ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org
WINTER 2020
Issue 70

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

1 Greeting
2 Rare Disease Day
3 Awareness News
4 Research News
5 Lung Transplant Updates
9 Fundraising News
13 Report from Stichting ACD (Netherlands)
15 Report from The David Ashwell Foundation (UK)
16 Remembering Our Babies and Welcome to New Families
17 Safe Arrivals and Connect With Us

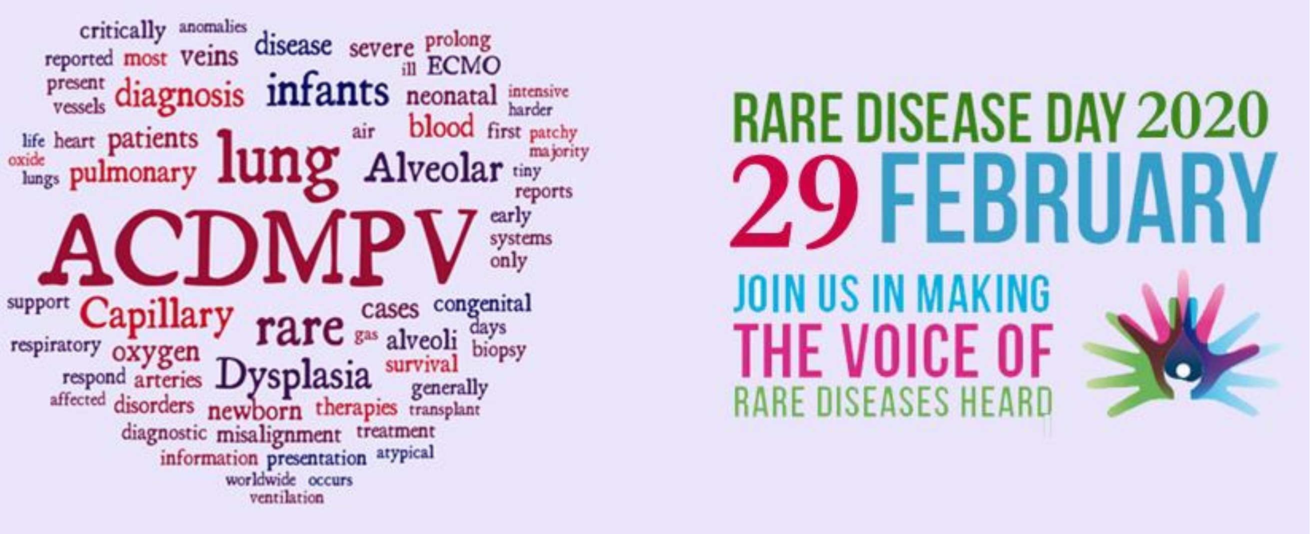
2019: Year in Review

As we take a look back at 2019:

- **Sixteen new families registered with the ACDA. These families are from the USA, the Netherlands, Germany, New Zealand and the UK.**
- **One NORD research grant in the amount of $50,000.**
- **Eight rainbow babies born to ACDA registered families.**
- **One participant in the British Transplant Games 2019.**
- **Two additional tattoos of the ACDA logo.**
- **More than fifteen journal articles published about ACDMPV, including the first articles suggesting possible therapeutic approaches pending the development of clinical trials.**
- **Numerous successful fundraisers for ACDMPV research and awareness events.**
- **One continued goal – To find the cause of and cure for ACDMPV.**

Regards, Eliza Rista, President

FEBRUARY 29, 2020 IS RARE DISEASE DAY



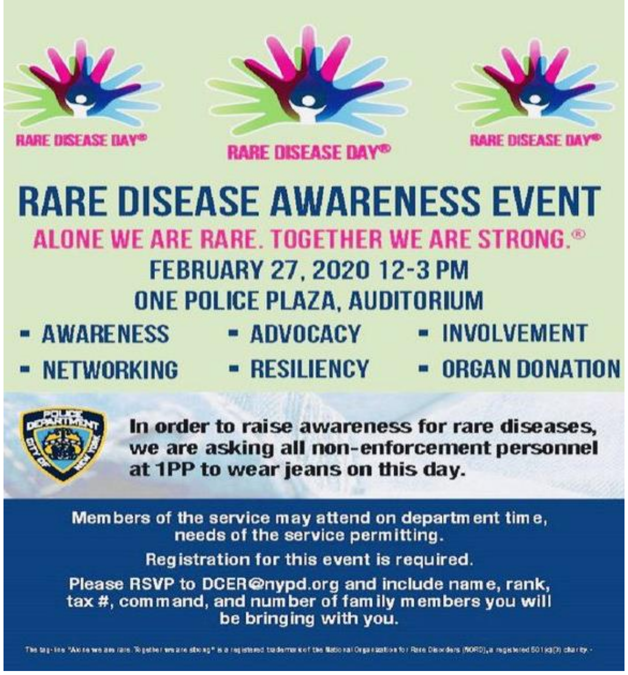
Rare Disease Day is an international advocacy day to bring widespread recognition of rare diseases. The day is celebrated on the last day of February every year – February 29 in 2020. The ACDA has signed on once again to partner with NORD to support this awareness campaign and we encourage everyone to participate in some way. **Click to see how the ACDA supported Rare Disease Day in prior years (2019, 2018, 2017 and 2016)!** Click HERE for ways to participate in the U.S. in 2020 and click HERE to visit EURORDIS for Rare Disease Day 2020 in Europe.

Below are a few suggested ideas:

- Click HERE ($), HERE (£) or HERE (€) to print a flyer for anyone to use at their workplace that encourages employees to donate $5 / £5 / €5 to the ACDA and wear jeans to work on Friday, February 28 for Rare Disease Day. **#JeansForGenes**
- Join a social media “rare disease day” campaign by changing your profile and cover pictures to share the importance of rare disease awareness! Click HERE to upload a photo and show how much you care about rare! Use the hashtags **#RareDiseaseDay**, **#ShowYourRare, #WRDD2020**, **#ACD**, **#ACDMPV**
- Organize a fundraiser to raise money for the next ACDMPV research grant.
- Contact your local newspaper to write an article about what Rare Disease Day means to you. Click HERE to read various articles previously written about our ACDA families.

AWARENESS NEWS

NYPD Awareness Event (James Perrella):



RARE DISEASE DAY® RARE DISEASE DAY® RARE DISEASE DAY®

RARE DISEASE AWARENESS EVENT

ALONE WE ARE RARE. TOGETHER WE ARE STRONG.®

FEBRUARY 27, 2020 12-3 PM

ONE POLICE PLAZA, AUDITORIUM

- AWARENESS
- ADVOCACY
- INVOLVEMENT
- NETWORKING
- RESILIENCY
- ORGAN DONATION

In order to raise awareness for rare diseases, we are asking all non-enforcement personnel at 1PP to wear jeans on this day.

Members of the service may attend on department time, needs of the service permitting.

Registration for this event is required.

Please RSVP to DCER@nypd.org and include name, rank, tax #, command, and number of family members you will be bringing with you.

John Rista, ACDA father to Johnny (February 20, 2013 – March 4, 2013), will briefly speak on behalf of the ACDA at the upcoming **Rare Disease Day Awareness Event** hosted by the **NYPD** in **New York City** on **Thursday, Feb. 27, 2020**. **Maria Catalano**, ACDA mother to James Perrella (January 23, 2019 – February 15, 2019), is a **featured guest speaker** and will share about her and **Jimmy Perrella**'s son, James, and their experience with ACDMPV.

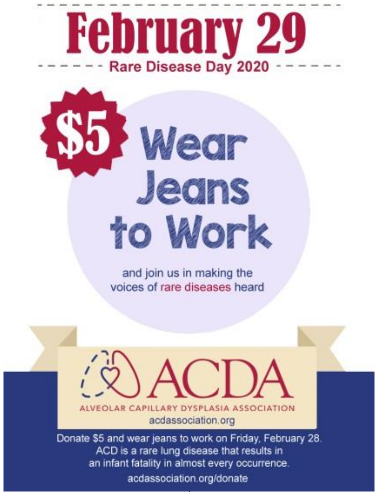
The event will also feature representatives from NORD, medical professionals from area hospitals, organ transplant specialists, law enforcement and other families touched by RDD. **Bob Rilling**, ACDA father to Fallon (October 10, 2013 – October 21, 2013), will also be in attendance in support of the ACDA and the Catalano/Perrella family.

Our special thanks to the NYC Police Department for organizing this important event and the Catalano/Perrella family.

Wear Jeans to Work Flyers:

As referenced on page 2, **the ACDA has created flyers for anyone to use at their workplace that encourages employees to donate $5 / £5 / €5 to the ACDA and wear jeans to work on Friday, February 28 for Rare Disease Day.** Click HERE ($), HERE (£) or HERE (€) to print or email the full size images. We hope you will consider asking your workplace to participate! This was a terrific awareness event and fundraiser last year on Rare Disease Day.

Donations can be submitted individually or collectively at **acdassociation.org/donate** and we are happy to track the amounts donated in your child's honor.



February 29

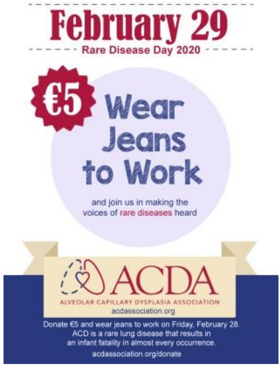
Rare Disease Day 2020

$5 Wear Jeans to Work

and join us in making the voices of rare diseases heard

ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org

Donate $5 and wear jeans to work on Friday, February 28.
ACD is a rare lung disease that results in
an infant fatality in almost every occurrence.
acdassociation.org/donate



February 29

Rare Disease Day 2020

€5 Wear Jeans to Work

and join us in making the voices of rare diseases heard

ACDA
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acdassociation.org

Donate €5 and wear jeans to work on Friday, February 28.
ACD is a rare lung disease that results in
an infant fatality in almost every occurrence.
acdassociation.org/donate

February 29

Rare Disease Day 2020

£5 Wear Jeans to Work

and join us in making the voices of rare diseases heard

ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org

Donate £5 and wear jeans to work on Friday, February 28.
ACD is a rare lung disease that results in
an infant fatality in almost every occurrence.
acdassociation.org/donate

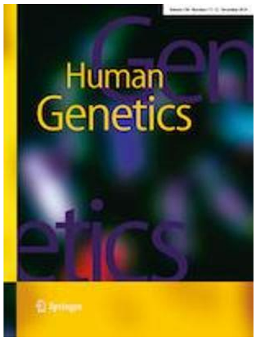
Families in the News (Barrett Bone):

Katy and Tyler Bone, ACDA parents to Barrett (June 14, 2019 – July 12, 2019), recently shared their beautiful story about Barrett in Love What Matters. Please read their touching story below:

‘It’s okay, baby, you can go.’ With tear-filled eyes, we held our little boy’s body as his soul went peacefully to Heaven to join his big brother.’: Parents lose newborn to Alveolar Capillary Dysplasia

RESEARCH NEWS

Journal Article (Hum Genet.):



The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently collaborated with an international team to publish a manuscript entitled, “*Association of rare non-coding SNVs in the lung-specific FOXF1 enhancer with a mitigation of the lethal ACDMPV phenotype.”* in Human Genetics, which can be found HERE.

From the article, “Here, we propose that rare non-coding SNVs, mapping within a 2 kb segment of the enhancer core, might have delayed the onset of ACDMPV or prevented development of lethal ACD features caused by FOXF1 deficiency.”

“In sum, our studies suggest that rare non-coding SNVs present within a regulatory region of a disease-implicated FOXF1 might modify the expressivity and/or the penetrance of the lethal ACDMPV phenotype. They also pinpoint the underappreciated role of non-coding variants in congenital disorders. Finally, they continue to strengthen the observation that almost 90% of disease-associated SNVs identified in genome-wide association studies do not localize to protein-coding sequences.”

Journal Article (J Med Genet.):

Genetic research teams at the University of Rochester in Rochester, New York, USA recently collaborated with the genetic research team at Baylor College of Medicine in Houston, Texas, USA to publish a manuscript entitled, “*Disruption of normal patterns of FOXF1 expression in a lethal disorder of lung development”* in the Journal of Medical Genetics, which can be found HERE.

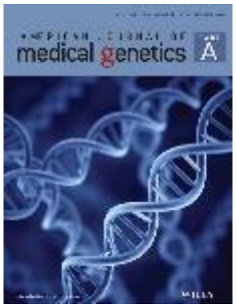
Abstract: “BACKGROUND: ACDMPV is associated with haploinsufficiency of the transcription factor FOXF1, which plays an important role in the development of the lung and intestine. CNVs upstream of the FOXF1 gene have also been associated with an ACDMPV phenotype, but mechanism(s) by which these deletions disrupt lung development are not well understood. The objective of our study is to gain insights into the mechanisms by which CNVs contribute to an ACDMPV phenotype.

METHODS: We analysed primary lung tissue from an infant with classic clinical and histological findings of ACDMPV and harboured a 340 kb deletion on chromosome 16q24.1 located 250 kb upstream of FOXF1.

RESULTS: In RNA generated from paraffin-fixed lung sections, our patient had lower expression of FOXF1 than age-matched controls. He also had an abnormal pattern of FOXF1 protein expression, with a dramatic loss of FOXF1 expression in the lung. To gain insights into the mechanisms underlying these changes, we assessed the epigenetic landscape using chromatin immunoprecipitation, which demonstrated loss of histone H3 lysine 27 acetylation (H3K27Ac), an epigenetic mark of active enhancers, in the region of the deletion.

CONCLUSIONS: Together, these data suggest that the deletion disrupts an enhancer responsible for directing FOXF1 expression in the developing lung and provide novel insights into the mechanisms underlying a fatal developmental lung disorder."

Journal Article (Am J Med Genet A.):



The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently collaborated with an international team to publish a manuscript entitled, "*A recurrent 8 bp frameshifting indel in FOXF1 defines a novel mutation hotspot associated with alveolar capillary dysplasia with misalignment of pulmonary veins"* in the American Journal of Medical Genetics, which can be found HERE.

Abstract: "Alveolar capillary dysplasia with misalignment of pulmonary veins (ACDMPV) is a rare lethal lung developmental disease. Affected infants manifest with severe respiratory distress and refractory pulmonary hypertension and uniformly die in the first month of life. Heterozygous point mutations or copy-number variant deletions involving FOXF1 and/or its upstream lung-specific enhancer on 16q24.1 have been identified in the vast majority of ACDMPV patients. We have previously described two unrelated families with a de novo pathogenic frameshift variant c.691_698del (p.Ala231Argfs*61) in the exon 1 of FOXF1. Here, we present a third unrelated ACDMPV family with the same de novo variant and propose that a direct tandem repeat of eight consecutive nucleotides GCGGCGGC within the ~4 kb CpG island in FOXF1 exon 1 is a novel mutation hotspot causative for ACDMPV."

LUNG TRANSPLANT UPDATES

Live Donor Single Lobe Lung (Japan):

Although the family has not contacted or registered with the ACDA yet, a case report was published in December 2019 about a six year old boy (unconfirmed location believed to be Japan) who underwent a single-lobe lung transplantation with the right lower lobe from his mother. See the manuscript entitled "*Living-donor single-lobe lung transplantation for pulmonary hypertension due to alveolar capillary dysplasia with misalignment of pulmonary veins"* in the American Journal of Transplantation, which can be found HERE.

Abstract: "This is a case report of successful single-lobe lung transplantation for pulmonary hypertension secondary to alveolar capillary dysplasia with misalignment of pulmonary veins (ACD/MPV). A 6-year-old boy underwent living-donor single-lobe transplantation with the right lower lobe from his 31-year-old mother."

FUNDRAISING NEWS

Donations:

To make a secure tax deductible donation to the ACDA or the NORD Research Fund (ACD), please visit our website for full instructions.

acdassociation.org/donate

The ACDA is a 501(c)(3) non-profit, tax-exempt organization as designated by the Internal Revenue Code of the United States.

Update from NORD:

The minimum amount required for the issuance of a 2020 NORD grant is $35,000.

Balance of ACDA account:

The balance of the ACDA bank accounts as of February 7, 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 July 1 and September 30, 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

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 October 12, 2019 and February 7, 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 20% off everything from February 12-14, 2020!**

Donations Received:

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

[redacted]	[redacted]
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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.*

#GivingTuesday Update:

WOW. The ACDA's fundraising goal for #GivingTuesday on December 3, 2019 was $1,000 and, with your help, we were able to bring in over **$2,500 (with a total of 28 different honorees, see the list below)**!!

One day, one mission, one BIG thank you. We give our thanks to those who donated to the ACDA on #GivingTuesday. The money raised will be contributed directly to ACDMPV research and supports the efforts of the medical community to find the cause of and cure for ACDMPV.

Our gratitude extends not only to our amazing donors but to each and every person who shared a post or email to spread awareness, asked their family and friends to consider a donation or helped in any possible way to make our #GivingTuesday campaign a huge success in 2019.

Thank you for the generous #GivingTuesday donations in honor of *Sadie McCasland, Finley Smith, Luca Palmisano, Ronan Bush, Phoebe Bush, Caleb Carrigan, Griffin Brady, Alex Cummins, Johnny Rista, Xavier Parker, Barrett Bone, Annabelle Logue, Dean Grant, Callie Murray, Brando Nascimento lins, Ayla Prushansky, Fallon Rilling, Ezekiel Smith, Chelsea Cole, Isaac McKeever, Dawson Nye, Noah Butler, Xavier Kaczynski, Amelia Weaver, Caleb Highley, Ethan Kimberlin, Jackson Camariotes and Garrett Powell.*

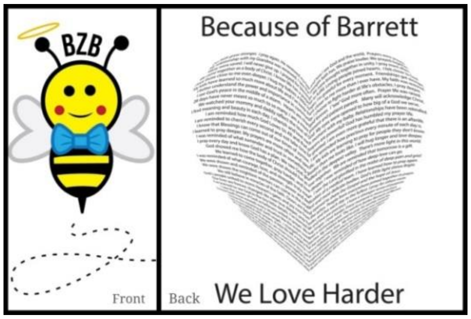
Safelite AutoGlass (Callie Murray):

Safelite AutoGlass Foundation donated $2,500 to the ACDA in honor of Callie Murray

The ACDA would like to extend its sincere appreciation to Safelite AutoGlass Foundation for its **$2,500 donation to the ACDA in honor of Callie Murray** (May 15, 2015 – May 23, 2015), daughter of ACDA parents Renee and Jason Murray. Please read the story below in Renee's own words.

Renee and Jason's friend "explained that the company he works for (Safelite Auto Glass) is family owned and oriented. He said they truly believe in giving back and through the Safelite Foundation, they have a BIG GIVE Campaign. Earlier in the month their District Manager, Joe Rotolo, asked the team if anyone knew of an organization that could benefit from a donation from Safelite. Ben with the help of Jaime told Callie's story and how the Alveolar Capillary Dysplasia Association could greatly benefit from a donation to fund research as they work to find a cure. In a quick amount of time, Safelite came through, showing by example what a true caring heart can look like. In a short amount of time, Ben's request came back approved and a check in the amount of $2,500 was on its way to the ACDA! Ben shared how **touched everyone was by hearing Callie's story and learning how we continue to raise awareness and celebrate her.**"

T-Shirt & Jewelry fundraisers (Barrett Bone):



Shirts in honor of Barrett Bone - the heart is comprised of personal responses as to how Barrett changed lives

In addition to their awareness efforts featured on page 3, Katy and Tyler Bone, ACDA parents to Barrett (June 14, 2019 – July 12, 2019), are also **raising funds for ACDMPV research in Barrett's honor**. As introduced in Issue #69 of ACDA Notes, they worked with a designer to create shirts for Barrett and **$500** in proceeds from the sales was contributed to the ACDA on December 3, 2019 for #GivingTuesday in honor of Barrett. In addition, the Bones raised **$250** through a live jewelry sale party hosted by Pretty Little Things on September 28, 2019. The event included accessories and freebies with a portion of the sales donated to the ACDA in honor of Barrett. Thank you, Bone family!

SEP 28 In Honor of Barrett — FUNDRAISING EVENT
Public · Hosted by Pretty Little Things

$250 was raised through a jewelry event in honor of Barrett Bone

Jewelry fundraiser (Callie Murray):


DECEMBER 7 @ 7PM CST/8PM EST

In Honor of Callie

PORTION OF SALES WILL GO TO THE ACD ASSOCIATION

DEC 7 In Honor of Callie—Fundraising EVENT

Public · Hosted by Pretty Little Things

$150 was raised through a live jewelry sale in honor of Callie Murray!

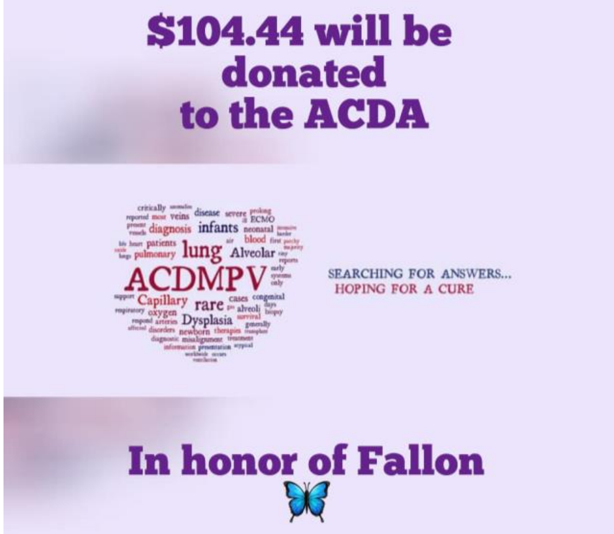
Renee Murray, ACDA mother to Callie (May 15, 2015 – May 23, 2015), raised **$150** through a live jewelry sale party on December 7, 2019 hosted by Pretty Little Things. Inspired by Katy Bone's successful event above, Renee organized a similar event with a portion of the sales donated to the ACDA in honor of Callie. In Renee's own words, "We are planning our next fundraiser for the Alveolar Capillary Dysplasia Association in a fun and dynamic way. ACD is the rare disease that took our daughter, Callie's life at only 8 days old. We desperately want a cure and fundraising helps us get closer to that and also helps us celebrate her." Thank you, Renee!

School Fundraiser (Imogen Bolton):

In December 2019, **Aliessia, age 14,** daughter of ACDA mom Hayley Bolton and older sister of lung transplant recipient Imogen Bolton, independently organized a fundraiser at her school to raise funds for ACDMPV research. She made and sold little hot chocolate cones, cakes and other bits and bobs. Aliessia also displayed the massive poster she created in the past explaining all about ACDMVP and Imogen's story. **She raised £35 ($45)** on 48 hours notice!! The ACDA is so incredibly proud of this young lady's hard work and continued dedication to ACDMPV research!

Color Street Nail Fundraiser (Fallon Rilling):

In January 2020 with a beautiful collaboration between two ACDA mothers, **$104.44** was raised in honor of **Fallon Rilling** through a **Color Street fundraiser**! Susan Logue, ACDA mother to Annabelle (September 26, 2013 – October 25, 2013) was the stylist for a Color Street nail bar hosted by Kristen Rilling, ACDA mother to Fallon (October 10, 2013 – October 21, 2013) in honor of Fallon. In Susan's own words, "This cause is so important to me because I have also lost a child to Alveolar Capillary Dysplasia. So let's raise some money for a great cause and get some awesome looking nails at the same time!!"



Birthday Fundraiser (Markiewicz family):

[redacted] Allen's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association

by [redacted]

Fundraiser Ended

Thanks to everyone who donated!

Allen raised $60 through a Facebook birthday fundraiser in honor of AJ, Shannon and Noah Markiewicz. Thank you, Allen!

In October 2019, **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 50th Birthday on Sunday. I am asking everyone to please donate to a wonderful cause that I have been a part of since 1999 after my beloved daughter, Shannon Alyane Markiewicz, was diagnosed with ACD. These babies should never die before their parents. 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. I've included information about Alveolar Capillary Dysplasia Association below. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder."

Birthday Fundraiser (Barrett Bone):

[redacted] Kelli's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association

by [redacted]

Fundraiser Ended

Kelli reached her birthday goal! Thanks to everyone who donated.

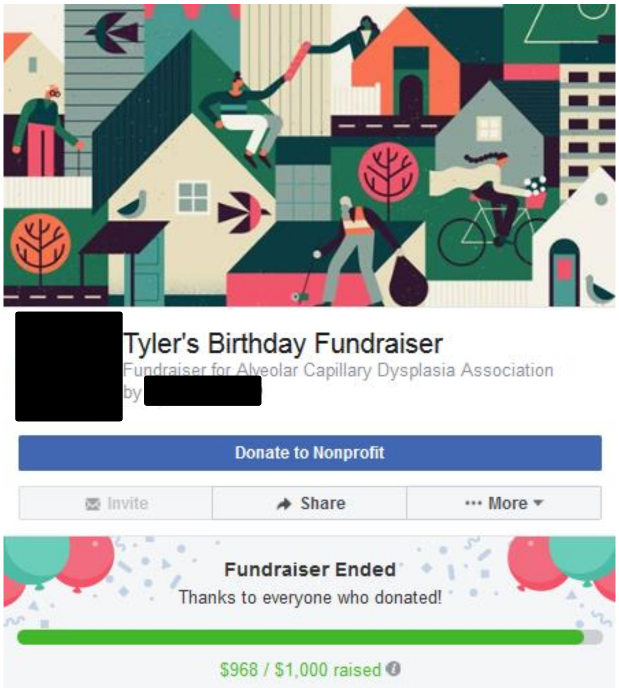
$435 / $400 raised

Kelli exceeded her goal by raising $435 through a Facebook birthday fundraiser in honor of Barrett Bone. Thank you, Kelli!

In October 2019, **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, "For my birthday this year I would like to honor the life and legacy of Barrett Zachary Bone. 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. I've included information about Alveolar Capillary Dysplasia Association below. 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):


[redacted]

Tyler's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association

by [redacted]

Fundraiser Ended

Thanks to everyone who donated!

$968 / $1,000 raised

Tyler raised almost $1,000 through a Facebook birthday fundraiser in honor of his son, Barrett Bone. Thank you, Tyler!

In October 2019, **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, "This would mean the world to me. To find treatment and possibly screening and an answer as to why this rare disease exists. In Barrett's memory. So that no other infant goes through what my son did. 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. I've included information about Alveolar Capillary Dysplasia Association below. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder.

Birthday Fundraiser (Barrett Bone):


[redacted]

Katy's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association

by [redacted]

Fundraiser Ended

Katy reached her birthday goal! Thanks to everyone who donated.

$1,555 / $1,000 raised

Katy exceeded her original $1,000 goal by raising $1,555 through a Facebook birthday fundraiser in honor of her son, Barrett Bone. Thank you, Katy!

In January 2020, **Katy Bone**, mother to Barrett (June 14, 2019 – July 12, 2019), organized a birthday fundraiser for **ACDMPV research in honor of Barrett Bone**. In Katy's own words, "This year is my 30th birthday and I had imagined my birthday much different than this. Please consider donating to this organization and help us find a cure. Every parent's worst nightmare is for their child to die so please let's help find a cure so other parents don't have to endure this pain. Any amount helps. Thank you from the bottom of my heart. This would mean the world to me….To find treatment and possibly screening and an answer as to why this rare disease exists. In Barrett's memory. So that no other infant goes through what my son did. 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."

Birthday Fundraiser (Kaylin Cone):

[redacted]

Jacob's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association by [redacted]

1 Week Left

Help Jacob reach his birthday goal!

$325 / $350 raised

Jacob has *almost* reached his $350 goal by raising $325 (with a week left to donate!) through a Facebook birthday fundraiser in honor of his sister, Kaylin Cone. Thank you, Jacob!

In January 2020, **Jacob Cone**, ACDA sibling to Kaylin (February 7, 2000 – February 21, 2000), organized a birthday fundraiser for **ACDMPV research in honor of his sister, Kaylin Cone**. In Jacob's own words, "In honor of my sister Kaylin Marie Cone this year for our birthday. (Born on the same day 4 years apart) 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. I've included information about Alveolar Capillary Dysplasia Association below. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder. Kaylin Marie Cone (Feb 7th, 2000-Feb 21st, 2000)."

Birthday Fundraiser (Merridith Kateridge):

[redacted]

Jimm's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association by [redacted]

2 Weeks Left

Help Jimm reach his birthday goal!

$105 / $200 raised

Jimm is over halfway to his $200 goal (with two weeks left to donate!) through a Facebook birthday fundraiser in honor of his niece, Merridith Kateridge. Thank you, Jimm!

In February 2020, **Jimm Albert** organized a birthday fundraiser for **ACDMPV research in honor of his niece, Merridith Kateridge** (March 9, 2017 – April 5, 2017), daughter of ACDA mom Alexis Kateridge. In Jimm's own words, "A few years ago my beautiful and wonderful niece Merridith was born with this unfortunate ailment. She fought hard until the very end. Every day she is missed. So 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."

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

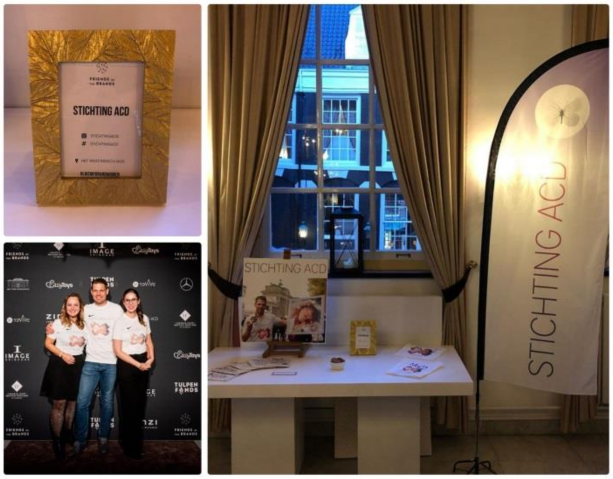
REPORT FROM STICHTING ACD (NETHERLANDS):

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, including his upcoming marathon in Chicago, USA in October 2020!** For additional information about the upcoming runs highlighted below, please visit Run4ACD on Stichting ACD’s website.

TCS Amsterdam Marathon Kids Run (October 20, 2019):

Mathijs and **kids** from team Stichting ACD ran the **TCS Amsterdam Marathon Kids Run on October 20, 2019** to raise ACDMPV awareness! The Kids Run is a children’s run that takes place during the TCS Amsterdam Marathon. Children aged 4 to 12 can participate in the 700-metre run, which starts behind the stadium and finishes in the stadium itself. A particularly proud moment for Mathijs was watching **his young son, Alec, participate in the event in honor of Alec’s sister, Myla.**

Friends of the Brands (November 2019):



Friends Of The Brands brings bloggers, influencers and celebrities in contact with all kinds of (new) brands. In addition, they always work together with a good cause. Friends of the brands: Like My Brand Women 2019 featured Stichting ACD! Mathijs introduced Stitching ACD and made a wonderful speech. Read an article HERE in Style My Day.

NN Marathon Rotterdam (April 5, 2020):

NN MARATHON ROTTERDAM

Approved by Like2Run

Upcoming Event: Mathijs and Stichting ACD will run the **Rotterdam marathon on April 5, 2020 for the fourth year in a row**. The ACDA sends our very best to Mathijs and the team of Stichting ACD runners in Rotterdam. We look forward to providing pictures and an update in the next newsletter!

Chicago Marathon (October 11, 2020):

BANK OF AMERICA Chicago Marathon.

Upcoming Event: Chasing the dream to cross the world with Myla! Mathijs is coming to the USA!! In his own words, "I am selected for the **Chicago Marathon** on **October 11, 2020**! I am really, really excited and this means that my dream to run the world with Myla for ACDMPV gets a great continuation after Rotterdam, Amsterdam and Berlin. I know it's still a long time, but **does anybody want to meet and join the team** then? Together we stand stronger! About logistics: Can anyone help us a bit regarding the city? Any suggestions about staying in the right part of the city maybe to find a decent hotel? We will go with 5 people, so maybe Airbnb is a nice solution? In which part of the city?" Please contact Mathijs at contact@stichtingacd.nl if you want to join the team, cheer him on or can help with the logistics!

Bracelets for Myla's 4th Birthday:

Jessica Anderson, ACDA mom to Myla, and Mathijs worked on a cool collaboration for a fundraiser for Myla's 4th birthday in November 2019. Bracelets specially made for Myla's birthday and featuring special mantras were sold for € 9,95 each with all proceeds going to Stichting ACD. *Be Brave, You Rock, Stay True, Be You, Shine On, Be Love.* This is such a beautiful way to raise funds for ACDMPV research in honor of Myla! (Special note: Curious about how old Myla has become? Count the small beads.)

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. If you would like your child to be included in the gallery, please contact Mathijs at contact@stichtingacd.nl and send him a picture with full name, birth date and angel date.

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 planning on organizing a 10th birthday ceilidh for David in North Yorkshire in March 2021. Aside from events, 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.

We are now up to **£2,749.87** since our donation to NORD ACDMPV research fund in April 2019. So a lot more to raise before the next donation. **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 fundraise 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

REMEMBERING OUR BABIES

[redacted]

[redacted]

[redacted]

[redacted]

Welcome to New Families

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

[redacted]

[redacted]

Safe Arrivals!

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

[redacted]

[redacted]

[redacted]

[redacted]

- [redacted]
- [redacted]
- [redacted]

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)