CHERUBS

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

The Silver Lining

Spring 2002

CHERUBS
1109 Williamsboro St
Oxford, NC 27565

Dear Members,

Our newsletter is back in printing after a 6-month hiatus due to lack of stories of our cherubs. We still need more stories to fill future newsletters, it's far too expensive to print and mail newsletters with just a few stories. Please send your cherub's story to us by e-mail (preferred) or by postal mail.

Our 2002 International Conference was cancelled; please see the article for more details. We hope to raise enough funding to continue this annual event in 2003.

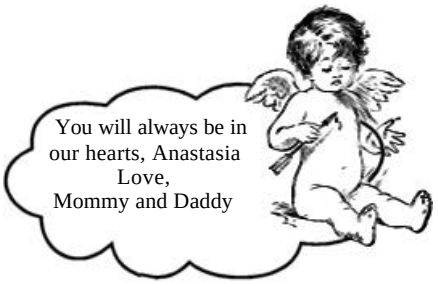
As usual, we are busy, busy, busy here. Our 2001 CDH Survey Results will be published in our Summer newsletter; we are revamping our entire web site; many local get-togethers are planned; and we are actively trying to get grant funding and sponsorship for CHERUBS. We now have over 1150 members, including over 1000 families, in all 50 states and 35 countries. We have just gotten too large for my small house and only 1 full-time volunteer. Please see the article for more details.

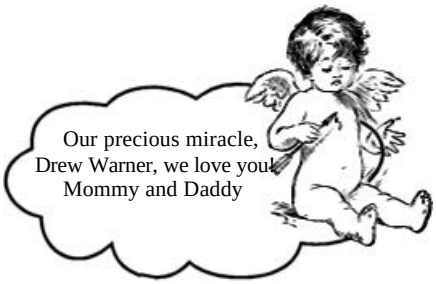
We are still in dire need of donations. Yes, the donation column is quite long this newsletter, but it lists donations made over 7 months. ANY amount will help. As we go, our printing costs and mailing costs increase, but donations have not. If you can afford to, please remember to make your annual $20.00 Family Membership Donation or $30.00 Professional Membership Donation. We also have a large amount of cookbooks and t-shirts still to sell, so please keep CHERUBS in mind for gift-giving ideas.

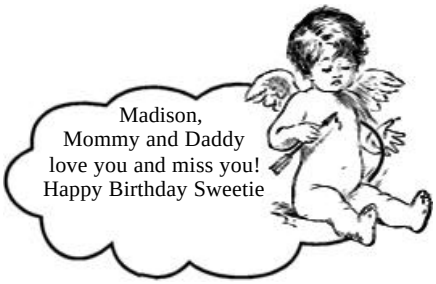
My apology goes out to members and friends who purchased Valentine's Day Tributes. To try to make it up to you, your tribute will be posted in both this issue and our Summer Issue.

I hope everyone has a safe and healthy summer.

Dawn M. Torrence, President and Founder







Local Get-Togethers

The following states are planning local get-togethers. For more information, please contact the State Representatives.

State	Representative	Phone Number	E-Mail
Alabama	Alicia O'Malley	256-389-8110	alicia@cherubs-cdh.org
Ohio	Tara Hall	614-275-0858	tara@cherubs-cdh.org
Texas	Shelly Evans Monica Nedrow Malini Rao	254-793-3039 817-329-2402 469-232-0245	shelly@cherubs-cdh.org monica@cherubs-cdh.org malini@cherubs-cdh.org

New Arrivals

(*siblings of Cherubs)

Kayla Marie Abaurrea*
Adriana Abel*
Faith Marie Atkins
Chloe' Gabrielle Barbee
Meghan M. Baxter
Chloe Claire Belden
Brodie McKibbin Bennett
Sean Mitchell Benson
Josiah Stephen Blay
Asa Carney Bookout
Jonathan Raymond Brewster
Ariana Brown
Laura Genevieve Browning*
Patrick Neil Bryant
Kirsten J. Burgess
Kieran Andrew Card
Jonah Alexander Carrier
Miles Whalen Lloyd Chamberlain
Tracy Eric Chavis
Jordon Michael Choyfoo
Sorcha Aine Clarke-Hagan
Tyler James Clyde
Santania W. Courtney
Cassidy Riley Currence
Abigail Faith Curtis
Sarah Ann D'Ambrosi
Jenna Rose Dayton
Tristan Dean
Joshua Jeffrey Dill*
Jesse James Drugmand
Taylor Elizabeth Edmond
Emily Ann Ennis
Janelle White Esler
Mason Earl Evans*
Jackson Gunner Griffin
Robert Severance Halliday, II
Roisin Hartigan*
Kurtis Claude Heer
Adam A. Herrera
Aaron Jacob Hoewing
James Patrick Howitt
Elizabeth Joy Huffman
Kennedy Elaine Keckler
Lewis David Kelly
Noah Edward Kelly
Andrew Christopher Kemmer
Jason Thomas Kennemer
Darrin Zach Laengerer
Anna Christine Langan
Victoria Destiny Lavallée-Khalil
Dakota Montgomery Linton
Harrison Alan Lovell
Anna Lee Marchesseault
Sydney Olivia Matthews
Joshua Edward Mercier-Fehr
Debwewin Mitchell
Amber Nicole Mitchell
Mary Elizabeth Motts
Owen W. J. Mulak – MacPhee
Hope Katherine Niebrugge*
Alyssa Noel Niedziela
Bryceton D. J. Nordin
Aaron Josef Oakes
Madysen Olczak*
Riley T Padgett
Seannah Allissabeth Palamarczuk
Isabella Pavlinac
Anna K. Piasecki
Darien Daishawn Pitts
Trevor Mathew Rademaker*
Elizabeth M. Sanders
Sidney A. Saunders
Cherylynn Renee' Smith
Beau C. Stelly
Kathryn Nicole Stevenson*
Alexander Joseph Terry
Adam Joseph Vella
Michael Reed Wallis
Callum Philip Weber
Jarrod Allen Williams
Oscar Steven Wood
Julia Cora Zieger

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

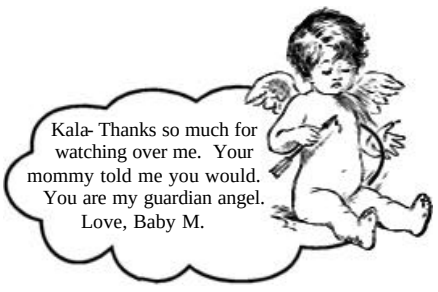
Elizabeth Doyle
Roni Evans
Shelly Evans
Ramona Gallegos
Freedom Green
Tara Hall
Patricia Jones
Laura Lewis
Daphne Parker
Christy Stevenson
Robin Sum
Sophia Tucker
Tommy Williams
All of our Wonderful Volunteers!

This Newsletter Is Dedicated To the Memories of:

Tarquin Mikhail Adcock
Dale Linden Appleyard
Chloe' Gabrielle Barbee
Meghan M. Baxter
Brodie McKibbin Bennett
Aaron Kyle Blank
Josiah Stephen Blay
Hannah Kate Bowring
Tracy Eric Chavis
Amelia M. Coolbaugh
Kelsey Brooke Cunningham
Sydney Elise Curlock
Cassidy Riley Currence
Vincent Steven D'Ulisse
Jenna Rose Dayton
Emily Elizabeth Templar Earl
Taylor Elizabeth Edmond
Emily Ann Ennis
Robert Severance Halliday, II
Sean E. Harkins
Adam A. Herrera
Megan Iona Hirst
James Patrick Howitt
Elizabeth Joy Huffman
Austin Bradley Johnson
Maximillian Gerard Kastner
Kennedy Elaine Keckler
Allison Ann Koetters
Darrin Zach Laengerer
Jeremy Ryan Lawrence
Owen Isaac Looney
Lamont Maurice Lusby, Jr
Sydney Olivia Matthews
Julian James Martinez
Pietra Agnelli Martinelli
Jacob Collin McDonald
Joshua Edward Mercier-Fehr
Debwewin Mitchell
Mary Elizabeth Motts
Ryan Matthew Mudderman
Bryceton D. J. Nordin
Aaron Josef Oakes
Gage Richard Ollerenshaw
Jak Thomas Parsons
Isabella Pavlinac
Anna K. Piasecki
Darien Daishawn Pitts
Olivia Plymale
Colten "CJ" Regier
Elizabeth M. Sanders
Cherylynn Renee' Smith
Damien Smith
Alexander Joseph Terry
Callum Philip Weber
Holly Jane White
Jarrod Allen Williams
Oscar Steven Wood
Julia Cora Zieger

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

Tarquin Mikhail Adcock
Dale Linden Appleyard
Sarina Lily Asher
Faith Marie Atkins
Baby Boy Avelino
Katja Baeumler
Baby Girl Bagherian
Meghan M. Baxter
Matthew Tyler Beach
K. P. Beachnau
Baby Girl Beard
Chloe Claire Belden
Sean Mitchell Benson
Aaron Kyle Blank
Josiah Stephen Blay
Kailyn Brooke Bost
Victoria Maria Botero
Hannah Kate Bowring
Jonathan Raymond Brewster
Benjamin Joseph Broom
Ariana Brown
Patrick Neil Bryant
Kirsten J. Burgess
Ava Katherine Butler
Kieran Andrew Card
Jonah Alexander Carrier
Miles Whalen Lloyd Chamberlain
Kevin S. Charrin
Tracy Eric Chavis
Jordon Michael Choyfoo
Olivia Ann Christopher
Sorcha Aine Clarke-Hagan
Tyler James Clyde
Emalee Lillian Charity Coker
Amelia M. Coolbaugh
Santania W. Courtney
Lisa M. Coy
Alan Mikeal Cross
Kelsey Brooke Cunningham
Cassidy Riley Currence
Abigail Faith Curtis
Sarah Ann D'Ambrosi
Fiona Heather Suzanne Daniels-Brown
Jenna Rose Dayton
David Jonathon Dayton
Tristan Dean
Anthony Jake DiCesare
Lily Marie Dover
Jesse James Drugmand
Emily Elizabeth Templar Earl
Taylor Elizabeth Edmond
Baby Edwards
Spencer Elting
Emily Ann Ennis
Janelle White Esler
Dante T. Frazier
Ashleigh Michelle Garcia
Sophia Gehrka
Keiley Jaye Gilliard
Gerard Taylor Goetz
Tristan Anthony Francis Goldstein
Alec James Golocevac
Jaylin Natasha Gonzalez Eddy
Jackson Gunner Griffin
Alfred Anthony Guarisco
Abdullah Habib
Robert Severance Halliday, II
Blake Hanlon
Sean E. Harkins
Kurtis Claude Heer
Aidan Christopher Hepworth
Carter Ray Herbolsheimer
Adam A. Herrera
Caden Joseph Hickel
Taylor Lynn Hill
Megan Iona Hirst
Kathryn Ann Howard
James Patrick Howitt
Elizabeth Joy Huffman
Lillian Marie Hutchens
Austin Bradley Johnson
Ximena Karaman
Maximillian Gerard Kastner
Kennedy Elaine Keckler
Noah Edward Kelly
Lewis David Kelly
Andrew Christopher Kemmer
Jason Thomas Kennemer
Baby Boy Kerns
Baby Kirby
Christopher S. Knowles
Allison Ann Koetters
William James Kowalski
Darrin Zach Laengerer
Victoria Destiny Lavallée-Khalil
Jeremy Ryan Lawrence
Dakota Montgomery Linton
Owen Isaac Looney
Omar Dario Lopera
Abraham Leo Lopez
Harrison Alan Lovell
Lamont Maurice Lusby, Jr
Isabelle Marie Lyons
Cody A.J. Maerten
Baby Boy Manes
Julian James Martinez
Jacob Aaron Matulevich
Jacob Collin McDonald
Joshua Edward Mercier-Fehr
Alexander Drake Milam
Kaylee M. Miller
Debwewin Mitchell
Amber Nicole Mitchell
Franklin A. Morton
Mary Elizabeth Motts
Ryan Matthew Mudderman
Gregory Allen Mueller
Owen W. J. Mulak - MacPhee
Taylor Theresa Marie Murphy
Kaleigh Marie Myers
Alyssa Noel Niedziela
Bryceton D. J. Nordin
Jay Ashleigh Ogburn
Gage Richard Ollerenshaw
Samantha Olmstead
Riley T Padgett
Alison Joanne Parker
Payton Alan Parks
Jak Thomas Parsons
Isabella Pavlinac
Jessica Hope Peet
Patrick M. Perala
Sheree Helen Beth Pettit
Anna K. Piasecki
Darien Daishawn Pitts
Olivia Plymale
Baby Boy Prince
Jessica A. Quillman
Poppy E. Ramsay
Jac'Quan Damion Rawlinson
Colten "CJ" Regier
Isaiah Luis Rivera
Elizabeth M. Sanders
Sidney A. Saunders
Baby Scheinkoenig
Baby Boy Schuler
Cherylynn Renee' Smith
Damien Smith
Austin Wayne Smith
Beau C. Stelly
Jason M. Swiger
Alexander Joseph Terry
Stephanie Ann Thompson
Carson David Trotzer
Crystal Rose Tweeten
Adam Joseph Vella
Lilliann Marie Walder
Michael Reed Wallis
Josh Alan Walsh-Dunne
Callum Philip Weber
Brooke E. Weiss
Gavin A.N. Werner
Christopher Wharton
Keegan Douglas White
Adam V. Whitelock
Elliot Michael Wollaston
Oscar Steven Wood
Carolyn Elaine Wylie
Julia Cora Zieger
Hayden Zimmerman

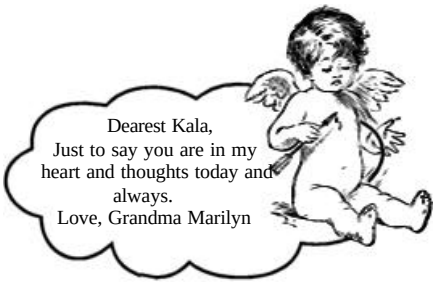


We Would Like To Thank The Following People For Their Generous Donations:

A. Finkl & Sons Co. - in memory of Elizabeth Marie Sanders
Heidi Abaurrea - in honor of her daughter, Bethany Taylor Abaurrea
Iris Adame - in memory of her daughter, Aileen Iris Adame
Iris Adame - in memory of Sarah Christina Lewis
Iris Adame - in memory of Cecilia Winn Propst
Julio and Iris Adame - in memory of their daughter, Aileen Iris Adame
Jackie Alvey - in memory of Emily Ennis
Jacqueline Amarino - in memory of Sydney Olivia Matthews
Keith and Catherine Archambault - in honor of thier daughter, Emily Archambault
Andrea Atwood - in honor of her daughter Caitlin Kraft
Sue Audi - in memory of Hailey Rogula
Jackie Baxter - in memory of her daughter, Meghan M. Baxter
Colleen and James Biondi - in memory of Joshua Edward Mercier-Fehr
Jennifer Blair - in honor of her daugher, Caitlin Blair
Mickey Blake and Mary McEneaney - in honor of their daughter, Mia Elizabeth Blake
Dietrich and Regina Blumenroehr - in memory of their sons, Lars and Samuel Blumenroehr
Vicki Bilak - in memory of her granddaughter, Anneliese Mae Browning
Brian and Holly Bost - in honor of thier daughter, Kailyn Brooke Bost
Edwin and Lenore Botero - in honor of their daughter, Victoria Maria Botero
Theresa Bray - in memory of Emily Ennis
Charles and Kathleen Breen - in honor of their daughter, Caitlin Breen
Patricia Bruli - in memory of Elizabeth Marie Sanders
Scott and Kathy Browning - in memory of their daughter, Anneliese Mae Browning
Frank Bryant and Dawn McGee - in memory of Isabella V. DaSilva Pavlinac
Margaret Bryant - in memory of Isabella V. DaSilva Pavlinac
Rick and Nancy Bryant - in honor of their son, Patrick Neil Bryant
Bret Bryon
Mary Beth Buist - in honor of her daughter, Becky Buist
Keith and Rebecca Bunselmeyer - in memory of their daughter, Kayci Ann Bunselmeyer
Laura Burns - honor of her daughter, Megan Hope Burns
Ed and Anne Callahan - in memory of Bridget Hope Jussaume
Edward Carlson
Charlene and John Cassese - in honor of their daughter, Caroline Harpur Cassese
Valerie Chavis - in memory of her son, Tracy Eric Chavis
Michele Childress - in memory of her daughter, Kayla Mae Michele Childress
Circuit City - in memory of Tracy Eric Chavis, II
Patricia Clark - in memory of Cassidy Riley Currence
Zane and Natalie Cody - in honor of their son, Dylan Joseph Cody
Timothy and Carolyn Conway - in memory of Robert Severance Halliday, II
Donna Crowley
Shannon Daniels - in honor of her daughter, Fiona Daniels-Brown
Stefanie Day - in honor of Robin Day, mom of Seth Lewis
Geoff and Stacie Dayton - in memory of their daughter, Jenna Rose Dayton
David and Jeanette Dill - in memory of Grace Caroline Dill
Mark and Lise Dill - in memory of their daughter, Grace Caroline Dill
Brian & Cary Doherty - in memory of Elizabeth Marie Sanders
Diane Durham - in memory of Cassidy Riley Currence
Eaton Hydraulic Operations - in memory of Cherylynn Renee Smith
Eaton Hydraulic Operations - in memory of Madison Nichole Hogan
Barbara A. Eisele - in memory of her granddaughter, Reese Gabrielle Eisele-Elizondo
Barbara A. Eisele - in memory of Tracy Eric Chavis, II
Ernandez Family - in memory of Joshua Edward Mercier-Fehr
Mrs. R. Evora - in memory of Julia Cora Zieger
Albert and Claudia Faraldi - in memory of their son, Christopher Faraldi
Albert and Claudia Faraldi - in memory of Kayla Childress
Albert and Claudia Faraldi - in memory of Paige Muraglia
Albert and Claudia Faraldi - in memory of Anthony Pompeo
Albert and Claudia Faraldi - in memory of Shane Torrence
Allan Fehr, Joanne Mercier, and Jonah Mercier-Fehr- in memory of their son and brother, Joshua Edward Mercier-Fehr
Vic, Shirley, Cliff, and Pauline Fehr - in memory of Joshua Edward Mercier-Fehr
Geralyn Fallon - in memory of Elizabeth Marie Sanders
Dorothy M. Feigl - in memory of Elizabeth Marie Sanders
Anthony Fiore - in memory of Elizabeth Marie Sanders
Achilles and Valentina Flores - in memory of their grandson, Tracy Eric Chavis
Martha Fortunato - in memory of Sidney Olivia Matthews
Cesar Galasso - in honor of Mattson Edward Houghton
GE Capital Franchise Finance - in memory of Kolton Grayson Seibert
Valerie L. Gillis - in honor of Mattson Edward Houghton

Wendy and Andrew Glatz - in memory of Sydney Olivia Matthews
Sean and Diane Gleason - in memory of their daughter, Sarah Kay Gleason
Jennifer and Andrew Grasby - in memory of Joshua Edward Mercier-Fehr
Jim and Susie Grubb - in honor of their son, Tyler Grubb
Jim and Susie Grubb - in memory of Jeremy "Shane" Torrence
Shirley Guinn - in honor of Mattson Edward Houghton
Shirley Guinn - in memory of Mattson Houghton's Great-Grandfather, John Cochran
Joseph, Mary, Kristen, Amber, and Anna Hales - in memory of their son and brother, Joseph Michael Hales
Jeff and Tara Hall - in honor of their son, Brandon Hall
Ruth Harris
Tiernan and Colette Hartigan - in honor of their son, Thomas Hartigan
Stan and Sara Heer - in honor of their son, Kurtis Claude Heer
Robert and Loretta Higgins - in memory of Robert Severance Halliday, II
R. Patricia Hoemke - in memory of her great-grandson, Cade Andrew Turner
Renata Hoskins - in honor of her son, Killian Roberts
Shanttel Houston - in memory of her brother, Tracy Eric Chavis
Shayla Houston - in memory of her brother, Tracy Eric Chavis
Steve, Anne-Marie, Ben, & Jon Huffman - in honor of their cherub, Elizabeth Joy Huffman
Peter and Mary Hurdle - in honor of their son, Patrick Joseph Hurdle
David and Albretta Husik - in memory of Kennedy Elaine Keckler
Carol and Earl Irons - in memory of their granddaughter, Sydney Olivia Matthews
Resty E. Isaac - in memory of Julia Cora Zieger
Katy Jacobs - in memory of her grandson, Kolton Grayson Seibert
Dale and Lisa James - in honor of Mattson Edward Houghton
Andrew and Jessica Jarrett - in honor of their daughter, Hayley Jarrett
Andrea Julian - in memory of Robert Severance Halliday, II
Erin Keaney-Harrington - in memory of Julia Cora Zieger
Roland and Patty Klein - in memory of her cousin's daughter, Kennedy Elaine Keckler
Kimberly-Clark Foundation - in honor of Alison Joanne Parker
John and Juliana King - in memory of Elizabeth Marie Sanders
Tina Fiore Knight - in memory of Elizabeth Marie Sanders
Christina Kraus - in memory of Kayci Ann Bunselmeyer
Bryan and Kelly Krulikowski - in memory of Isabella V. DaSilva Pavlinac
Michele, Kevin & Zachary Kokinda - in memory of their cherub, Michaela Anne Kokinda
Richard and Linda Kryk - in memory of their son, Brandon Scott Kryk
Jacob Langer, MD
Raymond and Elizabeth Lawrence - in memory of Robert Severance Halliday, II
Suzanne Layman - in memory of Emily Ennis
Patrick Lee & Theresa Connelly - in honor of their son, Michael Patrick Lee
Howard and Laura Lewis - in memory of their daughter, Sarah Christina Lewis
Raymond Lum
Glen and Dawnn Matthews - in memory of their daughter, Sydney Olivia Matthews
Donna Matthews
Edwin and Bernadette Mantel - in memory of Elizabeth Marie Sanders
Marcia and Jim Memery - in memory of their great-neice, Grace Caroline Dill
Elaine Moats - in honor of her daughter, Kristin Marie Moats
Nancy Maris, Phyllis Hanson, Charlotte Millette, Sue Beden, Paula Driex, Mary Jo Bulawa, Dianne Anderson, in memory of Josiah Blay
Felicia Marti - in memory of her daughter, Kala Marti
Nancy and Jack Martin - in memory of Elizabeth Marie Sanders
Patty Martin and George Wilson - in memory of Elizabeth Marie Sanders
Santino and Dana Martinelli
Natalie Maxfield - in memory of Connor Ellis McLuckie
Thomas and Cynthia McDavitt - in honor of their son, Shawn McDavitt
Laura McFatter
Kathy McMerriman - in memory of her daughter, Sarah Ann McMerriman
Patricia Melchione - in memory of her great-niece, Sydney Olivia Matthews
Shirley Mercier - in memory of her grandson, Joshua Edward Mercier-Fehr
Faye Merolla - in memory of her niece, Kala Marti
Marilyn Merolla-Nalewaik - in memory of her granddaughter, Kala Marti
Peter and Grace Modica - in memory of Maximillian Gerard Kastner
Karen Gabriel Moss - in memory of Robert Severance Halliday, II
Nina Murphy - in memory of Kennedy Elaine Keckler
Kenneth and Deanne Niedziela - in honor of their daughter, Alyssa Noel Niedziela
Lori O'Connor - in honor of her daughter, Clare O'Connor
John and Alicia O'Malley - in honor of their son, Jonathan Michael O'Malley
Kimberly Owens - in memory of Emily Ennis
Daphne and Bruce Parker - in honor of their daughter, Alison Joanne Parker
Jerome Pate - in memory of Robert Severance Halliday, II
Daniel and Patricia Pavlinac - in memory of their daughter, Isabella Pavlinac
Pizzulli Family - in memory of Maximillian Gerard Kastner
Charles and Sandy Plymale - in memory of their daughter, Olivia Plymale
Robert Potter - in honor of Mattson Edward Houghton

Brian Propst & Elizabeth Doyle-Propst - in memory of their daughter, Cecilia Winn Propst
Brian Propst & Elizabeth Doyle-Propst - in memory of Christopher Michael Toth
Brian Propst & Elizabeth Doyle-Propst - in memory of Jeremy "Shane" Torrence
Brian Propst & Elizabeth Doyle-Propst - in memory of Debra Jones, aunt of Shane Torrence
Kevin and Marlene Pytyck - in memory of their son, Benjamin Michael Pytyck
Amy and Pete Rademaker - in honor of their son, Trevor Mathew Rademaker
Pete and Amy Rademaker - in memory of their son's, Jonathan Luke Rademaker's, 4th birthday
Julie Rasmussen
Donald and Jeanne Rooks - in memory of Elizabeth Marie Sanders
Rosner & Associates, LLC - in memory of Robert Severance Halliday, II
Virginia Seggerman - in memory of Elizabeth Marie Sanders
Achla Sharma - in honor of her daughter, Manisha Sharma
Angie and Gregg Siebert - in memory of their son, Kolton Grayson Seibert
Thomas Sniffen - in memory of Julia Cora Zieger
Cynthia Stockwell - in honor of Raquel Stockwell
Gregory & Carmelina Stoklosa - in memory of Elizabeth Marie Sanders
Kristine Terry - in memory of her son, Alexander Joseph Terry
Daniel and Teresa Thompson - in honor of their daughter, Stephanie Ann Thompson
Claudine Torfs
Dawn Torrence - in memory of her sister, Debra Jones
Dawn Torrence - in memory of her grandmother-in-law, Hester Fortson
Dawn Torrence - in memory of her son, Jeremy "Shane" Torrence
Jeremy Torrence - in memory of his son, Jeremy "Shane" Torrence
Melanie Turowski - in memory of Kylee Freedom Green
Paul and Lisa Sisley-Vallins - in memory of their daughter, Anastasia Michelle Vallins
Paul and Lisa Sisley-Vallins - in memory of Jeremy "Shane" Torrence
Mary VanderSchaaf - in honor of her nephew, Ryan VanderSchaaf
Karen Vella - in honor of her son, Adam Joseph Vella
Barbara Vosburg - in honor of Dr. J. Angou German
Barbara Vosburg - in honor of her son, Ross Vosburg
Joe Ward
Mike and Nikki Warner - in honor of their son, Drew Michael Warner
Stephanie Warnock - in honor of her sister, Amy Kolacia, mom of cherub Gabriel Kolacia
Laura Watson - in memory of Robert Severance Halliday, II
Tom, Kim, & Cole Webster - in memory of Shae Ashley Webster
Sonia Winkels - in honor of her son, Juan Sampedro Winkels
Ann and Brian Wolfe - in memory of their son, Michael Wolfe
Christina Yocum - in honor of her son, Jarrod Allen Williams
Mari Alice Zacharyasz - in memory of Robert Severance Halliday, II
Paul and Jan Zieger - in memory of their daughter, Julia Cora Zieger
Brad and Faith Zimmerman - in honor of their son, Hayden Zimmerman



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, 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.

REGION	REPRESENTATIVE	PHONE#
Australia	Danielle Kessner	(03) 5135 6999
Canada	Karen Jenkins	905-852-9410
Canada	Laurelle Lehmann	(250) 838-2250
Germany	Renata Hoskins	907-245-8817
Great Britain	Rachel Wyatt	01908 565574
Great Britain	Kevin & Brenda Lane	01553 762884
India	Shankari Murali	6164934
India	Malini Rao	469-232-0245
Ireland	Mick and Mary Blake	01 4921595
New Zealand	Nikki Hodson	04 9724841
South Africa	Amanda Dean	+2712 5474207
Spain	Sonia Winkels	34-91-3004029
AK	Renata Hoskins	907-245-8817
AK	Suellen Nelles	907-452-1769
AL	Alicia O'Malley	256-389-8110
AZ	Anne Marie Kastner	480-837-1895
CA	Sherry Franklin Amlin	916-428-2738
CO	Dave & Clare Retterer	303-644-4779
CT	Toni Fiorillo	
GA	Annette Lichtenstein	404-325-2368
IA	Tami Logsdon	515-277-6316
IL	Rachele Alessandrini	(708) 283-9006
KS	Jody Hill	913-859-0389
KY	Lori Welsh	859-239-8970
LA	Sheila Ezernack	318-645-9361
MA	Heidi Cadwell	603-465-3311
MD	Brenda Slavin	410-956-4406
MO	Jody Hill	913-859-0389
MS	Melissa Clark	228-432-8942
MT	Elaine Moats	406-232-5038
ND	Elaine Moats	406-232-5038
NE	Kristen Stiner	402-502-9310
NH	Heidi Cadwell	603-465-3311
OH	Tara Hall	614-275-0858
OK	Jeannette Davis	405-670-9937
OK	Scott Lenhart	918-371-3020
OR	Kimberly Doades	503-625-7343
OR	Marion Lansdon	360-882-5502
PA	Tammy Sincavage	610-796-7324
RI	John & Charlene Cassese	(401) 884-0269
SC	Susan Grubb	864-877-1446
SD	Elaine Moats	406-232-5038
TX	Shelly Evans	254-793-3039
TX	Monica Nedrow	817-329-2402
TX	Malini Rao	469-232-0245
VA	Elizabeth Doyle-Propst	804-293-4602
WA	Marion Lansdon	360-882-5502
WA	Grace Massie	360-933-0411
WV	Sharon Munson	304-947-7162

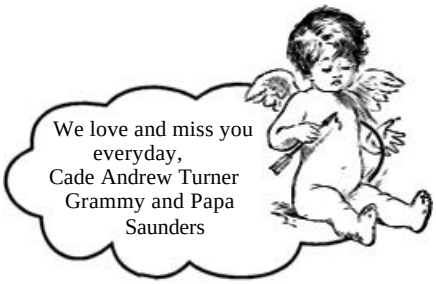
On-Call Volunteers

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
Jolene Halbeisen - 419-333-8384	Melissa Clark - 228-432-8942	Kerrie Chamberlain - 541-535-4744
Tara Hall - 614-275-0858	Shelly Evans - 254-793-3039	Kimberly Doades - 503-625-7343
Elaine Moats - 406-232-5038	Freedom Green - 770-479-0378	Jody Hill - 913-859-0389
Daphne Parker - 918-298-8652	Michelle Huether - 618-853-4157	Linda West - 07 3263 4203 (Australia)
Deeshia Partin - 770-919-2162	Tracy Keckler - 419-423-7422	Sonia Winkels - 34-91-3004029 (Spain)
Ann Peterson - 509-735-7208	Marion Lansdon - 360-882-5502	Rachel Wyatt - 01908 565574 (Great Britain)
Pamela Pruitt - 864-814-7880	Malini Rao - 469-232-0245	
Jeannette Davis - 405-670-9937	Dawnn Matthews - 732-458-5960	
Amanda Dean - +2712 5474207 (South Africa)	Amanda McLuckie - 214-821-7128	
	Niki Naus - 757-887-3742	
	Suellen Nelles - 907-452-1769	
	Amy Rademaker - 616-844-4156	
	Danielle Kessner - (03) 5135 6999 (Australia)	
	Laurelle Lehmann - (250) 838-2250 (Canada)	

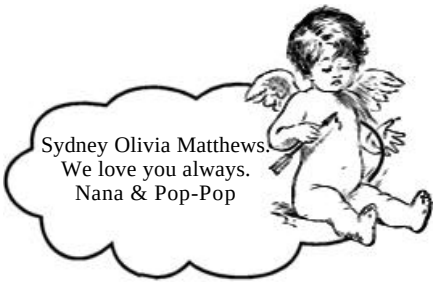
CHERUBS' 2002 Conference

Our 2002 International Member Conference that was scheduled for May, 2002, was cancelled due to lack of funding. Next year's Conference is tentatively planned for July 2003 in the Boston, Massachusetts area. If you would like to volunteer or to contribute to conference funding, please contact Dawn.



2002 Ebay Auction

Our celebrity Ebay auction was a success! We raised over $1200.00, thanks to the efforts of our volunteers who contacted celebrities for donations of autographed items. Over 100 celebrities donated photographs, manuscripts, CD's, and other articles. Our next auction is scheduled for January 2003. Please contact Dawn if you would to volunteer to contact celebrities, we need several volunteers to pull this off again and we need to get started ASAP. A special thank-you goes out to the following volunteers who helped out on our April auction; Daphne Parker, Robin Sum, Freedom Green, Elizabeth Doyle Propst, Laura Lewis, and Ramona Gallegos.



CHERUBS Sponsorship

This summer, CHERUBS will be in full-swing trying to gain grant funding and corporate sponsorship. 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 by September to fund an office (my little house just isn't big enough to hold CHERUBS anymore), 2 full-time employees, our conferences, medical research, and emergency funds for families. If you would like more information, would like to volunteer for our fundraising and grant committees, or would like to sponsor CHERUBS, please contact Dawn.

You Know You Have A Special Child When....

(author unknown)

You know you have a child with special needs when.....

✓ You compare ER's instead of grocery stores.
✓ You compare your child's oxygen saturations.
✓ You view toys as "therapy.'
✓ You don't take a new day for granted.
✓ You teach your child HOW to pull things out of the cupboard, off the bookcases, and that feeding the dog from the table is fun.
✓ The clothes your infant wore last fall still fit her this fall.
✓ Everything is an educational opportunity instead of just having plain old fun.
✓ You cheer instead of scold when they blow bubbles in their juice while sitting at the dinner table (that's speech therapy), smear ketchup all over their high chair (that's OT), or throw their toys (that's PT).
✓ You also don't mind if your child goes thru the house tooting a tin whistle.
✓ You fired at least 3 pediatricians and can teach your family doctor a thing or two.
✓ You can name at least 3 genes on chromosome 21. (You really know your toast if you can spell the full names correctly)
✓ You have been told you are "in denial" by at least 3 medical or therapy professionals. This makes you laugh!
✓ You have that incredible sinking feeling that you've forgotten SOMETHING on those few days that you don't have some sort of appointment somewhere!
✓ You get irritated when friends with healthy kids complain about ONE sleepless night when they're child is ill!
✓ Your vocabulary consists of all the letters OT, PT, SP, ASD, VSD, IFSP, etc.
✓ You keep your appointment at the specialist even though a tropical storm is raging because you just want to get this one over with.....you waited 8 months to get it.....and besides, no one else will be there!
✓ Fighting and wrestling with siblings is PT.
✓ Speech therapy occurs in the tub with a sibling.
✓ When potty training is complete, you take out a full-page public notice in the Washington Post.
✓ When the Doctors/Specialist/Hospitals etc. all know you by your name without referring to your chart.
✓ You keep a daily growth chart.
✓ You calculate monthly statistics for the number of times your child vomits, and did this for more then one year.
✓ You phone all your friends when your child sits up for the first time, at age two.
✓ With a big smile on your face you tell a stranger that your four year old just started walking last week.
✓ Her medical file is two inches and growing.
✓ You have a new belief.....that angels live with us on earth.

Stories of CHERUBS

On August 30th, 1999 (at 39 weeks gestation), I went in for an ultrasound because our doctor thought that the baby was breech. It was during this ultrasound that they discovered that his heart was pushed more to the right than what it should have been. They quickly set me up with an ultrasound the next day at a hospital better equipped in dealing with high risk pregnancies and deliveries. During this ultrasound, they discovered that he had a hole in his diaphragm.

They prepared us for the worst by telling us that our son could be stillborn if he had Trisomy 18 (a chromosome abnormality known to cause CDH). Our choice was to have an amniocentesis to see if he had this disease (the result would have taken two days at the earliest to find out) or to induce labour with the likelihood of a c-section, which would result in a stillbirth if he had Trisomy 18. We chose to induce and accept the possibility of surgery (C-Section) with a stillbirth.

On September 2nd our son was born alive by C-Section. He weighed 4 lbs 13 ozs. We heard one little screech out of him before he was taken away by NICU doctors and prepared to be put on a ventilator. We had to wait three to four hours before we could go down to see him. He looked so horrible with all the tubes and IV's and what not being poked into his tiny body. He was on a ventilator and an oscillator and was injected with paralyzing drugs so that he could not move or fight the machines. We were both apprehensive about touching him even though the nurses said that it was important to do so. At one point in time he was also placed on ECMO to help his lungs get stronger.

At five days old he had surgery to repair the hole and pull down the intestines that were in his chest cavity. The surgery took a couple of hours, and we were told that everything went well. Four days later he came off the ventilator, and we were finally allowed to hold him. The feeling was incredible, and it was at that point that I think we both knew that our son would be coming home with us soon. This was the moment that I really felt like I bonded with my son.

Over the next two weeks Cody had more good days than bad. He eventually progressed to the PCU where he stayed for 5 days so that they could monitor his weight gain and how well he did without any oxygen. On Saturday, September 25th (after 23 days in the hospital) we arrived at the hospital to visit with him. We knew that he would be coming home soon, but we were shocked when they asked if we wanted to take him home that day. Of course we said yes. When he left the hospital, he was free of oxygen, eating well, and weighed 5 lbs 8 ozs.

Today, at two and a half years old, Cody is a happy, healthy toddler who loves life as well as his eight-month-old sister, Samantha (born perfectly healthy). Developmentally, he was behind for quite a while. He didn't crawl until after his first birthday, and he didn't walk until 18 months of age. Healthwise, he tends to get a lot of throat and ear infections, has suffered from several episodes of febrile seizures, has had croup at least a half a dozen times, and has been hospitalized for croup and pneumonia once. There is also the possibility that he has asthma. We do our best to keep him away from other sick children as he tends to pick up viruses very easily. He still has a 5-inch scar across his lower abdomen, which will fade as he grows. Just like any other toddler, Cody is very busy and can try our patience, but all it takes is to look at our fridge where we have placed a picture of Cody shortly after his birth in the NICU, and this reminds us of how lucky we are that he survived and is now a happy, healthy toddler.

Marty and Stephanie Maerten (parents of Cody Albert John Maerten, 9/2/99, 20 North Street East, Tillsonburg, ONT N4G 1B3, Canada, 519-688-4692, Maer10fam@AOL.com)

My daughter was born 06-12-1999 with a left side diaphragmatic hernia. There were no known factors that made anyone think that she wouldn't be healthy. I was in labor for a long time, and they could feel her head, but she was stuck in the birth canal. An emergency c-section was then decided. They tore my bladder among other things getting her out, but that was okay because the health of my baby was my first priority, my sweet little angel-Stephanie. My husband went with Stephanie to be checked out while the surgeons continued to work on me.

When I was in recovery, the doctors came in to tell me that Stephanie had tests and X-rays taken and that she had a diaphragmatic hernia. She was going to be packed up and transported to Egleston Children's Hospital in Atlanta, Georgia. My husband once again went with Stephanie. I had to wait in Columbus, Georgia until my OBGYN would release me from the hospital.

I was released from the hospital the same day that Stephanie had her surgery to fix her hernia. Steve called me at the house to let me know that she came through the surgery great, and they didn't expect any complications. I just sat on the couch and cried that she came through the surgery with flying colors but also that I couldn't be with my baby on the hardest day of her little life. I packed up what I could, and the next morning I was off to Atlanta with a catheter bag for my bladder, stitches in my belly, and a spirit that I was going to see my baby no matter what the day held! When we got to the hospital, the NICU let all my family come back with me to all cherish the mother-daughter reunion. It was the best day of my life getting to see and hold my daughter for the first time after all the things we just went through.

She was released from Egleston after 20 days with an NG Tube and a few minor feeding problems, but all in all she is as healthy as you can get from such an ordeal. Now she is 2, and her development is normal; she is just 2 but going on 10. However, she is having an Atelectasis problem of the lower left lobe on her lung. She also has Reactive Airway Disease, but it is somewhat under control with medications. With modern science and the help of the Lord above, I know we as a family can overcome any obstacles that may come our way.

Teresa Thompson (mom of Stephanie Ann Thompson, 6/12/99, 5825 Glenlake Court, Columbus, GA 31909, 706-561-2439, tthompson@tomsfoods.com)

We were diagnosed with CDH at 18 weeks through a routine ultrasound. I was not having any problems; we just wanted to know the sex of the baby.

After diagnosis, we saw a specialist every 4 weeks to check on the progress of his hole. It appeared that our son had a left-sided hernia with stomach and a loop of bowel in his chest cavity. Both lungs could be seen, however the size of the left lung was unclear. We live in Central Illinois, and our hospitals were unable to handle the CDH repair. My husband and I researched hospitals with successful CDH repairs. We chose Children's Hospital after meeting with the surgeons and touring their NICU. We felt very comfortable with the quality of their facility. They also had the ECMO machine, which we had been told that our son might need.

On February 2, 2002, I gave birth to Aaron Jacob Hoewing, weighing 8 lbs 12 ounces and 22 inches long at 6:37 PM. The delivery was a 39-week induction, and I delivered Aaron vaginally with help from the vacuum suction. I had a pretty normal pregnancy until the last 3 weeks in which I had excessive amounts of fluid, which is sometimes common with CDH babies because they are unable to take in as much amniotic fluid. He was delivered at Barnes Jewish Hospital in St. Louis, MO across the catwalk from Children's Hospital. When Aaron was born we heard a faint cry that sounded like a little lamb. My husband and I were excited because we had been told previously that he would not make a sound. He looked so beautiful and healthy on the outside that it was hard to believe that there was anything wrong with him. He was immediately intubated and placed on medicine that kept him paralyzed. His Apgar scores were 2 and 7. His initial heart rate was 46. CPR was begun, and he was then stabilized. We were told that we could gently touch him but not to stroke him. We held his hand and took quick pictures before he had to be whisked away. I told my husband and family to go with him while I waited for my epidural to wear off. The NICU doctor called me immediately after Aaron was admitted to tell me that he was stable and that they would watch him carefully through the night and would meet me in the morning.

I finally got to see my son the next morning. He was still on a regular vent but at very high settings. I was not allowed to hold him. Later that day Aaron was switched to a high frequency vent called an oscillator. The next day Aaron was put on Nitric Oxide, which he remained on through his surgery.

The surgeons came by to check on Aaron every hour. I did not know how sick our son was; we thought this was normal procedure. The surgeons postponed Aaron's repair until they felt that he was stable enough to handle the surgery. The repair was done when he was 5 days old in the NICU because they were unsure whether Aaron would handle being moved to the OR. The entire NICU had to be shut down for our son's surgery. We felt terrible because that meant that other parents could not see their children during this time. We found out later that surgery had never been done in the NICU before Aaron.

The surgery was a success. Aaron had enough muscle in his diaphragm that he did not need a gortex patch. His stomach, spleen, and loop of intestine had been put back where they belonged. The surgeons informed us that the surgery was just a small part of the entire CDH recovery. Aaron was not out of the woods yet.

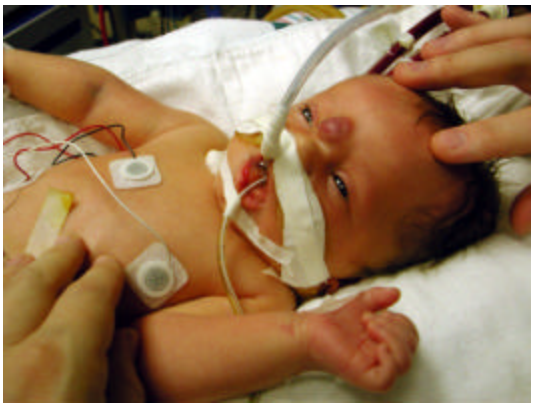
On Feb. 19th, Aaron was placed back on a regular vent. WE FINALLY GOT TO HOLD OUR SON!! They took off the paralyzing medicine. We were beginning to see movement for the first time. Each activity was a big deal to us. The first time his foot moved, eyes opened, wiggled his fingers-- it was good medicine for both our son and for us. Aaron began recovering very quickly. His settings were lowered each day. On March 6, 2002, Aaron was extubated!

He was put on C-Pap for two days and then finally to nasal plugs at 30% oxygen. His medicine was switched from IV to oral medicine. We were able to try feeding him from a bottle on March 14, 2002. He seemed to have an oral aversion. The nurses explained that this was normal for babies who had been as sick as our son was. They have never had anything good put in their mouths before so naturally they hate anything put in it.

We worked on feeding issues for the next couple weeks while Aaron continued to get stronger each day. He was weaned from all medicines and taken off oxygen on March 28, 2002. We were able to take Aaron home on April 10, 2002 without ANYTHING!! He is presently on no medication or oxygen. To look at our son you would never know that there was ever a problem. He weighs 12 lbs 5 ounces and is 23 inches long. He is a happy baby, always alert and smiling. Everyone comments on how alert he is. We have Occupational and Physical Therapy that come to our house one time a week to work on range of motion activity. Since Aaron was paralyzed for so long, some of his muscles became stiff.

We know that Aaron's success is from the many prayers that were prayed on his behalf. We had several churches praying for our son ever since we were diagnosed. We believe that God has a special plan for our son. We are excited that we will get the chance to witness our precious cherub grow and become the man that God intended him to be. Thank you so much for your website. The initial diagnosis can be so overwhelming. It is so comforting to know that there are other people out there going through the same things.

Lisa Hoewing (mom of Aaron Jacob Hoewing, 2/2/02, 5559 E. William St., Decatur, IL 62521, 217-425-9674, rlhwing@attglobal.net)



We have two beautiful boys, Benjamin and Jonathan. We learned that we were expecting when Jonathan was 8 months old. We learned at 20 weeks gestation that we were having a girl who had a Congenital Diaphragmatic Hernia (CDH). This came as quite a blow, especially after our son Jonathan had just been diagnosed and had surgery for neuroblastoma (cancer) just 3 weeks earlier. We were numb. We had an amniocentisis to check for genetic abnormalities, since her ultrasound showed a growth on her forehead. After a VERY LONG 10 days we found she was genetically normal. We had a visit to the Indiana University Medical Center and Riley Hospital for Children scheduled for us for February 15, when our son Jonathan was due to have his next CT scan.

The fifteenth was an overwhelming day, ending in a fetal MRI for mom, an ultrasound with the perinatologist and cardiologist, a meeting with Dr. Trautman (in neonatology) and a meeting with Dr. Deborah Billmire, who was to be Elizabeth's surgeon. We left completely exhausted, but very confident in Elizabeth's future doctors. Every question we had was answered in full (of course we always heard, "You never know until the baby's born").

We arrived back at IU to be induced on Monday, March 25, 2002. I was 38 weeks along. I received a pill to prepare my cervix, since I had not started to dilate. Labor began after about 6 hours, and that night I had some Nubane to allow me to rest a while. I woke up around 6:00 and knew I was in transition. There had been trouble finding Elizabeth's heartbeat all night, so I requested that they check her position now, since I was very near delivery. I had a great deal of fluid, due to the CDH, and Elizabeth had turned again to a breech position. I felt the urge to push and summoned the doctor. I ended up with general anesthesia. Elizabeth's feet were already in the cervix. She was born via c-section at 7:28 a.m. My husband, Steve followed Elizabeth as they tried to stabilize her at IU. They transported her to Riley through the tunnel where she arrived at 9:30 a.m. I was waking up in my room with Steve when Dr. Billmire called. She said Elizabeth's oxygen level was at 50% and asked if we wanted her to go on ECMO (Extra Corporeal Membrane Oxygenation). There was no alternative but death, so we agreed.

After the surgery to put Elizabeth on ECMO, I was able to see her. I had a LONG wheelchair ride through the tunnel to the NICU at Riley. Elizabeth was so beautiful. The growth on her forehead was just a hemangioma (birthmark that fades over time). We could not hold her or stimulate her much, due to the ECMO cannulas in her neck.

Six days later, Elizabeth would have surgery while on ECMO. She was not able to progress any further without it and needed more lung power. Her liver, intestines, spleen, and stomach were in her chest cavity and were keeping whatever left lung was there from expanding. We prayed there would be some lung on her left side to assist her larger, but smaller-than-normal right lung. The surgery went very well. Dr. Billmire went over what happened and that even though it went well, we still did not have enough evidence to show whether she could survive. Her lungs expanded and each day we checked her X-rays and blood gases to find evidence of progress. She soon seemed ready to be taken off of ECMO. After several days of weaning (up and down on the ECMO support level), she seemed to be doing very well at a low level.

On Friday, April 5, she was removed from ECMO. She seemed to be doing well at first, but that night was AWFUL. She seemed to have developed pulmonary hypertension. The cardiologist was summoned in at 10:30 p.m. to do an echocardiogram. I listened to a very sobering description of the implications of this problem. Basically, it was not easy to resolve in any short amount of time. I went back to our hotel to get some rest. At 1:30, Dr. Evan Kokoska called me and said that my daughter was doing very poorly. I asked how long she would last, and he said it could be several hours. I said a prayer for strength to accept God's will for us and left for Riley.

When I arrived, a very tired Dr. Kokoska and her nurse Mary Lynn, had done all they could think of. I sat down with Elizabeth and prayed and talked to her. About 20 minutes later, little drops of urine started dripping from her Foley, signaling that kidney function was resuming. Praise God! Elizabeth made a comeback and continued to progress all through the weekend. It was Sunday before I began to progress from the shock.

The week went well to begin with. Her paralysis was stopped Tuesday, and she started producing stools. She was allowed her first tube-feeding Wednesday night. I came back to the hospital, excited to see how it went. While she was keeping the milk down, her oxygen and blood pressure were not as steady. I went home and was in contact with Kelly, her nurse, every few hours. She called at 6:15 a.m. and said that Elizabeth was back on the oscillating ventilator. I knew that wasn't good. I got to the hospital at 8:00 and waited there all day as her doctors tried many things to get her oxygen levels to improve. They were around 80 most of the day, but dipped into the 70's and even 60's at some times. I called my husband to start driving from Mishawaka. I knew from her experience Friday, that they had done everything they could think of, and she was still not improving. At 5:00 p.m. when Steve arrived, we talked to Dr. Billmire about her condition. She would probably not survive the night. We were so thankful to Dr. Billmire throughout this that she was always calm and honest, not giving us false hope or telling us what we wanted to hear. We sought her out whenever we wanted to REALLY know how Elizabeth was doing.

We brought our sons back to the hospital to see their little sister for the first and last time (it was RSV season and they were not allowed in prior to this). Everyone was very understanding and helpful. The nurse put curtains up around our bed so we could have privacy, and at 9:00 p.m. we asked to be able to hold her. She was still on her oscillator and all of the wires and tubes, so this was a feat. I held my Elizabeth Joy for the first time. She was so light. After four hours, Steve took a turn. I sat with them and watched her color fade and knew she was slipping away.

We had the most wonderful nurse in the world, Cheryl, who, with a cheerful face, helped us accomplish all of our firsts with Elizabeth as the happy, bittersweet moments that they were. She and another sweet nurse helped us make a hand cast of her beautiful little hand, and brought us drinks and food as necessary. I took Elizabeth back from Steve, and we talked with Dr. Torrine (her neonatologist) about what to do next. This woman was amazing. Pregnant herself, she was there all night and helped us say goodbye to our sweet Elizabeth with compassion and skill.

I knew that Elizabeth was not really with us anymore, but her heart was still beating. First, we turned off the dopamine and dobutamine, which didn't do much. The oscillating ventilator was keeping her heart beating, although her little body could not be surviving at her oxygen level (30 at this point). I held her and helped remove the ventilator. This was the first time I'd seen her without her vent taped to her face. She was so beautiful, with sweet little lips and a tiny, perfect nose. I held her close and sang her a special song that I'd sung to all my children as I rocked them to sleep. Dr. Torrine came to check her about 20 minutes later, and she had gone. I had to say goodbye to my little girl, who I'd only given birth to 17 days earlier. We have no regrets and cherish those days more than anything on earth.

Our little treasure, Elizabeth, is in heaven, but we have a great treasure in the incredible friends in Christ we have here. There will be a day when I go to meet Elizabeth. I long for it. Yet I know that I have two little boys who need a mom to help them accomplish what God has planned for them. In heaven, we'll be a family of five once again.

Anne-Marie Huffman (mom of Elizabeth Joy Huffman, 3/26/02-4/12/02, 515 Downey Ave., Mishawaka, IN 46544, 219-257-4656, shuffman27@attbi.com)

This is the story of our son Lewis who was diagnosed in utero at 20 weeks with a left-sided diaphragmatic hernia. My wife Clare and I were trying for our first baby, and to our surprise, she fell pregnant almost immediately; we were thrilled to bits. But at six weeks, Clare started to bleed and from then on the pregnancy seemed to go from bad to worse. The baby survived the bleed and when our 20-week scan finally came around, we were excited to see our healthy growing baby. These feelings were soon stamped on when the sonographer said there was something wrong. We had a feeling something was not right when there was a silence throughout the scan. The sonographer told us that she was pretty certain that our baby had a diaphragmatic hernia and that she was going to check with a colleague. She then left the room. Clare and I looked at each other in horror-- what the hell was a diaphragmatic hernia? We waited a good 15 minutes before someone finally returned and explained to us how serious the problem was. We were both devastated since our baby was only given a mere 5% chance of surviving; we went home and told the family the bad news. Our specialist had given us two options, firstly to end the pregnancy and secondly to carry on knowing the bleak outlook. We considered the first option but not for very long. Our baby only had 5% chance of making it, but that meant that there was a chance, and we couldn't throw that chance away so we chose to carry on.

Clare had an ultrasound scan every 4 weeks and also had an MRI scan to confirm that the liver had not herniated into the chest. The liver appeared to be in its normal position, which was something anyway. The scans revealed that our baby had a large left-sided CDH, and the stomach, intestines, and bowel were all in the chest, which pushed the heart over to the right side and compressed his growing left lung. Later in the pregnancy, the baby's lung to head ratio was 1.67 which we were told was a good figure, and Clare was booked in to have 4 courses of steroid injections to encourage lung maturity. It seemed that at every scan there was a little more glimmer of hope, the chance of survival had risen from 5% to more like 50%. A foetal blood sample was done to rule out any other abnormalities, and after two weeks of agony the results came back normal. It was from this test that we found out we were expecting a baby boy. Each time we came away from the hospital we both felt more reassured that our baby would be alright, but at the back of our minds we knew that whatever the outcome it was going to be a bumpy ride and that our son was going to have major surgery if he was to survive.

On the 24th January 2002, at 8:30 am, Clare was induced due to high blood pressure. It was decided that this would be best, since the delivery team would have everything prepared in order to give our son every possible chance. The contractions came on quick and strong, and it wasn't long before Clare requested an epidural. Eight hours later our son Lewis was finally born vaginally with the use of forceps. He made his entrance at 5:04 pm, weighing in at 6 lb 14oz.

Our son was beautiful, and he even managed a little squeak before being swiftly whisked away to the other side of the delivery room. The delivery team worked fast, and we were soon given the thumbs up that he was stable. Neither of us was able to hold him or touch him, but we were given another quick glimpse of our gorgeous son before he was taken to SCBU.

While Clare was recovering from the birth, we were informed that Lewis was doing well and only required 40% oxygen. After about an hour, Clare was feeling up to visiting Lewis, and doctors said that he was settled enough for us to see him. The walk to SCBU was nerve-racking, not really knowing what we were about to see. It was quite strange really because you tend to look past all the tubes and wires and look at the beautiful person underneath, and at that moment we were so proud of our little boy, and we felt so blessed to have him even though his future still hung in the balance.

That night the local chaplain came at our request to christen Lewis. He was surrounded by immediate family who all loved him very much, and the short service was very moving for all. Lewis was sedated and remained stable during his first night, so the decision was made to transfer him to Alder Hey Children's Hospital Liverpool the next morning in preparation for his surgery. We knew all about ECMO and nitric oxide and were so relieved that Lewis was stable, needing oxygen only, and the transfer took 40 minutes without any problems. As soon as Clare was discharged, we rushed over to be with Lewis, and the nurses looking after him said that the surgeon was happy to repair his diaphragm the next day. We settled into our room at the Ronald McDonald house that evening and prayed that everything would go smoothly. The next day Lewis was wheeled down to theatre at 4 pm. It was so emotional watching our son being taken away, not knowing if we would ever see him alive again, although the nurses were very reassuring. Four agonising hours passed, and Lewis finally returned to ICU. He had made it, and the surgeon said that everything had gone as planned and that the defect was large and needed a gortex patch to cover it.

Lewis's honeymoon period lasted 48 hours, and after that, things seemed to improve. He had good blood gases, so they started to wean down his oxygen. Lewis was proving to be a little fighter, and we were both so proud of him. Apart from being a little jaundiced, he looked settled. Feeding started on 5 mls of breastmilk every 3 hours through the use of an NG tube. He tolerated it well at first, and it soon went up to 40 mls. Lewis continued to do well, and on day 6 of his life, the doctors decided to try him off the ventilator. We were so happy and excited that we might get to finally hold our beautiful son. Our hopes were soon dashed as Lewis lasted only 12 hours off the ventilator before being put back on. His chest was recessing too much, and his breaths per minute increased. We came to the conclusion that it was just too early for him, but it was very hard seeing him with all the tubes taped to his face again. He so nearly made it to the next step, but we weren't disappointed with him. The doctors told us that he had done extremely well to come this far, and that it was only a matter of time before his lungs would expand enough for him to breath independently.

The next few weeks were up and down. Some days Lewis would appear to be improving, only to find him getting worse the next day. Desaturation became a major problem some days, as did distention of his stomach. He also caught an infection from his central groin lines, a combination of all these problems ended up with Lewis's oxygen levels increasing. It was really depressing watching all the other sick children come and go while we still came day after day to be with Lewis. We had to be patient; the doctors kept telling us, "It just takes time."

On the 9th February, Lewis's condition started to deteriorate. His stomach would suddenly fill with air and distend, putting pressure on his already immature lungs. This made it really hard for him to breath. His feeds had stopped because of severe vomiting, and as a result, he was put on TPN. The nurses had to keep aspirating the air every hour or so by a syringe on the end of his NG tube. Seeing the pain in his face was really upsetting. He hated it when the pysio's cleared his tube with suction. He would lash out, and his sats would drop. I remember one day when his oxygen input was at 100%, and he was doing very little breathing on his own. The doctors told us there was a possibility of pyloric stenosis or malrotation of the stomach, which would have explained the vomiting and stomach distention. Lewis had an ultrasound scan which looked normal; we were so relieved, but the problem still couldn't be explained. They gave Lewis a Barium Dye Test, which showed that there was an obstruction in his tummy, and that it seemed to move in spasm, which explained why he was so uncomfortable. The surgeons decided to operate on Lewis again, but the operation would carry a risk of infecting his patch. We really didn't want him to be operated on again, but this was the only way they could help him.

During the operation the doctors found that Lewis had a kinked duodenum because his stomach was lying abnormally and that he also had a lot of scar tissue adhesions. After finding the cause of the problems, they then straightened his duodenum and removed the adhesions. They also fitted a broviac line into an artery in his chest. After 6 long hours, we were able to see our son again. He hadn't tolerated the surgery as well this time, and he looked grey and lifeless. The doctors told us that despite how he looked, the operation had gone well, and that he was now on less oxygen than previously (55%).

Over the next few days, Lewis slowly recovered, his bowel and stomach had been handled so much that they temporarily shut down to recover. The colour of his stomach acid was checked regularly and changed from dark green to pale yellow, which was a good sign, and as soon as it changed to yellow, feedings started again. During the week following his operation, Lewis made a speedy recovery, which was a shock to us all considering he had been so ill the week before. We could hardly believe that just one week post-op, he was saturating at 100% without any help. It was such a big step after four hard weeks, and amongst all the joy, we both prayed that he wouldn't have to be reventilated.

On Friday 22nd February 2002, Clare and I finally got to hold and cuddle our son for the first time ever. He was so peaceful and settled, it was an unforgettable experience, and we both felt so overwhelmed and lucky to have him in our arms. That day Lewis was transferred onto a ward where we all started to get to know one another. He started to increase his feeds, gained weight, and finally got rid of all his tubes and lines. The week spent on the ward was a completely different experience to being on intensive care. We finally felt like parents to a newborn baby. Lewis was discharged from hospital on March 4th 2002, and it couldn't have been a better day as it was my birthday. It was the best birthday present a father could ever have. The three of us were now a proper family, and Clare and I were very excited to get our son home 5 weeks and 4 days after he was born.

Lewis has been home now for 8 weeks, and so far there have been no major problems. He doesn't seem to suffer from reflux, and apart from being a snacker and having pretty bad colic, he feeds quite well. Although he's gaining weight at a good pace (about 1oz per day), he is small for his age at 10 lb 3oz, but we are hopeful that he will eventually catch up. He's had three colds since we came home, and Clare and I have been really anxious and worried but they haven't seemed to bother him any more than any other baby. His scars have healed really well and are shrinking as he gets bigger, and he is right up to date with his development. All in all, Lewis is a very alert 3-month-old who enjoys playing on his activity gym. The whole family loves him to bits, and he is a very spoilt baby but with good reason. Both family and friends, especially the grandparents, can't believe how well he's done, and we all cherish every moment with him. We thank god for letting us keep hold of our son. Clare and I believe he is truly a miracle, and we are so grateful to have him in our lives today. Thank you, Cherubs for being there every step of the way. Keep up the good work!!!

Mark & Clare Kelly (parents of Lewis Kelly, 1/24/02, 76 Statham Road, Bidston, Wirral CH43 7XS, Great Britain, 01516522597, clare@mk76.fsnet.co.uk)

I became pregnant with my first child in winter of 1995. What a wonderful time it was (at least for the first 6 months). My husband and I had been married for five years and couldn't wait to start our family. We had our first ultrasound at 20 weeks and everything seemed fine. We were told we were having a boy and immediately named him Anthony Urban. My husband's name is Anthony, and my late father-in-law's name was Urban. It was perfect. Everything seemed to be going along normally for the first 6 months of my pregnancy. I was enjoying the attention I was getting and loved being pregnant. I was working full-time as an administrative assistant for a large steel company in Cleveland. Life was good!

One day at work I went into the bathroom (as we all do several times a day during pregnancy) and noticed some spotting in my underpants. I immediately called my doctor, and she wanted to see me right away. I wasn't too worried at that point, but I cleaned off my desk because I had a feeling I might not be going back to work for a while. When I got to the doctor's office, she gave me an exam and said she thought I had a clot on my cervix, but that I needed to go to the hospital for more tests. I called my husband from the doctor's office and broke down crying. I couldn't believe something was going wrong with my pregnancy. This wasn't supposed to be happening. My husband met me at home and we headed to the hospital. When we got there, we went to the labor and delivery floor, and they immediately hooked me up to a fetal monitor. The baby's heartbeat was strong and steady. I was starving, but they wouldn't give me anything to eat. After several hours there, they said I would need to spend the night and have an ultrasound the next day. After I got checked into my room, my husband left, and we had a tearful goodbye.

The next morning my husband came back to the hospital, and we went for our ultrasound. It seemed to take forever. The technician really took her time. She did have a strange look on her face. She left the room and went to get a pediatric cardiologist. We were so scared. Could something be wrong with our little Anthony? He came in and continued the ultrasound. Afterward he told me to get cleaned up and that he wanted to talk to me and my husband in a private room. After he left the room, I lost it. I knew it was very bad news. He explained to us that our son had a hole in his diaphragm. He said it appeared to be a small defect, but that it would require surgery as soon as possible after he was born. We were in shock! I wouldn't be bringing my baby home with me. That wasn't right. What did I do wrong?

I got back to my hospital room and broke the news to my mom and dad. They were devastated. Then my mom began to call relatives to let them know what was going on. During all of this, everyone seemed to forget about the spotting I had. The next day, my ob came in and said I could go home. I was so happy. I just wanted to go home. A few minutes later, she came back and said I wasn't going anywhere. I had placenta previa. My placenta was blocking my cervix and causing the bleeding. This condition would require strict bedrest and regular ultrasounds to see if it would improve. I had my husband go home and pack me a bag of clothes and personal items I would need.

I spent 7 weeks in the hospital on very strict bedrest. I had several bleeding episodes and got more scared with each one. I was told it was critical that I keep this baby inside of me as long as possible to increase his chance of survival. A pediatric surgeon met with us as well as a neonatologist. They both explained to me what would be happening once Anthony was born. He would have quite an uphill battle and so would we.

On March 10, 1996, my OB performed an emergency C-section on me. I was 36 weeks pregnant, and the bleeding had gotten worse. If they didn't do it now, both mine and my baby's life would be in danger. Anthony was actually born at 12:01 am on March 11, 1996. He weighed 7 lbs, 4 oz. Quite big for only 36 weeks! He already had size on his side. They whisked him away to the NICU, and I didn't see or hear him. By the time they got me sewn up and to the recovery room, I was exhausted. My family members came in to see me, but I made them all go home. It had been a long night, and there was nothing they could do. I spent 14 hours in recovery with excessive bleeding and had to receive 2 units of blood. My body was traumatized and so was my mind.

Anthony had his first surgery at 1 day old. The surgery itself went well, but the defect was much worse than they thought. He had virtually no diaphragm on his right side. Luckily his liver had prevented other organs from going into his chest, and he had a full lung on the left side and a half lung on the right. That was a lot more lung tissue the doctors would have predicted for such a large defect. This was great news. His first night post-op was very rough. The next morning the doctors began talking about ECMO. But a wonderful NICU neonatologist was patient. She said Anthony needed some time to recover from a very invasive surgery. She was right.

Eventually after a few weeks, Anthony was able to wean down on his ventilator. He did spend some time on the oscillator and nitric oxide. The oscillator really helped him. He spent 6 weeks in the NICU. He had a lot of trouble coming off the vent. Every time they tried, it would last a few hours and then his stats would drop. It was so frustrating. I remember one time when they tried; I was holding him, and I didn't want to let go. I didn't even realize that he was turning blue in my arms. It was as if he and I were the only two people in the world, and I couldn't hear the nurses trying to tell me he needed to go back on the vent. I guess I really didn't want to hear that.

After 7 weeks in the hospital, we brought Anthony home. Everything seemed to be great. I did begin to notice that he was turning quite blue when he cried and that he wasn't putting on any weight. We brought him for a checkup on July 31, 1996, with the surgeon and were informed that his hernia was back. They performed surgery on him that day and the roller coaster ride started again. This time he tolerated the repair very well. By the way, they inserted a Gortex patch inside his chest. I forgot to mention that earlier.

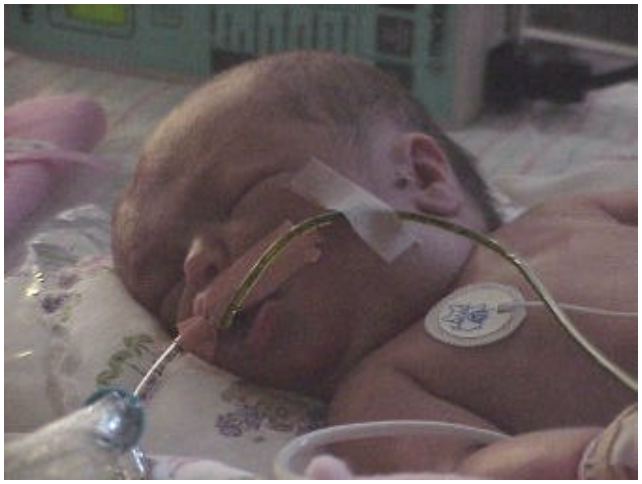
It was a few days after the surgery while he was in the PICU that I noticed a lump on his abdomen. It turned out to be a bowel obstruction and once again he needed to go under the knife. This time Anthony had a very rough time. It had only been a few days since the re-repair and his body didn't like being opened up again. He was bleeding very badly from his abdominal wound. This was the first time I saw a worried look in his surgeon's face. My husband and I prayed and prayed and prayed. We called our friends and family and asked that they start a prayer chain for our son. At the end of the day we went home with heavy hearts. That night we got a call at 4:00 am from the nurse, telling us that we should get to the hospital because they couldn't stop the bleeding. We rushed down there, and I sat by my son's bedside. I sang to him and read to him. My husband went to visit his father's gravesite and then to church. When he came back, Anthony began to make a turnaround. By the end of the day, Anthony's bleeding stopped. It was truly a miracle.

As a result of the surgery, Anthony had a colostomy for a few months. The doctor wanted to give his bowel some time to rest. We brought Anthony home in mid-August once again. This time he was great. No turning blue. He had his colostomy reversed in October and was home in 2 days. What a difference!

We just celebrated Anthony's 6th birthday last week. I can't believe it. He still sees his surgeon twice a year and gets an annual MRI to check his chest wall measurements. They think that at some point in the future he will need another surgery to replace the Gortex patch with a larger one. I try not to think about that too much, though. I just enjoy every minute I spend with him. He is in kindergarten and is thriving. He plays on the soccer and baseball teams in our town. I only dreamed of these days 6 years ago and now they're my reality. We also have a beautiful 4 1/2 year old daughter. I got pregnant with her when Anthony was only 9 months old. We really didn't plan it that way, and I was scared to death that something might be wrong with her, too. But she was born perfectly healthy. I'm glad I had her so soon after Anthony. It really helped me heal to know that we could have a healthy child and that I didn't do anything wrong.

God bless each and every one of you. We are all part of a family. We share a bond that can never be broken.

Mary Iacobucci (mom of Anthony Urban Iacobucci, 3/11/96, 1544 Parker Drive, Mayfield Heights, OH 44124, 440-449-3873, tonyyock@aol.com)



My husband and I were on our honeymoon in October of 2000, when we found out that I was pregnant. After our honeymoon was over, we flew back to Japan where we were both stationed. Upon arriving back in Japan, we went to the hospital to confirm that I was indeed pregnant. I had the normal morning sickness and nausea that is involved with being pregnant; other that that, everything was going well.

I had my first ultrasound done at 18 weeks in Feb of '01. My husband and I were looking forward to finding out what were we having; we were never expecting what we were going to be told that day. We found out that we were having a little girl, whom we decided to name Emily. The doctor told us that her stomach was enlarged, but that they didn't know why. I was told to come back in for a follow-up ultrasound in about 4 weeks. Three weeks later at 21 weeks, my husband and I were back in the hospital for another ultrasound and were told the same thing. Again they had seen that Emily's stomach was enlarged, and they still didn't know why. The doctor called me at work that afternoon and told me that he was sending me to Okinawa, Japan, to see a Maternal Fetal Specialist at the Naval Hospital there.

I spent my first few days in Okinawa alone, due to the fact that my husband could not accompany me there because the military could not afford to send him with me. I went to the Naval Hospital for an ultrasound at 22 weeks, where the doctor said that she suspected that Emily had a diaphragmatic hernia. I called my husband, and the doctor explained to him what she suspected. She insisted that I get an amino done to rule out any other birth defects, and we agreed to it. Needless to say, my husband was on the next flight down to Okinawa to be with me. While we were there, we talked with the neonatalogist, and Emily was given a 30% chance of survival. At the time we were told that Emily had a left-sided hernia and that her heart was being pushed to the right. I was informed that I needed to be transferred back to the states ASAP.

Upon returning to my base, I continued to have my appointments every 4 weeks. I was told that I was going to be seen as a regular patient and not as a high-risk pregnancy. At one of my appointments around my 28th week, I was told that I measured big by three weeks. When I asked the doctor if that was bad, she replied that it meant that I was going to have a big baby. I had to fight with the doctors just to give me an ultrasound to check on Emily.

Finally in April of '01, my husband and I were going to be transferred to Texas. By this time I was 30 weeks pregnant, and we flew the 17 hours to the states and finally made it to Texas on April 21st. Upon arrival in TX, I was instructed to report to the hospital on the base. I was admitted to the hospital on April 22nd, where I was put on monitors to check on Emily. I had been having contractions the entire flight and even after arriving in the states.

My doctor released me from the hospital on my husband's birthday, April 23rd. I was told that I was on bedrest until I delivered, which was supposed to be June 28, '01. We didn't have a place to live yet, so we were staying in temporary lodging on the base. My husband had to report to work that morning, so I was left there for the day. He came back around 0900 to get something; when I got up to help him find it, my water broke. I was rushed to the hospital, where I was admitted again. At this time, I was only 30 weeks pregnant. I was given magnesium to stop my contractions. It was at this time that they started running tests and checking to make sure that there was nothing else wrong. At this time, I found out that I had polyhydramnios, severe pre-eclampsia, and gestational diabetes. I was put on a special diet and kept on the monitors 24 hours a day. I was also given steroid shots to try to help her lung development.

On the 27th of April, early in the morning, I started to get very sick and was vomiting and shaking uncontrollably. The doctors finally got it under control for a little while. Around 10 pm, the doctors decided to induce my labor due to my severe pre-eclampsia. Finally at 11:38 p.m., Emily Nicole was born; this was the beginning of the longest 5 days of our lives. She was immediately taken by the peds for resuscitation and placed in the NICU. We were able to see Emily 6 hours after she was born. We were told that Emily had a right-sided diaphragmatic hernia, pulmonary hypoplasia, dysphasia of the lung, intraventricular hemorrhage, RDS, hypotension, grade IV bleed. She was given dopa/dobutamine, epinephrine, pavalon and many other meds. Emily was placed on a high frequency oscillator and a high-pressure ventilator.

Emily fought for her life for 5 long days. On the 2nd of May, the doctors called us and told us that she was not doing too well and that they would call back. They called us 10 minutes later and told us to get to the hospital. Her saturation levels were really low and her heart rate was so high. We were told that they had done everything that they could and had all of her vents as high as they could go. My husband and I decided to let Emily go. With our parents there, we had the doctors change out her vent, so that I could hold her. It would be the first and only time that I got to hold Emily. Emily passed away in my arms. She was 5 days old. I'll never forget being next to her bed, having my finger in her hand, and she was squeezing it as hard as she could.

We had Emily flown home to Missouri, where she was buried next to my little sister. The Air Force paid all of her medical bills and for her funeral. It has been a year since Emily was born and since she has been gone. This has been so hard on me and my husband. I miss Emily so very much, but I know that she is in a better place.

Melissa Clark (mom of Emily Nicole Clark, 4/27/01-5/3/01, 1664 Beach Blvd, Apt 53, Biloxi, MS 39531, 228-432-8942, mjclark@cableone.net)

The winter of 2000 was full of excitement and change for the Gallagher family. Anne was pregnant with our second child, and we decided to put our new home in Minnesota up for sale and relocate to Arizona. Early in 2001, Anne began prenatal care in Minnesota. At sixteen weeks (March 2001), Anne had an ultrasound to confirm the due date. A great ultrasound report coupled with the fact that our son was born in 1998 following a perfect pregnancy gave us all the confidence we needed for a second healthy baby.

In late March, we closed on both homes and set off for Arizona. This is when the havoc began. Our movers were dishonest and failed to deliver our household items for over a month leaving us in a new but very empty house. Anne started going to her new doctor in Arizona and after her first appointment, was sent for another "routine" ultrasound to check the baby's development. The idea of being able to have a second ultrasound excited Anne and I, as we really were anxious to know if we were going to have another little boy or a girl. We knew in advance of our son's birth and really enjoyed preparing for his arrival.

During April, Anne was having a lot of morning, noon, and night sickness and really did not feel right, but we were not sure if it was the move, an empty house, or the pregnancy. When the day came for the second ultrasound, we were so excited, laughing and joking about possible names for our little blessing. We came up with some names for girls and could not agree on one name for a boy. I remember sitting in that waiting room filled with so much hope and tenderness thinking about the chance to have a second little miracle come into our lives and how truly blessed I felt. When it was our turn for the ultrasound, the technician started out by showing us the head, then arms, then legs and asked us if we wanted to know the sex of the baby. We both looked at each other with huge smiles on our faces and nodded an excited yes! The baby was a girl, and we both started to cry tears of joy upon hearing the news. The technician suddenly stopped the ultrasound and indicated that something did not look right but wanted the doctor to take a look. She left the room to get the doctor; leaving us in the room as our minds raced with the fear of the unknown and our tears of joy changing to tears of fright. She came back in and said that we needed to move into another room where we spent the longest ten minutes of our lives waiting.

The doctor came in and proceeded to perform a level two ultrasound. He spent a long time looking closely at the baby, especially around the chest area. He then proceeded to tell us, in a very dry and unemotional way, that our little girl had a birth defect called a diaphragmatic hernia and that she would probably die shortly after birth. He quoted us very low survival rates and then added that since her hernia was on the right side, the prognosis was even grimmer. We were heartbroken and very confused about what we were just told and unsure about our future. That evening, after many tears, we decided to look up CDH on the Internet to find out any information that we could about our baby's condition. We found several CDH sites but most of them were in medical jargon that was not easily understood by us and actually served to confuse and scare us even more. We also read many sad stories about families that lost their babies with this defect. I also found a research paper written by a pediatric surgeon at Shands' Children's Hospital in Florida. This was a very technical paper full of medical terminology that we didn't understand but one thing stuck out - 92% survival rate.

The following Monday, I emailed Dr. Kays and Shands asking questions about CDH and treatment options. Dr. Kays replied with a little bit of information and an offer to call to talk further. I was put in touch with a wonderful woman named Janice who spent almost an hour with me on the phone explaining Dr. Kays' methods and his results. She also gave us names and phone numbers of three families with happy, healthy babies that Dr. Kays cared for, the Firestones, the Toneys and the Bunches. They were such huge blessings to me and Anne, more than they will ever know. They gave us hope at a time that we had none. They all spoke about their children and what they went through with Dr. Kays and how our baby had an excellent chance for survival under his amazing care. At this time, our very special families went to work. My sister Kathy tapped every medical resource she had to find out more information. Anne's mom, who was a Godsend throughout this whole process, asked Anne's Doctor in Minnesota to help gather more information. The Toneys, the Firestones, the Bunches and our families gave us their love, support, and friendship when we needed it most. After speaking with Janice, she suggested that I leave a message for Dr. Kays to call when we was finished with his hospital rounds. Not ten minutes after I hung up with Janice, Dr. Kays was on the phone. He explained CDH and helped me understand more of this birth defect and what we were facing.

The next day we went back to meet with a perinatologist here in Phoenix. It was this doctor that told us about our options, most of which were very bleak. He said an amnio would have to be done before we could venture any further to check if the baby had any chromosomal abnormalities. He also suggested that if the amnio came back showing any abnormalities that the baby would not be a candidate for surgery and thus would have minimal chance of survival. He went on to say that we would then have to make a decision about continuing or terminating the pregnancy. Anne and I were shocked and angry that he even suggested that option. We knew we were scared but knowing that terminating the pregnancy was neither the answer nor something we believe in. Anne then started having bi-monthly and then weekly appointments, each time seeing a different doctor that gave us different answers to our questions and concerns. Many times, we received answers that were in conflict with the information that we received from Dr. Kays. Throughout this period, Anne was still feeling sick all of the time and was having difficulty catching her breath due to what we thought was the size of the baby. Every time Anne would mention this, her concerns were dismissed as "part of being pregnant." Finally, a subsequent ultrasound revealed that Anne had polyhydramnios - presence of high amniotic fluid level. To manage this, we were told that ultrasounds would now be done on a weekly basis, as it was important for the fluid level not to reach dangerous levels.

At the end of April, after a month of living in a pretty empty house, we finally got our house furnishings. That was however, the morning after Anne experienced pre-term labor and spent the night in the ER having been given terbutaline to stop the contractions. The next day, during our doctor visit, we were told that Anne's fluid level was even higher, and the suggestion was to drain some of the fluid. As with everything in this pregnancy, drainage had miscarriage risks.

We decided to wait and fly to Florida and meet with Dr. Richards and Dr. Kays to get more answers and get a better understanding of what we should do. The Toney family was so gracious and invited us to stay with them and since their son, Caleb, had an appointment the same day with Dr. Kays, we were able to follow them right to Shands. Dr. Richards performed a level two ultrasound and then took us to his office and explained Emma's right diaphragmatic hernia in great detail, even drawing pictures of a "normal" baby's chest and abdomen and then drawing pictures of Emma's, so we could better understand. We then went on to meet with Dr. Kays, but somehow our scheduled appointment was not in the computer. We were told that Dr. Kays would still see us after he saw all of his scheduled appointments. Now usually I am extremely impatient while waiting, but this time it was different. We met some other families with CDH children who where there for follow-up appointments with Dr. Kays. What an amazing feeling to see these children running around and laughing. Dr. Kays also introduced us to Heidi and Dave Gardner and their son Sammy. The Gardner's had their son, Sammy, in January at Shands and it was now such a beautiful sight to see him sleeping very contently in his Daddy's arms.

Finally, after Dr. Kays had already put in a very long day, he was ready for us. We thought that we had flown all the way from Arizona to Florida, and waited all this time and would probably get only a few minutes of his time. Boy, were we WRONG! Dr. Kays spent the next 2 1/2 hours going over every term, procedure and process involved in treating a CDH baby. Dr. Kays even brought us into his office where he had a huge bulletin board filled with pictures of children born under his care with diaphragmatic hernias. From those pictures, he proceeded to tell us each of their names, what they went through and how they were progressing. You could tell by the smile on his face that he has such a special place in his heart for all of these children. He then gave us a tour of the NICU showing us a couple of babies, explaining the machines that they were attached to and what they were doing for the baby. We said goodbye to Dr. Kays that afternoon, feeling for the first time that we understood what we were facing and what we needed to do. On the plane ride home we started making plans for Emma to be born in Florida at Shands so Dr. Kays could take care of our daughter.

After flying home, Anne's fluid level continued to rise and so did the occurrences of pre-term labor. Due to Anne's increasing difficultly breathing and the ongoing contractions, we decided that we couldn't put off having fluid drained any longer. Anne was scared but knew it had to be done. The procedure was very simple, putting a needle into Anne's abdomen and attaching a suction machine and removing the excess fluid. The doctor's intent was to remove three liters of fluid, but he stopped at a little less than two liters due to Anne's extreme discomfort. After the procedure, Anne started contracting again which forced us to stay in the hospital overnight. Unfortunately, the amount of fluid drained had returned by the end of the week.

Though we had already decided to deliver in Florida, we knew that the potential existed for Anne to go into labor at any time due to the continuing high amniotic levels. We knew we had to be prepared to deliver here in Arizona. We met with a neonatologist and a pediatric surgeon here in Phoenix who knew very little about Emma's condition and what the correct treatment should be. They gave us little hope, and we left feeling like we had wasted their time. We were hoping that this meeting might cause us to reconsider the trip to Florida. There was no comparison. One of the doctors promised to call us after he read a copy of Dr. Kays' paper that we left with him. The call never came. This doctor visit confirmed, that indeed, we made the right decision about traveling to Gainesville.

In July, Anne's fluid level had risen to its' highest level and another amnio drainage was done. This time 3 1/2 liters of fluid were removed, and again contractions steadily progressed, and we stayed overnight in the hospital again. Anne had some relief after this drainage, but it was short-lived, and on the next ultrasound, the technician noticed membranes floating around. She went to ask the doctor in the office that day if it was something to be concerned about, saying some doctors don't like to see that, others don't think it is anything to worry about. The doctor in the office that particular day said it was "no big deal." Knowing that we were planning to deliver in Florida, she called Dr. Richards, and it was decided Anne should head down to Florida the next day, about a week earlier than planned. So the next morning Anne was on a plane to Florida with an appointment to see Dr. Richards in two days. Heidi and Dave Gardner, the couple we met back in May at Dr. Kays' office, invited Anne to stay with them until I could arrive in a week and a half. As if we didn't have enough going on, I had several job interviews scheduled that week. On Friday, Heidi took Anne to Gainesvillle for her appointment with Dr. Richards. Dr. Richards was extremely concerned when he noticed the membranes floating near the umbilical cord, indicating it was very dangerous and in few instances have resulted in the death of the baby. Anne went right from Dr. Richards' office to be admitted to labor and delivery in the hospital where she would stay until Emma was born. I flew down to Florida with our son Jack the very next day, and Anne's mom flew in Sunday afternoon. On Monday, it was decided that a C-section would be done on Tuesday two weeks earlier than planned. Although the baby was only 36 weeks, she was already over 7 pounds.

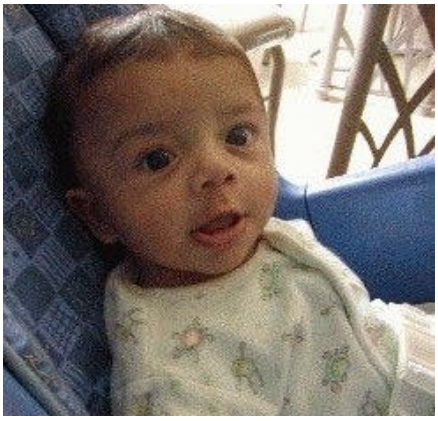
In the morning, the doctors came in and talked about what would happen during the C-section and what teams would be present. Anne was prepped and wheeled out the door to the operating room. I sat alone in the room and cried, scared for my wife and our little girl. A long fifteen minutes later, I was given scrubs and put in a room where I waited another long 10 minutes, my mind racing. I must have looked a bit flushed like I was going to faint because many people who passed by stopped to ask if I was alright. Finally, I was brought into the room with Anne and the C-section started. There were about twenty people in the room ready to take care of my precious family. Within minutes, the baby was born, and we were lucky enough to hear three muffled cries, and then she was gone into a crowd of doctors and nurses waiting to intubate and evaluate her. Dr. Kays then brought our little bundle of joy over for a quick kiss and then she was off to the NICU.

We waited several hours in the recovery room to hear any news. Finally, Dr. Kays came in and said that Emma was stable and that the next few days would be critical and would tell us what direction treatment would go. Emma was born at 12:50 p.m. on July 31st, and I was able to go see her around 7:00 that evening. It was heart-wrenching to look at her heavily sedated and hooked up to so many machines. The next day proved to be even more difficult as Emma had her worst day. Emma spent the next several days in stable condition not fighting the machines, just letting them do their jobs. Dr. Kays decided that Saturday, August 4th, was going to be the day for her repair surgery. The surgery lasted about 3 hours, and then Dr. Kays came out and said that Emma tolerated the surgery well, having more than 50% of her liver up in her chest along with the small intestine and colon. A large gortex patch was used to cover over 75-80% of the diaphragmatic surface. Another hurdle passed, and Emma was on the road to recovery. Every day Dr. Kays would take chest x-rays and blood gasses and each one looked better than the previous. After two weeks, I had to return home to start a new job on Monday, August 13th. Our son and I returned to Arizona while Anne's mom stayed in Florida with her and Emma. My mom flew from Florida to Arizona to watch Jack so that I could begin my new job.

We spent 2 1/2 weeks apart, aching to be with each other and the other child that we were away from, having no idea how long this would last. Several weeks after surgery, Emma started some tiny feedings with pumped breast milk. She was able to take up to 20 cc. and then started refluxing terribly. An upper GI was done and confirmed that indeed she did have reflux, which was controlled with medication. This was great news as another surgery was thus avoided. After about 6 weeks, Dr. Kays said Emma could go home to Arizona! On September 5th, I flew back to Florida, and then the following day, we all boarded a plane and flew home. Emma was on a very low setting of oxygen for about a month all of the time, and then on oxygen for another month just during the night while she was sleeping.

Looking at Emma today just over 4 months old, you would never know all that she had been through. Emma is a very happy and smiley sweet gift from God that we treasure every single day and look happily to her bright future with us. Both Anne and I were amazed at the kindness of strangers, the willingness from so many to help, especially the many prayers that were said for our family and Emma. We know in our hearts that if it wasn't for Dr. Kays and the amazing doctors and nurses at Shands, along with all of the prayers, love and support from our families and friends that this story would have had quite a different ending. We feel that we are very blessed!!

Mike Gallagher (dad to Emma Elizabeth Gallagher, 7/31/01, 6135 S. Teresa Drive, Chandler, AZ 85249, 480-206-4726, azgallagher@home.com)



When we found out we were expecting, we were both elated and afraid. We had lost a baby 4 months earlier at 12 weeks into the pregnancy. However this pregnancy was very different; everything was picture perfect. It was a textbook pregnancy. I had been taking prenatal vitamins before conception. I stopped eating fast food, caffeine, and junk food. The doctors assured us that all was well with the baby. At 20 weeks we had a scare. A routine ultrasound showed that the baby was at risk of having Down syndrome. We were thrilled when the amnio came back normal. The doctors decided that the baby was healthy and further ultrasounds were not needed. I felt uneasy, that something was not right. I asked for another u/s, but my OB said that it was not medically necessary. I prayed that I was wrong. I didn't take any of the baby shower gifts out of their boxes. These feelings I had I kept to myself.

At 35 weeks, I was induced due to decelerations in his heartbeat. I cried tears of joy when I saw my little baby boy. He looked exactly like his big brother. They let me hold him for one second and then grabbed him from me when his eyes rolled back. Our baby was unable to breath at birth. He was rushed to the NICU.

An X-ray revealed that Chris was born with a diaphragmatic hernia. This means there was a hole in his diaphragm, which allowed his abdominal organs to move into his chest. Our world collapsed when the doctors explained the severity of our baby's condition. As a result of this, his right lung was underdeveloped, and his left one was practically non-existent. His heart was displaced over to the right side of his chest.

Chris had surgery when he was 2 days old to repair his diaphragm and bring all of his abdominal organs back in their place. I suffered spinal leakage during a routine epidural and could not get out of my hospital bed. It was a few days before I could see my baby. I will never forget that feeling-- thinking that my baby was going to die, and I wasn't able to be with him.

The day I had blood inserted into my spine to repair the damage, I went immediately to see Chris. Nothing could prepare me for that. He had tubes coming out of everywhere. He had a chest tube, a stomach tube, he was on a ventilator, and he had a central line. A central line is a catheter inserted into a main vein near his heart.

Chris recovered nicely from his surgery and was off oxygen in 4 weeks and ready to come home. We were thrilled and ready to move on with our lives. However, Chris developed severe reflux. He would throw up more than half his formula during each feeding. He was not gaining any weight. He developed a severe cough due to the formula entering his lungs, an aspirated pneumonia. We took him for an X-ray that revealed a partial right lung collapse, and back into the NICU he went.

Christopher associated eating with pain, and he started eating less and less. At this time he was 6 weeks old and had not gained a single pound since birth. He was diagnosed as "failure to thrive."

Three days after he was readmitted, his abdomen swelled up, and he became very ill. An X-ray revealed he had necrotizing endocolotis. This is death of the small and large intestine. Once again our baby was critically ill. That night when we went to see him, the doctor was waiting for us along with a social worker.

Once again my baby had tubes coming out of everywhere. He had a stomach tube coming out of his nose, draining blood from his stomach. He also had bloody stools. I had to consent to an emergency blood transfusion. Another central line had to be inserted. Chris was put on 3 antibiotics, and he did not receive any food for 12 days, in order to rest his intestines. Chris never ate again. When he was 8 weeks old he had surgery to install a gastrostomy tube.

At this time a geneticist examined Christopher and determined that he has a genetic condition. He has performed a blood test for chromosome analysis that has come back normal. Chris had a muscle biopsy that came back normal. However, the geneticist is positive that Chris has a genetic condition. Further testing is presently pending. As of now, Chris is considered to have an unknown syndrome.

After an additional 6 weeks in the NICU, Chris came home on March 1, 2002. His reflux is still an issue. He is on a feeding pump and medication to control his reflux. He still has problems gaining weight and refuses to take anything orally. He is now 4 months old. He is finally starting to fit into a size 0-3 months. He just started wearing a size one diaper. We are so thankful and happy to have him in our lives. He is living proof of one of God's miracles. Many people near and far prayed for Chris. We are very thankful for that. Yes, we still have a long road ahead of us. But each morning when I wake up, Chris greets me with one of his big toothless smiles, and I know that everything is going to be ok.

Maricella Rodriguez (mom of Christopher William Rodriguez, 12/7/01, 324 East 108th St, Apt. #19-A, NY, NY 10029-4203, 212-360-5032, 212-360-5032, lovelyfate@aol.com)

My name is Heather Campbell and my beautiful baby boy Brady was born on July 14, 1999. My husband, Lee, had taken me to the doctor's office for my monthly check-up when I was about two months pregnant. He had decided that he wasn't going to go in this time because we had our daughter and son with us. I had had an ultrasound done about a week before this appointment and was really excited to hear the results. My doctor informed me that she thought that she had seen a problem with the baby and that she wanted me to go to a specialist in Columbus.

When I left her office, I was sick. I went out to the parking lot and waited for my husband to pick me up. I guess the funny part is that I had had some trouble with my other two children (medically) and had always told my husband that I was afraid to try to have another baby, because I knew in my heart that something would go wrong and that I would lose him. I don't know how I knew, I just did.

My husband and I went to see the specialist that my doctor had referred me to. While there, we were informed that it looked as if our son

had CDH. The specialist told me that to find out whether there were any other abnormalities, I should have an amnio done. We went to have the amnio done, and the doctor told me that if we could wait, he would tell me the results right away. We waited. He informed me that our son did indeed have CDH and that the likelihood that he would die from it was very good. He told me that I basically had two options...I could have an abortion, or I could deliver the baby and watch my son die. I am strongly against abortion, and I felt that if my son died, it wouldn't be because I had taken his life.

I should tell you that at no time during my pregnancy did any doctor tell me that I could look into having surgery to repair the damage while I was still pregnant. I was also never told that I could take steroids to help his lung development. I was given absolutely no information on his condition until after he was born.

On July 14, 1999, my son was born. My labor was induced on the 13th, and after it was discovered that there was no room for him in the NICU at Children's Hospital, my doctor decided to stop my labor and have me wait until the following morning to actually deliver.

I was told that my son wouldn't cry. They said that if he did, it would be very surprising. Well, he cried. I guess I filled myself with false hope. I thought, "Well, if they were wrong about that, then maybe they are wrong about everything else too." After Brady was born, I was taken to a room to recover in. They put me in a room in the maternity section, so that I could hear all of the babies cry and listen to all of the other mothers ooh and aah over their new children.

I waited for about an hour before I was taken down to see my baby. I couldn't stay long because it broke my heart to see him hooked to all of the machines. When I had decided that it was time for me to go, a nurse was wheeling me down the hall when one of the other nurses hollered, "Does she want to have him baptized? I really think that she should, because I don't see him lasting very long." I couldn't believe what I had heard. To this day, I don't know if he was ever baptized. I vaguely remember nodding my head yes and being taken back to my room.

The next day, I left. Brady had been taken across town to the Children's Hospital, and not knowing how long he would be here, I wanted to be with him.

He hung on for 11 days. He suffered through ECMO, chest tubes, edema, and Lord only knows how much pain. They say that there was no way he felt any pain, yet when I held his hand, he tightened his finger around my finger, when I rubbed his foot, he pulled away as if it tickled him. If he felt all of that, then how do they know that he couldn't feel any pain?

On July 25th, I was told that it was no use. He would never get any better, and he was just "using blood through the ECMO machine that could be used for a child that did have a chance."

I called my family and they made the two-hour drive to say their good-byes and to be with me and my husband. I still regret that I didn't spend any special time with him that day. I now know that I was putting off the inevitable. I knew that as long as I wasn't back there, they couldn't remove him from his machines. So I stayed away as long as possible.

When I finally did go, I sat down in a rocking chair, and they handed me my beautiful baby boy for the first and last time. I held him and talked to him. I told him how very much I loved him and that I was sorry that there was nothing that I could do for him. And then, I told him that it was okay. That he could go.

I felt my son die. I have no way of explaining it except to say that, when he left, I knew-- because he took a part of my heart with him. I felt the ache in my chest. I remember the nurse telling me that she had to check his heart rate using the stethoscope. I told her that she didn't have to, that he was gone. I handed my precious little angel to the nurse, and I walked out. I vaguely remember slumping against a wall in the waiting area outside of the NICU, being led outside and my mother-in-law handing me one of her anti-depressants. I can't really remember much after that.

Just last year, I was looking out my living room window, talking to my mother on the phone when a white hearse drove past. I told my mom that I had never seen a white hearse before, and she said, "Honey, you followed a white hearse all the way to the cemetery the day we buried Brady. You were right behind it. Don't you remember?" No, I didn't. Like I said, I don't remember anything about it. All I remember is the feeling of my boy squeezing my finger right after I told him he could let go, and the feeling of him leaving.

Thanks for letting me vent a little bit. And please, if anyone has any information on helping the siblings of Cherubs to deal with their grief, please send it to me. Brady died two years ago, and my now 7-year-old daughter has never really cried for him. I would like to help her. I would also like to help my 5-year-old son who never seems to STOP talking about him. THANK YOU.

Heather Campbell (mom of Brady Joseph Campbell, 7/14/99-7/25/99, 1325 Morton Avenue, Cambridge, OH 43725, 740-432-7947, tinkerboo@jadeinc.com)

I remember the day I found out that our baby had a diaphragmatic hernia. I had never heard of it. I found the CHERUBS website and cried and cried and cried. I called my mom and told her more about this terrible birth defect and brought home information to my husband. We cried some more. Days passed, and each day I would go to work and read more stories off the CHERUBS website. It upset me so much, but I wanted to find out all the information I could so that we would be prepared. I finally came to the conclusion that it was not going to do any good for me to be miserable for the next four months. My family and I prayed a lot and hoped for the best. I remember thinking that one day I was going to have a good story to put on the website.

Well, it has been 18 months, and I am finally writing Caitlin's story, and it is a good story.

My husband and I had tried to get pregnant for a year and a half before we finally got good news on November 5, 1999, that I was pregnant. We were so excited and our parents were on cloud 9 since this would be the first grandbaby. The months went by and I felt wonderful. I went to the doctor for my five-month checkup, and on the way out, I remembered that they could do an ultrasound to determine the sex of the baby this month. Since the doctor didn't mention it, I decided to ask him if I could have an ultrasound done. He said I could and an appointment was set up for March 2, 1999.

My husband and I, along with the two anxious grandmas, went to find out the sex of our little one. As the girl was doing the ultrasound, everything looked good, and she said it looked like we were going to have a baby girl. The grandmas had to leave, and Lee and I were enjoying watching our little girl moving around. About that time, the doctor came in, and he and the girl doing the ultrasound were looking at the screen and talking softly. Lee and I looked at each other and knew that something was odd.

The doctor told us that it looked like the stomach was up higher than it should be, and he wanted to send us to a specialist for a second opinion. He told us that it was hard to tell because she kept moving around. We were shocked, but we figured everything was fine, and he just couldn't see it right since she was so active.

That next week, I received some paperwork to bring with me when I saw the specialist. It was noted on the paperwork that their prognosis was that our baby had a diaphragmatic hernia. This is when I began finding all the information I could on this defect, but at the same time praying and hoping that the doctor was wrong. On March 9th, we went to Arnold Palmer Hospital, and it was confirmed. We were bombarded with information, and our roller coaster ride began. We were put in touch with a genetic counselor, neonatologist, pediatric surgeon and fetal specialist. Lee and I and our families were all in shock and we all cried a lot. I told myself that it was not going to do any good to cry and make myself sick for the next four months, so I put it in God's hands. He made our baby, and he has a reason for everything. We had a few church services on miracles and healing. This built my faith, and I gave it to God. People all over were praying, and that was all we could do.

On March 21, we saw our fetal specialist to have an amnio done. When the doctor came in, he asked me if I wanted to have an amnio done. I said, "Not really," and he said he would do an ultrasound and then we could talk about it. He kept saying head - normal, lip - normal, everything was normal, and we were so encouraged. Afterwards, he said everything else looked fine, and it was up to me to do the amnio. We decided not to do it, and we left with smiles on our faces. He was the first doctor to give us hope.

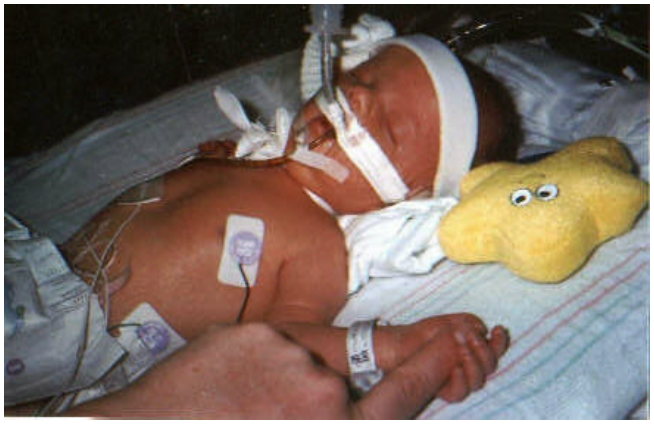
The months progressed and everything was going well. On June 5, 2000, Caitlin was born, one month before her due date. When she came out, she didn't cry, and I didn't get to hold her because they intubated her right away. They had prepared us for what she would look like the first time we got to see her. There were tubes everywhere, and she was so small at 4 1/2 pounds. One week after she was born, she had her first surgery to repair her diaphragm and put her organs back in place. She had her stomach, all of her intestines, her spleen and part of her liver up in her tiny chest. It was a miracle that she needed so little oxygen up until then. One of the nurses told us that after Caitlin was born, they put her by the ECMO machine because they thought she would need it, but she never did, thank the Lord!

The next few weeks were up and down, and Caitlin did not seem to be improving. She was still on the ventilator and had lots of tubes everywhere. She developed a condition called cylothorax, where a tear in her chest lining was allowing all of the fluid and nutrition that she received to come out of her chest tube. When Caitlin continued not to improve, the doctors decided that a hole in Caitlin's heart was the problem. We got to hold our little angel for the first time one month after she was born. I know the reason they let us hold her was because they didn't know if she would make it through the heart surgery. They repaired her heart and cylothorax on July 5th. She had two holes in her heart, a VSD and an ASD. The surgery was a success, and she began to improve. Slowly, the nurses started giving her milk through a tube and started decreasing her vent settings. After a lot of ups and downs, Caitlin had learned to breath on her own and drink her milk through a bottle. She came home on August 22, 2000. Caitlin was on oxygen and required lots of medications and breathing treatments three times a day. We know that it could have been a lot worse, and we thank God every day.

Caitlin is now 18 months old and is doing great. We still see several specialists quite often, and she will probably require surgery again to repair her curved spine. She has had three colds and done really well with the help of breathing treatments. Not a day goes by that we don't thank God for what he has done. Looking back, I know that God had a perfect plan, and he put so many people in the right place at the right time. I even think that he made her a feisty little redhead because he knew that she would have to fight to survive from day one. She is our "miracle," our angel from heaven.

To all of you who are pregnant, who have CDH children or who have lost a child, my thoughts and prayers are with you daily. I know it is easy to get discouraged and we think "why me?" But I know that God knows what he is doing and he has a perfect plan for each of us, even though sometimes it seems so hard to understand.

Jennifer Blair (mom of Caitlin L. Blair, 6/5/00, 1485 Violet Ave, Titusville, FL 32796, 321-383-7901, caijen@msn.com)



I was 35 years old when Glen & I found out that we were finally going to have a baby. We were trying forever and finally we were blessed.

I had a very easy pregnancy, but because of my age, I was sent to a high-risk pregnancy specialist. During my sonogram, the sonogram specialist called the doctor over and asked, "Did you see this?" As they talked, I started to get nervous. Something was obviously wrong. The doctor started to tell me that our baby had a birth defect called a congenital diaphragmatic hernia. Like all of you reading this, I was in shock. What is this? How did it happen? I had a million questions, and the answer was always the same... "Every baby is different" or "We won't know the severity of the defect until she is born." We went through 9 months knowing that she had a 50/50 chance of survival.

I tried to get information about CDH on the Internet. The more I read, the more scared I became. I found the CHERUBS website and used it as my bible. We decided to go to Saint Christopher's Children's Hospital in Philadelphia, after we were introduced to Doctor Douglas Katz, one of their surgeons. Doctor Katz took the time to meet with us and explain everything that came with CDH. When it was time to deliver, there was an entire team waiting to take care of Sydney. We prayed that she wouldn't need ECMO and that her defect would be a minor one, but that was not the case. Doctor Katz told us that she would need ECMO, and she was put on the machine. For the next 37 days, I lived at St. Christopher's Hospital. Sydney had the most wonderful neonatal & ECMO teams taking care of her. We have never met such wonderful people in our lives. We will never forget them.

Syd's defect was severe, but she fought with strength that was unbelievable. When she was finally strong enough for her surgery, we were told that she had almost no diaphragm at all, everything was up in her chest. She had only one lung, & they weren't sure if it would be enough to support her. Doctor Katz constructed a diaphragm for her out of gortex. Her spleen had to be removed & all of her intestines couldn't fit back inside of her stomach when the surgery was completed.

She spent the next week with a bag called a silo suspended over her stomach with her intestines inside it. It is hard to imagine having to see your precious new baby like this. I don't know how we got through it. Her stomach finally stretched enough to fit everything inside.

After five weeks on ECMO, it was time to see if Sydney's lung would be enough to support her. It wasn't. We were faced with the hardest decision a parent could have. Sydney would have to be taken off of the ECMO machine.

It wasn't fair. Why would she conquer every obstacle she had to face for five weeks, only to find out that her lung wouldn't support her? The only way that we can get through this is to believe that Sydney was giving us as much time with her as she could. She fought for US. For us to get the chance to see her beautiful face & have her hold our fingers with her tiny little hand & look at us with her beautiful eyes. Thank you, Sydney, for holding on as long as you could for your mommy & daddy. I know that my tiny little angel is still with me and always will be in my heart.

Dawnn Matthews (mom of Sydney Olivia Matthews, 11/28/01-1/4/02, 137 Brandywine Court, Brick, NJ 08724, 732-458-5960, tattooedandbroke@aol.com)

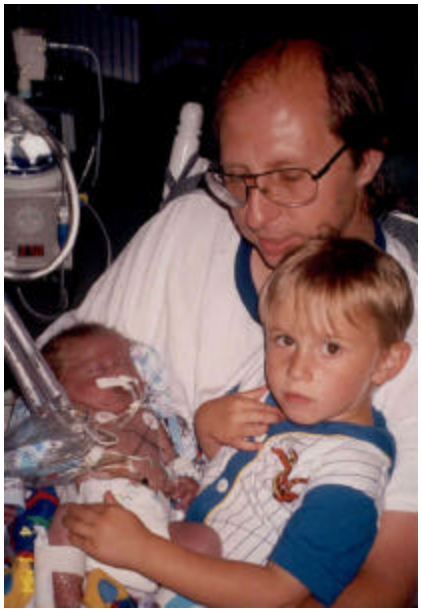
This is Kailyn Brooke. She is 14 months old. She was born January 3, 2001 by C-section, full-term, weighing 8 lbs. 2oz. Kailyn let out one beautiful cry when she was born, then the room became silent. We didn't hear her voice for another 3 1/2 weeks. Our first-born baby had an undiagnosed left-sided CDH.

Kailyn was rushed to Children's Hospital, and I was left to recover from the C-section with only Polaroids of our new baby. I was lucky to get an early release from the hospital 36 hours after the C-section. I had to see our baby and be by her side. Kailyn had surgery when she was 4 days old. Her diaphragm was able to be closed with sutures only. Her stomach, spleen, and intestines were in her left chest cavity and her mediastinum was pushed to the right. She had a very small bud of lung in the left and almost a full right lung. Her appendix was also removed. She was on the ventilator for 24 days with 5 of those days on an oscillating ventilator. Then she was on CPAP for 6 days. Kailyn was on oxygen a total of 33 days and came home after a long 41 days.

After she came home, she spent 7 weeks on the NJ and NG tubes, then went straight to the bottle with hardly any reflux problems at all. My husband and I spent a great deal of time offering Kailyn the bottle and pacifier early on to prevent oral aversion. We would encourage her and get so excited when she would take just a couple cc's of milk! She worked her way up to 4 oz. pretty quickly. I do believe this was a very important step in Kailyn's development.

Today Kailyn is a typical 1 year old with no feeding or developmental problems at all. She is such a smart, active little girl with a lot of determination and a huge heart. Thanks so much to all the wonderful people at Mercy and Children's Hospitals in Cincinnati for their compassion and expertise, and for diagnosing Kailyn's condition quickly. Also, thanks to our family and friends for all their support and prayers. Our hearts and prayers to all the families of cherubs.

Holly & Brian Bost (parents of Kailyn Brooke Bost, 1/3/01, 3862 Niemoeller Dr., Hamilton, OH 45011, 513-942-8799, Hollybost@msn.com)



I became pregnant with my third child after losing a baby, Jesse, a year and a half before to anencephaly. On June 23rd, my water broke, and we went to the hospital in Waterloo to deliver what we thought was a healthy child with no problems. We were going to have a repeat C-section (I had a C-section with my first). I was prepped, and we were giggling and having a good time. I was giving Tony a hard time because I wanted a girl, and we didn't know at the time what we were having.

The baby came and Ryan Matthew Mudderman was born into the world at 4:00 in the afternoon. He was blue minutes after delivery, and I was told he was having trouble breathing. I didn't know all the details because I was still on the operating table. Later I was in my room, and the priest was in the NICU baptizing my baby. They called specialists to take Ryan to Iowa City by helicopter because he was diagnosed with CDH. I hadn't seen my baby yet, and the nurses were telling me that I wouldn't be able to see him until I got to Iowa City. I told them that he was not leaving this hospital until I saw him. Well, you've never seen nurses move so fast-- two hours after a C-section I was on my feet in the NICU.

My little boy was so full of tubes and wires, it was like a nightmare. I saw Ryan's doctor Nicole, who flew directly to receive her little patient. She told me that Ryan might not make it through the helicopter ride, and I lost it. I was transported an hour after that by ambulance to Iowa City, and there I asked to see my little boy and wanted to know how he was. They said he was holding his own. My little angel was never coherent after that; they had him on so much medication, and he was so sick they could not stabilize him enough to have the surgery that he needed. They said they could not do anymore for him, and he was put in my arms, his tubes removed. Before he went to heaven, he was visited by all his family, and his big brother Jayson held him and counted his little toes and kissed him goodbye. Jayson gave Ryan three toys to play with in heaven-- Thomas the tank engine to remember his brother Jayson, a John Deere tractor to remember his daddy because daddy makes them at work, a helicopter to remember his first flight, and I gave him a stuffed rabbit that was made by me before we knew that he was a boy so it had ribbon flowers on it.

Denise Dunfee and Tony Mudderman (parents of Ryan Matthew Mudderman, 6/23/01-6/25/01, 1824 170th Street, Hazelton, IA 50641, 319-334-6698, dendun1970yahoo.com)

Tristan, my second son, was born a beautiful 3,15 kg baby on 8 May 2001. He seemed healthy, but the unexpected happened. When Tristan was about two weeks old, a blocked nose left us no other option than to pad his cot with pillows in order for him to sit and sleep, which I believe saved his life. Later, terrible cramps made this four-week-old infant's life more difficult than expected, and after many clinic visits, little sleep, and change of formula, my husband and I realised something else had to be wrong.

On 29 June, our seven-week-old Tristan cried non-stop from 4:00 am on, and at 10:00 am we were sitting in the paediatrician's consulting room. Her opinion was that pneumonia could be the reason for Tristan's discomfort, but x-rays and a second opinion left all of us in awe. When another doctor introduced himself, it was no secret that something terrible was wrong. My son's intestines were lying on his lungs. When you forget your husband's phone number, you realize you are in shock, and after the paediatrician explained the situation to me, actions were taken that no one had anticipated. "Diaphragmatic Hernia" (CDH) was after all the reason for Tristan's tears and sleepless nights.

After Tristan was admitted into Medforums's Paediatric ICU, I appreciated the personal attention and paperwork (which was my last priority) that was handled while my son was taken away from me. I understood his screaming and crying when the sister told me they were preparing him for surgery. Oxygen, drips and pipes were not easy to cope with concerning his small body.

Because of Tristan's age and weight, this critical operation had a very good chance of being successful. Everyone was astonished that this baby lived with CDH for seven weeks and survived. Usually CDH is identified by sonar while the baby is still in the mother's womb and an operation is then done immediately after birth. Tristan had a hole, approximately the size of a one-cent piece, in the rear portion of his diaphragm, near his ribs. Doctors suspected that this was the situation with birth and that his intestines gradually went through the hole.

Tristan went into surgery at 17:00 and finally returned at 18:45. It was an unpleasant sight. His sedated body was covered with drips, an attached ventilator and many machines. Gradually, everything started to get less and better, and finally on Thursday, 5 July, he was moved to High-care. This time pneumonia attacked his body, and he was moved back to ICU. Nine long days went by and on 14 July, we were all back home and slept sound in our own beds.

This brave young man goes for regular check-ups and his smiling face confirms his well-being. Tristan really is a healthy baby now and his chubby body tells you that. We would like to show our gratitude to Dr. F. French, paediatrician, Dr. M. van Niekerk, the surgeon. and all the staff members at Medforum Hospital. Especially thank you to Sister Anne Blunden for doing a marvelous job!

Amanda Dean (mom of Tristan Dean, 5/8/01, P.O. Box 83249, Doornpoort, Gauteng, South Africa, +2712 5474207, adean@ananzi.co.za)

Dad's Corner

A Father's Loss

By Brian S. Propst, father of Cecilia Winn Propst (11/2/99-12/10/99)

I would like to write this to support all those fathers out there that have suffered as I have. Looking back on the past few years the hardest thing that my wife and I have endured together was losing our daughter Cecilia to CDH. That was a very turbulent time from the time she was diagnosed.

When we found out about the CDH, my wife and I were both very emotional. My instincts at that point took over and I wanted, or chose, to ignore what had been said to us. As time passed, I still was hurting but felt I could not show it.

After she was born, as her father, I was so happy because she was so beautiful and perfect on the outside and had a lot of fight like her mother.

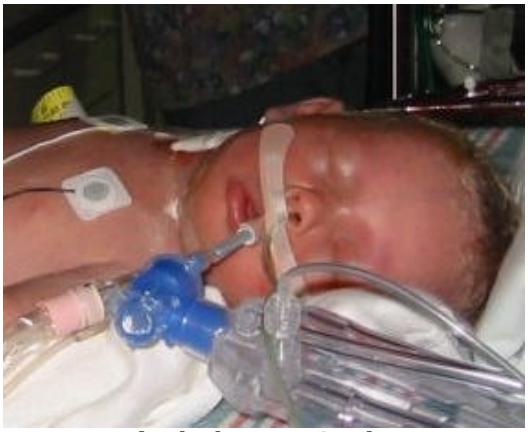
Elizabeth and I watched her fight for 38 days and as much as I wanted her to be okay, she fought too hard. We believe that sometimes too much fight for a CDH babe is not good.

After her passing, I was an emotional wreck inside. It was tough to hide how much I was hurting, so I used humor to get through it. Some use work, hobbies, alcohol or just revert to irresponsible behavior; I chose to cover my feelings with humor. Through all of it, I noticed that society seems more concerned about the mothers of these CHERUBS, and the fathers fade into the background. Everyone I came in contact with has always been so concerned about my wife and asked about her all the time. Fathers are seldom asked about how we are doing considering that we also lost that child. It is frustrating to me as a father to know that I hurt as much as my wife but society believes because I am a man, it shouldn't bother me as much.

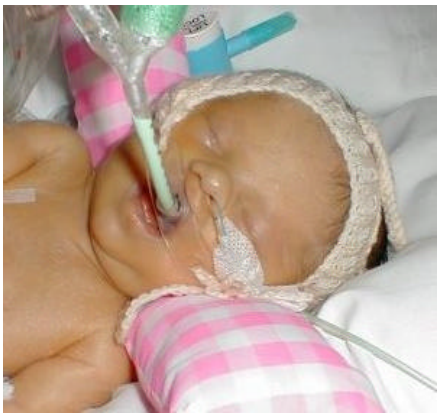
And today, when someone finds out about Cecilia, they always apologize to me. In my opinion, why should they be sorry; they didn't know. I guess they have to say something and an apology is better than nothing. Personally, I don't want their sympathy. I just want everyone to realize that not only the mothers suffer from the loss.

Pictures of Cherubs

Nicole Kaylynn Wright
3/22/00

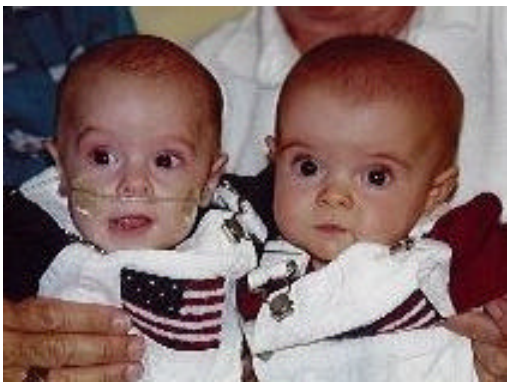


Elizabeth Marie Sanders
1/30/02 - 2/26/02

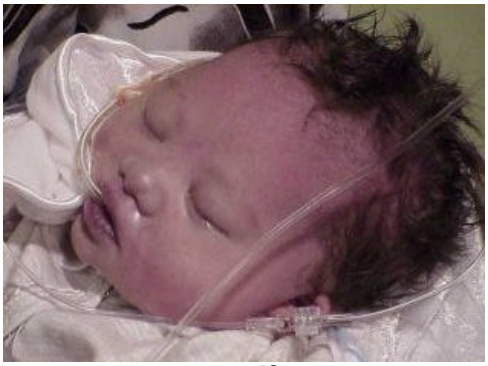


Holly Jane White
3/24/01 - 3/30/01

James Paul Rowe
3/30/92



Noah Brandon Wilson
3/1/99



Tracy Eric Chavis, II
10/23/01 - 10/23/01