ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 14, Issue 2 http://www.acd-association.com Spring 2012

Dear Friends and Family,

Thanks to all of you that have completed the ACD survey developed by Amelia Lake and Simon Ashwell. As you will read in this newsletter, in order for the survey to provide useful data, we need 100% participation. This is something so easy for all of us to do in memory of our children so please take the time to make a difference.

As you travel about the world this summer on vacation or holiday, look in the ACDA directory to see if there is another ACDA family that lives near where you are going. Connections with other families that have also lost a baby to ACD will help all of us as we grieve and remember. If you need an updated directory, please contact us. We are planning to meet our Minnesota area families in late July!

If you have a story to share, please send it to us. It could help you in your healing process.

Fondly,

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

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NORD Grant Process Underway

The National Organization for Rare Disorders (NORD) has posted the ACD grant for $94,342 for researchers to respond to! You can view the Request for Proposal (RFP) by visiting https://www.rarediseases.org/medical-professionals/research-grants/rfps.

The first step in this grant process is for the medical community to submit an abstract which includes a one page summary of their proposal and their budget information. The submission deadline is May 4, 2012. Then, in late July, NORD will send an invitation to submit a full proposal to those whose abstracts have been accepted. The full proposals will be due in September with an award expected in November.

This grant would not have been possible without the support of you, our ACDA families, their families and their friends. Please share this wonderful news with all of your loved ones that have supported you.

ACDA Members to Meet in Minnesota

Steve and I will be traveling to Chaska, Minnesota, just outside of Minneapolis, in late July. We are planning a gathering of ACDA families during the week of July 23. At publication time, all the details are still being worked out. If you live close by or will be visiting the area at that time and are interested in attending, please contact us at sdesj@verizon.net. We are looking forward to meeting other parents!

Research News

From Diana Locke
4wheelin@earthlink.net

ACDA Parental Questionnaire

By Simon Ashwell and Amelia Lake
Parents of David

The ACDA parental questionnaire has been live since March 2012. To date, we have had only 38 families respond. We thought we would give you small taster of what we have found out so far… it's a small sample but it's already providing some interesting facts. With more responses we could be more confident in the results, so please respond to the questionnaire.

- 40% of infants with ACD were second born; while 30% first born infants.
- 57% of infants were male and 60% had other birth defects of which the majority was intestinal mal rotation of the gut.
- Of the respondents so far, 43% have had genetic analysis done and 57% have had genetic counseling.
- Of those infants who had chromosome 16 analysis done, 50% were abnormal. Of those who had foxf1 analysis done, 44% were abnormal.
- 20% of respondents have had prenatal tests for ACD in subsequent pregnancies.

We all want to know more about ACD, the results above gives an indication of some questions we have 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 find those similarities and differences, an international team of academics, clinicians and the ACDA, with input from parents, have 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 have all 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.
2) To provide information that will be of interest to parents who have had an infant/ infants affected by ACD.

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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.

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 now until 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 response.

The survey is secure, anonymous and is only available online. Please go to the following link to begin the survey. 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, please contact us at sdesj@verizon.net

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

Diana Locke, mom to Christopher, gave another lecture at Gainesville Medical School on May 18, with more than 110 medical students present this time. She even had some of the instructors in the room soaking up the presentation!! Thanks for raising awareness of ACD for these future doctors!

Family Support News

From Kim Anderson Bush
ratherbinak@yahoo.com

Spring is often seen as a time of renewal and the transition into summer brings life to the nature that lay dormant during the winter months. Whether considering a memorial garden to honor your child or looking for a plant for their gravesite, knowing their symbolic meanings may help guide the plant(s) you choose.

Some plants and their symbolic meanings:

Blue violet symbolizes faithfulness
Daisy symbolizes beauty and innocence
Magnolia symbolizes perseverance
Lily of the Valley symbolizes the return of happiness
Cala Lily symbolizes splendid beauty
Bellflower symbolizes gratitude
Forget-Me-Not symbolizes true love and remembrance
Marigold symbolizes affection
Myrtle symbolizes love and remembrance
Baby's Breath symbolizes innocence and a pure heart
Gardenia symbolizes loveliness and untold love
Holly symbolizes hope
Orchid symbolizes beauty
Sunflower symbolizes pure love
Zinnia symbolizes affection and remembrance
Iris symbolizes hope, faith, wisdom and friendship
Lilac symbolizes love particularly first love
White lilac symbolizes youthful innocence
Honeysuckle symbolizes happiness
Aloe symbolizes healing, protection and affection
Goldenrod symbolizes encouragement
Heliotrope symbolizes eternal love
Lemon balm symbolizes sympathy
Oak symbolizes strength
Rose symbolizes love
Rosemary symbolizes rememberance
Blue salvia symbolizes I think of you
Red salvia symbolizes forever mine
Sorrel symbolizes affection
Thyme symbolizes courage, strength
Willow symbolizes sadness

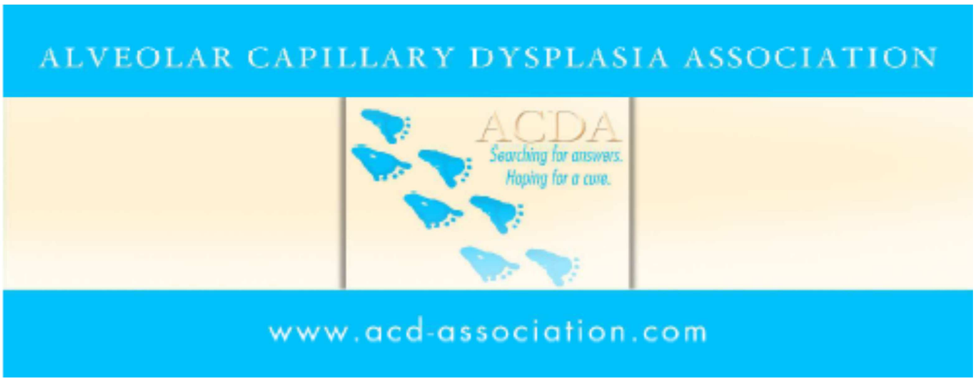
Fundraising Update

From Emily Eschweiler

Emily_Eschweiler@comcast.net

Announcements

- As of June 22, 2012, the total of the ACD restricted research fund at NORD was $5,594. The $94,000+ grant to be awarded in November has been previously deducted.
- Cindy Thayer, who has been our contact in Accounts Receivable at NORD for many years, has moved to Accounts Payable. So, if you need to confirm that a donation was actually sent to the ACD restricted research fund, please contact Cecilia Hall at chall@rarediseases.org. Cecilia has taken over Accounts Receivable. Many thanks to Cindy for her support and welcome Cecilia!
- If you would like to have the ACDA banner for your fundraiser, please contact us. We can ship it around the United States. See below for a picture of the banner. It is 80” x 30”. We think that it would be great to have a banner on every continent for families to share, so if you are interested in being the lead family for your continent, please contact us. We will send you the artwork and you can have a banner made in your hometown.



Café Press

Remember that you can order a variety of ACD awareness products from our Café Press website. You can have the awareness ribbon or logo printed on items such as shirts, mugs, buttons, messenger bags, necklaces, and key chains. Go to http://www.cafepress.com/acdawareness

To date, we have raised $150 from this site!

Benefit Concert Raises Money for ACD Research

By Donna & Steve Hanson
Parents of Eric

Sara Hickman, the 2010 Texas State Musician, headlined a benefit concert in Dallas, Texas on June 15 for ACD research. We welcomed family, friends and guests to Uncle Calvin's Coffeehouse for a night of live acoustic music by Sara and the Houston based trio, 2-Bit Palomino.

Sara donated a portion of each ticket sale, 2-Bit Palomino donated part of their fee and Uncle Calvin's donated their proceeds to NORD. Uncle Calvin's also put out a "tip" jar so that people could make donations during the evening. In addition, Sara surprised us when she made a personal donation of a brand new Takamine guitar which she auctioned to the highest bidder. She told the audience that she would not take anything but a large bid for the guitar and even added that she would paint the guitar or come to the house of the winning bidder to perform a song if the price was right! She reminded everyone to keep in mind that they were supporting a cause to help babies. The guitar brought in an additional $1,000 for the fundraiser!

Friends that could not attend the concert sent in donations to NORD so we are still waiting to make the final calculation on how much money we raised but expect over $3,000. It was a memorable evening full of laughter, raising awareness (even with our friends) and a moment of silence for Eric. Our heartfelt thanks go to Sara, Bill, Ren and Andi of 2-Bit Palomino and the volunteers at Uncle Calvin's Coffeehouse for a wonderful evening and for their support of ACD research. And thanks to all our family and friends that spent the evening with us.

Check to see if Sara and 2-Bit Palomino are coming to a town near you! If you see them, please tell them thank you!

http://sarahickman.com/
http://2bitpalomino.com/

Bill Ward, Ren Renfree and Andi Renfree (2-Bit Palomino), Sara Hickman, Jennifer Hanson, Donna Hanson, Stephanie Hanson and Steve Hanson

Sara Hickman with the winning bidders Deanna Hogan and Laura McFerrin

Photo by Ira Hantz

Sara Hickman

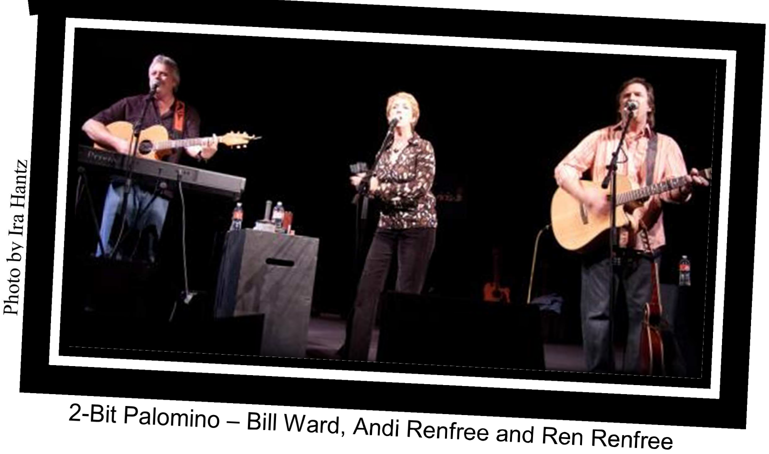


Photo by Ira Hantz

2-Bit Palomino – Bill Ward, Andi Renfree and Ren Renfree

Update from The David Ashwell Foundation

From Simon Ashwell and Amelia Lake
Parents of David

Since March 2011, we have raised £53,600 ($84,245) for ACD Research. £33,118.00 ($52,053) was transferred in February to NORD and over £20,482 ($32,192) has been raised **since** the NORD transfer in Feb 2012. As ever, Simon and Amelia have been overwhelmed with people's generosity and kindness in donating to ACD Research via The David Ashwell Foundation. Through the amazing efforts of [redacted] [redacted] (mum to [redacted]) we are the chosen charity for Thomson Airline's Gatwick base.

There were three events organized by David's grandparents, Malcolm & Vida Lake in Omagh, Northern Ireland; a charity table quiz, a 'coffee morning' called "Tea & Cake with Vida Lake" and a choir concert (approximately £3000 from three events).

Fundraisers have included the inspirational ACD mum [redacted] [redacted] (mum to [redacted]) running the London Marathon (raised over £8000) and friend of ACDA members [redacted] [redacted] & [redacted] [redacted], [redacted] [redacted] raising around £3000.

In Perth Australia, Kay Dury (a friend of Amelia's sister Anisa) set herself a physical challenge and raised £170. In Dubai, Anisa (Amelia's sister) raised £400 with her second stall at a flea market. Helen McGlynn, a local photographer, raised £90 doing Facebook timeline photos.

On Saturday 28th April, the Treebridge Hotel & Restaurant in Stokesley played host to the inaugural 'Rock, Frocks & Frolics' charity event; a wonderful evening of fine dining, entertainment and fundraising. Rock, Frocks & Frolics welcomed 153 generously paying guests, who were treated to a delicious meal, table magic, floor-filling music by 'The Black Sheep Band', as well as regional radio personality – Steve Furnell as compere for the evening. Through ticket sales for the event, an extensive list of fantastic raffle prizes, a Silent Auction, which included some truly 'Money Can't Buy' prizes, coupled with extremely generous personal donations on the evening, Rock, Frocks & Frolics raised **£7,900 ($12,400).**

The many wonderful raffle prizes and silent auction Lots were only possible due to the overwhelming generosity and support of local and national businesses. Raffle prizes included weekend breaks to

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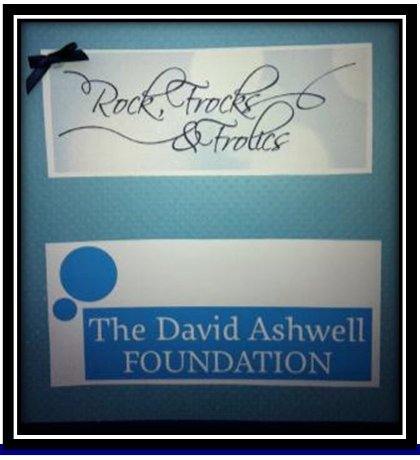
Steve Furnell, north east radio star who was compere for Rock, Frocks & Frolics with organizer Laura Cowie



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London and dining experiences at some of the top regional eateries. The silent auction offered many unique opportunities for bidders, including specially commissioned art, a signed, framed Middlesbrough Football shirt and a trip to Belfast for 2 people, which included an all-expenses-paid dinner with highly acclaimed Irish Actor Aidan Gillen, most recently known as 'Tommy Carcetti' from hit TV series 'The Wire'.

Our upcoming fundraisers include two cycle challenges. Andrew Heath was one of the 2011 one day coast-to-coast cyclists with Simon (David's Dad). In 2012, he is taking on the world's hardest Cyclosportive - the Marmotte Cyclosportive on 7th July 2012. This challenge takes place in the French Alps and involves 108 miles of tough climbing and hair-raising descending. Climbing 17,000 feet in total, it incorporates the legendary cols of - Glandon, Telegraphe, Galibier, and the most feared of them all, Alpe D'Huez. Andy is in training to beat a time of 8 hours 30 minutes. Please support him! **http://uk.virginmoneygiving.com/AndrewHeath73**

Also cycling are Serena and Andrew doing 'The MMM Challenge' cycling 1,000km in 10 days. They will be cycling the **length of Ireland**, from its most northerly point, Malin Head, to its most southwesterly, Mizen Head. They will be hugging the undulating west coast for over **1000 km**, taking in the dramatic landscape of Donegal, Connemara, the Burren and the Macgillycuddys Reeks. All this in **10 days**! Follow Serena and Andrew on twitter@mmm_challenge **http://uk.virginmoneygiving.com/mmmChallenge.** Read their blog: **http://mmmchallenge.blogspot.com/**

On the 12th of August, friends have organized a motorshow in aid of The David Ashwell Foundation, which is a day-time family event!

Simon and Amelia are expecting David's brother or sister on 20th July. It's a busy time in North Yorkshire but we are more than happy to hear from other families who would like to use the charity to raise money for ACD Research. All money raised will be transferred to NORD.

If you live in the UK, there are a number of options available for funding ACD research through The David Ashwell Foundation. You can make a donation directly, use the website to gather donations for your fundraiser, fundraise while you shop (The Giving Machine) or when you ebay (ebay for Charity). For additional information, use the links of that webpage to contact Simon and Amelia. http://David Ashwell Foundation
davidashwellfoundation@yahoo.co.uk

Rock, Frocks & Frolics Event
Left to right:
Laura Cowie (organizer), Amelia, Alex Atkin (husband of organizer Jade & organizer of car show in August), Simon, Anisa (Amelia's sister) Jade Atkin (organizer)

RUNNING FOR [redacted] ……… THE 2012 VIRGIN LONDON MARATHON

By [redacted] [redacted], mom to [redacted]

In the last edition of the ACDA Newsletter, I wrote a short piece on my training and preparation for running the 2012 Virgin London Marathon to raise money for ACD research in memory of our first born son [redacted].

Over eight weeks have passed since I completed the Marathon, and it seems like a dim and distant memory; in fact, there are times when I question if it really happened at all. It is like an amazing dream that happened to someone else!

I think it is fair to say it was an emotional, physical and mental challenge. On the day itself I parted company with my friend and training partner and the tears were in my eyes. It felt like I was about to step off a cliff into the unknown and to some extent that is exactly what it was like. I was wearing the running vest I had printed with my name on the front, a picture of my beautiful boy on the back and the words “Running for [redacted] ....” I deposited my belongings, queued for the loos and took my place in the crowd of about 30,000 runners. I was scared, my heart was pounding - how on earth was I ever going to run 26.2 miles?

The race started at 9.45am and 10 minutes later I crossed the start line. The first half went well. I saw my sister at 8.5 miles and my legs were powering through. I crossed Tower Bridge just before the halfway point still feeling fine. I saw a friend at mile 14, another at 17 and another at 19 – but by this point the tiredness had kicked in and the will to stop and walk was tremendous. I just kept focusing on getting out of the Isle of Dogs and Canary Wharf and making it to 21 miles. Psychologically I had convinced myself that once I knew there was only 5 miles to go it would be manageable. Despite taking on sports gels, sweets and water, my body’s resources were at an all time low. I kept on going, my legs and body now no longer seemed part of me – my mind was just concentrating on getting to the next point, another mile conquered. It was incredibly hard but the crowds along the Embankment were fantastic. I saw one of my friends again between miles 24 and 25 and that really spurred me on. I turned the corner into Birdcage Walk and the next thing I knew I was running past the Houses of Parliament and Big Ben. I picked up the pace, another mile and I swung past Buckingham Palace and headed down The Mall – I was smiling, I couldn’t believe that I had made it this far non-stop.

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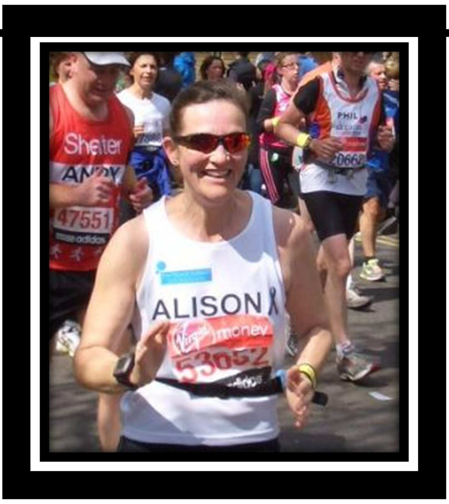

[redacted] is still smiling!

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The "mile markers" stop at 25 miles and they count you down in yards. The motor that kept my legs turning, my mental focus and the cheering crowds was an exhilarating combination for that last stretch towards the finish. My little legs trotted through in 4 hours, 20 minutes and 43 seconds. It is true what they say it is a race of two halves – the first 20 and the last 6.2 – and I had done it!

As for the fundraising, I was humbled and overwhelmed at people's generosity for what was an original target of £1000 to now exceed £7000 (£8000 if you include gift-aid or $12,500). I am delighted that all of this money will be going directly to ACD research – but more importantly I am exceptionally proud that I did it all in memory of [redacted].

My fundraising page does stay open for 6 months – I know the target has been exceeded, but if for some reason you meant to – but never quite got round to it, don't despair there is still time to donate.

http://uk.virginmoneygiving.com/AlisonHardisty

Look closely at [redacted]'s shirt.
Running for [redacted]…

UK Airline Charity Collection -The David Ashwell Foundation

By [redacted] [redacted] mom to [redacted]

As some of you know, I work as a Flight Attendant for a UK-based airline called Thomson Airways. At the end of each flight, we collect money for charity. Half of all money collected goes to The Family Holiday Association; one quarter goes towards Born Free (Animal Rescue) charity; and the other quarter goes to a local charity or something close to our hearts that is voted for by the crew at that base.

This year, I put forward The David Ashwell Foundation as the charity for London Gatwick Airport - Thomson's largest base. At the end of April, we got the news that my colleagues had voted for us by a huge majority and so the Foundation will receive a quarter of all money raised from 1st May 2012 until the end of April 2013.

An announcement is made at the end of each flight explaining the charities and so each week approximately 20,000 people will hear about ACD. So, not only will we be raising money, we will be raising awareness of the condition.

I'm not back at work yet, but after talking to some of my work friends recently, lots of money is being collected already and with the busy summer months approaching, hopefully more will be raised.

We will let you know next year how much has been raised but I'm secretly hoping we can get one grant from NORD judging by past amounts raised. Keep your fingers crossed!!

JO TAYLOR'S CHARITY
The David Ashwell Foundation

Remembering Our Babies

[redacted]

Please Welcome…

[redacted]

***

[redacted]

[redacted]

***

[redacted]

Safe Arrival

Congratulations!

[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 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

Executive Directors

Steve and Donna Hanson
5902 Marcie Court
Garland, TX 75044-4958
USA
(972) 414-7722
Email – sdesj@verizon.net

Committee Chairpersons

- *Fundraising: Emily & Tim Eschweiler*
  - *Email: Emily_Eschweiler@comcast.net*
- *Research: Diana Locke*
  - *Email: 4wheelin@earthlink.net*
- *Family Support: Kim Anderson Bush*
  - *Email: ratherbinak@yahoo.com*