

ACDA NOTES

From The Alveolar Capillary Dysplasia Association

Volume 14, Issue 3

<http://www.acd-association.com>

Summer 2012

Dear Friends and Family,

As our numbers grow, we all need to reach out to our families to ensure they know they are not alone and that there are other families that can help them through a difficult time. More members also mean that we have a bigger voice to spread the word about this tragic disorder and our voices will be heard around the world. We know it may be painful at first to talk about the baby you lost, but honor your baby by sharing him or her with the world.

We have a lot of news to share so we hope you will find the information in this newsletter both inspiring and helpful. Please share your news with us – whether you have a safe arrival, a fundraiser or a way that you have discovered to remember your baby. We'd love to share your poems, your stories and your thoughts.

Lastly, we need your ideas for updating the ACDA logo! See page 17 for yet another way for you to participate in the ACDA.

Fondly,

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



Table of Contents

1	Survey Deadline
2	Research News
3	Lung Transplant
4	Family Support News
6	Fundraising Update
9	Announcements
10	ACDA Statistics
16	Safe Arrivals
17	Welcome New Families

Deadline for ACD Survey Approaching

Thanks to those of you that have completed the ACD survey. **The deadline for completing the survey is October 31** so PLEASE find a few minutes to help further research for the devastating disease that affected all of us in such a personal and tragic way.

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. Thank you in advance for your participation.

Survey Information

The survey is secure, anonymous and is only available online. Please go to the following link to begin the survey:

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

If you have any issues with completing the questionnaire, please contact Amelia (Ashwell) Lake at Amelia.lake@durham.ac.uk. She is an ACDA mom as well as the lead researcher on this project. If you have any concerns or comments, please contact Steve and Donna Hanson at sdesj@verizon.net.

RESEARCH NEWS

From Diana Locke
4wheelin@earthlink.net

Hello ACDA families,

On August 22, 2012, I once again gave a presentation on ACD/MPV to 110 first year medical students at the University of Florida. The change this year was instead of getting the students at the end of their first year rotation, we got them when they were in their second week of medical school. This seemed to go better than previous years as we had fresh minds that seemed to be more interested in the information. Lots of questions were asked. I reconfigured the presentation (along with Professor Brian Harfe, PhD) to include updated genetic teaching material and pictures and names of our babies. If you would like me to add your baby's picture and dates for next year, email me at 4wheelin@earthlink.net. I do not use baby's photos or names without permission of the parents.

Our future lectures are planned for August of every year. The presentation is made available to the students online and any professors or MDs who would like to learn more about ACD/MPV. The medical school has liked the feedback from the students about how the genetics class is taught (with parent and/or patient presentations) over the years so much that they are going to pilot a program for the medical students education based on this concept.

After my presentation, I contacted Dr. Sen to let him know what response we had and he has offered to come to Gainesville to present a seminar on ACD/MPV in the future. I am working with the Pediatric Genetics department at the school to get this arranged. If it gets scheduled before the next newsletter, we will send out an email to let everyone know the date, time and location in case anyone would like to attend.

There will also be a new research paper coming out soon from Dr. Sen, his Baylor team and a nucleus of international doctors:

European Journal of Human Genetics (2012)
"A familial case of alveolar capillary dysplasia with
misalignment of pulmonary veins supports paternal
imprinting of FOXF1 in human"

As always, there is an open invitation anytime a parent or family member would like to attend the Genetics presentation that I do every year. Just email me and let me know you would like to attend and I can email you the info.

■■■■'s Story

A Story of Lung Transplantation for ACD

By ■■■■, mom to ■■■■
■■■■@gmail.com

My daughter, ■■■■, is 11 months old and received a double lung transplant in June 2012. She was perfectly healthy, or so we thought, until three months of age. At this time, she just required some supplemental oxygen. In May, she underwent an open lung biopsy at St. Louis Children's Hospital to determine why she required oxygen. She was a relatively "normal" nine month old when we arrived on May 25. They told us we would be home in one to two days. We got discharged after eight weeks!

■■■■, we call her ■■■■, crashed 13 times in the first four days after her biopsy and they quickly realized that she was in bad shape. We were told she was the sickest and most critical child they had seen. She was placed on ECMO with no other options for survival. After 11 days on ECMO, we made the difficult decision to place ■■■■ on a lung assist device called Quadrox. She was listed for a transplant and we were told she had a very small chance of surviving. We were told to expect the wait to be 6-8 months.



Four days after going on Quadrox, ■■■■ got her lung transplant. This made her the fourth child in the world to use a lung assist device but she is the first child in the world to successfully bridge to transplant. The interesting part is that after her transplant they reviewed her old lungs and discovered that she indeed had Alveolar Capillary Dysplasia with misalignment of the pulmonary veins. She was nine months old when she had her biopsy and nine and a half months when she was formally diagnosed. She has successfully been transplanted and is doing fantastic. Her story is on Children's hospital webpage.

<http://www.stlouischildrens.org/articles/features/2012/new-medical-approach-helps-baby-with-rare-disease>

An update from ■■■■ on September 8, 2012: ■■■■ is doing fantastic. She is approaching her three month post-transplant date on the September 12 and the doctors are amazed at how well she is doing. She is almost caught up with her development. She has had some minor bumps the last couple weeks but we have conquered them all. She got c diff and was in the hospital and then she had literally no white blood cells. Then, her broviac broke and her white count was too high. Things are regulating again though. I look forward to parents hearing Ellie's story. I would love to talk to other families.

Family Support News

From Kim Anderson Bush
ratherbinak@yahoo.com

Connect With Other Families On Facebook

For those of you on Facebook, we encourage you to “like” the ACDA’s public page, which promotes ACD awareness and encourages families to contact the ACDA, (<https://www.facebook.com/ACD.Association#!/ACD.Association>) and to encourage your friends and family to do the same. We’re also happy to “like” the NICUs where your babies stayed in order to help promote the word about ACD.

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).

Grief is Like a River

*My grief is like a river--
I have to let it flow,
But I myself determine
Just where the banks will go.*

*Some days the current takes me
In waves of guilt and pain,
But there are always quiet pools
Where I can rest again.*

*I crash on rocks of anger--
My faith seems faith indeed,
But there are other swimmers
Who know that what I need.*

*Are loving hands to hold me
When the waters are too swift,
and someone kind to listen
When I just seem to drift.*

*Grief's river is a process
Of relinquishing the past.
By swimming in Hope's channels
I'll reach the shore at last.*

~Cynthia G. Kelley

Dealing With Your Grief

Elisabeth Kubler-Ross described the five stages of grief: denial, anger, bargaining, depression and acceptance. To me, grief feels more like waves. They may lap gently at the shore, a quiet reminder of the grief that is always there. Or they may crash over you without warning, and you find yourself once again disoriented and struggling for breath. We all have those moments, those “I didn’t know it could hurt this bad” moments or those moments when you don’t know how you will make it through this second, let alone the next minute, hour, day or week. When those moments come, which they inevitably will, it’s important to have a reminder that whatever you’re feeling, it’s normal.

From the grief newsletter from St. Louis Children’s Hospital (re-used with permission):

Normal Feelings During Grief:

Because grief can be so painful and seem overwhelming, it can frighten us. Many people who are in a grief situation seem to wonder if they are grieving the “right” way and wonder if their feelings are normal. It may be reassuring to know that most people who suffer a loss experience one of more of the following:

- Feel a tightness in the throat or a heaviness in the chest
- Have an empty feeling in their stomachs and lose their appetites
- Feel guilty at times; angry at others
- Feel restless and look for an activity but find it difficult to concentrate
- Feel as though the loss is not real, that it didn’t really happen
- Sense the child’s presence
- Wander aimlessly, forget and be unable to finish projects
- Have difficulty sleeping and dream of their child frequently
- Experience an intense preoccupation with the life of the child
- Feel guilty or angry over things that did not happen in their relationship with the child
- Feel intensely angry at the child for leaving them
- Need to tell and retell and remember things about the child and the experience of death
- Feel mood changes/cry unexpectedly over the slightest thing
- Feel out of place with other people

If you should have physical symptoms, it is a good idea to check with your physician. Your resistance to infection may be lowered and you need to take care of your health. We realize grief is hard work. It is a process that takes a lot of time and energy. Talk about your feelings when you need to. Especially, do not be afraid to ask for help.

Fundraising Update

From Emily Eschweiler
Emily_Eschweiler@comcast.net

Greetings parents!

It has been a slow quarter for fundraisers in the U.S. I would very much encourage you to get involved and plan a fundraiser in memory of your child.

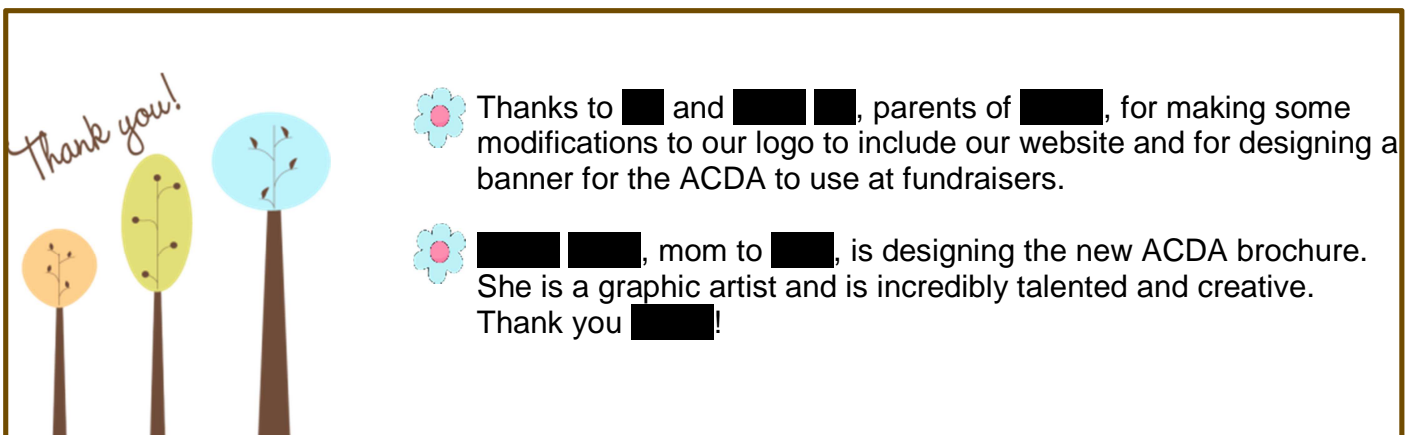
The CafePress site is still a work in progress, but I am happy to report that we have so far raised \$155! I will work on adding some items for the holidays. If anyone has any ideas, please email me at emily_eschweiler@comcast.net. You can reach the site at: <http://www.cafepress.com/acdawareness/8662542>

I am also looking into Charity Wines and a couple of other leads. Until we have 501(c)(3) status, it is hard to find fundraising opportunities.

I would also like to say a special thank you to both of my grandmothers, Betty Barker and Ilah John, who contributed money to the ACD Restricted Fund in memory of my grandfathers, Ted Barker and Robert John, and to thank all the family members of ACD angels, who make contributions to the fund.

For this quarter, I challenge every one of us to give up a lunch out, a cup of coffee, or the latest CD from iTunes, and instead make a donation of that amount to NORD:

<https://www.rarediseases.org/about/support/research-donations> selecting "Alveolar Capillary Dysplasia" from the drop down menu. Let's make our cumulative small donations turn into a large donation to help find a cure!



David Ashwell Foundation Update

By ACDA Members Simon Ashwell and Amelia Ashwell Lake

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 £68,537 (\$109,714) for ACD Research. £33,118.00 (\$52,053) was transferred in February 2012 to NORD and over £38,000 (\$60,800) has been raised **since** the NORD transfer. In other news.... On 16 July 2012, David's little brother Auden David Metta Ashwell was born after a long delivery (see photo in Safe Arrivals).

Completed Fundraisers:

- Through the amazing efforts of ■■■■■ (mum to ■■■■■) we are the chosen charity for Thomson Airline's Gatwick base – which has raised £5255 (\$8,400) since May 2012.
- There have been two cycle challenges this summer; one in France and one in Ireland.

Serena & Andrew completed 'The MMM Challenge'. Cycling 1,000km in 10 days and raising £1500 for ACD Research. Cycling the length of Ireland, from its most northerly point, Malin Head, to its most southwesterly, Mizen Head. You can watch a film they have made of their 1000 km http://www.youtube.com/watch?feature=player_embedded&v=9LVyLFVFk0

Also, you can read their blog, where ACD parent ■■■■■ has written a guest blog: <http://mmmchallenge.blogspot.com/> (look for July 7 entry)

- In July, Amelia's antenatal teacher planned a 'bump' photo shoot of pregnant women to raise money for The David Ashwell Foundation. I actually went into labour with our son Auden that morning and despite wanting to, could not attend – the photos are fantastic and the event generated lots of media interest.



<http://www.sundaysun.co.uk/news/north-east-news/2012/07/15/pregnant-mums-called-for-saltburn-pier-charity-photo-shoot-79310-31398123/>

- On 12th August, friends organized a motor show in aid of The David Ashwell Foundation. It was a sunny warm day and over 1,200 visitors flocked to the motor show. See reports in our local paper:

<http://www.gazettelive.co.uk/multimedia/news/local-news/2012/08/13/cars-on-display-at-stokesley-charity-motor-show-84229-31614048/>
<http://www.yourmainevent.co.uk/#/charity-motor-show/4567712994>

They are planning to make this an annual event – we loved it and can't wait till next year but need **volunteers** – so if any ACD families fancy coming to help – we'd be very grateful!

New Stamp Fundraiser:

We all receive letters in the mail every day and now we can save our stamps to help raise money for ACD research! There is a stamp store in England that pays charities for cancelled (used) stamps and the more unusual, the better. We have ACDA members from all over the world, so I know we can collect some awesome stamps (Dubai, Australia, New Zealand, Singapore, Switzerland). Please save your stamps and ask your friends and family to send you letters from their travels. The specific instructions are as follows:

All types of stamps are welcome. However, a mix which is almost entirely the standard 1st and 2nd class stamps will get less per kilo (2.2 lbs.) than a mix that's brimming with international, colorful special issue stamps, and stamps of non-letter rate denominations. For more details see <http://www.stamp-shop.com/charity-stamps-FAQ.html>

ABOUT THE STAMPS

- Stamps should be on single thickness backing paper (i.e. **not front and back** of the envelope) and the backing paper should be trimmed to about 4mm to 8mm.
- Nothing else should be mixed with the stamps (e.g. coins, postcards).
- You do not need to sort stamps into different categories.

ABOUT PACKING

- Preferably stamps should be in clear plastic bags inside a strong envelope/box.

ABOUT SENDING

- If outside the United States, please mail to:
Charity Stamps Direct (The David Ashwell Foundation)
5 Inverleith Gardens,
Edinburgh EH3 5PU
- If you reside in the United States, hold your stamps for now. We need some time to figure out the most efficient way to deliver the stamps to the UK.
- Mark the name of the charity to benefit on the **outside** of the package. Any material received which does not specify a charity, will have the proceeds allocated to a general fund to be split pro rata with the other charities.
- Do not enclose anything else.
- **ONLY** donations of stamps should be sent to the "Charity Stamps Direct" address.

More information can be found here <http://www.stamp-shop.com/charity-stamps-direct-1.html>

Upcoming Events in Autumn 2012:

- There are two runners in this year's Great North Run which is the world's biggest half marathon. On 16th September, David's Aunt (Gemma Ashwell) is taking part in Ironman Wales in order to raise money in memory of her mum (David's grandmother) and David. 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. The triathlon will push Gemma to her absolute limits but an arguably more difficult part has been the grueling training schedule for the 9 months before the event. Gemma (a doctor) has been fitting in between 2-7 hours of running, cycling or swimming each day around her job. Please read her story and support her.
<http://uk.virginmoneygiving.com/GemmaAshwell>
- We are having a Pampered Chef party to fundraise in November – so there is a lot happening to raise money for research!

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 (and elsewhere), 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://DavidAshwellFoundation> davidashwellfoundation@yahoo.co.uk



Announcements

- *Stefanie Putkowski, the NORD Research Program Administrator, has indicated that NORD received more applications for the ACD grant than expected, especially considering the rareness of ACD. She said two separate applications received outstanding scores by NORD's Medical Advisory Committee (MAC). She can't give out the exact number of initial applications that were received for our grant, however. Full proposals are due at NORD at the end of September. They will then be forwarded to NORD's MAC, who will determine the award recipients in late November.*
- *If you have an upcoming fundraiser and want to use the ACDA banner, please contact us.*
- *The current balance of the ACD Restricted Research Account at NORD is \$8,945. This does not include approximately \$44,000 that The David Ashwell Foundation has raised this year.*

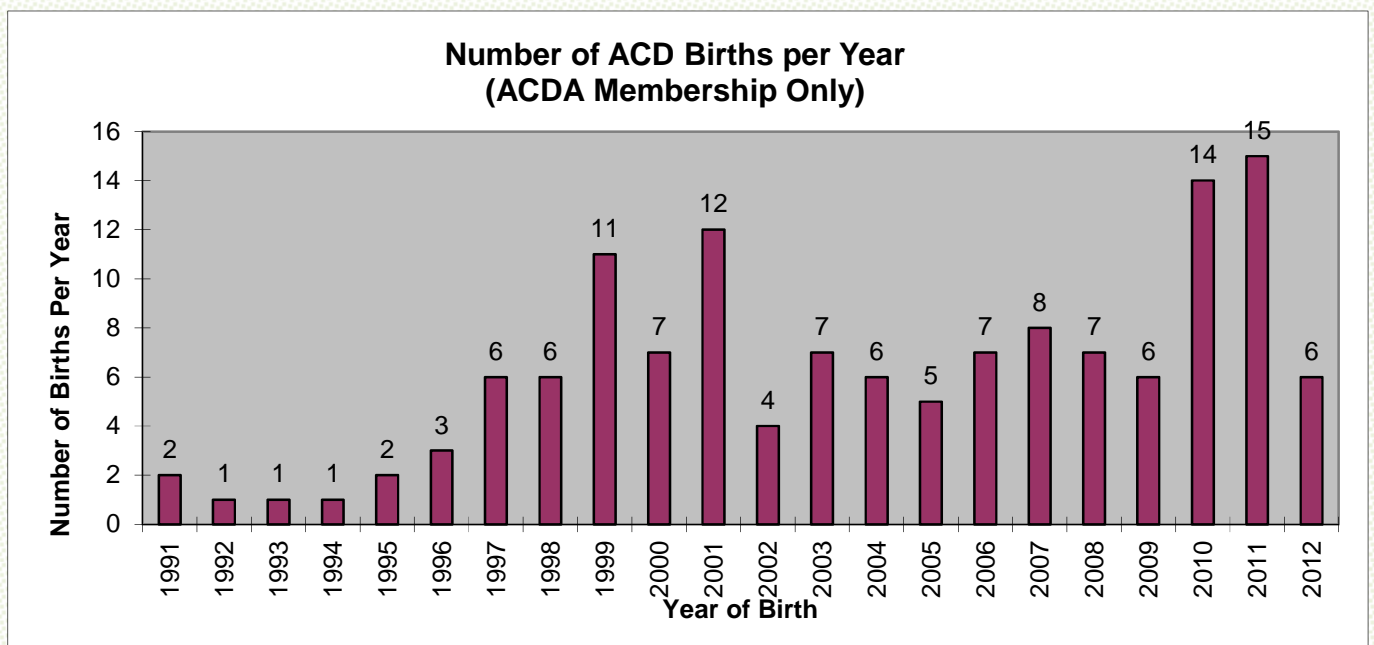
ACDA - Who Are We?

It's been about two years since we provided a statistical look at the ACDA membership. The following **data is only on ACDA members and DOES NOT include all reported or known cases of ACD**. We hope the charts and reports answer some of your questions and provide insight into ACD. And if you find all this interesting, the ACD survey will aim to provide the most comprehensive statistics on ACD to date so be sure to take the survey before October 31 (see page 1 for details.)

A couple of notes on the data:

- We are respectful of members' privacy, and if you have requested that certain information not be shared, we suppress it in any data shared with other people (e.g. the ACDA membership directory). However, all of the data is used to generate reports and charts because that information is not uniquely identifiable to a specific family.
- The data is accurate to the best of our knowledge, but we know that some is not current as we have lost contact with several families. However, we believe it is reasonably representative of the ACDA membership.

1. How many children are represented in the ACDA? Since 2010, there have been an additional 35 children born with ACD in the ACDA bringing the total to 137 live births and 2 unborn. That indicates that approximately 25% of the number of cases has occurred in the last 2.5 years. That might indicate that knowledge and awareness of ACD in the medical community is on the rise, but 2012 data (so far) does not support that trend.



2. What are the chances that our next child will have ACD? This is the most common question we receive and it is a difficult question to answer as the cause(s) of ACD is not known. This data is based on the 135 families in the ACDA database:

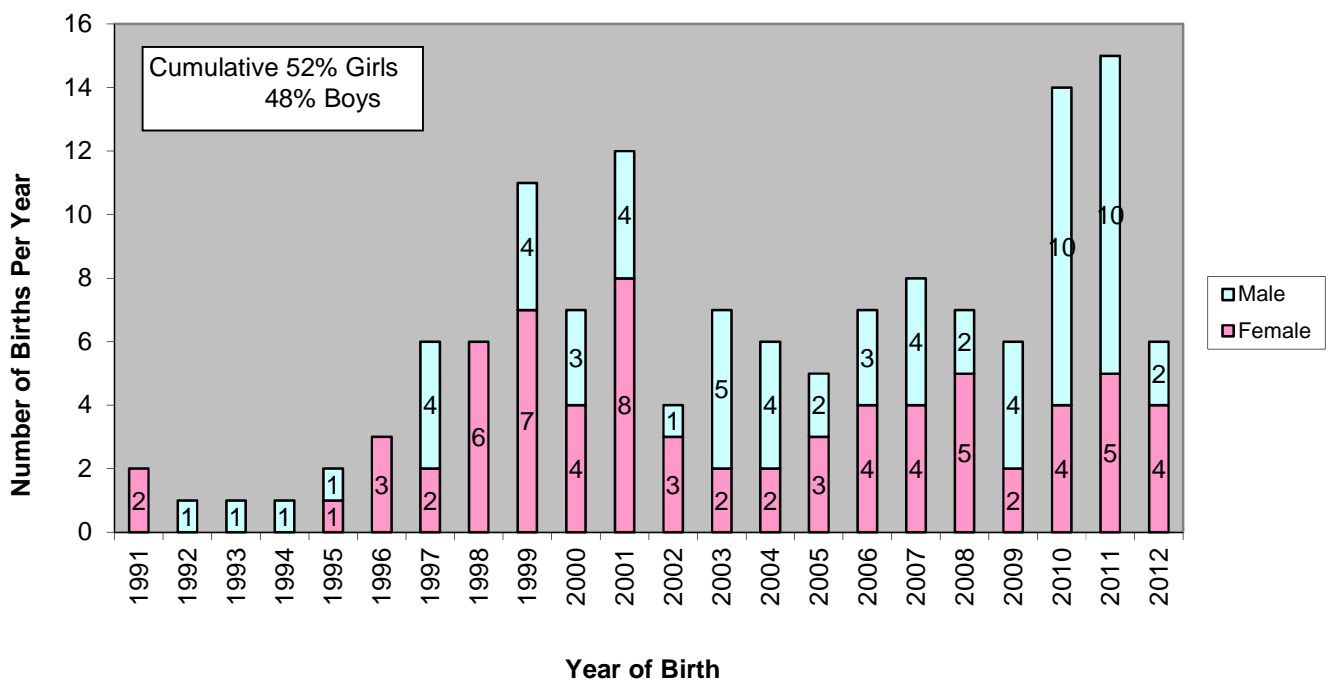
Families with one child born with ACD	129
Families* with two children born with ACD	4
Families with unborn ACD child	1
Families with child that survived ACD (transplant – see newsletter)	1
Families that had a healthy child after an ACD baby **	71
Families who have not had another child (or not known to us)	64

* A Family is defined as children from the same parents (i.e. re-marrying would be another family).

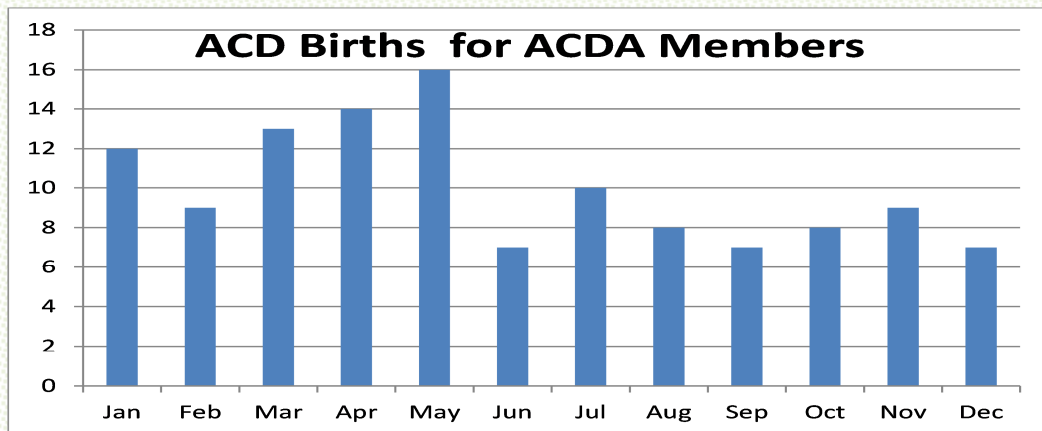
** Two of the four families that had two ACD babies went on to have a healthy child. The other two families with two ACD babies have not had another child together.

3. Does ACD affect males and females equally? The research papers we have seen indicate that ACD affects males and females equally. The 2010 data from the ACDA membership generally supported that with 57% female and 43% male, although the sample size was relatively small. With a larger sample size we now show 52% female and 48% male so this appears to be converging to a 50/50 ratio as the sample size increases.

**Number of ACD Births per Year
and Number of Males and Females
(ACDA Database Only)**

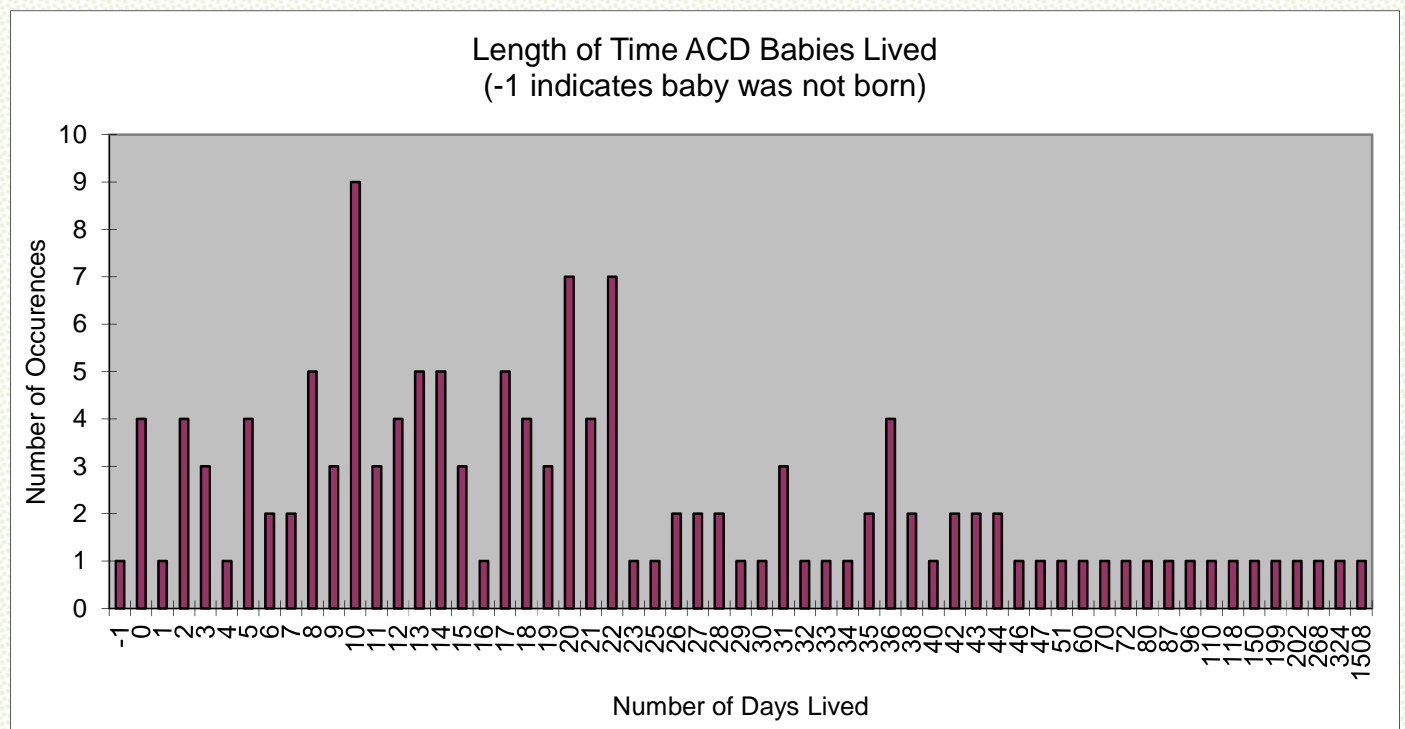


4. Are ACD babies more likely to be born at certain times of the year? Looking at the ACDA member data, there appears to be a minor trend of more babies born in the Spring, but maybe more children in general are born then. A larger sample size is needed.



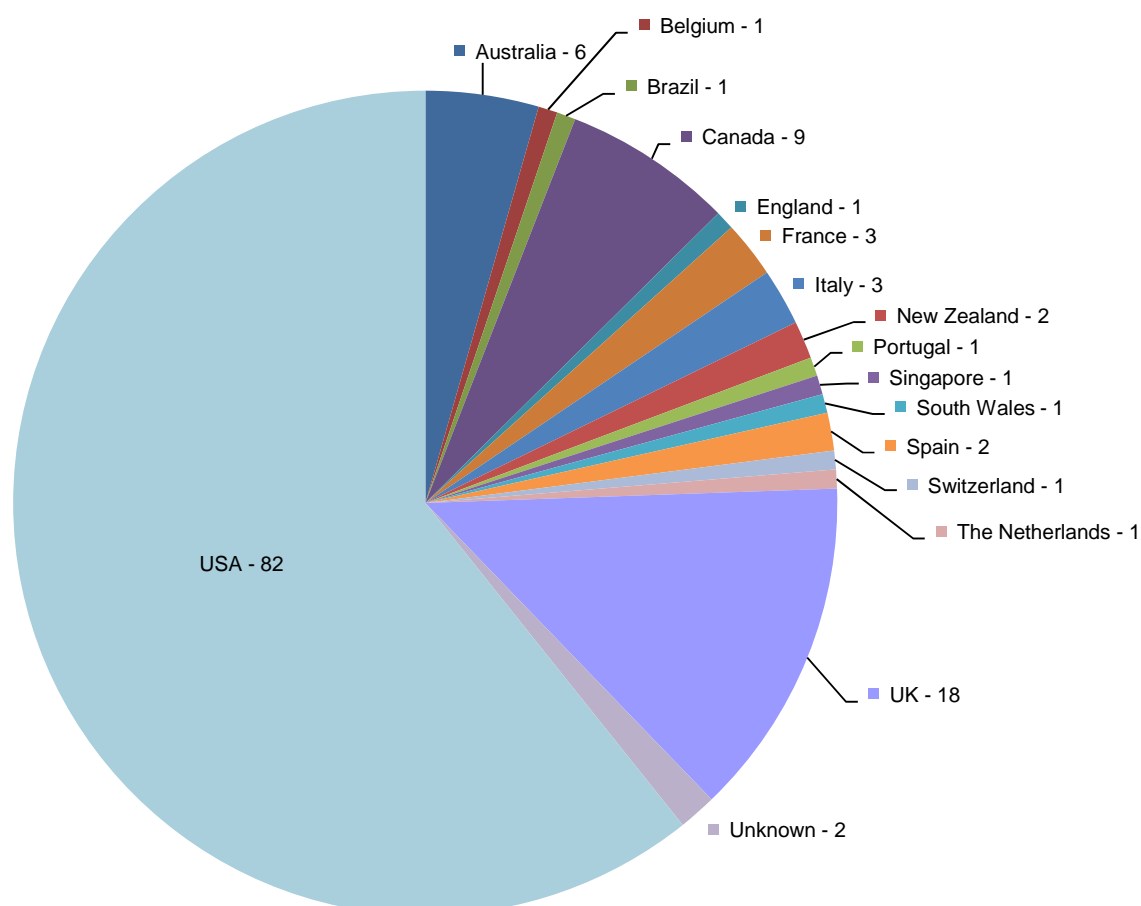
5. How long do babies with ACD live? ACD is a fatal disorder unless heart/lung transplant surgery is performed. Transplants are limited by the short time frame available, limited pool of donor organs and need for matching. Check out the amazing article in this newsletter on a child that has recently survived a heart/lung transplant. We have been told of two other transplants prior to 2010, but they are not ACDA members and we are not aware of the outcome.

ACD often presents itself within a few hours or days while the baby is still in the hospital, but in several cases it has not presented until weeks later. When the symptoms present and the level of care available to an ACD baby affect how long the baby will live. We don't have specific data on when babies presented with ACD or what levels of care were provided, but the following chart shows that babies live from less than a day to more than a year in one case.



6. Where do ACDA members live? ACDA Members are currently located in 16 countries throughout the world, which is an increase of 4 countries since 2010. The two largest groups consist of approximately 60% in the USA, 13% in the UK and 7% in Canada. We suspect there are many other families around the world affected that have either not been diagnosed, don't have access to find the ACDA or who do not speak English and have not contacted us.

Number of ACD Cases per Country - ACDA Members Only



7. Are there any ACDA members that live near me? One of the benefits of being an ACDA member is being able to connect with others that have also experienced the loss of a child to ACD. When you feel all alone and like no one really knows what you've been through, communicating with other members can be very healing. The map below shows ACDA member locations around the world. See if anyone lives near you to allow more interaction for support or collaboration on a fundraiser. Consult the ACDA directory for more specific contact information. We can email you an updated directory if you need one.



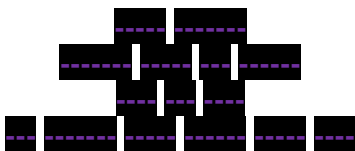
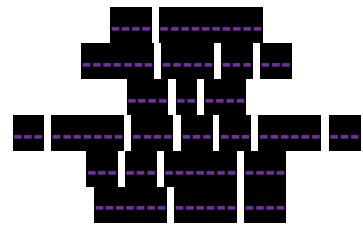
Clicking on the link below will take you to an interactive version of the map that shows ACDA member locations. This will allow you to zoom in and see if anyone lives near you to allow more interaction for support or collaboration on a fundraiser. Consult the ACDA directory for more specific contact information.

<http://batchgeo.com/map/8dc06a690ec5ac9dab0b129b7832169b>

Note: this is an "unlisted" map and only the link above allows access.

Safe Arrivals

**Congratulations
to these families
on their new
additions to their
family tree!**



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Remembering Our Babies



Note: Some of the graphics found in this newsletter were created by Laura Strickland at [© Laura Strickland/MyCuteGraphics.com](https://www.laurastrickland.com)



Please Welcome...



We Need Your Help!

If you or someone you know is creative, we need you! We are looking to update the ACDA's "look." We want to update our logo and would love to have everyone's ideas and input. If you would like to help out, please send us your ideas, sketches, artwork using the following guidelines:

- The logo should reflect the purpose/mission of the ACDA.
- We would like to use the colors of the awareness ribbon designed by ACDA mom Raquel Smith and Jason Davis, which is inspired by the un-oxygenated blood's transition from blue, to purple, to red as it is oxygenated. Sadly, this is what the lungs of ACD babies are unable to do.
- We want to include the name of the organization in the logo but if you have an idea for just the graphics, feel free to send that.
- The logo would be printed on our letterhead, brochure, website and our Café Press items.

Please send your ideas by November 1 and we will combine the best ideas into our new "look."

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

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