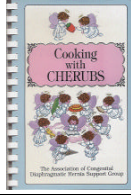


Beau C. Stelly
12/24/01



Anthony Charles Thomas
5/23/02

CHERUBS' Fundraisers & Donations



Cooking With CHERUBS Volume 2

The second volume of our cookbook, "Cooking With Cherubs" includes 500 delicious new recipes contributed by members and their families and friends from around the world. A great gift idea or treat for yourself.

Cost: \$8.00 each
Shipping: \$2.50 each

Tax-Deductible Donations

Help us to help families affected by Congenital Diaphragmatic Hernia. By making a tax-deductible donation to CHERUBS, you help us to reach more families and give them the information and support needed as deal with the traumatic effects of CDH. A wonderful and touching gift idea for the holidays, birthdays, and memorials. An acknowledgement card is sent to families, so please include their contact information.

Family Contact Information For Acknowledgement:

Name(s): _____

Mailing Address: _____

Newsletter Tributes

These tributes are personalized graphics printed in our newsletter, with different graphics for each season. While raising money for CHERUBS, these tributes give families the opportunity to send special messages to their cherubs both here and in Heaven. They are only in color on our web site; in our printed newsletters they are black and white. The cost of your tributes are \$10.00 each and are considered a donation and are tax-deductible.

Valentine Tributes



Spring Tributes



Summer Tributes



Holiday Tributes



CHERUBS' T-Shirts

Adult Sizes: S, M, L, XL, XXL, XXXL
Adult T-Shirt: \$15.00 each + \$3.00 Shipping

Child Sizes: Infant (18m), Child (S), Youth (L)
Child T-Shirt: \$10.00 + \$2.00 Shipping

<p>I'm a proud member of CHERUBS</p> <p>The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Adult Member T-Shirt (pink/blue)</p>	<p>I'm a Cherub</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Girl Cherub T-Shirt (pink)</p>	<p>I'm a Cherub</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Boy Cherub T-Shirt (blue)</p>	<p>Daddy's Little Cherub</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Daddy's/Mommy's Little Cherub - Boy (blue)</p>	<p>Daddy's Little Cherub</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Daddy's/Mommy's Little Cherub- Girl (blue)</p>
<p>Grandpa's Little Cherub</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Grandma/Grandpa's Little Cherub- Boy</p>	<p>Grandma's Little Cherub</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Grandma/Grandpa's Little Cherub- Girl</p>	<p>I Save Cherubs</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Male Doctor/Nurse T-Shirt (blue)</p>	<p>I Save Cherubs</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Female Doctor T-Shirt (pink)</p>	<p>I Save Cherubs</p> <p>CHERUBS The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support</p> <p>Female Nurse T-Shirt (pink)</p>

Fundraiser Order Form

Please make checks or money orders out to: CHERUBS

CHERUBS
 1109 Williamsboro St
 Oxford, NC 27565
 USA

Your Name: _____
 Address: _____
 Phone: _____
 E-Mail: _____

CHERUBS' T-Shirts		No.	Size(s)	Cost Each	Shipping Each	Total
Child Sizes: Infant (18m), Child (S), Youth (L) Adult Sizes: S, M, L, XL, XXL, XXXL						
Girls T-Shirts (pink)	_____	_____		\$10.00	\$2.00	\$ _____
Boys T-Shirts (blue)	_____	_____		\$10.00	\$2.00	\$ _____
Mommy's Little Cherub T-Shirts (pink)	_____	_____		\$10.00	\$2.00	\$ _____
Mommy's Little Cherub T-Shirts (blue)	_____	_____		\$10.00	\$2.00	\$ _____
Daddy's Little Cherub T-Shirts (pink)	_____	_____		\$10.00	\$2.00	\$ _____
Daddy's Little Cherub T-Shirts (blue)	_____	_____		\$10.00	\$2.00	\$ _____
Grandma's Little Cherub T-Shirts (pink)	_____	_____		\$10.00	\$2.00	\$ _____
Grandma's Little Cherub T-Shirts (blue)	_____	_____		\$10.00	\$2.00	\$ _____
Grandpa's Little Cherub T-Shirts (pink)	_____	_____		\$10.00	\$2.00	\$ _____
Grandpa's Little Cherub T-Shirts (blue)	_____	_____		\$10.00	\$2.00	\$ _____
Ladies T-Shirts (pink, Adult Member T-Shirt)	_____	_____		\$15.00	\$3.00	\$ _____
Men's T-Shirts (blue, Adult Member T-Shirt)	_____	_____		\$15.00	\$3.00	\$ _____
Male Doctor/Nurse T-Shirts (blue)	_____	_____		\$15.00	\$3.00	\$ _____
Female Doctor T-Shirts (pink)	_____	_____		\$15.00	\$3.00	\$ _____
Female Nurse T-Shirts (pink)	_____	_____		\$15.00	\$3.00	\$ _____

Cookbooks	No.	Cost Each	Shipping Each	Total
Cooking With Cherubs, Vol. II	_____	\$8.00	\$2.50	\$ _____

Tributes	No.	Color	Inscription	Cost Each	Total
Valentine Tributes	_____	_____	_____	\$10.00	\$ _____
Holiday Tributes	_____	_____	_____	\$10.00	\$ _____
Spring Tributes	_____	_____	_____	\$10.00	\$ _____
Summer Tributes	_____	_____	_____	\$10.00	\$ _____

Donations		Amount
Annual Membership Fee:	\$20.00 per family, \$30.00 per medical professional. This is VOLUNTARY.	\$ _____
Donation In Honor of:	_____	\$ _____
Donation In Memory of:	_____	\$ _____