As we take a look back at 2020:

- One global pandemic.
- Ten new families registered with the ACDA. These families are from the USA, UK, Canada and Switzerland.
- One research grant in the amount of $50,000.
- Fourteen rainbow babies born to ACDA registered families.
- Five additional tattoos of the ACDA logo.
- Three families at a Rare Disease Day event in New York City featuring ACDMPV.
- More than twenty journal articles published about ACDMPV.
- 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
Rare Disease Day is an international advocacy day to bring widespread recognition of rare diseases as a global health challenge. The day is celebrated on the last day of February every year – February 28 in 2021. 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 (2020, 2019, 2018, 2017 and 2016)!

Click HERE for ways to participate in the U.S. in 2021 and click HERE to visit EURORDIS for Rare Disease Day 2021 in Europe.

Below are a few suggested ideas:

➢ Join the ACDA on social media by using the new ACDA profile frame (access HERE) to share that you love someone rare! Also use the hashtags #RareDiseaseDay, #ShowYourRare, #WRDD2021, #ACD, #ACDMPV

➢ Organize a fundraiser (Facebook or direct give) 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.
RESEARCH NEWS

Journal Article (Am J Respir Cell Mol Biol):

The research team at Cincinnati Children’s Hospital Medical Center in Cincinnati, Ohio, USA (see Issues #57, #62-63, #68-69 and #71-72 of ACDA Notes) recently published a manuscript entitled, “Nanoparticle Delivery Systems with Cell-specific Targeting for Pulmonary Diseases” in the American Journal of Respiratory Cell and Molecular Biology, which can be found HERE.

Abstract: “Respiratory disorders are among the most important medical problems threatening human life. The conventional therapeutics for respiratory disorders are hindered by insufficient drug concentrations at pathological lesions, lack of cell-specific targeting, and various bio-barriers in the conducting airways and alveoli. To address these critical issues, various nanoparticle delivery systems have been developed to serve as carriers of specific drugs, DNA expression vectors and RNAs. The unique properties of nanoparticles, such as controlled size and distribution, surface functional groups, high payload capacity, and drug release triggering capabilities, are tailored to specific requirements in drug/gene delivery to overcome major delivery barriers in pulmonary diseases. To avoid off-target effects and improve therapeutic efficacy, nanoparticles with high cell-targeting specificity are essential for successful nanoparticle therapies. Furthermore, low toxicity and high degradability of the nanoparticles are among the most important requirements in the nanoparticle designs. In this review, we provide the most up-to-date research and clinical outcomes in nanoparticle therapies for pulmonary diseases. We also address the current critical issues in key areas of pulmonary cell targeting, bio-safety and compatibility, and molecular mechanisms for selective cellular uptake.”

Journal Article (Am J Respir Crit Care Med):

The research team at Cincinnati Children’s Hospital Medical Center in Cincinnati, Ohio, USA (see above and Issues #57, #62-63, #68-69 and #71-72 of ACDA Notes) also recently published a manuscript entitled, “In Vivo Generation of Lung and Thyroid Tissues from Embryonic Stem Cells using Blastocyst Complementation” in the American Journal of Respiratory and Critical Care Medicine, which can be found HERE.

“Rationale: Regeneration or replacement of lung cells or tissues from iPSC- or ESC-derived cells represent future therapies for life-threatening pulmonary disorders but are limited by technical challenges to produce highly differentiated cells able to maintain lung function. Functional lung tissue containing airways, alveoli, vasculature and stroma has never been produced via directed differentiation of ESCs or iPSCs. We sought to produce all tissue components of the lung from bronchi to alveoli by embryo complementation.

Objective: To determine whether ESCs are capable of generating lung tissue in Nkx2-1/- mouse embryos with lung agenesis.

Conclusions: Lung and thyroid tissues were generated in vivo from ESCs by blastocyst complementation. Nkx2-1/- chimeras can be used as "bioreactors" for in vivo differentiation and functional studies of ESC-derived progenitor cells.”
AWARENESS NEWS

New Facebook Profile Frame:

Join the ACDA on social media by using the new ACDA profile frame (access HERE) to share that you love someone rare!

Families in the News (Barrett Bone):

In honor of Pregnancy and Infant Loss Awareness Month in October 2020, Katy and Tyler Bone, ACDA parents to Barrett (June 14, 2019 – July 12, 2019), shared what pregnancy and infant loss means to their family. Please read their touching story below:

As Pregnancy and Infant Loss Awareness Month comes to an end, local families left coping with tragedy year-round

ACDA Tattoo (Naomi Ondocsin):

On November 7, 2020, Allison Ondocsin, ACDA mom to Naomi (November 7, 2019 – December 5, 2019), and Allison’s husband, mother and two friends ALL got a tattoo of the ACDA logo to celebrate Naomi’s first birthday. In Allison’s own words, “We celebrated our beautiful Naomi’s first birthday yesterday. We laughed, we cried, we danced, we got tattoos and we partied hard for our girl! 🎈❤️”

The ACDA is now aware of a total of thirteen tattoos featuring the ACDA logo!

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
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 2021 NORD grant is $35,000.

Balance of ACDA account:

The available balance of the ACDA bank accounts as of February 3, 2021 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, 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 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 2, 2020 and February 1, 2021 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 now through February 7, 2021!

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]

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

WOW. The ACDA’s fundraising goal for #GivingTuesday on December 1, 2020 was $1,000 and, with your help, we were able to bring in over $2,300 (with a total of 13 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 2020.

Thank you for the generous #GivingTuesday donations in honor of Joey E., Annabelle, Ayla, Dean, Fallon, Finley, Joey R., Katelyn, Phoebe, Ronan, Sadie, Johnny and Xavier.

*We are sorry we do not know the child for whom the memorial contribution was made. Please contact us to let us know.*
October 15 Fundraiser (James Perrella):

Maria's fundraiser for Alveolar Capillary Dysplasia Association
Fundraiser for Alveolar Capillary Dysplasia Association by Public

The fundraiser has ended, but you can still support the cause Maria cares about.

$7,145 raised of $5,000

Maria and Jimmy exceeded their original $5,000 goal by raising $7,145 through a Facebook fundraiser in honor of baby James Perrella, with 107 individual donors! Amazing!!

In October 2020, Maria Catalano and Jimmy Perrella, ACDA parents to James (January 23, 2019 – February 15, 2019), organized a fundraiser for ACDMPV research in honor of Baby James Perrella. In Maria’s own words, “October 15 is Pregnancy and Infant Loss Awareness day. In honor of our son, Baby James, we are again fundraising on behalf of the ACDA. As you may know, our son was born in January 2019 and passed away February 2019 from a rare disease called Alveolar Capillary Dysplasia. We would like to sincerely thank everyone for their love and support in the past with Baby James, and we couldn’t be more blessed having friends and family like all of you. We hope that our combined donations can help the Association work towards discovering more information about ACD, and assist in the development of treatment methods in the future.

Last year with your help, we raised over $10,000 for the ACDA to assist in their research to find a cure. The National Organization for Rare Disorders (NORD), requires research funds to total $35,000 before initiating the grant process, awarding research money to the medical community. Therefore, the goal of the ACDA and The David Ashwell Foundation is to raise at least $35,000 annually through NORD for research. Your donations will also assist us in reaching that goal, so that another research grant can be provided by NORD. Thank you all for helping to honor and remember Baby James, and for continuing to play such a profound role in the funding of research into ACD, and working towards a future where effective treatment is a reality.

“A life need not be long to be meaningful.” - unknown

I'm raising money for Alveolar Capillary Dysplasia Association and your contribution will make an impact, whether you donate $5 or $500. Every little bit helps. Thank you for your support. 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!
#GivingTuesday Fundraiser (Fallon Rilling):

Kira's GivingTuesday Fundraiser
#InHonorofFallonJade
#444
Fundraiser for Alveolar Capillary Dysplasia Association by [Name] • Public

The fundraiser has ended, but you can still support the cause Kira cares about.

Kira raised $44 through a Facebook fundraiser for #GivingTuesday in honor of Fallon Rilling. Thank you, Kira!!

In December 2020, Kira Alaine, friend of Kristen and Bob Rilling, ACDA parents to Fallon (October 10, 2013 – October 21, 2013), organized a #GivingTuesday fundraiser for ACDMPV research in honor of Fallon Rilling. In Kira’s own words, “Want to join me in supporting a good cause? This #GivingTuesday I’m raising money for Alveolar Capillary Dysplasia Association and your contribution will make an impact, whether you donate $5 or $500. Every little bit helps. And on GivingTuesday Dec 1, Facebook will match $7 million in qualifying donations. Thank you for your support.

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 (Fallon Rilling):

Kerry's birthday fundraiser
Fundraiser for Alveolar Capillary Dysplasia Association by [Name] • Public

Fundraiser Ended
Kerry reached her birthday goal! Thanks to everyone who donated.

$514 raised

Kerry exceeded her original goal of $444 by raising $514 through a Facebook birthday fundraiser in honor of Fallon Rilling. Thank you, Kerry!!

In December 2020, Kerry Centorcelli, friend of Kristen and Bob Rilling, ACDA parents to Fallon (October 10, 2013 – October 21, 2013), organized a birthday fundraiser for ACDMPV research in honor of Fallon Rilling. In Kerry’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 honor baby Fallon, who continues to inspire us all and sends many signs from above.

If you feel compelled to donate, please include the number 4 somewhere :) whether it’s $4 or $44 it would be much appreciated. ❤️❤️❤️❤️”
Birthday Fundraiser (Xavier Parker):

Nicki's birthday fundraiser
Fundraiser for Alveolar Capillary Dysplasia Association by [Redacted] • Public

The fundraiser has ended, but you can still support the cause Nicki cares about.

Nicki raised $25 through a Facebook birthday fundraiser in honor of Xavier Parker. Thank you, Nicki!!

In December 2020, Nicki Parker, mother to Xavier (July 23, 2015 – August 11, 2015), organized a birthday fundraiser for ACDMPV research in honor of Xavier Parker. In Nicki’s own words, “For my birthday this year, I'm asking for donations to Alveolar Capillary Dysplasia Association. This is what Xavier died from. 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. Facebook pays all the processing fees for you, so 100% of your donation goes directly to the nonprofit.”

Birthday Fundraiser (Barrett Bone):

Help Katy's birthday fundraiser in honor of Barrett
Fundraiser for Alveolar Capillary Dysplasia Association by [Redacted] • Public

The fundraiser has ended, but you can still support the cause Katy cares about.

Katy exceeded her original $1,000 goal by raising $1,175 through a Facebook birthday fundraiser in honor of her son, Barrett Bone. Thank you, Katy!!

In January 2021, 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, “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. Facebook pays all the processing fees for you, so 100% of your donation goes directly to the nonprofit.”
Birthday Fundraiser (Kaylin Cone):

Jacob has *almost* reached his $500 goal by raising $470 (with a week left to donate!) through a Facebook birthday fundraiser in honor of his sister, Kaylin Cone. Thank you, Jacob!

In January 2021, 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, “Last year we raised over 340 dollars for the ACDA foundation and this year I believe we can raise even more so in honor of my sister and all the infants lost to ACD I’m asking for donations to Alveolar Capillary Dysplasia Association to help find a cure. I’ve chosen this nonprofit because their mission means a lot to me my family and many others around the world. Every little bit will help me reach my goal i know times are tough right now and if you cant donate all I ask is for you to please share. 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. Facebook pays all the processing fees for you, so 100% of your donation goes directly to the nonprofit.”

Color Street Nail Fundraiser (Fallon Rilling and Annabelle Logue):

In December 2020 with a beautiful (second time!) collaboration between two ACDA mothers, $548.44 was raised in honor of both Fallon Rilling and Annabelle Logue 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). Kristen converted sets into monetary donations to the ACDA. In Kristen’s own words, “Thank you so much to all of you that have already ordered. It means a lot to me, Fallon and Annabelle!”
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 Rotterdam Marathon (April 2017, 2018 and 2019), Amsterdam Marathon (October 2016 (half), 2017, 2018 (Kids Run), 2019 (Kids Run)), Berlin Marathon (September 2019), Marathon #1 (October 2020) 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! For additional information about the upcoming runs highlighted below, please visit Run4ACD on Stichting ACD’s website.

**Stichting ACD Marathon #1 (October 25, 2020):**

Mathijs and team Stichting ACD ran the very first Stichting ACD Marathon #1 on October 25, 2020 to raise ACDMPV awareness! In Mathijs’ own words two days before the big event: “Running marathons worldwide has become my prime goal to raise awareness for this terrible disease, but as we all know, the world has changed a lot last year. Big events worldwide have been cancelled so that made me think… Let’s just do it ourselves!! And so our very first special marathon event for ACD was born. Of course it is small and corona-proof. So this Sunday we will run the 26.2 miles 42.195km with the four of us and some runners doing a shorter distance of 6.5km all for ACD and to collect this very, very special medal!”

Special medals made by Stichting ACD in honor of Marathon #1 on October 25, 2020!

We are definitely getting somewhere, researchers are involved and so are medical professionals! Giving up is not an option!”

After the marathon, Mathijs provided an update on the perfect day, “It was amazing and again, a beautiful day with lovely friends and family around us with Myla in the center! Our way to honor our babygirl and our own way to make a difference for the future taking small steps forward. A professor once told me that I needed
to have ‘a long breath’ (dutch saying) and that still motivates me.

I am still determined and so dedicated. It is our life with Myla and it still feels so right and it is a beautiful adventure although it came from the saddest period in our life.

There is so much love to share.

For the complete album please check out Stichting ACD I just uploaded the whole album.”

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**Video (Stichting ACD Marathon #1):**

Please watch this very special video about Stichting ACD’s first-ever marathon featuring famous Dutch personality, Anouk Smulders. Mathijs and team met Ms. Smulders during a Friends Of The Brands event and have kept in touch. In Mathijs’ own words, “She rightly remarked that she thought it was so special that everyone was / is so involved. Exactly what we think is so special and what makes our beautiful foundation a success! Erik Hurkkens captured this special day on video of Anouk talking to us about us, Myla and the foundation combined with beautiful running moments!” Watch [HERE](https://www.youtube.com/watch?v=video_id).

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**Marathon (April 11, 2021):**

**Upcoming Event:** Mathijs and team Stichting ACD are organizing their next Marathon on April 11, 2021 to raise ACDMPV awareness! In Mathijs’ own words, “On April 11th we will run our own marathon again through beautiful Twiske! Enough time to (start) training. Are you coming along? We are going to plot three routes over 5, 12 and 42.2 km...Sign up and earn that beautiful Stichting ACD medal!”

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**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.
March 2021 will be 10 years since David was born and we became part of the ACDMPV family. I know a few families also have a 10th anniversary this year so be on the lookout for possible plans. 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!

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
Welcome to New Families

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

- [Names and details of families]
Safe Arrivals!

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

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)