ACDA NOTES

From The Alveolar Capillary Dysplasia Association

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Dear Friends and Family,

As the holiday season draws near, please never forget that your ACDA family is here to support you. Through the efforts of several moms, the Facebook page has taken off and is a great area for support by people who know what it is like to have a child who died from ACD. Please join us if you haven't already and share your child's story. It is a closed group, so anything you post on this site is not shared on your regular Facebook page. It is a safe place. https://www.facebook.com/groups/168480916544514/

Lastly, there is a way for you help the ACDA realize a long-time goal to become a non-profit. See page 3 for all the details.

Steve and Donna
ACDA Executive Directors
Parents of Eric – June 7 -17, 1997

INSIDE

Tattoos for Angels

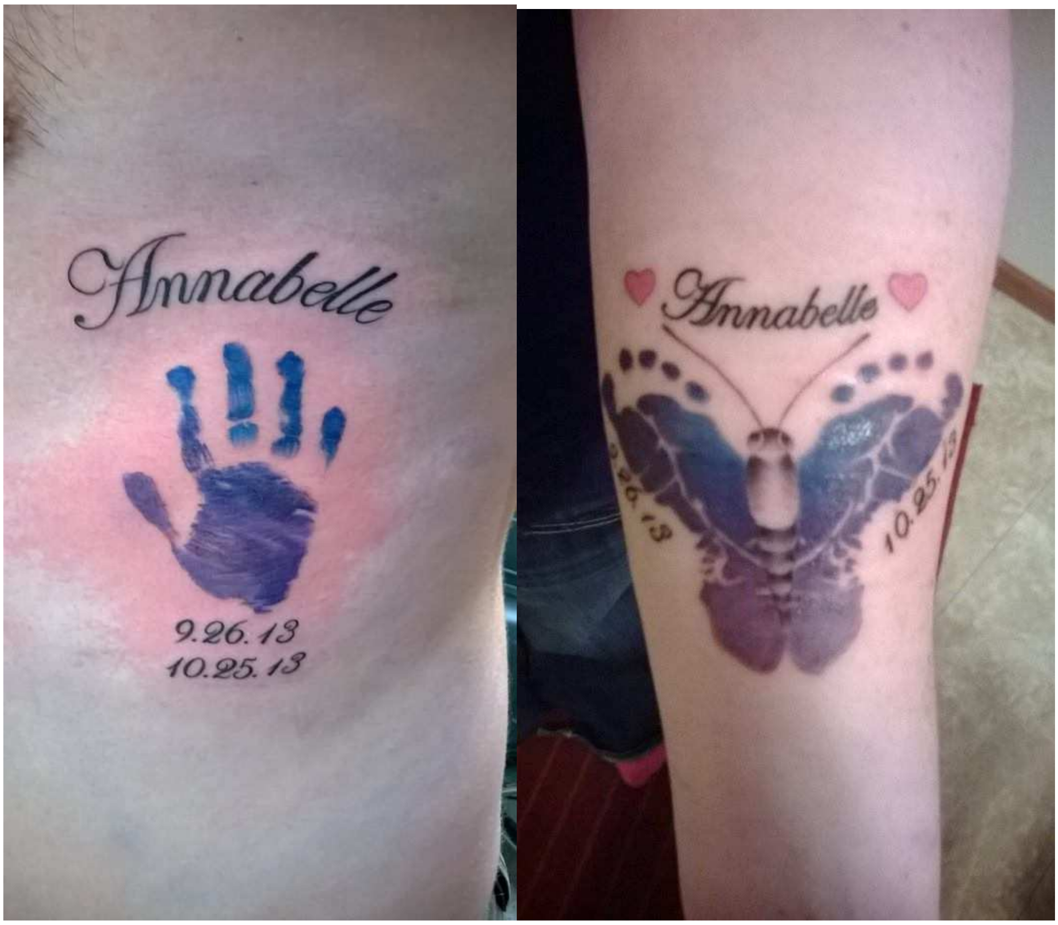
Some of our ACD Moms and Dads have recently gotten tattoos in memory of their angels. Some meanings of tattoos:

- Eagle Tattoos: Represent power, success, prosperity, freedom and wealth, eagle tattoos are always in style.
- Cherry blossom: Are fitting for tattoo enthusiasts who seek body art with the inspirational message to seize each day, particularly those with fondness for Japanese culture.
- Cross Tattoos: Are not always intended to represent religious sentiments. Many people choose crosses for their simplicity in design. Others choose a cross tattoo with roses and/or a flowing banner to honor someone in their lives who passed away.
- Heart Tattoo: Symbolize love, devotion, betrayal or sacrifice; heart tattoos can reveal deeply meaningful messages.
- Rose tattoo: Are some of the most versatile and popular forms of body art chosen today. They are selected by both men and women. Rose tattoos can be any size and placed anywhere on the body.
- Chinese Writing Tattoo: Some of the most exotic and mysterious tattoos are Chinese symbols. Their meanings are hidden from those passing by. They can come in any word, phrase, or idea.

It is very common for people to get tattoos in memory of a loved one who died a hero, a significant other, etc. http://students.depaul.edu/~szillige/lab4.htm

Some of our ACDA members have gotten in honor of their babies. See the examples on page 2.

TATTOOS!



James & Susan Logue’s tattoos in memory of their daughter, Annabelle.

ACDA UPDATES FROM DONNA & STEVE HANSON

It has been over 11 years since we took over as Executive Directors of the ACDA from Madonna Myers, the organization's founder. To be able to make a difference in our son's memory has been rewarding and fulfilling. While we have, among other things, facilitated progress into finding answers to all our questions about ACD, there is still much work to be done. However, we feel it is time for us to step down and allow someone with fresh ideas and energy to take the organization to the next level.

We are pleased to announce that Kim Anderson Bush, assisted by Diana Locke, has agreed to transition to the new ACDA leadership over the next year. As you know, Kim and Diana have been active in the organization for several years as Chairpersons for Family Support and Research, respectively. Kim is a chiropractor in Michigan and she and her husband, Chris, have lost two children to ACD. Diana, who is a nurse, has dedicated an enormous amount of her time raising awareness of ACD among the young medical students in the Florida area. Diana and her husband lost their son, Christopher, to ACD in 2006. So, we will be working closely with them during the next 12 months to ensure a seamless transition. In the coming months, you will learn more about their roles and responsibilities in the organization.

We are confident that Kim and Diana will lead the organization effectively and compassionately. We hope that as they look to other ACDA families for help in continuing the work of the ACDA that some of you will sincerely consider what you can do to make a difference in memory of your baby(ies). Thank you Kim and Diana for stepping up to lead the ACDA! If you have any questions about this transition, please feel free to contact us at sdesj@verizon.net. As always, thank you for your continued support of the ACDA.

Steve and Donna Hanson

ACDA Working Towards Non-Profit Status

We are excited to announce that for several months we have been working with the Law School at Southern Methodist University (SMU) to complete the paperwork to obtain non-profit status with the State of Texas and the United States Internal Revenue Service (IRS). Kim Anderson Bush has agreed to join us on the Board of Directors to work with us for at least the first year. Among other things, we have a Certificate of Formation from the State of Texas and we have set up a bank account. In January, we expect to submit our application to the IRS which is the final step in this process. The amount of the IRS application fee, which is still to be determined pending the review of our application by SMU, will be anywhere from $300 to $750. If you would like to make a small donation to help us pay for this IRS application fee, please send it to our address on the last page of this newsletter. Since we are not a legal non-profit until we receive IRS approval, your donation will not be tax deductible. However, even small donations add up quickly. We will keep everyone posted on the donations on Facebook and via email. Thank you!!!

We have been warned that the IRS will take up to 18 months to approve our application but we are excited to be in the final stages of fulfilling a goal for the ACDA. - Steve and Donna Hanson

Family Support News

By Kim Anderson Bush
ACDA Family Support
Committee Chairperson

Holiday seasons are so difficult for families of child loss! When a child is missing, the holiday lights seem dim, the sparkle from the tree is missing, there is a hollow feeling giving gifts, and family gatherings are full of pain because we are incomplete -- not a family circle any more without our child. Yet, the world continues to go on in spite of our pain and society as a whole puts demands on us to be "jolly" in spite of our deep, inner pain. So, most of the time we wear our "mask" and painfully push through the days and when the holiday is over we collapse from exhaustion. Grief from child loss is real and it affects every part of our body, mind, and soul!

Fundraising News

By Emily & Tim Eschweiler
ACDA Fundraising Committee Chairpersons

Greetings!

The end of the year is upon us. For those of you who have been making donations to the NORD restricted fund, a big THANK YOU! For those of you who would like to donate, there is still time to donate before year end. The easiest way to donate is through the restricted fund donation page on the NORD website: https://salsa3.salsalabs.com/o/51076/donate_page/research-donations. Remember to select "Alveolar Capillary Dysplasia" from the drop down menu. You can also easily share this link and encourage friends and family to donate as well! As of 11/30/13, the research fund balance is $8,210.00.

Another great way to easily raise funds for NORD, while obtaining a keepsake in memory of your angel, is through the CafePress site. Items can be found here: http://www.cafepress.com/acdawareness. New for 2013, is a line of products with a design by Kate Minto in honor of her son, Fletcher. Thank you Kate for sharing your design! So far, the site has earned $173.97, and there is an additional $9.40 pending. All profits go to the ACDA. Thank you to everyone who has ordered!

Reminder: It takes all of us to continue the efforts to raise funds! Please share your ideas and fundraisers with the group! If you have an idea for a fundraiser, please feel free to contact me. Articles for future newsletters of your fundraiser are highly encouraged and can be sent directly to Diana at any time! - Emily

Update on Thomson Airways Fundraiser

As you know, my work Thomson Airways has been raising money for the David Ashwell Foundation from May 2012 until the end of August 2013. August is always our busiest month with school holidays and so I am pleased to announce that £3385.90 was raised during this month bringing the final total to £36021.32 ($59,236) - an amazing achievement by all my colleagues! The amount raised for us was just a quarter of all the small change that was donated over the 15 months so we have very generous passengers at Gatwick!

We also have an ex-colleague Dave Upton who is running from London to Brighton in May next year and raising money for the Foundation. Dave's wife Sarah is still cabin crew with Thomson Airways and Dave is now a police officer, so hopefully he'll have lots of sponsors! It is 62 miles from Richmond (where strangely I used to live) to Brighton (near where I live now!) and is classed as an Ultra Marathon as it will be cross country. Dave has run 2 previous marathons so is used to the hard work. He is running with a friend so we wish them well with their training and I'll keep you updated. Thank you Dave!

To donate, their page is http://m.virginmoneygiving.com/mt/uk.virginmoneygiving.com/team/Dupton

Jo, Chris & James

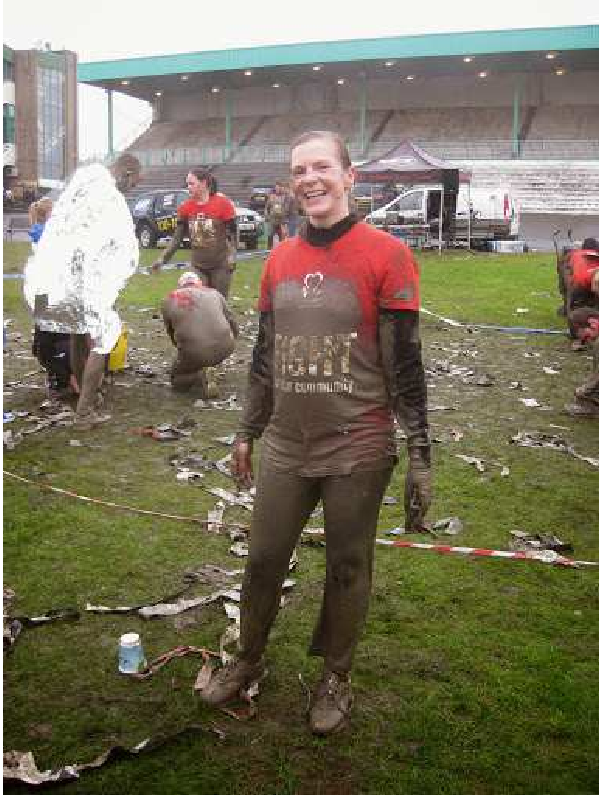
The photo we sent in to say thank you that was put on the Charity Noticeboard in the Gatwick Crew Room.

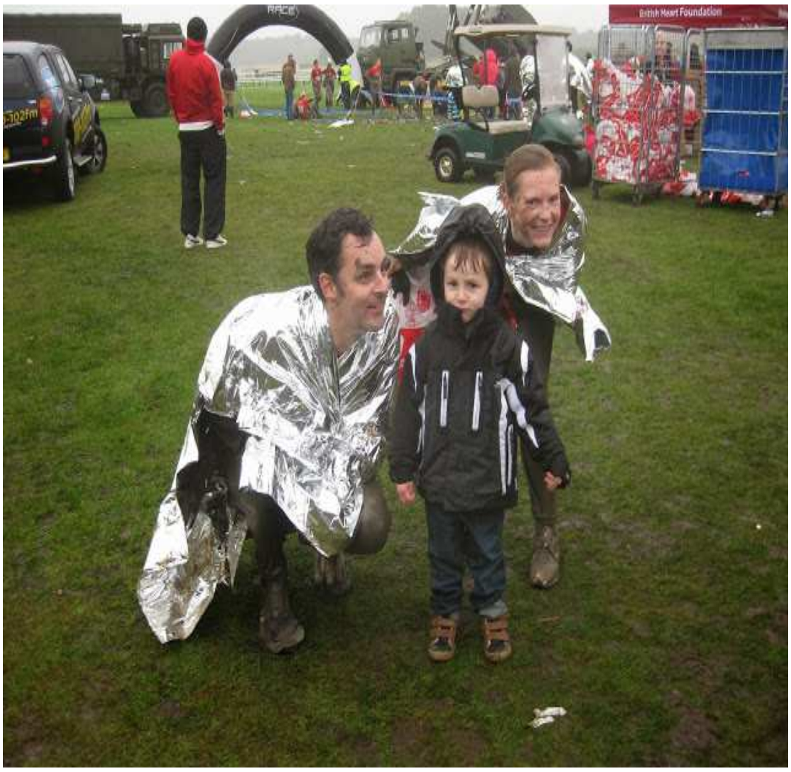
Update from The David Ashwell Foundation

Despite the fact we are no longer the charity of choice for Thomson Airlines, donations to ACD Research via The David Ashwell Foundation have been continuing. As ever the donations mentioned here are not just as a result of our efforts but those of other UK and European ACD families. We are so pleased that the charity can be used in this way. Only by US fundraising can we answer questions about this disease.

Since March 2011 we have raised £119,411 ($187,833) for ACD Research. £33,118.00 ($52,053) was transferred in February 2012 to NORD and over £91,435 ($149,697) has been raised **since** the NORD transfer in Feb 2012. To have raised over £124,553 ($203,918) in memory of David and other babies is beyond what I could have imagined.

We have had a few events since September. An ex-colleague of Amelia's, Emma Mudd, took part in the Muddy Challenge along with her husband Chris Mudd. This was the second fundraiser Emma had organized. It was a cold grey day in October and Emma & Chris did a fantastic amount of £505 ($826) for research into this rare disease.





In Omagh N. Ireland Amelia's mum – Vida Lake - (David's grandmother) organized a Tupperware party. They had craft items for sale that Vida and her friends make. In total they raised £305 ($499). In November, Amelia had an Usborne book party at her home. A number of friends came and through sales plus the commission of the very kind Usborne host over £280 ($458). Coming up to Christmas these 'at home' parties are a great way for friends to do their Christmas shopping plus donate to a charity which has such importance!

At this time of year please don't forget to use The Giving Machine to shop and in Germany the equivalent website (thanks to Karin!).

We have been asked if we produce Christmas cards… which we don't however many people have donated money in lieu of Christmas cards or presents (in the workplace) and already offers of this have come through! It makes me feel very honored that people continue to remember David.

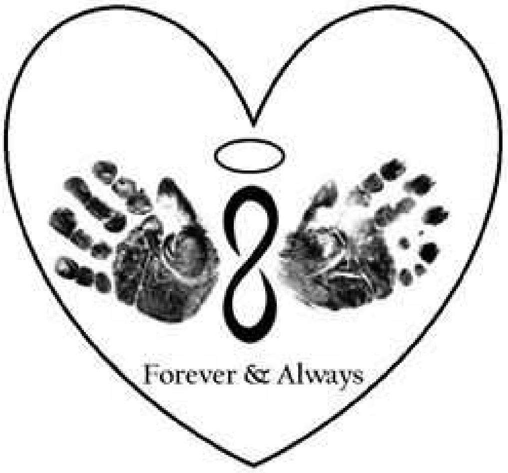
Stamp donations continue to come through! Thank you all for your contributions.

All UK & Europe based families are welcome to use The David Ashwell Foundation as a means of fundraising for ACD Research.

If you live in the UK (and elsewhere), there are a number of options available for funding ACD research through The David Ashwell Foundation.

1. You can make a donation directly, using the Virgin Money giving website to gather donations for your fundraiser. http://David Ashwell Foundation
2. Fundraise while you shop (The Giving Machine) (a percentage of what you spend is donated)
3. Fundraise when you ebay (ebay for Charity).
4. Collect postage stamps http://David Ashwell Foundation

For additional information, please contact Simon and Amelia.
http://David Ashwell Foundation
davidashwellfoundation@yahoo.co.uk
Amelia's mobile: 07855473686



Kate Minto (Mom of Fletcher) designed something new using his hand prints. This design is available on our Café Press site on different items such as: T-shirts, mugs, as Christmas Ornaments, Long Sleeve Shirts at http://www.cafepress.com/acdawareness/10886586

A SPECIAL NOTE FROM KATIE MINTO (MOM OF FLETCHER)

I came up with the design originally by feeling the need to make something special to represent Fletcher that I could share with others. I always tell my children that I love them Infinity and knew I wanted to include the infinity symbol in there somewhere so I started drawing. I did a drawing with the hand prints and thought I would use the infinity symbol as the body. I showed my daughter and she said she liked it but suggested I put it in a heart... so I added the heart.
My Infinity Angel.

Thank you for letting me share my love for Fletcher with everyone.

Love and Light,

Kate

Please Welcome Our New ACDA Families:

[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. In the “Additional Comments” box, type “Alveolar Capillary Dysplasia Restricted Research Account.”

Special Information for Families Living Outside of the United States

NORD recommends that families living outside of the United States 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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