

CHERUBS

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



The Silver Lining

Winter, 2004

CHERUBS

P.O. Box 945
Oxford, NC 27565

Dear Members,

Our newsletter is back in printing after a year due to lack of funding. The past 2 years have been very hard on the economy and hard on CHERUBS. Voluntary membership fees are paid by less than 5% of our 1400 families, we still do not have grant funding, and we are subsisting solely on donations, which have greatly decreased. Donations and membership fees pay for our newsletter printing, mailing costs, new member info packets, web site fees, and phone costs. We have no paid employees and we have moved the office back to my home to greatly reduce overhead. I am asking all of you to please make tax-deductible holiday donations if you can so that we can continue our work.

Because of lack of donations and membership fees, for the first time in our history we regretfully are implementing a new Silver Lining subscription for all those who wish to receive the newsletter by postal mail. It will still be available to download for free on our web site but we are now requiring a \$20.00 annual subscription fee for printed copies. If you are not on-line and cannot afford to subscribe to the newsletter, please fill in the appropriate box on the form found in the back of this newsletter and we will try our best to make sure that you continue to receive a copy of our newsletter. Our newsletters will be mailed out without fail 4 times a year starting in February of 2004 now that we will hopefully be able to cover the costs of printing.

There are many CDH studies going on currently, please see that article for more information. Also, CHERUBS' will be represented at the 2004 International Congenital Diaphragmatic Hernia Study Group Conference by volunteer, Heidi Cadwell. Heidi will talk to the doctors about what it is like to be the parent of a child born with CDH. We would like to thank Dr. Jay Wilson for making that possible.

Once again, we are trying for an International Members Conference in Boston next June. Sponsorship and volunteers are greatly needed. Please contact me if you can help.

We have new contact information here at CHERUBS. My e-mail address has changed to dawn_torrence@cherubs-cdh.org and our mailing address has changed to CHERUBS, P.O. Box 945, Oxford, NC 27565. Our phone numbers remain the same.

We had server problems this summer and in the process of repair, we lost quite a few new member work sheets and volunteer forms. If you filled out a membership form or requested to volunteer and haven't been contacted by us yet, please fill out our on-line form again. I apologize for the inconvenience. Thank you all for your patience and continued support.

Sincerely,

Dawn M. Torrence, President and Founder

CHERUBS' Newsletter Subscription & Parent Membership Fees

In 2001 we implemented \$20.00 annual, Voluntary Parent Membership Dues. Unfortunately, less than 3% of members have donated these dues, even though it is voluntary and tax-deductible. We are requesting again, that all members who can afford to make donations to please do so. CHERUBS subsists off of donations – we are not government or grant funded, we do not have any corporate sponsors, and 75% of our donations unfortunately come from funerals of cherubs when families request donations in lieu of flowers. We have no paid employees, only volunteers. Every dime of your donation goes directly to help us help CDH families. Please note our Thank You column in this issue – the list may seem long but it covers an entire year's worth of donations.

Because the Voluntary Parent Membership Fee idea was such a bomb and because donations are sorely lacking, we have to take drastic measures. This is the last issue of our newsletter that will be mailed out free of charge. We never wanted to charge families for any of our services but the cost of printing and postage for 1,000 families around the world on our mailing list has just become impossible to cover. Beginning with our next issue, we request a \$20.00 annual subscription fee to receive a printed copy of our newsletter. It will still be viewable on-line for free. If you cannot afford to pay for a subscription and are not on-line, please just check the appropriate box on the form below and we will do our best to ensure that you stay on the mailing list. We truly do not want any parents to miss our newsletter issues, but we can no longer skip issues because of lack of funding when we know there is a need for information and support.

CHERUBS' Newsletter Subscription & Parent Membership Form

Your Name: _____ Your Cherub's Name: _____

Your Mailing Address: _____

2004 Silver Lining Subscription (\$20.00): _____

2004 Annual Voluntary Parent Membership Fee (\$20.00): _____

Additional Donation: _____

I cannot afford to donate at this time, but please keep me on the newsletter mailing list _____

Please mail to: CHERUBS, P.O. Box 945, Oxford, NC 27565

New Arrivals

(*siblings of Cherubs)

Brianna Nicole Adams
 Hunter James Alexander
 Camille Rosette Archer
 Mahalah Theresa Arnold
 Philip Meade Austin
 Reilly Caleb Ayers
 Joshua Bruce Baker
 Nathen James Barsch
 Conner Blake Bass
 Logan Daniel Benedict*
 Melanie Marie Berge
 Milo Blake*
 Gage William Blalock
 Connor John Boyle
 Madison Brooks
 Meredith Jane Bryant*
 Cole Patrick Campsey
 Cian Card*
 Alexander Phillip Castaldo
 Joshua Morgan Clement-Doble
 Tyler James Clewes-Pritchard
 Laura Grace Culler
 Donnalee D' Ambrosi*
 Zoe Doyle
 Dylan Michael Edmond*
 Elizabeth Danielle Edmond*
 Guy Edmond, Jr*
 Mackenzie Grace Edmond*
 Ashlynn Lee Elliott
 Baby Boy Engelby
 Grayson Ranae Enoch
 Sean Anthony Feaster
 Alexander Miguel Flynn-Nesbeth
 Douglas Hunter Footit*
 Cain Anthony Fredricks
 Sara Friedlander*
 Jonathan Paul Andre Gingras
 Alexandra Sharifa Burke Graham
 Avery Lynn Graham
 Joseph Martin Green, III*
 Kaleb Matthew Groce
 Baby Girl Hajratwala
 Nizhoni Lee Hamm
 Luke Hatfield
 Noah Mathew Hausman
 Brent Edward Hodgson
 Sam Hodson*
 Victoria Frances Howard*
 Micah T. Hughes
 Ethan Michael Huizenga
 Kaleb Richard Job
 Baby Boy King
 Isabella Hope Kirby
 William Gregory Klinzing
 Liam Mackenzie Knott
 Denali K. Korb
 Carys Amber Lamb
 Charley Frederick Langford
 Devin Michael Lewis
 Jayden Michael Liwanag
 Maxwell Christopher Lowenstein
 Kahlil Jamal Macklin
 Jesse Maddox
 Benjamin Massoud
 Dillon Christopher Mawby
 Madeline Adell May
 Maia Christine McCabe
 Sterling Bowen McCaw
 Maryann "Lexi" Alexis McKean
 Baby Boy Moore
 Amari Bless Moore
 Baby Boy Morris
 Brayden Wayne Morris
 Hannah Maree Mueller*
 Taylor Theresa Marie Murphy
 Aubrey Maddison Myers*
 Angellove May Natale
 Nicholas G. Nelson
 Baby Girl Newberry
 Caitlyn Makenzie Niemi
 Joshua Tobechi Onwubuche
 Hannah Abigail Paslay
 Kaitlyn Ava Peters
 Cole Walker Pittman
 Aiden Derrick Plaisted
 Alexander John Pope
 Isaac D. Pratt
 Baby Ragsdale
 Angel M. E. Rawlin
 Mary Gray Reames
 Jacob Thomas Reinhardt
 Allyson Keolani Reynolds
 Olivia Raine Richards
 Baby Girl Rivera
 Baby Girl Rodriguez
 Benjamin James Rubin
 Abigail Rae Rush
 Serena Ann Rush
 Graham Walter Russell
 Kaleigh Lynn Schad
 Martin Schau
 Baby Boy Schiffbauer
 Owen Timothy Schultz*
 Shane Worthington Shannon
 Dylan Joel Smith
 William E. Smith
 Caitlin Somerside
 Lindy Rose Spence
 Eli I. Stewart
 Michael Ann Stockwell*
 Averie Maryssa Stroud
 Ethan Brock Terrell
 Mya Quinn Verdin*
 George Roman Walen
 Joshua Colton Walker
 Carson Robert Warner*
 Jaide Iona Weber*
 Lindsey Grace Weldon*
 Gunnar Ray White
 Makai Alexandra Whitten
 Whitney Caroline Williford
 Joshua Pershing Wood
 Lachlan Christopher Matthew Wood
 Aidan P. Wozny
 Alex Arthur Wyatt*
 Isabelle Yap
 Christina Anne Zeitler
 Dylan James Zofnas

**This Newsletter Is Dedicated
To the Memories of:**

Jakob Nelson Andriacchi
 Mahalah Theresa Arnold
 Philip Meade Austin
 Reilly Caleb Ayers
 Joshua Bruce Baker
 Conner Blake Bass
 Seth Christopher BeBus
 Gage William Blalock
 Madison Brooks
 Alexander Phillip Castaldo
 Joshua Morgan Clement-Doble*
 Tyler James Clewes-Pritchard
 Jaelah Iliana Coello
 Laura Grace Culler
 Christopher B. Earley
 Guy Edmond, Jr*
 Sean Anthony Feaster
 Alexander Miguel Flynn-Nesbeth
 Cameron Lamond Gilreath
 Avery Lynn Graham
 Reece H. Griffith
 Kaleb Matthew Groce
 Nizhoni Lee Hamm
 Jeremy Lason Harer
 John Connor Hoskin
 Paul Huffman*
 Ethan Michael Huizenga
 Cameron Anthony Kennel
 Jonathan James Kilby
 William Gregory Klinzing
 Denali K. Korb
 Carys Amber Lamb
 Kahlil Jamal Macklin
 Sterling Bowen McCaw
 Maryann "Lexi" Alexis McKean
 Sarah Gwen Mehrhoff
 Joshua Tobechi Onwubuche
 Zachary Lane Pittman
 Aiden Derrick Plaisted
 Angel M. E. Rawlin
 Mary Gray Reames
 Olivia Raine Richards
 Ty'Quez Javon Richardson
 Brayden William Ross
 Kaleigh Lynn Schad
 Dee Scheibly*
 Trent Montgomery Sincavage
 Hailey Elizabeth Steiner
 Christa R. Thovson
 Gunnar Ray White
 Lachlan Christopher Matthew Wood
 Isabelle Yap



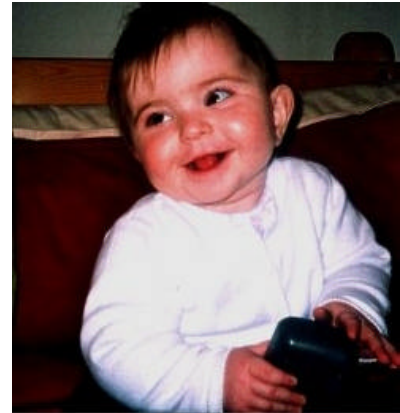
We Would Like To Welcome The Families Of The Following New Members:

(This list includes only those new members who gave permission to have their names published. It is approximately 60% of all new members)

Brianna Nicole Adams	Jonathan Paul Andre Gingras	Hannah Abigail Paslay
Hunter James Alexander	Alexandra Sharifa Burke Graham	Kaitlyn Ava Peters
Gabriella Alicea	Avery Lynn Graham	Tory Piperno
Jakob Nelson Andriacchi	Dylan Cole Gray	Zachary Lane Pittman
Mahalah Theresa Arnold	Jagger M. Gray	Aiden Derrick Plaisted
Camille Rosette Archer	Reece H. Griffith	Jennifer M. Poole
Mercedez Kayeanna Austin	Adam Christopher Grigsby	Rachel Anekah Posthumus
Philip Meade Austin	Trevor Lowell Grossett	Isaac D. Pratt
Joshua Bruce Baker	Baby Hajratwala	Baby Ragsdale
Natalie E. Banks	Nizhoni Lee Hamm	Thad Michael Rasberry
Nathen James Barsch	Ashleigh Michelle Hand	Angel M. E. Rawlin
Conner Blake Bass	Jeremy Lason Harer	Jacob Thomas Reinhardt
Baby Bayardo	Luke Hatfield	Allyson Keolani Reynolds
Noah J. Beaumont	Noah Mathew Hausman	Olivia Raine Richards
Seth Christopher BeBus	Brent Edward Hodgson	Ty'Quez Javon Richardson
John Mark Bennett	Megan Hogg	Baby Rivera
Melanie Marie Berge	Luke X. Horner	Baby Rodriguez
Brandon Blaine Bjella	John Connor Hoskin	Monica Ruth Rogers
Payden Janelle Black	Micah T. Hughes	Benjamin James Rubin
Gage William Blalock	Ethan Michael Huizenga	Abigail Rae Rush
Adam John Blecki	Jennifer Kay Jennifer	Serena Ann Rush
Baby Boyle	Emma Katherine Keene	Graham Walter Russell
Connor John Boyle	Cameron Anthony Kennell	Kaleigh Lynn Schad
Caleb Bradley	Jonathan James Kilby	Martin Schau
Jack Hugh Brady	Kaleb M. Kinert	Baby Schiffbauer
Peter Lee Briggs	William Gregory Klinzing	Jacob Charles Schueller
Madison Brooks	Liam Mackenzie Knott	Zachary Max Schultz
Jayce Lee Bult	Denali K. Korb	Shane Worthington Shannon
Cole Patrick Campsey	Abigail Lynn Kubeck	Cary Anne Smith
Alexander Phillip Castaldo	Carys Amber Lamb	Stacey Jayne Smith
Luke Anthony Cecil	Charley Frederick Langford	William E. Smith
Baby Christenson	Baby Leffler	Caitlin Somerside
Joshua M. Clement-Doble	Devin Michael Lewis	Lindy Rose Spence
Tyler James Clewes-Pritchard	Jayden Michael Liwanag	Eli I. Stewart
Jaelah Iliana Coello	Maxwell Christopher Lowenstein	Averie Maryssa Stroud
Baby Collins	Anna Rose Luken	Ethan Brock Terrell
Rani Louise Costello	Evan Alan Malaer	Rebecca Ann Tharp
Laura Grace Culler	Michael Joseph Mason	Tony Austin Thomas
Lois Jean Dean	Benjamin Massoud	Christa R. Thovson
Courtney Lynn Deuro	Madeline Adell May	Caitlyn Elisabeth Marie Titchenal
Zoe Doyle	Caleb Austin McAndrew	Brandon O. Toledo
Niko H. Duerr	Maia Christine McCabe	Jayson R. Villarreal
Sean T. Dunn	Sterling Bowen McCaw	George Roman Walen
Christopher B. Earley	Maryann "Lexi" Alexis McKean	Ian Matthew Wallace
Jack Robert Ellis	Connor J. McKenzie	Zane Lee Warner
Baby Engelby	Sarah Gwen Mehrhoff	Joshua Dale Weaver
Grayson Ranae Enoch	Ashlyn Mikel Meldrum	Gunnar Ray White
Wyatt Weston Escue	Baby Moore	Makai Alexandra Whitten
Baby Boy Farrell	Baby Morris	Baby Williams
Sean Anthony Feaster	Brayden Wayne Morris	Whitney Caroline Williford
Kimberly Susan Fetcko	Angellove May Natale	Allison B. Wine
Alexander Miguel Flynn-Nesbeth	Nicholas G. Nelson	Joshua Pershing Wood
Ella Foley	Abigail Jane Neu	Lachlan Christopher Matthew Wood
Jason William Frank	Baby Newberry	Thomas William Woolley
Cain Anthony Fredricks	Caitlyn Makenzie Niemi	Aidan P. Wozny
Jake W Frye	Jake Lee O'Connor	Isabelle Yap
Baby Galvan	Joshua Tobechei Onwubuche	Dylan James Zofnas
Cameron Lamond Gilreath	Matthew Raven Ortiz	

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

35th District Court, Plymouth MI - in memory of Ann Posywak, great-grandmother of Amanda Pagano
 82nd & V. Church of Christ - in memory of Samuel David Chisum
 Nadia Adida - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Jeffrey & Laralee Alderson-Beck - in honor of their son, Brendan Beck
 David and Georgia Anderson - in memory of David O. Hawkins
 Debra Antonitis - in memory of Dylan James Arsenault
 John and Susan Arsenault - in memory of their grandson, Dylan James Arsenault
 Brian and Brenda Austin - in memory of their son, Philip Meade Austin
 Helen Bailey - in memory of Samuel David Chisum
 Todd and Annette Banning - in honor of Aaron Jacob Hoewing
 Ellen and Arthur Bass - in memory of Mary Gray Reames
 William and Jean Beebe - in memory of Dylan James Arsenault
 Devon and Christy Bell - in memory of their son, John Brody Bell
 Beth Berge - in honor of Melanie Marie Berge
 Bob and Mary Batenhorst - in memory of Cameron Gerard Nau
 Christie and Charlie Bates - in memory of Mary Gray Reames
 Therese Beckey - in memory of Cameron Gerard Nau
 Vicki Bilak - in memory of her granddaughter, Anneliese Mae Browning
 Don and Marlene Blaesing - in memory of Cameron Gerard Nau
 Mrs. Earl Blanchard - in memory of David O. Hawkins
 Blue Ridge Bank and Trust Co. - in memory of Benjamin Joseph Broom
 Lynda Bolin - in memory of her son, Kyan Bolin
 Charles and Kathleen Breen - in honor of their daughter, Caitlin Breen
 Kipp and Christie Brooks - in memory of their daughter, Madison Brooks
 Mark and Sharon Butterworth - in memory of Cameron Gerard Nau
 Nancy Bryant - in honor of her son, Neil Patrick Bryant
 Anne and Ed Callahan - in memory of Bridget Hope Jussaume
 Susan Camara - in memory of Keeton Shawn Wolters
 Scott and Penny Campsey - in honor of their son, Cole Campsey
 Joseph and Melissa Cantrell - in memory of Mary Gray Reames
 Mary Beth Carey - in memory of Cameron Gerard Nau
 John and Charlene Cassese - in honor of their daughter, Caroline Harpur Casesse
 Sandra Childs - in memory of Samuel David Chisum
 Aminta Coggeshall - in memory of Cameron Nau
 The Coggeshall Family - in memory of Cameron Nau
 Donald and Joyce Coggins - in memory of David O. Hawkins
 Don and Lillian Colaavecchio - in memory of Dylan James Arsenault
 Gerald and Lee Ellen Collier - in honor of Aaron Jacob Hoewing
 Barbara Collins - in memory of her niece, Ashley Hope Footit
 Patrick and Clare Conway - in memory of their granddaughter, Ashley Hope Footit
 Robert and Sandra Crum - in memory of William Gregory Klinzing
 D.C. Trucking, Inc. - in memory of David O. Hawkins
 Larry and Nancy Danielson - in memory of Cameron Gerard Nau
 Marion Daves - in memory of David O. Hawkins
 Elaine Davis - in memory of Dylan James Arsenault
 Amy Diaz - in memory of Samuel David Chisum
 Lisa, Joe, and Meghan Dolan - in honor of Owen Michael Cuccia
 Ray and Rosie Dietrich - in memory of Cameron Gerard Nau
 Josh and Jonna Eder Duke - in memory of their daughter, Brina Grace Eder Duke
 Thomas and Jane Dunn - in honor of Sean Dunn
 Barbara A. Eisele - in memory of her granddaughter, Reese Eisele-Elizondo
 Nicholas Elliott - in memory of Mary Gray Reames
 Patricia Ellis
 Saskia Ericson
 Paul and Giselle Evora - in memory of Julia Cora Zieger
 Paul and Giselle Evora - in honor of the wedding of Aileen Santos and Terence Keaney
 Mr. and Mrs. G.E. Fahy, Jr - in memory of Dylan James Arsenault
 Bill Fahy - in memory of Cameron Nau
 Albert and Claudia Faraldi - in memory of all our dear cherubs
 Camille Favreau - in memory of Dylan James Arsenault
 Robert and Anita Fay - in memory of Dylan James Arsenault
 Doranne Frano - in memory of Samuel David Chisum
 David & Julie Feaster II - in memory of their son, Sean Anthony Feaster
 Larry and Christine Felts - in memory of Mary Gray Reames
 Tom and Julia Fox - in memory of Cameron Gerard Nau
 Fuel Technical Graphics - in memory of Mara Noelle Hufford
 Karen Fuss - in honor of her daughter, Anna Fuss
 Edith Gable - in memory of Mary Gray Reames
 Gallivan, White & Boyd, PA - in memory of David O. Hawkins
 Brad, Nonalee, and Katie Gardner - in memory of Cameron Gerard Nau
 Philip and Tammy Gary - in memory of David O. Hawkins
 The Gentile Family - in memory of Elizabeth Marie Sanders



Mia Blake
11/15/00



Harry Brian Tabernal
2/2/00 - 2/2/00



Alexander William Snowball
5/13/99

James Gibert - in memory of David O. Hawkins
 Leoni Gingras - in honor of her son, Jonathan Paul Andre Gingras
 Penny and Scott Gordy - in memory of Cameron Gerard Nau
 Mr. and Mrs. Larry Green - in memory of David O. Hawkins
 Marty and Peggy Green - in memory of their granddaughter, Kylee Freedom Green
 Griffin Gear - in memory of David O. Hawkins
 Granville County, North Carolina United Way
 Carla Griswold - in memory of Lily Angel Winsell
 Tom and Barb Gross - in memory of Cameron Gerard Nau
 Sandy and Paul Grunder - in memory of Cameron Gerard Nau
 Virginia Guck - in memory of Cameron Gerard Nau
 Cynthia Cohen-Gugisch - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Gary and Nancy Gusse - in memory of Cameron Gerard Nau
 Mary Haaf - in memory of Cameron Gerard Nau
 Anne Mette Haigh
 Brian Halliday - in memory of his son, Robert Severance Halliday, II
 Butchford and Mary Hanes - in memory of Mary Gray Reames
 Mary Jane Hanron - in honor of James Matthew Hanron
 Bill and Joan Hargis - in memory of William Gregory Klinzing
 Charles L Harper, III - in memory of Mary Gray Reames
 Tiernan and Colette Hartigan - in honor of their son, Thomas Hartigan
 Hartwell Presbyterian Church Bible Study Group - in honor of Baby Girl Kirby
 Stan and Sara Heer - in honor of their son, Kurtis Claude Heer
 BP North America, Inc - in honor of Emily Archambault
 Hills Bank - in memory of Cameron Gerard Nau
 Aram Hintlian - in memory of Dylan James Arsenault
 R. Patricia Hoemke - in memory of Cade Andrew Turner's neighbor, Joshua
 Lisa and Rodney Hoewing - in honor of their son, Aaron Jacob Hoewing
 Angilique D. Hoff - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Edward and Karen Hogan - in memory of Alexander M. Flynn-Nesbeth
 Rex and Deanne Hoggard - in memory of Isabell Rue
 Scott & Holly Sander Hollenbeck - in memory of Cameron Nau
 Dawnell Holt - in honor of her nephew, Jacob Howard
 Thomas A. Holt - in memory of his granddaughter, Sarah Ann McMerriman
 Daryl and Kendoll Hoskin - in memory of their son, John Connor Hoskin
 T. L. Hughston, Jr - in memory of David O. Hawkins
 Aaron and Alysa Huizenga - in memory of their son, Ethan Michael Huizenga
 Peter Hurdle - in honor of his son, Patrick Joseph Hurdle
 J. Brandon Hylton - in memory of Mary Gray Reames
 Bill Christine Jahn
 The Jannack Family - in memory of David O. Hawkins and in honor of Allison Pruitt
 Ed and Judy Johnson - in memory of Mary Gray Reames
 C. Roland Jones, Jr. - in memory of David O. Hawkins
 The Kairey Family - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Matthew, Tracy, & Kayla Keckler - in memory of their daughter and sister, Kennedy Elaine Keckler
 William Keene - in honor of Emma Katherine Keene
 William and Alice Kellahan - in memory of Mary Gray Reames
 Kimberly Clark Foundation - in honor of Alison Parker
 Richard Kitchens - in honor of Aaron Jacob Hoewing
 Patrick E. Knie - in memory of David O. Hawkins
 Beverly M. Knight - in memory of David O. Hawkins
 James and Janet Knoblach
 Jerrold Kuntz - in memory of Alexander Phillip Castaldo
 Myrna LaManque - in memory of Mary Gray Reames
 Ken and Michele Lane - in memory of Cameron Gerard Nau
 Donald J. Larson - in memory of Samuel David Chisum
 Craig and Laura Laughlin - in honor of their son, Clint Nelson Laughlin
 Pat and Willie Lenz - in memory of Cameron Gerard Nau
 Lister, Flynn, & Kelly, PA - in memory of David O. Hawkins
 Sheila Lockhart - in memory of Mary Gray Reames
 Julie Stetz Lutes - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Mariners SS Class, Good Shepard UMC - in honor of Stephen and Kimberly Carpenter
 Lockheed Martin Combined Charities of Choice
 Jacqueline Martinelli - in memory of Cameron Gerard Nau
 Terry and Zora Massing - in memory of David O. Hawkins
 Scott Maynard - in honor of Thomas John Picarelli
 Drew and Alexa McClary - in memory of Mary Gray Reames
 Carolyn McConnell - in memory of Mary Gray Reames
 Ron and Amy McConnell - in honor of their daughter, Emily McConnell
 Joseph A. McCullough - in memory of David O. Hawkins
 Laura Condry McFatter
 Patricia McMahon - in memory of Trent Sincavage
 Faye Merolla - in memory of Kala Marti
 Charles and Denise Miller and Family - in memory of Dylan James Arsenault
 Minnesota Automobile Dealers Association - in memory of William Gregory Klinzing
 Michael and Suzanne Monk - in memory of Dylan James Arsenault



Paul Leslie Noble
12/22/66



Johnathan Robert Martin
2/26/99 - 6/9/99



Benjamin James Bogdanovic
8/18/00

Charles and Nancy Monks - in memory of Dylan James Arsenault
 John and Deanna Motts - in memory of their daughter, Mary Elizabeth Motts
 John and Sue Muir - in memory of Cameron Gerard Nau
 Nina Murphy - in memory of Kennedy Elaine Keckler
 Robert and Sharon Nau - in memory of Cameron Gerard Nau
 Tod and Wendy Nau - in memory of Cameron Gerard Nau
 Bruce and Lucy Nelson - in honor of Owen Michael Cuccia
 Kevin and Sue Newhouse - in memory of William Gregory Klinzing
 Nichols & Hope, Inc. - in memory of David O. Hawkins
 Glenda W. Nix - in memory of David O. Hawkins
 Norfolk Children's School - in memory of Dylan James Arsenault
 The Nutt Corporation - in memory of David O. Hawkins
 Mike & Sophia O'Shields & Employees of Reidville Rd. Auto Service, Inc. - in memory of David Hawkins
 Amanda Pagano - in memory of her great-grandmother, Ann Poszywak
 Brenda and Steve Pagano - for past 5 years, in honor of their daughter, Amanda Pagano
 Barbara and Michael Palladino - in memory of Dylan James Arsenault
 Ryan and Ana Palladino - in memory of Dylan James Arsenault
 Gene and Wilma Panther - in memory of Cameron Gerard Nau
 Nikki Pecorelli - in memory of Samuel David Chisum
 Emilio and Florence Perez - in honor of Alison Joanne Parker
 Steve and Donna Perger - in memory of Mary Gray Reames
 Mr. And Mrs. I. H. Petersen - in memory of Cameron Gerard Nau
 The Pizzulli Family - in memory of Max Kastner
 Andrew N. Poliakoff - in memory of David O. Hawkins
 Elizabeth Pressley - in memory of David O. Hawkins
 David and Cathy Price - in honor of their daughter, Sydney Price
 Yvonna Price - in honor of Aaron Jacob Hoewing
 Bill and Joy Quinn - in memory of Keeton Shawn Wolters
 Pete and Amy Rademaker - in memory of in memory of their son's, Jonathan Luke Rademaker's birthday
 The Ramapo Catskill Library System - in memory of Alexander Phillip Castaldo
 Francisco Ramirez - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Malini Rao - in memory of her son, Rahal Hanabe
 Arthur Ravenel, Jr - in memory of David O. Hawkins
 Rehabilitation Care Coordination - in memory of Cameron Gerard Nau
 MaryAnn and Wayne Riley - in memory of David O. Hawkins
 O'Neal and Ida Roberts - in honor of Aaron Jacob Hoewing
 Jane and Arthur Robison - in memory of Dylan James Arsenault
 Carol Rocha - in memory of Samuel David Chisum
 Bill and Jeanette Rogan - in memory of Cameron Gerard Nau
 Danita Ross - in memory of her grandson, Gunnar Ray White
 Will Sandin - in memory of Alexander M. Flynn-Nesbeth
 Gerald Scheiber - in memory of William Gregory Klinzing
 Peter and Helen Schnitzer - in memory of Alexander M. Flynn-Nesbeth
 Andrew and Wendy Schultz - in honor of their son, Zachary Max Schultz
 Rosemary Schwarzwalder - in honor of her great-granddaughter, Isabella Hope Kirby
 Rosemary Schwarzwalder's Bible Study Group - in honor of her great-granddaughter, Isabella Hope Kirby
 Fred and Alice Seagren - in memory of William Gregory Klinzing
 Angie, Gregg, and Dalton Seibert - in memory of their son and brother, Kolton Grayson Seibert
 Erin M. Shea - in memory of Alexander Miguel Flynn-Nesbeth
 Marsha J. Shea - in memory of Alexander M. Flynn-Nesbeth
 Mary Shembab - in memory of David O. Hawkins
 Harry Shuris and Maria Russo - in memory of Dylan James Arsenault
 Robert and Mary Siefman - in honor of Aaron Jacob Hoewing
 Dorothy Staton - in memory of Mary Gray Reames
 Stravolo & Company, PA - in memory of David O. Hawkins
 Jim and Gen Sweeney - in memory of Dylan James Arsenault
 TCOYF November Newborns - in memory of Gabriel Chance
 Earl and Joan Talley - in memory of Mary Gray Reames
 Rita Tavel Fogelman - in memory of Alexander Phillip Castaldo
 Marie Taylor - in memory of Cameron Gerard Nau
 Dawn M. Torrence - in memory of her son, Shane Torrence
 Jamie, Dante & Brighton Thomas - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 United Way of Rhode Island
 George and Barbara Vaccari - in memory of Dylan James Arsenault
 The Van Dyken Family - in memory of Keeton Shawn Wolters
 Steve and Gloria Villarreal - in memory of Keeton Shawn Wolters
 Vickie Visser - in memory of Keeton Shawn Wolters
 Barbara and Bob Vosburg - in honor of Dr. J.A.N. German
 Barbara and Bob Vosburg - in honor of their son, Ross Vosburg
 Andrew and Jennifer Walen - in honor of their son, George Roman Walen
 Robert and Martha Walker - in memory of David O. Hawkins
 George and Faye Waller - in memory of Mary Gray Reames
 Douglas and Sharon West - in memory of David O. Hawkins
 Mr. and Mrs. David White - in memory of David O. Hawkins
 Mr. And Mrs. John B. White - in memory of David O. Hawkins
 John Williams
 Patrick Winsell - in memory of Lily Angel Winsell



Bethany Taylor Abaurrea
12/12/97



Noah Edward Kelly
3/27/01



Harrison Alan Lovell
9/20/01

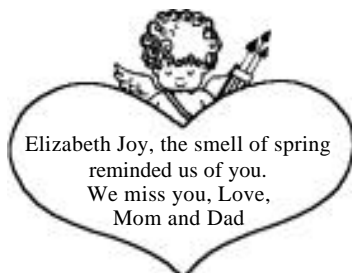
Rita and Carl Winsell - in memory of their granddaughter, Lily Angel Winsell
 David Wojtkowski
 Alicia and Craig Wood - in memory of their son, Lachlan Christopher Matthew Wood
 Galen and Amy Wong - in memory of Isabelle Yap and in honor of Kai Adrian Antonio Lopez
 Christine Yee - in memory of Robert Severance Halliday, II
 Paul and Jan Zieger - in memory of their daughter, Julia Cora Zieger
 Paul and Jan Zieger - in honor of the wedding of Aileen Santos and Terence Keaney



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, Brazil, Chile, Columbia, Denmark, Egypt, France, Greece, Hong Kong, Israel, Italy, Japan, Lithuania, Malta, 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.

<u>REGION</u>	<u>REPRESENTATIVE</u>	<u>PHONE#</u>	<u>REGION</u>	<u>REPRESENTATIVE</u>	<u>PHONE#</u>
Australia	Danielle Kessner	(03) 5135 6999	LA	Sheila Ezernack	318-645-9361
Canada	Karen Jenkins	(905) 852-9410	MA	Heidi Cadwell	603-465-3311
Canada	Laurelle Lehmann	(250) 838-2250	MD	Brenda Slavin	410-956-4406
Germany	Renata Hoskins	907-245-8817	MO	Carol Lynn Cole	816-305-3832
Great Britain	Rachel Wyatt	01908 565574	MO	Jody Hill	913-859-0389
Great Britain	Kevin & Brenda Lane	01553 762884	MS	Melissa Clark	228-432-8942
India	Shankari Murali	6164934	MT	Elaine Moats	406-232-5038
India	Malini Rao	469-232-0245	ND	Elaine Moats	406-232-5038
Ireland	Mick and Mary Blake	01 4921595	NE	Kristen Stiner	402-502-9310
New Zealand	Nikki Hodson	04 9724841	NH	Heidi Cadwell	603-465-3311
South Africa	Amanda Dean	+2712 5474207	OH	Tara Hall	614-275-0858
South Africa	Karen Howard	082 850 0851	OK	Daphne Parker	918-298-8652
Spain	Sonia Winkels	34-91-3004029	OK	Jeannette Davis	405-670-9937
AK	Renata Hoskins	907-245-8817	OK	Michael Culwell	918-647-5850
AK	Suellen Nelles	907-452-1769	OK	Scott Lenhart	918-371-3020
AL	Alicia O'Malley	256-389-8110	OR	Kimberly Doades	503-625-7343
AZ	Anne Marie Kastner	480-837-1895	OR	Marion Lansdon	360-882-5502
CA	Tamara Mueller	808-422-6565	PA	Tammy Sincavage	610-796-7324
CO	Dave & Clare Retterer	303-644-4779	RI	John & Charlene Cassese	401-884-0269
CT	Toni Fiorillo	rerefi@aol.com	SD	Elaine Moats	406-232-5038
GA	Annette Lichtenstein	404-325-2368	TX	Shelly Evans	254-793-3039
IA	Tami Logsdon	515-277-6316	TX	Monica Nedrow	817-329-2402
ID	Tonya Rupe	208-552-1889	TX	Malini Rao	469-232-0245
IL	Rachele Alessandrini	708 283-9006	WA	Marion Lansdon	360-882-5502
KS	Jody Hill	913-859-0389	WA	Grace Massie	360-933-0411
KY	Lori Welsh	859-239-8970	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
Carol Lynn Cole - 816-305-3832 Michael Culwell - 918-647-5850 Jolene Halbeisen - 419-333-8384 Tara Hall - 614-275-0858 Elaine Moats - 406-232-5038 Daphne Parker - 918-298-8652 Deeshia Partin - 770-919-2162 Ann Peterson - 509-735-7208 Pamela Pruitt - 864-814-7880 Jeannette Davis - 405-670-9937 Amanda Dean - +2712 5474207 (South Africa)	Melissa Clark - 228-432-8942 Shelly Evans - 254-793-3039 Freedom Green - 770-479-0378 Michelle Huether - 618-853-4157 Tracy Keckler - 419-423-7422 Marion Lansdon - 360-882-5502 Malini Rao - 469-232-0245 Dawn Matthews - 732-458-5960 Amanda McLuckie - 214-821-7128 Karen Myers - 228-396-9647 Niki Naus - 757-887-3742 Suellen Nelles - 907-452-1769 Amy Rademaker - 616-844-4156 Danielle Kessner - (03) 5135 6999 (Australia) Laurelle Lehmann - (250) 838-2250 (Canada)	Kerrie Chamberlain - 541-535-4744 Kimberly Doades - 503-625-7343 Jody Hill - 913-859-0389 Anne Wolfe - 610-481-4178 Linda West - 07 3263 4203 (Australia) Sonia Winkels - 34-91-3004029 (Spain) Rachel Wyatt - 01908 565574 (Great Britain)

CHERUBS' Art Contest!

We are inviting all kids (young and young at heart!) to enter our art contest. Cherubs, siblings, parents, and friends all welcome to submit entries. We are looking for artwork for our fundraising items. The only requirement is that the artwork includes cherubs. The artwork will be added to clothing, coffee mugs, holiday ornaments, clocks, calendars, and much more. All artwork will be featured on our web site and included on merchandise to raise funds for CHERUBS. The best part is EVERYONE is a winner because ALL artwork will be featured. Have your child submit a drawing and you can purchase his/her artwork on items that would make great holiday gifts. We will also combine entries to use on calendars, or submit 12 seasonal designs for a calendar featuring just your artwork. To view our fundraising items that will feature contest entries, you can visit our web site at <http://www.cherubs-cdh.org/fundraisers/cafeexpress.html>

CHERUBS' Fundraising Contest!

We are inviting all members and their families and friends to enter our 1st Annual CHERUBS' Fundraising Contest. The winner will receive \$250.00 cash donated by local businesses specifically for this contest. Our goal is to raise \$10,000 through this contest, but we need your help! This is a great way to earn money to attend our CHERUBS' International Member Conference in July! Take pictures of your event and it will be included in our newsletter.

Contest Rules:

1. You must follow all national, state, and local laws.
2. No gambling, bingo, raffles, scratch cards or other such questionable events.
3. All events must be safe! No skydiving, car racing, bungee jumping, etc by amateurs.
4. You accept all responsibility for collection of funds raised until the funds reach our main office.
5. When in doubt whether your event is a good idea, ask Dawn!
6. All direct donations are tax-deductible.
7. Donations can be made in honor/memory of your cherub.
8. The deadline for sending in your contribution is June 1, 2004.



Some Suggestions For Your Fundraising Event:

- Yard Sale
- Bake Sale
- Lemonade Stand
- Neighborhood Music Recital
- Craft Show
- Walk-a-thon
- Car Wash
- Marathon
- Rubber Ducky Race
- Read-a-thon
- Ebay Auction
- Phone Telethon
- Art Show
- Fashion Show
- Talent Show

Recruit Friends, Family, and Businesses for Donations

Stories of Cherubs



It's only been five months. We are still trying to understand why. I was 33 weeks pregnant and so very excited, just as any expecting parent would be. My husband and I spent that Sunday shopping. We went out to get groceries, and ended up at a baby store purchasing Maggie's nursery furniture. We spent the whole day shopping, and throughout the day, I noticed that I was losing some fluid. I really didn't think much about it until we got home. I called my mother who is a nurse, and she suggested that I go to the hospital to have it checked out. They informed me that my water had not broken, but I should see my doctor first thing in the morning. That was a Monday. I went in, and he checked me again. No he said, but he had a hunch that something was going on, so he sent me to the hospital to get admitted. I was monitored and was then sent to have an ultrasound. That was the beginning of the end. The hospital, of course, had better equipment than the doctor's office, and the tech informed me that he could see something wrong. He called my doctor and he quickly made his way to the hospital. Apparently, they couldn't see the fourth chamber of Maggie's heart. My doctor told me that he was going to call a referral, and do some research. I stayed in the hospital overnight fearing that my first child, my

daughter, had a heart defect. The next morning my doctor arrived and told us that I was going to Atlanta to a group of doctors who were "top notch." I arrived in Atlanta on the 26th of June. I was admitted into the high risk delivery unit for three days. On the first day, they took me in for an ultrasound. That was when we found out that Maggie had CDH. The doctors wanted to take her immediately. The doctor who performed the ultrasound said, "I am very worried about your baby." So, off we went, down to prepare for an emergency C-section. The anesthesiologist came in and gave me an epidural, and my husband was suited up to accompany me. As soon as we were about to head out, the doctors came in and told us that they had decided to wait. Unfortunately, there were no ECMO beds available at the children's hospital where Maggie would be transferred to. We were given many options. Stay there, transfer to Augusta (which they didn't highly recommend), or transfer to Birmingham. The out of town options had ECMO beds available, but it was up to us. Of course, we wanted to do what they recommended. They said that we should stay in Atlanta, and they would check every day for the ECMO availability. As soon as a bed became available, they would perform the surgery. Three days later, a bed was open, but they decided not to do the c-section. They thought that Maggie had a better chance the longer she stayed inside the womb. My question was "If the lungs are the last thing to develop and the CDH is putting pressure on that area, why not take her before it gets worse?" Wouldn't you think so? Well, that wasn't the case. I was then transferred to the high risk prenatal unit for another three weeks. I had ultrasounds performed everyday, and was monitored twice a day. My water broke during the night on July 4th. They didn't think much about it, so they let her stay in, on top of giving me daily antibiotic treatments intravenously. I remained that way for two weeks. During that time, one of the doctors informed me that he didn't see any reason for me to stay in the hospital and that I might get to go home with once a week ultrasounds and monitoring. It didn't happen that way. My whole family thought that was totally out of the question. At 37½ weeks, another doctor came in to tell me that they were finally going to take Maggie. AND once she was stabilized, they would perform the surgery to repair the left-sided CDH, and that I would be taking home a "normal, healthy baby." We had no idea what CDH was. They never told us what could happen. Sure, they gave us survival percentages, which grew from 50/50 to 70/30. She looked great they said! Well, they decided to induce labor. My cervix wasn't dilated so they inserted Cervadil. About 45 minutes later, Maggie's heart rate dropped dramatically. Nurses and doctors rushed in, mashing my belly, trying to get her back. The anesthesiologist came in and asked if I was allergic to anything, and my mother said no. Then he asked "Is there anything wrong with this baby?" and my mother replied, well, yes, she has CDH. And he then said, "Then what in the H is she doing in here?" They rushed me into the surgery and Maggie was born. I woke up in recovery with my husband by my side, and they brought Maggie to see me. She was in a big see-through case where I got to hold her hand. The nurse informed me that she was very sick and that they had to get her to the children's hospital right away. I told my husband to go with her, that I would be fine. She was born about 2:00 in the afternoon. At around 6:00 the next morning, we lost her. We had no idea that it was that severe. The children's hospital informed my husband that Maggie had a right-sided hernia, not a left. Maggie's doctor couldn't believe that we had been told that she had a left-sided hernia. Apparently, right-sided is worse. We still don't understand everything that happened. We can't figure out why the doctors made the decisions that they made. We are still in shock. We can't understand why. My doctor here in town told me that it was nothing that I did. That it was a fluke of nature. Will this happen again? I am so scared that it will. I have been told that it won't, but I can't help but worry. We are trying again, but we will never replace Maggie. She was so beautiful. So perfect on the outside. CDH is a horrible defect. We had never heard of it before. We pray every day for people who have to go through this like we did. For everyone that has gone through it, we feel your pain. A pain that will never go away! God bless you all, God bless Maggie, and may God bless all of your CHERUBS!

Jamie & Jason McSwain (parents of Margret Faith McSwain, 7/18/02-7/19/02, 116 Tanglewood Trail, Griffin, GA 30223, 770-228-0839, mcswainsonic@aol.com)

My story starts in July 1997, it was my 20 week scan & I was told the baby wasn't in the right position to see the chest wall & could I come back the next week. The following week I was told my son had a severe diaphragmatic hernia to the left side & was very unlikely to survive so it would be best if I terminate my pregnancy! Well as you could imagine I was devastated, I refused to terminate & was referred to a hospital with better equipment, I developed polyhydramnios & was kept in hospital for 7 weeks before my son was delivered by c/section which was on the November 20, 1997. He weighed 10 lbs, 10 oz & we called him Cameron Anthony after his dad. The doctors made it clear there wasn't much hope as it was a bad hernia. He held on for 18 hours but then lost the fight on the November 21, 97. I still don't regret not having the termination, otherwise I would never have seen my son's big chubby face. Eleven months later, I had another son who was stillborn. This time through a totally different reason. You wouldn't believe my terror at being told I'd lost another child. They are now together at the crematorium & I visit almost every week. I went on to have a healthy boy & girl to go with my 9 year old son but it doesn't get any easier & I'll never forget. Finding this site is a Godsend in itself. I thank all of you who take part in it.

Sandra Kennell (mother of Cameron Anthony Kennell, 11/20/97- 11/21/97, 2 Makepeace Walk, Crumpsall, M8 4HL, Great Britain, 0161 720 9097, Sh4rk1410@aol.com)



Madison was born 12-28-01 at a healthy 7lbs, 9 oz. She was a very fussy baby and the doctor said it was just what some babies do. She never liked to be held against you she would just cry. When she was about 2½ months old, we started the day off as usual. Later that day we had to go out so I put her in her car seat and everything seemed fine. Then out of the blue she started crying. She wouldn't stop, so we went home. I thought maybe she had gas because her tummy felt like it was tightening up a lot. I gave her some gas drops and that didn't seem to work. I then gave her some water thinking maybe it was constipation. When my husband came home about a hour later, she had gotten to the point where she wasn't really crying any more. She was more like gasping for air, so we rushed her to the Emergency Room in the next town over. At first, the nurse was pretty rude telling me she was dehydrated and was trying to give her water (which she was spitting back up) about 5 minutes or so later. They thought she looked a Little blue around the mouth and me and my husband thought she looked a little pale. They put something on her toe and decided from there they would give her oxygen. They then took her to have an x-ray. At this point, we didn't know what was going on. They came out and went straight to the phone to call a doctor to come in right away. The nurse during all this was asking my husband how I treated my daughter and if I seemed to be stressed with her (trying to insinuate that I did something to injure her). When the doctor came, he told us her left lung was collapsed and they needed to put in a chest tube. They didn't think she'd make it with out it. Then they where going to fly her to Wichita, a bigger city. When they put in the chest tube, it wouldn't re-inflate her lung like they said it should. I flew with her and my husband had to drive 2½ hours away by car. The doctor looked at her and her x-rays

when we got there and said she had a cyst on her lung and it had burst and they would have to take out part of her lung. It was so stressful on her and us. She had to wait till the next afternoon to go to surgery. In the meantime, they used a big needle and removed a lot of fluid they thought was from her lung. When they were finished with the surgery, the doctor came out and said that she actually had a diaphragmatic hernia and that they put her stomach and spleen back through the hole. They also said when they did that, her lung re-inflated back to normal – the fluid they removed was actually formula from her stomach. The doctor said that she was lucky, her spleen was acting as a plug allowing her lungs to develop normally. She was in the hospital for 5 days and then went home. It was hard for a few weeks. My mother came from out of state to help me with her. She didn't want to be held at all – she stayed in her swing most of the time. She got better each day and today is a happy healthy almost 12 month old. She's always smiling. We have a picture of the doctor holding Madison on her bedroom door so every time we go in there, we know how thankful we need to be that he saved our baby. We love you Madison! Love, mom, dad and all your family members.

Melanie and Brian Kelsay (parents of Madison Elizabeth Kelsay, 12/28/01, P.O. Box 596, Cimarron, KS 67835, CK147@hotmail.com)

My name is Pam Rutheford, and my daughter Madeline is 6 months old. She was born on January 1, 2002, 4 days late but she had a normal weight. She was the first baby of 2002 in Indianapolis. An hour and a half later, she was diagnosed with CDH. The doctors told us that she would be transported to Riley Hospital for Children shortly after she was born. She was put on a ventilator before she was transported. I got to hold her for a minute when she was first born, but not again until she was two and a half weeks old.

She had her surgery at seven days old. The doctors said that it was a good sign that she did not go on ECMO. She went to the infant ICU when she was three weeks old, but she only had to stay there for a few days. She got to come home when she was 23 days old. She came home with a NG-tube and oxygen. We didn't care, though, as long as we had her with us. I still remember the first thing that the surgeon said to me – it was that she had about a 50%-60% chance of making it through the surgery. I think that was the scariest moment in my life.

The doctors did not find the hernia when I was pregnant with her, so when she was born, we thought she looked healthy and happy. But when they tell you that something is wrong and that the baby won't come home with you when you get released, then your whole perspective changes. She is a miracle in all of our lives. She has been through so much and is very loved by everyone that is around us and some people that we don't even know. Her condition got a lot of publicity because of her being the first baby of the year and being on the news. Just to see her smile and see her starting to crawl is the happiest time for all of us. She has a brother that is three years old, and he is always helping with her and getting her toys and stuff. He shows how much he loves her every day. It was very different having him come home with us and her not. When you come home and see a crib that is suppose to have a baby in it and it doesn't, it makes you want to cry every time you see it empty and not knowing when it will be full with the cries and laughs of a child. She is our little angel.

Pam Rutheford (mother of Madeline Jo Rutheford, 1/1/02, 2219 Harlan St, Indianapolis, IN 46203, DIANEMAMAW@aol.com)



from that point everything would be fine.

The following week I went to an unscheduled doctor's appointment because I was still sick and I thought I was having contractions. My weight wasn't great and although I thought I was having contractions, there were no signs of labor. We made some small talk and I told her that I was

I found out I was pregnant in late March 2001. As soon as I got the news, I began to worry. We had just bought our home and I had painted for almost 2 weeks straight. I immediately told my doctor, who insisted everything was fine. I began bleeding a few days later. I went in and was told again that this was not completely abnormal. After an ultrasound, I was told everything looked good, 9 weeks and 5 days. I was still worried but I just told myself I already had one child and he was fine – besides birth defects don't happen to people like us. Contrary to my first pregnancy, this one was awful. I had uncontrollable morning sickness, backaches, fatigue and was having trouble gaining weight. This made me think a little less about my initial fears of problems our baby could have. I had my mid-way ultrasound at 19 weeks. I was so excited. I already had a son from a previous relationship and my husband already had a daughter. My husband said he didn't care what we had so long as it was healthy. I agreed on the healthy part but I wanted to give my husband his first son. My husband is adopted and knows nothing about his birth family. I wanted him to have his little boy who would look and act just like him. We got the best news of my entire pregnancy when they said, "little boy, plain as day.....he's not shy." I believed

having a boy. That must have sparked her memory because she said, "Oh by the way, I was going to call you. The ultrasound technician sent a very odd report that the left lung doesn't appear to be working." My heart sank. I asked if I did anything wrong and she said this was nothing that I had done. I remember she said this really long diagnosis, but then said, "but don't worry, all his organs are in the right place so it can't be that and it is possibly just a fluke." She said I was going to go to a bigger hospital for a more detailed ultrasound and more than likely everything would be fine. "Just think of it as another opportunity to see our son." As soon as I got home I looked up "birth defects involving the left lung" and that is when I first learned about CDH. After reading that it is most commonly on the left side and is found more often in boys, I was certain this is what it was. I even found information that a lot of fetuses with this defect had been exposed to paint and paint thinner fumes early in pregnancy. I also found that the mortality rate was very high. My fears were coming true, there was something wrong and it was bad. I found out everything I could about this defect. My husband and I went 2 weeks later and after a 2 hour ultrasound, we were told it was a CCAM (Congenital Cystic Adenomatoid Malformation of the Lung). When the doctor explained the diagnosis, we asked about the CDH. She insisted he had a diaphragm and all organs were in place. She said if it were CDH, she would be discussing abortion. What a relief! The doctors said this defect was very treatable with a lower mortality rate. On the way home, we actually said how glad we were that he had this defect – I mean this was much better than CDH. We picked out his name and always referred to him as Caleb, not just the baby. Caleb had a name and he was going to beat this. I had a follow up appointment 2 weeks later. His condition took a turn for the worse. The CCAM was growing. My son's heart was pushed to the right side and was being crushed and they were worried about hydrops. I was given steroids shots to try to get his lungs developed in case they had to take him early. We toured the NICU and spoke to surgeons. Then, slowly his condition seemed to get better. The CCAM stopped growing. He was getting bigger but the CCAM wasn't. His heart was now in the normal spot. I told my husband just to go to work and I would take friends and relatives to appointments.

Then came the day I asked my husband to go. I don't know why, I just wanted him there. Almost every time I went for check-ups, I would hear someone crying. I felt lucky, our son was going to be okay. The whole time they did the ultrasound, something seemed weird. Normally, the technicians talked to us and even laughed – but this time there was nothing. She left the room and came back with the doctor. The doctor did another scan. She finally said, "I don't know how to tell you this, but your son's heart is being pushed to the right again, we can't find his stomach, his intestines are in his chest, the CCAM is still there and we can't find his diaphragm." Then we cried. A lot of it seems hazy. I remember a lot of surgeons came down and talked to us, they said they could help. Then they talked about other hospitals. It was decided we would go to CHOP (Children's Hospital of Philadelphia). This time I went home and my husband and I found everything we could about CDH. We wrote down all the different treatments he could have and any questions we wanted answers to. Of course, the biggest question was what were his odds of survival? We went down to CHOP 2 days later. I had every test imagined. A 4 hour ultrasound, fetal echocardiogram, fetal MRI – I can't even remember them all. We finally had the diagnosis: CDH on the left side, Bronchopulmonary Sequestration on the left side and a displaced left kidney. It seemed to me that his entire left side didn't form correctly. We toured the NICU at CHOP and spoke to a surgeon, Alan Flake. Unlike the surgeons at the last hospital I was at, he had a lot of experience repairing this defect. He assured me he could help our son.

After a discussion with the surgical team, it was agreed that Caleb's only chance was going to be at this hospital so we would come back to Philadelphia in 2 weeks and stay until he was born. While we were there, my husband waited until November 1st and ran out and got me a mother's ring with what would be his birthstone (he waited until then just in case Caleb came early). We were there 3 weeks and then came the big day. On Monday November 12, 2001 with my husband and mother by my side, they started inducing me at 10:30 a.m. and at 2:04 p.m. he was born. We actually had him at the hospital right next door, Hospital of the University of Pennsylvania. As soon as he was born, they took him. My husband got to go into the room and see him before they took him next door, but I had to wait. I knew when he first came out he wasn't breathing because the cord got wrapped around his neck. God, what else could go wrong? My husband came back and told me he was breathing and seemed to be doing okay. We waited until they called and said we could come over. Although I knew what to expect, I was still shocked when I saw all the machines, wires, tubes and I.V.'s. All I wanted was to hold him and I couldn't even do that. Surgery was the next day. We spent all day with him before that. I wanted to see his eyes, but he wouldn't wake up. I wanted to hear him cry, but he couldn't. My aunt came and we all waited together. After almost 4 hours, the surgeon came out. Caleb made it through the surgery.

The next few days we sat and watched as they weaned him off the vent and slowly reduced his pain medication. He was a trooper. His vitals were always steady. On Sunday, they finally removed the vent tube. They warned us that he may need to go back on if his breathing became labored, but he never did. I could finally hold him. He was starting to wake up. I could see his eyes and then I finally heard him cry!!! My husband and I took turns holding him. We were so proud because he was doing better than anyone expected. We decided it was safe enough for us to go home and get our other two children and finally introduce them to their new brother. We made the 4 hour trip home. We called to check on him and got bad news. He got an infection. We returned expecting the worst. They did a spinal tap but could not figure out what the infection was. But he fought this like everything else. Soon he would start learning how to eat. A little trouble at first, so we took N.G. tube feeding classes but after about a week, he figured it out. We had to learn how to give him medications for reflux (Zantac and Reglin). Then came the milk allergy. Blood in his stool, but after switching his formula he was fine within a few days.

Finally, came December 6, 2001 (the day after my birthday). We could take him home!!! I had the best belated birthday present ever and very Merry Christmas to look forward to. Our son is now 14 months old and shows no signs of lasting effects. Although he has asthma, that doesn't stop him. He started walking the day after his birthday and just got his 7th tooth 2 days ago. He is pretty big for his age, almost 30 pounds. He laughs, babbles, runs, climbs on the couch, plays with toys and his brother and sister. With his clothes on, you would just think he is a normal baby but we know Caleb is our "Miracle Baby." And my husband has his little boy that looks and acts just like him.

Michelle McAndrew (mother of Caleb McAndrew, 11/12/01, 129 Woodward Ave, Lock Haven, PA 17745, 570-748-0248, rcmcandrew@adelphia.net)



ripple effect from her tummy to her chest with each breath.

Kathryn was delivered by Caesarian section at the Olivedale Clinic in Johannesburg, South Africa. I was absolutely petrified and remember shaking like a leaf as they were getting me ready. It was only when the cord was cut (after being removed from being tightly wrapped around her neck) and the deathly silence in the theatre, that I realised there was something wrong. Kathryn was whipped away by her paed., Dr. Li Wan Po, and I watched as he manually bagged her. He chased my husband away from his side and shouted across theatre to get a ventilator ready. The answer from NICU was, "There isn't one!" With that, he raced out of theatre with Kathryn in an incubator, bagging her as he ran. Apparently, he took her out when the lift proved to take too long and ran with her in his arms, bagging her to the NICU unit. It was a 3-bed vent unit, and she was the 8th baby to go in! Additional nurses were summonsed from adult ICU, the matron and the PRO were called to assist. Staff worked frantically to stabilise her, not even knowing whose baby she was. Ironically, my friend was in the ICU at the time with her premature baby, and she filled us in on all the drama. She said that watching Kathryn trying to breath was like watching the waves at the sea; there was a

Over 5 hours later, Dr. Li finally managed to come and see us with an explanation -- Kathryn had a severe congenital diaphragmatic hernia. Her heart was way over on her right lung, her esophagus was askew, and all her intestines, colon, bowel and stomach were sitting on her left lung. Her Appgar was one, intubated. The big bonus was that she weighed a whopping 3.7 kg and she was a girl. I was wheeled down at 9:00 p.m. to have my first look at our new baby. It was a scary sight as she looked like a little corpse and there was nowhere to touch her. She was squashed into a corner of the ICU unit surrounded by machinery. We were told that the top paediatric surgeon had been called to look at her, but we would have to wait 72 hours before they could operate.

Unfortunately, on day 3, a Sunday, she just got progressively worse. We went to see her in the morning, and we had no sooner arrived home, and I was nagging, eventually resorting to tears to be taken back. Kathryn was not coping well. Dr. Li eventually said, "Look, Mommy, we have done everything we can do, you have to pray now. She must stabilize, so we can operate tomorrow." I didn't pray; I begged. My mom-in-law and I took turns, unbeknownst to one another to go to the loo, to kneel down, and beg God to spare Kathryn's life. We even begged the doctors and nurses to operate on her immediately, as we didn't think she would make it through the night. Sister Heike was going gray in the face looking after her that day, and later said that she was too scared to phone the hospital on Monday morning and eventually only did so in the afternoon, as she did not think Kathryn had made it! After an extremely long night, we arrived at the hospital, when we spoke to the anaesthetist, he said he was not confident that they would proceed with the operation as Kathryn was not stable enough. Thank God for Dr. Beale; he arrived as cool, calm and confident as can be and instructed the theatre staff to pack their things and move down to the extremely small and packed NICU unit. They would not be moving her, but operating on her in the unit. When the operation was finally finished, he walked out and said, "This one is going to make it." He didn't count on her turning septic, which was yet another life and death struggle. To be honest, we were unaware just how close it was until she was on the mend and Dr. Li said to us, "Mommy, that was touch and go, touch and go!"

He had not counted on the fact that Kathryn is a fighter (and an Aries, I kept telling her that as an Aries, she is stubborn and would fight!). It was 4 long weeks before we could even see what colour her eyes were. But eventually after 6 weeks, a seizure on the vent, and a doctor who cancelled his holiday plans, she was finally off the vent and in the oxygen box. From then on, the improvement was remarkable. And a week later, we started breastfeeding and were able to hold her for the first time. An amazing feeling!

We are so blessed to have Kathryn, but we do question the gynae who delivered her and the radiology unit who scanned me (twice) -- that they failed to notice that I was carrying a lot of amnio fluid and that they didn't notice that her tummy was empty. This can even be seen in the picture of Kathryn as she was whipped out of my tummy; her tummy is concave and her chest was convex. But what is scary is that my husband had his heart set on a home delivery, and I kept saying, what if something goes wrong ... the consequences could have been tragic. This was an extremely traumatic time for us as a family. On the day Kathryn had a seizure on the vent, we were told that doctors had advised that her Great Grandpa, who was in ICU in Durban, should have his life support machine turned off. Somehow he fought back to hear how Kathryn was doing. He passed away just days after she was discharged from hospital.

I was put under added pressure, as I had my own company at the time in partnership with two people I had considered friends. At the time of my pregnancy, the two had gone off to open another business and ignored our existing business except for salary time! They had the audacity to come and see me shortly after Kathryn was born and told me, "There is no money to pay you; besides you are not working!" I later found out that I had been completely betrayed by them in the most underhand, callous manner, at a time when I could not fight back for the company I had started. (They had been trying to sell the company to the company my brother worked for!) I do sometimes wonder if the intense pressure I was under due to their actions at the time of my pregnancy and delivery did not assist in Kathryn's problems!

Having Kathryn in hospital was particularly difficult for Dylan, who couldn't understand why he was not allowed in to see his sister, and even told his gran that "he was part of that family." It was also hard to try and split my time between the two, as I felt guilty if I spent too much time at the hospital and guilty if I wasn't there. The experience has also brought us closer to God -- one can't go through something like this without realising just how great His power is. Unbeknownst to us, there were 24-hour prayer chains going during her worst moments.

Finally, I would like to thank my husband for his unbelievable strength during the ordeal, our families, our friends (in particular Lisa, Janet, Shirley and the other moms in the ICU at the time!), and most importantly Kathryn's doctors, Dr. Li and Beale and the fantastic staff of the Neonatal ICU unit at Olivedale, Sisters Jo, Jo, Heike, Janet, Karen, etc., from the bottom of our hearts. Thank you, thank you, thank you! (I believe that the Gynae who delivered Kathryn has subsequently left the country, which perhaps explains why he would not purchase a new scanner and rather sent us to the Radiology unit.)

I am assisting with the establishment of Cherubs South Africa, in order to assist parents of babies born with CDH with support and information, as well as to educate the doctors about the condition. If you are from Southern Africa, and read this, please get in touch with us!

I would also like to advise people who are in the process of going through this experience to keep a diary and disposable camera at your babies bedside. I feel that looking back after 17 months, there are huge gaps in our story, and missed photo opportunities, and quite honestly, I think I was living in La La Land for a large percentage of the time!

Karen Howard (mother of Kathryn Howard, 4/4/01, 23 Cotswold Drive, Saxonwold, Johannesburg, Gauteng 2196, South Africa, 2711 880 0472)



7lbs., 20.8 inches at 36½ weeks and looked like the healthiest baby ever. On the 4th day, the doctors said they would do the tests over the next day but didn't expect to see a change. We called our families and pastor to come be with us the next day.

Hi! I am from Timpson, Texas and have lost a son due to CDH. We were expecting Kaleb Matthew to be born the end of October 2002 healthy and well. That is until about 32 weeks when I began swelling terribly due to polyhydramnios. The doctor got worried about it and finally at 33 weeks, it was discovered that Kaleb had CDH. This is after the technicians at Memorial Hospital in Nacogdoches told me that the baby was healthy and that both lungs looked great.

After a week in Galveston, Texas my NST showed the baby's heart rate to be in the 190's. They immediately rushed me into surgery for an emergency caesarian section. When Kaleb was brought into this world, he actually cried twice. He was then taken to the NICU.

He was born at 11:22 a.m., October 3, 2002. He was doing fine until midnight that night when the doctors came in and asked me to sign the papers to have him put on ECMO. I told them to do whatever they could to help him. Five and a half hours later they came in and said that fluid had built up around his heart and had caused it to stop beating on it's own. A drain tube was placed in his chest to drain the fluid.

For 4 days we hoped and prayed that this would help him to pull out of this. He was

The next day, October 8th, the tests were done and deterioration was found in his little heart. He wasn't a candidate for a heart transplant because of the CDH and there was nothing else to be done. Slowly the machines were turned down and Matt and I sat and watched our little angel slip away. It was the hardest thing I have ever done to tell them to do it. Our 2½ year old son could not understand why he could not have his baby brother, but a kind lady in the waiting room explained it to him and also said the rain outside was Jesus' tears. All the nurses, doctors and technicians that were with him stayed right by our side through it all. They even cried right along with us. His doctor, Dr. McKinney wanted to do an autopsy to find out what happened because she believed he had a heart attack. We buried him on October 11th in Timpson, Texas. We later found out in the autopsy results that the ECMO had somehow bruised his heart but they said that without it he would have only had a 15% chance of survival. So it was necessary for the two surgeries he had to have. We had a wonderful 5 days with our son and truly miss him. The doctors, staff and everyone at UTMB was wonderful to us, as well as the people at the Ronald McDonald house and all the wonderful help we have received from CHERUBS. God Bless and God Keep!

Emily Groce (mother of Kaleb Matthew Groce, 10/3/02-10/7/02, 2591 Cr 4098, Timpson, TX 75975, 936-254-9807, emily20_1980@yahoo.com)



We were very excited when we found out we were expecting our first child. Everything was going pretty smoothly. We had a relatively uneventful pregnancy. I didn't have much morning sickness and didn't swell up much until toward the end. On September 21, 2001, our 5th wedding anniversary, I had a routine doctor's appointment. Imagine my surprise when I was told that I was well into labor and 5 cm dilated! We rushed home for my bags and headed for the hospital.

We checked in about 11:00 a.m. through the Emergency Room. (We heard there was less of a wait there!) We were taken to L&D Room 1, where we got settled in. I asked for and got my epidural shortly thereafter; my water was broken and was given pitocin to help things along. About 3:00 p.m. the pain started to kick in, and I soon felt the urge to push. After 54 minutes of pushing, our angel was born at 5:13 p.m. He weighed 8 pounds, 9 ounces and was 21 inches long.

We had taken birthing classes, so we knew pretty much what to expect. As soon as he was born, I knew something was wrong. He was placed on my belly for Daddy to cut the cord, but then instead of leaving him with us to cuddle, he was immediately taken over to a bed in the corner of the room where nurses huddled by. He didn't cry, and when he would try to breathe, his whole little belly would cave in. His Aggar scores were low. I later learned that he was being bagged right there in the delivery room, as they did not want him to try to breathe on his own. The doctor was conveniently blocking my line of sight, but my husband could see them bagging him, and he later told me he thought they were doing CPR.

They took the baby to the nursery before the doctor was done with me. I kept asking if he was OK, and the doctor kept telling me he was fine, but I knew deep down that something was wrong. I wanted to believe him, but there was a part of me that just knew.

They finally finished up with me and were getting ready to move me to the maternity ward, when "someone from the nursery needs to come and talk to you." I thought he was dead. The nurse came in and gently explained that the baby had something called a Congenital Diaphragmatic Hernia (CDH). Basically, the diaphragm is the muscle that separates the chest from the abdomen. His diaphragm didn't close, and had a hole in it. Some of his abdominal organs had come through that hole in utero and had impeded his lung growth on the left side. They had to intubate him because the more he breathed, the more damage he could do. Then he fought the ventilator tube, so they had to sedate him. He would have to be life-flighted to Children's Hospital in Pittsburgh. They had called for a helicopter, and I could see him before he was taken. They wanted us to name him, but crazy me -- I wanted to see him first. Throughout his entire hospital stay, all of his tags said, "Unknown Bryant" because of that!

Around 8:00 p.m., the helicopter was finally there. They had brought a respirator with them, as Washington Hospital didn't have the machine for infants. Up until then, someone had to stand with Patrick, continuously using a bag to push air into his little lungs. He was hooked up to the machine, and I was wheeled in to say hello and goodbye to my newborn son. He was lying there, motionless, seemingly asleep. I got to touch his little hand, but he could not squeeze me back. Saying goodbye to him was the hardest thing I have ever had to do. I didn't know whether I would see him alive again. We named our lovely son Patrick Neil and sent him in the care of the kind transport team. I even remember telling the pilot to fly safely with my little guy -- he must've thought I was crazy!

I was required to stay in the hospital overnight. It was decided that my husband and parents would stay in Washington and my husband's parents would make the trip to Children's to be with Patrick. God bless them. They spent the night in the NICU waiting room to try to give me some kind of peace of mind. I will never forget that. I insisted that my husband and parents go back to the house and try to get some sleep -- we all knew that Saturday would be a long day. I also asked Rick to look this Diaphragmatic Hernia thing up on the Internet and bring me more info.

Needless to say, I didn't sleep at all that night. I tried to watch TV just so it wouldn't be so quiet, but I couldn't stop thinking about Patrick. Rick came in at 7:00 a.m. with some printouts that I later learned were censored for my sanity. CDH affects about 1 in 2,500 babies, mostly boys, mostly on the left side. (That's where Patrick's was.) It requires surgery to repair the hole. I later learned that the survival rate is 50%. At 7:30 a.m., my doctor came in and offered to release me. So after a shower and a little clean-up work, we headed to Pittsburgh.

They try so hard to prepare you for what you are going to see when you go into the NICU, but nothing can prepare you for the sight of your child hooked up to all of those tubes and wires. And then they have to tell you all the things that can go wrong. Mind you, you have no choice but the surgery, but they still have to tell you the possible consequences. It was mind numbing to hear it all at once, while still trying to comprehend that that is your SON under all those tubes and wires. I made Rick sign the papers -- I'm such a sissy.

They had to wait for his stats to stabilize before doing the surgery. The plans were to operate on Monday and they almost went through with that, but they didn't like the looks of the pressure in his lungs (pulmonary hypertension). So then they thought they'd wait until Wednesday. Well, on Tuesday, he looked so good and stable that our surgeon, who was OFF that day, came in and performed the surgery at 5:00 p.m. They did his surgery right there in the NICU; they were afraid he might destabilize if they tried to move him. Just past 7:00, they came out to tell us it had been a success. The hole was small enough to repair without needing a patch. His small intestines, spleen, and part of his large intestines were in the chest cavity. Fortunately, his abdomen was large enough to hold all of them, so everything was repositioned, the hole was closed, and the healing could begin. But now the hard part would begin.

For days they worked on getting the respirator settings down. They were slowly allowing him to wake up enough to take some breaths, but worried because he was breathing at a fast rate. One day he tried to pull out his vent tube, so they tried to take him off the machine, but he wasn't quite ready. Two days later, they took him off the vent for good. They were a little worried about how his digestive system would process food through his stomach, as all of those organs were out of his body during the surgery. So they very slowly started to turn down the IV feeds and increase the feeding tube amount. They had to use a feeding tube, because they were afraid to feed him orally right away because his breathing

rate was so high, they feared he would aspirate. Finally, he was allowed to start bottle-feeding. I had been pumping and pumping, so he was started on my milk. He took to the bottle really well, and after a few days, we were allowed to start nursing. He was eating really well before long and gaining weight. As long as he continued to gain weight, we could finally think about going home.

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

Patrick is now a happy, healthy 10-month-old, weighing in at 25 pounds and 30 inches long. He loves cereal and baby food, and sleeps all through the night, from 8:00 p.m. to 7:00 a.m. He is a very pleasant baby to be around -- he's got a great laugh and a big smile. To see him now, you would never know that he had these problems. But to us, he will always be a miracle. We returned to Children's in May for another follow-up with the surgeon and his xray shows that his lung is already growing. We continue to hope and pray that he will have no long-term effects from his CDH.

I know it is the love and prayers of our family and friends, the skill and talent of the doctors at Children's that have caused Patrick to be with us today. I will never forget the support we received from so many different places. We are so blessed in so many ways.

Nancy Bryant (mother of Patrick Neil Bryant, 9/21/01, 45 Lobell Drive, Washington, PA 15301, rbryant@nb.net)

Where do I begin, considering it has only been 6 weeks since the passing of Aiden? Well, I guess I will start at the beginning. Austin and I have been married 2½ years and together for 6½ years. We have a beautiful little boy that just turned 2 in August. When Caleb was just a year Austin and I decided that we wanted to try again. Because I had the IUD, the doctor told us that once the IUD was out, we would more than likely get pregnant in the first 2 months. He was right. Exactly 2 months later, I found out as early as you could possibly know. I was only 4 weeks. It was so exciting. The pregnancy was going great. I had a small spell of morning sickness for the first 4 months. Considering the fact that when we were pregnant with our now 2 year old, I had quite a difficult time. I had Paracarditise of the heart (inflammation of the lining surrounding the heart) and acid reflux disease and he tried to come a little too early (32 weeks). This pregnancy was wonderful. I worked until I was 36 weeks. I had all the normal blood testing and ultrasounds.

I had my second ultrasound when I was 17½ weeks. My doctor had written down that he suspected that Aiden was "small." The ultrasound technician stated that everything was fine. Time just seemed to fly by. On June 27, 2003 I stopped working because it was just getting way too difficult to walk a lot, and Aiden had dropped quite a bit. When the time came closer and closer, I began having pains in my lower back and pelvic area. The doctor said I was fine and that it was "lightening." I had gone to the hospital when I was 37 weeks because that I thought I was having contractions 2-3 minutes apart and lasting 45-50 seconds and they were very consistent. When I got there they stopped. I was so frustrated. So they say that gravity helps labor so Austin and I would go walking every night for the next week. Nothing happened. I asked my doctor if I could get induced. He wanted to see the position of the baby so he did a small ultra sound on that Friday. I was 38 weeks. He told me that my amniotic fluid was a little low. The doctor said that he wanted to see me on Monday to check again. The weekend flew by. Monday was here and I went to the doctor. My doctor was worried. He thought that my fluid was measuring at only 5. He sent me to the hospital to get a better ultrasound. The technician there said that the baby was fine and that my amniotic fluid was at 11.2 and he hated me at an 8.

I never dilated except for a finger tip. So on July 21, 2003 at 10 p.m., I was induced. On the morning of July 22, the nurse began the PIT. By then I had dilated to 2 centimeters. As the morning went on, the pain grew strong and to the point that I couldn't handle it anymore so I asked for some medication through my IV. That helped me to relax. I took a nap. Then I remember the nurse coming in to check the monitor and seeing the look on her face. Please bear with me because everything from then on is somewhat of a blur. I do remember the doctor coming in and saying my blood pressure was up and so was the baby's. But two separate monitors where saying different. My doctor decided because I hadn't progressed, it would be good to just have a C-section. He said he didn't want to stress the baby anymore. I agreed. I called Austin because he was on his way to drop off Caleb and my sister at home, they were in visiting me earlier.

I remember a little in the OR. Austin and I were talking and waiting patiently. Finally Aiden was born at 2:45 p.m. Then my life stopped. They never showed me his face, you know, how they do it on TV, I remember looking over and seeing his little bum and the back of his head. I saw a lot of nurses. I asked if he was okay. I remember hearing someone say he is fine he just needs a little help breathing. Then I was brought into the recovery room. I was all alone for 30 minutes. No one told me anything. Austin, of course, was with Aiden. Then my doctor came and told me that Aiden would need more help that what our hospital could give him. So they were planning on transporting him by helicopter to Sacred Heart Children's Hospital in Spokane, WA. I requested to see him before they left. I don't remember much after they brought him to me until Austin received the phone call from the Neonatologist saying that we needed to get there ASAP due to the fact that Aiden was slipping away and he only had a 1% chance of living. I freaked out and screamed at the nurse to get the doctor in now I wanted to leave. The doctor came and said that he had made arrangements with Sacred Heart for us to stay there until I was ready to go home. The paramedics were in my room in 15 minutes. I put myself on the gurney and we were off. The ride was a blur due to all of the medication they were pumping into me. The next thing I remember is being in the hospital room and the nurse came in to tell me that I could go and see Aiden. They brought me into the NICU still in the bed. I sat by his side what felt like forever. I sang to him and told him that we loved him. He was so tiny. I learned from the NICU nurse that he was only 4 lbs, 6 oz. and 17½ inches long. The nurse also told me that the medication that they were giving him was keeping him alive until my mother-in-law arrived. The next thing I remember asking where my husband was. I felt so alone. I felt as if they were all starring at me wondering why my child was there and what did I do to cause this. Finally, my mother-in-law arrived. It felt like moments later. The doctor brought Aiden to our room. He turned off the machines. Once the doctor put Aiden into my arms, I knew that he was gone. I was an emotional wreck. Then all of a sudden, I felt something telling me that it was okay. I calmed down and played his elephant that his big brother had got him. "Now I lay me down to sleep, I pray the Lord my soul to keep, Angels watch me through the light, until I wake in the morning light. Amen." I then gave him to Austin to hold. He held Aiden for quite sometime. I felt so much pain for my husband. I had never seen him like this. He was just as an emotional wreck as I was. Austin then gave Aiden to my mother. Everything seemed like a big cloud for the next 24 hours. I was unconscious to the world. I had my heart torn apart. I am sure my husband had felt the same way. Then I was able to see Caleb. He brought a smile to our faces. Austin and I have said that if it weren't for him, we don't know where we would be today.

Later I had learned that my mother, mother-in-law, and two sister-in-laws went to a room with Aiden and held him. That made me feel good to know that they were able to know Aiden and to love him.

I don't remember if it was the next day that we learned that Aiden had passed due to Pulmonary Hypoplasia due to Diaphragmatic Hernia. I had no clue what this was. The doctor explained it to us. He also said that Aiden had a possible muscle disorder. This reason was because he was so small and that CDH children usually are not that small unless there is something else going on. Aiden lived for 12 hours and 25 minutes. He fought every moment he was here on Earth.

The staff at Sacred Heart were amazing. They are wonderful, compassionate people. I will never forget any of those that were there during this emotional roller coaster. After Aiden had passed, one of the NICU nurses came in and gave me a beautiful box. It had mementos of Aiden. The blanket he used, little pieces of hair, hand prints & foot prints, pictures, the little knitted hat that he wore, and a few other items.

I went home on Friday. We had a grave side service for him on Tuesday, July 27th. It was beautiful. We sent balloons into the sky. There was music played "Amazing Grace" with bag pipes in honor of Austin and my families. Austin's mother is Irish and my 2 siblings, my mother and I are Scottish.

It has been getting easier to live by the day. The nights for me are hard. Austin has had headaches since Aiden's passing. He mentioned to me the other night that they aren't as bad as what they have been.

On September 2, 2003 we learned that Aiden had no chromosomal disorders and that he had an Eventration Diaphragmatic Hernia, meaning that he had the outer wall to his diaphragm but no muscle. His liver, stomach and intestines had moved up into his chest cavity. We also learned that he had stopped growing 4-6 weeks prior to me giving birth. The reason is unknown. My placenta was "crap." They used large words that I have yet to understand. But, I have been looking into the medical terminology, so I will update the reasons for my placenta not working right later on. The neonatologist mentioned that he didn't understand why at the last ultrasound it wasn't noticed that he was very small. His head was the size of a 41 week gestation newborn but his body was that of a 32 week old baby.

We know that there will be questions never answered. And we know that Aiden is in heaven waiting on our arrival. I feel like he was here for a purpose. He brought our family closer together in more ways than anyone knows. He has created me a new path to walk down. If it wasn't for my precious little angel, I wouldn't be here telling the incredible journey he had. I wouldn't know about CDH and would never have learned of CHERUBS. I thank Jesus for giving me the honor to meet my son, even though it was only a short time.

Aiden – Mommy and Daddy love you and miss you very much. Your big brother Caleb will always be reminded of you as our other little Angel from heaven. Big Eskimo kisses and Bear hugs. XOXO

Lesla Plaisted (Mother of Aiden Plaisted, 7/22/03-7/23/03, 8966 B Tinker Loop, Moses Lake, WA 98837, 509-764-1896, austinplaisted@msn.com)



This afternoon, we had a perfect family moment – one of those times you hold onto throughout your life that remind you of how lucky you are to have such a great family. My husband was playing *Yellow Submarine* on the guitar while our 5-year-old son, Sam, danced and 9-month-old Ben, a CDH survivor, bounced cross-legged on the floor in tune to the music. I videotaped the scene with tears in my eyes, grateful beyond belief that Ben was here and healthy and totally fine!

Ben was born 4 weeks early on October 4, 2001, after about 17 hours of labor. We were able to hold him and pose for a family photo with his big brother before they took him to the NICU for a closer look because he wasn't crying and was having a little trouble breathing. Our older son, Sam, had been in the NICU, too; he was 5 weeks early and had trouble maintaining his body temperature, so we weren't too concerned. However, after an hour or so, the NICU doctor came up to tell us the bad news: Ben had a left-sided diaphragmatic hernia; his spleen and intestines were in his chest cavity; his left lung was compressed; and, his heart was pushed to the right. He was put on pain medication, a sedative and a ventilator right away, and would need surgery to repair the hole and put everything back in place.

We were stunned and surprised. My pregnancy had been relatively uneventful, although I had had some unexplained pain late in the pregnancy and had measured big consistently. I had two Level II ultrasounds (one only 4 weeks before he was born), an amniocentesis and nothing was ever found to be wrong.

When Ben was one-day-old, the doctors discovered he also had Persistent Pulmonary Hypertension, and another medication was added to the mix. We were not allowed to hold him, or even touch him; when we did – his blood pressure skyrocketed and his oxygen saturation level

went down. At 4 days, his hernia was repaired. The surgeon performed it laproscopically, since that would give Ben smaller scars and would also avoid having the doctor actually touch the small bowel, which could cause small bowel obstructions later in life. Ben was one of the youngest babies in the country to have this done laproscopically.

The surgery went well, but took a long time -- almost 4 hours! Afterwards, the surgeon told us that things had gone well, but that he had had to make a slightly larger incision at the end to get the spleen back in place. We went home that day relieved, sure that now that all of Ben's parts were back in the right places, he would recover quickly and come home to us. We were wrong. His saturation levels continued going down, and he was put on an oscillating ventilator. It was very upsetting to come in that day and see his little body vibrating on the warmer. Then they tried nitric oxide. That also didn't really help and we spent a very long night at the hospital waiting for the results of hourly blood gases.

When Ben was 6 days old, they told us that he might need ECMO because his saturations continued to be low, so he would need to be transferred to Children's National Medical Center, a children's hospital in Washington, D.C. We were devastated to think he might need to go on ECMO, which we had thought of as a last resort. We were also scared because the hospital was in D.C. and this was right after the terrorist attacks of September 11. But off Ben went in the ambulance. We met him there later and the NICU fellow told us Ben was "marginal."

Thank God for the doctors and nurses at Children's. They nurtured our family through our ordeal. The doctors answered all of our questions until we understood the answers (and we asked a lot of questions, over and over again). The nurses took great care of Ben, dressing his bed with cute baby blankets, making cards for us, and encouraging us to bring in pieces of home for Ben.

He did need to go on ECMO at 10 days old. The doctors told us Ben had a 50% to 60% chance of surviving – better than even odds, but not high enough to bring much comfort at the start.

For the first day or two, the doctors had trouble getting the cannulas in Ben's neck positioned correctly, and we worried that the treatment wasn't going to work. We sat at his bedside day after day, talking and singing to him and willing him to live. We made cassette tapes of ourselves reading stories with our older son and of our older son singing and talking, and the nurses played them next to his bed when we couldn't be there. Our older son, Sam, bought him Speckles the hippo, a special bed-friend to keep him from getting scared at night. I pumped breast-milk every 4 hours and froze it. I produced so much milk that the hospital told me to stop bringing it in; I had used up my allotted space in the deep freezer. So, I started storing it at friends' houses. I kept pumping, even though Ben couldn't yet drink the milk, as a sign of faith that one day soon he would use it.

We found it was essential to develop a good routine for going to the hospital *and* for coming home; our other son needed his parents too, and we needed time away from the hospital to help preserve our physical and emotional strength. We depended heavily on friends and family to watch Sam, to clean our house, to prepare us meals, and to give us moral support throughout our ordeal.

We cried a lot, and we comforted each other. My husband and I had different ways of coping with the worry and the stress and we found it was important to use whatever coping tools we could find. It was so hard to remain hopeful at times, but we knew we couldn't give up on Ben. Perhaps the hardest time we can remember was during a discussion with the hospital counselor about what might lie in store for Ben. We needed to know that the doctors wouldn't give up on Ben before he had every chance to recover and get well. The counselor assured us that they would keep working with Ben as long as we wanted them to, but she also told us to always try to keep in mind what would be best for Ben – that there might come a time when we wouldn't want to ask Ben to continue on. That was a scary thought, but also an enlightening one. It refocused our attention on our son and what was best for him and not just on how his predicament made us feel.

As Ben slowly made progress, they reduced the flow and then the saturation levels until, after 11 days, he was ready to come off ECMO. But the doctors warned us that progress would be fitful, and 5 days after coming off ECMO, Ben developed chylothorax – a leakage of fluid from the lymphatic system that gathered in his left chest cavity and collapsed his left lung. He had to have a chest tube put in to drain the fluid, so we still were not able to hold or feed him.

Finally, after 33 days, Ben's saturation levels were good enough that we could take him off the ventilator and move him to a CPAP – and we were able to hear him cry for the first time! When I called that night to check on him, the nurse held the phone up to his crib and said, "Do you hear him? That's your baby crying." Never, ever, has a baby's cry sounded so good! The next day, Ben's chest tube came out. I got to hold Ben for the first time since his birth and my husband got to hold him for the first time ever. From then on, we pretty much held him constantly when we were at the hospital. We tried feeding him with a bottle at 37 days, but his blood pressure skyrocketed and he had a lot of spit-ups, so we backed off. An upper GI and a renal ultrasound both showed nothing wrong, so we continued to hope and pray that he would continue improving.

At this point, we were pretty sure he would be okay, but we kept running into roadblocks that slowed down his homecoming. This was hard to bear; we kept getting our hopes up for a Christmas homecoming and then some other problem would crop up that would make reaching that goal uncertain. A week and a half later, we restarted Ben's feeds through an NG tube in his nose. It was slow going; he had a hard time digesting the breast milk, and after 3 hours, he still had a lot of residue in his stomach. Still, he was moved into a real crib from the warmer and that helped improve our spirits. At 47 days, he was taken off the nasal cannula and was able, finally, to breathe on his own! Two days later, it was Thanksgiving and Ben started really drinking his bottles – 9 cc's in 2 hours was a huge victory for Ben and for us – and he started smiling at us.

At a little over 7 weeks, Ben was moved back to Fairfax Hospital, where he was born, to continue learning to eat. A day later, he breastfed for the first time. Two weeks later, he came home.

Since coming home, Ben has had only one scary cold when we had to go to the doctor's in the middle of the night for Albuterol and oxygen. He has reflux, and is on Zantac and Reglan to help with that. I can tell that he really needs it, too, because when he gains too much weight for his dosage, he starts regurgitating a little and sounds very slushy. Because of some early delay in gross motor skills, a physical therapist had been visiting Ben once a month or so, but Ben long ago seemed to recover any ground he lost to those first few difficult months. At 11 months, Ben was dismissed from physical therapy because he had already reached his 13-month milestones.

A friend asked me recently if Ben is really fine. I was happy to tell him that yes, he really is fine! He is a normal little boy who giggles at his brother's antics and loves to be out and about. He has a huge smile that melts your heart; he tries to eat everything he finds on the floor, and tries to climb on everything. In other words, he's totally normal, except for his souvenir scars. And every time we see those scars on his chest and that long scar on his neck that marks him as a CDH survivor, it reminds us of how precious life is and how lucky we are to have this beautiful boy with us.

Patty Tuttle-Newby and Darek Newby (parents of Benjamin Liam Newby, 10/4/01, 3087 S. Abingdon Street, Arlington, VA 22206, 703-820-8802, ptuttlenewby@comcast.net)

When we found out we were pregnant with our third child we were happy. We tried a couple months before but got so busy with work we just didn't think about it until I got the positive test. We were so young when we had our first two. I wanted to read everything possible so that I would know everything. We had 2 ultrasounds, one at 10 weeks and one at about 22 weeks. My doctor said all looked good. The whole pregnancy was real good, I had no problems. Towards the end of my pregnancy, I was really freaking out about how big I was. My doctor assured me that I just didn't remember what it was like. My legs were sore a lot so they did a vein ultrasound but found nothing wrong. My due date was March 7, 2002. I was so big and uncomfortable and complained to my doctor A LOT! He said he could induce me at 6 a.m. on March 6, 2002. When I woke up that morning, I didn't want to go. I told myself to not be so lazy – just get ready! I did. My cervix was long and it took a lot to break the water. I was real uncomfortable with the whole thing – my other two children came when they were ready. Once they got the pitocin going, I got going. I was in labor for about 3 to 4 hours. Our baby boy (who we were told was a girl) was finally here. I was so exhausted and surprised about the boy part! My sister-in-law and mom and mom-in-law were with me (my husband can't stomach it!) when all of a sudden I realized something was wrong. Why wasn't my baby crying? Why didn't they bring him to me? I asked but got no answer. Before I knew it, there were about 7 people in there besides me and family. They were pumping air into my baby. They finally told me they had to take him for x-rays and they had to call St. Louis Children's Hospital. My husband said he would go. We were deciding on a name since we had a girls' name picked out. My husband said he was going to see what was going on. He came back like 2 seconds later and said they wouldn't let him in and a nurse came out crying. About an hour later, a doctor I recognized from earlier came in with the x-rays. He said our baby didn't make it and he began to tell us what was wrong. I couldn't comprehend what he was saying. Did he just tell me our baby died?!? Why did this happen?!? What happened?!? I really couldn't hear him with all that was going through my mind. Our baby had many problems that we weren't aware of: VSD – ventricular septal defect, CDH and hypoplastic left lung. When you can't prepare for something you feel lost. When this happened, I was so lost that I couldn't deal with it all. For 3 months I still had no clue what happened and why. I had to make myself get out all the paper work and start reading about it. Almost all the stories I've read, people knew what might happen, that something was wrong with their babies. Why couldn't this have been true for us? I know you can never really be prepared for death, but knowing would have helped. I hope no one ever has to go through this – without knowing before birth. I hope that very soon someone can figure out why this happens and can make it stop. We are pregnant again and I'm reading a lot more than I ever have about birth and congenital diseases and birth defects. I never thought my child would be born with anything wrong. I have felt so selfish and foolish. There is a lot more to our case that I can't mention now, but basically, this is our story. Thank You to CHERUBS!

Melissa Halterman (Mother of Zarek Ryan Halterman, 3/6/02- 3/6/02, 15765 Talon Lane, St. Robert, MO 65584, 573-336-7469, zarekzoom@hotmail.com)



I have been trying to write this for 2 years now. Every time I look at my son, Joshua, my heart just melts. This is the story of Joshua Liam Siddhattha Eck.

My OB knew that I had problems with my first two children being preemies, so they kept a close watch on me. I had ultrasounds every other week from 16 weeks on. At 31 weeks, I was put in hospital for pre-term labor and bleeding. I was there for 8 days until my water broke. The hospital I was at, was unable to care for preemies younger than 35 weeks, so I was sent to another hospital near by. It was then that they found the CDH. I knew something was wrong when the tech turned the screen so I couldn't see it. I kept asking what was wrong with my son, but she never answered. It wasn't until several hours later when 2 pediatric surgeons, the hospital social worker and a nurse came into my room with a tray. They told me I needed to have an amnio done because my baby had a CDH. I had no idea what that even was! After the amnio was done, the surgeons told me that my baby would most likely need to be on ECMO and they would have to send me to yet another hospital. I was taken to the University Of Michigan Medical Center, where I had Joshua on February 17, 2001. This move was so sudden, that my husband was not there for the birth of our third child. I didn't even have a chance to look at Joshua after he was born. They just rushed him out so fast! I did, however, hear him cry – something that they never expected him to do!! It was 4½ hours before I was allowed to see him. They told me to be prepared for the worst. I walked in the NICU to see my tiny 4 pound baby hooked up to tubes and wires and he had the ventilator tube that covered his whole face. I was shaking

so bad, that they had to help me sit down. I have never seen anything like that before! I just sat there for hours, waiting for something to happen. The doctors told me the first 48 hours were the most crucial and "not to get my hopes up to high." The next day, my husband Dave brought our two older children, Cameron and Madeline down to the hospital to see Joshy. Maddie wouldn't even look at him and Cam just wanted to know why Joshy was sick. We didn't have any answers for him. That night, we were checked into the Ronald McDonald house. The doctor called us at 3:45 that morning to tell us that Joshy had just crashed on full life support and we needed to get down there right away. I went in and the ECMO machine was next to his bassinet. They were about to put him on ECMO but for some reason, he had stabilized. I didn't leave his side for the next 10 hours. He was improving, slowly. He was 9 days old the day he had his first surgery. It seemed to take forever, although it was only 2 hours. He looked so different. His chest no longer made him look like a football player. He looked normal, with the exception of the swollen face and hands that he had. The next 9 days went by with no problems, so we decided to take a day trip home so the kids could play with their own toys and visit with close friends. The 10th day Joshua was removed from the ventilator! After looking at him for 19 days and only being able to touch his little feet, we got to hold him for the first time! I cried so many happy tears that day! The rest of his stay in the NICU was spent trying to teach him to eat. He didn't pick up on that right away. He never wanted to nurse, so I was pumping and we were feeding him by bottle and NG tube. We got to bring Joshua home on April 4! But our story does not end there. Two weeks after we came home, Joshua re-ruptured and needed emergency surgery. He spent a week back in Motts Children's Hospital. Everything seemed fine until the first week of June. He was acting funny and not eating without gagging. We went back to Ann Arbor only to find out he needed yet another surgery. His reflux was so bad, they decided to do a Nissen wrap and remove the pyloric stenosis. Two hours into his surgery, someone came out and told us that Joshy's insides were all fused together and had nothing but scar tissue and that's what was taking his so long. A few days after his surgery, we got some very bad news. Some how during the surgery, 6 inches of his small intestine had died and they had to remove it. By doing this, Joshy ended up with a very serious case of E. Coli. Then, more bad news. He had a fungal infection that had reached his left kidney and his heart. He was given the nasty anti-biotic Amphoterrison – or Ampho-terrible, as the nurses liked to call it. He was on that for 21 days. Joshua spent 2 months in the PICU because every time he got better, he ended up sick again. But finally once he was eating by mouth and by his feeding tube without gagging, we got to bring his home! He has had several hospital stays since then, but nothing like those 4 months! He is still using a nebulizer for his asthma and we found out that he has lung and heart disease. We are taking it one day at a time and every day I thank the stars that I am able to have him with us! Joshy just turned 2 and I can't believe how much he has changed! I just want to thank everyone at CHERUBS for the support and advice that I have received during these 2 years. Thank You so much! All my love, Cristie – A picture of my Joshy taken just a few weeks before his 2 birthday, is being sent along with this email. Thanks again!!!

Christie Eck (mother of Joshua Liam Siddhattha Eck, 2/17/01, 911 Farrand Street, Lansing, MI 48906, 517-485-7166, cristie_eck@yahoo.com)



When I was pregnant with Lisa I had gestational diabetes. It was an uncomfortable pregnancy and as the due date neared, I was getting nervous about the size of the baby. My first baby had been 4.44kg at birth and I knew the diabetes would probably make this one bigger. My endocrinologist predicted she would be "a 10 pounder".

Nothing had been picked up during my pregnancy besides the diabetes. I had an amniocentesis and a couple of ultrasounds because of a late miscarriage the year before.

Lisa was born after 2½ hours labour and no pain relief. She weighed 4.81kgs (10 lbs, 10 oz. in the old school). My doctor had obviously looked up the biggest baby born at the hospital because while she was being weighed, he said if she topped 5.1kgs she would be the biggest!

She was just beautiful and 2 hours later she was introduced to her big brother Lachlan.

When Lachlan was a baby he had severe oesophageal reflux. It had been a traumatic time for all of us until he was diagnosed at 5 months and I weaned him. Therefore, with Lisa I was particularly attentive to any potential feeding problems, so if need be I would address possible reflux as early as possible.

My milk came in on the second day and I was able to feed Lisa. Unlike Lachlan, she was a sleepy baby who wasn't particularly hungry. She took the feed well but immediately vomited. Fortunately, I knew the difference between a vomit and a posset. I nursed her upright watching for further signs of some reflux. Instead, she vomited again and again and by this time it was looking like bile. I called the nurse

who also noticed she was panting. She called the paediatrician who examined Lisa but couldn't find anything and suggested we wait a little while longer to see what happened. By this time we were into Lisa's third day and I knew something was wrong. The paediatrician examined her again and although he didn't hear anything, ordered an ultrasound of the chest. By this time she kept regurgitating and I was starting to feel ill as well. A short while later, the paediatrician came to see me and told me they found Lisa had a diaphragmatic hernia. Thinking along the lines of a hiatus hernia I didn't feel too worried! He must have thought I was remarkably calm!

The surgeon came a short time later to explain the hernia. He started by saying that if you were going to have a baby with a diaphragmatic hernia, ours was the baby to have. She was a "pink puffer." He even drew diagrams as he explained that Lisa's spleen, stomach and bowel had pushed up through the hernia collapsing her left lung. He believed it hadn't been picked up during the amnio or ultrasounds because the spleen had blocked it. He explained the surgery would take place that evening and they were waiting for an anaesthetist who would work on such a young baby.

Everything was almost surreal for me, as I did feel strangely calm. The only alarm I felt was when the nurses came in to take Lisa and suggested I wait until they prepared her before I came to the special care nursery to see her.

Lisa was born at the Wesley in Brisbane and was operated on at the Mater Mothers. They were superb. Every step was explained to us. We followed the ambulance and they had a special parking bay next to the ambulance for us. They walked us in and let me hold her little hand while she was wheeled down to the theatre. It was here we met the anaesthetist who explained why he wanted to narcotise Lisa rather than have her ventilated after the operation.

The hardest part was kissing her goodbye before she went into the theatre. The operation took longer than expected and a couple hours later the surgeon came out to see us. He explained that Lisa's diaphragm hadn't actually herniated but had eventrated instead. The effect was the same and the diaphragm would probably be affected but he was very pleased with the outcome. As we walked with our baby and the team back to intensive care, the anaesthetist explained he had been so pleased to see that Lisa's lungs, albeit the left was damaged, were the size of lungs one would see in a 6 week old. Ironically her weight and size – the only thing I had been worried about during my pregnancy – was to now be her saving grace!

Lisa stayed 3 days at the Mater. Because she was so heavily narcotised, we weren't allowed to touch her for the first 24 hours and I ached to hold her. I found out later that early the next morning after her operation, there were several groups of nursing and medical students, interns, etc., sent to see her, as she was a truly successful case!

Lisa came back to the Wesley and we stayed 2 more days before coming home. The surgeon told us to make sure we had a good paediatrician and to ensure that her heart was always checked during examination – but we didn't know why! We had a post op visit with him 3 weeks later and he was very pleased with her progress. He asked if we would mind letting him know now and then how she was. Most unusual for a surgeon!

Things went reasonably well for a couple of months until Lisa got her first cold.

She developed a very rattly chest and coughed like a heavy smoker. It was quite frightening and worrying as she struggled to cough up the mucus. At Christmas time, I took her to the Royal Children's one night as she struggled to breathe. They examined her and heard bowel sounds in the lower left lung. She was x-rayed and then had another cine swallow. By this time we had decided to change paediatricians and in the meantime, took the results of the tests back to the surgeon. The results were fine in that the diaphragm hadn't herniated and no further surgery was required. But her left lung was much smaller, her heart was pushed over towards the middle of the chest and her diaphragm although not paralysed, did not move in-sync, therefore was ineffective. It was important we had a good paediatrician to guide us through and monitor Lisa's progress.

Lisa had continuous colds and coughs for months. She was put on Ventolin and Intel as a preventor. These eased her breathing but as the winter months loomed she struggled. Eventually she was admitted to hospital struggling to breathe. Her O2 stats were below 90% and she was on continuous oxygen. She was also intravenously hydrated as Lisa refused to eat. Another irony was my fear she wouldn't breastfeed properly as Lisa prefers breastfeeding to ALL other nutrition. When she is ill, she flatly refuses to take other liquids or food, hence the IV.

We understand it will take time for Lisa's lung functioning to improve although her left lung may not grow anymore than it has. She is now a petite baby not yet 10kgs – another irony. But she is intelligent, feisty and cheeky. We are blessed to have her and her brother.

And the final irony? I have always called Lisa a little cherub so after we came home from hospital this last time, when I searched the net for information about diaphragmatic hernias and found CHERUBS. I knew we had found something really special!

Cheryl & Mark Warnock (parents of Lisa Warnock, 6/30/01, 66 Crosby Road, Albion 4010, Australia, 07 362 8608, cherylwk@optusnet.com.au)

Local Get-Togethers



Texas State Get-Together
April 26, 2003



Ohio State Get-Together
September 20, 2003

CHERUBS' New Fundraising Items

CHERUBS' has partnered with CafePress.com to offer our members hundreds of new fundraising items. Through CafePress, we are now offering clothing, hats, picture frames, bumper stickers, kitchen items, lunch boxes, carrying cases, clocks, and much, much more! You can purchase items with our logo or with individual logo characters that resemble your cherub. Because CafePress creates each item as it's ordered, CHERUBS' doesn't have to pay for any of the production – we get 100% of the profit without having to invest anything in these fundraising items!

To take a look at our many new items you can visit our web site at <http://www.cherubs-cdh.org/fundraisers/cafepress.html>



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

Tara Beck
Heidi Cadwell
Tim Canfield
Roni Evans
Tara Hall

Kathy Judd Jenkins
Patricia Jones
Trisha Joyner
Daphne Parker

Silvanus Slaughter
Robert Soderlund
Software Dimensions
Lesli A. Taylor, MD

Judi Toth
Dustin Warren
George Watkins
Jay Wilson, MD

Current CDH Research Studies

- Identifying Genes Which Cause CDH**
Massachusetts General Hospital, Boston, Massachusetts
Drs. Patricia Donahue and Lewis Holmes
Contact: Meaghan Russell, Clinical Coordinator, at (617) 726-0828
- Fryn's Syndrome**
University of California, San Francisco, California
Department of Pediatrics
Contact: Anne Slavotinek, (415) 514-1783
- Identifying Genes Which Cause CDH**
Emergen Labs, Salt Lake City, Utah
Contact: Mary Meade, MMeade@emergen.com
- Identifying Causes and Solutions of CDH**
CHERUBS, Oxford, North Carolina
Don't forget to send in updated forms and CDH Research Surveys!



