In October 2020, the ACDA created a written word project in observance of Pregnancy and Infant Loss Awareness month. Please see page 3 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 Thursday, 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

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, 2020 – 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.
In October 2020, the ACDA created a written word project for Pregnancy and Infant Loss Awareness Month. Projects in prior years have included collages of our babies, a photo project of bereaved parents, memorial wall, luminaries and calligraphy.

This year we are focusing on grief over time. The purpose of this written word project was to paint a picture of grief at different moments in time as experienced by our ACDA parents, whether it be the profound sadness of the first anniversary of loss or grappling with decades old fears in anticipation of the birth of a first grandchild. While compiling this project, we began to notice a common theme and words that were applied universally by our parents regardless of when their loss had occurred. Words like Always. Love. Child. Will. Time. Never. You can see these prominent words reflected in the word cloud generated from a compilation of the individual quotes above. We encourage you to take a moment to read through the quotes and reflect on the lives of these precious children and the heartbreaking loss endured by their respective families, friends and loved ones.

Please go HERE to learn how to participate in the ACDA Wave of Light on October 15, 2020. #WaveofLight #ACDAWaveofLight
On October 10, 2020, 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 seventh birthday of Fallon Rilling (October 10, 2013 – October 21, 2013). In 2014, Suffolk County officials declared every October 10th 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 throughout the years.

## LUNG TRANSPLANT UPDATES

### Lung Transplant Update (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, #61, #65 and #68 of ACDA Notes). For a listing of articles featuring Imogen, please click [HERE](#) and also follow Imogen’s story on Facebook [HERE](#). Imogen will celebrate her fifth birthday in November 2020!

Imogen started school in September 2020 and her family has been busy spreading her story throughout the UK and raising awareness for ACDMPV and organ donation. Please be sure to watch the news video below where Hayley Bolton, ACDA mother to Imogen, is joined by Amelia Ashwell, ACDA mother to David (March 4, 2011 – March 19, 2011).

(see news clippings on following page)
“Youngest girl in UK to have lung transplant has first day at school”
**The Argus**, September 9, 2020

“Girl enjoys her first day at school thanks to the gift of life from her ‘guardian angel’”
**Daily Express**, September 24, 2020

“Youngest lung swap girl hits a new milestone”
**Daily Mirror**, September 28, 2020

Hayley Bolton, ACDA Mother to Imogen, interviewed and joined by Amelia Ashwell, ACDA mother to David (March 4, 2011 – March 19, 2011)
**ITV News, Meridian**, September 29, 2020
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.

[link to website]

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 2021 NORD grant is $35,000.

Balance of ACDA account:

The available balance of the ACDA bank accounts as of October 13, 2020 is [amount].

Update from AmazonSmile:

The ACDA was issued a [amount] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between April 1 and June 30, 2020. To date, AmazonSmile has donated a total of [amount] to the ACDA. To designate the ACDA as your charity, please follow the link below so that all of your eligible shopping will benefit the ACDA: [link to AmazonSmile].

Update from Spreadshirt:

Our Spreadshirt store was recently REORGANIZED and REFRESHED with NEW products so be sure to check it out! Items with the ACDA logo are available for purchase in our Spreadshirt store [link]. The accrued commission payment from Spreadshirt between August 2, 2020 and October 1, 2020 is [amount]. Please continue to shop 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 20% off everything on October 21-22, 2020!

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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<th>In Memory Of</th>
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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.

Brochures:

View, save, email or print your own copies of the ACDA brochure; click for [link to website].
Fundraising Idea (SO EASY!!):

Please consider participating in the ACDA’s sixth 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” and paperless express 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 or paperless express sales. Please contact us to get involved!

Matching Gifts:

1. YOU DONATE.
2. THEY MATCH.
3. DOUBLE THE IMPACT.

Don’t forget about Matching Gifts – If your employer has a Matching Gifts Program for charitable organizations, your contributions to ACDMPV research can grow! Please check with your Human Resources department. The ACDA Tax Identification Number is 46-2915711.

The ACDA extends our sincere thanks to AMC Theaters, Bank of America, Chevron, Goldman Sachs, Schneider Electric, Tokyo Electron and Verisk Analytics for their matching gifts for ACDMPV research!

#GIVINGTUESDAY

December 1, 2020

DONATE

GivingTuesday is a global generosity movement unleashing the power of people and organizations to transform their communities and the world. GivingTuesday was created in 2012 as a simple idea: a day that encourages people to do good. Over the past seven years, it has grown into a global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity. The ACDA raised $1,600 (2017), $2,630 (2018) and $2,500 (2019) on this one day alone!

• What: A global day of giving
• When: The Tuesday following Black Friday (December 1, 2020)
• 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 giving season by promoting the #GivingTuesday campaign on December 1, 2020 in support of the ACDA.
In September 2020, Georgia Easter, mother to Leah (January 2, 2020 – February 3, 2020), organized a birthday fundraiser for **ACDMPV research in honor of Leah Mckenna Botton**. In Georgia’s own words, “For my birthday this year, I’m asking for donations to Alveolar Capillary Dysplasia Association. I’ve chosen this charity because their mission means a lot to me, and I hope that you’ll consider contributing as a way of celebrating with me. Every little bit will help me reach my goal. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder.”

In September 2020, Tyler Bone, father to Barrett (June 14, 2019 – July 12, 2019), organized a birthday fundraiser for **ACDMPV research in honor of Barrett Bone**. In Tyler’s own words, “For my birthday this year, I’m asking for donations to Alveolar Capillary Dysplasia Association. I’ve chosen this nonprofit because their mission means a lot to me, and I hope you'll consider contributing as a way to celebrate with me. Every little bit will help me reach my goal. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder.”

**Here’s how to set up a birthday fundraiser on Facebook!**
**Birthday Fundraiser (Barrett Bone):**

Kelli is over halfway to her $200 goal (with two weeks left to donate!) through a Facebook birthday fundraiser in honor of Barrett Bone. Thank you, Kelli!

In October 2020, Kelli Acord, friend of Katy and Tyler Bone, ACDA parents to Barrett Bone (June 14, 2019 - July 12, 2019), organized a birthday fundraiser for **ACDMPV research in honor of Barrett Bone**. In Kelli’s own words, “I would like to honor the life and legacy of precious baby boy, Barrett Zachary Bone again this year for my birthday. I’m raising money for Alveolar Capillary Dysplasia Association. My prayer is for a cure so that no one will ever have to experience the loss like my best friends and their families did by losing Barrett to this terrible disease. This fundraiser ends on my birthday. BZB❤️(rotation emoji)❤️(rotation emoji)❤️(rotation emoji) Thank you for your support. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder.”

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**Birthday Fundraiser (Markiewicz family):**

Allen is on his way to his $200 goal (with two weeks left to donate!) through a Facebook birthday fundraiser in honor of AJ, Shannon and Noah Markiewicz. Thank you, Allen!

In October 2020, Allen Markiewicz, ACDA father to AJ (September 5, 1997 – October 1, 1997), Shannon (March 24, 1999 – April 20, 1999) and Noah (September 30, 2012 – August 17, 2013), organized a birthday fundraiser for **ACDMPV research in honor of his family**. In Allen’s own words, “For my birthday this year, I'm asking for donations to Alveolar Capillary Dysplasia Association. I've chosen this nonprofit because their mission means a lot to me, and I hope you'll consider contributing as a way to celebrate with me. Every little bit will help me reach my goal. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder.”
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 plans to continue running marathons for ACDMPV awareness in Europe and then worldwide! He previously completed the Rotterdam Marathon (April 2017, 2018 and 2019), Amsterdam Marathon (October 2016 (half), 2017, 2018 (Kids Run), 2019 (Kids Run)), Berlin Marathon (September 2019) and various other running events. Please contact Mathijs if you are interested in participating or cheering on his upcoming plans to raise ACDMPV awareness in the Netherlands or beyond! For additional information about the upcoming runs highlighted below, please visit Run4ACD on Stichting ACD’s website.

Marathon #1 Amsterdam (October 25, 2020):

Upcoming Event: Mathijs and team Stichting ACD are organizing their own Marathon #1 on October 25, 2020 to raise ACDMPV awareness! In Mathijs’ own words, “More good news... As I have mentioned before, big running events have been cancelled, so we have decided to organize a marathon event ourselves! Very limited entry off course due to the circumstances, but I can keep my promise to Myla to run a marathon again!

And I am already so proud, and we haven’t even ran yet... I just think the flyer for the event is wonderful with Myla’s face in the runner!

And the publication on the Grace&Us platform will be continued that day! We will do an interview with the founder and she will be present to cheer with us and celebrate life and remember Myla’s life. It’s going to be a very special day again.”

Angel Gallery:

You are invited to view the “Angel Gallery” on Stichting ACD’s website for a touching image display featuring many of our ACDA babies. To be added, please contact Mathijs at contact@stichtingacd.nl and send him a picture with name, birth date and angel date.

Book:

In addition to his work on the marathons, Mathijs has written a book. If you would like to order a copy of Mathijs’ book describing his experience of being Myla’s father, the book is for sale and the proceeds benefit Stichting ACD.
REPORT FROM THE DAVID ASHWELL FOUNDATION (UK):

March 2021 will be 10 years since David was born and we became part of the ACDMPV family. I am always open to suggestions of what is a good way to fundraise for ACD research so please get in touch, particularly ideas that are automated – like The Giving Machine.

Thank you to those families who have set up direct debits for the charity and whose families fundraise at work for us. Looking back since March 2011 over £200,000 has been raised for ACD Research by families in the UK and Europe (exact amount next newsletter!). 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 (GO HERE) 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! 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!

Please use The David Ashwell Foundation Virgin Money Giving pages. 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 ACD 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).

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

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 raise money in memory of their precious child. For additional information, contact Simon and Amelia.

Website: http://David_Ashwell_Foundation
Email: davidashwellfoundation@yahoo.co.uk
Twitter: @TDavidAshwellF
Mobile (Amelia): 07855473686
Welcome to New Families

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

•
Safe Arrivals!

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

- [Name 1]
- [Name 2]
- [Name 3]
- [Name 4]
- [Name 5]

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

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)