CHERUBS
P.O. Box 1150
Creedmoor, NC 27522
USA

CHERUBS

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

The Silver Lining

Spring 2000

Dear Members,

As usual, it is extremely busy here at CHERUBS. Our membership has reached over 550 parents and adult survivors, plus 100 more medical professionals and grandparents. We now have members in 18 countries and 49 states (still can't reach families in Nevada for some reason). We attended the Annual Pediatric Surgical Association's conference, our first International Member Conference went really well, some of our members got together in Charlottesville, VA and we are tentatively planning an informal get-together for parents of non-survivors. More local get-togethers will be coming up as our Representatives plan them. We still need Representatives for some states and countries and translators for many languages. If you would like to volunteer, please let us know.

We are also busy applying for grants, working on getting our CDH Survey Results published, representing CDH families at more medical conferences, putting together our holiday fundraiser, and are looking into lobbying for such causes as national mandatory certification of all ultrasound technicians and mandatory referrals to support groups for better "whole family patient care".

I hope you all have safe summers.

Dawn M. Torrence, President and Founder

Non-Survivor Get-Together

Our member conference went really well, but we had a very low turn out of families of non-survivors. It is often hard for grieving parents to come face-to-face with cherubs and other children, even though we are extremely happy that our families of survivors have been so blessed.

We are tentatively planning an informal weekend get-together for our grieving members in Virginia for October of this year. It will not be a sponsored event, just a get-together of friends that can meet face-to-face and talk about their cherubs and how they are coping with grief. There will be no speakers or lecturers, no fee to attend, and parents will need to cover their own expenses. This will be a grieving parents-only get-together. To try to make this as comfortable as possible for everyone, including the newly grieving parents who aren't ready to be around other children, and because we don't have time to find babysitters, we won't be including siblings.

We have our International Conference for all members and children that seems to work well for families of survivors and state get-togethers for local families, but a lot of our grieving parents would not feel comfortable attending, as much as they would like to meet parents of survivors that they have become close friends with. This is by no way meant to divide our membership. It is meant to be an additional informal meeting, as our International Conference will always be THE conference for all members.

The planning is still under way and the exact date and location have not been decided. We are trying to get a "feel" if this something that our grieving parents would be interested in and benefit from. If you are a parent of a CDH non-survivor and would like to attend, please contact Dawn.

Calling All Survivors Ages 13 And Over!

For our next issue we would like to include an article about our "older" survivors, from 13-years-old and up. We want to include pictures and stories not only from the parents' perspectives, but the kids also (what they remember; how they deal with lasting medical problems, if any; what they think about their scars; etc.). Parents' stories are not required to participate (permission if you're under 18 is!). Your stories will give hope to a lot of families out there!

New Friends

(1) Colette Hartigan, Dawn Torrence, Judi Toth, and Jeremy Torrence (2) Hollie Fremeau, Matthew Cheffer, & Patti Cheffer (3) Lisa Nagurski, Jeremy Torrence, Naomi Nagurski, & Ben Nagurski (5) Elaine Moats & Judi Toth (6) Rene' Fields & Barb Wagner (7) Onno Zwart, Judi Toth, and Colette Hartigan (8) Colette Hartigan & Matthew Cheffer (9) Heidi Cadwell & Judi Toth (10) Tara Hall & Sherry Macormic (11) Lisa Doll, Steve Pagano, Elaine Moats, Brenda Pagano, & Lynne Hedrick (12) Brandon Hall, Tara Hall, Jeff Hall, Jessica Wilon, Carol Sprang, & Lisa Doll (13) Jessica Wilson & Lisa Doll

The Kids (can you tell the cherubs from the siblings?)

From left to right, top to bottom: (1) Brittannie Hedrick, Matthew Cheffer, & Rebecca Wilson (2) Tyler Grubb & Logan Wagner (3) Ben & Naomi Nagurski (4) Haley McGill (5) Natalie and Mark LaJoie (6) Jeff Hall, Kerry Hedrick, & Brandon Hall (7) Shane Wagner (8) Chris Hastings (9) Kerry, Lynne, Danny, Meghan, and Brittannie Hedrick (10) Brittany Moats (11) Kristin Moats (12) Kerry Hedrick (13) Matthew Cheffer & Chris Hastings (14) Matthew Cheffer (15) Erica Bunch

New Arrivals

(*siblings of Cherubs)

Bailey, Alice Quinn*
Blackwood, Olivia Kelly
Bracken, Jarod Carter*
Buckeye, Grace Antonia
Callow, Brandon E.
Casadecalvo, Callie Jane
DiMaria, Sydney Lynn
Doades, Nicholas Robert
Eisele-Elizondo, Reese Gabrielle
Forman, Candis Nakole
Fraissinet, Natalie Mary
Halbeisen, Saydie
Hudson, Samantha Marie
Hutto, Belle Kathleen
Martin, Joshua Dylan
Mitchell, Adam Cole
Mozingo, Hunter Cole
Niebrugge, Brighton James
Panetta, Jonathan Nicholas
Price, Zackary James*
Pulse, Cole Robert
Rapisarda, Christian G.
Sheldon, Nolan Stanton William
Tackett, Hunter Dylan
Taylor, Mersayd Margaret
Thomas, Luke Joseph
Thompson, Payton Jay
Whittle, Rachael D.
Zalis, Caroline Joyce

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This Newsletter Is Dedicated To the Memories of:

Casadecalvo, Callie Jane
Cowling, Christopher Cade
Eisele-Elizondo, Reese Gabrielle
Forman, Candis Nakole
Fraissinet, Natalie Mary
Hutto, Belle Kathleen
Martin, Joshua Dylan
Mozingo, Hunter Cole
Niebrugge, Brighton James
Pulse, Cole Robert
Quast, McKenna Faith
Rapisarda, Christian G.
Sheldon, Nolan Stanton William
Taylor, Mersayd Margaret

CHERUBS is an international organization for families and care-givers of children and adults who are diagnosed with Congenital Diaphragmatic Hernias (CDH). We are a volunteer organization an Internal Revenue Service recognized Non-Profit Association. Donations are very welcomed and tax-deductible. Checks can be made out to CHERUBS. The opinions shared in this newsletter do not necessarily represent the opinions of all members or staff. The information in this newsletter is by no means to be substituted for proper medical advice. Remember, every child is different. You can't compare the progress of another CDH child to the progress of your own child. They are all little angels.....CHERUBS

Contacting CHERUBS

P.O. Box 1150
Creedmoor, NC 27522
USA
919.693.8158
888.834.8158 (toll-free)
707.924.1114 (fax)

www.cherubs-cdh.org
dawntorrence@cherubs-cdh.org
info@cherubs-cdh.org
membership@cherubs-cdh.org
volunteer@cherubs-cdh.org
donations@cherubs-cdh.org

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

Augustson, Jack
Bindy, Baby
Blackwood, Olivia Kelly
Blumberg, Nathaniel J.
Buckeye, Grace Antonia
Callow, Brandon E.
Cowling, Christopher Cade
Coy, Lisa
Crawford, Angelia D.
DiMaria, Sydney Lynn
Eisele-Elizondo, Reese Gabrielle
Fields, Bethany Nicole
Fremeau, Michael B.
Hutto, Belle Kathleen
Jones, Sara R.
Jones, Gwyneth Anne
Jones, Brianna Faith
Koehler, Benjamin Aaron
LaJoie, Natalie Erin
Martin, Joshua Dylan
Mitchell, Adam Cole
Moschilla, Anthony
Niebrugge, Brighton James
Oakley, Claire Terese
Panetta, Jonathan
Perez, Matthew Michael
Pulse, Cole Robert
Quast, McKenna Faith
Rapisarda, Christian G.
Riley, Kevin
Sheldon, Nolan Stanton William
Snow, Richard Carl
Solomon Cowan, Finn
Tackett, Hunter Dylan
Taylor, Mersayd Margaret
Thomas, Luke Joseph
Thompson, Payton Jay
Vanesko, Anthony John
Vleugels, Fredrick
Walton, Eva Louise
Watson, Kyanni Renea
Weldon, Allison Brooke
Whittle, Rachael D.
Wiik, Eirik
Yi, Bryttni H.
Zalis, Caroline Joyce

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

(*Conference Help)

Mary Avery
Black Angus Restaurant*
Patty Bornick, RN*
Judy Bunch*
Heidi Cadwell*
Jeannette Davis
Econo Lodge Maingate, Kissimmee*
Paula Giammanco*
Jim and Susan Grubb*
Jeff and Tara Hall*
David Kays, MD*
Danielle Kessner
Annette Lichtenstein
Mark and Jeffie LaJoie*
Keith and Sherry Macormic*
Kati McGill
Chris Muratore, MD*
Elaine Moats*
Lisa Nagurski*
Ruben Quintero, MD*
Kathleen Rogula *
Elaine Smith*
Carol Sprang*
Jeremy Torrence*
Judi Toth*
Kevin, Barbara, and Shane Wagner*
Jay Wilson, MD*
Walt Disney World*
Onno Zwart*

Some Of Our Attending Members

From left to right, top to bottom: (1) Hollie, Mike ,and Michael Fremeau (2) Sherry and Keith Macormic (3) Tara, Brandon, and Jeff Hall (4) Patti and Matthew Cheffer (5) Barb, Logan, and Shane Wagner (6) Elaine and Kristin Moats (7) Theresa and Chris Hastings (8) Dawn and Jeremy Torrence (9) Jim, Tyler, and Susie Grubb (10) Judi Toth (11) Erica, Judy, and Ian Bunch (12) Jessica and Rebecca Wilson (13) Heidi Cadwell (14) Colette Hartigan (15) Onno Zwart (16) Jeffie and Natalie LaJoie (17) Danny and John Hedrick

Our Meetings

From left to right, top to bottom: (1) Elaine Moats, Lisa Nagurski, Lisa Doll, Tara Hall, Colette Hartigan, Susie Grubb, Lynne Hedrick, Brenda Pagano, Steve Pagano, Theresa Hastings, Judy Bunch, Mark LaJoie, Barb Wagner, Kevin Wagner, & Shane Wagner (2) Lisa Nagurski, Jeremy Torrence, Naomi Nagurski, and Ben Nagurski (3) Theresa Hastings, Chris Hastings, Lynne Hedrick, Jeffie LaJoie, John Hedrick, Danny Hedrick, Dr. David Kays, Sherry Macormic, and Dr. Jay Wilson (4) Dr. Jay Wilson, Dr. Chris Muratore, Dr. David Kays and guest, Lisa Doll, and Rene' Fields. (5) Tanina Cadwell, Heidi Cadwell, & Dr. Jay Wilson (6) Carol Sprang, Brandon Hall, Jeffie LaJoie, Natalie LaJoie, Chris Hastings, Tara Hall, Mark LaJoie, Theresa Hastings, Judy Bunch, & Ian Bunch (7) Judy Toth, Patty Barnick, and Dr. Ruben Quintero (8) Meghan Hedrick, Lynne Hedrick, Susan Knittel, Danny Hedrick, Rebecca Wilson, Jessica Wilson, Judy Toth, Onno Zwart, & Hollie Fremeau

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

Atwood, Andrea in honor of her daughter, Caitlin Kraft
Ball, Iris M.- in memory of her granddaughter, Aileen Iris Adame
Bray, Joy- in memory of her daughter, Kalley Madison Bray
Breen, Kathleen- in honor of her daughter, Caitlin Breen
Bunch, Judy- in honor of her son, Ian Bunch
Burns, Laura - in honor of her daughter Megan Hope Burns
Cadwell, Heidi- in memory of her grandfather, Peter Van De Carr
Callahan, Anne and Ed- in memory of Bridget Hope Jussaume
Callahan, Colin- in memory of Bridget Hope Jussaume
Callahan, Eddie and Cathy- in memory of Bridget Hope Jussaume
Callahan, Mike and Mary- in memory of Bridget Hope Jussaume
Callanan, David and Barbara- in memory of Bridget Hope Jussaume
Childress, Michele and Larry- in memory of their daughter, Kayla Mae Michele Childress, and all of the precious cherubs in heaven
Connelly, Patrick Lee & Theresa - in honor of their son, Michael Patrick Lee
Cox, Diana- in honor of her son, Dallas Cox
Davison Avenue School Employees- in memory of Natalie Mary Fraissinet
Edson, Clifford and Lynn- in memory of Natalie Mary Fraissinet
Feeney, Edward and Harriet- in memory of Natalie Mary Fraissinet
Foley, Joanne and Brian- in memory of Bridget Hope Jussaume
Fraissinet, Robert and Hannah- in memory of Natalie Mary Fraissinet
Golding, Charlene Flynn- in honor of her daughter, Millicent Golding
Guariano, Joe and Susan- in honor of her daughter, Marissa Guariano
Guess, Jon and Lynn- in memory of Natalie Mary Fraissinet
Hall, Tara- in honor of her son, Brandon Hall
Harrison, Dr. Michael R.
Hoemke, R. Patricia- in memory of her great-grandson, Cade Andrew Turner
Kayser,, John and Sarah- in memory of their daughter, Madeline Jane Kayser
Kelley, Donna- in memory of Harold Lichtenstein
Kokinda, Michele and Kevin- in memory of their daughter, Michaela Anne Kokinda
Lamkin, Gail- in memory of her daughter, Sara Hope Lamkin
Langer, Dr. Jacob
Lichtenstein, Annette- in honor of her son, Ivan Lichtenstein
Macormic, Sherry
Mahr, Shelley- in memory of Natalie Mary Fraissinet
Mailman, Randy and Ann Marie- in memory of Natalie Mary Fraissinet
Massie, Wayne and Grace- in honor of their son, Blake Massie
Midwest Pediatric Surgical Associates
Patel, Mita- in honor of her daughter, Payal Patel
Preceptor Epsilon Alpha
Pruitt, Pamela- in honor of her daughter, Allison Lane Pruitt
Reid, Pat, Cindy, Annie, & Jacob- in memory of Connor McLuckie
RFX, Inc.- in memory of Natalie Mary Fraissinet
Rodriquez, Jaime M.- in memory of his niece, Aileen Iris Adame Scarola, Anna- in memory of Gabriel Scarola
Schoenthaler, Rob and Lauren- in honor of Callahan Patrick Growney
Serra, Earon - in honor of her daughter, Maresa Serra
Shockro, Jennifer- in memory of Natalie Mary Fraissinet Snow Catherine- in honor of her son, Richard Carl Snow
Stevens, Bob and Jennifer- in memory of their son, Hunter Jeffrey Stevens

Stronach, Nancy and Jim- in memory of Bridget Hope Jussaume
Swindell, Terry and Wanda- in honor of Connor McLuckie
The Milbrook Press Employees- in memory of Ana Katherine LaPalme
Torrence, Jeremy and Dawn- in memory of John Terriault
Torrence, Jeremy and Dawn- in memory of their son, Shane Torrence
Toth, Judi- in memory of her son, Christopher Michael Toth
Vigo, Denise- in memory of her daughter, Alexis Vigo
Wagner, Barb- in honor of her son, Logan Lee Wagner
Watson, Dianne- in honor of her daughter, Cameron Dianne Watson
White-Perez, Kimberly A.- in honor of her son, Matthew Michael Perez
Wilson, Jessica- in honor of her son, Noah Brandon Wilson
Woessner, Dorothea- in memory of Natalie Mary Fraissinet
Zalis, Tony and Sharon - in honor of their daughter, Caroline Joyce Zalis

Cooking With CHERUBS Volume 2

We are putting together a 2nd cookbook as this year's holiday fundraiser. We need recipes and volunteers to type and/or sell! If you would like to contribute recipes (by e-mail is easier for our typists) or volunteer, please contact Elaine (bmoats@midrivers.com) or Judi (AuntiAgi@aol.com):

Judi Toth
2859 Madeira Court
Lake Ridge, VA 22192-1942

Deadline is July 31st!

Elaine Moats
2118 Batchelor Street
Miles City, MT 59301

Brenda's Corner

"Do We Have A Sixth Sense?" by Brenda Slavin

As I (finally) finished watching the movie "The Sixth Sense", I realized some of us may have our own sort of sixth sense about relating to the children, parents, relatives, and friends we have lost. I do believe that there are a lot of signs out there if we pay close attention to them. I would like to share some of Bob and my experiences with you. The night before our daughter Amanda's funeral, Bob had a dream that he was holding her and talking with her. She said to him "Come on Daddy we don't want tion he realized it was to her funeral. She didn't seem sad. Instead more like in a hurry to get to a birthday party. In her eyes it was a celebration in ours it was pure sorrow. Around a month later when the shock began to wear off, I went into a deep depression. I missed her so badly. Bob & I kissed goodbye one morning and as we kissed I could smell her scent in between us. It was such an awesome moment. My spirit no longer felt heavy and I began the long journey into my grieving process. I certainly don't know exactly what happens to a person once they die, but I do believe that they want us so badly to know that they are OK. They know how much we miss them and how painful it is without them. When our son Nicholas was born a year later there was no doubt from anyone in the delivery room that Amanda was there. She waited while we said hello and then a very sad goodbye to Nicholas before she held her baby brothers hand and they crossed over together. The most ironic thing with my two babies is they were born exactly 2 years apart on the same day both spontaneous vaginal deliveries. I still talk to them, and although I don't get a vocal response back I feel my soul has received their messages. We now have a 2 1/2 year old son Stephen. We have pictures of Amanda and Nicholas on the wall to our stairway. He has asked us who they are and we told him his brother and sister. One night on his way up to take a bath, he stopped at Amanda's picture. I said "Who is that Stephen" He turned to me and sai
know what an angel is!!! Another sign? I think so. I think on many nights Amanda & Nicholas come to Stephen in his dreams so the three of them can play together. Our sixth sense is the doorway of our soul receiving a message. A loving, warm message that is very important in comforting us through our pain and sorrow.

Maybe I'll get another message in this lifetime and maybe I won't. But I have three to hold onto that will ALWAYS bring a smile to my face and will touch me from the depths of my soul forever.....

Elaine Moats, Sherry Macormic, Jeremy Torrence, Dawn Torrence, Onno Zwart, Lisa Doll, Jeff Hall, Susie Grubb, Tara Hall, Jessica Wilson, Brandon Hall, Judi Toth, and Barb Wagner

Judi Toth, Susie Grubb, Tara & Brandon Hall, Natalie, Mark, & Jeffie LaJoie, Carol Sprang, Jessica Wilson, & Lisa Doll

Some of our members talking to guest speakers Drs. Jay Wilson, David Kays, and Chris Muratore

CHERUBS 2000 Annual Member Conference

Our first international member conference was full of education, friendship, and fun! After a few hitches in the planning, and thanks to 2 extremely generous sponsors, members came from as far as Ireland and Holland to attend. It was such a pleasure to meet friends made over the internet and telephone, to see our cherubs, and just get together with people who actually understand what it is like to be a CDH parent.

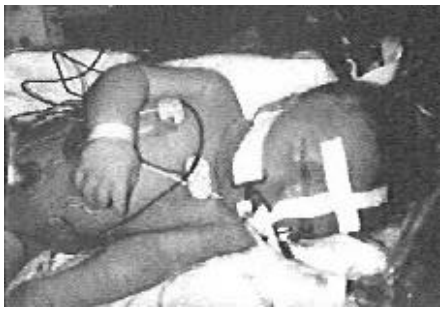
Our wonderful guest speakers taught us more than the basics on CDH treatments. They answered questions, updated us on the latest research, and showed us the personal side of the medical profession, which is sometimes hard for us to see when our own worlds are falling apart. We sincerely thank Jay Wilson and Chris Muratore from Boston Children's Hospital, David Kays from Shands in Gainesville, and Ruben Quintero and Patty Bornick from the Fetal Treatment Program in Panama, Florida for their excellent and educational speeches. They all did wonderful with the speeches and the families. Copies of their research articles and literature are available (contact us).

We would also like to thank our other volunteers- listed in our "Thank You" column. Thank you to our terrific discussion leaders for leading round discussions on such important topics as feeding issues, grief, and much more. And a huge thank you to our babysitting volunteers, who kept the kids happy and occupied and allowed the parents to attend the speeches and discussions. Our families were able to open up and discuss their hopes and worries, ask questions or other members, and talk about subjects that only other CDH parents can relate to.

We all took to each other right away- even the littlest children seemed to realize that they all had a common bond. It wasn't all just meetings- we had a lot of fun after hours too visiting the local attractions, hitting the pool, and getting to know each other.

All in all, it went great! No one ended up in the E.R., no one got so lost as to end up in the wrong state (we had some directional problems), all of our speakers and discussion leaders made it, 24 families attended, and despite the smoke and ashes from the nearby forest fire (just our luck!), everything went well. We laughed. We cried. We learned a lot. We had fun. We all hopefully left with a little more knowledge and a lot of new friends. Hope to see all of our members next year (location not yet decided)!

Some of our attending families. Unfortunately our group pictures didn't come out too well and we had a hard time gathering everyone together. Now that we some experience under our belt, we can better plan next year's pictures. For many more pictures of this year's conference, you can visit the Silver Lining section of our web site.



In Memory of Johnathan Robert Martin
written by his "Granny Jo"

My Sweet Cherub Baby,
Child of My Child,
God's Precious Gift
I Held For Awhile.

There Were So Many Dreams
I Had Wrapped Up In You,
And It's hard To Accept
They Won't Ever Come True.

Forever I'll Miss
Your Curious Eyes,
The Cuddly Baby,
Your Silent Cries.

There Will Never Be
A Goofy Child,
Sticky Kisses, Or
Watching You Grow Up.

I Never Will See
This World Through Your Eyes,
The Laughter, The Wonder,
The Magical Times.

My Beautiful Boy
I Wish You Were Still Here
To Hold You, and Kiss You,
And Keep You Near.

Oh, My Brave Baby
I Tried to Understand
Why You Suffered So Much!
What Was God's Plan?

So Many People,
Prayed that You'd Live.
So, I Believe that God Knew
You Had The Strength To Give
Your Short Life Here On Earth
To Unite People In Prayer,
So They Could Discover That
God's Eternity Is Theirs.

For, I Know, My Cherub Baby,
Your Soul Now is Free -
There'll Be No More Respirators No
More Surgeries.

Now, You Can Dance
All Over Heaven,
Ride Upon Rainbows,
Swim In Blue Oceans,

Sail On Moonbeams,
Climb On God's Trees,
Laugh With The Angels,
And Sit On God's Knee.

Love Your Great Grandpas,
Your Great Grandmas too;
And, Kiss Grandpa R -
He Left Us Too Soon.

Find Your Great Uncle -
Your Baby Cousin too,
For, They'll Want to Play
Around Heaven With You.

Pray Every Day For Your
Mommy and Daddy - Sister and
Brother - Aunts and Uncles,
Plus All of your Cousins.

And, Don't Forget to Pray
For Your Nana and Pappaw,
Grampa David and also
For Me - Granny Jo.

And, I will Cherish
Each Day That God Gives
To Me, And Try Not
To Wish My Life Here Away.

I will Pray Every Day
To My Savior and Friend,
Until Someday, My Sweet Johnathan,
I'll See you Again.

Until then, My Cherub Baby,
Run, Laugh, and Play
And Give God A Kiss
At the End of Your Day.

CHERUBS State and International Representatives

Our members are encouraged to contact our Representatives. For your Representative's email 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; Ireland, Belgium, Northern Ireland, Papau New Guinea, Spain, The Netherlands, Chile, Israel, India, and Hong Kong. If your state or country does not have a representative (or even if they already do), please consider volunteering. You do not have to be on-line to be a Representative. If you are interested, please contact our Volunteer Coordinator, Barb, (810-249-5279 or Purphaze19@aol.com) for more details.

AREA	REPRESENTATIVE	PHONE#	AREA	REPRESENTATIVE	PHONE#
AL	Earon Serra	334) 824-1590	ND*	Elaine Moats	406) 232-503
AK	Danny & Carol Crow	907) 694-7951	OH	Tara Hall	514) 777-490
AR*	Barb Wagner	810) 249-5279		Dawn Halley	514) 279-830
CA	Jill Coon	530) 582-1261		Kathleen Dunn	514) 841-985
	Shirley DeMercurio	925) 439-8382	OR*	Heidi Forney	208) 584-370
CO	Amanda Owen	970) 246-3337	PA	Tammy Sincavage	510) 796-732
CT	Laura Webster	203) 284-2199		Brenda L. Eaken	510) 916-702
DE	Susan Guariano	302) 731-1922	SC	Vanessa Hutchinson	343) 770-010
FL	Ray Donahue	407) 636-5937		Susan Grubb	364) 877-144
	Tammy Warr	850) 235-9004	SD*	Elaine Moats	406) 232-503
GA	Dodie Dickerson	770) 461-8874	TN	Leigh Cheney	515) 907-130
	Annette Lichtenstein	404) 325-2368	TX	Tari Jacobs	972) 491-027
HI	Stacy Dinay Everett	808) 244-7444	UT	Tova Heaton	301) 282-607
ID	Heidi Forney	208) 584-3708	VA	Elizabeth Doyle	304) 293-460
IN	Lea Donahue	219) 289-5746	WA	Heidi Forney	208) 584-370
KS	Dawn McVey	316) 664-6055	WV	Sharon Munson	304) 947-716
KY*	Leigh Cheney	615) 907-1301	WI	Karen Nuthals	508) 845-316
LA	Christi Andrus	318) 856-2890	WY*	Elaine Moats	406) 232-503
	Sheila Ezernack	318) 645-9361	Australia	Danielle Kessner	03) 9437 677
ME	Teri Morse	207) 538-4049	Canada	Karen Jenkins	905) 852-941
MD	Brenda Slavin	410) 923-1032		Dawna Haines	905) 852-425
MA	Heidi Cadwell	603) 878-2283		Laurelle Lehmann	250) 838-225
MI	Barb Wagner	810) 249-5279	England	Kevin & Brenda Lane	01553 762884
MO*	Barb Wagner	810) 249-5279		Karen Longman	1628 67364
MT	Elaine Moats	406) 232-5038	New Zealan	Christine Taylor	04 9020670
NV*	Heidi Forney	208) 584-3708		Lisa Harris	54 09 533 831
NH	Heidi Cadwell	603) 878-2283	Germany	Renata Hoskins	8123/990229
NJ	Sophia Tucker	908) 684-8701	Norway	Victoria Serkland	47-359-41284
	Lynne Rogers	973) 316-0304	Scotland	Karen Longman	1628 67364
NM	Lisa Nagurski	505) 268-1268			

On-Call Volunteers for Non-Survivors

On-Call Volunteer	Phone Number
Danielle Kessner (Australia)	(03) 9437 6778
Laurelle Lehmann (Canada)	(250) 838-2250
Amy Rademaker	(616) 844-4156
Kate Rogula	(313) 565-8722
Jennifer Wasik	(602) 962-8251
Monica Young	(308) 995-8903

On-Call Volunteers for Survivors

On-Call Volunteer	Phone Number
Ann-Marie Peterson	(509) 735-7208
Jill Coon	(530) 582-1261
Peggy Rhodes	(912) 467-2780
Debbie Mourtsen	(520) 526-7976
Elaine Moats	(406) 232-5038
Tara Hall	(614) 777-4906
Heidi Forney	(208) 584-3708

Charlottesville, VA Get-Together

Some of our members got together informally in April. You can see from the pictures how much fun they had!

Elizabeth Doyle, Brandon Hall, Tara Hall, Judi Toth, Adrienne Dumas, and Jenn Dumas

Adrienne Dumas and Brandon Hall

Brian Propst, Brandon Hall, Tara Hall, and Elizabeth Doyle

I was 14 weeks pregnant when we found out that the baby I was carrying had CDH. It was found by coincidence during an ultrasound scan, which was carried out to check the placenta as I had had some bleeding. The doctor was really upset when she told me the news but I don't think the full impact of what was happening hit me until I went home and looked up CDH on the Internet, found CHERUBS and realised just how serious this was. Our baby had a 50% chance of survival and was in for a very traumatic start to life.

Claude and I decided to try and stay focused and positive during the pregnancy for our own sakes and also for the baby. The amniocentesis showed there were no chromosomal abnormalities and also that we were having a boy. He became known to us as Harlee and I felt very close and protective of him throughout the pregnancy and in many ways didn't want the pregnancy to end as I knew he was safe and well as long as he stayed inside me.

There was nothing that could really be done for Harlee whilst I was pregnant. I looked into in utero surgery but we decided the risks involved were too great for us to take. We were told it was really a matter of "wait and see" once Harlee was born. I did have a course of steroid injections which were to help the lung growth and many, many ultrasounds, including link ups to other hospitals.

Harlee was born in Townsville on 1st November, 1999. A big boy at 8lb. I was induced because my waters broke the previous day and 5 hours later Harlee was born. I never got to hold him and only saw glimpses of him as the doctors proceeded to bag him and put tubes into him. Harlee was whisked off to Intensive Care and I was whisked off to theatre as I had post partum haemorrhaging and needed to have the placenta manually removed.

I saw Harlee two hours later, connected to machines and monitors and looking very small and fragile. In some ways we were prepared for this as we had been taken through Intensive Care when I was pregnant so that we could see what to expect when our baby was there. Although that was helpful I don't think anything can really prepare you for seeing your own child surrounded by machines, paralysed by drugs and being so sick and helpless and not being able to do anything at all to help or protect him. Harlee was operated on when he was 5 days old. The operation lasted 2 hours and he did very well considering the extent of the defect. He had a left sided CDH with no diaphragm at all on that side. The stomach, intestines and liver were up in the chest cavity and there was no lung growth on the left hand side, just a bud.

Harlee was on full ventilation as well as nitric oxide and steroids. He was sedated and given muscle relaxants so that he wouldn't fight the ventilation. Harlee was in hospital for 45 days. His recovery was complicated by two serious bouts of infection but once he was breathing on his own and breast feeding his improvement was dramatic.

We spent every day in hospital with him, talking to him, reading, singing and massaging him. We wanted him to know that we were there for him and that he was safe and loved. The hospital staff were all wonderful, very supportive and understanding. He came home the week before Christmas, which was the best Christmas present we could ever have hoped for.

He is now a happy, healthy little boy, 6 months old with two bottom teeth and is nearly crawling! He has no ongoing problems or health concerns at all and the latest X-ray shows signs of lung growth on the left had side with very good oxygen sounds on that side meaning it is also functioning lung.

Knowing about the CDH in advance meant that the doctors were prepared at the birth and also meant we could prepare ourselves mentally but it also deprived us of the joy and anticipation that most expectant couples experience. Staying positive and focused during the pregnancy really helped us get through as well as the wonderful support of close friends and also members of CHERUBS. In many ways Harlee has taught us so much about living in the present and enjoying each day we have and never taking each other for granted.

Judy Scherrenberg (mother of Harlee James Scherrenberg Timms, 1/1/99, 77 The Esplanade, Townsville, QLD 4810, Australia, 07-4774 1535, beach_shack@iprimus.com.au)

Letters To CHERUBS

I really enjoyed the information that you sent me because it showed us that we aren't alone in the way we feel because of our terrible loss. It also showed me that what I did to help my precious Aileen in her passing were the right things (although I already knew it because I was doing what my heart told me was right) such as holding her tight, kissing her, saying sweet things to her, telling her how loved she is, singing to her and reassuring to her that it was ok to go because she needed to rest, to end her suffering. Even to this day we feel her terrible loss, she was here with us for only four weeks, but they were very special for all of us. We were very hopeful as all the relatives of all the cherubs are and we found it very difficult to accept the truth. Thank you for sending my daughter names and addresses of other grieving mothers because this makes her aware that she is not alone.

God bless you,
Iris M. Ball (grandmother of Aileen Adame, 8/18/99- 9/15/99)

I was watching TV tonight and I caught the end of ABC news special. I wanted to read the transcript about children born with CDH because my fourth child, Christian Matthew was born on April 8, 1996, with this condition he only lived 4 days. He passed away April 11, 1996.

He was born at Columbia Presbyterian hospital. We knew from the 16th week he had this problem. My uncle, John Rowe, is president of Mt. Sinai hospital in New York and put me in touch with Dr. Richard Berkowitz who performed an ultrasound examination of me and my baby, confirming what my OB had detected.

He told us that we had to see Dr. Stolar at Columbia Presbyterian hospital who gave us encouraging news that our precious baby had an 80% chance of survival. Everyone agreed that I should not risk the in utero procedure because of the placement of his liver and his stomach did not make us good candidates. Additionally we had 3 other children at the time (we have four with us now).

The pregnancy was carefully monitored and he was induced one week prior to the due date. He weighed 7 lbs. and initially everything looked very good. Later his condition deteriorated and he was put on a rapid ventilator. He continued to decline and eventually needed ECMO. He suffered cardiac arrest during the procedure and he had coarctation of the aorta. His testicles were not descended and he had a "stork mark" on his forehead. Finally he suffered a cranial hemorrhage, possibly because of the heparin. We took him off life support and he died in our arms 20 minutes later.

Would it be helpful if we gave you the data and medical history of Christian in building your database. Could it help other children? If so we would be happy to try and get his files. Both my husband and I have enormous respect for the work of people like Dr. Harrison, as well as the doctors who treated our son. Please let us know if there is anything we can do to help. If we had to do everything all over again, knowing what we know now, we would have done exactly the same thing. Thank you for the website, it is both informative and healing.

Diane K. Bischoff

Stories of Cherubs

I was having a pretty "normal" pregnancy with no problems initially. My AFP test had come back with an elevated risk of Downs so it was recommended that I have an amnio. I was 32 so I wasn't going to automatically have one but I opted to do it due to the result of the AFP. (When I was pregnant with my daughter three years prior, I had the same thing happen so I just thought, "here we go again.") My amnio was normal and the detailed ultrasound they did prior to it and during it revealed no abnormalities. I was very relieved and happy I was carrying a healthy baby, so my pregnancy proceeded with me feeling very well. I knew I was carrying a boy and my husband and I felt very lucky and were trying to prepare our two-year-old daughter for the arrival of her little brother.

About a week before Christmas, I was 31 weeks by then, I went in for my normal checkup and the doctor measured the height of my uterus. He said I was measuring 35 weeks along and that he wanted to do an ultrasound. I told him that my first baby was big and that I wanted one done at 38 weeks so I could decide if I wanted another cesarean. He said I could have one then, but he wanted one now. (Thank God for him. This was the first step to saving my baby's life)

My husband and I went in a few days later. The ultrasound revealed what was initially believed to be a problem with the heart. Our baby's heart was shoved way to the left of his chest. We were devastated and when we saw my OB, she gave me a big hug and said that she didn't know what was wrong with the baby, but she was going to send us to specialists and that she was going to do everything to help our baby.

It took a couple of visits with level 2 ultrasounds to narrow the problem down. The doctor couldn't get a good picture of the baby and it was either a type of mass in the chest, or a diaphragmatic hernia. (Initially they thought there might be something wrong with the structure of the heart, but it was because the heart was being smashed up against the wall of the chest.) The doctor recommended to deliver at a hospital that has ECMO and explained to us why. He gave us a couple of options, the closest of which was Gainesville, FL (we live in Jacksonville) He had also mentioned the in-utero surgery they do in San Francisco but we did not like the success rate percentage.

We met with the OB specialist who did another ultrasound. He definitely could diagnose it as a diaphragmatic hernia. He said that it was right sided and the intestines were probably up there and most of the liver. We then met with Dr. David Kays who is one of the pediatric surgeons at Shands hospital and who also specializes and has done many repairs of CDH. He went through all of the scenarios that could take place. We all decided on a cesarean set for 39 weeks. I would be given two steroid shots starting two days prior to my cesarean.

All this time was devastating. I was trying to be cheerful over the holidays for my daughter's sake, plus I didn't think that crying 24 hours a day would be good for the baby, however, I couldn't control my emotions at night. I would pray and cry for hours every night until my pillow was soaked. The one thing the doctors were able to get across to me was the seriousness of this defect.

At my weekly visits and non-stress tests I would have at my OB's, I asked her what I should do if I go into labor and she had said to call and come right away and she would send me by helicopter if necessary to Gainesville. I laughed at the idea of me going by helicopter and even told my cousin to "pray my water doesn't break and I don't have to ride in some damn helicopter!" At 37 weeks, that's exactly what happened.

I was at my mom and dad's with my daughter and I started leaking amniotic fluid. I called my doctor and went to the office, which was located at Baptist hospital in Jacksonville. She verified I was in labor and called Dr. Kays' office in Gainesville. They asked her to give me a shot of Beta Meth and send me on my way. I was already dilated two centimeters, so she decided to get me there as quickly as possible.

3 weeks ago, I never would have dreamed that I would be writing about the death of my little baby girl. We had all of the hopes and dreams of any other expectant couple. We had already been blessed with 2 healthy daughters. Rebecca who is now 5 1/2 and Myra who is 4. We decided to try again, in the hopes of maybe having a son. We knew our chances were 50/50 and agreed that another daughter would be just as good. A healthy baby was all that mattered. My husband was hesitant at first of even having another child. He said that we had 2 healthy children and we should not press our luck. I longed for a baby again. So with a little convincing, we headed toward the road of pregnancy. It only took a few months before I found that I was pregnant. My pregnancy was like a textbook case. I had my first and only ultrasound at 18 weeks. It was so exciting to see our baby moving around inside of me. I remember the tech's words so clearly. "Looks like a healthy baby-everything seems to be normal." She said that she was 70% sure that we were having another little girl, which was fine with my husband and me. I remember my drive home and how lucky I felt that we had gotten such a good report. When we got home we shared the news with all of our family. My girls were so excited about having a baby sister. My pregnancy progressed normally as the weeks went by. Occasionally I measured about a week or two more than my due date, which did not seem of any concern. At 35 weeks, I started having a lot of Braxton Hicks contractions and started passing some blood tinged mucous. I went to the doctor and was told that they would like for me to go at least another week before I had the baby. I was already starting to dilate. I received 2 doses of Brethine, which stopped the contractions and was sent back home. Two days later on Thursday night, I started having contractions again. We went to the hospital, thinking this was the day. I was 3cm dilated. The doctor still wanted me to go a little longer, so I received more Brethine and went back home. By Saturday night I started having hard contractions that were becoming very regular. I sat up for several hours until I could not stand it anymore. At 3:30a.m. we headed to the hospital. When we got there at 4a.m. I was already 5cm dilated. This was finally the day. My husband and I were excited at the thought of finally having our baby. Labor progressed quickly. The doctor broke my water and it was like a flood. He commented on how much amniotic fluid there was, but did not let on any signs of concern. I had my baby girl shortly after that. When she came out we immediately knew that something was wrong. They suctioned her nose and mouth but she still did not cry. I could feel my heart drop, and in my mind all I could do is pray "Please let my baby cry". The minutes seemed to pass like hours as they worked on my baby at my bedside. Finally they said that they were going to take her to the nursery where they could give her better care. They were gone for what seemed like hours. The doctor came in and told us that things did not look good and a short while later the pediatrician came in with the news that our daughter was gone. It felt like a knife go through my chest and rip something out. The emptiness is still there and I wonder now if it will ever be filled. We got to see our baby, but at the time I was so upset that I could not bear to hold her. We went home the next day and leaving the hospital without my baby was the hardest thing that I have ever had to do. I have shed so many tears, that at times I feel like I cannot cry anymore. Then out of nowhere they come again. We had a beautiful graveside funeral service for our Belle and we could not believe the outpouring of love from all of our family and friends. It has only been almost 2 weeks but it still seems like yesterday. Not a moment passes that I don't think about my baby and all the plans that we had made. I do find some comfort in knowing that Belle is in a much better place now where she will never know the pain and suffering of today's world. She is in God's protecting arms and I can look forward to seeing her again. Even though Belle's life was very short - she has taught me a valuable lesson. Life is precious and we should never take it for granted. The things that I often thought only happen to other people, can happen to me too. I will forever be touched by my little Belle, and will always cherish the short time that I got to know her.

Angela Hutto (mother of Belle Kathleen Hutto, 3/19/00-3/19/00, Rt. 2 Box 115-B, Branchville, SC 29432, 803-245-1528, mellonfarmer@oburg.net)

Somewhere in between the pain my mother came in. I was so glad to see her! I had a contraction that started and never stopped until I got my Epidural. (NOT A MINUTE TOO SOON!!) Finally at 8:05pm March 4 Steven was born. And all the pain and trouble I went through delivering him was nothing compared to the fight he was to have for his life. He was being bagged on the other side of the room while I was being stitched up. It was so sad not to ever hear him cry, but at least I got to see something no one else seen. That was his beautiful eyes! There were black as coals, but also so bright and beautiful1. I think he would have ended up with brown eyes later on. We knew what to expect when he was delivered because we were very well informed beforehand. We all hoped for a quiet time until his surgery date the following Wednesday. After Steven was born he was taken to I.C.U. right down the hall from my room. And family was allowed to see him if accompanied by Jody, but they were told no loud talking and no camera flashes, well this didn't seem to set well with some family members, but they should have been putting Stevens needs ahead of their own.

Anyway, I mostly stayed in my room, because my blood pressure was dangerously high. I have been criticized by some for not spending more time in the I.C.U. with Steven. The truth is, I regret now not doing just that, but at the time it hurt me so bad seeing him laying there with tubes running all through his body, he looked so helpless. And my arms ached to hold him but I wasn't allowed to even touch my precious baby. I thought he would stabilize enough for surgery, but early Monday morning one of his doctors phoned my hospital room to tell me Steven had a very rough night. I knew then my baby wouldn't live much longer. For one thing, the I.C.U. staff never called my room with good or bad news, so I knew it must be serious. I called my husband and my mother because I couldn't bear to be alone.

All day Monday we waited on any word of Steven's condition, but were told nothing because they were too busy working trying to save his life. We would walk back to the I.C.U. but couldn't see him for all the Doctors surrounding him. Then about 10:00p.m. one of his Doctors came to my room to tell me they could do no more for Steven. All their efforts were in vain. He did not even expect him to make it through the night. They would keep him hooked up to everything and continue his medications and painkillers, so we would have our chance to hold him and spend time with him before he passed away. So from 10:00pm til about 7:00am the following morning Jody, my mother and myself got to hold Steven, talk to him, sing to him, take pictures of him and just enjoy his very limited time with us. It was strange though, I had called friends and family to tell them about the baby's declining health, but no one was able to come that night we had a terrible storm. Driving visibility would probably have been zero. Even the hospital parking lot flooded. So only the three of us got to spend those precious hours with him. It was quite in there except for the beeping of the machines keeping him alive. I am so glad the three of us got to be the ones to develop a bond with him (even though short). One of my most dear memories is of my mother holding him and singing to him, every time she came near him his vitals would go up, I know in my heart he knew when his Maw-Maw was holding him. I don't want to leave out the doctors and nurses who took care of him. They were wonderful. When no one was in the room with Steven, his caretakers would hold his hand and sing to him. It really touched me and I will always be grateful to them. Especially Amy Schaepen. She was his primary caretaker, and she could not have been more caring to our son. She and several doctors and nurses shed a few tears when he passed away. So I know he had the best possible care. About 9:00a.m. Tuesday morning the rest of family and friends arrived to say goodbye to Steven. They were allowed to hold him, but I know it couldn't have compared to the time we shared with him the night before. Our precious baby had started turning black from lack of oxygen and he also started swelling. So my husband decided to remove his life support to spare him any further suffering. But on his way to the I.C.U. with the doctors, our precious baby passed away on his own, sparing my husband the pain of unplugging him.

I thank Jehovah for giving me the strength to cope with this. And there are so many people here on earth I want to thank, but I would never have enough paper. So I will name just a few. Thank you Mom and Dad, CHERUBS, Amanda and Mark, all my brothers and sisters from the Kingdom Hall, all the people who took care of Steven, and the understanding people at Valhalla. We love you Steven!! (P.S.) He was laid to rest with the soft, cuddly white puffalump we bought him.

Charlene and Jody Gartman (parents of Steven Tyler Gartman, 3/4/99-3/9/99, 11470 Bladon Springs Ave., Wilmer, AL 36587, 334-645-1098, Jodysgirl27@aol.com)

My husband, mother, and daughter, were there and said they would meet me in Gainesville since nobody was able to ride with me. As soon as I was at Shands hospital, they set me up on a magnesium sulfate drip to slow the labor. Dr. Kays came in to talk to me and said they were going to hold me off for quite a while because I needed some time to pass and then another steroid shot. They had to put me on the maximum of the drip to finally get my labor to slow down.

The next day they were able to reduce it a little so I could be a little more comfortable. The doctors would check me minimally so as to not cause anymore dilating. I had been admitted on a Tuesday and on Thursday morning, I was in a lot of pain and felt like I had dilated more. They checked me and I was five centimeters and they said it could not be stopped now. Dr. Kays came in and said that they would do the cesarean at 11:30am and he would be in the delivery room ready to help my baby.

I had sent my family home since I didn't think I would be delivering this early and the only reason my husband agreed is so he could work more so that he could stay for a long time after the baby was born. I called him to come back to Shands but there was not much time before I was taken to the operating room.

When they lifted my baby out, I heard someone say, "Judy, look quickly!" I saw my son for a split second before they handed him to Dr. Kays' team. I'll never forget that big "waaaa" face with no sound coming out, except for a quick little noise that I can't explain, sort of like what it sounds like when someone gets the breath knocked out of them.

I looked over to the little bed where Ian was but I could not see because there were too many people around it working on Ian. The two anesthesiologists were talking to me to keep my mind off things and they would look over and then try to reassure me. I kept hearing someone call out each minute that passed, and knew things weren't going well. All this time I was praying as fast as I could and straining to see my son. At one point, one of the anesthesiologists went to look at Ian and then I saw him look at the other one and he was as white as a ghost. When four minutes had passed I still hadn't heard anything and then finally Dr. Kays came up to me and said that Ian was very serious but they finally got him stable enough and were taking him to NICU. After they took him out of the room, someone came to tell me that my husband just arrived and got to see Ian for a second, and that he would be waiting in the recovery room for me.

I was taken back to my room to recover from the surgery. After an hour or so, someone brought me a polaroid of my son. He was on a ventilator and almost his entire body was covered with wires and tubes. At two hours old, we were told we could go to see him. I sent my husband and my mother to go look at him and come back and tell me how he was. When they came back, I begged my recovery nurse to let me go to see. She helped me to the wheelchair and I was taken to see him. When I went in, Dr. Kays explained to me how serious Ian was. He said he went a long time without oxygen in the beginning because he was very hard to intubate. When I looked at Ian, the vent was working his body so hard that his chest was dramatically rising and falling. The nurse was there to answer any questions about all the wires or machines that we needed to ask. I couldn't stop crying every time I looked at him. He was so beautiful. He looked so much like our daughter when she was born. He was a good size (7lbs. 14oz) which the Dr. said was in our favor, and also that it seemed he had a strong heart. I would visit again and again. I couldn't stay away from him. It was like I was trying to engrave his face in my mind because I thought I would lose him. At about 3 o'clock in the morning, I went to see him again, and there I saw the surgeon, Dr. Kays, still by Ian's side. That is when I realized that we were in the best place we could be.

The next day, only 24 hours after he was born, Dr. Kays came to tell us that Ian was not doing well and that he had a small window of time to get his surgery done. He really didn't want Ian to go on ECMO without having done his repair yet, so he was going to do the surgery even though Ian was so marginal. He did Ian's surgery right in NICU because he was too unstable to move. Ian made it through the surgery. Dr. Kays said that 85% of his liver and almost all of his intestines were in his chest. He said that Ian basically had no diaphragm and he showed us the gortex that he used as a patch. He said it was the biggest patch he's ever had to do. The X-rays revealed that Ian's right lung was extremely small, about 30% of what it should have been, and his left lung was about 70% of what it should be. Dr. Kays said Ian's lung and liver were bruised somewhat because the vent was causing them to hit each other.

The next day, Ian's blood gases were so poor, he had to be put on ECMO. That was the worst day of my life. Even though the ECMO program was the initial reason we went to Shands, I was hoping all along that it would not be needed. I was told that Ian's lungs had been worked too hard and ECMO allowed them to turn down the vent and give Ian's lungs a rest and that hopefully, his lungs would grow and expand with the room in his chest recently created by the repair surgery.

I can't explain ECMO. It was the worst sight I've ever seen. I thought seeing him with all the tubes, vent, and other stuff was bad, however it was nothing compared to this. A huge machine was parked right next to Ian's bed, with big fat tubes filled with blood going from the machine surgically attached to his jugular vein. The only redeeming quality was that for the first time, my son looked more peaceful because the vent had been turned down and it was not pumping his lungs like it had been. I could understand the concept of what ECMO could do for Ian. It would oxygenate his blood so his lungs could be given a rest and hopefully start to grow and work. I asked Dr. Kays how long he thought Ian would have to be on ECMO. He said given how sick Ian was, probably somewhere between 10 and 14 days.

Life on ECMO was extremely hard. Ian would have one good day, two bad. Then have two good days and one bad. At one point we were very encouraged because a blood gas showed more oxygen than what they were giving Ian, which meant his lungs were beginning to work. He had to go through two circuit changes (that's when they change out the whole machine with another one filled with all new blood.) They would have to do that because the blood in the machine would start to clot after about five days, which would be extremely dangerous. After both circuit changes, Ian would have a very bad day and a half, probably because it was a shock to his system. At about day 10, Dr. Kays tried a second attempt of trial off ECMO. That's when they fix the machine so they can see how Ian would do without it. Again, Ian's blood gases were too poor and he had to put him back on. Eventually, on day 16, it was time for another circuit change, but Dr. Kays had been preparing the machine, turning the flow down for a few days, hoping that this time Ian was going to do it. He made it off and the next time I went in, the machine was gone. The next nine days, Ian was slowly weaned off the vent. When he was 22 days old, I walked into NICU and Sandy, Ian's nurse, had him dressed in a little shirt and had washed his hair for the first time. She and Michele, the nurse practitioner, asked if I wanted to hold him. I had never asked any of the nurses when I would be able to hold him because I was afraid I would not like the answer, but mainly because I knew I wouldn't be able to ask the question without breaking down and crying. I would cry when I would see the other parents in NICU get to hold their babies because I so much needed to hold him.

They put an oxy-hood on him at first, then switched him to a nasal cannula. This is the first time I saw my baby's beautiful mouth. His cry was raspy and weak, but it was music to my ears. At this point, he started making progress in leaps and bounds. It was a continual positive progression from here. They did an upper GI to see how bad his reflux was going to be. The test showed minimal reflux. We started slowly introducing feeds by mouth. I had been pumping breast milk and when they first placed the NG tube, that was the first real food (not IV) he received.

Increasing the feeds by mouth was a painstaking process. Eventually I was able to breastfeed. Since breastfeeding is not an exact science, every day I anticipated when he would be weighed hoping for a nice gain. At the same time the nurses were teaching me how to give Ian his meds by mouth since I would be doing that once I took him home. After Dr Kays was satisfied with Ian's weight gain and progress, after 50 days in NICU, we were able to take Ian home.

He came home on portable oxygen by nasal cannula. I had a huge tank set up in his room and he had a 20 foot tube so I could walk around the house a little with him. He was also on a heart monitor constantly for the first few months and then just at night. He had to take many meds by mouth every day. Nifedipine he took initially because he had pulmonary hypertension, which he was off in a couple of months. He also took Cisapride, Pepcid, which helped with reflux, and Lasix. He remained on oxygen until his first birthday. In his first year and a half he was hospitalized three times for respiratory infections, none of which were RSV. As he gets older, he seems to get sick less often, and tolerates the viruses better.

Today, he is two years old, is saying six word sentences, runs and plays with his older sister, and is in the 50% for height and weight of normal children his age. Nobody can believe he was as sick as he was. He looks so healthy and is extremely active like any two year old.

We found on the ultrasound that I wasn't as far along as first thought, so they couldn't really tell the sex for sure, but they thought it was a boy! I was so excited I barely heard her mention something about his heart, but she said not to worry because I wasn't far along enough to see anything clearly, to come back about around 24 weeks gestation and they would have another look. I wasn't worried, everything seemed routine to me. (BOY WAS I EVER WRONG). Everything was pretty quiet after that until my next scheduled ultrasound appointment, which was January 5th. This time it was only my husband and I. They confirmed on this one that it was a boy. And also briefly mentioned something about his stomach being high. I questioned her but she was all smiles, I guess she knew what was wrong, but didn't want to tell me. So she just kept smiling and said she would have me come back on the eighth so a specialist could have a look. So my husband and I were sitting in the waiting area while our next appointment was being made, and I noticed a group of doctors gathered around talking, and I was sure they were discussing my baby! I voiced my concerns to Jody (my husband), but he told me I was being paranoid. I had a regular maternity visit on the seventh, so I asked the receptionist for my ultrasound results to give to my OB/GYN, which they have always in the past let me take them myself. But on this day I thought it was very strange for her to say she would fax them herself.

We left there very confused but didn't know what we were confused about! So we decided not to worry until we were sure we had anything to worry about. So two days later, I go to my regular OB visit. I had wanted someone to go with me, but my husband had to work and my mother was already taking her neighbor to the doctor. I was so uneasy and nervous, I didn't want to get any bad news alone. For the first time EVER I was taken in promptly. I swear people were acting so strange! When the receptionist walked away to make copies, I glanced at my chart and my heart began to beat out of control! All I seen was a little postie note saying, "Patient is unaware of findings". I knew it was going to be awful!! And it was. The OB sugarcoated everything for me, but the specialist confirmed everything for us the next day. I could not believe the words that were coming out of that woman's mouth!! How could my baby have a life threatening condition? And what was a Diaphragmatic Hernia anyway?? Jody and I were so numb! And all the stats she gave us for his chances of survival were very grim. And I am so grateful she knew of CHERUBS, It was our only sanity in an insane situation. Next came the task of telling our families. This is only my feelings, but I wish our families could have been more supportive. I guess they didn't believe how serious our baby's condition was. We even had one family member suggest getting an abortion!! And I was 7 months pregnant!! Those words hurt me so bad. But as I have come to learn, a lot of people say a lot of things out of ignorance. We had an appointment to go to Birmingham, Alabama to consult with Dr. Georgeson, because that was the only place equipped to handle a CDH baby fully in our area. But because of conflicts in their ideas of treatment and our ideas of treatment, we decided to have our baby close to home, here in Mobile. I spoke with the Pediatric Surgeon, Dr. Beals, and he made me feel very comfortable leaving my baby in his hands. I had started steroid shots on the advice of Dr. Georgeson. All we had to do now was wait. My due date wasn't until March 28, 1999. In February I had my baby shower. It really felt weird, because I didn't know what the outcome would be. I remember when I got home and put the things away I got at my baby shower, I just sat in the middle of the baby's room on the floor and cried my eyes out! Wondering if he would ever use the things received. On Wednesday March 3, I was admitted in the hospital for Pre-eclampsia. Within the hour I was surrounded by very close friends and my sweet husband Jody. About four o clock that evening I was given a pill in my cervix to loosen it. I had a few contractions here and there, but nothing to write home about. In fact I was pretty comfortable. I don't remember the exact time Jody's parents arrived from Georgia, but I do know they stayed in that room with me just about the whole time. That was something new for this hospital, (to let family be with you through thick and thin). I'm not really sure how I feel about that yet. But I was so glad my husband was there, he was a really big help. Even as far as retrieving my bedpan when needed. (now that's got to be love!) The pills they were using was not working. I was not dilating as I should have been. I was starting to have some good contractions but that's all. My cervix was not opening. About three o'clock Thursday afternoon (March 4) the doctor wanted to insert a balloon in my cervix to try and open it, I had never heard of such, but by then I was in some kind of pain!!! And all I wanted to do was get this over with! Well wouldn't you know it, it didn't work! By that time I was screaming for an Epidural.

My name is Jenni Forman and my husband Robert, and I recently had a baby with CDH. I had a very normal pregnancy up until 32 weeks. I went to see my OB/GYN for a routine visit. Dr. Settle was worried because I weighed and measured the same as I had at 27 weeks. He decided to see me a week later to see if I had gained any more weight or measured any bigger. A week came and still I was the same as I was at 27 weeks. I had an ultrasound at 27 weeks that was normal except for her cleft lip. Dr. Settle decided to send me to the hospital for another ultrasound to check fetal growth. The x-ray technician took a bunch of pictures and told me they would have the results on Friday. I felt like something wasn't right. I called Dr. Settle on Friday and he never called me back until Monday morning. He told me that the baby had a hole in her diaphragm. He said that he wanted to send me to University hospital in Oklahoma City (about 300 miles away) to a high risk OB/GYN. On Tuesday January 11th I saw Dr. Coleman in OKC. He did another ultrasound and confirmed the CDH and cleft lip. He said the baby could possibly have Trisomy 13. He did not want to do an amniocentesis because of the risk of premature labor or infection this late in the pregnancy. He gave us an 80% chance she would die and a 20% chance she would live. He sent me back home and said to come back for a check up on February 17th. He never offered to let us talk to the baby's doctor or tour the NICU at Children's Hospital. He never explained ECMO or anything about the treatment of CDH. We went home in shock. We stayed that way for about 3 weeks until we saw the program about the baby with CDH on 20/20. After seeing that, we started doing research on the internet and that is how we found CHERUBS. When we returned to Dr. Coleman on February 17th, we had a lot of questions. He answered most of them, but was still very negative about the outcome. He told us we would do a c-section February 24th. We went back home. We were very angry about the negativity so we called his partner Dr. Stanley. He called us back and answered all our questions. He had one of the neonatologists call us to explain what we could expect from them. Dr. Mantor told us that they would not allow the baby to cry or anything. He said she would be intubated immediately and taken across the street to Children's Hospital of Oklahoma. Dr. Mantor then contacted Dr. Coleman and Dr. Stanley and they decided to do my c-section on February 22nd. We arrived in OKC at University Hospital at 9:00am on the 22nd. At 12:10pm, February 22nd 2000, Candis Nakole Forman was born 11 days early weighing 4lbs 7oz and was 18 ¼ " long. She was intubated and taken to x-ray. After her x-rays were done they brought her by so I could see her before she went to Children's Hospital. About 3 hours after she was born the neonatologist came and told us that she had a heart problem that could not be fixed and that she would be lucky if she made it through the night. My husband and parents went to see her several times during the day. Around 9:00 that night I was finally able to go see her. When we got over to Children's Hospital she was dropping very fast. When I talked to her, her vital signs went up for about 25 minutes. We had her baptized and she passed away in her daddy's arms at 9:30pm. We got to hold her and tell her how much we loved her. We told her that it was ok to go home. We found out a couple of days later that she did have Trisomy-13. We will always love her and miss her, but she is in a much better place now. She will never feel pain or sickness the way we do. We know that we will all be together again.

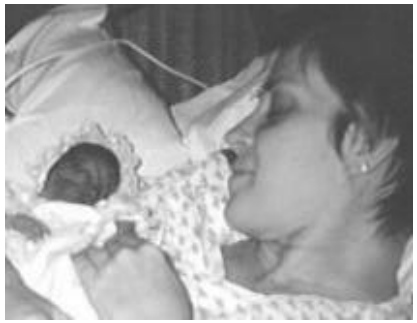
Jenni, Robert, and Brenton Forman (family of 97 Candis Nakole Forman, 2/22/00-2/22/00, Paul Ave., Guymon, OK 73942, 580-338-5827, wooo@ptsi.net)

It's been almost a year now since my baby Steven Tyler Gartman has passed away, so I have decided to tell his story. Not that the pain is any less, just that I want everyone to know what a sweet baby he was and how much he was wanted. In July of 1998, I found out I was pregnant. It was a BIG shock at first, but the more I thought about having another baby to cuddle and play with, the happier I became. Even though I was only about 7 weeks pregnant, we bought the baby his/her first toy. A soft, cuddly white puffalump. I couldn't wait to have my first ultrasound to see what we would be having. But my first one would not be until late October. It seemed like an eternity, but it finally arrived. My husband, my youngest son and myself would see our new addition today.

Ian would not be here if it weren't for his surgeon, Dr. David Kays, who is a pioneer in changing the way babies with Congenital Diaphragmatic Hernia are treated. He has the best published diaphragmatic hernia data with a survival rate of 92% of babies that are born at Shands. He and the wonderful nurses and therapists provided Ian's little body with everything that it needed to grow and work and heal. We are so lucky we found our way to Shands.

We are so lucky in many ways, and knowing how different it could have been, makes us count our blessings every single day for our miracle baby.

Judy Bunch (mom of Ian Raymond Bunch, 1/28/98, 8758 Canopy Oaks Dr., Jacksonville, FL 32256, 904-363-0660, JudithBunch@aol.com)



This is the story of our precious daughter, Taylor Saige Cooper. Taylor came to us, as well as left us, on February 6, 1999. In only a few weeks it will be one year ago already. At times it's as if it were only yesterday, and at times it's as though it was a lifetime ago. I would like to honor her by sharing her story with you.

My name is Chrissie Cooper. My husband, Skip, and I will be married 10 years in March. We have twin daughters, Tara and Rheannon, who are eight years old. We also have two sons, Ian and Christian who are 11 months old. They are Taylor's little womb mates. Taylor was part of a very unique pregnancy. Taylor was one of a sextuplet pregnancy. Ian and Christian are the only survivors of the pregnancy.

My first pregnancy was achieved with the help of Clomid. It was a very difficult pregnancy as at 24 weeks I was diagnosed with an incompetent cervix. I spent 6 ½ weeks hospitalized hanging head down and feet up. Tara and Rheannon entered the world 10 weeks early very tiny but healthy. When the girls were four, we decided to try again to conceive. Clomid was again prescribed. I developed a serious complication from it, and could no longer use it. Injectable drugs were then suggested. These drugs made me nervous. I did not want to get pregnant with high order multiples, and so we declined for the time. After 2 ½ years of trying without success, we finally decided to try the injectable drugs. We researched them thoroughly and spoke at great lengths to our fertility specialist about the drugs. We had also decided to proceed on any cycle that more than three follicles were present. Three follicles would optimize our chances to conceive just one baby, and there was a less than 5% chance that all three follicles would be fertilized- Even if they did, at best we would have triplets. In July of 1998, during my second cycle of the drugs, I had to be hospitalized due to severe ovarian hyper stimulation. This is a serious complication of the ovulation inducing drugs. I had 30 pounds of fluid accumulated in my abdominal cavity, my kidneys were closing down ... I was gravely ill. It was during this time, that we found out that I was pregnant. We could not believe it! Skip and I were both immediately scared though. I had been on so many drugs for the hyper stimulation. Would the baby be harmed by any of the medicine we asked. We were told not to worry. They assured us that all the drugs used to treat me were safe for use in pregnancy.

After a two weeks hospital stay, I was sent home on bed rest. I was still very ill. The fertility doctor wanted to do an ultrasound during the sixth week of my pregnancy to confirm the pregnancy and to make sure it is in the uterus and not the tubes. In the back of my mind I was suspecting twins or triplets because my HCG levels were high. I was however not prepared for what they told me that morning. They measured six maybe seven sacs in my uterus. It was too soon for heartbeats, so exactly how many were viable would not be known for a few more weeks. I can only cry. My mother is in the waiting room with my daughters and Skip is at work. My mind is spinning. The chances of carrying this many babies to viability are quite slim. I also have to have my abdominal cavity tapped again because it is filling with fluid and I cannot breathe.

I call Skip at work and give him the news over the phone. He responded with a calm that I'm sure he was not feeling at the time, but he assured me that we were just going to trust the Lord for whatever was ahead of us.

Two weeks pass, and again a scan is done to see for sure how many babies there are. There are six babies. One baby's heartbeat is weak and they think probably will not survive long. Fetal reduction is given as an option. We had told our Dr. that this was just not an option. We had discussed our feelings regarding this matter with him even before going on the drugs. It was just NOT something that was right for us.

One week later another scan reveals that one of our babies has indeed died. We are now being turned over to a perinatologist. They will be in charge of my entire pregnancy. Our first meeting with the doctor was overwhelming to say the least. The risks for the five babies as well as for me were great. I'm still on bedrest at home and that would have to continue. I will have to be hospitalized around week twenty for the duration of the pregnancy. There is a 50 to 60% chance of losing all the babies before the 18th week. They warn that the risk of congenital abnormalities is greater because of the number of babies we are carrying. Of course we are at great risk for a very premature delivery and with that comes the risk of severe complications to the babies. I was at risk for life threatening complications during the pregnancy and delivery. Still, fetal reduction was not an option for us. We were just going to let this in God's hands. It was all up to Him.

I am scanned weekly. Week nine reveals that another one of our babies has died. The reason unknown. We are saddened but not allowed to grieve. Doctors feel this gives the other babies a better chance now that they don't have as many to share space and nutrients with. For us though it was horrible... these were our children and we will never get to meet these two little babies in this lifetime. We wanted to grieve, but instead had to keep focused for the sake of the surviving babies growing inside of me.

Week 13 a cerclage is placed in my cervix. All four babies seem to be doing well. Then, one week later, I began bleeding very heavily. I am again hospitalized and the doctors cannot find the source of the bleeding at first. All four babies are doing good, but the bleeding is not a good sign and it is causing my uterus to contract. The doctors tell me that they feel there is no hope for the pregnancy. They also warn that my life is already being threatened because my blood counts are dangerously low and if I continue to bleed then my life is at risk. To give us some kind of a chance, they recommend reducing the pregnancy to one baby. We again decline. My mental state is so frail right now. I am afraid for these precious babies. God knows my pain and my fears and uncertainties regarding this pregnancy. He also loves each of these little lives. We need to find rest and comfort in that. It is around this time that we find out they we are carrying two boys and two girls. Baby A is a boy his name is Ian, Baby B is our other son, Christian, Baby C a girl, Taylor, and baby D our other daughter her name is Saige. Ian, Christian, and Saige are all good size, but Taylor is much smaller than the other three. The doctors warn that we will probably lose her before too long. They have the contractions under control, I'm given a blood transfusion and sent home on a contraction monitor and strict bed rest.

In early November we were in for our weekly scan and I cannot shake the feeling that something is wrong. I voice my fears to Skip, and he reminds me to stay calm. We soon find out that my fears are correct. The doctor says that something is wrong and we need to talk. They take Tara and Rheannon in to another room. The Dr. tells us that Baby C, Taylor, has a Congenital Diaphragmatic Hernia. She proceeds to give us all the horrible facts and statistics. She explains that this can go along with other congenital abnormalities, but any further testing to see if this was the case would be impossible because it would risk the other babies. It's amazing how quickly your world can turn upside down. My biggest fears with this pregnancy to this point had been miscarrying or premature delivery. Birth defects were the furthest thing from my mind. The CDH was bad enough, but Taylor was small and the risk for premature birth made her odds much worse than in she were the only baby we were carrying. Again, fetal reduction is given as an option. Absolutely not ... we have to give her every chance. This defect will cause her no problems as long as she's inside of me. God created her and loves her as do we. We must give her every chance. It was at this point that I found out about CHERUBS. A friend of mine got your info from the internet, and quite honestly as I began to read the stories I became even more terrified than before. I had to put the newsletter away. It was just too much at that point in my pregnancy

December 1, 1998 I am admitted to the hospital for the duration of this pregnancy. I am 20 weeks along now. Quads typically deliver around 27-30 weeks gestation. On December 10 my first ultrasound since coming to the hospital is to be done. I was so tense because in the past they had been looking at baby A's (Ian) heart. We're told that it's not until around week 22 that they are able to get good views of the , 12/10/98. Ian is not in a good position today so they cannot tell. They do though confirm my suspicions that Ian may have a congenital heart defect called transposition of the great vessels. I cannot believe this. How could two of our children have such different and devastating birth defects? No time to think of it right then.

Tierney's operation to repair her diaphragmatic hernia was performed by Dr. Croitoro on February 5, 1992. The surgery went well and Tierney recuperated in the PICU. She looked so relaxed and I can remember her sucking her tongue in her sleep. Tierney needed very little medication and was sent home earlier than expected on February 9, 1992.

The 1st 6 months of Tierney's life were pretty uneventful. I breast fed her and she thrived very well. She did have a tendency to vomit on occasion but I thought it was from overindulging herself with milk. When Tierney was 6 months old she started to have bouts of severe vomiting and abdominal pain. After several visits to our pediatrician and finally a visit to the hospital for dehydration, we were told she had reflux and she was put on two different medications. We were relieved to hear a diagnosis and to have a solution to the problem. Our relief was gone shortly as she started vomiting again and her pain seemed to intensify. We spent many nights walking with Tierney as she only seemed comfortable when you held her upright and she did not like us to sit down. I even took her for late night drives in the car because my back would ache from carrying her. We had monthly visits with the Pediatric Gastroenterologist (PG) that diagnosed her with reflux and he assured us that Tierney would eventually grow out of having reflux. Many times I discussed her CDH with him but he said there was no correlation between her CDH and her current problems. Tierney's weight gain was very slow and she became a very picky eater. We would go for a week or two with no problems when suddenly she would vomit for a few days in a row and would be extremely uncomfortable. On Tierney's "bad days" she would sometimes hold a cookie (that she would normally love to eat) in her hand for hours on end! She knew she would like to eat it but she couldn't because she felt so lousy!

We continued to see our PG and Tierney had X-rays, ultrasounds. Upper GI's, Lower GI's etc. but nothing was ever seen to be abnormal. Tierney was put on IV liquids a few times for dehydration and was even hospitalized for a few days right after her 2nd birthday but the diagnosis was the same – REFLUX.

In September of 1994 Tierney experienced a severe bout of vomiting and pain. She couldn't even brush her teeth without vomiting. Her pain seemed to come and go and was so severe she would tighten up her legs and be straight as a board and then when she had a little relief her eyes would roll back. Perry and I decided we needed to get her to the hospital. Tierney was admitted but they had to rule out appendicitis and other things so they couldn't give her pain medication. She was in such pain and no one seemed to know what to do so we finally called Dr. Croitoro's office and they sent Dr. Donald Nuss to see her. He reviewed a recent upper GI and determined that she may have blockage caused by adhesions and she needed immediate surgery.

Dr. Nuss operated on Tierney the very same night he examined her. After the operation Dr. Nuss told us Tierney was a very sick little girl and that her threshold for pain must be extremely high because she had a volvulus. Apparently her intestines never adhered to the stomach wall after her CDH repair and they were twisting and turning until they finally tied into a complete knot that could not untwist. Dr. Nuss told us that Tierney would have died if he did not perform the operation. Tierney was closely monitored in the PICU and after 24 hours Dr. Nuss operated again to perform a resection on her intestines. Tierney spent a few days in the PICU with a tube through her nose to drain the "gunk" in her stomach and was later moved to a regular room. After 2 weeks Tierney was well enough to go home.

Tierney sometimes complains of stomach pain but for the most part she is a happy, healthy, well-adjusted child. We had one bad scare a few months after her surgery with severe abdominal pain but we found she had eaten a large amount of peanuts and she suffered blockage from the peanuts that she could not digest properly. We don't allow her to eat peanuts but other than that she eats a normal diet. Tierney is now eight and is in second grade. She is on a swim team, participates in Brownies, Soccer and Basketball. In addition to Tierney's older sister, she has two younger sisters and one younger brother. After reading several other stories we realize we are very lucky but we hope the potential for intestinal problems is not overlooked by doctors of CDH survivors in the future. We know Tierney could have been spared a lot of pain if a connection could have been recognized earlier in her life.

Theresa Hohman (mom of Tierney Elizabeth Hohman, 2/3/92, 1604 Bay Point Dr., Virginia Beach, VA 23454, 757-496-2115, thohman@rscre.com)

At 35 weeks of pregnancy with my first child, the doctor ordered another ultrasound because my belly was too big, needed to make sure we didn't have a huge boy in there. That is when they noticed the baby's heart was not in the proper place, it was moved to the right. At that time, they told us it could be a CDH, tumor, or a chromosome problem. They did the amino the same day, which came out fine. They decided that it was a CDH, and referred us to Children's Hospital Oakland. My care had been switched to a different doctor also. We met with neonatologist and surgeons immediately, who told us our chances were between 50-75% survival. At 38 weeks 5 days they induced labor. After 3 1/2 hours our boy entered this world, the doctors immediately took him and put him on a ventilator, and prepared him for transport to the other hospital. They did let me touch his little cheek, and before they transported him, they brought my baby through my room for me to see for a moment. Ryan (my baby) was strong enough for surgery the next day, as soon as I was discharged I went and waited, the doctor came to me and said Ryan had made it and there was enough lung tissue for survival. Two days later they took him off the ventilator, that was a rough day, but he was strong and did well. A week later they removed the chest drain tube, I finally got to hold my baby ten days after birth, they also started to feed him breast milk through a tube. I knew from my research, that feedings were going to be difficult, they fed him through a tube for a few days they tried to nipple him, which was rough. After about a week of going round and round with nutritionist and doctors about how much Ryan needed to eat. They kept nippleling and then gavaging the remaining amount they thought he needed, and he kept throwing it up. They finally asked what I thought, I told them that I wanted to get him home and see what feeding schedule he wanted to be on, instead of making him conform to the hospital schedule. I told them I wanted to take him home, they said "Let's see if we can get them out before rush hour"! That was 20 days after birth. They sent us home with a feeding tube down the nose, and we were supposed to gavage what he wouldn't nipple. I had no intention of using the tube once we got home, thankfully, Ryan took to the breast immediately. Three days later, in the middle of the night, Ryan started to remove the tube, I woke to him coughing, we pulled the tube the rest of the way out. The next day, we had a pediatrician appointment, Ryan had gained weight and we didn't need to replace the tube. So our ordeal was the best of a horribly scary situation. 20 days in the hospital and now we have a baby with a scar and 1 & 2/3 lungs. We are so thankful for the outcome, especially after reading some of the stories on your website.

Cara Thompson (mom of Ryan Treasure Thompson, 11/30/99)

My due date with our second child, Tierney, was January 24, 1992. My pregnancy was very normal in all respects and I had the usual ultrasound at 20 weeks with no abnormalities shown. January 24 came and went with no sign of Tierney coming into the world yet! At 41 weeks I had another ultrasound and a stress test that indicated no problems. On February 3 I went into labor and after a fairly short labor Tierney was born. Tierney, at 6 lbs. 12 ounces, was smaller than we expected for an overdue baby but appeared perfectly normal and had very good Apgar scores.

On the morning of February 4 I was getting ready to go home when our pediatrician came in to see me. He said that a nurse thought she heard Tierney's heart on the right side rather than the left and therefore they had x-rays taken of her chest. He pulled the x-ray out and showed me that her heart was indeed on the right side of her chest and her intestines were where her heart should have been. I asked him what this meant and he said he had never seen this before but that a surgeon would be in to see me. I was devastated!

The surgeon, Dr. Croitoro, came in and told me Tierney had a diaphragmatic hernia and needed an operation to repair it. I was more than upset and very confused but Dr. Croitoro assured me that Tierney was very lucky because her lungs were perfectly okay. He said the hernia may have been caused very late in my pregnancy and he even discussed viewing my ultrasound to see if it was apparent at such time (I don't think he ever did this).

They had to move on to look at the other babies. Baby B (Christian) looks great his heart appears normal. Baby C (Taylor) her heart is small and pushed to the right due to the CDH but appears normal in its structure. Baby D (Saige) as they begin to scan her I ask "What are we looking at here ... something does not look right to me I say. "The room was full. Myself and Skip, our daughters, 3 doctors and two technicians and yet the silence in the room was deafening. "I'm sorry Ch
doctor quietly tells us. How can that be? I ask. She had looked great two weeks ago. Of the four remaining babies they had expected this for Taylor, but it came as a total shock for Saige. It seemed as though things were spinning hopelessly out of control. My emotional state is so frail. I thank God for my husband who never gave up hope and always reminded me of the fact that God was in control and allowing all of this for a reason. Skip was an amazing source of strength for myself and our daughters who were terribly scared and confused through all of this. We also had many people and churches upholding us through their prayers, and yet, quite honestly, most days I was very restless at heart. I wanted so desperately to help all my children, those I was carrying as well as Tara and Rheannon. Yet, all I could do was to lay in a hospital bed helpless.

Things just went from bad to worse. Two days after learning of Saige's death I began bleeding again. Saige's body was collapsing due to the other babies pushing on her and this was causing the bleeding. The bleeding was causing my uterus to contract and at only 22 weeks gestation we needed the contractions stopped. My doctors act quickly and find a medicine to get the contractions under control. The bleeding soon stops as well. The next morning December 13 we are given more devastating news ... an ultrasound reveals the fact that Ian does indeed have transposition of the great vessels. My heart can bear no more. I vividly remember one of the NICU doctors telling me that "We should not hold out much hope for this baby either" A heart defect coupled with probable lung prematurity this is just not a good combination. I cannot even begin to put into words the emotions I was feeling at that time. Looking back I wonder how we ever survived it all. God's grace was sufficient just as He promises. Days and weeks drag on. Taylor's situation is looking worse with each scan. She has severe IUGR. She is so much smaller than Ian & Christian. At 30 weeks they are each over 3 lbs. And Taylor only 1 ½ lbs. The doctors think her small size may be a sign that she could have Trisomy 18. Her blood flow into her umbilical cord is extremely poor and she has little fluid around her. Even though we've made it to 30 weeks (a true miracle), she is far too small for the ECMO or life saving surgery she will need to correct the hernia. I want to be hopeful but I am so scared for her. I ask God to please make her path very clear to us. I did not want for us to have to be the ones who would have to decide her fate. The NICU doctors were wonderful. It was the same doctors who had cared for Tara and Rheannon. They assured us that they would be there for us every step of the way, and they were.

Saturday February 6, 1999 we have made it to 31 weeks today. By early afternoon I'm contracting more than usual. By 5:00p.m. I'm at the point of no return. The stitch in my cervix is threatening to tear and they cannot get the contractions under control. They get me prepped for a Csection. God was working every step of the way. The NICU was fully staffed, Skip and the girls were with me as well as my parents. I was so worried things would happen in the middle of the night and Skip would not make it in time. They were also able to give me an epidural. This was also an answer to prayer because I had to be completely under for my first delivery. I wanted desperately to be awake to be a part of any decisions regarding our babies. I did not want Skip to have to do it all alone. I called to have the prayer chain at our church started before going to the OR. I pray and ask God to please help me as I have never known such fear in my life. This was it. I just wanted to keep the babies inside of me where they were safe and alive. All that was waiting for me in that delivery room was uncertainties especially for Taylor and Ian. Certain death also awaited me there because there was Saige. Would I want to see her? Skip knew for sure that he wanted to, I was not so sure. Before they take me, I give Tara, Rheannon, and my parents a kiss. The girls are both crying, my doctor assures them that he will take good care of me. The epidural is placed and they bring Skip in with me. He prays with me before they begin. It is impossible not to sense the tension in the OR as they begin. And so on February 6, 1999 we welcomed; Ian Remington came first at 6:27 pm weighing 3 lbs 6 oz and 16 1/4 inches long. Christian Earl, 6:28 pm, weighing 3 lbs 4 oz, 14 3/4 inches long. Taylor Saige, 6:29 pm, 1 lb 8 oz, 13 inches. Saige Leigh, 6:30 pm 3 oz, 8 inches.

Ian, Christian, and Taylor all entered the world crying. Taylor's was faint, but she cried and that gave me hope. Thank You Lord.

Skip went to check on the babies as the doctors began to stitch me back up. My joy is very short lived as Skip reenters the room crying. He tells me that other than a double thumb Taylor appears normal, bur the doctors think she has little to no lung function. They want to know if we want them to put her on a vent or just let her go. Before I can even answer a NICU doctor tells us that she did pink up and so he felt we should put her on a vent and do some blood gases

As they are finishing with me Skip comes back, the look on his face says it all...Taylor has declared herself. She does not have enough lung function to live. Did we want to keep her on a vent or just hold her for whatever time we might be given? Thinking back on it now is so unbearable. At the time it seemed so surreal. I felt as though I was on the outside of someone else's life and I was just watching. Something this horrible could not be happening to us. I was emotionally numb!

As he finished sewing me back up, my Dr. tells me that he will take me to see the babies. I could not believe this. We were going to have to meet our little girl only to have to say good-bye. As much as I thought I had prepared myself for this scenario, I was in no way prepared. Nothing and no one could possibly prepare you to say good-bye to a precious life that's only just begun. We were to have a lifetime and instead we would have only moments. As they wheel my bed into the NICU we are surrounded by doctors and nurses. Skip was holding Taylor and he gently placed her in my arms. Skip is holding me as I'm holding Taylor. She is so tiny but so beautiful. Such big and beautiful eyes for such a tiny girl. The nurses said she opened them big to look at her daddy. It seems we only had time to tell her that we loved her before she left us. I thank God for the time that He did give us. I could see and feel the emotion in the NICU that night. So many doctors and nurses had been hoping and praying for a miracle for Taylor. I guess the miracle came in that Taylor was a fighter. She kept going against all odds, and she kept on fighting long enough to allow us to meet her while she was still alive and to glimpse into her big and beautiful eyes even if only for a moment.

After Taylor died in our arms, they take me to see Ian and Christian. Then I have to be taken to a recovery room for observation. They allow Skip to bathe Taylor. Rheannon wants to help him with this. Tara did not want to be a part of this, she was scared. I'm angry because they did not allow me to be a part of this. I am glad that Skip got that chance to be with Taylor though because he would have to travel to another hospital to be with Ian later that night. After Skip and Rheannon bathed and dressed Taylor, they let all those who wanted to hold her to do so. It was then that Tara changed her mind and wanted to hold her sister. The nurses were all so amazed at the strength and dignity Tara and Rheannon exhibited that night. I have a beautiful picture of each of the girls holding Taylor that I will always cherish. Skip, the girls, grandparents, many who loved her held her until around midnight. Skip and Tara and Rheannon also chose to see Saige. Skip asked if I wanted to see her. He told me that her little body had really collapsed. She now weighed only 3 ounces and she was somewhat mangled from delivery. I just could not bring myself to even look at a picture of her that evening, let alone to actually view her in this condition.

My emotions were just absolutely raw ... I felt as though my heart could bear no more pain and so I declined. A decision I regret now, but I did what felt right at the time. There again, I was so proud of my daughters and their strength. After they had seen Saige, they told me that she looked like a little dinosaur. The honesty and straight forwardness of a child is amazing.

Around midnight everyone left. I'm still in recovery, grandparents take the girls home, and Skip needs to go to the other hospital that Ian is being flown to. Diane, an ultrasound technician for my Dr. and who is also a bereavement counselor offers to stay the night with me. This is very welcome since Skip cannot stay with me. Diane was such a blessing to me that night, she took many pictures of Taylor and Saige. She got their footprints and handprints and she also encouraged me to hold Taylor. I was scared. I had not seen her since she had died in our arms. Diane reminded me that this would be the only time that I would have with her. I ask Diane to bring her to me. I will always cherish those hours I had with Taylor. She was dressed in a little white dress and matching bonnet. My beautiful little girl. I held her in my arms for hours. I would nod off from time to time and wake to find her in my arms. She looked as though she was only sleeping. It felt so right to have her in my arms. I did not want it to end. As Diane took Taylor from me, I just could not allow myself to think of the reality of it all.. this was it. There will be no firsts for Taylor. No first smile or first steps. There will be no good night kisses. Our only kiss will be that of good-bye. This was the most heart wrenching pain imaginable, and yet at least we had these few moments with Taylor. We would not have them with Saige because her frail little body could not be held, and our two other sweet babies, we only have a few ultrasound pictures of their brief time with us. We do, however, have the hope of being reunited with them one day in Heaven.

Christian did well right from the start. He was our one healthy baby. He was also one of the babies they would have reduced out of the pregnancy because of his placement in my uterus. He has the biggest blue eyes and the chubbiest cheeks. I cannot imagine our lives without him.

Not long after Taylor's death, Ian began having cardiac problems. He was flown the night of his birth to Hershey Medical Center where they performed heart cath to temporarily save his life. This procedure would temporarily allow his blood to mix until he was stable enough for them to switch the vessels of his heart. When he was six days old, they performed his surgery. He was the tiniest baby they had ever attempted the surgery on.

I stayed up that whole night and cried. I was terrified every minute that someone would come into my room and tell me Sydney didn't make it. Nobody did. The person that finally came was my husband. It was morning and he returned from the NICU to tell me the doctors thought they could operate and possibly save Sydney. They weren't sure if her lungs would inflate, but at least it was worth a try. She had a 50% chance to live.

Sydney remained critical but stable. We stayed at her bedside every possible second. We wiped whatever skin we could reach with gauze and put baby lotion on her. We combed her hair and sang to her. We changed her diapers. Her nurses helped us and encouraged us. They were her angels: Peggy, Angie, Amelia, Jessica, Debbie.

On Friday, when she was three days old, Sydney had her operation. The whole process from start to finish lasted three hours. Her surgeon, Dr. Steven Palder, closed her diaphragm with sutures, but her intestines had grown too big for her body. A Gore-Tex patch was sewn into her abdominal wall to give her more room. She came out of surgery with more tubes than when she went in.

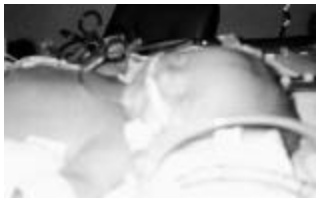
Thankfully, the weekend proved to be uneventful. On Monday, they removed one chest tube, one foot IV, and her arterial IV's. On Tuesday, they extubated her, removed the other foot IV, and took out her nose tube. It was the first time we saw her face. They began to bottle-feed her my expressed breast milk. Wednesday they removed the other chest tube, her hand IV's, and her staples. We were finally able to hold her. On Thursday they watched her eat, pee, and poop, and on Friday we took her home. She was ten days old. Everyone called her the Miracle Baby.

The first few weeks at home were a little scary. We were new parents, with a baby that just had surgery. It was flu season, so she wasn't allowed out of the house and we couldn't have visitors. She never did learn to nurse, so I continued to pump my milk for her. We had to keep going back to the hospital for weight checks, blood tests, x-rays, and hearing tests. She did fine through it all.

She is now 3 ½ months old and perfectly healthy. She sleeps through the night and eats well. She is more than double her birth weight. She loves ceiling fans and her daddy. She is always smiling and laughing. She recently discovered her hands, and discovered that the best place for them is in her mouth. She just started trying to roll over. I am still trying to sort out in my mind everything that's happened. I pray every night that my baby wakes up in the morning, and every morning I give thanks for another day with her in my life. My biggest concern at the moment is that the Gore-Tex patch in her abdominal wall may have to be removed, which is another major surgery. Hopefully, if it doesn't bother her, she will be able to keep it forever.

The CHERUBS web site and the friends I've made there have been a great source of comfort and information for me. I've written this story for Sydney, and to help other parents about to embark on the most challenging journey of their lives. Sydney was very lucky; I realize that many others are not. I hope that someday a cause and a cure can be found for Congenital Diaphragmatic Hernia so that no baby ever has to suffer through this again.

Jennifer DiMaria (mother of Sydney DiMaria, 2/15/00, 18 Jersey Avenue, Old Bridge, NJ 08857, 732-679-5177, vin411@aol.com)



It all started when I was about 3 months. It was a regular check-up. The DR. found she had C.D.H. I was not too sure what was about to happen. So 5 months later the doctors from San Francisco called me and told me my best bet would be to deliver there. So 4 days later I headed up there. The doctor ran every test possible. So 2 days later she was delivered by C-section, Alexyss was born at 7:59 a.m. on March 23, 1998. She weighed 8lbs 2oz. and 21in. She was rushed to the N.I.C.U. ECMO bay. She had her surgery on 4/1/98 and came off E.C.M.O. She really did good until her nitric oxide machine failed. The doctors. came and told me what was going on, that she had no chance to live. So we decided to pull her life support. Alexyss lived for almost a month. Alexyss would be two years old this year. My other two daughters talk about her all the time. We miss you baby girl, and we all will be together some day. Love You, Mommy, Brandi, and Breeanne.

Rachel Paige (mother of Alexyss Miller, 3/23/98-4/19/98, 559-224-9468, PackerGirl24@aol.com)

Amazingly, he never had any breathing trouble but continued with intestinal problems. This still comes and goes. He was hospitalized five times in his first two years.

Last January 2000, he had eye surgery to fix strabismus. The surgery seems to have been a success! In addition to the strabismus, he's also bowlegged, pigeon toed, and has syndactyl toes but these things seem so minor that I hardly notice them. Besides, nothing gets in the way of this little boy. We'll keep him, scars and all. He's truly our "Miracle Baby."

Grace and Wayne Massie (parents of Blake Massie, 11/13/96, gracem5@gte.net)

My husband and I planned for a long time to have a baby. Finally, when the time came, we were very lucky to conceive right away. We were so excited! I loved being pregnant and I felt great. My husband laid his head on my belly every night to listen to the baby and to feel the baby kick.

I went to my obstetrician regularly and passed every test with flying colors. We had an ultrasound at 20 weeks and everything was fine. We found out we were having a girl! We began decorating her room, picking out baby things, and reading baby name books. We were having so much fun; we couldn't wait to meet our daughter!

At 29 weeks, while still feeling fine, I awoke one morning bleeding. We went to Saint Peter's University Hospital in New Brunswick, NJ. After being examined, it was determined that I was in pre-term labor for some unknown reason. Since the baby appeared fine, they decided to stop the contractions. I was released the next day, on medication and bed rest. For the next 7 weeks I visited my doctor once a week and each time everything was fine. At 36 weeks I was taken off the medication. I began cramping and spotting immediately, with the severity increasing slowly and steadily over the next week. At 37 weeks, I returned to the hospital in full labor. I was given an epidural and six hours later we had our baby! Sydney Lynn was born on Tuesday, February 15, 2000 at 6:33 p.m. She weighed 6 pounds, 6 ounces, and was 19 ¼ inches long. It was the most amazing moment of our entire lives. Experiencing her birth was truly a miracle.

As soon as she came out, the doctor placed her on my belly. She was so beautiful! My husband took her picture and cut the cord. She looked so perfect; nobody had any idea something could be so wrong. But Sydney wasn't crying. The nurse took Sydney to the bassinet next to my bed. She tried rubbing her to stimulate her to cry, but nothing. Then she tried giving her oxygen, and still nothing. The doctor and nurse looked at one another, and the nurse pressed a button on the wall. Within seconds the room flooded with doctors and they all gathered around Sydney. They worked on her for a moment, then bagged her and wheeled her away, with my husband in tow. I stayed in the delivery room, empty, alone, and terrified.

Within an hour my husband was back. The doctors thought maybe Sydney had either an infection or fluid in her lungs. Neither sounded too serious to me, but I still couldn't understand why any of this was happening. We were supposed to have a healthy baby. Nothing like this has ever happened to anyone in our families before.

Next I was taken to a private room and my husband went back to the NICU to be with Sydney. This time when he returned, I took one look at his face and immediately knew there was something seriously wrong. He was completely pale and on the verge of bursting into tears. He explained that the baby had a diaphragmatic hernia. Her intestines were up in her chest, her heart was pushed all the way over to the right, and her lungs were not developed. I was crying hysterically. I wanted my baby back. I didn't believe what they were saying. How could I have done this to her?

They worked on Sydney all night. She kept crashing and they kept working. They took turns and they took breaks and finally at some point she stabilized. Later that same night I went to see her. She was a complete mass of machines and wires. She had tubes everywhere and monitors all over her. There wasn't one inch of my little baby visible. I died looking at her. I wasn't allowed to touch her. They handed me Polaroids.

The 7 hour surgery went well, but 7 hours post-op Ian's vital signs plummeted causing severe damage to the left ventricle of his heart. They told us that Ian probably would not survive that day. I remember praying for Ian and for the first time in my life realizing just what God had done for me in sending His one and only Son to die for me. What right did I have to ask God to spare my son's life when He had so freely given His own Son's for mine? We did pray for Ian though, and God intervened and saved Ian's life.

For almost one month we could not even face or deal with the death of our daughters because at that time Ian's outcome was so uncertain. March 09, 1999 Ian is stable enough to send back to York Hospital to feed and to grow with Christian. This is an answer to prayer because we are exhausted from traveling between the two hospitals. Now we must face the inevitable ...saying goodbye to our babies. March 11, 1999, we held a memorial service at our church. We are touched by the number of people who came. Nearly 100 people came Many in our families came, as well as people from church, doctors, nurses, ultrasound techs. We were truly blessed by so many coming to share in our sorrow. The next morning we buried Taylor & Saige together in one little white casket. It seemed only right to bury them together ... they began life together and so it should also be in death for them… together forever.

Christian came home 3/28/99 and Ian 4/08/99. They are filling our lives with much laughter, joy, and love. Christian and Taylor had the same little profile, and I'll bet Saige probably looked like Ian. I like to believe that we'll always have a little glimpse of them in Ian and Christian.

To Taylor, Saige, and our two other babies we lost, we would like to say that we will always love each of you. We thank God for the time that He gave us with each of you. We now entrust each of you back to Him. It is a comforting thought for us to know that you will be held in the everlasting arms of our Lord, and that we have the hope of being reunited one day in Heaven when we will have eternity to get to know each of you.

In closing, I would like to say that through all of this that God was Faithful.. We have so much to be thankful for. We have our beautiful children both here with us as well as those in Heaven. I had two wonderful doctors and their staff who helped me through an extremely difficult pregnancy. We were blessed to have an excellent hospital for my lengthy stay. The nurses went out of their way to make things bearable for me and my family during that stay. York Hospital also has a wonderful NICU staffed with caring and compassionate doctors and nurses. We were also fortunate enough to have one the finest pediatric heart surgeons to do Ian's surgery at Hershey Medical center, as well as a great NICU and PICU who saw Ian through an extremely critical time. We thank God for each and every person who helped us through this difficult time.

I'm thankful for being blessed with the most wonderful man to call my husband. I always had his love and support surrounding me and holding me... helping me every step of our journey. God also gave me the special gift of two strong and courageous daughters ... Tara and Rheannon were so wonderful throughout my bed rest at home, my hospitalization, and everything that followed the birth. I know they were so scared, but they hung in there with us through all the tears and the triumphs. They are now wonderful big sisters.

We were also blessed with family and friends who selflessly gave of themselves and their time to pray for us, provide childcare, cook meals, etc. I'm thankful, too, for CHERUBS. Your group has been a source of strength for me. My prayer is that some day doctors will find a way to make the odds for surviving CDH much higher they are today. In my heart of hearts, I feel that one of the medicines I took will someday be linked to CDH ... only time will tell. Thank you for taking the time to read this. May God bless each of you and your CHERUBS.

Chrissie Cooper (mom of Taylor Saige Cooper, 2/6/99-2/6/99, 2735 Ridings Way, York, PA 17404, 717-792-0433)

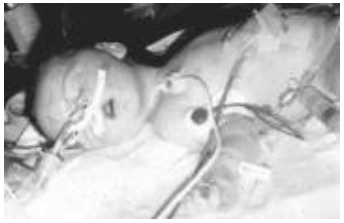
My first pregnancy was completely uneventful. Our son, Colton, was born on his due date 8-8-98, and he weighed 8 lbs 8 oz. We were fortunate in that he was an exceptionally good baby. He was always happy. He slept well and he rarely cried. I was eager for another child almost immediately and I became pregnant again when Colton was only 6 months old.

My second pregnancy was as uneventful as the first. I had two completely normal ultrasounds, both before 22 weeks gestation. Never, was there an indication of a problem. We did not want to know the sex of this child even though we did with the first. I gained a lot of weight (60lbs!) but I had gained (and lost) the same amount with the first

pregnancy. The only difference this time was that my hands and feet were more swollen and I developed carpal tunnel syndrome in both wrists.

Strictly for convenience, I was scheduled for induction at 7:00am Monday, October 25, 1999 at River Oaks East in Jackson, Mississippi. The day progressed rather well and everything seemed to going on schedule. My first delivery had been 3 solid hours of pushing to deliver an 81b 8oz OP baby (OP positioned face down and more difficult to deliver vaginally). Because of that, my doctor expected a shorter, easier delivery this time around. It was shorter, but by only 15 mins. After 2hrs 45mins of pushing, the head was delivered and my nursed exclaimed "Oh, my God!" This is not what you want to hear at a moment like this. I couldn't imagine what was wrong with my baby. But the nurse's next statement was, "Look at the size of the baby!" Cameron Dianne Watson was born at 345 pm and weighed 10lbs 0oz. I was trying to catch a glimpse of my new daughter when I noticed the nurses attending to her were whispering and they sent for a pediatrician. Immediately, my husband and I asked what was wrong. The nurses said she was probably fine, she was just breathing a little fast. She was not in distress. She wasn't blue. Her color was pretty good, so we weren't terribly upset (yet). I was allowed to hold her for a brief moment before they let my husband carry her past our waiting family to the nursery. They were supposed to bring Cameron to my room to nurse after their standard 4 hour period of observation had passed. When the time came, the nursery called my room to say they needed to watch her another couple of hours. Two hours later, I was told they needed to observe her another couple of hours. Cameron's respiratory rate was staying around 100/min. I was told that this happened in large babies occasionally, but that it usually resolved on its on, and that she should be fi ne by morning. I was allowed to go to the nursery and attempt nursing her there under the watchful eye of a nurse to monitor her respiration. A few hours later, she was moved to NICU because her CBC had a high white count and her respiratory rate was still around 100/min. There were 5 other babies in the NICU that were all born prematurely. Cameron weighed more than all 5 babies put together. My husband and I went to the NICU and sat with Cameron for the rest of the night. I was trying to think of a way to describe the way Cameron was breathing to a friend, and all I could think of was that she was breathing like an animal that had been hit by a car and had ruptured its diaphragm. (My husband and I are both veterinarians and unfortunately, we compare everything to animals.) I never really considered the fact that my daughter might have a diaphragmatic hernia. I was just trying to describe what her respiration was like. The next morning, a chest radiograph was taken. The neonatologist brought the film out and held it up to a light for my husband and I to see. We said simultaneously, she has a diaphragmatic hernia. At that instant, I was almost relieved because we now had a diagnosis and we could correct the problem. Then I began to worry because my child was about to undergo surgery. I was going on the assumption that the hernia had occurred at birth. I didn't want to think about the possibility of the hernia having been present for very long and her having underdeveloped lungs. At 3:45 pm, when Cameron was exactly 24hrs old, they took her away to surgery. Her surgery lasted just under an hour, and shortly after she was returned to NICU, we were allowed to see her. I was so relieved that she had survived surgery that I didn't notice all the tubes and IV's she had in her. She had had a left sided hernia and there was no need for a patch to correct it. Almost all of her intestines had been in her thorax, but nothing else. She came off the respirator by midnight that very same night, and she steadily improved. One by one, all the tubes were removed. After only 8 days, we brought Cameron home. She is perfect. She is steadily growing. She has no problem with reflux or anything else. I read the letters from other mothers with children who had diaphragmatic hernias and I thank God again for blessing us with complete recovery. I don't know why my child was born with a hernia and I don't know why she recovered so quickly when most children do not. I do know that Cameron had an entire community praying for her, as I am sure many of your babies have too. So many of the stories I've read have ended in such tragedy. I just wanted to write Cameron's story because it has such a happy ending.

Dianne Watson (mom of Cameron Dianne Watson, 10/25/99, P.O. Box 3939, Brookhaven, MS 39603, 601-833-1223, bwatson@telapex.com)



My son, Sean Matthew, was born on April 29th, 1988 in St. Peter's Hospital, New Brunswick, NJ. When Sean couldn't breathe on his own, X-rays revealed he had a Diaphragmatic Hernia.

Sean survived the surgery that repaired the hole in his diaphragm. The plan was for him to be flown out-of-state to Pittsburgh's Children's Hospital, and be placed on the only available lung bypass machine.

Sean never made it to the Pittsburgh Airport. He

died during the flight, having lived only 15 hours.

Though his life on earth was short, and I was permitted to hold him for just a few seconds before he was rushed off to surgery, Sean has had a profound affect on my life and that of his brothers. I will always love and miss Sean. He is in my heart, forever.

At nine months pregnant, I was looking forward to bringing my second little boy home. My first born, Brian, was 18 months old. My then-husband, Michael, and I had recently purchased a real bed for Brian, leaving his crib for the new baby.

Since we knew that I was once again pregnant with a boy, we picked a boy's name right away, and always referred to the baby as Sean. Ironically, the ultrasound revealed the sex of our child, but not the birth defect.

Preparing for a life with two little boys, we painted their room blue and decorated it with Disney characters. We dreamed of our lives as a family of four, with two little boys growing up together, both in Little League, going to school together, double dating, being best friends.

Our dream shattered in pieces, with the shock of Sean's birth defect and death, and culminated in the breakup of our marriage and family.

April 29th, 1999 is the 11th anniversary of Sean's birthday. His big brother, Brian, is 12 1/2, learning to play guitar, getting straight A's in the sixth grade, and excelling in track, basketball, soccer, and football. Brian is also an artist, an avid reader, and music lover.

Five years after Sean, there is another brother, Joey. Joey is in Kindergarten and almost six years old. Mischievous and always on the go, Joey takes everything apart to "see how it works," enjoys building things with Lego's, K'Nex, and even paper, tape, and cardboard boxes. He dreams of being an inventor.

I have a full life as a single, working Mom to Brian and Joey, but I always long for my second-born, Sean. I wonder what Sean's dreams and talents would have been, and I regret that I didn't get the chance to hold him, kiss him, help him with his homework, and even scold him for teasing his little brother, sneaking the dogs into his room, or muddying the living room carpet.

When I say I have two boys, I always think three. In my heart, I love Sean as much as I love his brothers. I will always miss him.

Susana Maria Rosende (mother of Sean Matthew Lutz, 4/29/88- 4/30/88, 2708 Tannery Court, Orlando, FL 32817, 407-671-7637, suemrose@gdi.net)

Reading the stories of other Cherubs has been so therapeutic for me that I figure it's high time I write my own Cherub's story.

To look at Blake today you'd never guess what a rocky beginning he had. He appears to be a normal, healthy, happy 3 year-old. He loves toy trucks, especially construction machines, and has quite a Tonka collection. During his quieter moments, he enjoys going to the library and reading books about - you guessed it - TRUCKS. He's done a lot of catching up but he's still a little smaller than most of his friends.

Blake Christian Massie was born November 13, 1996 weighing 6 lb 4 oz and was 20 inches long. He joined two brothers and a sister. He wasn't diagnosed until several hours after birth. In addition to the CDH, he also had malrotation of the gut. He was airlifted to Seattle Children's Hospital and had surgery the next morning. His left lung was only half formed but his heart migrated back into the proper position. Because of the malrotation all of his internal organs weren't able to be put back into the correct places but everything worked! Luckily he only needed a ventilator for 9 days. Feeding came slowly, he had some oral aversion, and he had some problems with reflux and weight gain. He was able to nurse with two supplemental bottle (breastmilk/formula mix) feedings per day. He was so unusually quiet as an infant that it was worrisome. He was and continues to be a good-natured little guy.

At seven months, he had a closed loop bowel obstruction that led to gangrene and peritonitis that nearly killed him. He was rushed by ambulance back to Children's where his gifted surgeon once again saved him.