ACDA NOTES
From The Alveolar Capillary Dysplasia Association
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FALLON'S STORY

From ACDA Mom, Kristen Rilling

First and foremost, thank you very much for warmly welcoming us into the ACDA. Like most of you, we had never heard of ACD before Fallon's diagnosis on December 18th and we were thrown into a whole new world of learning about this condition and how it came to be that we lost our beautiful, perfect daughter.

Fallon Jade Rilling was born at 4:44 am on Thursday, October 10th, 2013 , and she passed away on Monday, October 21st, 2013. I won't go into details about everything she went through (and everything we went through) because I'm sure the story is very similar to your own.

All that needs to be said is that it was heart-breaking. We were devastated after losing her – and I have to say, 4 months later, we're still just as devastated.

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INSIDE

Hello all,

As parents of wonderful ACD children, we have come together to give each other love, support and long distance hugs. Some feel they don't know how to contribute to the cause of funding ACD research, some feel they don't know what they can do to make a difference. I know from experience that anything makes a difference. From telling your baby's story, to giving support to another parent/family. It doesn't matter what you do, it matters that you do it.

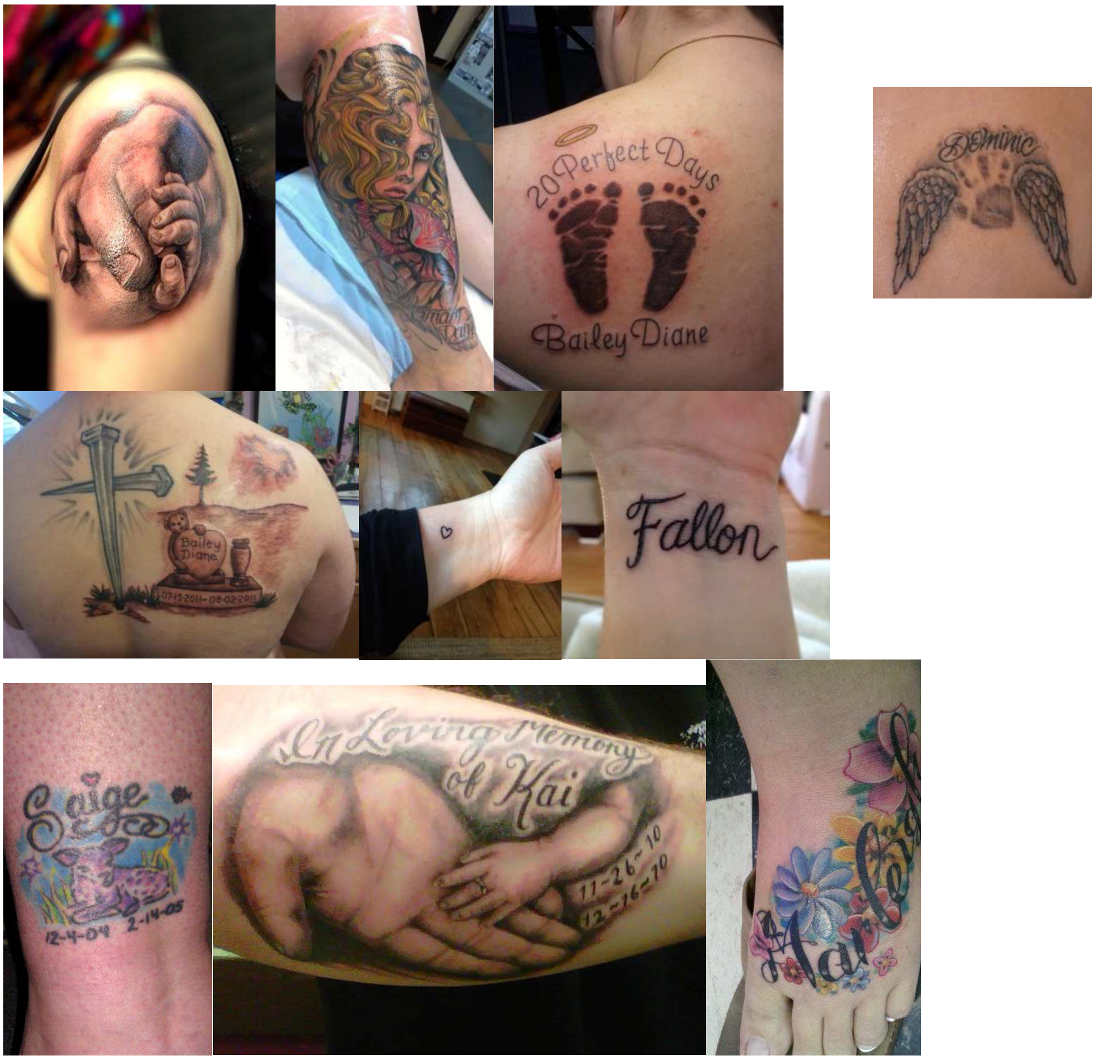
Our Facebook page now has 108 members and is growing (sadly) every day, it seems.
One idea that the group has come up with is to send mass mailings of the ACDA brochure to hospitals, NICUs, pediatric cardiologists, pulmonologists, neonatologists, and anybody we can think of. It may not seem like much, but if each family mails brochures to their local hospitals and doctors, the word can be spread and it will raise awareness! Ultimately, that can help raise funds and promote research! Any little bit helps!

If you would like to help, email me at 4wheelin@earthlink.net and I will get brochures and ideas to you!

Sending you all many hugs,

Diana Locke
Mom to Christopher

TATTOOS!



Our tattoos can be elaborate or simple but they all have special meaning.
Here are some from fellow parents:
From top left: Roelina Jut in memory of her daughter Jasmijn, Ashley Leffler in memory of Omari Danger, Megan Gosiak in memory of Bailey, Aunt (sister of Diane Dellasandro) of Dominic
Middle row: Adam Gosiak in memory of Bailey, Marit Muijtjens in memory of Guus, Kristen Rilling in memory of Fallon
Bottom row: Ali Lundmark in memory of Saige, Steve (Amanda Seamons) in memory of Kai, Stephanie Sanders in memory of Marleigh.

Family Support News

By Kim Anderson Bush
ACDA Family Support Committee Chairperson

Continued from Page 1:

Fallon's story

We're learning how to survive without her, only because we have to. We've been given no other alternative choices.

We couldn't save her, no matter what we tried and what the doctors tried. Our prayers and the collective prayers of friends and family couldn't save her. We were left with many questions, one of which was, "Well, what now?" We decided that if we could help save even one baby and spare even one family the pain and agony that we went through, we'd do whatever we could to make that happen. Our best option to achieve this was to make a large donation to the ACD research fund at NORD.

We had many friends, family members, and complete strangers follow our journey with Fallon. It was as if social media made the world very small , and everyone seemed to hang on to every word that Bob & I had posted on Facebook during her 11 days. We knew that this collective group of people was going to help our cause. We knew this because we had so much support after Fallon passed away. We had food deliveries, monetary donations, collections for tree plantings, collections for bench donations, and offers to help us in ANY way possible.

Bob & I had decided that we wanted to put together annual fundraisers in Fallon's name every October. We didn't know what we wanted to do or how to even go about doing it, but that was our goal. We were so motivated, however, that we just couldn't wait. We wanted to piggy-back off the momentum we had. As sad as it sounds, we wanted to host a fundraiser while our beautiful daughter, Fallon, was still on the minds of others. She will always be on our minds and in our hearts, but the truth of the matter is, everyone else's lives go on. So we decided to take everyone up on their offers of "What can I do? Where can I donate?" and we created a GoFundMe page and we put it out there, in the virtual world, right after Christmas.

Our page talked about how, on February 10th, 2013, we found out we were pregnant – one of the happiest days of our lives. We put up the most beautiful picture we have of Fallon. We put a photo of me, holding Fallon, on her best day (health-wise) and my most precious day with her. We talked about ACD and how it took our Fallon away. And we talked about the ACDA and the ACD fund at NORD and the whole process about raising enough money to enter the world of research grants. We stated that we wanted to make a large donation to this fund, in Fallon's name ~ and we asked our friends and family and anyone else out there ~ to help our cause. And we said whatever we raised, we'd donate to the ACD fund at NORD on February 10th, 2014. Our original goal for Fallon was $4,444. We reached that goal in 3 days. We then upped her goal to $10,444 ~ and we hit that second goal on Day 19. We decided to increase her goal, once more, to $14,444 in the hopes that donations would still come in. We created a video, a photo montage set to Pink's "Beam Me Up" ~ and shared that with everyone to show them just what they were donating for. And then I shared her page on Facebook every Monday. When I updated the page, it went out on Facebook and to my e-mail contacts. We had many people 'share' the page, helping to reach others. And on Monday, February 10th, 2014 – we had raised a total of $18,265.

This fundraiser showed us a lot about love. We had complete strangers make donations. We saw people dig deep: the young women who work at the daycare attended by our two older children made donations on their paydays, parting with money that they could barely spare. The generosity and support of our community amazed us and brought tears to our eyes. We always knew that Fallon is a super-star. Now the world knows it, too.

We pray every day that a cause and a cure for ACD are found through research. We still are confused and upset that ACD has taken our Fallon away. It doesn't make sense. And I suppose it won't ever make sense. What we can all do, as an ACD family, is band together and continue to be strong for one another. When one of us falls, there will always be another ready to lift up the fallen, to be the shoulder to lean and cry on, and the arms that give a great big hug. We want to thank you all for being there for us. Together, we will keep the memory of our beautiful babies alive. Together, we will help the scientific world kick ACD to the curb. Let's do this, in honor of all our beautiful babies, gone way WAY too soon.

FundraiSing News

By Emily & Tim Eschweiler
ACDA Fundraising Committee Chairpersons

Update from The David Ashwell Foundation

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 £127,955 ($212,920) for ACD Research. £33,118.00 ($52,053) was transferred in February 2012 to NORD and over £94,836 ($157,819) was transferred to the NORD ACD account in March 2014. To have raised over £127,000 ($212,920) in memory of David and other babies is simply incredible – we are not many people and it's a great effort!

We have had a few events since December. Dave Upton, a friend of Jo Taylor, has been doing a lot of running (see separate report on page 8).

Amelia's university friend Clare Pettinger is running a half marathon for David. Clare has twin boys who are 6 months younger than David would have been (2 ½ years old), so she really has her hands full!
http://uk.virginmoneygiving.com/ClarePettinger

In January in Dubai, Amelia's sister (Anisa) held her fourth flea market stall for The David Ashwell Foundation. Amelia's mum Vida was visiting and together they raised over £500.

Please don't forget to use The Giving Machine to shop and in Germany the equivalent website (thanks to Karin!). If any other European country has a Giving Machine equivalent and a UK charity can be your charity, please get in touch!

Stamp donations continue to come through! Thank you all for your contributions. We have raised £43.75 through collecting used stamps. Please all collect your used stamps for me – even if you are in US, Australia anywhere in the world – please collect them and we will figure out a way of getting them here!

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.

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

Update on Research at Baylor

We have recently learned that Dr. Partha Sen, who had been the main researcher of ACD at Baylor University, has lost his position with the university. We were pleased to hear, however, that the research will continue under the direction of Dr. Pawel Stankiewicz, who has also been actively researching ACD. Dr. Stankiewicz is now the primary contact at Baylor for the ACDA. All samples that are currently at Baylor will remain under the care of Dr. Stankiewicz. In a recent phone conversation with Dr. Stankiewicz, he confirmed his, as well as Baylor University's, commitment to continue research on ACD. They believe that ACD has unique genetics and what they are learning from the research can be generalized to other more common lung disorders as well as contributing to a better understanding of ACD.

Dr. Stankiewicz also shared that they are using micro-array analysis to test for deletions that are farther away from the FOXF1 gene on chromosome 16. This type of analysis has allowed them to better detect these "upstream" deletions; however, the tray holds four samples and due to cost concerns they must be filled before running the test. This may introduce delays in getting results.

Lastly, Dr. Stankiewicz has recently had several articles accepted for publication. As final revisions of these articles are made available we will share them as we have access to them.

Fundraising News continued!

From Emily…..

Thank you, thank you, thank you to all of you have donated to the NORD restricted fund since the last newsletter!

Here is a breakdown of the donations to NORD since the last newsletter:

Starting balance (November 30, 2013):	$ 8,210.00
December 1 – 31, 2013:	$ 9,630.00
January 1 – 31, 2014:	$ 8,810.00
February 1 – 28, 2014:	$16,644.44
Total balance (March 1, 2014):	**$35,084.44**

Note: The March 1, 2014 balance DOES NOT include the £94,000 that were transferred by the David Ashwell Foundation after March 1st. NORD has advised that they are aiming to release the Requests for Proposals for new research at the end of the month. With the David Ashwell Foundation funds, this should encourage significant research on ACD!!

Facebook:

The **ACD Parent Group** page has now reached 110 members. Please know that this is a safe place for you to share your thoughts, questions, and memories of your babies. Membership on this page is limited to parents who have lost a child to ACD, parents who have a living child diagnosed with ACD, or (in limited circumstances) parents whose child was initially suspected to have ACD and whose journeys are similar enough that it makes sense for them to remain members.

Recently we have received requests from additional family members. To address these, we have set up an **Alveolar Capillary Dysplasia Family Group** page. So far, this page has not had a lot of activity. However, it is hoped that this will be a new page where those who also loved the child will be able to find a support network.

Finally, the **Alveolar Capillary Dysplasia Association** page is the official Facebook page for the ACDA. This is a public page and you should encourage anyone and everyone to "like" this page. As we try to increase the profile of ACD in the medical community, please let me know if your baby's medical facility has a FB page and the ACDA page can "like" that page and try to increase visibility. If you have any questions or concerns about the Facebook pages or activity, please contact me either through Facebook or at Emily_eschweiler@comcast.net.

CafePress: www.cafepress.com/acdawareness.com 10% of the sales price is sent to the ACDA whenever the fund balance reaches $50.00 or more. (The fund balance is almost to the threshold if anyone is looking for a cool new t-shirt or beach bag for the summer!)

Emily Eschweiler (Emily_eschweiler@comcast.net)
ACDA Fundraising Chairperson

Fundraising News continued!

From Jo Taylor and Chis Coe . . . .

We would like to thank everyone who has donated to The David Ashwell Foundation on behalf of our son Alexander Taylor Coe, who died of ACD as David did. The generosity shown through Thomson Airways Gatwick onboard charity has been amazing and hopefully we will be able to stop other families going through what we are by helping the research into this rare fatal condition. Over the last 15 months, £36000 ($49,594) was raised - thank you all!

Long miles, Sore Muscles and Happy Memories

By Dave Upton, Friend of Jo Taylor

It was late 2004 and I had been working as Cabin Crew for about a year at Britannia. I had been given a trip to Goa in India and was in the crew room meeting the crew one of whom was Jo Taylor. From the first time you meet Jo you know she is one of life's good gals, she is happy, bubbly and ever so positive.

From then on I would bump in to Jo from time to time on flights around the world and she was always smiling and asking after me. As the years passed I met Sarah, my wife and we had our first baby, Jacob. I moved on from Britannia and became a policeman but Sarah kept me up to date with news from the airline.

It was while Sarah was pregnant with our second, Harry, that she told me the awful news about Jo. As a parent and with Sarah pregnant neither of us could even comprehend what Jo or people in her situation must be going through it really made us sit back and see how lucky we were.

I don't know how I would have coped in that situation and yet some time the following year I saw Jo at a friend's wedding, and there she was, the same Jo still positive still asking after our boys and still smiling. I said to her there and then I wanted to help the David Ashwell Foundation in some way and we had a brief talk about how it could be done.

Initially we thought the 2013 Brighton Marathon would be a good idea; however there were only a few months until the event and I did not think I would have enough time to raise much money. Then I read about the London2brighton Ultra Marathon and an idea was born.

I contacted Jo who put me in touch with Amelia and we got the ball rolling. My plan was to run the Brighton Half Marathon, The Brighton Marathon and then the Ultra meaning that I could build up to the Ultra a few (lot of) miles at a time.

I have been training now since September, I have covered over 300 miles in around 44 hours. I have to say I love the training, as hard as it is I am finding new routes and seeing the countryside at all times of day and I am raising money for a great cause.

So I ran the Brighton Half on February the 16th. It was a glorious day sandwiched in the middle of the storms so I knew someone was looking out for me. I ran it in 1 hour and 41 minutes which I was pretty happy with. The full marathon is on the 6th of April and I am hoping to run it in under 4 hours. Then on the 24th of May the Ultra is on!

62 miles from Richmond Park to Brighton Race Course, I'm running with a friend and we are hoping to do it in around 11 1/2 hours.

That Brighton half seemed to kick start the fundraising and colleagues and friends are donating that hard earned cash to a great cause. If you want to see a bit more about my training you can follow me on Twitter @Duptonruns and you can also see updates at the fundraising page which is virginmoneygiving.com/team/Dupton

The support I am getting is amazing and I hope to raise lots more money before I am done, we are currently at £450 with giftaid which is great.

And that's it really, the charity shirts are printed up and there are pictures on twitter so if you are in Brighton on the 6th keep an eye out and give me a shout. I am slowing the miles down before the Marathon over the next few weeks and then after that have a few 30 and 40 mile training runs booked, keep an eye on the web page to see how I get on.

I am so happy to be helping such an important cause and I hope to do Jo and Amelia's boys proud.

Dupton x

Update on the Non-Profit Application for the ACDA

Steve and Donna Hanson

Unfortunately, the supervising lawyer at Southern Methodist University (SMU) has been reviewing our final application and forms for several months. We have asked to have the final forms submitted to the IRS before the end of SMU's spring semester. Once we submit the application, it could take a year to obtain non-profit status.
In the meantime, if anyone has any knowledge of private foundations that might be interested in funding our efforts, please let us know.

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A special THANK YOU to those who have donated towards the ACDA non-profit application:

Rilling Family
Rista Family
Wille Family
Eschweiler Family
Bush Family
Ashwell Family

A total of $604 dollars has been donated towards our goal of $750.

Thank you to the Kinchington family who donated £10,000 from a sponsorship for the west highland way to The David Ashwell Foundation and donated £500 from Victoria's mums funeral collection.

Safe Arrivals

[redacted]

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. 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.

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