We hope all of our ACDA families will participate in the **ACDA Wave of Light** on Pregnancy and Infant Loss Remembrance Day (see page 2 for details). The Wave of Light provides a time for quiet remembrance and reflection and can be a powerful experience for bereaved families, friends and loved ones.

On **Sunday, October 15** at 7:00 p.m. in your respective time zone, please share a photo of your candle on the ACDA public Facebook page to create an ACDA Wave of Light. Please also use the public forum to share your child’s name or special memory.

During the ACDA Wave of Light, please also look for the luminary bags displaying names requested by parents in the “ACD Parent Group” on Facebook. All parents who have lost a child to ACDMPV or whose child has been diagnosed with ACDMPV are encouraged to join this active and private Facebook group.

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

Regards,
Eliza Rista, President
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, 2017 – 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.
#SharingOurBabiesStories (Hannah Miller)

“Pregnancy After Loss Support” is running a series entitled #SharingOurBabiesStories this October for Pregnancy and Infant Loss Awareness Month. Our very own Jessica Miller, ACDA mom to Hannah (Dec 4, 2013 – Dec 10, 2013), was featured on October 1, 2017. Below are the beautiful words this Courageous Mama wrote to describe life as Hannah’s mother.

I am Hannah’s Mom:

I am a mother of three beautiful babies (and a fur baby), although on the outside I look like I only have two little ones. I hold my firstborn, Hannah, in my heart endlessly. It’s been almost four years since I fell in love with Hannah. She was born with a very rare and fatal lung disorder called Alveolar Capillary Dysplasia. After fighting for six days, she lost her battle and remains in my heart until the day we meet again. In these four years, I have endured incredible heartbreak but I have also rekindled my love of life when I had Hannah's little brother and sister.

Parenting is so challenging but parenting a child who is no longer on this earth is incomparable. Navigating through life after loss is complex, messy, uncontrollable and mostly, intense. Some days, tears of happiness roll down my face and some days, I feel trapped under a black cloud. Parenting after loss can be so emotional - it can blind side you in a second, it can turn your day around with an innocent trigger, it can bring you to your knees. Yes, even after four years.

Hannah’s short but powerful life often replays in my head - sometimes I can smile at the memories we made and sometimes regret overcomes me with all the things I wish I had did differently and sometimes I am brought right back to the day she passed away.

These memories replay in my mind often. As much as people think I have "moved on", the death of my child is prevalent in every aspect of my life. Every milestone my living children have, makes my heart swell with pride and gratitude but also heartache. Parenting my children is so incredibly bittersweet and will continue to be for the rest of my life. I often cannot grasp the words to express what life after loss is like. I can only hold my living children extra close, kiss them with those sweet kisses I wish I could give to Hannah and honour their big sister in the best way I can. My grief journey is always evolving. I will always miss my daughter but perhaps the most painful aspect of time passing is that other people forget. Every parent wants their children to be acknowledged and loved but when that child dies, people have the misconception that you will eventually get over that death.

This month is about the babies gone far too soon. It's time for friends, family, and the community to come together and acknowledge these babies very precious lives. All it takes is to mention their name in love and tell that parent that their child did make an impact on them and this world. Please join me in remembering my daughter and all of the children who are loved wholeheartedly in our hearts instead of our arms.
AWARENESS NEWS

Lights in Suffolk County (Fallon Rilling):

On October 10, 2017, 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 fourth birthday of Fallon Rilling (October 10, 2013 – October 21, 2013). The ACDA is infinitely grateful to the Rilling family for their incredible awareness and fundraising efforts.

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 142 first year medical students at the University of Florida College of Medicine in Gainesville, Florida, USA on August 18, 2017. The presentation focused on ACDMPV, Christopher’s case and other ACDMPV babies. With this program, future doctors now know about ACDMPV. Below please read a touching thank you note received by Diana from an attendee in UFCOM Class of 2021.

UPDATE FROM “STICHTING ACD” IN THE NETHERLANDS:

Mathijs Lourens, ACDA father to Myla (November 20, 2015 - December 17, 2015), is running the Amsterdam marathon on October 15, 2017 in support of his Dutch ACD foundation, “Stichting ACD.” Please contact Mathijs if you would like to cheer for Team Myla during the Amsterdam marathon this Sunday to raise awareness for ACDMPV!

The ACDA sends our very best to Mathijs and the team of Stichting ACD runners in Amsterdam. We look forward to providing pictures and an update in the next newsletter!

Please click HERE to read more (in Dutch) about Myla’s story and Mathijs’ remarkable contributions, as published in Kind & Zorg on September 20, 2017.
LUNG TRANSPLANT UPDATES:

**Lung Transplant Update (Imogen Bolton):**

Imogen Bolton’s story remains in the headlines in the UK and beyond! Most recently, Imogen was featured in the latest issue of *Woman Magazine* in the UK. We introduced you to Imogen as an ACDMPV survivor in the UK and Europe’s smallest lung transplant recipient (see Issues #56 and #58 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 second birthday in November 2017!**

**Lung Transplant Update (Luca Palmisano):**

Luca Palmisano continues to make news! As you may recall, Luca received a lung transplant in November 2016 at 4.5 months old at Children’s Hospital of Philadelphia (CHOP) in the USA (see Issues #57, #58 and #59 of ACDA Notes). Now CHOP is describing Luca’s experience in their Lung Transplant Program. Click [HERE](#) to read the article published on CHOP’s website on September 19, 2017. In the words of Luca’s mom, Ashley Palmisano, “Thank you Children’s Hospital of Philadelphia for saving his life and sharing his story!!!”

The Palmisano family was also recently featured in a video that played at a live auction and golf fun day on September 18, 2017. The event was hosted by Fred’s Footsteps, which is a charity that provides family financial support in the Philadelphia region to those struggling with the cost of caring for a seriously ill, injured, or disabled child. Ashley and Thomas spoke at the event as well. To watch the moving video featuring their family, please click [HERE](#).

Finally, in honor of Luca and his battle with ACDMPV, Team Luca is throwing a 5k!

Where: Mercer County Park - West Picnic Area
Paxson Ave.
West Windsor Twp. 08550

When: Sunday, November 5th 2017, 9:30am

You can follow Luca’s Lung Transplant Story [HERE](#). #teamluca
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.

Balance of ACDA account:

The balance of the ACDA bank accounts as of October 13, 2017 is [XXXXX].

Update from AmazonSmile:

The ACDA was issued a [XXXXX] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between April 1 and June 30, 2017. 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 memorial contribution was made. Please contact us to let us know.

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] to discuss sign-up for availability and shipping information.
Coffee for Callie (Callie Murray):

COFFEE FOR CALLIE

25% of each bag purchased goes to the Alveolar Capillary Dysplasia Association

PLACE YOUR ORDER TODAY!

Warm up with a cup of coffee, tea, or hot chocolate from Giving Bean this fall and winter and support the ACDA! #coffeeforcallie #acda

“Did you know October is National Pregnancy and Infant loss awareness month? This is obviously a cause very near and dear to our hearts. We are selling roast-to-order coffee, tea, and more through Giving Bean again this year. Many of you ordered two years ago as this was our first fundraiser after Callie passed. It’s very good! We are repeat customers and haven’t been disappointed with any coffee, tea, or hot chocolate. 25% of every bag sold online will go to the Alveolar Capillary Dysplasia Association. The ACDA funds critically important research to make advances in this rare disease and hopefully one day a cure! Order yours today and help us raise funds and awareness!! Ordering is so easy! Just click the LINK, make your choice, and it will be at your door in no time! Feel free to share! Thanks all, The Murrays”

FUNDRAISING IDEA: Please consider participating in the ACDA’s third annual coffee fundraiser this holiday season through Giving Bean. In addition to the “online” purchases described above, “in-person” sales can also easily be organized with 40% of such in-person sales going 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 28, 2017
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.

• 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 28, 2017 in support of the ACDA.
REPORT FROM THE DAVID ASHWELL FOUNDATION:

I would like to thank the families who have a standing order and put money into The David Ashwell Foundation charity bank account each month (ACDMPV and non ACDMPV families) and individuals who chose to donate to the charity in memory of a loved one.

Since March 2011, £181,327 ($243,630) has been raised for ACDMPV Research by families in the UK and Europe. This has contributed to the funding raised internationally to the ACDA. In these 6 years, the ACDA and TDAF have funded 6 research grants. Sometimes I think it is worth pausing and thinking about this, thankfully we are not many – and look what we have and are achieving. Thank you all for your support. Some fundraising news....

Over the summer we have been selling on eBay some new Rapha cycling kit which was donating, raising approx £600 ($806).

I am about to start planning the 3rd ‘Ceilidh for David’ in Stokesley (it’s on Saturday 3rd March 2018 in case anyone would like to attend/ help!)

If anyone wants to organize a fundraiser please let me know – I am happy to support! Ideas might be to host an Usborne book party, Tupperware party, etc. and donate the commission to TDAF… handy with Christmas nearly on us!

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 raise in memory of their precious child.

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

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

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
Safe Arrivals!

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

CONNECT WITH US

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

Email:
- President@acdassociation.org (Eliza Rista)
- 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.

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