

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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In October 2023, the ACDA created a **map project** in observance of Pregnancy and Infant Loss Awareness month. Please see **page 3** for the completed project or [view it online for the interactive details](#), such as names, locations and dates.

We also invite 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, 2023 – 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 Map Project: October 2023

In October 2023, the ACDA created an interactive map project for Pregnancy and Infant Loss Awareness Month. Each candle on the [interactive map](#) represents a child affected by ACDMPV in our ACDA registered families.



Please click on the [interactive map](#) and use the zoom in/out to view individual names, locations and dates.

Maps provide perspective and context of the heartbreaking impacts of ACDMPV on a global scale. We hope the narrative demonstrated by the above maps will provide a sense of community within our ACDA families.

A suggested idea is to view the map details while lighting your candle on October 15 during the ACDA Wave of Light. [Learn how to participate](#) in the ACDA Wave of Light on October 15, 2023. #WaveofLight #ACDAWaveofLight

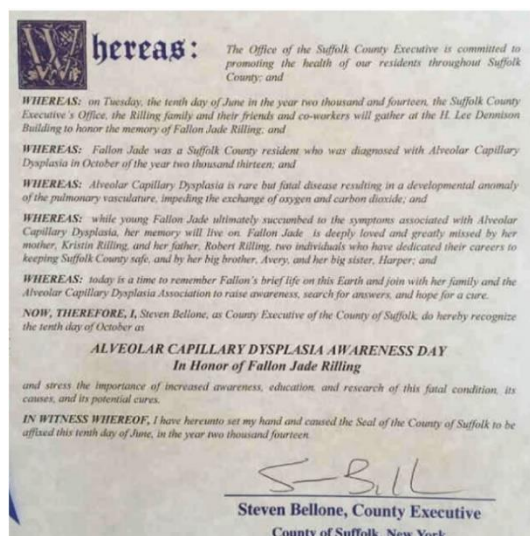
Projects for October 15 in prior years have included collages of our babies, photo project of bereaved parents, memorial wall, luminaries, calligraphy, written word project about grief over time, audio compilation of spoken names and a story-telling project about the meaning behind the names of children affected by ACDMPV. Many of the past projects can be viewed at any time on our [website](#).

Lights in Suffolk County (Fallon Rilling):



On October 10, 2023, 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 tenth 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.

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 10th as ACD Awareness Day in Suffolk County, New York

The ACDA will always be grateful



RESEARCH NEWS

2023 Grant Update:



As shared via social media in August 2023, it is the great pleasure of the ACDA and The David Ashwell Foundation to announce a **\$100,000 grant is available in 2023 for applicants for ACDMPV research**. The ACDA is partnering with the **American Thoracic Society (ATS)** and its excellent research program for this grant cycle. The ATS, with funding from the ACDA and The David Ashwell Foundation, is accepting applications for a total of \$100,000 for scientific research studies and/or clinical research studies related to ACDMPV (see the box to the right for additional application information).

As background, **over \$750,000 has been issued for ACDMPV research with a total of thirteen grants since 2005**. Thank you for keeping the momentum going with annual research grants.

Every single dollar matters in rare disease research, perhaps more than ever as significant research developments regarding possible therapeutic approaches for ACDMPV are emerging, pending the development of clinical trials. The smaller seed grants issued in recent years through money raised

by ACDMPV affected families and friends has collected data for use in larger multi-year government grants, including the recently announced \$3,100,000+ NIH grant in August 2023 and the previous \$1,900,000+ NIH grant in 2017, each awarded to Baylor College of Medicine for four-year studies. The seed grants also sustain ACDMPV research during the very difficult NIH or FDA application processes. It can take research institutions a few years (and rejections) to finally have enough research material for NIH or FDA approval. **Larger governmental grants and approvals would simply be inaccessible without the ongoing seed grants raised by families and friends affected by ACDMPV.** So please keep up those birthday fundraisers, restaurant nights, off-roading events, marathon pledges and all the other amazing ways you raise money for ACDMPV research! Progress is being made each year and we are thankful for every donation. Please visit our website [HERE](#) to read a full history of grants for ACDMPV research.

ATS Request for Full Applications – 2023 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 \$100,000** 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 2023 funding. **The Full Application Deadline is January 8, 2024. See full information [HERE](#).**



2023 NIH Grant Update:



Grant Budget:
Awardee Organization:
Project Leader:
Project Start & End Dates:
Title:

\$3,173,568 (\$793,392 per year)
Baylor College of Medicine
Pawel Stankiewicz, MD, PhD
August 15, 2023 - June 1, 2027
Etiology and pathogenesis of lethal lung developmental disorders in neonates



As shared via social media and on our website in August 2023, the **ACDA is pleased to announce Baylor College of Medicine** in Houston, Texas, USA was recently awarded a **NIH R01 grant** in August 2023 in excess of **\$3.1 million** for ACDMPV research over the course of **four years** (\$793,392 per year). This multi-year study at Baylor hopes to identify new genetic variants, allowing for more precise diagnosis and prognosis of Lethal lung developmental disorders (LLDDs), facilitating more informative genetic counseling, and providing targets for development of potential in utero treatments for LLDDs and pulmonary arterial hypertension (PAH). It is Baylor's hope their data will also help to better understand incomplete penetrance and variable expressivity phenomena in human genetics in general.

gene responsible for ACDMPV. **The ACDA extends our heartfelt thanks to Dr. Pawel Stankiewicz (Project Leader for both the 2017 and the 2023 NIH grants) and Dr. Przemyslaw Szafranski at Baylor College of Medicine for their tireless efforts to secure substantial NIH funding.** As background, R01 grants from the NIH are highly competitive and are known as the gold standard due to it being one of the most respected mechanisms of financial support in the medical research world.

Please join us in publicizing this tremendous and significant news by sharing this announcement. We look forward to providing updates on the results of the research through this NIH grant as we continue our steadfast mission to find the cause of and cure for ACDMPV.

The 2023 NIH grant award follows a 2017 NIH grant for \$1,952,000 that explored how enhancers in chromosome 16q24.1, including long noncoding RNAs (lncRNAs), regulated expression of the FOXF1

As mentioned above for the ATS grant, none of this would be possible without the ongoing seed grants raised by families and friends affected by ACDMPV. Among other objectives, prior seed grants have helped Baylor accumulate and maintain the largest collection of DNA and



tissue samples related to ACDMPV in the world and to detect mutations and deletions therein. The smaller seed grants (approx \$50,000) issued in recent years through money raised by ACDMPV affected families and friends has helped to collect data for use in the 2017 and 2023 larger multi-year government grants, which was the exact purpose of those seed grants. We will continue to focus on annual seed grants to investigate ACDMPV from all perspectives, including genetic, biological, clinical, pathology, etc. Our thanks, always, to the numerous individuals and organizations who continue to support our very important mission from the ground up.

NIH GRANTS & FUNDING AT A GLANCE (2023 ANNOUNCEMENT):

Title:	Etiology and pathogenesis of lethal lung developmental disorders in neonates
Project Leader:	Pawel Stankiewicz, MD, PhD
Awardee Organization:	Baylor College of Medicine
Total Funding:	\$3,173,568 (\$793,392 per year)
Project Start Date:	August 15, 2023
Project End Date:	June 1, 2027
Project Number:	1R01HL165301-01A1

Public Health Relevance Statement (Project Narrative): The main focus of our research is studying the role of SHH-FOXF1 and TBX4-FGF10 signaling pathways in epithelial-mesenchyme interactions during human lung development as well as in etiology of lethal lung developmental disorders (LLDD) and pulmonary arterial hypertension (PAH) in neonates. In particular, we are interested in an interplay between the pathogenic coding variants and the regulatory non-

coding regulatory elements of the FOXF1, FENDRR, TBX4, and FGF10 genes, implied in complex compound inheritance of these disorders. We hypothesize that (i) non-coding variants are promising therapeutic target and (ii) that a little known transmembrane protein TMEM100 mediates SHH-FOXF1 and TBX4-FGF10 signaling during human lung development.

New research institution (Phoenix Children's, University of Arizona College of Medicine – Phoenix):



We are excited to announce that **Phoenix Children's, University of Arizona College of Medicine – Phoenix** in Phoenix, Arizona, USA will include a focus on ACDMPV research. Dr. Vladimir Kalinchenko recently transferred to Phoenix Children's with his developmental biology research lab from Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, USA (see Issues #57, #62-63, #68-69, #71-72, #74-76 and #81 of ACDA Notes). Dr. Alan Kenny (the 2021 ACDA grant recipient) and other contacts remain at Cincinnati Children's and both institutions will continue to closely collaborate on ACDMPV research with full support for continued involvement and partnership. Dr. Kalinchenko's new appointment as Director for the Phoenix Children's Research Institute at the University of Arizona College of Medicine – Phoenix, and professor of Child Health, will enable him to further his research into ACDMPV and other rare lung diseases. See the [announcement from Phoenix Children's](#) regarding Dr. Kalinchenko's new role.



Journal Article (Biologics):



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, #74-76 and #81 of ACDA Notes)

published an important manuscript this spring entitled, *"Demonstration of Safety in Wild Type Mice of npFOXF1, a Novel Nanoparticle-Based Gene Therapy for Alveolar Capillary Dysplasia with Misaligned Pulmonary Veins"* in the Biologics research journal, which can be found [HERE](#). **Note, this groundbreaking work was funded in part by the 2021 ACDA research grant, funded directly to Cincinnati Children's Hospital in the amount of \$50,000.** Partial Abstract:

"Introduction: ...Currently, no treatment exists for ACDMPV, although recent murine research in the Kalinichenko lab demonstrates nanoparticle delivery improves survival and reconstitutes normal alveolar-capillary architecture. **The aim of the present study is to investigate the safety of intravenous administration of FOXF1-expressing PEI-PEG nanoparticles (npFOXF1), our pioneering treatment for ACDMPV.**

Results: With treatment we observed no lethality, and the general condition of mice revealed no obvious abnormalities. Serum chemistry, whole blood, and histologic toxicity was assayed on P16 and P21 and revealed no abnormality.

Discussion: In conclusion, **npFOXF1 has a very good safety profile and combined with preceding studies showing therapeutic efficacy, npFOXF1 can be considered as a good candidate therapy for ACDMPV in human neonates."**

Also from the article, "Research has shown nanoparticles can serve therapeutic purposes to deliver both biologic (DNA, mRNA, et cet. For gene expression) and inorganic compounds to the cytoplasm. They can be utilized as vaccines and to treat cancer, immune disorders, and diabetes. They have tremendous potential for use in tissue regeneration. Recent research in the Kalinichenko lab used newly developed polyethylenimine-(5) myristic acid/poly(ethylene glycol)-oleic acid/cholesterol (PEI600-MA5/PEG-OA/Cho) nanoparticle to deliver non-integrating angiogenic cDNA-expressing plasmids into the neonatal pulmonary bloodstream in order to improve pulmonary capillary formation and alveolarization in diseases like ACDMPV."

REQUEST to ACDA families: In order to fast-track the important research above, please contact the ACDA (president@acdassociation.org) if you have any connections to a corporate partner capable of producing the potential treatment in GMP (i.e., Good Manufacturing Practice) grade.

Journal Article (Non-Coding RNA):



The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently published a manuscript entitled, *"A Small De Novo CNV Deletion of the*

Paternal Copy of FOXF1, Leaving lncRNA FENDRR Intact, Provides Insight into Their Bidirectional Promoter Region" in the Non-Coding RNA research journal, which can be found [HERE](#). Abstract:

"Pathogenic single-nucleotide variants (SNVs) and copy-number variant (CNV) deletions involving the FOXF1 transcription factor gene or CNV deletions of its distant lung-specific enhancer are responsible for alveolar capillary dysplasia with misalignment of pulmonary veins



(ACDMPV), a rarely diagnosed lethal lung developmental disorder in neonates. In contrast to SNVs within *FOXF1* and CNV deletions involving only the *FOXF1* enhancer, larger-sized deletions involving *FOXF1* and the adjacent, oppositely oriented lncRNA gene *FENDRR* have additionally been associated with hypoplastic left heart syndrome and single umbilical artery (SUA). Here, in an ACDMPV infant without any congenital heart defect or SUA, we identified a small 5 kb CNV deletion that removed the paternal allele of *FOXF1* and its promoter, leaving *FENDRR* and its promoter intact. Reporter assay in the IMR-90 fetal cell line implied that the deletion may indeed not have significantly affected *FENDRR* expression. It also showed a polarization of the *FOXF1*-*FENDRR* inter-promoter region consisting of its ability to increase the transcription of *FENDRR* but not *FOXF1*. Interestingly, this transcription-stimulating activity was suppressed in the presence of the *FOXF1* promoter. **Our data shed more light on the interactions between neighboring promoters of *FOXF1*-*FENDRR* and possibly other divergently transcribed mRNA-lncRNA gene pairs.**

Journal Article (*Genes (Basel)*):



An international team in Poland collaborated with the genetic research team at Baylor College of Medicine in Houston, Texas, USA and University of Washington School of Medicine to publish a case study entitled, “*Prenatal Detection of a *FOXF1* Deletion in a Fetus with ACDMPV and Hydronephrosis*” in the *Genes (Basel)* journal, which can be found [HERE](#). Partial Abstract:

“Thus far, most of the described ACDMPV patients have been diagnosed post mortem, based on

histologic evaluation of the lung tissue and/or genetic testing. Here, we report a case of a **prenatally detected de novo CNV deletion (~0.74 Mb) involving the *FOXF1* gene** in a fetus with ACDMPV and hydronephrosis. Since ACDMPV is challenging to detect by ultrasound examination, the more widespread implementation of prenatal genetic testing can facilitate early diagnosis, improve appropriate genetic counselling, and further management.”

Journal Article (*Am J Respir Crit Care Med*):



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, #74-76 and #81 of ACDA Notes) and the genetic research team at Baylor College of Medicine in Houston, Texas, USA collaborated with multiple other research teams to publish a manuscript entitled, “*Single Cell Multiomics Identifies Cells and Genetic Networks Underlying Alveolar Capillary Dysplasia*” in the *American Journal of Respiratory and Critical Care Medicine* research journal, which can be found [HERE](#). Partial Abstract:

“Rationale: Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV) is a lethal developmental disorder of lung morphogenesis caused by insufficiency of *FOXF1* (forkhead box F1) transcription factor function. The cellular and transcriptional mechanisms by which *FOXF1* deficiency disrupts human lung formation are unknown. **Objectives:** To identify cell types, gene networks, and cell-cell interactions underlying the pathogenesis of ACDMPV.

Conclusions: Distinct *FOXF1* gene regulatory networks were identified in subsets of pulmonary endothelial and fibroblast progenitors, providing both **cellular and**



molecular targets for the development of therapies for ACDMPV and other diffuse lung diseases of infancy.”

PhD Thesis (University of Cincinnati):

Dr. Abid Al Reza in Cincinnati, Ohio published his PhD dissertation entitled, “*The Role of Forkhead Box F1 Transcription Factor in Mesenchymal-Epithelial Signaling During Lung Development*” published by University of Cincinnati, which can be found [HERE](#).

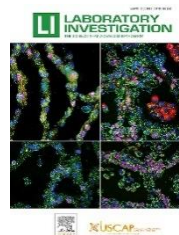
Journal Article (Neonatology):



Research teams at the Mayo Clinic in Rochester, Minnesota, USA published a case report entitled, “*Neonatal Diagnosis of Alveolar Capillary Dysplasia via Rapid Genomic Sequencing: A New Gold Standard?*” in the Neonatology research journal, which can be found [HERE](#). Partial Abstract:

“No curative treatment is currently available. Although definitive diagnosis is obtained by histology, lung biopsy is often challenging in unstable, critically ill neonates. Molecular diagnosis has been achieved with chromosomal microarray and targeted gene sequencing; however, each of these modalities can be limited by turnaround time, coverage of the genome, and inability to detect all pathogenic variant types for ACDMPV. We present a case of ACDMPV diagnosed via rapid genome sequencing and posit that **rapid genomic sequencing, including both rapid exome and genome sequencing, has an expanding role** in severe neonatal respiratory failure as a comprehensive and noninvasive approach to timely diagnosis.”

Journal Article (Lab Invest.):



The genetic research team at Erasmus University Medical Center in Rotterdam, The Netherlands recently published a manuscript entitled, “*Clinical Relevance of Rapid FOXF1-Targeted Sequencing in Patients Suspected of Alveolar Capillary Dysplasia With Misalignment of Pulmonary Veins*” in the Laboratory Investigations research journal, which can be found [HERE](#). Abstract:

“Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV) is a lethal congenital lung disorder that presents shortly after birth with respiratory failure and therapy-resistant pulmonary hypertension. It is associated with heterozygous point mutations and genomic deletions that involve the FOXF1 gene or its upstream regulatory region. Patients are unresponsive to the intensive treatment regimens and suffer unnecessarily because ACDMPV is not always timely recognized and histologic diagnosis is invasive and time consuming. Here, we demonstrate the **usefulness of a noninvasive, fast genetic test for FOXF1 variants** that we previously developed to rapidly diagnose ACDMPV and reduce the time of hospitalization.”

Journal Article (Chinese Journal of Medical Genetics):



Research teams in China published a manuscript entitled, “*Genetic analysis of an infant death due to a paternally derived FOXF1 somatic-gonadal mosaic variant*” in the Chinese Journal of Medical Genetics, which can be found [HERE](#). Abstract:

“**Objective:** To investigate the genetic



characteristics and cause of death for an infant with alveolar capillary dysplasia and pulmonary vein misalignment (ACD/MPV).

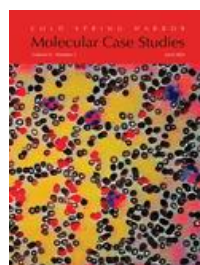
Methods: An infant with ACD/MPV diagnosed at the Affiliated Maternity and Child Health Care Hospital of Nantong University in September 2022 was selected as the study subject. Clinical data of the infant were collected. Whole exome sequencing (WES) was carried out to detect genetic variants in the skin tissue, and Sanger sequencing was performed for verifying the candidate variants in the parents. **Droplet digital PCR (ddPCR) was used to determine the mosaicism ratio of the variant in different germ layer-derived samples** from the father.

Results: The infant had died within 2 days after birth due to hypoxemia and respiratory distress. WES revealed that she has harbored a c.433C>T nonsense variant in exon 1 of the FOXF1 gene, which was unreported previously. Sanger sequencing has verified the variant in the infant, with her mother's locus being the wild-type and a minor variant peak noted in her father. ddPCR indicated that the mosaic ratio of the c.433C>T variant in the father's sperm was 27.18%, with the mosaic ratios of the variant in tissues originating from the three germ layers ranging from 11% to 28%.

Conclusion: The c.433C>T variant derived from the paternal germline and somatic mosaicism of the FOXF1 gene had probably predisposed to the neonatal death of this infant. ddPCR is an effective method for detecting mosaic variants.”

Journal Article (Cold Spring Harb Mol Case Stud.):

Research teams in Utah, USA published a manuscript entitled, *“Rapid genome diagnosis of alveolar capillary dysplasia leading to treatment in a child with*



respiratory and cardiac failure” in the Cold Spring Harbor Molecular Case Studies, which can be found [HERE](#). Abstract:

“Alveolar Capillary Dysplasia (ACD) is a fatal disorder that typically presents in the neonatal period with refractory hypoxemia and pulmonary hypertension. Lung biopsy is traditionally required to establish the diagnosis. We report a 22-month-old male who presented with anemia, severe pulmonary hypertension, and right heart failure. He had a complicated hospital course resulting in cardiac arrest and requirement for extracorporeal membrane oxygenation. Computed tomography (CT) of the chest showed a heterogenous pattern of interlobular septal thickening and pulmonary edema. The etiology of his condition was unknown, lung biopsy was contraindicated because of his medical fragility, and discussions were held to move to palliative care. Rapid whole genome sequencing (rWGS) was performed. In 2 days it resulted revealing a novel FOXF1 gene pathogenic variant that led to the presumptive diagnosis of atypical ACD. Cases of atypical ACD have been reported with survival in patients using medical therapy or lung transplantation. Based on the rWGS diagnosis and more favorable potential of atypical ACD, aggressive medical treatment was pursued. The patient was discharged home after 67 days in the hospital; he is currently doing well more than thirty months after his initial presentation with only one subsequent hospitalization and no requirement for lung transplantation. Our case reveals the potential for use of rWGS in a critically ill child where the diagnosis is unknown. rWGS and other advanced genetic tests can guide clinical management and expand our understanding of atypical ACD and other conditions.”



FUNDRAISING NEWS

Donations:

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



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.

Spreadshirt:



Items with the ACDA logo are available for purchase in our [Spreadshirt](#) store.



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!**



Donations Received:

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

[illegible]

[illegible][illegible]

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



Fundraising Idea (SO EASY!!):



Please consider participating in the ACDA's **ninth 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, Premier, Schneider Electric, Tokyo Electron and Verisk Analytics** for their matching gifts for ACDMPV research!

#GIVINGTUESDAY

November 28, 2023

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) and \$1,580 (2022) on this one day alone!

- **What:** A global day of giving
- **When:** The Tuesday following Black Friday (November 28, 2023)
- **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 November 28, 2023 in support of the ACDA.**

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](#).

Instagram:

- Follow us [alveolar capillary dysplasia](#)

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)

