ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Dear Friends and Family,

We are so excited about all the activity going on amongst ACD members. We know that you too will be thrilled to learn about a new ACD Awareness Ribbon that ACDA mom, [redacted] [redacted], has asked the ACDA to adopt. You are keeping us busy with all your wonderful fundraisers and awareness efforts and we are so grateful for your contributions to ACDA.

Thanks to all of you that have purchased a candle from our fundraiser with Blessings Candles. Some of you have pasted the link in your Facebook account and other websites so thank you so much for spreading the word.

Lastly, please welcome our three new families that have recently lost a baby to ACD. Please take the time to send them a quick email or give them a call if they live nearby to introduce yourself and your family.

Fondly,

Steve & Donna Hanson
ACDA Executive Directors
sdesj@verizon.net

INSIDE

ACD Awareness Ribbon

[redacted] [redacted], mom [redacted] [redacted], recently contacted the ACDA about an awareness ribbon that she and her husband's friend, [redacted] [redacted], designed. For [redacted]'s birthday, her friends put this design on scrabble tiles and made necklaces and pins. She wears a pin on her purse and she is ALWAYS asked what the "unusual" looking ribbon stands for. [redacted] says it is a GREAT conversation starter and opportunity to talk about ACD.

[redacted] told us that the design is inspired by unoxygenated blood's transition from blue, to purple, to red as it is oxygenated. Sadly, she witnessed this transition in reverse with [redacted].

With the help of [redacted] [redacted] (mom to [redacted]) and [redacted] [redacted] [redacted] (mom to [redacted]), [redacted]'s ribbon will become the official awareness ribbon for ACD. Many thanks to this committee who is finalizing the design of the ribbon and determining how to produce the ribbon so it can be shared with all of us in various forms. They have brainstormed some great ideas on ways to use the ribbon! Stay tuned!

A few of the proposed ribbon designs are displayed at: http://albums.phanfare.com/isolated/Tu8NXXhu/1/4816670.

Take a look at the designs and if you have any comments, ideas or suggestions or if you have a favorite design, the committee would like to hear from you. If you would like to join the Committee, they would love the help. You can email [redacted] at [redacted]

Thanks to [redacted] and [redacted] for this wonderful gift. As [redacted] [redacted] told us, "it was created with love and consideration for our little angels and their families" and we are so very grateful.

ACT NOW!

Contact Your Representative

Help to Make a Difference

Submitted by: [redacted]

ATTENTION FAMILIES LIVING IN THE UNITED STATES

Please encourage your Congressional Representative to join the Rare and Neglected Diseases Caucus. U.S. Representatives Joseph Crowley (D-NY) and Fred Upton (R-MI) have recently established the Rare and Neglected Diseases Caucus to focus on bringing attention to the 6,800 known rare diseases that currently have no approved therapies. The Rare and Neglected Diseases Caucus will focus on ensuring sufficient funding for research, encouraging companies to create new drugs and treatments, and providing an opportunity for members of Congress, families, and advocacy groups to exchange ideas and policy concerns.

Please encourage your Representative to become a member of this important Caucus. If you are uncertain who represents your district, please go to http://www.house.gov/ and type in your zip code (in the upper left). Identify yourself as a constituent and state your reasons for supporting the Caucus. It will take all of us contacting our representatives to get some action. It's easy and it's fast. Please act now!

Research News

- Dr. Pawel Stankiewicz of Baylor College of Medicine has received a grant from National Institutes of Health (NIH). 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 Baylor 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."

- Dr. Partha Sen, also of Baylor College of Medicine, reports that they have had an explosion of ACD/MPV cases this year. Pathologist Dr. Clare Langston has already consulted on over ten cases and they have recruited six families and are in the process of doing so with another family. This indicates that the disease is not as rare as previously thought - it has been undiagnosed. Baylor is in the process of preparing a manuscript where they will report three new cases of FoxF1 mutation in unrelated patients.

Candle Fundraiser for ACD

Available Until December 25

Earlier this year, we introduced you to a new ACD family from West Virginia, [redacted] [redacted] [redacted], who lost their daughter, [redacted], to ACD. You may remember that [redacted]'s cousin, [redacted], and her husband [redacted], were working on a compilation CD of music of which some proceeds will be donated to ACD research in [redacted]'s memory.

A few months ago, [redacted]'s good friend, [redacted] [redacted], gave [redacted] a late Christmas gift - a candle named "[redacted]." [redacted] owns a candle company yet knew nothing about Baby [redacted] until she gave [redacted] this candle. From this coincidence, a fundraising idea started coming together.

Deby has generously offered a very simple fundraiser to the ACD Association. Deby's candle company, Blessings Candles will make a donation to the ACD Restricted Research Fund at NORD for every "Bella" or other candle bought by ACDA members, their family and friends between now and the end of December. All you do is order a candle or two for yourself, your friends, family, or teachers. She will donate $9.00 for every 22 oz. candle and $4.00 for every 11 oz. candle bought by ACDA members, their friends and family. There are many scents to choose from in addition to the "Bella" candle.

INFORMATION ABOUT THE BELLA CANDLE

Sizes: 22 oz. and 11 oz.
Scent: Bella - citrus floral and others are available
Color: Bella - pink (see attached picture) and others are available
Specs: Double Wicked, Zinc and Lead-Free
Burn Time: 100 hours or more for the 22 oz.
Price: $19.95 for 22 oz. plus shipping ($9.00 of this goes to ACD Research)
$11.95 for 11 oz. plus shipping ($4.00 of this goes to ACD Research)
Payment: Paypal on http://blessingscandles.com/

For more information about Blessings Candles, go to Deby's website at: http://blessingscandles.com/

Please consider purchasing a few candles for yourself, family or friends. You can order directly on Deby's website any time and pay via Paypal. If you need to make payment using another method, contact Deby at sales@blessingscandles.com. Be sure to mention that you are an ACDA member.

IMPORTANT - So that Deby knows that you are part of this fundraiser, please type "ACD Fundraiser" in the "Add Special Instructions to the Seller" field in the

“Review Your Payment” screen in Paypal. That will ensure that Deby makes a donation to NORD for that sale. International families please contact Deby at sales@blessingscandles.com for international shipping information.

This is an easy way for all of us to help raise money for ACD research. We still need to reach $35,000 for the next grant to be issued by NORD so be sure to forward this information to your friends and family so that they can participate in this fundraiser also.

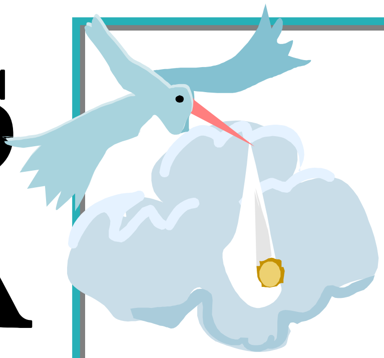
When you give the candle as a gift, you might consider adding a note similar to the one below to add a personal touch and to help others remember your son or daughter:

“A portion of the proceeds from the sale of this candle will be donated by Blessings Candles to the National Organization for Rare Diseases (NORD) for research on Alveolar Capillary Dysplasia (ACD). This is being done in memory of my son, Eric, and the other babies that have lost their lives to ACD.”

Please contact us if you have any questions.

Bella Candle

SAFE ARRIVAL



[redacted]

[redacted]

Announcements

- The balance of the ACD Restricted Research Account at NORD is $15,387 as of September 1, 2010. We are almost halfway to our goal of $35,000 for our next research grant!

- 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.

- [redacted] [redacted] and family recently hosted a children's books party for a friend. For the first 20 parties her friend had, the hostess got double the amount of books, so [redacted] was able to collect almost $250 in children's books. She then donated the books to the NICU where her son [redacted] was born.

- 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 [redacted] [redacted], mom to [redacted].

- [redacted] [redacted] [redacted] [redacted] are starting work on an ACD fundraiser in memory of their daughter, [redacted]. They are organizing a one-bike poker ride to be held next spring. If you have had a fundraiser and have some suggestions for the [redacted], they would love to hear from you. Contact [redacted] at [redacted]

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.

Remembering Our Babies

Music CD Proceeds to Benefit ACD Research

Cami and Randy McCraw, cousin of ACDA member [redacted] [redacted] and owners of Stretch Production, have spent many hours producing their latest CD. It is with great pride that on September 22, Baby Bella's 9 month birthday, Stretch Productions released their CD entitled, "The Answer" featuring the Keller Singers, Red White and Blues (http://members.cox.net/rwbgirls/bio.htm) and special guest Jordyn Shellhart. As you may remember Jordyn Shellhart has played at the Grand Ol' Oprey and performed at the Country Music Awards in Nashville, Tennessee. Jordyn's manager has also been the manager for Taylor Swift, Carrie Underwood and Lady Antebellum so expect Jordyn's career to take off. Check out Jordyn at http://www.jordynshellhart.com/ or http://www.facebook.com/JordynShellhartOfficial .

The McCraws will be donating a portion of the proceeds from the CD sales to our restricted research account at NORD. In addition, on the back cover of the CD there is a link to the ACDA website that explains how people can make a donation to NORD

Please go to http://stretchproductions.com/theanswer.html. to take a look at the CD cover and purchase one of the CDs for only $15 ($20 internationally) which includes shipping. In addition, those of you that are on Facebook or other social networking sites, please post this link with some information to help us spread the word about the CD.

Thank you to Cami and Randy for their hours and hours of work to bring this CD to fruition. It has truly been a labor of love in memory of [redacted] [redacted].

The following was provided by Stretch Productions and is part of the press release about the CD.

Finding answers is not always an easy path. Finding answers together, however, can make the path brighter and easier to travel. In search for a cure for Alveolar Capillary Dysplasia, and in memory of "[redacted] [redacted]", singers and songwriters from Keller, Texas to Nashville, Tennessee came together to form 'The Answer', a 12-track compilation album with proceeds benefiting ACD research. Artists such as Rebekah Jordan, Ryan Wood, Jordan Justice, Bailey Lawrence, Brittany Strother and Stephen Bolduc are all college students who have had extensive vocal and stage training and were chosen by Stretch Productions for this project during their time in the Keller School District. The album also includes a duet by Paula Jordan and Brad Lundy of the Keller area, a song from the band "Red White and Blues", and a full choir of Keller students performing a remake of 'Peace on Earth." Written by internationally-renowned music artist ("Mandalaband") and television presenter/archaeologist from the UK David Rohl, this 1985 EducAid Christmas single was a charity follow-up to BandAid, recorded by British students. David Rohl's willingness to share his fundraising song really set the tone for the beginning stages of this ACD CD.

Other songwriters we wish to thank include Tammy Branscom, Nashville, Tennessee; Heather Duncan, Indian River, Michigan; from "The Duggars: 19 Kids & Counting" wedding episode - songwriter Robert Greenlaw, Oklahoma City, Oklahoma; & ABC-TV's "General Hospital" actor/songwriter Christian Taylor.

Also from Nashville, Stretch Productions is proud to feature Jordyn Shellhart-up-and-coming country music starlet signed by Columbia Nashville, among the likes of Carrie Underwood, Brad Paisley and Miranda Lambert. Jordyn's song, 'You Don't Get To Get To Me', is from her debut album "In a Room".

welcome.....

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

[redacted]

[redacted]

[redacted]

Contact Information

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Make a Tax-deductible Contribution for ACD Research

The National Organization of Rare Diseases is a non-profit organization in the United States who is “dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. For the sixth consecutive year, 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 $35,000 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.