Dear Friends and Family,

At this holiday season, we give thanks to all of you that have supported our mission to find the cause and cure for ACD. There are so many of you that we cannot possibly list you all, but if you have donated your time, made financial donations, held fundraisers, made in-kind contributions, raised awareness by wearing or displaying our ribbon and artwork, THANK YOU!!

Our road to find some answers is not a short one but rather a long journey in which we must steadily persevere, for we know that one day we will have answers for why our precious babies are not with us. Along the way, we hope you will join us in some capacity in memory of your beloved baby(ies)

However you celebrate the holiday season, we wish you peace and joy. May you find a very special way to remember your baby(ies) during this joyous time of year. All our best to you and your families in the new year.

Fondly,

Steve & Donna Hanson
Executive Directors
Parents of Eric – June 7-17, 1997

NORD Awards Two Grants

The Medical Advisory Committee at NORD has completed their evaluation of the ACD proposals and because of very close scores (a few hundredths of a point difference), they split the funding and awarded two grants. Researchers at Baylor College of Medicine received both grants. Because of the split, the ACDA Executive Directors and the Chairpersons voted to add additional funding in our research account to the two grants bringing the total amount awarded to an amazing $104,411!

(1) Przemyslaw Szafarznski, PhD
Baylor College of Medicine
Department of Molecular and Human Genetics
Houston, TX USA
Award: $61,550 (Two-year study)

Title: Long Noncoding RNAs as Potential Diagnostic and Therapeutic Targets in Patients with Alveolar Capillary Dysplasia

The study will focus on unraveling the function of novel, identified IncRNAs (noncoding RNAs) identified with ACD in normal and pathological lung development in ACD patients. The goal is to expand tools for ACD diagnostics and gene therapy, while shedding light on the enigmatic role of IncRNA as gene regulators, in general.

(2) Partha Sen, Phd
Baylor College of Medicine
Department of Biochemistry
Houston, TX USA
Award: $42,861 (two-year study)

Title: To Investigate the Role of FOXF1 in Lung Development, Particularly with respect to Alveolar Capillary Dysplasia and Misalignment of Pulmonary Veins

The study will investigate the role of the FOXF1 gene and its effect on airway branches and sac-like structures of the lungs. This will be accomplished by using siRNA (small interfering RNA) that will knock down the FOXF1 protein. The goal is to provide a better understanding of the FOXF1 protein functions. hopefully leading to future therapies for ACD.

We are very excited about supporting two researchers and are extremely grateful to all of you that made this possible with fundraisers and donations! Thank you!
Partha Sen of Baylor College of Medicine has informed us that a manuscript on ACD has been submitted to the medical journal “Human Mutation.” While the manuscript has not been accepted for publication yet, Partha is very positive. In summary, the article reports on several mutations in patients with ACD/MPV. Most of the mutations are sporadic while a few are familial. The work resulted from the collaboration of scientists from four continents, thirteen countries and ten states in the USA. In addition, the abstract below is another article published in September as a result of the work of Partha and Pawel Stankiewicz.

A familial case of alveolar capillary dysplasia with misalignment of pulmonary veins supports paternal imprinting of FOXF1 in human.


**Source**

Department of Pediatrics, Baylor College of Medicine, Houston, TX, USA.

**Abstract**

Alveolar capillary dysplasia with misalignment of pulmonary veins (ACD/MPV) is a rare developmental lung disorder that is uniformly lethal. Affected infants die within the first few weeks of their life despite aggressive treatment, although a few cases of late manifestation and longer survival have been reported. We have shown previously that mutations and deletions in FOXF1 are a cause of this disorder. Although most of the cases of ACD/MPV are sporadic, there have been infrequent reports of familial cases. We present a family with five out of six children affected with ACD/MPV. DNA analysis identified a missense mutation (c.416G>T; p.Arg139Leu) in the FOXF1 gene that segregated in the three affected siblings tested. The same variant is also present as a de novo mutation in the mother and arose on her paternally derived chromosome 16. The two tested affected siblings share the same chromosome 16 haplotype inherited from their maternal grandfather. Their single healthy sibling has a different chromosome 16 haplotype inherited from the maternal grandmother. The results are consistent with paternal imprinting of FOXF1 in human. European Journal of Human Genetics advance online publication, 19 September 2012; doi:10.1038/ejhg.2012.171.
Join us on Sunday, December 9, 2012 along with other bereaved families, for the Sixteenth Compassionate Friends Worldwide Candle Lighting. Visit The Compassionate Friends website (www.compassionatefriends.org) to find a service open to the public near you, or light a candle in your home at 7 PM knowing you will be joined by hundreds of thousands of people who are thinking about the children around the world who are gone, but continue to live on in the hearts that they touched.

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

Thanks to the research of Emily Eschweiler, we have recently been in contact with the [name redacted] Family of Georgia. They had a son that passed away from ACD and then a daughter who was also born with ACD but who had a successful lung transplant. Here is a link to a news story about the daughter, [name redacted], and her family. http://www2.wjbf.com/news/2012/nov/19/5/wjbf-extra-hopes-rising-jordan-ar-5003367/
Café Press:
Our Café Press site ([http://www.cafepress.com/acdawareness](http://www.cafepress.com/acdawareness)) was updated and revised in November. So far, commissions from the site total $157.10. This money will be transferred to the fund balance at NORD. I have also designed a graphic for a holiday ornament. There are a few different choices available ([http://www.cafepress.com/acdawareness/9488940](http://www.cafepress.com/acdawareness/9488940)), as well as a keepsake box and other items. If there is anything else that you would like to see on the site, please let me know. It doesn’t appear that you can use savings codes directly through the ACD “shop” but I have found that the prices are often cheaper directly in the shop because the mark-up is limited to the 10% that goes to NORD. However, if you search “alveolar” you can typically pull up the full price product, and enter the code at check-out to compare which option is better. Also, if you have an upcoming walk and would like to design a t-shirt or buttons to the site, please let me know (emily_eschweiler@comcast.net). I would be happy to work with you on that. The price is likely to be slightly lower than purchasing directly without setting up a shop, and the 10% commission goes to NORD. Win-win!

Fundraising:
Many of us have posted on the ACD Parent Group page on Facebook that we would like additional information about the disorder that has taken most of our babies. There is exciting ongoing research. However, medical research requires funds. Let’s all think of ways in 2013 that we might be able to honor our children by raising the fund balance at NORD. Imagine how wonderful it would be if we were able to fund a grant every grant cycle or at least every other grant cycle. Let’s show the medical community that we care about this issue. Here are some ways (small and large) that you can help:

- Include the link to the NORD online donation site ([https://www.rarediseases.org/about/support/research-donations/fg_base_view_p3](https://www.rarediseases.org/about/support/research-donations/fg_base_view_p3)) on your Facebook page or Christmas card to encourage year end giving. Make sure that you ask your friends and family to select “alveolar capillary dysplasia” from the restricted fund drop down.
- Sell an item on eBay that you no longer need and send the proceeds of the auction to NORD.
- If you know someone who sells a product that offers opportunity for fundraisers, book a show, or an eshow. (If the organization needs to be a 501(c)(3) organization to be a recipient of the funds, contact me and I can put you in touch with someone at NORD who should be able to help you get the money directed to the correct research fund balance.)
- Start collecting things now for a summer garage sale.
- Check out online blogs for fundraising ideas, such as this one recommended by Amelia Ashwell Lake: [http://blog.justgiving.com/community/five-festive-fundraising-ideas/](http://blog.justgiving.com/community/five-festive-fundraising-ideas/)

As always, please feel free to contact me if you have any fundraising ideas!
The David Ashwell Foundation

By ACDA Members Simon Ashwell and Amelia Ashwell Lake
Parents of David

We continue to be amazed and overwhelmed with people’s generosity and kindness in donating to ACD Research via The David Ashwell Foundation. Since March 2011 we have raised £80,639 ($128,990) for ACD Research. £33,118.00 ($52,053) was transferred in February to NORD and over £47,521 ($76,014) has been raised since the NORD transfer in Feb 2012.

This phenomenal amount is in part due to the amazing efforts of and who nominated The David Ashwell Foundation as Thomson Airline’s local charity in memory of their son . Please see the article by .

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

There were two runners for The David Ashwell Foundation in this year’s Great North Run which is the world’s biggest half marathon, and there was one runner in the Loch Ness Marathon. On 16th September ‘s Aunt took part in Ironman Wales in order to raise money in memory of her mum and . The Ironman is a massive challenge; it involves a 2.4 mile swim, 112 mile bike ride and then a full marathon, 26.2 miles. was 22nd female out of 122 (5th in her age category) & completed her 2.4 mile swim/ 112 mile bike / 26.2 mile run in an amazing 11.36.52 - just fantastic!

In November Amelia hosted The Pampered Chef cookware party who donated a percentage of the amount people spent. Around 40 people attended and between ticket price, raffle prizes and sales we raised around £500 – plus we had a really fun night!

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](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](http://David Ashwell Foundation)

For additional information, please contact Simon and Amelia. [http://David Ashwell Foundation](http://David Ashwell Foundation) davidashwelfoundation@yahoo.co.uk. Amelia’s mobile: 07855473686

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.

Also, check out five festive fundraising ideas: [http://blog.justgiving.com/community/five-festive-fundraising-ideas/](http://blog.justgiving.com/community/five-festive-fundraising-ideas/)
**Thomson Airlines Fundraiser**

By --- ----, Mom to -------

As you know, I nominated The David Ashwell Foundation as the charity that the Gatwick base of Thomson Airlines (my work) would be raising funds for during Summer 2012.

We have had some very good news as usually the charity nominated only has monies raised from May until the following April, before you have to be elected again. However, as the financial years did not match, the Company have extended the time that we will receive donations. So we will now benefit from another summer too as the financial year finishes in October 2013. This is fantastic news as the summer is our busiest time for flights.

Up until the end of September 2012, The David Ashwell Foundation has received £15179.10 from donations on our flights. This amount is only a quarter of all monies collected so a massive achievement from my friends and colleagues. From my past experience of flying, people from the south of England are not known for their generosity to our charity collections so this is an amazing amount!!

Some of my closet friends at work have written heart-felt announcements that they read out and they have had passengers in tears (as well as giving very generous amounts). Although I don't want people in tears, if they go away learning about ACD, I’ll be happy. For those crew members who don't know me well, I have written an announcement that is read out at the end of flight that lands into Gatwick, explaining about ACD and how their donations can help.

We are still waiting for October’s amount to come through so we are not sure how much was raised over the whole summer, but it definitely the best amount that Gatwick have ever raised in the 10 years I have worked for Thomson Airways! Let's just hope it continues!!

Usually our winter months are quieter for flights but we still have lots of long haul flights to all over the Caribbean, India, Africa and the Maldives as well as Europe and our ski flights, so lots of opportunities but the amounts raised will not be as big as the summer months. However every penny, cent or euro all add up!!

---

**Thank Yous & Announcements!**

- Many thanks to ---- ---- mom to ----- for designing the update to the ACDA brochure. She is very creative!!!
- ---- ---- mom to ---- and her brother ---- who is an owner of a print company, donated the printing of the new brochures! They are really professional looking!!! Thank you! If you need some brochures for your fundraiser or awareness event, contact us and we will send you some. The brochure can also be found on the ACDA website.
- Thanks to those that submitted a design for our updated logo: ---- ---- (mom to -----) and her sister-law and Amelia Ashwell Lake (mom to David) and her cousin, Roshan. ---- ---- has offered to refine the ideas and design a logo. Stay tuned!
- Check out these updates to the ACDA website: The current newsletters have been added, Frequently Asked Questions have been modified and the ACDA brochure has been added as a pdf file so you can print a copy.
A True Survivor: A 1 Year Old Child’s Fight For Life

is a student writer at Hazelwood West High School in Hazelwood, Missouri. She decided to write this article about for her school newspaper because was third grade teacher and was always her favorite teacher. When was in fifth grade, she was in the hospital and came to visit her, even though she was no longer his student. Just knowing that he still cared and knowing how amazing he is, made decide to write the story when she heard about.

For months ’s parents waited by her hospital bed, waiting for answers, waiting for hope, waiting for the day that the doctor’s would tell them that their precious baby girl is healthy again, and they can take her home. After so long of waiting for a miracle, it seemed harder and harder to stay hopeful that their little bundle of joy, so happy and healthy just months before, would survive her mystery illness.

When was born on August 26th, 2011 her birth was nothing less than celebrated. She was born to Hazelwood School District elementary school gym teacher and Hazelwood School District early childhood special education teacher, parents of ’s big brother. For the first months of ’s life, everything seemed completely normal until she was 3 months old when was admitted to the hospital for diarrhea and dehydration. While in the hospital, ’s oxygen levels rapidly dropped lower than normal. The doctors thought it was a mistake, and tried switching out the monitor, warming her up, and nothing worked until they finally put her on an oxygen tube, and her oxygen levels went back up to normal.

After a few days, got over the virus, and they came to the conclusion that her oxygen levels were just low because the virus had taken a toll on her immune system, and she just needed a few weeks to recover. Weeks later, still wasn’t off the oxygen, and whenever they would try to take her off of it, she could not breathe on her own. After months and months of doctor visits, they were still unable to find out why a happy, healthy 8 month old couldn’t be taken off of oxygen and decided to do a lung biopsy, an inpatient procedure where they take a sample of her lung so they could test it to find out what is wrong.

After her surgery, when they tried to remove the breathing tube she was unable to breathe on her own, and during the 4 days after her surgery she went into respiratory distress 13 times. Her body just wasn’t able to keep her blood pressure, and oxygen levels at a normal level, and each time she went into distress it lasted longer and longer, the last crash she had lasting over 4 hours. Nearly 4 hours into her crash, the doctors told her parents that they had tried everything but a shot that they would be put directly in her heart, in hopes that it would strengthen her heart enough to operate on its own.

When they gave the shot, it boosted her heart just enough to put her on mechanical life support to do the work of her lungs and heart. She stayed on the life support for 11 days, until they decided to put her on the transplant list to await a perfect double lung match, where they were told she would have to wait between 6 and 7 months.

In order for her to be on the list though, she couldn’t be on the life support machine she was on, she had to
be taken off the machine in hopes that her organs were strong enough after the 11 day break that she could live on her own, giving her only a 20 percent chance of survival. The only other option was a different machine, which does the work of the lungs and would give her a 22 percent chance of survival. This machine had only been used 2 other times on infants, and both times the children passed away. In order for her to be put on the assist device, her parents had to meet with the ethics board, to make sure that they were aware that there was a 100 percent chance of their daughter having a stroke, and dying after being placed on the device, because it had happen with both children that had been placed on it. After speaking to the board and getting the approval that everything they were doing was ethical, they placed her on the lung assist device. Once June 8th, she was placed on the lung assist device and was now eligible to be put on the transplant and wait for a set of matching lungs.

For the month that she had been in the hospital, her father refused to leave the hospital. He slept there, ate there, he lived there, by her side every second possible. Finally, on June 11th, his wife finally got him to leave and go play hockey with his brothers. While driving home from the game with his son, received a call from his wife saying that she had gotten a phone call. He immediately expected the worst and pulled over on the side of the road, that’s when his wife said, “she has lungs!” He immediately started crying, and his son didn’t know what was happening, that’s when his father told him. “That’s when he let out a double fisted yes in pure joy”, says his father.

After receiving what he says to be the best news of his life, he went to the hospital where received her lungs June 12th, and ‘s 8 year wedding anniversary. After receiving her lungs, the doctors finally diagnosed her with Alveolar Capillary Dysplasia (ACD). According to Donna Hanson, the executive director of the ACDA, Alveolar Capillary Dysplasia Association) ACD is a very rare condition with only around 200 documented cases, characterized by the misalignment of the pulmonary veins. When most cases of ACD occur, they have immediate symptoms after birth, such as high lung blood pressure, respiratory distress and low oxygen levels. Other than , there are no other known cases of ACD where the child has lived to be older than a few months.

It’s still a mystery to doctors as to how was to go so long without having any symptoms of her condition. When asked why was able to survive against all odds, Hanson explains, “is the only child to successfully receive a double lung transplant, to our knowledge this is the only way to survive ACD. We have heard of only 2 other cases of transplant for babies with ACD.” Hanson describes ‘s story as “a demonstration of the progress that is being made in the treatment of ACD” as had been on the lung assist device and successfully used it as a bridge to transplant. “While I am finished having babies, I know that ‘s story is very encouraging to other families in the ACDA that are considering having another baby after losing a baby to ACD”, says Hanson.

Since ‘s transplant, she has recovered normally and is nearly back to being a normal one year old. Due to ‘s lungs not being her own they have to lower her immune system so that her body doesn’t attack them. Due to the lowered immune system, cannot be around reptiles, birds, caves, or dust particles. Other than these restrictions and taking multiple medications on a daily basis, is nor able to return to the life of a happy toddler.

“Being at Children’s Hospital, you listen to story after story, and each one is more and more amazing, and
it’s unbelievable”, describes _, “You hear all of these stories, and it breaks your heart, so we decided that we really want to pay it forward.” After so many people who _ and _ didn’t even know came together to help them, they decided to start a foundation in _’s name, so they can go to children’s hospital, and just give an amount of money to a family, who’s living the way they were living, “just because you have so many stresses in your life, and the biggest one you have is the one sitting next to you in the hospital, so you don’t need to be worrying about food or gas.”

While staying in the hospital, _ noticed that the name written on a patient’s door was Oaks, and realized that he had seen a story about the boy on the news, about a foundation a family had started for their son, called The Mighty Oaks Foundation, in support of their son who had all of these medical problems, but he had been overcoming all of them. _ had found the story very inspirational, and one day when he was walking into the hospital, he noticed dozens of people, both familiar and new, all who had spent hundreds of hours and given countless prayers for the fragile little boy, all lining the hallway near the boys room, “there wasn’t a dry eye in the place” he recalls. People whose hope was once strong, but had now diminished with the news of the 16 month old boys passing.

After that day, he went and found the Oaks’ mother’s Facebook, and read every post she had written for months and months, and found inspiration in the woman’s posts. “They knew things weren’t going well, but they would literally live every single day like he didn’t have any issues, and they enjoyed every single moment they possibly could. The little boy was in children’s hospital every single day of his life, except for 11 days”, says _. The same day that he had read the woman’s posts, they told them that _ might not make it. The only thought that got him through the night was that another family had gone through the same thing they were, and enjoyed every minute they had together. _ remembers telling himself “okay, we can do this.”

And he is. They all are. And while _’s condition still remains a mystery, she’s getting better each and every day. The _’s story has become an inspiration to many, and people they had never even met come to their fundraisers to help and show support. Now that _’s medical bills are taken care of, the _’s are now going to begin to start their own foundation, to “pay it forward” after so many people helped them.
Remembering Our Babies
Please send a note to our new members…
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](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](https://www.rarediseases.org/about/support/research-donations).