

# ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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We hope you will participate in the *International Wave of Light* as part of Pregnancy and Infant Loss Remembrance Day on October 15 (see page 2 for details). We invite our ACDA families to post a photo of their lit candle on the public ACDA Facebook page on October 15. If you have not done so already, please click [HERE](#) and “Like” our page to follow our updates on social media. We also have a Twitter account [HERE](#).

In addition to our public ACDA Facebook page linked above, please remember there is a **private Facebook group only for parents who have lost a child to ACDMPV or whose child has been diagnosed with ACDMPV. This group is extremely active with almost daily postings and interaction.** I encourage all of our parents to join as the well-established group is incredibly supportive and you can reach someone to talk to at any time of day due to its international reach. Please click [HERE](#) to join or search “ACD Parent Group” on Facebook. Note the views and opinions expressed in the parent group do not necessarily state or reflect those of the ACDA as it is not directly maintained by the ACDA.

Finally, **please consider participating in our second annual coffee fundraiser this holiday season through Giving Bean. In-person sales are fun to do (just like selling Girl Scout cookies!) and 40% of sales go to ACDMPV research! If you sell more than 50 bags through in-person sales, your bags will come with the ACDA logo affixed on the bag. The 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. We hope for a successful drive this year with lots of involvement by our ACDA families! Please send an email to [secretary@acdassociation.org](mailto:secretary@acdassociation.org) to sign-up to participate!**

Regards, Eliza Rista, Secretary

## October is Pregnancy and Infant Loss Awareness Month

In October 1988, President Ronald Reagan of the United States proclaimed October as National Pregnancy and Infant Loss Awareness Month. "When a child loses his parent, they are called an orphan. When a spouse loses her or his partner, they are called a widow or widower. When parents lose their child, there isn't a word to describe them. This month recognizes the loss so many parents experience across the United States and around the world."



## October 15, 2016 – Pregnancy and Infant Loss Remembrance Day

The October 15th Pregnancy and Infant Loss Remembrance Day campaign began in 2002 and is a day of remembrance for pregnancy loss and infant death. The day is observed with ceremonies and candle-lighting vigils, concluding with the International Wave of Light, a worldwide lighting of candles.

**The International Wave of Light invites participants from around the world to light a candle at 7:00 p.m. on October 15 in their respective time zones, and to leave the candle burning for at least an hour. The result is a continuous chain of light spanning the globe for a 24 hour period in honor and remembrance of our babies we have lost.**



## RESEARCH NEWS

### ***NORD Request for Proposals (“RFP”) – 2016 Research Grant:***

NORD, with funding from The David Ashwell Foundation and the Alveolar Capillary Dysplasia Association (ACDA), is **accepting applications for a total of \$50,000**, for scientific research studies and/or clinical research studies related to Alveolar Capillary Dysplasia/misalignment of the pulmonary veins (ACDMPV). NORD encourages all U.S. and international researchers interested in studying ACDMPV to consider applying for 2016 funding. The Abstract Submission Deadline is **October 21, 2016**. See the full RFP and abstract template [HERE](#).

### ***FOXF1 in Mouse Models:***

The genetic research team at Baylor College of Medicine in Houston, Texas, USA has worked in direct collaboration with a developmental biology research group at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, USA, including recently publishing together a **mouse** model of *FOXF1 overexpression*. The full manuscript entitled “*Lethal lung hypoplasia and vascular defects in mice with conditional Foxf1 overexpression*” as published in Biology Open can be found [HERE](#). The paper was based off the PhD thesis of Avinash Dharmadhikari, a graduate student and mentee of Dr. Pawel Stankiewicz at Baylor and used mouse models to research what happens in mice when the FOXF1 gene is overexpressed.

The research was a significant amount of work involving substantial experimentation with mice and follows up on prior work discussed in a 2014 paper. The 2014 study

investigated the outcomes of FOXF1 duplication where four unrelated living people with duplication of FOXF1 were identified. Unexpectedly, none of the four patients had any lung abnormalities. However, Baylor was unable to measure the expression levels of FOXF1 in the 2014 study because the patients were otherwise healthy with regards to respiratory issues so no lung biopsies could be performed. As such, in the 2016 paper, Baylor implemented a mouse model study to increase the availability of samples in which to study FOXF1 expression levels. They developed a conditional model to switch on FOXF1 when they want in mice to change the expression levels and observed lung abnormalities when FOXF1 was overexpressed. Similar to FOXF1 *loss*, FOXF1 *overexpression* in **mice** is lethal. Based on the results of the 2016 mouse models, the research concluded that to be on the safe side, any future gene therapy would need to be careful with manipulating the expression of FOXF1 gene in humans because it could be problematic in humans if FOXF1 is overexpressed too much. This has important clinical implications when considering potential gene therapy approaches to treat disorders of FOXF1 abnormal dosage, such as ACDMPV.

ACDMPV was also mentioned in an article about research being conducted by the Cincinnati group referenced above (click [HERE](#)). The research is currently only applicable in **mouse** models and considerable further research is needed as to how the compound would apply to human lung diseases. From the article, “Researchers are developing a new drug to treat life-threatening lung damage and breathing problems in people with severe infections like pneumonia, those undergoing certain cancer treatments and premature infants with underdeveloped, injury prone lungs...Two laboratories at Cincinnati Children's are developing a pharmacologic compound that in **mouse** models stimulates FOXF1 and promotes repair after lung injury.” The ACDA is hopeful for additional





research that provides a full understanding of the molecular mechanism as to how the compound works and then further research into whether this could ever be applied to human patients at some point in the future.

The ACDA is grateful for the continued collaborative efforts between the research teams at Baylor and Cincinnati Children's.

### ***NIH grant application:***

Baylor has applied again for a NIH grant in the USA to continue substantial ACDMPV research, which will be considered by the NIH on October 25-26, 2016.

### ***2012 and 2015 NORD Grant Update:***

Dr. Partha Sen was the recipient of a 2012 NORD research grant, which grant was extended to Northwestern University upon Dr. Sen's transfer from Baylor to Northwestern University. This grant has been completed and researchers are in the process of writing manuscripts using the data that came out of that funded research.

In addition, Dr. Sen was also one of the co-recipients at Northwestern University of the 2015 NORD research grant. Dr. Sen has recently departed Northwestern University and returned to Texas. As such, he has requested NORD to transfer the 2015 grant to his supervisor and co-recipient of the grant, Dr. Aaron Hamvas at Northwestern University. Dr. Hamvas is a well-known researcher in the field of surfactant proteins and has provided patients for ACDMPV research in the past. He was previously at St. Louis Children's Hospital-Washington University and involved in lung transplant cases of ACDMPV patients.

## **AWARENESS NEWS**

### ***ACDA tattoo (Luca Palmisano):***

Ashley Palmisano, ACDA mom to Luca, recently got an incredible tattoo in support of her son and the ACDA. Luca was born on June 21, 2016 and is currently awaiting a lung transplant at Children's Hospital of Philadelphia in the USA. You can read the Palmisano's story [HERE](#). According to the family's latest update, "He's been actively on the donor waitlist as the highest possible status since September 3rd. The perfect lungs could literally come any day. One of our doctors recently said, "if we get him though a transplant, there's been no irreversible damage, and you'll have a good kid after this." And that is what we pray for." Our hearts are with Ashley and Thomas, Luca and big sister, Ariana. [#teamluca](#)



### **Transplant Day at the Ballpark (Eleni Scott):**



Eleni Scott, a lung transplant recipient and daughter of ACDA parents Karen and Nick Scott, threw out the first pitch during 'Transplant Day at the Ballpark' at Busch Stadium, home of the Cardinals Major League Baseball team in St. Louis, Missouri, USA. Eleni was diagnosed with ACDMPV at eight months old and received a double lung transplant at nine months old. She recently celebrated her 5<sup>th</sup> birthday on August 26, 2016!

### **University of Florida presentation:**

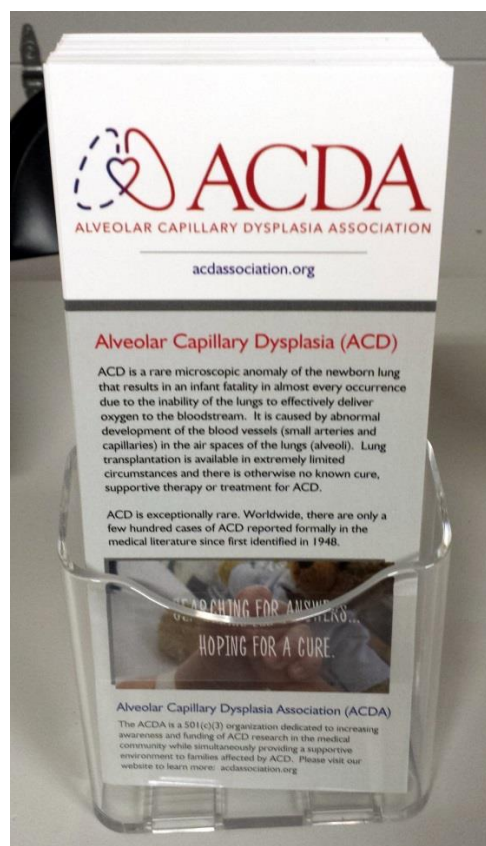


Diana Locke, a Registered Nurse and ACDA mom to Christopher (November 7, 2006 - December 17, 2006) gave her annual presentation to 135 first year medical students at the University of Florida College

of Medicine in Gainesville, Florida, USA on August 16, 2016. The presentation focused on ACDMPV, Christopher's case and other ACDMPV babies. With this program, future doctors now know about ACDMPV.

### **Rack Cards:**

The ACDA recently created a short informational "rack card" with key facts about ACDMPV. [HERE](#) is the link for the rack cards if anyone would like to order a set of cards for your own awareness or fundraising event. Please note the printing and shipping costs of the rack cards are not covered by the ACDA and are instead paid for out-of-pocket by individuals running events. The rack cards are the "80lb one-sided Glossy with UV Varnish" quality. Vistaprint ships internationally and you can check [retailmenot](#) to see if a coupon is available to reduce your cost.



## 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](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 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 October 7, 2016 is \$[REDACTED].

### Update from Spreadshirt:

The accrued commission payment from Spreadshirt between June 30, 2016 and October 5, 2016 is \$[REDACTED]. 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 April 1, 2016 and June 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>

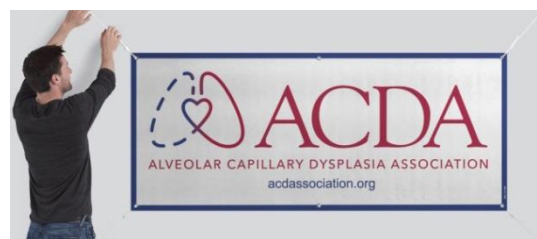
### Donations Received:

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

Donor	In Memory Of
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]

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

### Banners:



**Don't forget the ACDA recently announced the addition of two new custom ACDA banners!** If you would like to request use of a banner in the United States, please send an email to [secretary@acdassociation.org](mailto:secretary@acdassociation.org) to discuss sign-up for availability and shipping information.





### ***The Miracle of the Shared Lily Pad:***

Susan Anderson, mother to ACDA mom Kim Anderson Bush and grandmother to Phoebe (March 21, 2010 – April 21, 2010) and Ronan (April 27, 2011 – July 16, 2011), wrote and recently published a book entitled, “The Miracle of the Shared Lily Pad.” Ms. Anderson is generously donating a portion of the proceeds from the sale of her book to ACDMPV research. The website for the book is [www.writinggrammy.com](http://www.writinggrammy.com).

In addition, many of our ACDA families chose to have their child’s name(s) included, which are placed in alphabetical order throughout the book. As described by the author, “This children’s storybook follows the adventures of Freddie the frog who is given a special gift from God, a beautiful place to live. Freddie learns to share his gift and subsequently grows in his love for God’s other creatures. Every time he shares, God expands his pond. The biggest surprise for Freddie is how his heart grows with God’s love.”

If you would like to order a copy, please visit the book’s website. Additional ordering details from Ms. Anderson are as follows, “When you go to the website if you click on the Order Now under the picture, not the larger green Order Now, you will have your choice to order from me via email or from the publisher. The price is the same but I receive a larger royalty when bought directly from me and I will be able to send more for research. I have set up a PayPal account so you can order directly from me if you want by emailing [REDACTED]. Let me know how many books you would like along with the address to ship them to. Also if you want the books signed and if it is for someone in particular. I have a scale in my home so I can weigh each package and send you the total cost.”

### ***In honor of Callie and Cole Murray:***



On September 10th, 2016 the Murrays participated in an awareness and fundraising event in their community at a Fall Festival. Their table included information about ACDMPV that people could take home with them. The Murrays had countless conversations with complete strangers about their angels, Callie and Cole. They spoke their names proudly and were able to tell people about ACDMPV and how it affected their family. They also sold coupon books from a local convenience store with the proceeds going to the ACDA. They sold 190 out of 250 books they had. Once all of the books are sold, **the Murrays will be making a \$500 donation to the ACDA in honor of Callie who had ACDMPV and Cole who is also an angel but did not have ACDMPV.**



## REPORT FROM THE DAVID ASHWELL FOUNDATION:

I am going to start this report with a request...Can I please ask all the 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. With the run up to Christmas, please (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).

Over the summer friends of Jo and Chris (parents of Alex Taylor-Coe) raised £301 (\$391) by having a BBQ. We continue to be moved by people's generosity and kindness.

I (Amelia) will hold another ceilidh for David's 6<sup>th</sup> birthday on 4<sup>th</sup> March 2017 repeating the fun event I organised last year, which raised over £5000 for ACDMPV Research. Another example of some (small scale) fundraising I've been doing is selling my maternity clothes and baby items on ebay and facebook selling sites and donating it to the charity.

**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 ACD/MPV research.

Thank you to all who have used The David Ashwell Foundation to fundraise in memory of their precious child. Our current total is **£11,216 (\$14,597)**. Since David died in March 2011, The David Ashwell Foundation has raised £166,882 (\$217,180). [Please note there was an error in Amelia's Spring report!]

For additional information, please contact Simon and Amelia.

**Website:** <http://David Ashwell Foundation>  
**Email:** [davidashwellfoundation@yahoo.co.uk](mailto:davidashwellfoundation@yahoo.co.uk)  
**Twitter:** [@TDavidAshwellF](#)  
**Mobile (Amelia):** 07855473686





[illegible]

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

[illegible]

\_\_\_\_\_

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>



## Safe Arrivals!

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

- [REDACTED]
- [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](http://acdassociation.org)

### Email:

[President@acdassociation.org](mailto:President@acdassociation.org) (Steve Hanson)  
[Secretary@acdassociation.org](mailto:Secretary@acdassociation.org) (Eliza Rista)  
[Treasurer@acdassociation.org](mailto: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](mailto:Secretary@acdassociation.org).

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

