ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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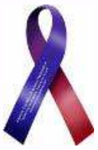
Dear Friends and Family,

Many thanks to all of you that have been busy raising money for ACD research. Judging by all the successful fundraisers, it looks like we will easily reach our goal of $33,500 by March 2012 so that an ACD grant will be part of the 2012 grant cycle at NORD. But do not stop or slow down – NORD will issue a grant for the amount we have in our account!

It is with regret that we announce the resignation of Lisa and Harry Durand as Fundraising Chairpersons due to other commitments. Emily and Tim Eschweiler have agreed to assume the responsibilities of the position. Therefore, we are looking for a member to take over the Family Support Chair. If you are interested, please see the article on this page and contact us.

Last, we have five new families that have recently joined the ACDA. Please take a moment to contact them and offer your support.



Fondly,

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

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WANTED:
Family Support Chairperson

The ACDA is looking for an energetic person to assume the position of Family Support Chairperson. Below is a summary of the duties of this chairperson:

- Contacts new families. After a family contacts the ACDA, Donna and Steve make the initial contact with the family and send an information package. The new family information is then forwarded to the Chairperson, who will send a follow-up note offering condolences and assisting with finding the appropriate resources for the family. In addition, the Chairperson will make initial contact with individuals who may not be aware of ACDA and encourage them to contact the ACDA.
- Be active on our Facebook page to support all families.
- Identify grief support resources (articles, websites, books, poems, etc.)
- Work in conjunction with Research Chair to contact Level III NICU's to make sure that they are aware of the ACDA and to provide them with contact information for the organization and for Dr. Sen's research study
- Send notes to existing members on the first birthday of their baby.
- Assist other chairs as applicable.
- Write a brief article for the quarterly newsletter.

If you are interested in becoming the Family Support Chairperson, please contact us at sdesj@verizon.net.

Research News From Diana Locke

Baylor Medical Genetics Laboratory Offers Prenatal Testing

Dr. Partha Sen, one of the lead researchers on ACD at Baylor, has provided some information on the ACD/MPV prenatal testing that is now available at the Baylor College of Medicine Medical Genetics Laboratory. This test can only be conducted if there is a previously identified familial mutation and the request for the test has to come from a medical provider, not the family. In the test, they conduct a FOXF1 sequence analysis (prenatal diagnosis) in which the DNA is usually isolated from the cells in amniotic fluid. The test includes sequencing of the region(s) containing the familial alteration(s). The results are conclusive in the sense that if there is a mutation or a deletion in the FOXF1 gene, then it will be identified. The absence of a deletion does not preclude the potential for ACD because not all ACD babies have the FOXF1 deletion. The test will not be of much help to test the parental DNA, as most ACD/MPV cases are sporadic. Baylor requires that the referring center (medical facility/hospital) consult with Baylor's laboratory genetic counselors regarding prenatal cases prior to submitting any samples. They can contact Baylor at 1-800-411-4363. The cost of the test is $1,550. For more information, the url for the Baylor Medical Genetic Laboratory is http://www.bcm.edu/geneticlabs/.

For additional information:

GeneTests Web site is a publicly funded medical genetics information resource developed for physicians, other healthcare providers, and researchers:
http://www.ncbi.nlm.nih.gov/sites/GeneTests/lab/clinical_disease_id/319131?db=genetests

For testing in the UK:
http://staging.labs.gosh.baigentpreview.com/laboratory-services/pmu/tests/foxf1 ()

Awareness Efforts by Diana Locke

On August 10th, I presented information on ACD to16 nurses from the Level 3 NICU at Shands of Jacksonville (Florida) during their "core classes." This is a class that all new NICU nurses attend and includes many topics to help them understand their roles as NICU nurses (such as ventilator management, feedings, warming the babies, etc.) and to teach them things they may not have learned in school. I will be presenting to them every year going forward.

The NICU manager is trying to schedule an appointment for me with the attendings for Neonatology to present the information to them as well. During our class discussion, the nurses mentioned that there was a baby who had just passed and they thought it sounded similar to ACD. They were going to approach the physician to see if they could ask the pathologist to look for ACD as a diagnosis.

I currently have emails out to the following NICUs about presenting information on ACD: Huntsville Hospital in Huntsville, Alabama; Birmingham Hospital NICU; Shands in Gainesville, Florida; and Wolfson's Children's Hospital Jacksonville, Florida.

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There has been some interest from other parents in the ACDA about presenting information on ACD in their community. I think that is great and will gladly provide any materials you would like to make this possible. You don't have to present to large groups, but the more information we get out there, the better. If you can help just one parent with your experiences, it is worth it.

I can be reached by phone (904) 655-1046 or email 4wheelin@earthlink.net.

Fundraising Update Thank you!

Ashwell Family

On September 10, Simon Ashwell, father of David, and five other cyclists rode 117 miles coast to coast (from Morecambe to Sandsend in England) to raise money for research and awareness for ACD (see picture below). Simon and Amelia have been very busy publicizing this event, as well as eight other events that have either recently occurred or will be occurring this fall. As of September 11, 2011, the David Ashwell Foundation had raised £10,130 ($15,845) for research! Way to go Amelia and Simon! The David Ashwell Foundation has a page on Facebook, and their fundraising page can be found at: http://uk.virginmoneygiving.com/charity-web/charity/finalCharityHomepage.action?uniqueVmgCharityUrl=davidashwellfoundation

Funds as of September 5, 2011 from the Ashwell's Events

- August 28, 2011 - Perth 12KM – Kay Drury –– £443.00 or $697
- August 2011 – 11-year old Dan Charlton bicycled from the Irish Sea at Whitehaven for 140 miles along the Coast to Coast Cycle route to the North Sea at Seaborn –- £645 or ($1015)
- September 10, 2011 – Simon Ashwell (David's Dad) and a team of consultants and colleagues from the James Cook University Hospital (John Main, Richard Cree, Andrew Heath, Mike Foley, and Simon Kendall and his son Thomas) cycled the Coast to Coast route in one Day (117 miles) – £5,533.50 ($8,570)
- Portugal in September – Vafa, Amelia's cousin, is running a half marathon - £260.00 ($409)
- September 18, 2011 – Rachel Tyrrell is running the Great North Run, which is a half marathon – £270.00 ($425)
- October 23, 2011 – Penny Rumbold is running the Birmingham half marathon
- Fiona Crosbie – Great North Run - £190.00 ($299)
- October 29, 2011 – Emma Mudd (Foster), Angela Craigie and a band of brave friends are ziplining across the river Tyne. £667.00 (goal is £2000 or $3,147)

Thanks to the Ashwells, their family, their colleagues and their friends for their support of ACD research!

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--------- Family

[redacted] [redacted] mom to [redacted], raised $2,000 for research in honor of [redacted]’s first birthday. This was a raffle fundraiser where people bought $1.00 raffle tickets for a particular item that they wanted. Then, [redacted] picked the winner out of all the tickets purchased. What a great fundraiser!

------- Family

[redacted] and [redacted] [redacted], parents of [redacted], had a car wash to raise funds. They raised $788! A group at their church that their children belong to is called "Kids Who Care." The kids, who are under the age of 6, held a car wash in [redacted]’s name. The [redacted]s plan to make the car wash an annual event. See below for pictures from the event.

[redacted] [redacted] [redacted] [redacted] [redacted] [redacted]

Family Support News

From Emily & Tim Eschweiler
emily_eschweiler@comcast.net

I hope that wherever you are in your journey, that this newsletter finds you well. As fall approaches, and we get closer to the holidays, I think it is only natural to reflect on our children who are no longer with us. In looking through past newsletters and other places, I have seen a number of really positive ways to honor our babies during the holidays. Some of those ideas include ornaments (or other holiday items) in honor of an angel, gifts to a toy drive appropriate for the age that your angel would have been, and donations to NORD honoring your angel. But it is also okay to be sad and to miss the child who isn't here to celebrate the holidays. I encourage you to reach out to other ACD families as resources, support and comfort.

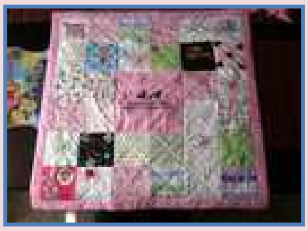
As mentioned in the last newsletter, there is now an ACD Parent Group page on Facebook. Thank you to everyone who has joined this page and who has contributed! We are now up to 44 parents in this group, which is a closed group – meaning that any parent can join, but you can feel comfortable discussing things as you need to be a member to view the information on the page. We invite and encourage any other ACD families who are on Facebook to join us. It is a great place to share information, get support and offer encouragement. There are also some adorable pictures of our babies and of tributes to our babies! In addition, there is an ACDA page to assist new families with finding our organization.

Also, I still have a number of magnets available. My preference is that you write the check directly to NORD. If you prefer to use a credit card, please let me know and we can work that out. The fridge magnets are 4 for $10 and the car magnets are $10 each. Please contact me at emily_eschweiler@comcast.net if you would like more details. (Note: e-mail address is emily ***underscore*** eschweiler as the underscore is hidden in the hyperlink.)

We are fast approaching the amount needed for our next research grant with NORD. We are currently researching whether it would be feasible to become a 501(c)(3) organization. If anyone has any experience (accounting, legal, etc.) with forming a 501(c)(3) organization, I would be very interested in talking to you further. There are definite advantages and disadvantages with continuing to raise funds strictly through NORD, and pros and cons which must be weighed with both approaches.

In the last newsletter, I asked if anyone was willing to share some special ideas that help keep their angels close. So many people have responded with such great ideas that I will include a few in this newsletter and more in the next. If anyone else would like to share, please feel free to contact me.

The first photo on the left is from [redacted] [redacted]' mom, [redacted]. It is a tattoo on her foot in the shape of [redacted]'s footprint. [redacted] also shared the photo of a special quilt made by [redacted]'s grandmother from clothing [redacted] never had the chance to wear.



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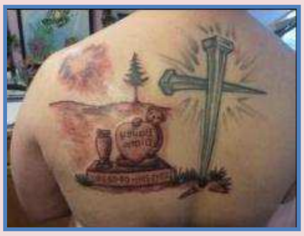
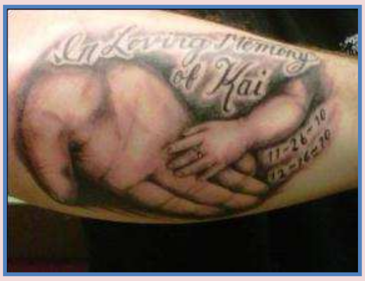
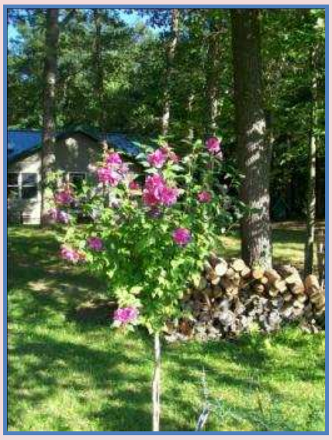
[redacted] [redacted] shared this photo of his tattoo in memory of his daughter, [redacted].



Another tattoo was shared by [redacted] [redacted]'s and is worn by [redacted], father of angel [redacted].



To the right, is a photo of [redacted] [redacted]'s tree in the baby garden [redacted] [redacted] and [redacted] [redacted] have planted in memory of their angels, [redacted] and [redacted].



The drawing to the left is of [redacted] [redacted] in the hands of Jesus and was drawn by his great-aunt, who then etched it beautifully in stone.

ANNOUNCEMENTS

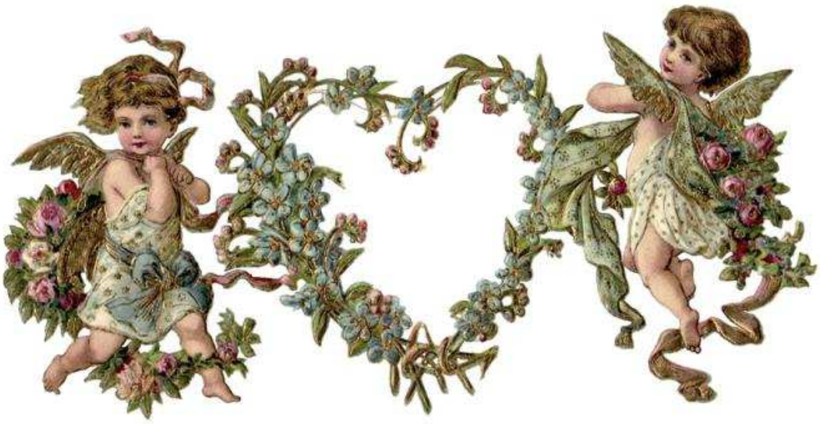
- The current balance of our ACD Restricted Research Account at NORD is $33,140 as of September 21, 2011. Only $360 to go! Thank you!
- Check out this link to an article about Stretch Productions CD benefitting ACD research: http://www.dfw.com/2011/07/25/486088/fort-worth-based-stretch-productions.html?storylink=addthis

Remembering Our Babies

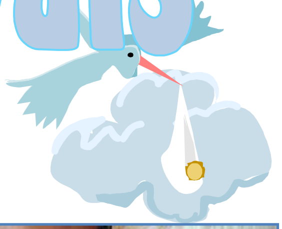
No matter how many years have passed, we remember. Please join us in celebrating the lives of the babies that are no longer with us.

[redacted]

[redacted]



Safe Arrivals



[redacted]

[redacted]

[redacted]

Congratulations!

welcome.....

Please welcome our new ACDA families:

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

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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  - *Email:*