

# ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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In October 2022, the ACDA created a **story telling 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 Saturday, October 15 at 7:00 p. m. in your respective time zone, please share a photo of your candle** on the ACDA Facebook or Instagram 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

Please follow us on  
**FACEBOOK** or  
**INSTAGRAM**  
and join the ACDA  
Wave of Light.

## October is Pregnancy and Infant Loss Awareness Month

In 1988, **October was established as National Pregnancy and Infant Loss Awareness Month** in the United States, with the following words: “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, 2022 – 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 Story Telling Project: October 2022*



**Press Play to View**

In October 2022, the ACDA created a story telling 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, calligraphy, written word project about grief over time and an audio compilation of spoken names

**This year we wanted to share the meaning behind the names of children affected by ACDMPV.** Bereaved parents often have limited opportunities to hear or say their **beloved child's name**, with even fewer chances to talk about its meaning. **We wanted to learn those stories.** Please watch the video above or view the individual name cards below. It is our hope that sharing the story of your loved one's name along with reading the names and stories of other children affected by ACDMPV will provide a sense of comfort and community within our ACDA families. A suggested idea is to read the final compilation of stories while lighting your candle on October 15 during the ACDA Wave of Light. [View Here](#)

Please go [HERE](#) to learn how to participate in the ACDA Wave of Light on October 15, 2022. #WaveofLight #ACDAWaveofLight





THERE IS A STORY  
BEHIND EVERY  
CHILD'S NAME.

*Alexander*

I had a dream whilst about 4 months pregnant that we had a boy called Alex. When I woke up, I told Chris my dream and we settled on Alexander Taylor Coe. Taylor is my surname so that part of my heritage continues.

*Amelia Lee*

Our Amelia is named after two of her great-great-grandmothers. My parents almost used this name when they were naming me, Amelia's mom. When I was a little girl I heard this name and learned about the beautiful women I was almost named after. I fell in love with the name and the meaning behind it! When Amelia's dad and I got married, we often talked about names for our future children. Amelia Lee was always at the top of our list and we just knew that this would be the name of our first daughter. Amelia Lee, Mommy and Daddy love you forever and always!

*Artur*

At the beginning of the pregnancy we were hesitating between two names, which we both liked very much. Artur was one of them. However, as soon as we learned the ACD diagnosis, the choice became obvious as we knew that our baby boy was a true and brave warrior, like King Arthur from the legend.

TELL US YOUR STORY.



*Aurora*

When Aurora's father and myself first started our lives together, we often talked about our future children, we talked about the excitement of having kids together and we also talked about the names we would choose for our babies. While we couldn't decide on a boy name yet, we always knew our daughter would be named Aurora. Fast forward to starting our family, we learned our first child would be a beautiful girl and from the second we found out, we knew no other name would be fitting. So Aurora Sophia Mercedes Splawn was born into her respectful and beautiful name. At the time we would have no idea just how fitting her name would be. It was strong and courageous just like her. Our beautiful sleeping beauty.

*Ayla*

Ayla was chosen long before we knew she had ACD. However, after we were given her diagnosis, a Rabbi asked us why we chose that name and if we chose it because in Hebrew it means "to ascend." I clearly remember that day because it gave me chills to think about how fitting the name as we withdrew life support and watched our Angel Baby ascend to heaven.

*Barrett*

We chose Barrett as our son's name before he was born. We've always loved the sound of the name and thought that "Bear" for short was really cool. It's also the name of a military sniper rifle. The name stuck with us for almost 10 years, before we were even married. When we found out we were pregnant with a boy, we just had to use it. Barrett's middle name is Zachary, same as his dad's middle name. We still love to hear his name out loud and see it written out. Love and miss you Baby Bear.



## Braylee Graylyn

Her Daddy had been out on a fire call in the middle of the night. He had just gotten home and got out of the shower and asked, "What do you think of Braylee?" It's part of Brandon and Ashley mixed (our names) and that was all.

## Breanna Barbara

About Breanna Barbara from her eulogy, Breanna comes from the Celtic root and is the feminine version of Brian which means strength. She lived up to this meaning, having survived numerous surgical procedures and living two months with bad lungs. Her nickname was BB, Breanna Barbara. The name Barbara was given to her as a tribute to her late Aunt Barbara, who died much too early in life of a broken heart. Our second born child was a very healthy girl: her name is Christianna Marie. Christianna comes from two special caregivers who made Breanna happy, Kristen the day shift nurse and Christine the night shift nurse and the anna from Breanna. We wanted to honor those special people: Marie was her grandmother's name.

## Brian

Named him after all dads.  
First name after his daddy's father (grandpa),  
his middle name after my father (grandpa) and  
he has his own daddy's last name.

## Caleb

Caleb is called "Whole Hearted" in the Bible, and is referred to as being faithful and fearless in the presence of his enemies. We picked this name before we knew that Caleb had ACD, but we loved the name even more after we found out, and as we thought about his bravery here on earth and his healed whole-heartedness once he joined Jesus in heaven.

## Caterina Maria

Caterina is the name of the Saint of Siena in Italy and  
Maria is the name of the Virgin Mary.

## Callie & Cole

We chose Callie and Cole because they were the only names we agreed upon and we thought each were perfect for our babies.

## Colbie Kathleen

Have always loved the name Colbie. We were down to two names but when she was born, we decided then and there she was definitely our sweet Colbie girl! Her middle name came from her late Grandma. Two strong names for two strong women!

## Dahlia

In Denmark, dahlias are in bloom in September, just when our Dahlia was born last year. It's one of the most beautiful and yet complex flowers I have ever seen, so it's the perfect name for our little flower Dahlia.





## David Fazullah Upeksha

David is named after Simon's father, his grandfather who died suddenly in 2006 and would have loved nothing more than being around with his grandchildren (David means 'beloved'). Fazlallah is my grandfather's name, he was an incredible man, larger than life and so brave (Fazlallah means 'bounty of God' in Arabic). Upeksha is one of the Buddhist sublime states and means equanimity (calmness and composure especially in a difficult situation).

## Davina Lee

Davina is the feminine version of David from the Bible, her name also means beloved! Her middle name was taken from both of her parents, after individuals in their families.

## Fallon Jade

We just loved the name. We had our son, Avery, and our daughter, Harper, both English and/or Irish surnames. Upon exploring other surnames, we came upon Fallon and just loved it so much so that no matter if our third child was a boy or a girl, his/her name would have been Fallon. We chose Fallon Jade for a girl and Fallon Jax for a boy. We never found out the genders of our children before birth, so we were anxiously awaiting the surprise. Fallon Jade was born (she came one day early and on her own terms!) on October 10th, and she couldn't have been more perfect. We love and miss her so much.

## Finley Kathleen

I wish I had a great story, but I just found it while searching on Pinterest. I saved a picture of it, but never told my husband about it, because he always vetoed the names I loved. One day, he saw it on my phone and said, "That's our daughter's name." From that moment on, we both started calling her that and it felt like the perfect name for her. Kathleen is also his mom's middle name. We kept her gender and name a secret until she was born. Finley was born around March Madness, so we made a name bracket with 16 girl names and 16 boy names for our family and friends to fill out. My mom was the only person who guessed her gender and name correctly.

## Gracie Gene

We knew we were going to have Gracie's middle name be Gene after her dad. Gracie was the name of the lead character in the movie Return to Me. We absolutely loved the storyline, the actors, and the music in the movie. The lead character, Gracie, had a heart defect. Our Gracie also had a heart defect that we knew about at our 20 week ultrasound. We thought it was a "sign" and the perfect name for our girl.

## Jaime

Love how it sounds, brought good memories.

## Baby James

Baby James was named after his grandfather and father who were both named James Alan. He was given the middle name Joseph for my cousin who passed away as a young adult from a rare form of cancer. We affectionately call him Baby James because his two older siblings referred to him as such while he was in my belly. This was fitting because his grandfather was called "Big Jim" and his father was called "Little Jim" since a baby and still is today, even though he is in his 40's (and he is not so little lol). So the name Baby James fit perfectly and stuck as his nickname. I remember saying while I was pregnant that "this baby is going to be 30 years old and still referred to as Baby James." We never expected that James Joseph would be called to heaven as a baby and his nickname might have more of a meaning than anyone could have thought at the time. He is truly our Angel and is up in heaven with Big Jim looking over us.

## Jasmijn Annalie

We thought it was a beautiful name at first. Because our daughter was/is as pretty as a flower when she was born, it was the perfect name for her! Her second name is a combination of the names of both of her grandmothers.



## Johnny

Johnny is named after multiple generations of family because John (Ioan in Romanian) is the name of his father, two great grandfathers and great-great grandfather. His name was picked early in the pregnancy and it was meant to be when he was born at 3:16pm (John 3:16).

## Laura Taylor

Laura was my great-aunts name and I loved Laura in the TV show, 'Little House on the Prairie'. Taylor was my mother-in-law's maiden name and we liked the two together.

## Jonathan Adam

His mother knew from the first second that his name would be Jonathan. It took his father a few days to realize it, but it soon became clear that he, of course, was a little Jonathan. Jonathan also shares his middle name, Adam, with his father. We will miss him forever.

## Lex

Because it felt right.

## Katie Jayne

Her first name because we loved it and her second name was after the wonderful friend who recognized we needed support and prayer without asking.

## Miller Asha Shauni

Miller was picked by her dad who loved the name. Asha means guardian of all children. Shauni was picked as her Grandad's name is Shaun.

## Landen

Found in a baby book and his daddy picked the spelling of it.

## Phoebe Johanna

I have always loved the name Phoebe. It wound up being the name we both liked the most from the "baby name" list. Her middle name, Johanna, was my grandmother's middle name. After Phoebe was born, we found out my husband's great-grandmother's name was Johanna.





## Poppy Eve Rose

Our little girl's name is just full of meaning, and I looked forward to the day that I'd be able to tell her all about it. Poppy was the name we used to call our grandfather, he passed away Dec. 27th 1999, and my due date was Dec. 27th 2020...so I thought if we'd a girl it would be a nice touch, even though Poppy's birth date was Dec. 18th. We chose Eve after her Daddy's Mom (Elizabeth) who sadly had passed away years ago. And we picked Rose after our wonderful Dr Barend, who delivered Poppy and her two brothers before her into this world. Poppy was Dr Barend's hat-trick baby, his first time to deliver 3 babies from the same Mom. His dear Nanny had only passed away a few weeks before Poppy was born, and so in honour of Dr Barend we called her Rose as his nanny was called Rosealyn. Poppy Eve Rose, our beautiful precious darling girl, loved and missed with all our hearts.

## Ronan Christopher

Both our families have some Irish, and we wanted a Celtic or Gaelic name in honor of both of our families. His middle name, Christopher, is his dad's first name.

## Ronan

Ronan's name was chosen as blend of his parent's respective family origins. On his dad's side, the "R" in Ronan honors his great-great-grandmother (Rose), who led the family out of Europe before the Holocaust. And on his mom's side, Ronan is the name for the sweet little seals of the western Irish coastline, who call out their love to their mythical mother, a sea-enchantress separated from them by a magical spell.

## Simeon William

We choose the name Simeon after my great-grandfather and William after my husband's brother. They were both strong and amazing men that passed away too soon. They both meant the world to us and had so much impact on both our lives. We thought it was only fitting for him to have their names.

## Timothy Michael

He was named after both of his grandfathers.

## In Loving Memory



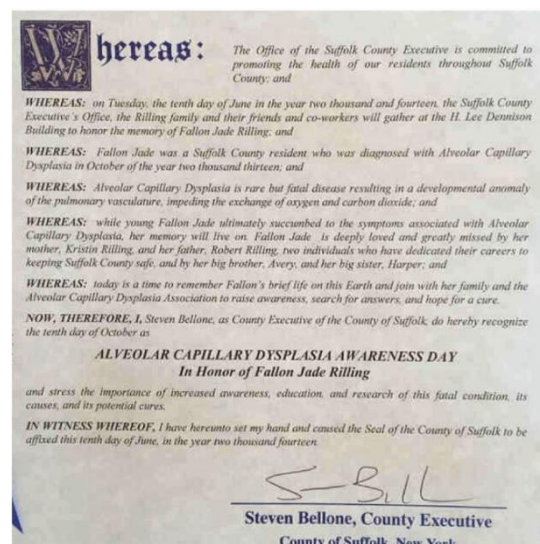


## Lights in Suffolk County (Fallon Rilling):



On October 10, 2022, 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 ninth 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 will always be grateful to the Rilling family for their incredible awareness and fundraising efforts throughout the years. We look forward to the purple Denison building each year, in honor of Fallon.



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

Reports from **Stichting ACD** (The Netherlands) and **The David Ashwell Foundation** (UK) will return in a following edition of ACDA Notes.



## RESEARCH NEWS

### Journal Article (Nature Communications):



The developmental biology research team at **Cincinnati Children's Hospital Medical Center** in Cincinnati, Ohio, USA (see Issues #57, #62-63, #68-69, #71-72 and #74-76 of ACDA Notes) published a manuscript this spring entitled, "*Endothelial progenitor cells stimulate neonatal lung angiogenesis through FOXF1-mediated activation of BMP9/ACVRL1 signaling*" in the Nature Communications research journal, which can be found [HERE](#). **Please also view various press releases ([HERE](#), [HERE](#) and [HERE](#)) regarding this research.** Abstract:

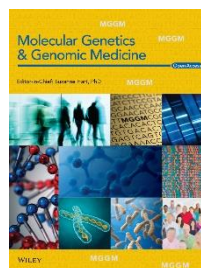
"Pulmonary endothelial progenitor cells (EPCs) are critical for neonatal lung angiogenesis and represent a subset of general capillary cells (gCAPs). Molecular mechanisms through which EPCs stimulate lung angiogenesis are unknown. Herein, we used single-cell RNA sequencing to identify the BMP9/ACVRL1/SMAD1 pathway signature in pulmonary EPCs. BMP9 receptor, ACVRL1, and its downstream target genes were inhibited in EPCs from *Foxf1* mutant mice, a model of alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV). Expression of *ACVRL1* and its targets were reduced in lungs of ACDMPV subjects. Inhibition of FOXF1 transcription factor reduced BMP9/ACVRL1 signaling and decreased angiogenesis in vitro. FOXF1 synergized with ETS transcription factor FLI1 to activate *ACVRL1* promoter.

Nanoparticle-mediated silencing of *ACVRL1* in newborn mice decreased neonatal lung angiogenesis and alveolarization. **Treatment with BMP9 restored lung angiogenesis and**

**alveolarization in ACVRL1-deficient and *Foxf1* mice. Altogether, EPCs promote neonatal lung angiogenesis and alveolarization through FOXF1-mediated activation of BMP9/ACVRL1 signaling."**

From the [press release](#): "The team found that **adding synthetic bone morphogenetic protein BMP9 to cells that were deficient for functional FOXF1 genes helped re-create the signaling pathway, stimulating Acvrl1 activity and instructing the lungs to keep making capillaries. The researchers confirmed this through tests in lab cell cultures and in mice.** BMP9 is one of about 20 different such proteins found in humans. Originally discovered to play major roles in bone growth, more recently this class of molecules has been shown to play a variety of roles in development. Two other related proteins (BMP7 and BMP2) have been approved by the US Food and Drug Administration for treating bone growth disorders. But so far, no drug that stimulates BMP9 activity has been approved for human use...**If a safe BMP9 "agonist" or synthetic BMP9 molecule suitable for human use can be developed, it could become more than a treatment strictly for ACDMPV,** Kalinichenko says."

### Journal Article (Mol Genet Genomic Med):



The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently collaborated with University of Colorado Anschutz Medical Campus and an international team in Poland to publish a manuscript entitled, "*High-level gonosomal mosaicism for a pathogenic non-coding CNV deletion of the lung-specific FOXF1 enhancer in*





an unaffected mother of an infant with ACDMPV” in the Molecular Genetics & Genomic Medicine research journal, which can be found [HERE](#). Partial Abstract:

**“Background:** Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV) results from haploinsufficiency of the mesenchymal transcription factor FOXF1 gene. To date, only one case of an ACDMPV-causative CNV deletion inherited from a very-low level somatic mosaic mother has been reported.

**Results:** A pathogenic CNV deletion of the lung-specific FOXF1 enhancer in the proband was found to be inherited from an unaffected mother, **36% mosaic for this deletion in her peripheral blood cells**. The qPCR analyses of **saliva, buccal cells, urine, nail, and hair samples revealed 19%, 18%, 15%, 19%, and 27% variant allele fraction, respectively, indicating a high recurrence risk**. Grandparental studies revealed that the deletion arose on the mother's paternal chromosome 16. PGT studies revealed **44% embryos with the deletion, reflecting high-level germline mosaicism**.

**Conclusion:** Our data further demonstrate the importance of **parental testing in ACDMPV families and reproductive usefulness of IVF** with PGT in families with high-level parental gonosomal mosaicism.”

### Journal Article (Eur J Hum Genet):

The genetic research team at Baylor College of Medicine in Houston, Texas, USA collaborated with an international team in Poland to publish a manuscript this summer entitled, *“Do paternal deletions involving the*

*FOXF1 locus on chromosome 16q24.1 manifest with more severe non-lung anomalies?”* in the European Journal of Human Genetics, which can be found [HERE](#). Abstract:

“Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV) is a rare lethal lung developmental disorder in neonates due to heterozygous loss-of-function of the mesenchymal transcription factor gene, FOXF1. Interestingly, unlike ACDMPV-causing point mutations in FOXF1 that can be inherited from the mother or father, causative copy-number variant (CNV) deletions arise de novo and almost exclusively on chromosome 16 inherited from the mother (n = 50 vs. n = 3). Here, we describe a fourth case of a de novo paternal CNV deletion encompassing FOXF1, its neighboring long non-coding RNA gene FENDRR, and their distant lung-specific enhancer, identified in a 21-week-old fetus with tetralogy of Fallot, gastrointestinal and genitourinary abnormalities, a single umbilical artery, and patchy histopathological findings of ACDMPV in autopsy lung. We also review the ACDMPV-causative CNV deletions detected prenatally and **propose that the majority of paternal deletions manifest with more severe additional non-lung abnormalities.**”

### Journal Article (Eur J Hum Genet):



The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently collaborated with international teams in Poland and Australia to publish a manuscript entitled, *“Variable expressivity in a four-generation ACDMPV family with a non-coding hypermorphic SNV in trans to the frameshifting FOXF1 variant”* in the European Journal of Human Genetics, which can be found [HERE](#). Abstract: **“Heterozygous single nucleotide**



variants (SNVs) or copy-number variant deletions involving FOXF1 or its distant lung-specific enhancer on chromosome 16q24.1 have been identified in 80-90% of patients with Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV), a lethal neonatal lung developmental disorder. We describe a four-generation family with a deceased ACDMPV neonate, her sibling from the electively terminated pregnancy, healthy mother with a history of pulmonary arterial hypertension (PAH), an unaffected aunt, an aunt deceased due to findings consistent with ACDMPV, and a reportedly unaffected grandmother, all with the frameshifting variant c.881\_902dup (p.Gly302Profs\*46) in FOXF1, and a deceased great-grandmother with a history of PAH. Genome sequencing analyses in the proband's unaffected mother revealed a non-coding putative regulatory SNV rs560517434-A within the lung-specific distant FOXF1 enhancer in trans to the FOXF1 frameshift mutation. Functional testing of this variant using an in vitro luciferase reporter assay showed that it increased FOXF1 promoter activity 10-fold. Our studies further demonstrate that non-coding SNVs in the FOXF1 enhancer region can rescue the lethal ACDMPV phenotype and support the compound inheritance gene dosage model."

#### **TBX4Life Initiative:**



In October 2022, the ACDA connected with fellow patient advocacy group, the [TBX4Life initiative](#). Dr. Eric Austin and Anton Morkin are the founders and leaders of TBX4Life, which is an international

initiative to improve the quality of life of those affected by **TBX4 Syndrome**, and to find a cure. TBX4 (along with ACDMPV, CAD, AcDys) is a subtype of lethal lung developmental disorders (LLDDs). The ACDA has a handful of families in our database with a retracted or differential diagnosis to TBX4. It is our hope to connect these families with Dr. Anton and Mr. Morkin in order to broaden the network of TBX4Life. Please visit the [TBX4Life initiative](#) to learn more.

#### **ATS Request for Full Applications – 2022 Research Grant:**



The American Thoracic Society (ATS), with funding from the Alveolar Capillary Dysplasia Association (ACDA) and The David Ashwell Foundation, is **currently accepting applications for up to \$50,000** for scientific research studies and/or clinical research studies related to Alveolar Capillary Dysplasia/misalignment of the pulmonary veins (ACDMPV). The ATS encourages all U.S. and international researchers interested in studying ACDMPV to consider applying for 2022 funding. **The Letter of Intent Submission deadline closed in September 2022 but the ATS will continue accepting Full Application submissions, even if an LOI was not submitted. The Full Application Deadline is January 10, 2023. See full information [HERE](#).**





## FUNDRAISING NEWS

### Donations:

To make a secure tax deductible donation to the ACDA, please visit our website.



[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.

### Balance of ACDA account:

The unallocated balance of the ACDA bank accounts as of [REDACTED]

### Update from AmazonSmile:



The ACDA was issued a [REDACTED] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between April 1 and June 30, 2022. 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>

### Update from Spreadshirt:



Items with the ACDA logo are available for purchase in our Spreadshirt store [HERE](#). The accrued commission payment from Spreadshirt

between May 17, 2022 and October 13, 2022 is [REDACTED]. 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 FREE SHIPPING on everything from October 19-23, 2022! No code needed!**

### 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]



### Fundraising Idea (SO EASY!!):



Please consider participating in the ACDA's **eighth 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:

#### 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, Google, Humana, Schneider Electric, Tokyo Electron and Verisk Analytics** for their matching gifts for ACDMPV research!

## #GIVINGTUESDAY

### December 1, 2022

## 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), \$2,500 (2019), \$2,300 (2020) and \$2,105 (2021) on this one day alone!

- **What:** A global day of giving
- **When:** The Tuesday following Black Friday (December 1, 2022)
- **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, 2022 in support of the ACDA.**



## REMEMBERING OUR BABIES

[REDACTED]

[REDACTED]

## Welcome to New Families

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

- [REDACTED]
- [REDACTED]



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

- [REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

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>

**Email:**

[President@acdassociation.org](mailto:President@acdassociation.org) (Eliza Rista)  
[Secretary@acdassociation.org](mailto:Secretary@acdassociation.org) (Renee Murray)  
[Treasurer@acdassociation.org](mailto:Treasurer@acdassociation.org) (John Rista)

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

Read about the private groups with [information on how to join](#).

- Follow us [alveolar\\_capillary\\_dysplasia](#)

- Follow us @acdassociation

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

**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)

