

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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<http://www.acd-association.com>

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Dear Friends and Family,

We are excited to announce some organizational changes at the ACD Association. As you will read in the article on this page, we felt it was in the best interest of our expanding organization that we add Committees to the structure of the organization. With the help of these new committee chairpersons, we are confident that the ACDA will be a more effective and responsive organization for you and new members. Read on for more details. Please support our new Chairpersons as they bring new ideas and energy to the ACDA.

Many people find comfort in sharing a story or poem about their baby so if you have a story, a poem or picture that you would like to share with the membership, please send it to us. The newsletters are for you so you are always welcome to contribute.

Fondly,

Steve & Donna Hanson
Executive Directors
sdesj@verizon.net



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ACDA Adds New Committees

As the ACDA has grown, it has become evident that the assistance and energy of additional members is necessary for managing the activities of the Association. ACD awareness is growing in part due to the efforts of many of you and we want to ensure that your efforts continue to be successful. Therefore, effective immediately, we are thrilled to announce that we are adding four committees to the organization. Because of their on-going and unwavering commitment to the ACDA, we have asked three families to each chair a committee. We are grateful that they agreed to volunteer their time, ideas and energy, and we know they will provide the ACDA membership with additional resources and energy. The Chairpersons are:

Fundraising Committee

Chairpersons - Lisa and Harry Durand, parents of Olivia

Email: casper119@aol.com

Committee Charter

1. Creates new ways to raise money
2. Tracks all the members fundraisers
3. Suggests fundraising ideas
4. Maintains a list of fundraisers
5. Writes an article for each ACDA newsletter

Lisa and Harry would like anyone that has had

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a fundraiser to contact them. This will allow them to start a list of successful fundraisers that they can share with other families.

Research Committee

Chairperson - Diana Locke, mother to Christopher

Email: 4wheelin@earthlink.net

Committee Charter

1. Serves as the contact person for researchers in the United States and abroad; maintains regular contact with medical community to keep abreast of ongoing and new research
2. Researches new articles in medical journals to keep the membership abreast of ongoing and new research
3. Works with the Family Support Chair to educate Level III NICUs about ACD resources, research and grief support
4. Works with pathologists to ensure up- to-date testing techniques during autopsies
5. Maintains contact with 3 Angels Memorial Fund for ACD Research to ensure that all families have current information about their research and awareness activities
6. Writes an article for quarterly ACDA newsletter
7. Assists other Chairpersons and committees as needed
8. Serves as contact for families interested in helping with research.

Family Support Committee

Chairpersons - Emily & Tim Eschweiler, parents of Joey

Email emily_eschweiler@comcast.net

Committee Charter

1. Makes follow-up contact with new families after initial contact is made by ACDA; makes initial contact with individuals who may not be aware of the ACDA and encourages them to contact the ACDA.
2. Identifies grief support resources (articles, websites, books, poems, etc.)
3. Works to increase presence in social media such as Facebook as another way for families to reach the ACDA
4. Works in conjunction with Research Chair to contact Level III NICUs to make sure that they are aware of the ACDA and to provide them with ACDA contact information and information for participating in current research studies
5. Sends notes to existing members on the first birthday of their baby
6. Assist other Chairs as applicable
7. Write an article for the quarterly newsletter.

The one remaining position of **Special Events Chairperson** remains open. If you are interested in heading up this committee, please contact us at sdesj@verizon.net. Below is a general description of this position; however, we welcome additional ideas.

Fundraising News

Durands Supporting Another Fundraiser

Harry and Lisa Durand of New York, parents of Olivia, have recently entered into a new business venture called La Moda Lisa – both an on-line and store front consignment boutique and photo art studio. Lisa describes the venture as “where your Marshall’s beer can budget meets your Sak’s Fifth Ave champagne taste.” Lisa’s 12 year old son, Alex, is making paracord bracelets (pictured below) for the store. The bracelets, made with military grade parachute cord, have thousands of applications for military personnel, firefighters, EMTs, and even everyday hikers and hunters! By wearing them, you always have them with you in case of an emergency. Each bracelet contains 6 - 10 feet of paracord easily untied for any emergency use. The bracelets are made to order based on your color selection and size.

The Durands will donate a portion of each paracord sold to the ACD Restricted Research Account at NORD (National Organization of Rare Diseases). Check out the bracelets on the website at <http://lamodalisa.com/2011/02/paracord-bracelets-sold-here/>. Many thanks to the Durand family who has raised a significant amount of money for ACD research since Olivia died in 2002. We are sure that this latest fundraiser will be as successful as their previous endeavors. We hope that you will support them.



Thirty One Totes

The [redacted] family and mom and dad to [redacted], would like to thank Nikki Huffman and Keisha Pritchard for one of their latest fundraising efforts. The Thirty-One lunch tote fundraiser brought in \$415 for the NORD account. These were sold to employees of [redacted]'s school district, Alexander County, North Carolina as well as to friends and family of the Sanders' family.

The [redacted]'s family would also like to add an additional thank you to the Harrington family. Rather than receiving gifts for the addition of the Harrington's newest family members, they asked the staff of Hiddenite Elementary School to make donations in [redacted]'s memory to NORD in honor of Hannah and Wesley Harrington.

"The Answer" CD

Cami McGraw, aunt to Bella, announced that Stretch Productions sent its first quarterly gift to ACD research. The donation is an on-going contribution based on CD sales and downloads. "The Answer" CD, produced by Cami and her husband Randy, can be purchased at the following places:

- **Stretch Productions Website:** <http://stretchproductions.com/theanswer.html>
- **CD Baby:** <http://www.cdbaby.com/cd/stretchproductions>
I-Tunes: <http://itunes.apple.com/us/album/the-answer/id396571667?i=396571689&ign-mpt=uo%3D4>
- **Amazon.com:** <http://www.amazon.com/>

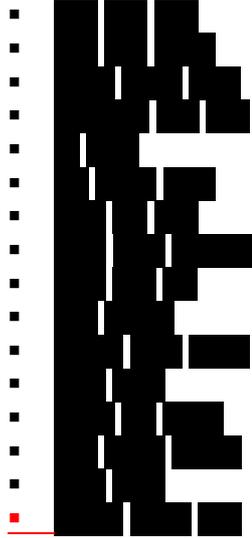
Safe Arrival



ACD Magnets Still Available

From Emily Eschweiler, Mom to Joey

If you didn't get your car or refrigerator magnets late last year, they are still available. All proceeds from the magnets go directly to NORD. To date, parents, friends, and family members have purchased 100 car magnets and 270 fridge magnets, raising \$860.10 for our research fund at NORD. Thank you to the families of the following babies that are helping us raise awareness of ACD through the magnets:



We found that the NICU nurse manager or the social services manager at our local children's hospitals were very willing to place a magnet on the NICU staff refrigerator. Thanks to an idea from Tim Eschweiler, we have alerted NICU doctors at Children's Medical Center Dallas and Cook Children's Hospital in Forth Worth about ACD. We hope you have had the same success at your local NICUs.

Another idea for the magnets came from Naomi Gunn Buytas, a friend of [redacted] and [redacted], who recently purchased 16 magnets. She works for the Charleston County (South Carolina) Emergency Management System (EMS). She has placed a magnet in each of the 14 stations as well as the headquarters and the final one on her own refrigerator.

Please contact Emily Emily at emily_eschweiler@comcast.net if you are interested in ordering magnets. Help us spread the word!

Announcement

- The ACD Research Fund at NORD reached \$24,066.00 as of February 9, 2011.

A Letter to Joey

Sue Barker, from Morgan Hill, California, aunt to Emily Eschweiler and great aunt to Joey, sent us this letter she wrote to Joey after his passing. She wanted to share it with us in hopes that it “will help others who have lived through or will live through what their family did as they prayed and hoped for a miracle for Joey.”

Today when I came home from work, my heart heavy with grief, I looked out the window and saw one of God's amazing miracles. You did not get a chance to experience this one; it is called a hummingbird. This tiny little whirl of energy shouldn't remain airborne; it shouldn't be able to turn on a dime, moving and hovering like a magic machine. But it does. And every time I see one, I am thrilled at the magnificence of one of God's tiny creatures.

You did not stay with us long enough to witness much of this world we call home while we live. It is a world, unfortunately, torn by war and strife, of poverty and pain and sometimes we forget that there are small miracles hovering right there in front of us.

You, dear Joey, are one of those miracles. You only were here on Earth for thirteen days; we all wished it could have been much longer. But, oh, sweet baby, what miracles you worked in that short time!

You showed people what courage was and what love was as we read what your beloved Mom wrote each night about you and your difficult fight to stay with us. She signed each note "Love, Joey" and we all fell in love and learned from you. We learned that nothing is stronger or more beautiful than the love of parents for their child. We learned about the incredible pain of loss and that thirteen days is enough for one small miracle to become a part of the hearts of an unbelievable number of people, including mine.

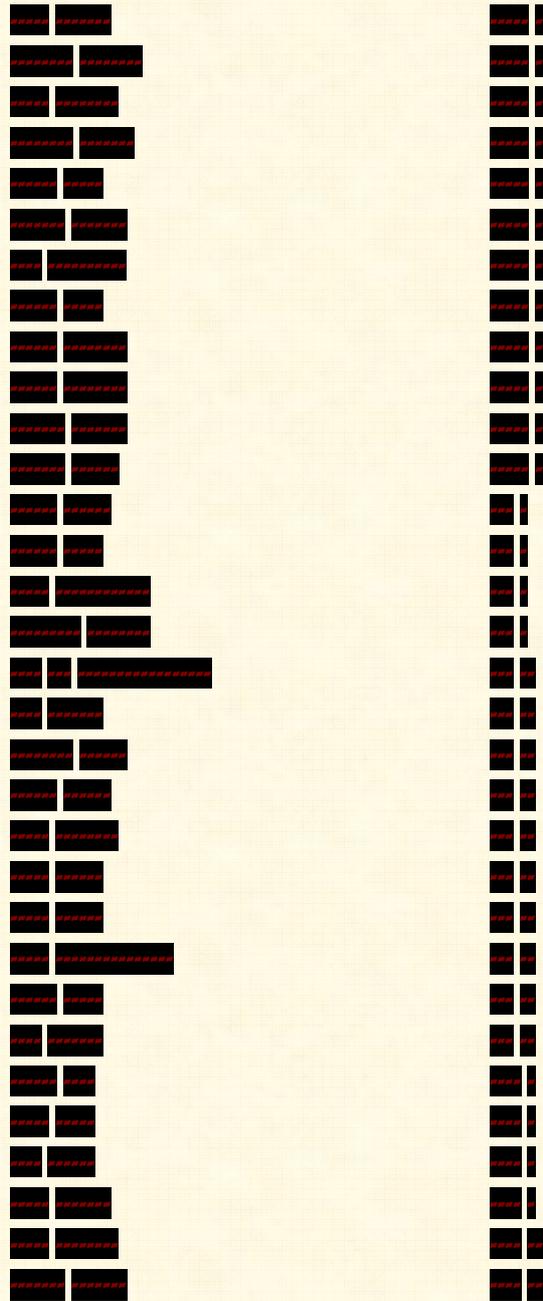
Like my hummingbird, you have hovered briefly for us to see your beauty and then flown swiftly from our sight. But like all beautiful treasures, you are only a memory away.

Fly high and joyfully, dear Joey. I love you.

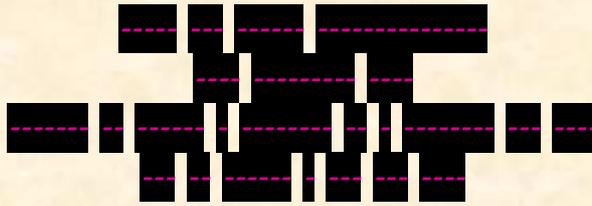
Love,

Remembering Our Babies

As the hustle and bustle of life resumes and it seems no one recognizes the sorrow in your heart, we remember. May you find a meaningful way to celebrate the precious life of your baby.



welcome.....



~Happy Birthday Angel ~

*As we wake up in the morning
and your not here to see,
we grasp for some reality...
that our dreams can never be.*

*We'll bake a cake & buy balloons,
we'll burn a candle too.
We'll play your music, look at pictures
and shed some tears for you.*

*We'll imagine what the day would bring,
if only you weren't gone.
You'd run and laugh, and jump about,
we'd sing the birthday song.*

*You should be here today,
excited as can be...
Sifting through the toys and wrap,
bursting forth with glee...*

*But God had other plans for you,
these plans, we'll never know.
Today, the candle burns,
...with no tiny lips to blow.*

*We'll do our best to make it through,
this day we meet with dread.
We'll do this all for you, my love...
on this road of grief we tread.*

Make a Tax-deductible Contribution for ACD Research

The National Organization of Rare Disorders is a non-profit organization in the United States that is "dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. For many years, NORD has been awarded the top rating for sound fiscal management by Charity Navigator, a leading evaluator of charities. Less than four cents of every dollar donated to NORD goes to administrative and fundraising costs. The ACDA has had a restricted research account at NORD since 2002 which allows our members to make tax deductible contributions for ACD research. Once this account reaches \$33,500 NORD will initiate the process to award a research grant. Previously, two such grants have been awarded to Baylor because of the generous donations of our members, friends and family. As evidenced by past grants, we are confident that our donations will be used for research. Therefore, please follow these steps when making a contribution to NORD:

- Please make your check payable to "NORD - Alveolar Capillary Dysplasia Restricted Research Fund" to earmark your donation for ACD research.
- In the memo section of the check or on a separate note attached to the check, state that the donation is "in memory of (name of child)."
- Your family and friends can attach a note to their check with your name and address and NORD will notify you of their gift.
- Send your check to the following address:

National Organization for Rare Disorders, Inc.
P.O. Box 1968
Danbury, CT 06813-1968 USA

The most critical part of this process is ensuring that your check is made out to "NORD - Alveolar Capillary Dysplasia Restricted Research Fund" to ensure that your donation is earmarked for our ACD Research Account.

You may also make a donation on the NORD website at <http://www.rarediseases.org/helping/donate>. When filling out the section entitled "You may enter the name of the person you wish to honor with your gift here" type in the name of the baby followed by "Alveolar Capillary Dysplasia," (example: Jane Doe/Alveolar Capillary Dysplasia). If the name of the baby is written first, the accounting department at NORD will immediately know that this is a restricted research donation in memory of your baby.

Special Information for Families Living Outside of the United States:

NORD recommends that families living outside of the United State use a credit card to make a donation since it costs less to convert international currency when using a credit card. The person to notify with the authorization amount, type of credit card (Master card, Visa), name on the card and the expiration date on the card is Cindy Thayer cthayer@rarediseases.org. Also, please be sure to indicate the donation is restricted for ACD research, the person's complete name it is given in memory of, and the name and address of whom NORD should send an acknowledgment to. Your own name and complete address should also be included in order to process the paperwork.

Contact Information

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