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

This year we are focusing on grief over time, as written in the words of our ACDA parents.

If you would like to participate, send a brief email to president@acdassociation.org answering the two questions below by SUNDAY, SEPTEMBER 20:

- 1. Complete this sentence (20 words or less): "Grief is \_\_\_\_\_."
- 2. Date (Month/Year) you lost your child(ren) to ACDMPV: (example: March 2013)

The purpose of this written word project is to tell a broader story about what grief looks like over time. We want to use your collective words and experiences to paint a picture of grief at many different stages of life. You may be struggling with the profound sadness of the first anniversary of loss or you may be grappling with decades old fears as you prepare for your rainbow baby to give birth to your first grandchild. You may have hope you want to share as to how your grief has transformed over time. No matter how you are feeling, we want to give a voice as to what grief means to you at the precise stage of life you are in at this moment.

All submissions will then be assembled into one compilation (without names but with the corresponding date of loss next to each quote) and posted on our website, social media and the upcoming newsletter. We hope you will participate and look forward to sharing the final version of this special project next month for Pregnancy and Infant Loss Awareness.



#### **RESEARCH NEWS**

#### Patent Application (Cincinnati Children's):



The research team at **Cincinnati Children's** Hospital

Medical Center in Cincinnati, Ohio, USA (see below and Issues #57, #62-63, #68-69 and #71 of ACDA Notes) filed for a patent to protect the following invention, which published application can be found HERE.

Title: Polyethylenimine Nanoparticles and Methods of Using Same (United States Patent Application 20200206134)

Filed: July 17, 2018

Publication date: July 2, 2020

Abstract: "Disclosed herein are nanoparticle compositions containing that may be created by functionalizing polyethylenimine (PEI) with fatty acids and carboxylate terminated poly(ethylene glycol) (PEG). The disclosed compositions may be delivered to an individual in need thereof via delivery into blood circulation, where the nanoparticle compositions show exceptionally high specificity to the pulmonary microvascular endothelium with targeting of other cell types in the lung, to provide delivery of therapeutic agents such as stabilized nucleic acids. Methods of using the compositions are also disclosed."

### Journal Article (Curr Stem Cell Rep):



The research team at **Cincinnati Children's** Hospital Medical Center in Cincinnati, Ohio, USA (see above and Issues #57, #62-63, #68-69 and #71 of ACDA Notes) recently published a

manuscript entitled, "Genome Editing for Rare Diseases" in the Journal of Current Stem Cell Reports, which can be found HERE.

**"Purpose of the Review:** Significant numbers of patients

worldwide are affected by various rare diseases, but the effective treatment options to these individuals are limited. Rare diseases remain underfunded compared with more common diseases, leading to significant delays in research progress and ultimately, to finding an effective cure. Here, we review the use of genome editing tools to understand the pathogenesis of rare diseases and develop additional therapeutic approaches with a high degree of precision.

Recent Findings: Several genome-editing approaches, including CRISPR/Cas9, TALEN, and ZFN, have been used to generate animal models of rare diseases, understand the disease pathogenesis, correct pathogenic mutations in patient-derived somatic cells and iPSCs, and develop new therapies for rare diseases. The CRISPR/Cas9 system stands out as the most extensively used method for genome editing due to its relative simplicity and superior efficiency compared with TALEN and ZFN. CRISPR/Cas9 is emerging as a feasible gene-editing option to treat rare monogenic and other genetically defined human diseases.

**Summary:** Less than 5% of ~ 7000 known rare diseases have FDA-approved therapies, providing a compelling need for additional research and clinical trials to identify efficient treatment options for patients with rare diseases. Development of efficient genome-editing tools capable to correct or replace dysfunctional genes will lead to novel therapeutic approaches in these diseases."

#### Journal Article (Pediatr Res):



A genetic research team at Erasmus University Medical Center in Rotterdam, The Netherlands recently published a manuscript entitled, "Fast detection of FOXF1



variants in patients with alveolar capillary dysplasia with misalignment of pulmonary veins using targeted sequencing" in the Journal of Stem Cell Research, which can be found HERE.

"BACKGROUND: The aim of this study was to reduce the time to diagnose ACDMPV by developing a targeted next-generation sequencing (NGS) panel that detects FOXF1 variants.

**METHODS**: A FOXF1-targeted NGS panel was developed for detection of mutations and large genomic alterations and used for retrospective testing of ACDMPV patients and controls. Results were confirmed with Sanger sequencing and SNP array analysis.

**RESULTS**: Each amplicon of the FOXF1-targeted NGS panel was efficiently sequenced using DNA isolated from blood or cell lines of 15 ACDMPV patients and 8 controls.

**CONCLUSION**: We successfully designed a fast and reliable targeted genetic test to detect variants in the FOXF1 gene and its regulatory region in one run."

#### **AWARENESS NEWS**

University of Florida College of Medicine presentation (Christopher Locke):

Diana Locke, a Registered Nurse and ACDA mom to Christopher (November 7, 2006 - December 17, 2006), gave her annual presentation to approximately 150 first year medical students (via Zoom this year due to COVID-19 but approximately 130 students attended on video and 20-30 in the physical auditorium) at the University of Florida College

of Medicine in Gainesville, Florida, USA on August 25, 2020. The presentation focused on ACDMPV, Christopher's case and other ACDMPV babies. With this program, future doctors now

know about ACDMPV.

This is the **12**<sup>th</sup> **year** that Diana has given the annual presentation at University of Florida College of Medicine. The ACDA sincerely appreciates Diana's teaching presentations to these future medical professionals.

## August 19, 2020 - Day of Hope

"August 19th is about coming together as a whole community to openly speak about these children and celebrating their short lives. Each year thousands of people around the globe take part in The Day Of Hope by hanging up prayer flags in honour of their babies and children that have died. Many people also share our Prayer Flag awareness images on facebook, instagram, twitter and other social networks." From the CarlyMarie Project.







Above prayer flags lovingly created for a prior August 19th "Day of Hope" by:

Candice McCasland (top), ACDA mom to Sadie (Feb 5, 2014 – Feb 19, 2014)

Renee Murray (left), ACDA mom to Callie (May 15, 2015 – May 23, 2015)

Jessica Miller (right), ACDA mom to Hannah (Dec 4, 2013 – Dec 10, 2013)



## **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, taxexempt organization as designated by the Internal Revenue Code of the United States.

#### **Update from NORD:**

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

#### Balance of ACDA account:

The available balance of the ACDA bank accounts as of August 31, 2020 is

#### Update from AmazonSmile:

The ACDA was issued a donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between January 1 and March 31, 2020. 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

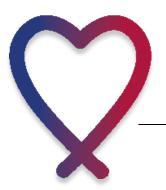
#### **Update from Spreadshirt:**

Our **Spreadshirt** store recently was 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 March 12, 2020 and August 1, 2020 is Please continue to shop at our store as new items and new features are added regularly. You have the option to customize your products by choosing "Create," including adding your child's name or picture to most items featuring the ACDA logo. Don't forget the ACDA earns a commission equal to 20% of every product sold! Look for free standard shipping September 14-15, 2020!

#### **Donations Received:**

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

Donor	In Memory Of







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

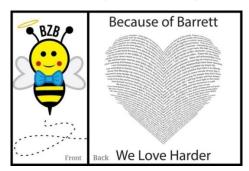
## Impromptu Fundraiser (Fallon Rilling):

# In honor of Fallon

On June 27, 2020, an impromptu fundraiser was arranged by friends and acquaintances of Kristen and Bob Rilling, ACDA parents to Fallon (October 10, 2013 – October 21, 2013). Thirty-one donations were swiftly made and totaled an

amazing **\$692.44** in support of the Rilling family. Thank you to everyone who contributed.

## T-Shirt fundraiser (Barrett Bone):



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

Katy and Tyler Bone, ACDA parents to Barrett (June 14, 2019 – July 12, 2019), continue to raise funds for ACDMPV research in Barrett's honor! As introduced in Issue #69 and updated in Issue #70 of ACDA Notes, the Bone family worked with a designer to create shirts for Barrett and another \$400 in proceeds from the sales was contributed to the ACDA on July 10, 2020. This is in addition to the previous \$500 from the t-shirts sales donated on #GivingTuesday2019 in honor of Barrett. Thank you, Bone family!

#### Birthday Fundraiser (Lacey Boothroyd):



Fundraiser for Alveolar Capillary

Dysplasia Association by

Public

Emma raised £90 through a Facebook birthday fundraiser in honor of her daughter, Lacey.

Thank you, Emma!

In spring 2020, **Emma Smith**, ACDA mother to Lacey (July 26, 2015 - August 12, 2015),



organized a birthday fundraiser for ACDMPV research in honor of Lacey Boothroyd.

## Birthday Fundraiser (Merridith Kateridge):



Anthony raised an outstanding \$500 through a Facebook birthday fundraiser in honor of his daughter, Merridith Kateridge.
Thank you, Anthony!

In August 2020, **Anthony Kateridge**, ACDA father to Merridith (March 9, 2017 – April 5, 2017), organized a birthday fundraiser for **ACDMPV research in honor of Merridith Kateridge**. In Anthony's own words, "For my birthday this year, I'm asking for donations to Alveolar Capillary Dysplasia Association. I've chosen this nonprofit because their mission means a lot to me, and I hope you'll consider contributing as a way to celebrate with me. Every little bit will help me reach my goal....To find the

cause of and cure for Alveolar Capillary Dysplasia with misalignment of the pulmonary veins (ACDMPV), a rare infant lung disorder."

#### Birthday Fundraiser (Felina Aßmann):



Jan is on his way to his €150 EUR goal (with three weeks left to donate!) through a Facebook birthday fundraiser in honor of his daughter, Felina Aßmann.

Thank you, Jan!

In August 2020, Jan Aßmann, ACDA father to Felina (October 2, 2017 - October 20, 2017), organized a birthday fundraiser for ACDMPV research in honor of Felina Aßmann. In Jan's own words, "This year on my birthday I am asking for donations for Alveolar Capillary Dysplasia Association. I have selected this nonprofit as I care deeply about their cause. Hope you are celebrating my birthday with a donation to this organization. Any amount that small helps to reach my goal. Below you will find information about the Alveolar Capillary Dysplasia Association. To find the cause of and cure for Alveolar Capillary Dysplasia with misalignment the pulmonary of veins (ACDMPV), a rare infant lung disorder."



**Click to Learn More** 



#### Volunteer Grants:

To honor those who give their time and service to causes important to them, Bank of America, NA, through its Bank of America Charitable Foundation, awards unrestricted grants for volunteer work to any eligible nonprofit organization for which an employee has committed substantial volunteer hours within a calendar year. For 50 hours of volunteer time within a calendar year, Bank of America Charitable Foundation will give a \$250 grant. For over 100 hours of volunteer time within a calendar year, the grant is \$500.

Thank you to **Bank of America**, **NA** for providing a \$500 grant to the ACDA in honor of **John Rista's volunteer work in 2019 for the ACDA**. Please let us know if similar volunteer grants are offered through your employer!

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

# 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." Prior to the COVID-19 closures, Mathijs has been running marathons for ACDMPV awareness in Europe! 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.

## Grace&Us (June 12, 2020):



Here's a recent update from Mathijs in his own words, "Hope everybody is well and safe. It's been a while since I have posted here in this crazy times. Running events are being cancelled and those are the main events for us to raise awareness for ACD. But we are not just waiting for the storm to pass. We are currently working in the background to expand our reach.

A nice article (click <u>HERE</u>) has been published on an international new platform named *Grace&Us*. Please have a look on the website and our article about us and ACD. You never know which doors may open up **3**."



## REPORT FROM THE DAVID **ASHWELL FOUNDATION (UK):**

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

Thank you to those families who have set up direct debits for the charity and whose families fundraise at work for us. Looking back since March 2011 over £200.000 has been raised for ACD Research by families in the UK and Europe (exact amount next newsletter!). This has contributed to the funding raised internationally to the ACDA. We are always very enthusiastic to raise more money for ACD research and would appreciate any help!



At the moment not many people are using The Giving Machine.

Please, UK families can you use The Giving Machine (GO HERE) to generate income from online shopping. Everyone in the UK can do this - it is so easy to register and is a way of earning easy and free money. Please also encourage your friends and family too! Watch HERE how it works! I have the giving machine app on my phone and it makes giving as I shop so easy. It's very quick and easy to sign up!



Please use The **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

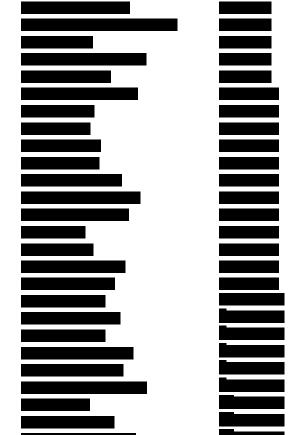
Foundation as a means of fundraising for ACDMPV Research. Please raise awareness of our small charity via social media including Twitter and Facebook. We are more than happy to hear from other families who would like to use the charity to raise money for ACDMPV Research. Simon and Amelia run The David 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: <a href="http://David Ashwell Foundation">http://David Ashwell Foundation</a> Email: davidashwellfoundation@yahoo.co.uk

Twitter: @TDavidAshwellF Mobile (Amelia): 07855473686



## REMEMBERING OUR BABIES





## **WELCOME TO NEW FAMILIES**

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



#### SAFE ARRIVALS!

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







#### **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

At the quarterly ACDA Board of Directors meeting in August 2020, Eliza Rista, Renee Murray and John Rista were unanimously reelected to serve as President, Secretary and Treasurer, respectively, of the ACDA Board of Directors until August 2021.

#### **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)