

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 14, Issue 1

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

Winter 2012

Dear Friends and Family,

Your fundraising efforts and donations have paid off! The ACD Restricted Research Fund at the National Organization of Rare Disorders (NORD) will award a grant for ACD research later this year! This is exciting news and we are grateful to all of you, your families and your friends that have made this possible. Thank you!

We are also thrilled to announce that the first ever survey on ACD has been developed and is ready for us to complete. We can't emphasize enough how important it is for all of us to take the time to complete the survey. This is one thing we can all do to make a difference in memory of our baby(ies). See page 2 for all the details.

As always, please take a few moments to contact our new members to offer your support as they will find comfort knowing they are not alone.

Fondly,

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



David Ashwell Foundation Makes Major Donation to NORD ACD Account

On Rare Disease Day (February 29, 2012), £33,118 or \$51,468 was transferred from The David Ashwell Foundation to NORD's restricted research account for ACD. This amount was the total of all the fundraising done by Simon and Amelia Ashwell in memory of their son, David, who died 11 months ago as well as fundraising by other ACDA members in the UK including the Hardisty, Taylor and Bremmer families. The dedication and generosity of the Ashwells, our UK families, their families and their friends will make a difference in our quest to find some answers about ACD. Their commitment to this goal is nothing short of amazing. On behalf of all the members of the ACDA, thank you Simon and Amelia. We know that David would be so proud.

Research Account Over \$90,000!

Because all of you that have made donations or held fundraisers over the last several years, we are so excited to announce that our ACD Restricted Research account is **\$94,341.93!** We have far exceeded the amount (\$33,500) required for NORD to initiate a grant for ACD research. In fact, this is almost three times that amount of each of the previous two grants that NORD awarded for ACD. You will find several articles in this newsletter that address this very successful campaign.

Thank you to everyone that has worked so hard to reach this goal and please be sure to share this wonderful news with your family and friends that have supported you.

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Parent Questionnaire Now On Line

By ACD Mom Amelia Ashwell Lake

Do you want to know more about ACD? We all have so many unanswered questions about ACD, many of which we discuss with each other. As parents we may share similar backgrounds, family histories and experiences with ACD. In order to identify those similarities and differences, an international team of academics, clinicians and the ACDA, with input from parents, has developed a questionnaire for parents to complete.

The team is led by ACDA mom Dr. Amelia (Ashwell) Lake who is an academic researcher at The School of Medicine and Health, Durham University (UK). The team includes Dr. Partha Sen (Baylor College of Medicine, Houston, Texas, USA), Dr. Jonathan Wyllie (Neonatal cardiologist, The James Cook University Hospital UK [JCUH]), Dr. Jane Cassidy (paediatric cardiothoracic anaesthetist, Freeman Hospital Newcastle, UK) and Dr. Simon Ashwell (Clinical input, JCUH, UK). The ACDA Executive Directors and Chairpersons have been instrumental in the questionnaire design and have reviewed the questionnaire at various stages. In developing the questionnaire, additional support has been provided by The Clinical Director of Northern Genetics Service (Institute of Genetic Medicine, Newcastle, UK), a Professor of Maternal & Perinatal Epidemiology (Newcastle University) and a Professor of Environmental Epidemiology (Newcastle University, UK).

The goals of the questionnaire are:

- 1) To describe the characteristics of ACD and explore similarities/ differences between occurrences.
- 2) To provide information that will be of interest to parents who have had an infant/ infants affected by ACD.
- 3) To describe the 'journey' of parents with an infant/ infants diagnosed with a rare condition.

The findings will help us understand more about this condition, how and when it presents and how infants were treated. The results of the questionnaire will be collated and made available to you via the ACDA.

Neither the research team nor the ACDA will be able to identify individuals. Only Dr. Amelia (Ashwell) Lake, at Durham University, will have access to your **anonymous** data for this study. Your participation in this study will be kept **confidential**. We are **not** collecting your name; you will be given a unique identification number so that data belonging to you cannot be recognized, which means that no data can be specifically linked back to you. The responses you give in the questionnaire will be analyzed and reported **without** your details attached to them.

Continued on Page 3

Parent Questionnaire Continued. . .

In order to make the data analysis effective and conclusive, it is imperative that we have a **large** number of families participate in the survey. Therefore, we would like all of our ACDA families to complete the survey at your convenience. Your response is very **important** to furthering the understanding of this condition. The survey will be open from March 2012 – October 31, 2012. However, it would be helpful for you to complete this survey as soon as possible.

This is an **opportunity** for us to work together and collate as much information on our backgrounds and experiences as we can. **Your response is vital to the success of this project.** We thank you in advance for your participation.

The survey is secure, anonymous and is only available online. Please go to the following link to begin the survey.

<https://www.survey.bris.ac.uk/durham/acda>

If you have any issues with completing the questionnaire please contact Amelia (Ashwell) Lake at Amelia.lake@durham.ac.uk . If you have any concerns or comments, please contact Steve and Donna Hanson at sdesj@verizon.net .

*5th International Conference
Neonatal and Childhood Pulmonary Vascular Disease
March 9, 2012*

Dr. Robin Steinhorn, MD of Northwestern University recently made a presentation on current ACD research. You can find her presentation at

<http://www.ucsfcmc.com/2012/slides/MPD12002/11SteinhornAlveolarCapillaryDysplasia.pdf>

Since the early days of the ACDA, Dr. Steinhorn has been supportive of the ACDA and ACD research.

Thank you Dr. Steinhorn for your years of dedication!

ACD RFP to be Released

At the end of March, NORD will issue a Request for Proposal (RFP) to the medical community for ACD research thanks to the dedicated fundraising efforts of our ACDA community. The final amount of the RFP is still to be determined but it will be for over \$90,000! We are in contact with NORD to decide the best way to structure the RFP and NORD has been very helpful and inclusive. Below is a summary of the schedule and selection process taken from the NORD website that NORD typically follows from RFP initiation to the award announcement.

"Requests for proposals (RFPs) are issued on a cyclical basis. Adequate funds must be in place before preparations to initiate a research grant begin. Therefore, to maximize the full benefits of international advertisements and wide circulation of the funding opportunity, donors should understand that it takes several months after an RFP is issued, until the grant is awarded and actual research can begin. The outline below depicts a typical cycle:

| | |
|-------------------|--|
| October - January | NORD prepares to initiate Request For Proposals (RFP) |
| March | Issue RFP |
| April/May | Deadline for preliminary proposals. NORD Medical Advisory Committee narrows applicants and invites finalists to submit detailed proposals. |
| July/August | Deadline for full proposals from finalists. Peer review of final proposals. |
| September/October | Winners selected and awards announced. |

Selection Process: The initial Request for Proposals asks scientists to submit a brief description (abstract) of their proposed research project along with their professional qualifications and a draft budget. Once that information is received, NORD's Medical Advisory Committee (composed of leading academic scientific experts) reviews all of the applications and selects finalists. The finalists are invited to submit a full grant application describing their proposed project in detail. NORD's Medical Advisory Committee then reviews the full grant applications (peer review) and ranks them through a scoring system. The highest scoring grant applications are recommended for funding to NORD's Board of Directors who votes on the final grant awards.

NORD's grant review process is based on the same peer review system utilized by the National Institutes of Health (NIH). Scoring of grants is done individually by each medical expert, and scores are added together to determine the final ranking of each proposal. Any reviewer with a conflict of interest is excused from voting on a specific proposal. **It is not possible for donors to signify how they want their donations spent (e.g., on a genetic test rather than development of a treatment), or which researcher should be funded.** The grant selection process is unbiased and independent; awards are based solely on scientific merit. Only the best research projects will be funded.

By encouraging research applicants to compete against each other on an international basis, NORD's Research Grant Program funds only the best proposals that are most likely to result in research breakthroughs that can be applied to the diagnosis or treatment of people with rare disorders."

Staying Connected

Losing a baby can be very isolating. It's hard to feel normal, and in fact "normal" has come to mean something different than you ever imagined it would. Acquaintances, co-workers, even close friends and loved ones are often at a loss for words. They don't know what to say or may be uncomfortable with how close to the surface your grief is. You often can't predict what will trigger your grief and it can come out of nowhere with such force that it takes your breath away.

People may feel that talking about your baby will be too hard for you, leaving you feeling alone in your grief. But staying connected to people is important, and the ACD Parent Group Facebook page is one way to do just that. This is a forum to share openly with people who, unfortunately, understand what you're going through. We've been there. We ARE there. It's a place to share what scares you, what inspires you, what brings you hope, what brings you joy, what overwhelms you. Or when you're just having a bad day.

Parents share what they are doing to honor their children that ACD took too soon, the fundraisers they are organizing, the joy and fear that comes with the rainbow pregnancy. They share their baby's story, grief resources, books they have found inspirational, their own blogs of this journey through grief.

I have been inspired by how strong other parents are in the most difficult situation possible, and by how so many have turned their grief into a way of giving back. We have become a strong support for each other and would welcome the opportunity to support other parents through this process.

Join the ACDA on Facebook

For those of you on Facebook, we encourage you to "like" the ACDA's public page, which promotes ACD awareness and encourages families to contact the ACDA, (<https://www.facebook.com/ACD.Association#!/ACD.Association>) and to encourage your friends and family to do the same. We're also happy to "like" the NICU's where your babies stayed in order to help promote the word about ACD.

We also encourage ACD parents to join the "ACD Parent Group" (<https://www.facebook.com/ACD.Association#!/groups/168480916544514/>).

The ACD Parent Group is a closed group that provides support, information, and a place for families to share pictures and stories of their babies. We are up to 59 group members, and we think that everyone who has joined would tell you that it is a wonderful group of amazing people that provides guidance, shares tears, and helps each other along our paths, no matter where we are on our journeys.

Contact Emily Eschweiler for more information at Emily_Eschweiler@comcast.net (or search for Emily John Eschweiler on Facebook).

Fundraising Update

From Emily Eschweiler
Emily_Eschweiler@comcast.net

Note from Emily

As you will see elsewhere in the newsletter, the ACD Restricted Research Fund total at NORD is very impressive! Thank you, thank you, thank you to everyone who has contributed to this fund and who has encouraged others to do so. NORD will be posting a very impressive grant for ACD research this spring! Let's continue our momentum and build the fund up again for the next grant cycle. The more research that is done, the more answers we will all receive.

Remember that no fundraiser is too small and that every dollar helps. Don't feel like you need to take on a project on a grand scale in order to fundraise. Some ideas for the spring: instead of going out to lunch or dinner, bring a bag lunch and donate the difference to NORD; host a rummage sale and send the proceeds to NORD; encourage your children to have a lemonade stand and to send the proceeds to NORD. Or, if you are feeling ambitious, start planning an event to honor your child and the other ACD babies. Some other fundraising items:

- I am still looking for a parent who would be interested in taking on a silicone bracelet project. Please contact me if you might be interested.
- Kim Anderson Bush has offered to look into the requirements for becoming a 501(c)(3) non-profit organization. If anyone has any experience with this and would like to help, please contact Kim at ratherbinak@yahoo.com.
- If you know of an organization or vendor who is interested in possibly teaming up with the ACDA to raise funds, please have them get in touch with me.
- There are a very limited number of magnets left from last year's fundraiser. If you are interested, please contact me for an order form.

Member Fundraisers

■■■■■, *mom to ACD baby* ■■■■■ knit a beautiful shawl that she used to raise funds for NORD. Friends, family members, and followers of her blog donated over \$700 for the chance to win the shawl. She drew the winner on February 29, Rare Disease Day, and the day that ■■■■■ would have been five months old. More information can be found at:

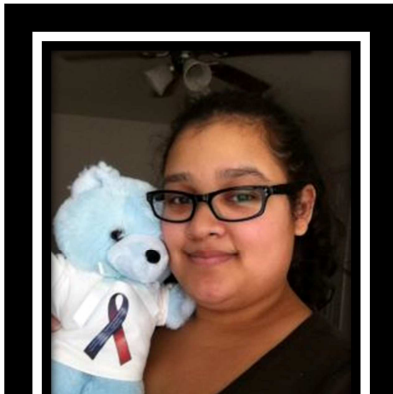
■■■■■, *father to ACD baby* ■■■■■, participated in a lap a thon on December 8, 2011 at the college where he teaches and covered an Ironman distance of 3.8 km, raising a total of roughly \$4,000-\$4,500 between direct sponsors and donations to NORD. He also participated in a triathlon in Abu Dhabi, U.A.E. on March 3, 2012 with 2,100 competitors from 62 countries including 52 world pros holding 16 world championships! He had friends and family join him as he completed the course in memory of ■■■■■ and all the ACD children. He finished in 2:33:01 and placed 290 out of a field of 600. His

next stop is the Ironman in Calgary, Alberta on July 29 covering 1.9 km swim, 94 km bike, and a 21 km run. Wish him luck!!

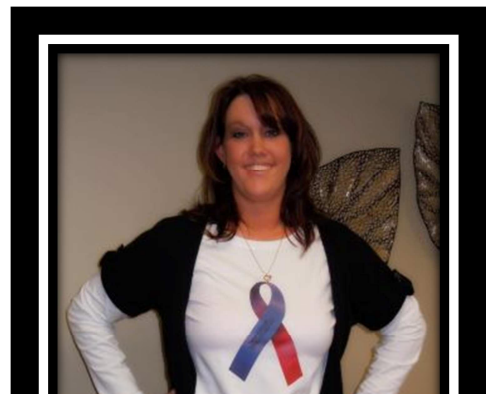
■■■■■, *father to* ■■■■■, will be participating in the Tough Mudder this spring, raising money and awareness for ACD. You can check out his story and sponsor him at:

Café Press: Emily has created a Café Press site at the request of some ACDA supporters who were looking for clothing and other merchandise with the ACD ribbon. The site is still a work in progress and ACDA logo items should be available soon. Suggestions and ideas are very much appreciated. All products with our designs earn a 10% commission, and Café Press will send the commissions directly to the Restricted Fund at NORD. According to Café Press, items purchased in the general marketplace at CafePress will still earn a 10% commission, but Emily has found that for most regularly priced products, the pricing is better through the direct link. If anyone is interested in creating a product specific to their baby (such as a button, mug, or other item) for friends or family members to order, please feel free to contact her. It takes 45-60 days for the commissions to clear, so we will start reporting our commissions in the next newsletter.

Here is a link to the site: <http://www.cafepress.com/acdawareness> and below are some pictures of two of the products that our members have purchased in memory of their angels.



■■■■■, mom to ■■■■■, with the CafePress bear:



■■■■■, mom to ■■■■■, wearing her parent of an angel shirt

More Donations Made to NORD from Sale of "The Answer" CD

Cami McCraw, aunt to ■■■■■, announced that Stretch Productions sent another quarterly donation to NORD. The donation is an on-going contribution based on CD sales and downloads for "The Answer" CD that she and her husband produced. The CD can be purchased at the following places:

Stretch Productions Website: <http://stretchproductions.com/theanswer.html>

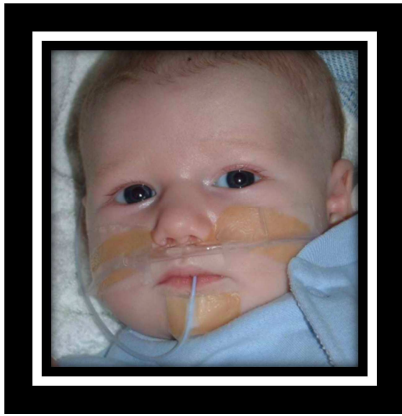
CD Baby: <http://www.cdbaby.com/cd/stretchproductions>

I-Tunes: <http://itunes.apple.com/us/album/the-answer/id396571667?i=396571689&ign-mpt=uo%3D4>

Amazon.com: <http://www.amazon.com/>

Cami is looking for ways to spread the word about this CD that raises money for ACD research. If you have a retail outlet or know of one that would be interested in selling the CD, please contact Cami at

cmccraw@swbell.net.



Running for



By ACD Member



On 4 April 2012, my son [REDACTED] would have been 7 years old. Eighteen days later I am running the 2012 Virgin London Marathon to raise money for ACD research. The charity I am running for is the David Ashwell Foundation (another ACD baby) and they will send the funds I raise to support the research in the USA.

I have never done anything like this before, but I was compelled to take up this opportunity to raise money for something so close to my heart. [REDACTED] was our first born and as with all expectant parents we were filled with both excitement and fear but nothing prepared us for the 31 short days that followed his birth. We hit roller coaster after roller coaster, the initial shock of him being admitted to Special Care, the chest drains and ventilator, him nearly dying at three days old and being asked to say goodbye. We then travelled the highs and lows that led to ACD, constant chest x-rays, scans, ECMO, MRI scans and finally a lung biopsy that diagnosed ACD.

I received tremendous support from the ACDA community, many people were happy to listen to [REDACTED]' story and share theirs and it really helped me to process what is anybody's worst nightmare. So, over the last three months I have been training, in all weathers. I have done hill repeats in minus 8 degrees, I have done a fast 6 miles in minus 6 with a wind chill that meant I couldn't feel my face or hands on return, and was unable to fill the kettle to make a well-deserved cup of tea. Today I went out in wind and rain for seven miles – and as I did I questioned my sanity but then I thought of why I was doing this and what it meant. I thought of [REDACTED]. Then just as I trudged uphill with the wind driving at me and the rain coming at me horizontally like razor blades I spotted a white feather. One small insignificant white feather but to me it was a sign.

When [REDACTED] passed away my aunt told me a story. If you find a white feather in your path it means your guardian angel has gone before you and made it safe. As I could no longer be a Mum and look after [REDACTED] I decided that he was my guardian angel and was looking after me. It may sound strange but grief does strange things and I found comfort in these white feathers.

My 40th birthday should have been my first birthday with [REDACTED] we had gone abroad to Florence, Italy for a bit of a holiday but it didn't detract from my mood and I was feeling robbed. My husband, [REDACTED] had put together a beautiful photo album of [REDACTED] and had given it to me for my birthday. We went out for an early morning walk through the city. On our return across the Ponte-Vecchio Bridge I was trying to hold back the tears, I just wanted my little baby to be in this world with me. It was a very misty morning and as I lent on the bridge and looked up, I could barely see more than a few feet above me but there floating from the grey sky was this perfect white feather. Time felt like it was standing still the hustle and bustle going on around me seemed to stop and as I slowly opened my hand it gently floated down landing smack in the middle of my palm, I closed my fingers over it, looked skyward and felt he was there, in his own way, looking after me.

When I run this marathon on the 22nd April I will be caught up in the excitement, the camaraderie, the hoping of getting round or better still doing well. I will have my Garmin watch on and pressing the "lap" button at every mile to try to pace myself. I am looking forward to the amazing atmosphere that everyone has told me about – but the one thing I will be looking out for, particularly when the going gets tough will be a white feather.

If you would like to sponsor me, please go to: uk.virginmoneygiving.com/AlisonHardisty . You don't have to live in the UK to support [REDACTED]!

WANTED: RUNNERS

[REDACTED] [REDACTED], mom to ACD angel [REDACTED], is interested in adding ACD as a charity for the Los Angeles Marathon. 25 runners are needed. If you are interested, please contact [REDACTED] [REDACTED] or at [REDACTED] [REDACTED] [REDACTED] [REDACTED] [REDACTED] [REDACTED]. Go [REDACTED]!!

ACDA Logo Update

Many thanks to [REDACTED] [REDACTED] [REDACTED], parents of ACD angel [REDACTED], for updating the ACDA logo for promotional purposes. [REDACTED] and [REDACTED] are the founders of [REDACTED], an advertising, marketing and public relations firm in San Antonio, Texas. [REDACTED]

ALVEOLAR CAPILLARY
DYSPLASIA ASSOCIATION



www.acd-association.com

Fundraising Update from The David Ashwell Foundation

by Amelia Ashwell Lake & Simon Ashwell

As was mentioned earlier, our fundraising still continues after donating over \$51,000 to the NORD account! Since the Winter ACDA newsletter, there have been a number of fundraising events including a Charity Quiz night in Omagh Northern Ireland (February) organised by Amelia's mum – Vida Lake. This event raised over £925.00 (\$1,455). Also in Omagh and organised by Amelia's mum was an event called 'Tea & Cake with Vida Lake' which raised £560.00 (\$881). Lots of friends baked cakes and donated crafts which were all sold in aid of ACD Research.



There are also quite a few live fundraisers! ACD mum [REDACTED] is in training for the 22 April London Marathon. [REDACTED] is doing really well with her training and fundraising. So far she has raised over £3313.00 (\$5,213.00). Also doing the London Marathon is a family friend of ACD parents [REDACTED] and [REDACTED] – [REDACTED] [REDACTED] - who has raised £738.00 (\$1,161.00). Check out these links to make donations.

In Perth, Australia [REDACTED] is doing her second challenge for ACD Research – Jacobs Ladder Challenge - which involves lots of stairs and weights and sounds very tough. This just went live and has already raised £165.00 (\$259.00). It would be great if the Australian ACD families could support her.

In Scotland, another friend, [REDACTED], is losing weight for ACD – she has been very successful!

Two friends have planned a 1000km cycle for ACD Research this summer. [REDACTED] and [REDACTED] will cycle the dramatic coastline from north west to south west Ireland. They have a blog and are on twitter! Please support them:

Anisa (Amelia's sister) is planning on doing another flea market sale for ACD Research in Dubai. Last time she raised £500 (\$786). Gemma (Simon's sister) has signed up for an Iron Man Challenge!

Locally, we are busy organising the Rock, Frock and Frolics event on 28 April. This is already a sold out show and we are busy trying to secure raffle and auction prizes. We have an amazing auction prize lined up - dinner with Aiden Gillen who played Tommy Carcetti in the HBO television show *The Wire*: http://en.wikipedia.org/wiki/Aidan_Gillen .

Raising Awareness

Media interest

On what would have been David Ashwell's first birthday, Sunday March 4, his mom, Amelia, wrote a piece for a regional newspaper called *The Sunday Sun*. The piece was featured on the front page and was a middle page double spread. Check out this wonderful article from England at:

<http://www.sundaysun.co.uk/news/north-east-news/2012/03/04/grief-and-joy-for-one-mum-on-mother-s-day-79310-30454443/>

Amelia's article in *The Sunday Sun*



Twitter

Thanks to Amelia Ashwell Lake and Simon Ashwell, the ACDA is now on twitter @ACDAssociation. We are engaging with other organizations and hope that we can raise the profile of ACD in the new world of social media. Amelia and Simon are trying to use lots of #ACD and #ACDResearch to

increase the profile and update other organizations about what we are doing.

<http://twitter.com/#!/acdassociation>

Information for Parents

Amelia and Simon Ashwell have written a short leaflet to give to the hospital where their son David was treated. The leaflet includes information about ACD for the parents and directs them to the ACDA website. It also has Amelia and Simon's contact details for parents to get in touch, if they want to. This can be adapted and updated for your own community with your own details. Just wanted everyone to know they are welcome to use it as a template. Contact Amelia at amelia.lake@durham.ac.uk.

Amelia & Simon have also been updating the general brochure on ACD – more information soon!

ACD Documentary

Emily Meisner graduated from Appalachian State University in December 2011, where she studied Electronic Media and Broadcasting. In one of her classes, she was asked to produce a ten-minute documentary on a topic of their choosing. She wanted to find a topic that interested her, first of all, but also one that might be of some use to others; one that would have a deeper meaning than just a class assignment. A sister in her sorority, Phi Mu, had recently lost her niece, [REDACTED], to ACD. None of them had ever heard of the disease before it took [REDACTED], and they were all quite shaken up by it. It's was hard for Emily to sit by and watch something hurt the people she loves and not be able to do anything about it. This project became her small way of showing her support to her Phi Mu sister and her family. Emily hopes that by increasing awareness of ACD more research will be done and that eventually a family may be spared the grief that so many have experienced.

You can listen to Emily's documentary on the ACDA website - [\[REDACTED\]'s Story an ACD Documentary](#) (Note this is a large file and will take some time to open). Thank you Emily for helping raise awareness of ACD!

Big Brother Speaks of ACD

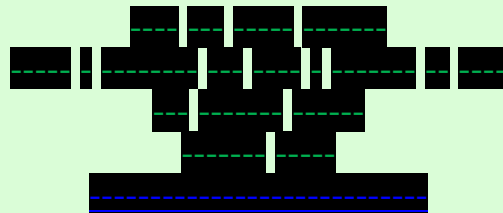
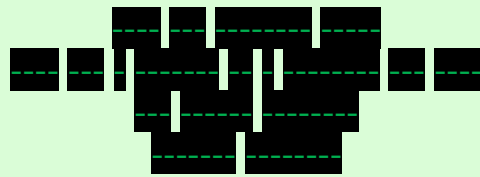
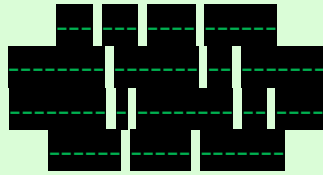
4th Grader Tristin, sister of ACD angel [REDACTED], recently presented a two-minute power point presentation on ACD to her Leadership class at the University of Houston through her Gifted and Talented class. The presentation went very well, and helped spread the word for this little known disorder. Way to go Tristin!



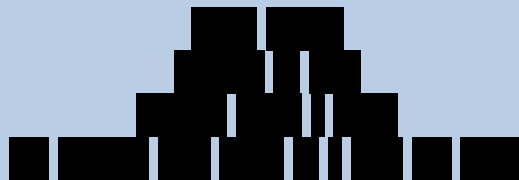
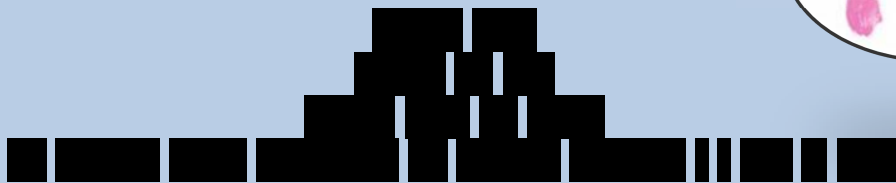
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Welcome...

Please welcome our new ACDA families:



Safe Arrivals



Congratulations!

Make a Tax-deductible Contribution for ACD Research

In the spring of 2002, the ACDA established an ACD Research Account at NORD. This means that your contribution to NORD can be earmarked specifically for ACD research. As stated below in *NORD's Rare Disease Clinical Research Program Policy*, NORD requires that a research account reach \$33,500 before it will initiate the grant process to award research money to the medical community. Therefore, the goal of the ACDA is to raise more than \$33,500 for research.

To make a tax-deductible contribution to NORD for ACD research either by mail or on the NORD website, please use one of the instructions:

*** Make a Donation by Mailing a Check ***

- 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 with promptly 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.

*** Make a Donation on the NORD Website ***

Go to <https://www.rarediseases.org/about/support/research-donations>. Select "Alveolar Capillary Dysplasia" in the research fund pull-down menu and complete the rest of the form.

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. Use the NORD website at <https://www.rarediseases.org/about/support/research-donations>.

Contact Information

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- Family Support: Kim Anderson Bush
 - Email: ratherbinak@yahoo.com