Rare Disease Day 2020 was a tremendous success for the ACDA. Together with The David Ashwell Foundation, we raised over $5,100! Our sincerest thanks to the families, friends, colleagues and classmates of the ACDA and The David Ashwell Foundation. Please read all the details on page 8!

Regards, Eliza Rista, President
The previously announced 2019 NORD grant (see Issue #67 of ACDA Notes) in the amount of $50,000 for ACDMPV research was recently awarded in April 2020 to Dr. Frances Flanagan at Boston Children’s Hospital in Boston, Massachusetts, USA for the study entitled, “Genetic determinants of ACD/MPV.”

As set forth in the statement of intent provided by Boston Children’s Hospital, “Identifying additional genetic etiologies of ACD/MPV is essential for non-invasive diagnosis, pre-natal counseling for subsequent pregnancies, for prognostication to avoid ineffective invasive or toxic therapeutic interventions, to determine genotype/phenotype correlations and to further understand the disease pathway and hence to potentially identify targeted therapies in the future.

In addition to the classic presentation of ACD, there are a small number of patients with late onset or less fulminant presentations that have been identified. Some of these patients have pathogenic mutations in FOXF1, but some do not have identified mutations. In those who do not have mutations in FOXF1 there may be genetic abnormalities in other genes involved in developmental pathways where FOXF1 is a key regulator. We hypothesize that many of these patients with a milder phenotype or patients with pathological features not fully consistent with ACD/MPV go unrecognized, as the pathological diagnosis of ACD/MPV can be difficult, especially in the setting of less fulminant presentations with patchy or focal findings leading to many in-determinant diagnoses. Understanding the genetic etiologies for these patients would be helpful to understand additional genes involved in the development of ACD like pathology, and allow more accurate disease categorizations.

As ACD/MPV is a rare condition, we plan to expand the significance of this project by including a cohort of patient with other severe disorders in lung growth and development, who presented in infancy with similar clinical features to ACD/MPV including hypoxemia, respiratory failure and/or pulmonary hypertension. These patients are found on lung biopsy or autopsy to have abnormalities in pulmonary alveolar development such as alveolar simplification and acinar dysplasia, or anomalies in pulmonary vasculature development, but do not meet the criteria for a diagnosis of ACD/MPV. Analysis of this cohort will inform our understanding of the alveolar stage in lung development and likely reveal an overlap between the genes involved in ACD/MPV and other disorders of alveolar growth and development.

In order to accomplish the aims of our study, we plan to capitalize on the expertise of our Pulmonary Genetics Center and the rich pathology sample biobank from our institution. Through our pathology laboratory database we have identified suitable pathology specimens from the following patient cohorts 1) patients with a pathological diagnosis of ACD/MPV, 2) patients with some, but incomplete pathologic features of ACV/MPV, and 3) patients with lung growth and developmental disorders…At our institution, we have access to the infrastructure and collaborations to carry out this and subsequent projects. In addition, if no gene variant is found via exome sequencing and analysis, we can move to performing whole genome sequencing in some of our patients, with the aim ultimately to lead to a genetic diagnosis for the majority of patients in our cohort with ACD/MPV and like disorders.”
It is the great pleasure of the ACDA and The David Ashwell Foundation to announce a $50,000 grant will be issued in 2020 for ACDMPV research. The ACDA announced the Request for Full Applications in May 2020 (see the box to the right for additional application information).

As background, over $650,000 has been issued for ACDMPV research with a total of twelve grants since 2005. Thank you for keeping the momentum going with annual ACDMPV research grants the last seven years in a row.

Every single dollar matters in rare disease research, perhaps more than ever as significant research developments regarding possible therapeutic approaches for ACDMPV are beginning to emerge, 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 $1,900,000+ grant awarded to Baylor College of Medicine from the NIH in 2017 for a four-year study. 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, off-roading events, softball tournaments, 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.

None of this would be possible without the hard work, contributions and fundraising efforts of families and friends affected by ACDMPV. We are deeply grateful for the support as we continue to work towards ending this disease.

ACDA Request for Full Applications – 2020 Research Grant:

The Alveolar Capillary Dysplasia Association (ACDA), on behalf of the ACDA and The David Ashwell Foundation, is currently accepting applications for a total of $50,000 for scientific research studies and/or clinical research studies related to Alveolar Capillary Dysplasia/misalignment of the pulmonary veins (ACDMPV). The ACDA encourages all U.S. and international researchers interested in studying ACDMPV to consider applying for 2020 funding. The Full Application Deadline is July 3, 2020. Contact president@acdassociation.org for the Full Application Details and Guidelines.
Journal Article (Am J Respir Crit Care Med.): The research team at Cincinnati Children’s Hospital Medical Center in Cincinnati, Ohio, USA (see section below and Issues #57, #62-63 and #68-69 of ACDA Notes) recently published a manuscript entitled, “Nanoparticle Delivery of Proangiogenic Transcription Factors into the Neonatal Circulation Inhibits Alveolar Simplification Caused by Hyperoxia” in the American Journal of Respiratory and Critical Care Medicine, which can be found HERE.

Abstract: RATIONALE: Advances in neonatal critical care have greatly improved the survival of preterm infants but the long-term complications of prematurity, including Bronchopulmonary dysplasia (BPD), cause mortality and morbidity later in life. While Vascular Endothelial Growth Factor (VEGF) improves lung structure and function in rodent BPD models, severe side effects of VEGF therapy prevent its use in BPD patients.

OBJECTIVES: To test whether nanoparticle delivery of proangiogenic transcription factors FOXM1 or FOXF1, both downstream targets of VEGF, can improve lung structure and function after neonatal hyperoxic injury.

MAIN RESULTS: [In mouse model], the nanoparticles efficiently targeted endothelial cells and myofibroblasts in the alveolar region. Nanoparticle delivery of either FOXM1 or FOXF1 did not protect endothelial cells from apoptosis caused by hyperoxia but increased endothelial proliferation and lung angiogenesis after the injury. FOXM1 and FOXF1 improved elastin fiber organization, decreased alveolar simplification and preserved lung function in mice reaching adulthood.

CONCLUSIONS: Nanoparticle delivery of FOXM1 or FOXF1 stimulates lung angiogenesis and alveolarization during recovery from neonatal hyperoxic injury. Delivery of proangiogenic transcription factors has promise as a therapy for BPD in preterm infants.” The FOXF1 itself could be potentially used in ACDMPV (avoiding potential questions about adverse effects of STAT3).

Journal Article (Am J Respir Crit Care Med.): Researchers at Children’s Hospital of Philadelphia (CHOP) and Stanford University School of Medicine recently published a discussion article about Dr. Kalinichenko and his colleagues’ recent research developments at Cincinnati Children’s (discussed above) entitled “Nanoparticle Delivery of Angiogenic Gene Therapy: Save the Vessels, Save the Lung!” which can be found HERE.

Despite questions regarding the timing, durability and the generalizability of this specific nanoparticle therapy as set forth therein, the authors conclude the observations reported by Dr. Kalinichenko and his colleagues “affirm the utility of nanoparticles to target the pulmonary vasculature.”

Journal Article (Am J Respir Crit Care Med.): The research team at Cincinnati Children’s Hospital Medical Center in Cincinnati, Ohio, USA (see section above and Issues #57, #62-63 and #68-69 of ACDA Notes) was recently published for their thematic poster session entitled, “Nanoparticle Delivery of STAT3 Alleviates Pulmonary Arterial Hypertension Caused by the S52F FOXF1 Mutation in Mouse Model of Alveolar Capillary Dysplasia” in the Abstract Issue for the ATS 2020 International Conference, which can be
found HERE.

Abstract: “Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV) is a rare, lethal congenital lung disorder which is associated with pulmonary arterial hypertension (PAH) and caused by mutations in FOXF1 gene. We have previously generated a mouse model of ACDMPV by inserting the S52F FOXF1 mutation (found in ACDMPV patient) into endogenous mouse Foxf1 gene locus. While S52F Foxf1 mice exhibit increased postnatal mortality, alveolar capillary dysplasia and misalignment of pulmonary veins similar to human ACDMPV, whether S52F Foxf1 mice develop PAH remains unknown. Methods: Echocardiography was performed to assess right ventricular hypertrophy and pulmonary artery velocity. Histology and qRT-PCR were used to evaluate expression of genes critical for PAH and lung remodeling. Nanoparticle delivery of FOXF1 target gene, STAT3, into neonatal circulation was performed to determine the efficacy of STAT3 gene therapy in S52F Foxf1 mice. Results: S52F Foxf1 mice exhibited PAH and right ventricular hypertrophy, which were associated with severity of alveolar capillary dysplasia. Expression of FOXF1 downstream target gene, STAT3, was decreased in pulmonary endothelial cells from S52F Foxf1 mice. PAH in S52F Foxf1 mice and human ACDMPV was associated with increased fibrotic depositions in alveolar regions. Using mouse chimeras we found that embryonic stem cells containing the S52F Foxf1 mutation aberrantly differentiated into myofibroblasts during postnatal lung development. Nanoparticle delivery of STAT3 into circulation of S52F Foxf1 newborn mice decreased lung fibrosis, alleviated PAH, reduced mortality of S52F Foxf1 mice and increased capillary density in lung tissue. Conclusions: The S52F Foxf1 mutation causes PAH and fibrosis in the neonatal lung. Nanoparticle delivery of STAT3 has a potential for treatment of human ACDMPV.”

Journal Article (Molecular Diagnostics): As an update to ACDA Notes #65 and #67, the genetic research team at Baylor College of Medicine in Houston, Texas, USA recently collaborated with an international team to publish a manuscript entitled, “Highly Sensitive Blocker Displacement Amplification and Droplet Digital PCR Reveal Low-Level Parental FOXF1 Somatic Mosaicism in Families with Alveolar Capillary Dysplasia with Misalignment of Pulmonary Veins” in the Journal of Molecular Diagnostics, which can be found HERE.

Abstract: “Detection of low-level somatic mosaicism [alternate allele fraction (AAF) ≤ 10%] in parents of affected individuals with the apparent de novo pathogenic variants enables more accurate estimate of recurrence risk. To date, only a few systematic analyses of low-level parental somatic mosaicism have been performed. Herein, highly sensitive blocker displacement amplification, droplet digital PCR, quantitative PCR, long-range PCR, and array comparative genomic hybridization were applied in families with alveolar capillary dysplasia with misalignment of pulmonary veins. We screened 18 unrelated families with the FOXF1 variant previously determined to be apparent de novo (n = 14), of unknown parental origin (n = 1), or inherited from a parent suspected to be somatic and/or germline mosaic (n = 3). We identified four (22%) families with FOXF1 parental somatic mosaic.
single-nucleotide variants \((n = 3)\) and copy number variant deletion \((n = 1)\) detected in parental blood samples and an AAF ranging between 0.03% and 19%. In one family, mosaic allele ratio in tissues originating from three germ layers ranged between <0.03% and 0.65%. Because the ratio of parental somatic mosaicism have significant implications for the recurrence risk, this study further implies the importance of a systematic screening of parental samples for low-level and very-low-level \((AAF \leq 1\%)\) somatic mosaicism using methods that are more sensitive than those routinely applied in diagnostics.”

**Journal Article (Stem Cell Res):**

A genetic research team at Sophia Children’s Hospital and Erasmus University Medical Center in Rotterdam, The Netherlands recently published a manuscript entitled, “Generation of three iPSC lines from two patients with heterozygous FOXF1 mutations associated to Alveolar Capillary Dysplasia with Misalignment of the Pulmonary Veins” in the Journal of Stem Cell Research, which can be found HERE.

**Abstract:** “Diagnosing Alveolar Capillary Dysplasia with Misalignment of the Pulmonary Veins (ACD/MPV) based on a genetic alteration in the FOXF1 gene, is complicated by the poor understanding of the causal relation between FOXF1 variants and the ACD/MPV phenotype. Here, we report the generation of human iPSC lines from two ACD/MPV patients, each carrying a different heterozygous FOXF1 mutation, which enables disease modeling for further research on the effect of FOXF1 variants in vitro. The iPSC lines were generated from skin fibroblasts using the non-integrating Sendai virus. The lines expressed pluripotency genes, retained the heterozygous mutation and were capable of trilineage differentiation.”

**Genetic Testing (Baylor):**

Since 2001, the ACDA has supported ACDMPV research at Baylor College of Medicine in Houston, Texas, USA. The ACDA encourages all newly registered members to donate DNA and tissue samples to the ACDMPV research team at Baylor in order to preserve all known samples in one central location and database. As such, Baylor has accumulated the largest collection of DNA and tissue samples related to ACDMPV in the world.

**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
Proclamation (Braylee Speed):

The County of Blount in the State of Tennessee, USA issued a Proclamation declaring February 13 as Alveolar Capillary Dysplasia Awareness Day in honor of Braylee Graylyn Speed. Thank you Speed family for all of your efforts.

NYPD Awareness Event (James Perrella):

As introduced in ACDA Notes #70, the NYPD hosted a Rare Disease Day Awareness Event on February 27, 2020 at NYPD Headquarters in New York City. Maria Catalano and Jimmy Perrella, ACDA parents to James (January 23, 2019 – February 15, 2019) were special guest speakers and shared a beautiful video and speech about their son, James. The ACDA was further represented by speaker, John Rista, ACDA father to Johnny (February 20, 2013 – March 4, 2013), and audience member, Bob Rilling, ACDA father to Fallon (October 10, 2013 – October 21, 2013).

The event also featured representatives from NORD, medical professionals from area hospitals, organ transplant specialists, law enforcement and other families touched by RDD. Our special thanks to the NYC Police Department for organizing this important event and the Catalano/Perrella family for inviting the ACDA. “Alone we are rare, together we are strong.”
Update on Rare Disease Day (February 29, 2020):

We are pleased to announce $3,803.44 was raised by the ACDA and an additional £1,144.85 was raised by our sister UK registered charity, The David Ashwell Foundation, for a grand total of $5,138 in connection with Rare Disease Day on February 29, 2020!! In addition to this amount, the family and friends of Caleb Carrigan also contributed an outstanding additional $9,229 (please read more on page 14). Our sincerest thanks to the families, friends, colleagues and classmates of the ACDA, The David Ashwell Foundation and Caleb Carrigan for raising such an incredible amount for ACDMPV research!

Please click HERE to check out our ACDA families and friends wearing the ACDA logo and #JeansForGenes on Rare Disease Day!

We would like to thank all of our individual donors and everyone who wore #JeansForGenes or sent pictures wearing the ACDA logo! Thank you for your outstanding support of our ACDA families.

In the U.S., we would like to give our very special thanks to:

- East Quogue Elementary School (East Quogue, NY)
- The Suffolk County District Attorney, Financial Investigations & Money Laundering Bureau (Hauppauge, NY)
- Suffolk County Department of Law (Hauppauge, NY)
- Suffolk County Budget Office & Management Office (Hauppauge, NY)
- Suffolk County Department of Audit & Control (Hauppauge, NY)
- Suffolk County Office of the Aging (Hauppauge, NY)
- Suffolk County Civil Service Department (Hauppauge, NY)

In the UK, we would like to give our very special thanks to:

- Handcross Park School
- Westons Pharmacy Brighton
- New Beginnings Nursery and Coomb Road School
- Mary Magdalene Catholic School
- Kirkby Great Broughton Church of England School & Nursery School
- Appleton Whiske School
- Manor House Surgery and Steel and Alloy Birmingham
The ACDA created flyers for use at workplaces and schools encouraging colleagues and classmates to donate $5 / £5 / €5 to wear jeans to work or school on February 29 for Rare Disease Day. The flyers can be modified for a Jeans Day at any time of year, contact the ACDA for help!

Below please find a “Thank You” badge for donations made on Rare Disease Day 2020 in your child’s honor:

(continued on next page)
International Bereaved Mother’s Day (May 3, 2020):

Love and light to our bereaved ACDA mothers this past International Bereaved Mother’s Day, which is observed annually on the first Sunday in May. It was created as part of the CarlyMarie Project to “educate society about the true meaning of Mother’s Day…it is a heart centered attempt at healing the official Mother’s Day.”

International Bereaved Father’s Day will be on Sunday, August 30, 2020 (observed on the last Sunday in August each year).
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](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.

**Update from NORD:**

The minimum amount required for the issuance of a 2021 NORD grant is $35,000.

**Balance of ACDA account:**

The balance of the ACDA bank accounts as of May 16, 2020 is **[Redacted]**.

**Update from AmazonSmile:**

The ACDA was issued a **[Redacted]** donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between October 1 and December 31, 2019. 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](http://smile.amazon.com/ch/46-2915711)

**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 HERE. The accrued commission payment from Spreadshirt between February 8, 2020 and March 11, 2020 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 **15% off** everything from May 27-28, 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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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](http://acdassociation.org/donate)

The ACD Association is a 501(c)(3) non-profit, tax-exempt organization as designated by the Internal Revenue Code of the United States.
Donate Button (Sadie McCasland):

Missing you, my Sadie Rose.

Candice and Bryan McCasland raised $264 through a Facebook Donate button in honor of their daughter, Sadie, on her sixth birthday.

On February 5, 2020, Candice McCasland, ACDA mom to Sadie (February 5, 2014 – February 19, 2014) added a Donate Button to her Facebook page for ACDMPV research in honor of Sadie. Thank you McCasland family!

Cocktail Night (Caleb Carrigan):

Cassie and Geoff Carrigan raised $9,229 for ACDMPV research in honor of their son, Caleb, through a fundraising event at a cocktail bar.

In February 2020, Cassie and Geoff Carrigan, ACDA parents to Caleb (August 9, 2019 - September 4, 2019), organized a fundraising event at District e11even cocktail bar in Colorado Springs, Colorado, USA. The fundraising efforts resulted in an outstanding total of $9,229 for ACDMPV research in honor of Caleb. Family, friends and colleagues attended to support the Carrigan family and, in addition to all of the individual donations, the bar donated 50% of the sales of food and alcohol that night to the ACDA. District e11even also donated rare whiskey bottles to auction off, which whiskey auction alone raised $3,480. In Cassie’s own words, “Thank you from the bottom of our hearts! We are so grateful. We feel loved, seen and supported through your generosity. Thank you for loving our boy Caleb even though he is not physically here. It means so much. We are humbled and speechless.” The ACDA also extends its sincere gratitude to the Carrigan family for supporting ACDMPV research in such a tremendous way.

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

$264 raised for Alveolar Capillary Dysplasia Association

Donate
Stephanie and Freddie Smith raised $1,925 through a Facebook Donate button in honor of their daughter, Finley, on her fifth birthday.

On March 18, 2020, Stephanie Smith, ACDA mom to Finley (March 18, 2015 - April 14, 2015) added a Donate Button to her Facebook page for ACDMPV research in honor of Finley.

In Stephanie’s own words, “Today Finley would be turning 5. While each birthday and special occasion is hard, this birthday seems extra hard. Five is such a milestone age. It makes me think of all the things she, and we, didn’t/don’t get to experience together. My little girl should be getting ready for Kindergarten registration in the next couple of weeks. But that will never happen, and it breaks my heart. Even though it hurts more than I can describe, I don’t want to focus on all the heartache. Instead, I want to focus on the one thing that makes my heart feel better, and that is remembering Finley’s purpose and how much of an impact her short life has made on this world.

First, she brought so much love into this world. Not only for Freddie and I, or our close family and friends, but to so many more. She brought us love from people we had never met before her existence: She brought us love from her wonderful caretakers at CMH. She brought us love from our ACDA family. She brought us love from other grieving families. And she brought us love from strangers that supported us.

Another impact her life has had on this world is helping others. In the first few years, with the help of loved ones and friends, we raised thousands and thousands of dollars for ACDA and Children’s Mercy Hospital in honor of Finley. Raising money on her behalf has always been such a healing experience for me. Knowing that she plays a part in helping to find a cure for ACDA so no other baby has to lose their life to this awful disease, and supporting the hospital that took such great care of her...and us, gives me so much joy. And finding joy after she was taken from us can be hard. So thank you to everyone that has supported us over the past five years with your outpouring of love and your generous donations.

Since selling our house, which had our wiffleball field, we haven’t had our wiffleball tournaments to raise money the last two years. For Finley’s 5th birthday I would love to make another BIG donation to ACDA. We would love it if you could donate, even if it is just a little, on behalf of our little girl for her 5th birthday. This is her legacy and we couldn’t make it happen without your support.

Thank you again from the bottom of our hearts for remembering and honoring Finley with us...today and everyday.”

The ACDA is grateful for the significant and sustained support by the friends and family of Finley Smith. Thank you.
Birthday Fundraiser (Merridith Kateridge):

Annette Botticello organized a birthday fundraiser for ACDMPV research in honor of Merridith Kateridge (March 9, 2017 – April 5, 2017), daughter of ACDA mom Alexis Kateridge. In Annette’s own words, “For my birthday this year, I’m asking for donations to Alveolar Capillary Dysplasia Association. My sweet pea was born 3 years ago and was taken from us far too soon. This association is near and dear to my heart 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.” Thank you to the family and friends of Merridith for your ongoing support of ACDMPV research!

10 for Phoebe’s 10th (Phoebe Bush):

Kim Anderson and Chris Bush raised $785 through an event called “10 for Phoebe’s 10th” Thank you Kim and Chris!

In March 2020, Kim Anderson and Chris Bush, ACDA parents to Phoebe (March 21, 2010 – April 21, 2010), organized a virtual 10K for ACDMPV research in honor of Phoebe. In Kim’s own words, “We are honoring Phoebe’s 10th birthday with a fundraiser/virtual 10K run, walk, hike, bike, or crawl. Suggested,

- 10K donation of $35 (roughly race entry fee) and can be made to the ACD Association.
- OR: $10 for Phoebe’s 10th.
- OR: Not a runner? Here are some other suggestions: 10 minutes a day of yoga or meditation, Walk 10 blocks, Hug 10 people or 10 random acts of kindness.

Can’t donate? Let us know what you are doing to remember Phoebe with us.”

Thank you, Kim and Chris, for all you’ve done for ACDMPV research in honor of your children.

Our ACDA families have organized very successful campaigns for the ACDA through Facebook birthday fundraisers and Donate buttons. Although the ACDA does not receive individual donor notifications, one hundred percent of funds donated through Facebook’s platform are passed on to the ACDA. Please see FAQs on our website with respect to Facebook fundraisers and Donate buttons.
Birthday Fundraiser (Aurora Splawn):

Darla Hensley raised $100 through a Facebook birthday fundraiser in honor of her granddaughter, Aurora Splawn. Thank you Darla!!

In May 2020, Tiffany Hensley and Dustyn Splawn, ACDA parents to Aurora (July 23, 2016 – August 6, 2016), supported a birthday fundraiser organized by Aurora’s grandmother for ACDMPV research in honor of Aurora. In Darla’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.” The ACDA is grateful for the support of our ACDA grandparents in honor of their grandchildren.

Banners:

If you would like to request use of a banner in the United States, please send an email to president@acdassociation.org to discuss sign-up for availability and shipping information.

Brochures:

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

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

Rack Cards:

Order an ACDA “rack card” with key facts about ACDMPV; click for ENGLISH.
A sad but warm welcome to the following newly registered families:
SAFE ARRIVALS!

Congratulations on the birth of the following little sibling in our ACDA registered family:

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)