ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
http://acdassociation.org
FALL 2015
Issue
54

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

With the holiday season upon us, I am thankful for our ACDA community and all of the meaningful ways you continue to show your support. Whether it is through a donation, a post in the parent support group on Facebook, organizing a charity event, a visit to our new website, volunteering to coordinate a fundraising drive, a tweet, a Like, exchanging Christmas ornaments with another bereaved ACDA parent, purchasing coffee or bracelets, a yard sale, designing an image for the website, running a foundation while caring for a newborn rainbow baby, wearing shirts featuring the ACDA logo for a family holiday picture, lighting a candle in remembrance of a child, attending a rare disease conference or sending messages of love on difficult anniversaries, I am continually in awe at the large and small ways this group continues to care for each other.

Please never forget your ACDA family is here to support you. Whether you're facing the first or the twentieth holiday without your child, there is always someone to talk to and know what it is like to have a child who died from ACD. You can email us directly or reach out to the private and active ACD Parent Group on Facebook (details on last page of this newsletter).

However you celebrate the holiday season, we wish you peace and joy.

Regards,
Eliza Rista, Secretary

February 29, 2016 is Rare Disease Day

Rare Disease Day is an international advocacy day to bring widespread recognition of rare diseases as a global health challenge. The day is celebrated on the last day of February every year – February 29 in 2016. The ACDA has signed on once again to partner with NORD to support this awareness campaign. Anyone can be involved in Rare Disease Day and there are many suggested activities. The day has been established as a grassroots advocacy day and we encourage everyone to participate in some way. Click HERE for a full list of ways to participate!

Below are a few suggested ideas:

- Join a social media "rare disease day" campaign by changing your profile and cover pictures to share the importance of rare disease awareness! Click HERE to upload a photo and show how much you care about rare! #RDD2016 and #RareDiseaseDay
- Organize a fundraiser to raise money for the next ACD research grant! The deadline is March 1, 2016 so a fundraising drive in February pairs perfectly with Rare Disease Day.
- Contact your local newspaper to write an article about what Rare Disease Day means to you. Click HERE to read various articles previously written about our ACDA families.

AWARENESS NEWS

2015 NORD Rare Diseases and Orphan Products Breakthrough Summit:

The 2015 NORD Rare Diseases and Orphan Products Breakthrough Summit in Washington, D.C., USA was October 21-22, 2015. We were pleased a parent representative was in attendance to promote Alveolar Capillary Dysplasia awareness and research. Please read the thoughts from our parent attendee on the last page of this newsletter. NORD's Rare Diseases and Orphan Products Breakthrough Summit is the largest and most meaningful multi-stakeholder event of its kind in the U.S. – historically featuring over 20 speakers from the FDA, participation from over 80 patient organizations and the Pharma/Biotech industry's foremost experts in orphan product innovation, investment and commercialization. You can read more about the Summit here: http://rarediseases.org/summit-overview/.

North Carolina House Bill 823, Establish Advisory Council on Rare Diseases:

My attendance at the Rare Disease Legislators breakfast on March 25, 2015 in Raleigh, North Carolina was summarized in the Spring 2015 ACDA Notes. Since that writing, N.C. House Bill 823, after passing the N.C. House *unanimously*, went on to pass *unanimously* in the N.C. Senate and was signed into law by the Governor of North Carolina on August 5, 2015. This makes North Carolina the second state (behind Connecticut) to have an official law in place for the Rare Disease community. This bill introduces a formal council made up of researchers, medical staff and rare disease survivors and advocates to advise on the research and care of rare diseases within North Carolina. I was asked to participate in a special patient advisory coalition that will essentially be the voice for the patient representative on the actual council. The patient advisory coalition had our first meeting on November 19, 2015 and many ideas were brought forth to be presented to the Governor and council. I'll continue to update on progress and am grateful for the opportunity to represent our ACD community! --John Rista, ACDA father to Johnny (Feb 20, 2013 – Mar 4, 2013)

FUNDRAISING NEWS

Donations:

To make a secure tax deductible donation to the ACDA or the NORD Research Fund (ACD), please visit our website for full instructions.

http://acdassociation.org/donate/

The ACDA is a 501(c)(3) non-profit, tax-exempt organization as designated by the Internal Revenue Code of the United States.

Update from NORD:

The NORD balance of the Research Fund (ACD) as of November 30, 2015 is **$9,194.29.**

Balance of ACDA account:

The balance of the ACDA bank account as of December 11, 2015 is **$7,131.88**. **This does not include the amounts listed below deposited or pending deposit through PayPal Giving Fund, Spreadshirt, Giving Bean, Bravelets and AmazonSmile.*

Update from PayPal Giving Fund:

The donation total through PayPal Giving Fund between October 1, 2015 and December 11, 2015 is **$511.00.**

Update from Spreadshirt:

The accrued commission payments through Spreadshirt between September 1, 2015 and December 14, 2015 is **$263.47.**

Update from Giving Bean:

The donation total through Giving Bean for purchases between November 2, 2015 and December 10, 2015 is **$1,076.95** (see more information on the next page!).

Update from Bravelets:

The donation total through Bravelets for purchases between October 9, 2015 and December 2, 2015 is **$1,200.00** (see more information on page 5!).

Update from AmazonSmile:

The ACDA was issued a **$54.72** donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between July 1, 2015 and September 30, 2015. To designate the ACDA as your charity, please follow the link below so that all of your eligible shopping will benefit the ACDA: http://smile.amazon.com/ch/46-2915711

The amounts listed above total **$19,432.31.** The deadline is March 1, 2016 to make a donation to help us reach our goal of $33,500 for another NORD research grant in 2016!

Other Fundraising News:

We hope to launch a new fundraiser in early 2016 to sell updated car magnets featuring the new logo and website address. Please watch your email and Facebook updates to purchase!

If anyone knows of a printer that would donate the printing of our letterhead and brochures, please contact us at secretary@acdassociation.org.

Donations Received:

Thank you to the following families and friends that have made donations to the ACDA since the last ACDA Notes:

Donor	In Memory Of
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]
[redacted]	[redacted]

Giving Bean:

The ACDA is pleased to announce a new fundraising drive for our U.S. families through **Giving Bean**, which is a gourmet coffee roaster providing a variety of freshly roasted coffees, fine tea, gourmet cocoa, chai, and biscotti. Prices are $12 for a standard bag of coffee and tea, comparable to other high quality coffees and teas, with lots of flavors. A Coffee Club is also available for auto-delivery every 4, 6 or 8 weeks of a coffee of your choice. Please click HERE to go directly to the ACDA supporter page and **25% of** online purchases made through such link will go to the ACDA!

In addition to the "online" fundraiser described above, **please consider running an "in-person" sale in your hometown**! Two ACDA families ran in-person sales and easily raised $805 and $240! Both ACDA families had a wonderful experience as their friends and family snapped up orders! In addition, the ACDA **earns 40% of in-person sales** (even more than the 25% earned in online sales!) AND **the ACDA logo is printed directly on the label if 50+ in-person bags are ordered**. Please contact Renee Murray ([redacted]) to get started with in-person sales! It is fun, easy to do, available to everyone and a great way to raise research funds in your child's honor!

The ACDA logo is printed directly on the label if an individual sells 50+ bags through in-person sales!

Thank you to Renee Murray, ACDA mom to Callie (May 15, 2015 – May 23, 2015), for coordinating the Giving Bean fundraiser! In addition, congratulations to Renee on raising an incredible $805 through in-person sales!!

#GivingTuesday:

December 1, 2015 was #GivingTuesday, a global day dedicated to giving back. On this single day, the ACDA received $877 in donations and $900 was raised through Bravelets (see summary below), which brings our grand total for #GivingTuesday fundraising to $1,777. We cannot thank everyone enough for their participation and generosity on #GivingTuesday!

Bravelets™:

Our heartfelt thanks to Stephanie Smith, ACDA mom to Finley (March 18, 2015 – April 14, 2015) for setting up the ACDA with a Bravelets account! An astounding $900 was raised on #GivingTuesday alone! Bravelets sells bracelets for profit in the U.S. with a mission to encourage people to be brave during hard times. $10 from each item purchased through this LINK will be donated to the ACDA.

Spreadshirt:

The Spreadshirt shop featuring the new ACDA logo has sold 67 items since opening in September 2015! Items with our logo are available for purchase in our store HERE.

In honor of Jannik Frech:

Karin Titze-Frech, mother of Jannik, collected donations for The David Ashwell Foundation, together with her family, friends and colleagues while shopping online through clicks4charity.net. 275 € was collected simply by clicking on the website before online shopping!

In honor of Amelia Lee Weaver:

Charity Yard Sale in Louisville!

On September 19, 2015 our family held a charity yard sale in memory of our sweet baby girl Amelia Lee Weaver in Louisville, Kentucky. Amelia passed away on June 19, 2015 from ACD. Shortly after, Amelia's Aunt, Kaitlin U'Sellis, approached us with the idea of having a yard sale to raise awareness and funds for the ACDA and The Kosair's Children Hospital- NICU, the hospital that took such wonderful care of Amelia. The yard sale was held at Amelia's Aunt and Uncle's house in a high trafficked area of town. We advertised the event through social media, word of mouth, and flyers. Friends, family, and co-workers volunteered and donated items to be sold at the yard sale. We were overwhelmed with the response and donations that we received. In addition to the donations to sell, we received raffle baskets and items to raffle off during the day. A close friend of the family also provided lunch for all of the volunteers at the event. Towards the end of the event we started doing $5 dollar grab bags. Customers paid $5 and got a bag to fill to get rid of what we had left and raise more money. We had a great turnout in spite of the overcast, drizzly day, and knew that Amelia was watching over us, keeping the rain away. Overall we raised $2,300 dollars for ACDA and Kosair's. We know that nothing will replace our daughter, but we are hoping that funds raised at events like this will help research to find a cure. -- Adam and Kimberly Weaver, ACDA parents to Amelia (May 24, 2015 – June 19, 2015)

REPORT FROM THE DAVID ASHWELL FOUNDATION:

Once again a huge thank you to our UK and European ACD family and friends for tirelessly fundraising in memory of their precious babies.

Our balance on 11th December 2015 was **£15,193.94** ($23,052.25) and this will be transferred to NORD in due course. Since March 2011 we have raised a total of £157,475 ($238,921) which has contributed to funding all five recent ACD/MPV grants.

We have a Virgin Money Giving account where you can set up a page in memory of your child or for special occasions (such as birthdays or Christmas).

Notable fundraisers since September include an event organised by the truly amazing Sarah Mariott (mum of Seb Blenkinsop) which raised over £2,700.00. Sarah continues to do an amazing job raising awareness & fundraising including a children's Christmas party.

A friend of Amelia's donated three bags of designer clothes which were sold by a local shop generating £446 ($676).

Amelia's mum Vida (David's grandma) continues to crochet baby blankets, hats & cardigans all for our charity – raising £80 ($121) in a few months (let me know if you have any orders!)

In October Amelia had her annual Usborne book party – but due to the arrival of Faye it was a 'virtual' party – it still raised £156 ($236).

In memory of Zachary, Lauren Jade has been busy making gorgeous personalised decorations from which a donation goes to The David Ashwell Foundation.

For 2016, Amelia is busy organising a ceilidh on 5th March to celebrate David's 5th birthday… if you have any ideas for fundraisers or would like to organise something, we can help!

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 online 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

Please raise awareness of our small charity via social media including Twitter and Facebook.

If anyone in UK would like to support us, or join the team please get in touch.

UK families, please don't forget to use The Giving Machine when you online shop! Using this has raised £850 ($1289) since 2011 and in Germany the equivalent website has raised 260 Euros ($285 thanks to Karin, see report!). 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. 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!

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

For additional information, please contact Simon and Amelia.

Website: http://David Ashwell Foundation
Email: davidashwellfoundation@yahoo.co.uk
Twitter: @TDavidAshwellF
Mobile (Amelia): 07855473686

We are more than happy to hear from other families who would like to use the charity to raise money for ACD Research. Simon and Amelia run The David Ashwell Foundation on a voluntary basis. **All** money raised will be transferred to NORD to fund ACDMPV Research.

REMEMBERING OUR BABIES

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

WELCOME TO NEW FAMILIES

A sad but warm welcome to the following newly registered families:

- [redacted]
- [redacted]
- [redacted]

Facebook Outreach:

In November 2015, the ACDA reached out to families in the ACD Parent Group on Facebook to invite any unregistered families to officially register with the ACDA. Please welcome these newly registered families that have previously been a part of the Facebook group:

- [redacted]
- [redacted]
- [redacted]
- [redacted]
- [redacted]
- [redacted]
- [redacted]

SAFE ARRIVALS!

Congratulations on the birth of the following little sibling in our ACDA registered families:

- [redacted]

WEBSITE

Please be sure to visit our new website to see the site redesign unveiled in the Summer 2015 ACDA Notes! So far over 1,200 unique visitors have visited our page.

http://acdassociation.org

ACDA COMMITTEE POSITIONS

Please check our website for a full listing of Board and Committee members and let us know if you would like to get involved!

http://acdassociation.org/board-members

REFLECTIONS

During my discussions with NORD about the ACDA becoming a NORD member organization, I was asked if I would be attending the NORD 2015 Summit in October. Ultimately, I was one of the fortunate few to receive a scholarship to attend the conference. During the two day conference, I spoke with a number of other rare disease parents, NORD staff, geneticists, medical professionals, researchers, and pharma company representatives. I shared my story about ACD, my son, Johnny, and all of our other ACD babies who unfortunately share a remarkably similar story. I came home with a pile of business cards and many contacts. For example, one researcher I exchanged information with works for a company exploring animal lungs as potential human transplant lungs and after speaking with her, Alveolar Capillary Dysplasia is now on their potential treatment/transplant target radar.

It was powerful being around so many like-minded people affected by rare disease. Sheldon Schuster, president of the Keck Graduate Institute, was moderator on a panel regarding drug repurposing but made perhaps the most memorable statement of the conference. To paraphrase, he said, "***I have learned what the most powerful force in the universe is... you may say gravity, no it's not that...nuclear energy, it's not that either...it is a parent of a child affected by a rare disease.***"

So with that, I hope we are a step closer to finding a cure, definitely a step further in raising awareness, but there are many, many steps ahead, and I just got new shoes to climb some more steps. Warmest Regards, John Rista, ACDA father to Johnny (February 20, 2013 – March 4, 2013)

CONNECT WITH US

Facebook:

- Official ACDA Public Page
- Parent Group (private)
- Family Group (private)

Read about the private groups on our website with information on how to join: http://acdassociation.org/support-groups/

Twitter:

- Follow us @acdassociation

Website:

http://acdassociation.org

Email:

President@acdassociation.org (Steve Hanson)
Secretary@acdassociation.org (Eliza Rista)
Treasurer@acdassociation.org (John Rista)

A note from the Secretary: We absolutely want to hear from you as to how we can best meet your needs with respect to information about ACDMPV and also grief support. We are here to help in any way we can. Please know we always want to hear your ideas and we love community involvement on any level. Please never hesitate to contact me at Secretary@acdassociation.org.

Regards, Eliza Rista, mom to Johnny
(February 20, 2013 – March 4, 2013)