ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 12, Issue 4
http://www.acd-association.com
Fall 2010

Dear Friends and Family,

It has been a busy year for the ACDA with 15 new families and many fundraising activities. Thank you to everyone that has supported our efforts to raise money for ACD research this year. Special thanks go to Emily Eschweiler who has spearheaded the ACD awareness ribbon project. We may be a small group but together we are increasing awareness of this rare disease, and we will make a difference for our children and their families with our fundraising. We ask for your continued support to reach our goal of $33,500 to fund another grant this spring through our account at NORD (see article this page).

In this holiday season, we hope that will find a special way to remember your baby(ies) that are no longer with us. We wish you a blessed holiday and all our best for a happy new year.

Fondly,

***Steve & Donna Hanson,* Executive Directors**
sdesj@verizon.net

"The mention of my child's name may bring tears to my eyes, but it also brings music to my ears." (Anonymous)

Help Us Reach Fundraising Goal

As many of you may know, the National Organization for Rare Disorders (NORD) issues research grants once a year for member organizations such as the ACDA that have raised at least $33,500 (down from $35,000). To date, the ACDA has raised funds for two research grants and with $20,862 currently in the account, we are close to funding another. The grant cycle at NORD typically involves issuance of a Request for Proposal (RFP) in mid-March, then a review by NORD's medical advisory board with an award made in September/October.

We are asking for your help to reach the goal of $33,500 by early March 2011. If we don't reach this goal, we will have to wait another year for the next RFP cycle.

So, here are some ways that you can help us reach our goal:

- Talk to your friends and family and ask them to make a donation to NORD in memory of your baby(ies). There are instructions on the last page of this newsletter on how to make a donation to our research account. Remember that donations are tax deductible.
- Find out if your employer will match your donation or if they will make a general donation. Several years ago, the company that Jeff Myers (dad to Shelby) worked for made a substantial donation when Jeff and Madonna approached them about the need for funds to meet our fundraising

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goal.

- Contact a private foundation in your area that supports medical or children's issues and write them a letter asking for their support.
- Contact someone you know that fundraises for a living and ask them for advice.
- Participate in our many fundraisers – magnets, candles and CDs. If you live outside the US, you might consider sharing the shipping costs with other families that live in your country.

Since the ACD community is so small, it is important that all of us support this fundraising goal so that we can continue to support ACD research and find answers for our losses.

We are aware of one very generous donation that was recently made to our account at NORD and want to say thank you. Jeffrey Bradley, friend of Donna and Steve Hanson, and a long time supporter of our efforts, made a significant donation in memory of Eric Hanson. If you would like to recognize your friends and family, please feel free to share the information with us. We think it is extremely important to say thank you to those friends and family members that contribute to our cause of "searching for an answer, hoping for a cure." Please consider how you can make a difference.

ACD Awareness Magnets

If you haven't ordered your ACD awareness magnets yet, they are still available. In addition to cars and refrigerators, they look great on Christmas trees. To date, 64 car magnets and 241 refrigerator magnets have been sold with $500 in profits going to NORD. Contact Emily Eschweiler at emily_eschweiler@comcast.net to order yours. Many of you who have ordered magnets have expressed an interest in ordering other products with the ACD Awareness ribbon. When Raquel Smith provided the original awareness ribbon to the organization, she indicated that the organization's members should feel free to use the ribbon for personal use. Similarly, members should feel free to use the ribbon with the added text. PDFs of both versions of the ribbon can be found at http://albums.phanfare.com/isolated/Tu8NXXhu/1/4816670 and on the Alveolar Capillary Dysplasia group page on Facebook.

Raquel's original design

Raquel's original design with added text

Personal Use: If you want to use either of the ribbons for your personal use, please feel free to do so. Examples would include using the ribbon on a T-shirt for a walk that you are doing in memory of your baby, adding the ribbon to one side of a coffee mug and adding a picture of your baby to the other side, or ordering return address labels or personalized postage stamps using the ribbon.

Fundraisers: If you want to use either of the ribbons for a fundraiser, please contact Donna and Steve Hanson at sdesj@verizon.net before doing so to explain the fundraiser, how the ribbon will be used, and the percentage of the profits that will be contributed to NORD.

Silicone Bracelets

There has been a lot of interest in ACD silicone awareness bracelets. Emily Eschweiler has looked into the possibility further and has not had much luck in finding a company that can make a bracelet that would match the awareness ribbon and show the transition from blue to purple to red. There are a number of companies that can make a three color bracelet, but it would be three solid colors without the transition in between. She is hopeful to eventually find a company that can make these, but for now this is on hold due to an inability to find a manufacturer who can make a bracelet that would match the awareness ribbon. If anyone else has suggestions, please feel free to pass those along to Emily at emily_eschweiler@comcast.net

Research Update

As we reported in the Summer 2010 ACDA Notes, Dr. Pawel Stankiewicz of Baylor College of Medicine received a four year grant from the National Institutes of Health (NIH) in May 2010. The title of the grant is "Pathogenetics of the FOX transcription factor gene cluster on 16q24.1." This is an extension of the work that Dr. Stankiewicz, Dr. Partha Sen and others completed in 2009 that resulted in the published paper entitled “Genomic and Genic Deletions of the FOX Gene Cluster on 16q24.1 and Inactivating Mutations of *FOXF1* Cause Alveolar Capillary Dysplasia and Other Malformations.”

There are three objectives of this grant:

1. To continue the study of gene regulation in the FOXF1 gene which is present in 40% of the ACD/MPV cases verified by Dr. Clare Langston. It is not evident yet whether there are genes other than the FOXF1 that are responsible for ACD or if other mechanisms (e.g. genomic imprinting) are in play that may be related to the FOXF1 gene. However, Dr. Stankiewicz continues to look for other gene defects in his analysis also.

2. To continue to work on the ACD mouse model. Several years ago researchers in Chicago recapitulated (repeated stages of evolutionary development during the embryonic stages) ACD in a mouse model. But it wasn’t until eight years later that a human connection to the disease was made by Baylor.

3. To attempt to manually heal the mice in the ACD mouse model using genetic therapy.

The research that is being done on ACD emphasizes the need for all of us to participate in this study by providing samples. Thank you to those of you that are already participating and we encourage everyone who is not to seriously consider the difference you could make in finding the cause and cure. Please contact us get more information on how you can participate.

Fundraising News

The [redacted] Family – in memory of [redacted]

The family of [redacted] and [redacted] [redacted] of North Carolina has been busy with several fundraisers in memory of [redacted], their daughter who died of ACD in September 2010. Approximately $1,044 will be donated to NORD through the "Willie, The White Tiger" fundraiser that has just recently ended. Cheryl Wall, an Avon representative, chose to donate the proceeds of the tiger sales after hearing about [redacted]'s story through [redacted]’s step-mother, [redacted] [redacted]. Twenty of the tigers that were sold for this fundraiser will be donated to the Brenner Children's Hospital where [redacted] spent all but two days of her life.

A second fundraiser, in effect now, has been created by the [redacted]’ grandparents and extended family. It's called "Give one up for [redacted]." The premise is that instead of asking for a certain gift during the holidays, you ask for money in order to make a donation ACD research being done at Baylor College of Medicine. Their goal is to raise $5,000.

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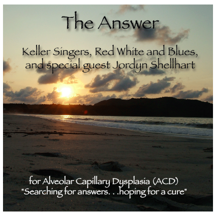
And the [redacted] are not stopping there…. Another fundraiser is planned for the new year! Many thanks to all the family and friends that have supported the [redacted]' efforts to raise money for ACD research. We hope they have inspired you!

The [redacted] Family – in memory of [redacted]

[redacted] and [redacted] [redacted], parents of [redacted], had their 5th annual fundraiser and raised approximately $2,700 for the ACD account at NORD. They had a bowling tournament that included music and all-you-can eat and drink. Raffles included Knicks tickets, Rangers tickets, massages, and baskets of goodies. Thank you to the [redacted] for raising money through the [redacted] [redacted] Memorial Foundation!

The [redacted] Family – in memory of Baby [redacted]

"The Answer" CD, produced by [redacted]'s Aunt Cami and Uncle Randy, can now be purchased at the following places. A portion of each sale will be earmarked for ACD research.



Stretch Productions Website:
Using Paypal (international shipping is also posted):
http://stretchproductions.com/theanswer.html
(Note: this site will be the fastest for a 'physical' CD to be mailed.)

CD Baby:
http://www.cdbaby.com/cd/stretchproductions
(Note: this site is great because you can hear clips of all the songs! And, you can order either the 'physical' CD or do the digital download!)

I-Tunes:
http://itunes.apple.com/us/album/the-answer/id396571667?i=396571689&ign-mpt=uo%3\D4
(Note: I-Tunes offers the digital download of the entire album, OR singles are even available. You can also hear clips of all songs.)

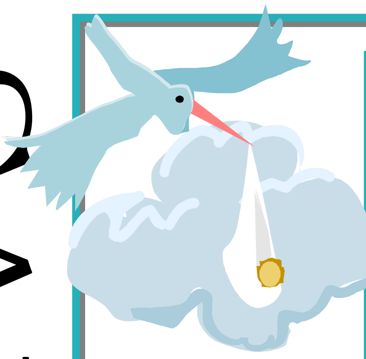
Amazon.com:
http://www.amazon.com/
From the 'search' field, select 'mp3 downloads' then type in 'Stretch Productions' in the blank right next to it. (The digital download of the entire album is offered, and clips of all songs.) Here is the direct link, but watch the long wrap:
http://www.amazon.com/Stretch-Productions-The-Answer/dp/B004619AQE/

Also, for those in the Keller, Texas area, Teach-Mart is now carrying it: 4324 Heritage Trace Pkwy, Keller, TX, 76244 (call for directions: 817-337-7337)

Candle Fundraiser – in memory of Baby [redacted]

December 31 is the deadline to purchase a candle from Blessings Candles. Owner Deby Sebastian will make a donation to the ACD our account at NORD for every candle purchased by ACD members, friends and family. These make great gifts for teachers, friends, family members or yourself. Deby will donate $9.00 for every 22 oz. candle and $4.00 for every 11 oz. candle bought. To order, go to Deby's website at: http://blessingscandles.com/ - just make sure you let Deby know that you are with the ACDA.

SAFE ARRIVAL



[redacted]

Announcements

- Use your holiday cards as a way to say thank you to friends and family that have supported your family, ACD research, and our fundraising activities.
- Thank you to Rob Garner, a friend of Steve and Donna Hanson, who has donated the host server for the ACDA website. The data has been transferred to the new server and we hope to incorporate some enhancements over the next year. We used approximately $10.00 of the funds donated to the ACDA to renew the domain name.
- The ACDA website has been updated to include our fundraisers. Be sure to check it out at http://acd-association.com/fundraisers.php
- Tammy Garcia, aunt to [redacted], composed a video in memory of her niece and has posted it on YouTube. http://www.youtube.com/watch?v=jhPRr8E3yjo
- If you have recently moved or changed your email address, be sure to let us know. If you have approved release of your information, we share your contact information with new families so they have others to reach out to for support and understanding.
- Please feel free to submit a poem, a story of your baby, a birthday tribute, or ways that you have kept your baby's memory alive. We are always looking for articles and we know it is important for all of us to always remember our babies.
- For those of you on Facebook, remember to check out http://www.facebook.com/group.php?gid=44736988739 , a Facebook page for ACD started by Madonna Myers, mom to Shelby.
- If you have a family member that would like to be added to the distribution list for newsletters, please send us their email address. We already have several family members that receive it and we would be glad to add others.

Surviving the Holidays

After the Loss: Coping with the Holidays

"I thought I was doing much better. The pain had subsided: I could laugh again. I was beginning to spend time with friends. My eating and sleeping patterns were back to normal. Then, I had to face my first holiday without him. I felt the familiar effect of grief over me and it was just like the healing process had never begun." (Anonymous)

Holidays. They can be the most joyous or the most painful days of the year, depending on how, and if, you're prepared for them. Holidays are especially difficult if you've recently lost the love of another person through the death. By planning ahead, however, and dealing realistically with your holiday expectations, you can help insure your days are filled with peaceful satisfaction rather than painful sadness. Holidays aren't just "something to be gotten through." They should be a time for rejuvenation and reflection.

Whether this holiday season is the first or the fortieth you've faced since losing a loved one, there are some special considerations you need to think about while making your holiday plans. The first years after the loss of a loved one are the most difficult, however, and it is these days this booklet focuses on.

Notice in the sentence above, it says: "the first years" are the most difficult. Not the first hours, the first days, or the first months, but the first years. It is important for you to realize that your loss is going to require an adjustment in your life. This is especially true around the holidays. Traditions may change, the amount of entertaining you do will likely be altered, and your celebrations may be somewhat tempered. Before reading any further, it is important to accept and admit this to yourself. If you can do this, you are halfway to the point of being able to enjoy peaceful and pain free-holidays.

<u>Anticipation:</u> Initially, the most difficult part about facing a holiday, or an entire holiday season, is the fear about how awful the day is going to be. Often, the anticipation prior to the event is worse that the day itself due to the worry about surviving the occasion. Looking ahead and imaging what the day will be like tends to intensify any feelings of grief because we're reminded of the lost love. Holidays also are a means of marking the passage of time and that too can be a painful reminder.

Writing down your fears in advance of a holiday will help you express your feelings. When writing, be entirely honest with yourself; it will help you gain control over your feelings. Clarifying your thoughts will help you feel less overwhelmed, especially when you begin to view the holiday as being made up of many small events rather than endless commitments and demands.

<u>Participation:</u> Actively participating in holiday activities, instead of thinking about what used to be, is a good way to begin your "holiday healing". By planning ahead, you'll have a grasp of what you do and do not want to do. This will prevent you from having to make decisions under pressure and give you the strength to say "no" if necessary. Also, being well-organized, you'll enable yourself to limit the amount of activity you plan while using your time most effectively during the holiday(s). You'll be able to build "quiet time" into your schedule without resenting having too much to do in a short periods of time.

Holidays are naturally demanding - - whether you've lost a loved one or not. They usually require entertaining or being entertained, shopping, commitments to spend time with family and friends, extra housework and cooking, etc. If you're invited to do something you'd rather not do, be tentative in giving

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your answer. An honest but brief explanation of how you've been feeling lately will be understood and will allow you flexibility. Simply tell your host or hostess that some days are better than others since your loss and if you're feeling up to it, you'd love to attend. This way, no firm commitment has been made and yet you still have the opportunity to enjoy the company of friends if you desire. This also allows you to observe realistic limits in your routine.

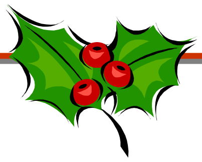
Preparation: You may find that getting into the "holiday spirit" is difficult for you this year. That's okay. If you're not ready to celebrate this year, don't. If you have small children, however, you'll need to discuss any holiday changes with them so that they don't feel punished or confused. If they are also suffering from a loss, a traditional family celebration might be good for them. Chances are, even if you don't feel up to it, you'll be able to count on family members to help make the holiday as "normal" as possible for your children. If you need help, discuss it in advance with members of your family so that the day will run smoothly.

Decorating for the holidays, although it may seem like more work that it is worth, will bring warmth into your home and should not be avoided. If purchasing and decorating your tree seems overwhelming to you, let your children, other family members, neighbors or friends help you. They'll provide valuable companionship and help make the project a special event rather than a chore. Once the decorating is done, you'll be happy to have the seasonal reminder that life is continuing on and so must you.

If you find yourself alone for the holidays, take advantage of the time and pamper yourself. Get a book you've wanted to read, write letters that are overdue, treat yourself to a special meal, or call a friend who may also be alone. Being alone does not necessarily mean being lonely though, and you may find you enjoy the time to think and reflect. If you know in advance that you don't want to be by yourself, **plan not to be**. It may mean calling family or friends and suggesting a special holiday activity, but it's a way for you to let them know you'd like to spend time with them. Fellowship with others often is the best medicine for a grieving heart.

Continuation: Regardless of how many commitments you have over the holidays, the most important thing to remember is to keep things simple. Say no to invitations you'd rather not accept, and don't be afraid to express you feelings. If you want to cry, do. If you need to talk about your feelings, do. If you want to be alone, it's okay as long as you continue to reach out to others on occasion. Above all, take the time necessary to be in touch with your feeling and expectations and react accordingly. If you do, you'll find you're actually enjoying the holidays rather than just coping with them.

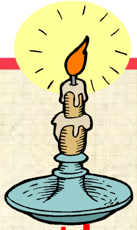
Reprinted from Article from Madonna Myers
2002

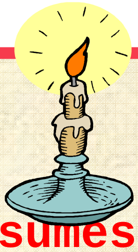


Family Remembers Son with Candle Lighting

October 15 was declared National Pregnancy and Infant Loss Awareness/Remembrance Day in 1988 by President Ronald Reagan. (http://www.october15th.com/) People around the world light a candle on this date in memory of their child.

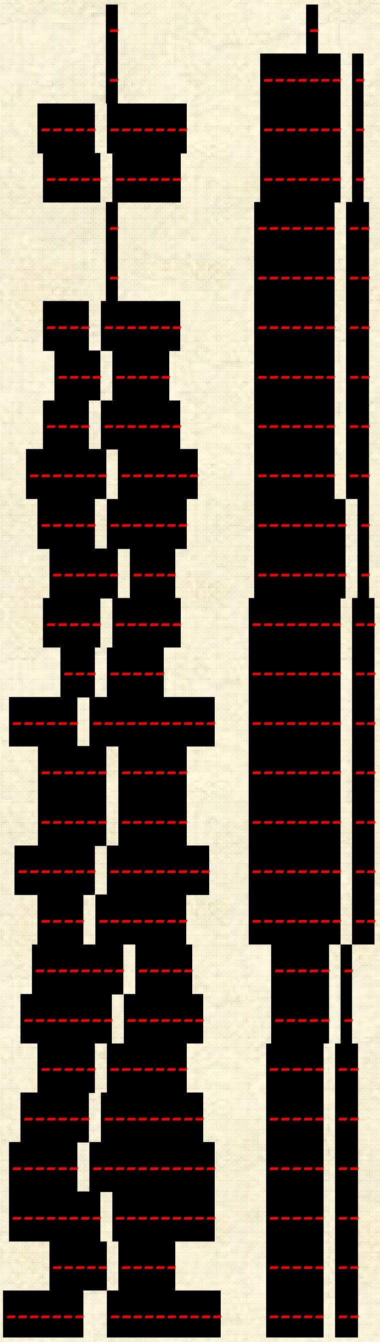
[redacted] [redacted] [redacted] [redacted] and their son [redacted] lit 200 candles (luminaries) in their driveway on October 15th at 7:00 pm in remembrance of their son [redacted] and all ACD babies. The picture below was taken by [redacted] from the roof of their house. Thank you to the [redacted] for remembering our loved ones.

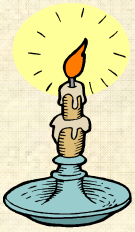


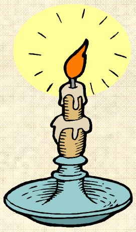


Remembering Our Babies

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.....

Please introduce yourself and share the story of your family with our new ACDA members.

[redacted]

*****

[redacted]

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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