

# ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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In October 2018, the ACDA organized a photo project in honor of Pregnancy and Infant Loss Awareness month. Please see pages 4-7 for the completed project and view it online [here](#). In addition, we invite all of our ACDA families to participate in the ACDA Wave of Light on Pregnancy and Infant Loss Remembrance Day. On **Monday, October 15 at 7:00 p. m.** in your respective time zone, **please share a photo of your candle** on the ACDA Facebook page to create an ACDA Wave of Light. Please also use the public forum to share your child's name or special memory in the comments. The ACDA Wave of Light provides a time for quiet remembrance and reflection and is a powerful worldwide experience in honor of our loved ones. #WaveofLight #ACDAWaveofLight

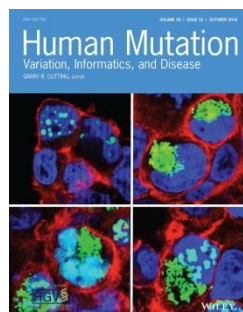
Please click [HERE](#) to "Like" our public Facebook page and join the ACDA Wave of Light.

Regards, Eliza Rista, President



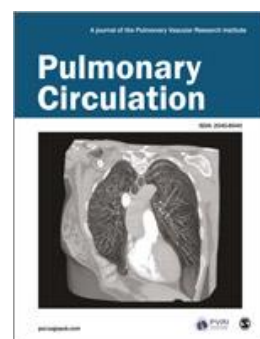
## RESEARCH NEWS

### Journal Article (Human Mutation):



The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently published a manuscript entitled “*LINE- and Alu-containing genomic instability hotspot at 16q24.1 associated with recurrent and nonrecurrent CNV deletions causative for ACDMPV*” in Human Mutation, which can be found [HERE](#). This paper shows the genomic structures predisposing the FOXF1 locus to DNA breaks, resulting in pathogenic deletions and ACDMPV.

### Journal Article (Pulmonary Circulation):



The team at Sophia Children's Hospital and Erasmus University Medical Center in Rotterdam, The Netherlands recently published a manuscript entitled “*Alveolar capillary dysplasia with misalignment of the pulmonary veins: clinical, histological, and genetic aspects*” in Pulmonary Circulation, which can be found [HERE](#). This paper provides an overview of the clinical aspects of ACDMPV, including guidance for clinicians, and reviews the ongoing research into the complex molecular mechanism causing this severe lung disorder.

### Genetic Testing (updates):



Since 2001, the ACDA has supported ACDMPV research at Baylor College of Medicine in Houston, Texas, USA. The ACDA encourages

all newly registered members to donate DNA and tissue samples to the ACDMPV research team at Baylor in order to keep all known samples in one central location and database. As such, Baylor has accumulated the largest collection of DNA and tissue samples related to ACDMPV in the world.

In 2014, Baylor investigated the issue of somatic mosaicism in the transmission of genetic diseases. Somatic mosaicism describes the situation where an individual has more than one type of genetic material in their body (e.g. both normal and abnormal copies of a gene). This arises due to mutations as our cells divide. Conventional genetic tests often fail to find somatic mosaicism as it is often low-level (sometimes <1% of DNA) and thus very difficult to detect. In theory, this could result in children with genetic diseases from parents with apparently normal DNA being labelled incorrectly as having a new ‘*de novo*’ genetic abnormality.

Baylor routinely tests with PCR sensitivity for low-level somatic mosaicism in parents of ACDMPV infants with FOXF1 related **deletions**.

The lab has been unable to test for somatic mosaicism in the parents of ACDMPV infants with a FOXF1 **mutation** due to unreliability of this test at such levels. However, Baylor has been working on a more sensitive method for mutation testing (approaching PCR sensitivity) and hopes to introduce the more sensitive mutation testing later this year or early next year.





## 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** saying, “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, 2018 – Pregnancy and Infant Loss Remembrance Day

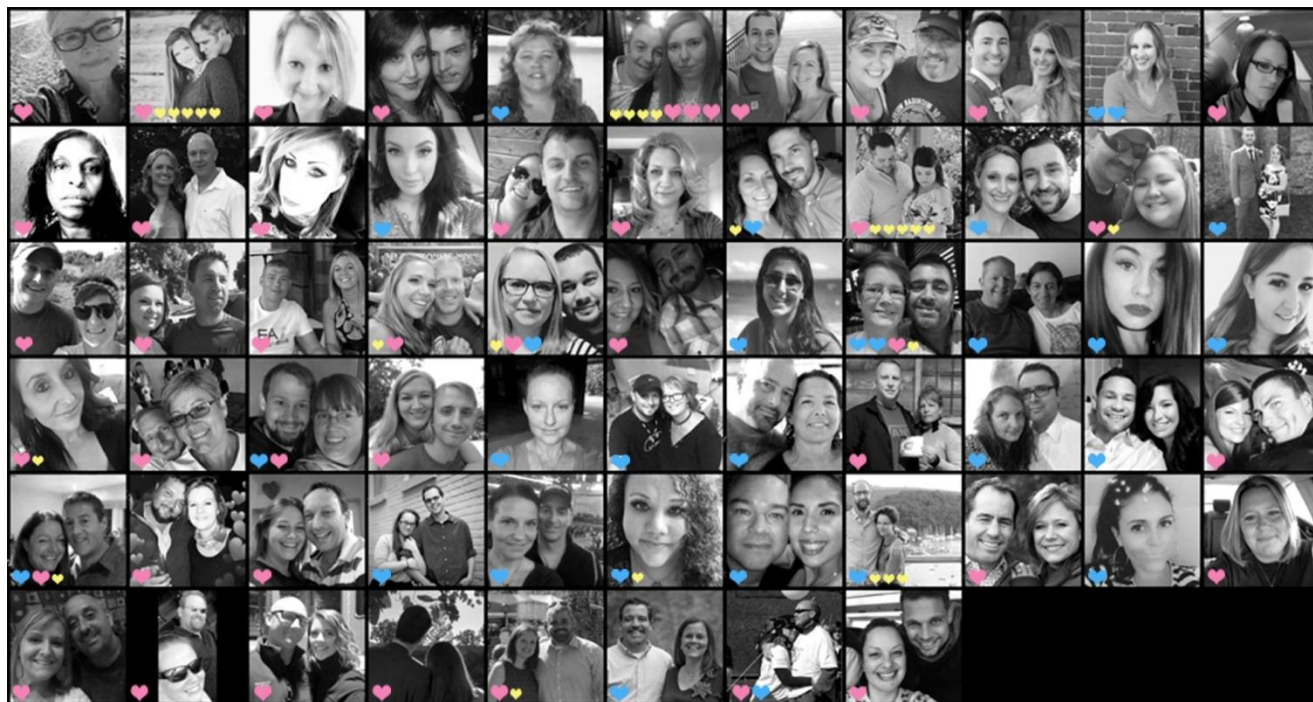
October 15 is Pregnancy and Infant Loss Remembrance Day. The day is observed with ceremonies and candle-lighting vigils, concluding with the International Wave of Light; a worldwide lighting of candles. **The International Wave of Light invites participants from around the world to light a candle at 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.**





## AWARENESS NEWS

### ACDA Photo Project: October 2018



*"When you can't look on the bright side,  
I will sit with you in the dark."*

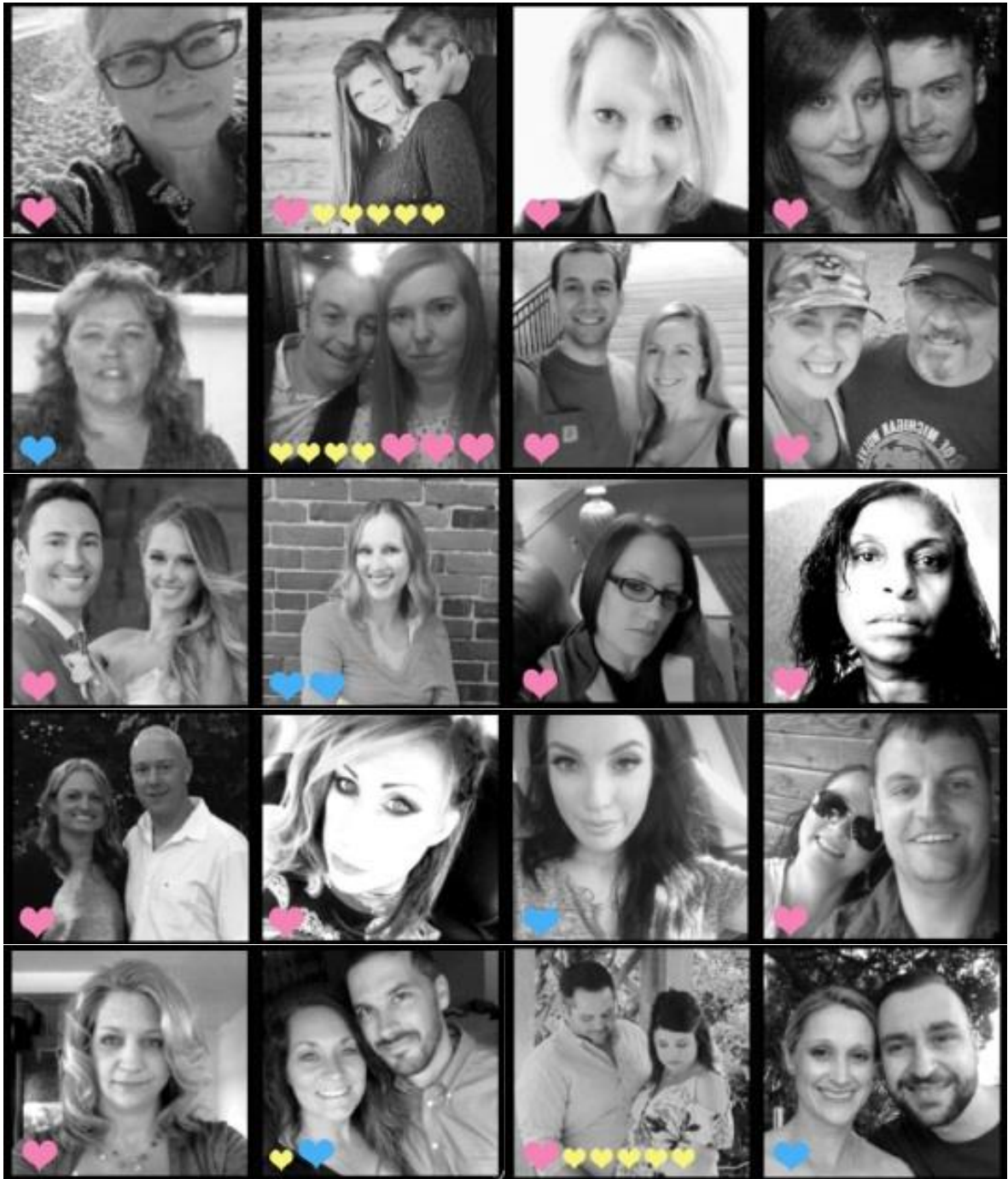
In October 2018, the ACDA organized a photo project in honor of **Pregnancy and Infant Loss Awareness month**. Projects in prior years have included collages of our babies, luminaries and calligraphy. **This year we are focusing on bereaved parents.** Each photo portrays an ACDA parent living with heartbreak. The pink hearts represent the loss of a baby daughter and the blue hearts signify the loss of a baby son. The yellow hearts symbolize pregnancy loss through miscarriage. We encourage you to take a moment to look through the photos and reflect on the loss endured by each of these parents and their respective families, friends and loved ones.

*"For those who understand, no explanation is needed; for those who do not understand, no explanation is possible."* The purpose of this photo project is to show what grief looks like on so many different faces and to see a wall of strength of bereaved parents honoring and remembering their babies, together. When you provide unconditional support to any of these parents, you are shining a light for us all.

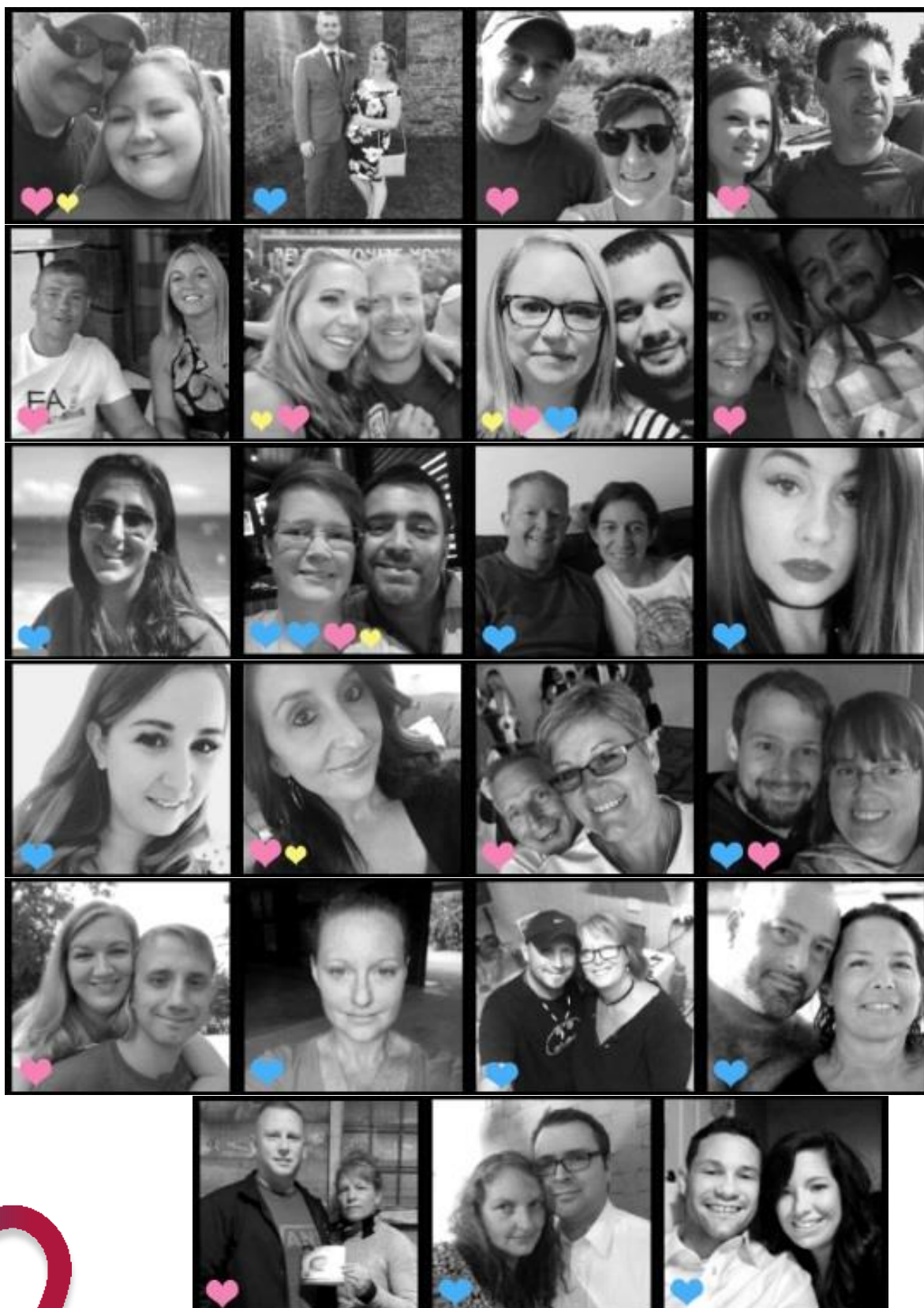
[photo project continues on following pages]

















## University of Florida College of Medicine presentation (Christopher Locke):



Diana Locke, a Registered Nurse and ACDA mom to Christopher (November 7, 2006 - December 17, 2006) gave her annual presentation to 160 first year medical students at the University of Florida College of Medicine in Gainesville, Florida, USA on August 14, 2018. The presentation focused on ACDMPV, Christopher's case and other ACDMPV babies. With this program, future doctors now know about ACDMPV.

Diana shared that the medical students were wonderful again this year with so many good questions! Diana plans to expand her presentation by reaching out to her contacts at Huntsville Hospital, which is a teaching facility for the University of Alabama-Birmingham's School of Medicine. Early in her nursing career, Diana worked with the Chief Nursing Officer at Huntsville Hospital for Women & Children and Diana's relative is a close contact of the CEO.

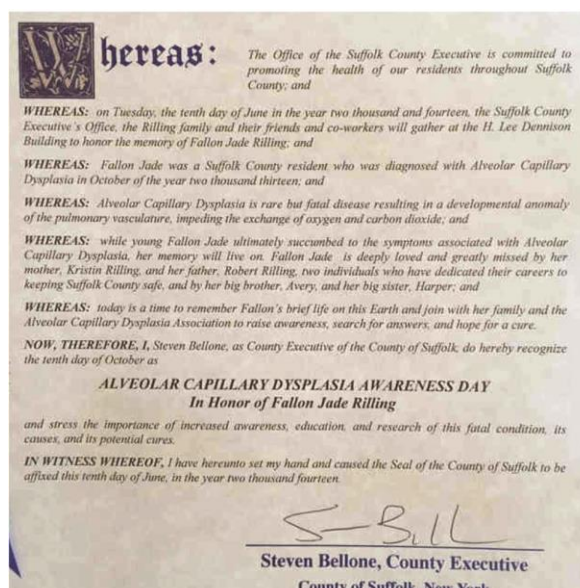
The ACDA appreciates Diana's teaching presentations to future medical professionals and looks forward to hearing about the expansion.

## Lights in Suffolk County (Fallon Rilling):



On October 10, 2018, the H. Lee Dennison Building in Suffolk County, New York, USA was once again lit purple to raise awareness for ACDMPV in honor of the fifth birthday of Fallon Rilling (October 10, 2013 – October 21, 2013). In 2014, Suffolk County officials declared every October 10<sup>th</sup> as "ACD Awareness Day" in Suffolk County, New York in honor of Fallon. As such, the county executive building has been lit each year to promote ACDMPV awareness.

The ACDA is infinitely grateful to the Rilling family for their incredible awareness and fundraising efforts.



**Proclamation in 2014 declaring every October 10<sup>th</sup> as ACD Awareness Day in Suffolk County, New York**





### **British Transplant Games (Imogen Bolton):**



Imogen Bolton's story remains in the headlines in the UK and beyond! We introduced you to Imogen as an ACDMPV survivor in the UK and Europe's smallest lung transplant recipient (see Issues #56, #58 and #61 of ACDA Notes). For a listing of articles featuring Imogen, please click [HERE](#) and also click [HERE](#) to follow Imogen's story on Facebook. **Imogen will**

**celebrate her third birthday in November 2018!**

Most recently, Imogen participated in the British Transplant Games 2018 in Birmingham. Imogen competed for GOSH Heart and Lungs and was the youngest participant in the entire competition. Imogen was sponsored for her efforts in the bean bag race, archery, 25M race and long jump competitions and raised a substantial sum of money directly for the heart and lung transplant team at GOSH that saved her life in 2016.



The British Transplant Games are the largest national charity in England promoting active recovery for transplant recipients and increasing awareness of the benefits of organ donation. Their aim is to raise awareness of the need for organ donation, encourage transplant recipients to lead active lifestyles, and show appreciation for and remember donors and their families.

### **Marks & Spencer (UK):**

In the UK, MARKS & Spencer launched a special t-shirt and candle to show its support for Baby Loss Awareness Week, which takes place in the UK from October 9-15. It's designed by one of the shop's buyers personally affected by loss and features the logo of a small red heart inside a bigger one. The tee is £9.50 and the candle can be purchased for £6. The store will also be donating £15,000 to the Baby Loss Awareness Week charity.



### **Classical Music:**

Angela Riley, ACDA mom to Ava (March 02, 2011 – March 12, 2011) recently shared a classical music selection composed by Antonín Dvořák. He wrote the piece for himself in the wake of multiple child loss, which masterpiece premiered in 1880. "It takes listeners on an emotionally honest journey through grief to spiritual healing, concluding with a radiant, optimistic ending." Please click [here](#) to read more and listen to the piece.

### **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>

At the quarterly ACDA Board of Directors meeting in September 2018, Eliza Rista, Renee Murray and John Rista were unanimously reelected to serve as President, Secretary and Treasurer, respectively, of the ACDA Board of Directors until August 2019.





**Donations:**

[acdassociation.org/donate](http://acdassociation.org/donate)

**Balance of ACDA account:**

**Update from AmazonSmile:**

**Update from Spreadshirt:**

at our store as new items and new features are added regularly. You have the option to customize your products by choosing "Create," including adding your child's name or picture to most items featuring the ACDA logo. Don't forget the ACDA earns a commission equal to **20% of every product sold!** **Look for FREE SHIPPING from October 22-24, 2018!** (Use code: SHIPFREE18)

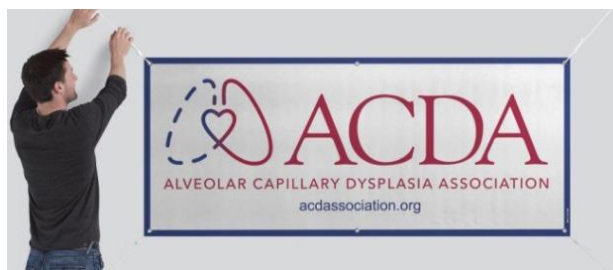
Thank you to the following families and friends that have made donations to the ACDA since the last ACDA Notes:

[illegible]

ALVEOLAR CAPILLARY DYSPLASIA | ACDA Notes



### Banners:



If you would like to request use of a banner for a fundraising or awareness event in the United States, please send an email to [president@acdassociation.org](mailto:president@acdassociation.org) to discuss sign-up for availability and shipping information.

### Brochures:

View, save, email or print your own copies of the ACDA brochure; click for [ENGLISH](#), [DUTCH](#) or [ITALIAN](#). (German coming soon!)

### Fundraising Idea (EASY!!):



Please consider participating in the ACDA's **fourth annual coffee fundraiser** this holiday season through [Giving Bean](#). In addition to "online" purchases with **25%** of every bag sold online donated to the ACDA, "in-person" sales can also easily be organized with **40%** of such in-person sales contributed to the ACDA!

Additionally, the ACDA logo is printed directly on the coffee bag label if more than 50 bags are ordered through such in-person sales.

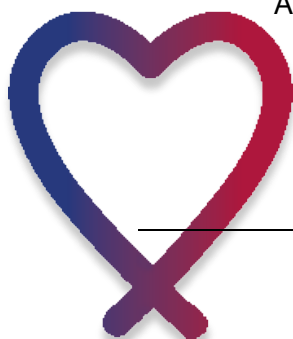
**Please contact us to get involved!**

#GIVINGTUESDAY™  
November 27, 2018  
DONATE

It seems the holiday season begins earlier every year, but the frenzy of shopping truly launches the day after Thanksgiving, commonly known as #BlackFriday. As more and more people began to turn to online shopping, #CyberMonday emerged too. Although all this shopping is done in the name of giving gifts to loved ones, it sometimes feels like the goodwill of the holiday season fades into the background. In 2012, a few nonprofit professionals decided to do something about it and raised over \$10 million in the inaugural event. But Giving Tuesday was just getting started. By 2016, the giving day raised over \$177 million online and over \$300 million online in 2017!

- **What:** A global day of giving
- **When:** The Tuesday following Black Friday
- **Where:** Everywhere. Organizations all over the world participate

**The biggest giving month of the year is right around the corner. In fact, about a third of all charitable giving happens in December. Please help us successfully kick off the holiday giving season by promoting the #GivingTuesday campaign on November 27, 2018 in support of the ACDA.**





### **GoFundMe (XzendriaSwenson):**

Vanji Unruh, ACDA mom to Xzendria Swenson (July 27, 1998 – August 8, 1998), recently organized a [GoFundMe](#) to raise money for ACDMPV research in honor of Xzendria. In Vanji's own words, "Alveolar Capillary Dysplasia with Misalignment of

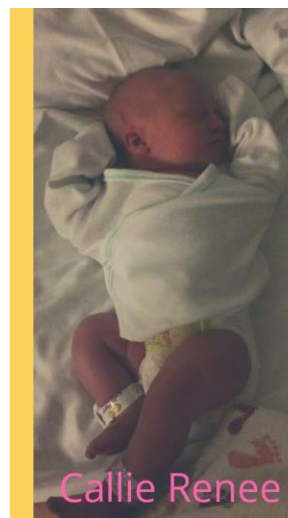


Pulmonary Veins (ACDMPV) stole her from us. ACDMPV stole Xzendria's life, her knowing her little sister Lyvia, now 21 years old. It stole from Xzen knowing her cousins, her grandparents, aunts, uncles and tons of more cousins. It stole from Xzen having her own dreams for a future, experiencing happiness, and having children of her own. ACDMPV also stole our dreams for Xzendria Leigh, our precious and very wanted & loved daughter...The Alveolar Capillary Dysplasia Association's (ACDA's) fundraising and donations have made a real impact by funding medical research grants, and advocating understanding and awareness for this rare disease. Without \$\$ donated by persons like you, there would still be no testing, no gene identification, and no hope for these babies or their families."

**Vanji raised almost \$1,000 through the GoFundMe campaign in Xzendria's honor.**

The ACDA extends its heartfelt thanks for this very generous donation for ACDMPV research.

### **Norwex party (Callie Murray):**



**Norwex party  
tonight at 8:30!  
Join the fun and  
help us raise  
money for the  
Alveolar Capil  
lary Dysplasia  
Association**

Renee Murray, ACDA mom to Callie (May 15, 2015 – May 23, 2015) hosted an online Norwex party on August 22, 2018 and **donated 20% of the profits to the ACDA in honor of Callie!**

### **Fundraiser (Billie Paras):**

Genesis Paras, mom to Billie (April 14, 2018 - April 16, 2018), joined the ACDA community in May 2018. A second opinion by Baylor's pathologist later revealed her precious daughter, Billie, did not have ACDMPV. However, Genesis was welcomed with open arms and is, and *always* will be, a special part of the ACDA community. Even more extraordinary, Genesis' entire family remains dedicated to the cause of ACDMPV funding and research. **Genesis' brother, Brandon Martinez, raised \$130 for his birthday for ACDMPV research in Billie's honor.** Genesis also plans to dedicate a walk in October for children with ACDMPV and shared she would like to do as much as possible to spread awareness. The ACDA is profoundly touched by this family's continued involvement with the ACDA on behalf of Billie.





## REPORT FROM STICHTING ACD (NETHERLANDS):

STICHTING ACD 

Mathijs Lourens, ACDA father to Myla (November 20, 2015 - December 17, 2015), continues his amazing work in support of his Dutch ACDMPV foundation, "[Stichting ACD](#)."



Mathijs trained hard with focus and determination for many months in order to expand his marathon adventure across the border. For his first foreign marathon, he planned to run the **marathon in Cologne, Germany on October 7, 2018** to raise ACDMPV awareness in Germany. Despite his best efforts and tremendous optimism, a significant cold mandated that Mathijs sit out this marathon. Mathijs previously completed the Rotterdam Marathon (April 2017 and April 2018) and the Amsterdam Marathon (October 2017) and plans to run marathons for ACDMPV awareness in Europe and then worldwide. Look for Mathijs' team in Amsterdam on October 21, 2018 for the KidsRun and the Rotterdam 2019 marathon! For additional information, please visit [Run4ACD](#) on Stichting ACD's website. **Please contact Mathijs if you are interested in participating or cheering on his upcoming plans!**

Below, please read Mathijs' thoughts in his own words about why he is inspired to run marathons, as written in August 2018 during his training for the Cologne marathon (please excuse translation errors made by the ACDA):

"A friend once told me, "Every marathon runner has a story." That's what I think. That's how I have my story, and so many times I hear, "How nice that you can handle your grief this way." Wrong!

In this way, I give shape to the life of Myla in a special way. I'm still running the lungs out of my body for Stichting ACD. That has become my higher goal. But why? I've lost loved ones to cancer, people around me seen with cancer and had cancer myself. Enough leads to put me in for that, for example.

I have chosen to commit myself to the fight against ACD, of course, because it affects our family personally, but also because rare diseases are often the poor children in the medical world. Little to no investigation because...no money can be earned? There's not enough honor to be gained? Not enough babies to die? Tell that to the parents of those babies! Even the rare diseases deserve a place on the medical agenda, and that is what I do every day.

I will continue to do so as long as I am satisfied and I continue to believe in a good result. My goal is to get a phone call from the hospital on a beautiful day with the announcement that a solution has been found for this nasty disease! That drives me back every day to get over that threshold for another 25 km of run, because you bet I still feel that threshold.

In 7 weeks, it'll be ready. Then marathon number 4 is on the program. This time in Cologne. But also in Amsterdam we will be present on 21 October with the KidsRun as its main objective. There are also notifications for the Rotterdam 2019 Marathon! And that makes me proud, and I'd like to see our teams expanded even further. I'm willing to do the heaviest work, but I can't do it alone. All small and large pieces help to get a bigger voice in the medical world. **We've already achieved quite a bit, but we're not there yet!**"





## REPORT FROM THE DAVID ASHWELL FOUNDATION:

Has anyone else has noticed on Facebook (in the UK) there has been a real move to have a *more 'meaningful' Christmas*? Rather than give unwanted gifts to try to do something positive. If you are going to give gifts **please, please use The Giving Machine** – as you shop you can give for free! **Watch [HERE](#) how it works.**

I have the giving machine app on my phone and it makes giving as I shop so easy. It's very quick and easy to **sign up [HERE](#).**

In your workplace you could suggest donating to The David Ashwell Foundation rather than giving gifts or Christmas cards. On our Virgin Money Giving pages, set up a page in for your precious baby/ child and encourage people to donate there.

We are here to help UK families fundraise for ACDMPV research so that we can help to find answers to the condition that has become such a major part of our lives.

Simon and I run this as well as working and bringing up our children, Auden and Faye. We are very, very grateful to anyone who uses this charity in memory of their precious babies. Thank you especially to those who have a standing order and put money into The David Ashwell Foundation charity bank account each month (ACDMPV and non ACDMPV families).

Still, on my (very long) to-do list for autumn is to enrol local schools and universities to take part in Rare Disease Day 2019 to make sure we get it into school calendars.

In May 2018 we transferred £16,221 (\$21,332) to the ACDMPV research fund at NORD.

Since March 2011 **£199, 218 (\$263,605)** has been raised for ACD Research by families in the UK and Europe. This has contributed to the funding raised internationally to the ACDA. We are always very enthusiastic to raise more money for ACD research and would appreciate any help!

At the moment not many people are using The Giving Machine. Please, UK families can you 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! It's very quick and easy to **sign up [HERE](#).**

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.
2. Fundraise while you online shop ([The Giving Machine](#)) (a percentage of what you spend is donated)
3. Collect [postage stamps](#)

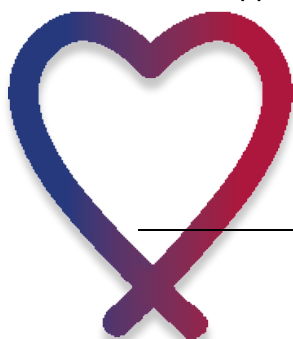
**All UK & Europe based families** are welcome to use The David Ashwell Foundation as a means of fundraising for ACDMPV Research. Please raise awareness of our small charity via social media including Twitter and Facebook.

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.

For additional information, please contact Simon and Amelia.

**Website:** <http://DavidAshwellFoundation>  
**Email:** [davidashwellfoundation@yahoo.co.uk](mailto:davidashwellfoundation@yahoo.co.uk)  
**Twitter:** [@TDavidAshwellF](https://twitter.com/TDavidAshwellF)  
**Mobile (Amelia):** 07855473686





## REMEMBERING OUR BABIES

[REDACTED]

[REDACTED]

[REDACTED]

## Welcome to New Families

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

[REDACTED]

[REDACTED]

**As of October 1, 2018**, the ACDA is starting a new pilot program to welcome new members. In addition to the welcome email correspondence and attachments currently provided by the President, a physical welcome package containing ACDA and bereavement materials will now be mailed to the home address of newly registered members in the USA and possibly abroad. During the pilot period, the physical welcome package is being funded and organized by Candice McCasland, ACDA mom to Sadie (Feb 5, 2014 – Feb 19, 2014). Please look for updates in future newsletters.





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

[illegible][illegible]

**Facebook:**

- [Official ACDA Public Page](#)
- [Parent Group](#) (private)
- [Family Group](#) (private)

Read about the private groups 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) (Eliza Rista)

**[Secretary@acdassociation.org](mailto:Secretary@acdassociation.org)** (Renee Murray)

**Treasurer@acdassociation.org** (John Rista)

**A note from the President:** 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 [President@acdassociation.org](mailto:President@acdassociation.org).

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

