Winter 1996

CHERUBS

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

CHERUBS
P.O. Box 1150
Creedmoor, NC 27525

Dear Members,

We would like to dedicate this and every winter newsletter to the families who have lost children to CDH; in order to remember and remind. I hope this newsletter will help our grieving parents to grieve and our non-grieving parents to give thanks. We all know that any one of could be one of the grieving parents and that all of those in grief should be remembered especially during the holiday season. So this newsletter and all winter newsletters will be filled with the stories of children who did not survive. I know it's hard for families of nonsurvivors to read stories of survivors and vice versa, but it's also therapeutic for all. We all have more in common than not. The 3 remaining newsletters each will continue to combine stories from both sets of parents. I want to be one organization, not divided into survivors and nonsurvivors; we have all dealt with CDH despite different outcomes. I hope this newsletter will do justice towards this goal.

I would like to apologize to Miss Kaylee Bentz. Her name was attached to the wrong picture in our last newsletter. The picture was of Kristin Moats. Please put your child's name on the back of pictures sent in. I will try not to make this mistake again.

Our research library inventory list are ready!!!!! In order to save postage, we will only mail these out to those of you who request a copy. So if you would like one, please send a letter or give me a call and I will be happy to mail one out to you. They are free and we will not charge postage costs for one copy for each family or professional. I hope you all take advantage of this offer. Our Congenital Diaphragmatic Hernia Survey results will be published in our Spring 1997 newsletter. Keep your fingers crossed!!

I hope all you find peace and happiness this holiday season.

Sincerely,

CHERUBS Would Like To Thank The Following For Their Help and Support:

Rhonda Montague
Bob and Brenda Slavin
Jay Schmidt, RN
Jeremy Torrence
Beth Zimmerman, RN, MS

CHERUBS Would Like To Thank The Following For Their Generous Donations:

Julianne Brian
Renata Hoskins
The University of North Carolina Holiday Card Project Fund
Mita Patel
Corinne Porter
Jessica Jarrett
Lesli A. Taylor, MD
Measurement, Inc. Printing Company

CHERUBS Wish List to Santa Clause

- A laser jet computer printer
- A computer scanner
- A copy machine
- Computer software and clip art
- A telephone answering machine
- Envelopes, all sizes
- Postage stamps

CHERUBS is an international organization for families and care-givers of children and adults who are diagnosed with Congenital Diaphragmatic Hernia (CDH). CHERUBS provides information, support, parent-to-parent matches, a research library, and a congenital diaphragmatic hernia research survey. There is no cost to parents for services provided by CHERUBS. We are a volunteer organization founded in February of 1995 and an Internal Revenue Service recognized Non-Profit Association. Donations are very welcomed and tax-deductible. The livlihood of CHERUBS depends on donations from our professional members, families, and the public. Check can be made out to CHERUBS. The opinions shared in this newsletter do not necessarily represent the views and 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 cannot compare the progress of another CDH child to the progress of your own child. They are all little angels............CHERUBS.

Meet Our Board Members

Dawn M. Torrence- President and Founder
Granville Co., NC Parent Advisor for Disabled Children

Lesli A. Taylor, MD- Vice-President
Assistant Professor of Surgery and Pediatrics
University of North Carolina at Chapel Hill

Rachel L. King, RN- Board Member
Nurse Supervisor, Pediatric Intensive Care Unit
Duke University, Durham, North Carolina

Jeremy D. Torrence- Board Member
Parent Advisor; Fathers, Franklinton, North Carolina

Brenda Slavin- Bereaved Parent Advisor
Parent, Edgewater, Maryland

Vincent R. Adolph, MD-Medical Advisor
Department of Pediatric Surgery
Ochsner Clinic, New Orleans, Louisiana

Michael R. Harrison, MD-Medical Advisor
Professor of Surgery and Pediatric
Director, Fetal Treatment Center
University of California, San Francisco

Aviva L. Katz, MD- Medical Advisor
Division of Pediatric Surgery
Alfred I. du Pont Institute, Philadelphia, Pennsylvania

Jacob C. Langer, MD, FRCS(C)- Medical Advisor
Associate Professor of Surgery and Pediatrics
Washington University in St. Louis, Missouri

Prem Puri, MS, FACS- Medical Advisor
Consultant Pediatric Surgeon
Children's Research Centre
Our Lady's Hospital for Sick Children
Crumlin, Dublin, Ireland

Jay Mark Wilson, MD- Medical Advisor
Assistant Professor of Surgery,
Harvard Medical School
Associate in Surgery; Director, ECMO Program
Boston's Children's Hospital, Massachusetts

Beth Zimmerman, RN, MS- Medical Advisor
Clinical Nurse Specialist
Section of Pediatric Surgery
Wyler Children's Hospital,
University of Chicago, Illinois

Claudine P. Torfs, PhD- Honorary Medical Advisor
Epidemiologist
California Birth Defects Monitoring Program

Wendy Barkley- Honorary Medical Advisor
Parent and Registered Dietician
Lawton, Oklahoma

Stories of Real CHERUBS

Max Robert Porter
September 1, 1996-September 14, 1996

October 16, 1996

Dear Dawn.

Hi! I have so much to tell you. I'll begin with the very sad news that Max was too sick to make it and he passed away September 14th.

We went to San Francisco July 29th for the in utero surgery. Unfortunately I was showing signs of premature labor (I was dilated to a cm.) so Dr. Harrison felt it would be far too risky to go ahead with the surgery, so we didn't. We stayed in San Francisco, I was in the hospital for 3 and half days, then we went to live in a motel room. The doctors wanted me to get to 36 weeks to insure Max would be big enough for ECMO. I was on elevated bed rest for 5 weeks. Bob was able to be with me the entire time, thank God! He took really good care of me. I was able to get up to go to the bathroom and go to the doctor 2 times a week so that was good. I started a few letters to you, but never finished them. We made it 2 days short of week 35 when they induced labor on September 1st. 2 days prior an ultrasound (about the millionth one I had!!!) showed that Max had developed hydrops around his heart and under his scalp. They felt it would endanger Max if he wasn't born then and they were able to tell he already weighed 5lbs which was big enough for ECMO. I was only in hard labor for about 5 hours, then Max came quickly!!! He was born at 11:49 pm. We even heard a small cry at first as they were taking him away. Dawn- he was such a beautiful boy- I'm so thankful I got to deliver him naturally- it was a wonderful experience.

Max did ok at first. They put him on a high frequency ventilator and he was doing well for the first 2 hours. Then they had to put him on ECMO. because he started going downhill fast. It was very upsetting at first to see him on the ECMO machine, but we knew it was keeping him alive and giving him the chance he needed. they didn't do surgery until he was 1 week old because when they had tried to take him off ECMO he didn't do very good until the 6th day. Surgery went well. but he went downhill after that. he began bleeding around his liver the day after surgery. They were able to stop it by trying an experimental procedure. But his tummy began swelling and they couldn't figure out why. Max had a pretty bad hernia- the entire right side was missing. His whole liver and some bowels were herniated. They took him off ECMO on September 13, 1996 and he simply could not do it on his own. We were at the hospital that night. We finally left his bedside at 11:00 to go get some sleep. I woke up at 2:45 and went back to him. When I walked into the bay and I saw the doctor's face, I just knew this was it. He told me to go get Bob because Max was struggling so bad. I did and we took a moment to pray. We went back and held Max on the ventilator, he was already turning blue. They took him off and he passed away at 5:30 am. God I miss him so. We had so much hope throughout but God had something else in mind. We hated seeing Max suffer the way he did. We never got to hear him cry other than the little cry when he was first born. At least we have that. We spent as much time as we could with him. but then again we were always worried we weren't spending enough time with him. It was so draining we were surprised at how tired we always were. We made the arrangements necessary to transport Max home and we left San Francisco the night he died. Our friends had driven our truck down to us 3 weeks prior so we drove home. We stopped twice and got home on Monday. It seemed so wrong to be coming home without our son. But it was nice to be home. We had Max's service on September 20th.

Bob went back to work 2 and a half weeks ago. I'm going back Nov. 1st. I think we are doing ok. We are able to talk to each other about how we are feeling and we have a very wonderful support system of family and friends. We've bought some really good books and we've joined a support group. We just miss him so much, the pain is so great at times. We know he's in a wonderful place and most importantly he isn't suffering! The picture I've sent is my favorite of him. He is 6 days old here. He looked so much like Bob! I always said I wanted him to look like Bob but have my hair and that's exactly what he came as!

Dawn, I'm so sorry it took so long for me to contact you. I know you were worried about us. I really want to stay a part of CHERUBS because if I, or Bob can ever help someone we really want to. I pray that no other parents will go through what we did. I know that's not realistic but I still feel that way! We were, are, and always will be so impressed and thankful for the doctors and nurses we had taking care of Max. They were great. The nurse on duty the night/morning Max passed away was especially wonderful. Well, I'm sure I'm leaving a lot of details out, but I wanted to let you know all that happened before anymore time went by. Hope all is good with you and your family. I'll keep in touch!

Take care,
Corinne Porter
26026 184th Ave SE
Kent, WA 98042
(206)-631-2693

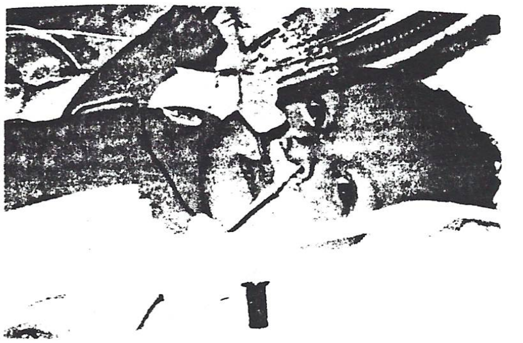
The following was written by my dear friend Rhonda. I wouldn't have printed some of this because it is so personal, except Rhonda asked me to. She was the first other parent of a CDH baby that I met and she was and is my rock. She is strong and outspoken and I know what she says here many of us have felt, but have been scared to say aloud. Rhonda has more courage than she gives herself credit for and I thank her for being so honest in telling her son's story. I know she will inspire many of you as she has inspired me.

To my dearest Dawn,

I don't know you from some newsletter, or phone call- I know you and your heartaches personally. We met through the doorway of a breastpump room on the 5th floor of Duke University- when I found out you had a CDH baby I felt your footsteps trailing behind mine. I knew what they had told you and what I knew would be different- none the less my heart pumped at the thought that I was no longer alone. We became very close over those 2 and a half months we were together. You were like a rock to me and you still are. When Preston died you were the one to comfort me. You brought me the blankets for my son to be held and take his last breath in and instead of one you brought me two- the other my son, Derrick, who is now 5 still uses every night when he curls up to go to sleep. I am so sorry to have left you out of my life the way I have- but you are not forgotten- my memories of Preston are a whole- the whole- thing- and you were a very significant part of that and so was Shane and Jeremy too. I envy your strength. What you have created in CHERUBS is such a powerful thing. It takes a lot of thought, time, and effort. I am amazed and so very proud of you. I knew you had it in you the way you were the first few weeks in the hospital- sad, cold, quiet, then you changed. You became a fighter just like Shane. You took control- things I would have loved to say to Preston's doctors you said to Shane's. And the support you gave to others- what a blessing it was to have your shoulder. I haven't been to see you, out of fear probably. As others, I have gone on with my life and it is so easy to do. Two healthy, wonderful children, a new house- the basic worries and petty things of life. But then there are those reminders. I know what that hospital, worry, adrenalin pump 24 hours a day is like- when all those petty things are so numbing to hear about. People argue, fuss, laugh and cry over nothing. When parents of sick babies are in their world- every moment is a moment cherished, hated, and loved in one breath. And always the fear- the dreaded fear of what next. Will there be a next? Sometimes I miss that so much. Why- because I knew he was there and in all his fight I could still help him, be with him, touch him. It has taken me three years and 8 months to be a part of my friend's CHERUBS- and there all you members are shared bonds- but strangers- when you lose a child you have to go on. My survival had been to repress feelings- I only let them come out when I am strong- only to find I am really weak- and those memories have not left my crumbling heart. So Dawn, please forgive me, as I knew you understood somehow. And to those mothers who may have needed me then. Please forgive me also. I will do my best to be here now.

I Love Ya Dawn,
Rhonda

Preston's story



Preston Carr Montague
December 29, 1992 – February 27, 1993

Preston, a name I chose, a name I love to say. It is the name of my son, a name, a baby, a person whom I will never forget. Preston, born 12/29/92, died 2/27/93. The birth of my second son, Preston, was not as joyful a moment as my first born son. Yes, I was one of those mothers. Screaming something is wrong before the doctors even realized it. Taken from my arms, surrounded by doctors and nurses- there lay my son, a diaphragmatic hernia baby- diagnosed 3 hours later- then transfered to UNC. After a long operation and 24 hours later, I finally saw him again. Within an hour after my arrival to UNC he was ife-flighted to Duke. I am sure that most mothers with sick hildren don't need an explaination of the memories, sounds, feelings of emotion, despair and helplessness of the days and months and many life-threatening decisions later. We all share a pain of our own in our own ways. My fondest memories of my son were wiping his dry lips with neosporin, giving him the only 2 real baths he ever had, playing different tunes on his cassette tape. Winding the special toys that I had carefully picked for him, holding the hand that had less tubes, wiping the matter that sealed his eyes shut so that he could see, keeping his diaper dry and bottom rash-free. This was the concern of a mother because the doctors and nurses weren't interested in bottom care! These were the things that made me the mommy and the others the doctors. It has been 3 years and 4 months since that hrrible day for us and finally a restful day of peace for my little one. I call those days the best and worst of my life. At times it feels like a dream I had long ago and at other times it feels so close to me that i can smell the smells, hear the beeping sounds. It was not long ago I had taken my newest miracle, Sierra (2 years) to ER for stitches. I had washed my hands with hospital soap as so many times in the past. The smell of that soap is like the scent of my son. I remember trying to keep my hands from touching things so that I could keep the scent as long as it would stay (my little girl was just fine, only a few stitches by the way!). To all of you parents, mostly the mothers because we are usually the sentimental ones. I would like to say; it is ok to cry, ok to be sad sometimes. Others will never understand. Do what you have to do to grieve. I do things that others wuold probably send me to a mental institution over. But, it is my way.... for example, i talk to Preston, dance with his picture, took my pregnancy test at his graveside, close my eyes and dream of him in heaven, take out his toys or tapes or pictures and just in my own way let him know that I love him an dhe is still alive in my heart. If this is crazy- so be it. I would rather be crazy than to be without him. I even have graveside and we send him balloons. Once I sent a balloon with all the children's name who had once been his beside friends. A lot of parents who have recently lost a child wonder how they will go on. First and most important- God is the key. Without Him I would not have survived this crisis in my life. People ask how do you do it and my reply is always the same- God's grace. He gave me my son. He made a place for my son and one day He will join me with my son- This was God's promise to me when I promised to be faithful in serving Him (I became saved the night Preston was born). To those of you that God is preaking to; hear me. Do Not Test God- Preston was God's link to my heart. And when the link was no longer needed- He took him home. Now I have to be faithful not only because he has someone I want to see again but because I truly love God and more than anything I want to be where He is.

Where do you go? What do you do after reality of this cruel world starts to set in; no more cards or phone calls, no more sympathy which sometimes I actually long for. you go on and it goes on living inside you. One of the hardest questions people ask is "How many children do you have?". Such a simple question; such a complex answer. To most i say "Three, one of which is in heaven" (there's that sympathy I wanted!). And on the days I'm not so strong, I jus say "Two" and in my heart I say "I'm sorry". Others won'twant to hear about or talk about it anymore. The take down the picture of the baby who never was and place it in an album. It has been 3 years. I have learned to exist with the heartache. I am a good mother and wife. My only regrets of guild is how my son suffered. His little body was pushed to the point it could no longer take it. His kidneys shut down; we pushed him to the point his skin began to tear all over- he became unrecognizable. On that sad morning at 10:30 we cut off his ventilator. He took 3 long breaths and then it was over. What he and we went through was all in God's plans. I'll never understand it really, but I think of (The Virgin) Mary- Her son was born. He taught the world a lasting lesson, and then early in life He suffered a terrible death. So that we may live forever. It may not be right to compare my life and my son's life to God's life. But as I have felt, Mary must have felt and my son will live forever too. And this makes me proud of him and to be his mommy.

This newsletter is dedicated to the memories of:

Samantha Rae Jonhson (November 4.-1996)

Max Robert Porter (September 1, 1996 - September 14, 1996)
&
Preston Carr Montague (December 29th, 1992 - February 27, 1993)

and all of the other Cherubs who were taken from us so soon

Trauma in Siblings

Derrick my first born was 22 months when Preston was born- fully potty trainted, sleeping in his toddler bed and expecting a new baby like the rest of us. He is a very sweet dispositioned child; very smart, very sensitive, had never been apart from mommy much. Those 2 and half months of his life changed him in a lot of ways. He was swept away from me for days at a time. Slept with everyone and still today comes in our bed even though he is now 5 years old. He had started wetting the bed at this time back in '92 and still today wears pull-ups the majority of the time. he was with Preston a lot; shared his toys and made special pictures for him. Even in his small age he had a great understanding. I hid nothing from him. However, seeing his mommy and daddy sad all the time must have been hard. Sometimes- most of the time- he was my greatest comfort. It had been only 3 days after Christmas and 2 and a half months later he finally returned home to play with his toy- the tree looking like someone had turned it to nothing was finally taken down late February. When Preston died we bought Derrick a plane mobile to hand in his room- a gift from Preston- to this day it still hangs and he remembers why. We've also in time given him one of Preston's special stuffed dogs- he sleeps with it every night. This is his little brother to him. He has his bond somehow. About a year ago we took him back to Duke. I hurt that he seemed bewildered. What I thought he would remember, like the shuttle (his favorite thing to do), or the fish tanks, or the parking deck where he'd tell me how to pard and which buttons on the elevator to push, or the Ronald McDonald house, where he played upstairs, he seemed unknown to it. Then later in the cafeteria he looked at me and his dad with tears in his eyes and said; "I don't remember all of Preston but i loved him a lot". Ripped my heart out and i wondered if I had pushed too hard to keep Preston's memory alive for him. During pre-school last year they were discussing someone's pet dying. Derrick began to talk about his brother dying- and he's a pretty shy little boy. His teacher was in awe and asked me about if it were true or not when I picked him up. My heart broke for him. We went to see Preston's grave that day and brushed the sand away, etc.. He didn't want to talk about that day at school. I knew that moment it would always be inside him just like it would be inside me.

Then there is my little girl, age 2. Oblivious to all that has happened and to the miracle she is to us. She hears his name and visits his grave and birthday parties also. I know she has a sense of this abstract being to be special. She'll find his pictures at our house and of course knows they are of "Preston". When she says his name she reminds me of another 2-year-old 3 years ago and I love to hear the song of that name a child's voice. Sierra visits the grave with us and even her first standing up on her own to walk was out there on Easter afternoon- of course there were pictures. This past Easter we hung a toy chicken thing on his grave and Sierra wanted it. She now drags it around and calls it "Preston". She has no idea. I truly hope that one day she will not fill second choice. Even though her life was based on the child we lost and the child we wanted. However, since my first baby doll years ago I have wanted my very own little girl and now I have just that from God above and she truly is the dream of a daughter I have always wanted. I hope she will see it this way. If you have siblings older or younger, remember to account their feelings. They are smart and sensitive to mommy and daddy at any age and they are special little miracles too.

A Bad Experience Leads To Comfort

I had a root canal not long ago. The first and hopefully the last. It still hurts!! However the dentists kept leaving me for long awaited minutes at a time. It was silent- I hate silence. it makes me think and feel- I can't deal with silence. In any case, laying there still, nothing to see but a light above me, goggles over my eyes and stuff in my mouth (they put one of those balloon things in there), i could hardly breathe, needed to swallow. It hit me; I was in his (Preston's) shoes. The doctor would come and go, I'd hear voices. They would do things to me then leave. I missed their presence- even though it hurt. I began to cry uncontrollably- the goggles were filling up on the sides. I kept thinking how nice it must have been to have someone come in at those times and play me music, hang mobiles for me to see, sing me songs, brush my dry lips with cold water, touch me tenderly and kiss my head. It made me realize all those moments I spent with him were probably as precious to him as it was to me. How comforting to realize this. Then the doctor pulled away my goggles and saw my tears- she didn't question it much. I remember running from the building and getting some fresh air.

Rhonda Montague
1300 Fairfield Lane
Lillington, NC 27546
(919) 639-3186

?????QUESTIONS AND ANSWERS!!!!!!!!

*Have any of our members had experience with Gamma Globulin Infusions (not the shots)?

Jeri Payne
2110B Santa Rosa Circle
Alameda, CA 94501

*Are there any members who are Native American?

Lisa Nagurski
1013 Vassar NE
Alburquerque, NM 87106

*Thank you to all the parents who answered my question about formula, I have taken your advice to Shane's doctor. Thanks!

*Is there any member who was born without most of one lung but the lung is now too big? Shane was born with only 25% of his left lung and now it has shaped into a "boot" going under his sternum.

*Are there any members whose children have suffered brain injuries (cerebral palsy, damage to the brain from lack of oxygen, etc.) and who have tried medications or radical therapy. I've been reading about this but I would rather talk to a parent who has tried it.

Dawn Torrence

*Several of our members have asked about bowel adhesions and other such complications, so if anyone has a story, advice, or information; send it in for our next newsletter.

CHRISTMAS CLOUDS

The following were purchased by donations in honor of or in memory of loved ones. The deadline for purchasing clouds is Nov. 15th preceeding the holidays. If you make a donation during the year and wish it to go the purchase of a cloud, please send your inscription along with your check. Thank you to all of our members who purchased these tributes. I hope everyone will purchase clouds next year!!!

In memory of my hospital room-mate and friend,

Preston Carr Montague
December 29, 1992 - February 27, 1993

I miss you and love you,

Shane

Wishing our precious

Payal Patel
another Merry Christmas
Love always,
Mom and Dad

Christmas 1996

In honor of our son,

Kilian Roberts
We love you!
Love,
Mom and Dad

Christmas 1996

ATTENTION EVERYONE!!!!!!

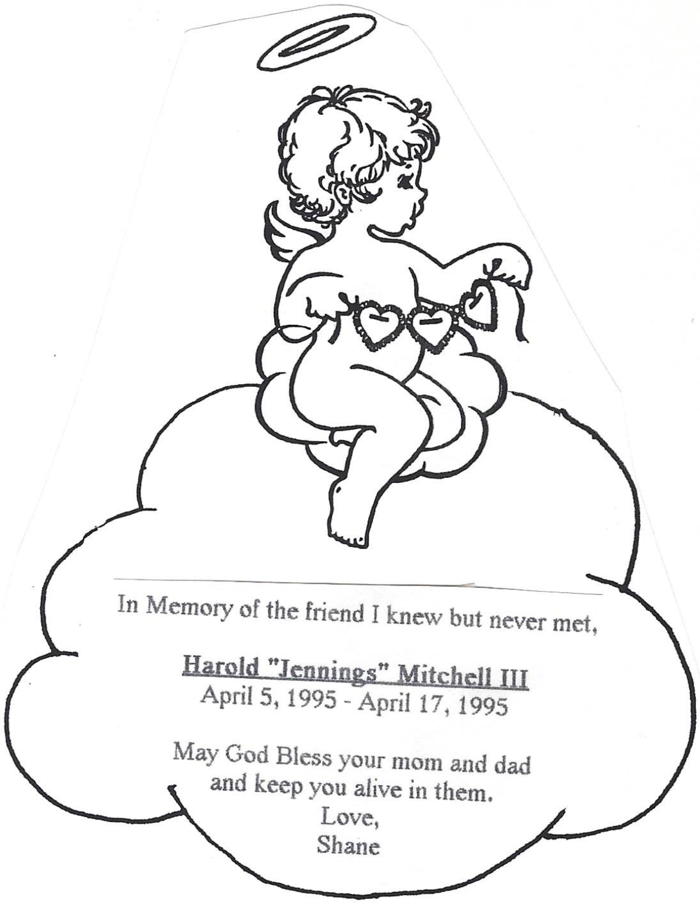
☎ **We've moved and we have a new telephone number!!!!** ☎

(919) 693-8158

In Memory of Our Son

Austin "Ridge" Mangum
May 30, 1996 - June 6, 1996

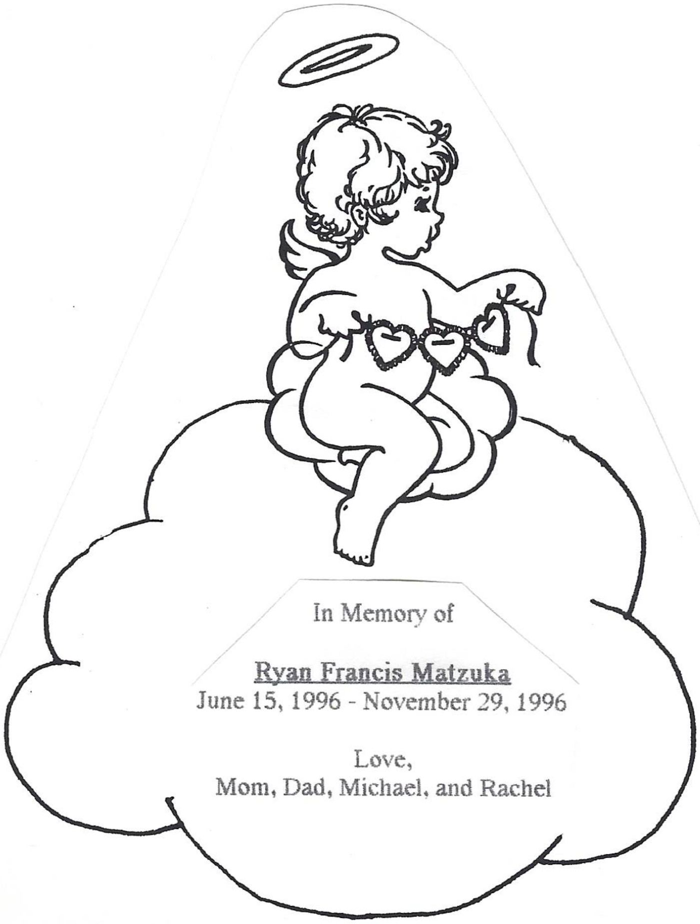
Love,
Mom and Dad



In Memory of the friend I knew but never met,

Harold "Jennings" Mitchell III
April 5, 1995 - April 17, 1995

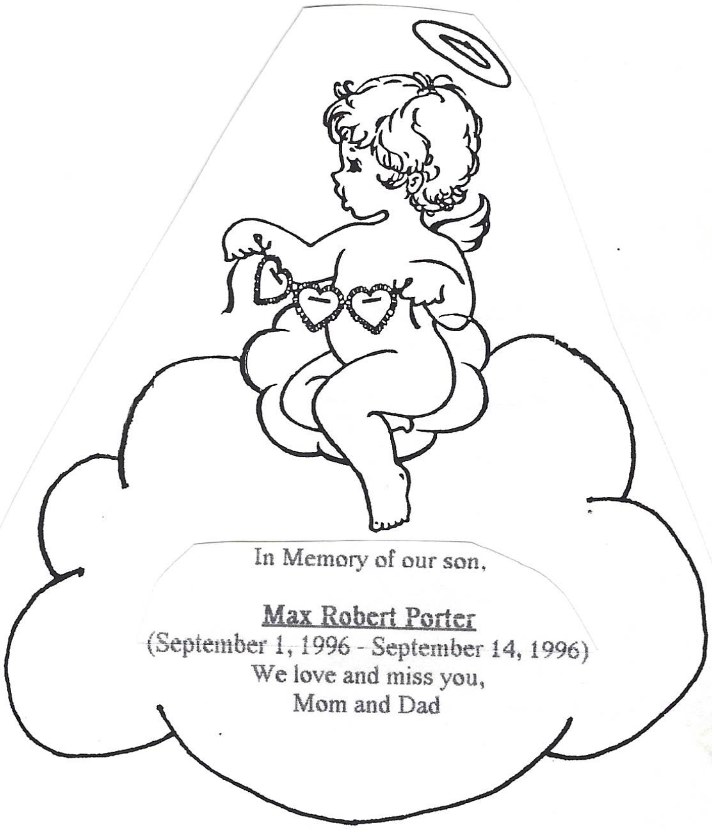
May God Bless your mom and dad
and keep you alive in them.
Love,
Shane



In Memory of

Ryan Francis Matzuka
June 15, 1996 - November 29, 1996

Love,
Mom, Dad, Michael, and Rachel



In Memory of our son,

Max Robert Porter
(September 1, 1996 - September 14, 1996)
We love and miss you,
Mom and Dad

CHERUBS

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

CHERUBS
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