

Issue  
**74**

# ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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## 2020: Year in Review

### As we take a look back at 2020:

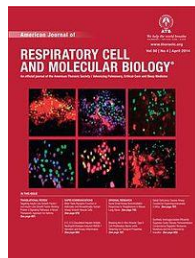
- One global pandemic.
- Ten new families registered with the ACDA. These families are from the USA, UK, Canada and Switzerland.
- One research grant in the amount of \$50,000.
- Fourteen rainbow babies born to ACDA registered families.
- Five additional tattoos of the ACDA logo.
- Three families at 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



## 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>



**Donations:**

[acdassociation.org/donate](http://acdassociation.org/donate)

**Update from NORD:**

**Balance of ACDA account:**

**Update from AmazonSmile:**

<http://smile.amazon.com/ch/46-2915711>



**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:

[illegible]



## October 15 Fundraiser (James Perrella):



### Maria's fundraiser for Alveolar Capillary Dysplasia Association

Fundraiser for Alveolar Capillary Dysplasia Association by [redacted] 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 [REDACTED] • 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 Elaine**, 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 [REDACTED] • Public



**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

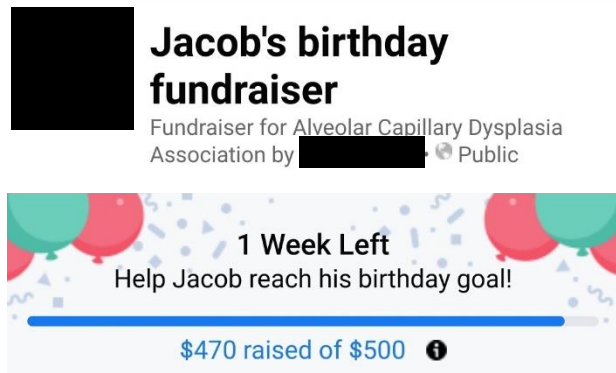
The fundraiser has ended, but you can still support the cause Katy cares about.



**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):

STICHTING ACD 

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. Off 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."



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

"The final score of our marathon: **€3124!!** All money to spend on raising awareness and in the end hopefully to contribute to research!"



### **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 Hurxkens captured this special day on video of Anouk talking to us about us, Myla and the foundation combined with beautiful running moments!" Watch [HERE](#).

### **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!"

### **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](mailto: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 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](#)!



**moneygiving** 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](http://David_Ashwell_Foundation)

**Email:** [davidashwellfoundation@yahoo.co.uk](mailto:davidashwellfoundation@yahoo.co.uk)

**Twitter:** [@TDAshwellF](https://twitter.com/TDAshwellF)

**Mobile (Amelia):** 07855473686

## REMEMBERING OUR BABIES

[REDACTED]

[REDACTED]

## Welcome to New Families

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

- [REDACTED]
- [REDACTED]





