ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org
WINTER 2017
Issue 58

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

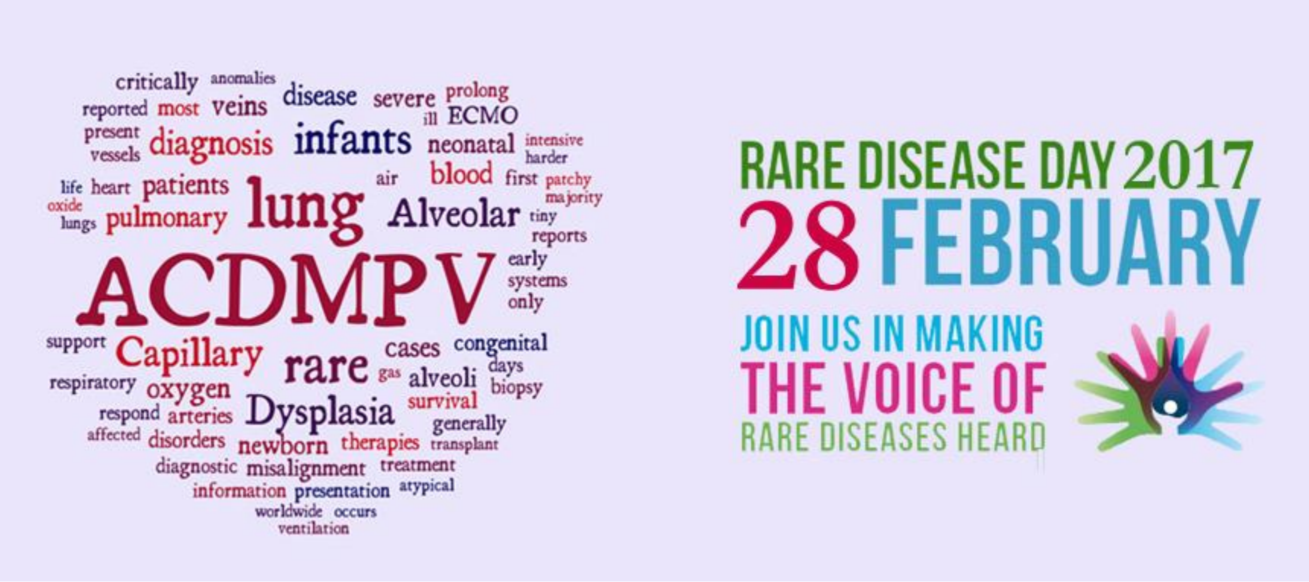
2016:
Year in Review

As we take a look back at 2016:

- **Twenty new families registered with the ACDA. These families are from the USA, UK, Netherlands, Germany, Philippines and Canada.**
- **Two lung transplants; one in the UK and one in the USA.**
- **Three confirmed prenatal diagnoses of ACDMPV without a family history.**
- **One NORD research grant in the amount of $50,000.**
- **Thirteen rainbow babies born to ACDA registered families.**
- **Two tattoos of the ACDA logo.**
- **More than ten journal articles published about ACDMPV.**
- **Numerous successful fundraisers for ACDMPV research and awareness events.**
- **One continued goal – To find the cause of and cure for ACDMPV.**

Regards, Eliza Rista, Secretary

February 28, 2017 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 28 in 2017. The ACDA has signed on once again to partner with NORD to support this awareness campaign and we encourage everyone to participate in some way. **Click HERE to see how the ACDA supported Rare Disease Day in 2016!** Click HERE for ways to participate in the U.S. in 2017 and click HERE to visit the EURORDIS website for Rare Disease Day 2017 in Europe.

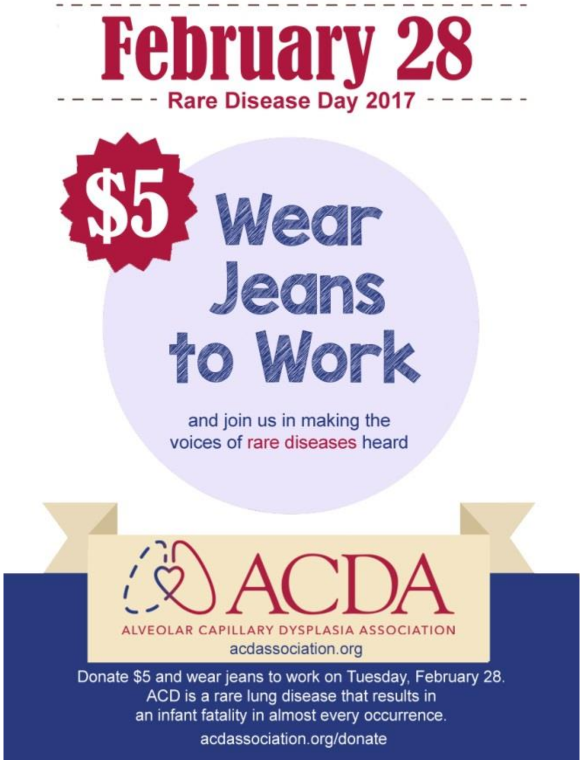
Below are a few suggested ideas:

- Click HERE ($) or HERE (£) to print a flyer for anyone to use at their workplace that encourages employees to donate $5 / £5 to the ACDA and wear jeans to work on Tuesday, February 28 for Rare Disease Day.
- 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! Use the hashtag #RareDiseaseDay
- Organize a fundraiser to raise money for the next ACDMPV research grant.
- 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.

RESEARCH NEWS

Novel deletion case:

The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently published a manuscript entitled "*Narrowing the FOXF1 distant enhancer region on 16q24.1 critical for ACDMPV"* in Clinical Epigenics, which can be found HERE. This paper examined a case study of an ACDMPV patient from New Mexico, USA with a de novo deletion upstream of FOXF1. The novel deletion "allowed us to further narrow the FOXF1 enhancer region and identify its critical 15-kb core interval, essential for lung development" and provided new insights into regulatory function and genomic imprinting. The case study highlights the importance of the submission of DNA and tissue samples to the ACDMPV research team at Baylor as one sample can provide unique insights in furtherance of ACDMPV research.


February 28
Rare Disease Day 2017

$5 Wear Jeans to Work

and join us in making the voices of rare diseases heard

ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org

Donate $5 and wear jeans to work on Tuesday, February 28.
ACD is a rare lung disease that results in an infant fatality in almost every occurrence.
acdassociation.org/donate

AWARENESS NEWS

Wear Jeans to Work Flyers:

As referenced on page 2, **the ACDA has created flyers for anyone to use at their workplace that encourages employees to donate $5 / £5 to the ACDA and wear jeans to work on Tuesday, February 28 for Rare Disease Day.** Click HERE (**$**) or HERE (**£**) to print or email the full size images. We hope you will consider asking your workplace to participate! This was a terrific awareness event and fundraiser last year on Rare Disease Day. Donations can be submitted individually or collectively at **acdassociation.org/donate** and we are happy to track the amounts donated in your child's honor.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Lights in Suffolk County (Fallon Rilling):

On October 10, 2016, the H. Lee Dennison Building in Suffolk County, New York, USA was lit purple to raise awareness for ACDMPV in honor of the third birthday of Fallon Rilling (October 10, 2013 – October 21, 2013). Our thanks to the Rilling family for their continued awareness and fundraising efforts.

ACDA tattoo (Tristan Zozaya):

Brookelynn Niles, ACDA mom to Tristan (January 3, 2011 - January 18, 2011), recently added the ACDA logo to her tattoo sleeve in honor of Tristan. Beautiful!

Half Marathon (Myla Lourens):

Mathijs Lourens, ACDA father to Myla (November 20, 2015 - December 17, 2015), ran a half-marathon in Amsterdam on October 16, 2016. In his own words, “Six months ago I started running out of love for children and especially in loving memory of my daughter Myla! I wanted to start a fight against ACD in my own way so I decided to raise awareness by running marathons. **Myla gives me superpower and she's with me every step of the way. I believe we can all make a difference in our own way.** Today was the start of my mission. I ran 21K for the first time of my life with Myla on the back of my shirt and a lot of support of my lovely family and friends. Together we can do this! I'm halfway now and in April will be my first marathon for ACD! Let's beat this thing all together! I will not stop running until that day for all ACD babies worldwide.”

Lung Transplant Update (Imogen Bolton):

In a prior ACDA Notes (Issue #56), we introduced you to Imogen Bolton, an ACDMPV survivor in the UK and Europe's smallest lung transplant recipient. Since that time, Imogen's story has traveled around the globe and featured in numerous publications, such as The Sun, NBC Today, Sky News, Chat magazine, The Telegraph, The Daily Mail, and many more. For a listing of articles featuring Imogen, please click HERE and also click HERE to follow Imogen's story on Facebook. **Imogen celebrated her first birthday in November 2016!**


Great Ormond Street Hospital for Children NHS

Roundabout

Season's Greetings and a happy New Year!

Imogen's story

Imogen was only five months old when she had a double lung transplant. Read her story on **page eight**.

Lung Transplant Update (Luca Palmisano):

In the last ACDA Notes (Issue #57), we introduced you to little Luca Palmisano who was diagnosed with ACDMPV and awaiting a lung transplant. We are pleased to report that Luca received a bilateral lung transplant at four and a half months old at Children's Hospital of Philadelphia in the USA. We are even more pleased to report that **Luca celebrated his seven month birthday at home after his release from the hospital in January 2017!** You can follow Luca's Lung Transplant Story HERE. Our heartfelt congratulations to Luca and his ACDA parents, Ashley and Thomas, and big sister, Ariana. #teamluca

Restoring a Mother's Heart Retreat:

In November 2016, three of our ACDA moms ([redacted]), attended a weekend retreat in Wisconsin, USA entitled "Restoring a Mother's Heart." As summarized by an organizer, "30 women gathered to learn to live with the death of their children, to find hope and community. These women mothered children through Congenital Heart Disease, Spinal Muscular Atrophy, Cancer, Rare Disease, Autism, and other chronic illnesses and special needs. In this group, these brave women were transformed, they found community, hope and purpose."

All three of our ACDA moms found this retreat to be healing and impactful on their lives. Even though this is not an official ACDA sponsored event, we are sharing information about the retreat in the event any of our other registered families also find it helpful in their grief journey. There are two similar retreats planned by the organizers in 2017: **April 7-9 & November 10-12**. We understand registration for April's retreat is live now and November's retreat will be live in June. Visit www.ethanlindberg.com/retreat to learn more from the organizers, including their scholarship information and tools to raise funds for yourself or a friend

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.

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 minimum amount required for the issuance of a 2017 NORD grant is $35,000 (increased from $33,500 effective as of the 2017 grant cycle).

Balance of ACDA account:

The balance of the ACDA bank account as of January 27, 2017 is $[redacted].

Update from Spreadshirt:

The accrued commission payment from Spreadshirt between October 6, 2016 and January 22, 2017 is $[redacted]. As of May 2016, the commission model changed from 25% of base product price to 20% affiliate price (now including base product price *and* print price). Items with the ACDA logo are available for purchase in our Spreadshirt store HERE.

Update from AmazonSmile:

The ACDA was issued a $[redacted] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between July 1 and September 30, 2016. 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

Donations Received:

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

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**We are sorry we do not know the child for whom the honorary contribution was made. Please contact us to let us know.*

In honor of Xavier Kaczynski:

The ACDA extends its sincere thanks to the family and friends of [redacted] [redacted]). Together they have **donated almost $5,000 to the ACDA** since November 2016. [redacted] is the son of ACDA parents, [redacted] [redacted], and brother to his three older siblings. The ACDA is touched by the generosity and kindness from the family and friends of [redacted].

Giving Bean:

The ACDA held our second annual **Giving Bean coffee fundraiser** during the 2016 holiday season!

In-person sales (40%): Please note we can re-open our in-person sales campaign at any time there is an interest in selling coffee for a fundraiser; just let the ACDA know! In-person sales are fun to do (just like selling Girl Scout cookies) and 40% of sales go to ACDMPV research. Additionally, if you sell more than 50 bags through in-person sales, your bags will come with the ACDA logo affixed on the bag.

John and Eliza Rista, ACDA parents to Johnny Rista (February 20, 2013 - March 4, 2013), raised $240 through in-person sales of fifty bags during the 2016 Giving Bean holiday drive.

Online sales (25%): As an alternative to the in-person sales option, please click HERE at any time to go directly to the ACDA supporter page and 25% of any purchases made through such link will go to the ACDA.

Giving Bean's flavor selection is vast and delicious and averages $12 a bag, which makes it a great gift and a wonderful way to raise funds for ACDMPV research.

NEW ACDA COMMITTEE MEMBER

A new ACDA committee member was approved in a Special ACDA Board of Directors meeting on January 19, 2017. The new member of the Communications Committee is:

- **McCayla Butler**, ACDA mom to Noah (June 5, 2013 - June 18, 2013) - McCayla will work with the Communications Committee to design and implement a new welcome package in 2017 for future ACDA families.

A big Thank You! to our new committee member and to the existing members for their continued contributions. The composition of the committees is now as shown below. If you have any ideas or suggestions, please always feel free to contact one of the committee members!

Communications Committee:

- McCayla Butler
- Emily Eschweiler
- Diana Woida Locke
- Candice McCasland
- Eliza Rista

Fundraising Committee:

- Renee Murray
- Kristen Rilling
- John Rista
- Stephanie Smith

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

REPORT FROM THE DAVID ASHWELL FOUNDATION:

Earlier this month Simon and I did the charity returns for the year 2015-16. Thanks to many of you and your donations we had raised a staggering £23,412 ($29,484). In February 2016 we transferred £18,262 ($22,998) to NORD for the ACD Research Fund.

Thank you to the family of Nathan and Ellie Flores – a donation in memory of Noah was made at the funeral of Nathan's great grandmother.

I held a 'virtual' Neals Yard (toiletries) party in November which raised £190.

As ever we had donations in lieu of Christmas Cards (total needs to be calculated). Simon's workplace raised over £200 rather than send cards.

I am busy organizing a ceilidh on 4th March. This is a significant date as it is David's 6th birthday. Hoping we can raise a good amount of money – though I still have lots of work to do and tickets to sell!

As ever, can I plea with all UK families to use the Giving Machine to generate income from online shopping. Everyone in the UK can do this – it is so easy to register and is a way of earning easy and free money. Please also encourage your friends and family too!

https://www.thegivingmachine.co.uk/causes/the-david-ashwell-foundation/support/

UK families you can set up direct debits to The David Ashwell Bank Account (we have a number of people who do this).

Additionally 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).

If you live in the UK (and elsewhere), there are a number of options available for funding ACDMPV 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

All UK & Europe based families are welcome to use The David Ashwell Foundation as a means of fundraising for ACDMPV Research. Please raise awareness of our small charity via social media including twitter and Facebook.

We are more than happy to hear from other families who would like to use the charity to raise money for ACDMPV 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.

Thank you to all who have used The David Ashwell Foundation to fundraise in memory of their precious child. Our current total is **£12,527 ($15,776)**. Since David died in March 2011, The David Ashwell Foundation has raised £168,192 ($211,815). For additional information, please contact Simon and Amelia.

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

Remembering Our Babies

[redacted]

[redacted]

[redacted]

[redacted]

Welcome to New Families

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

- [redacted]
- [redacted]

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

- [redacted]

Safe Arrivals!

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

[redacted]

- [redacted]

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:

- 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