ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org
SUMMER 2018
Issue
64

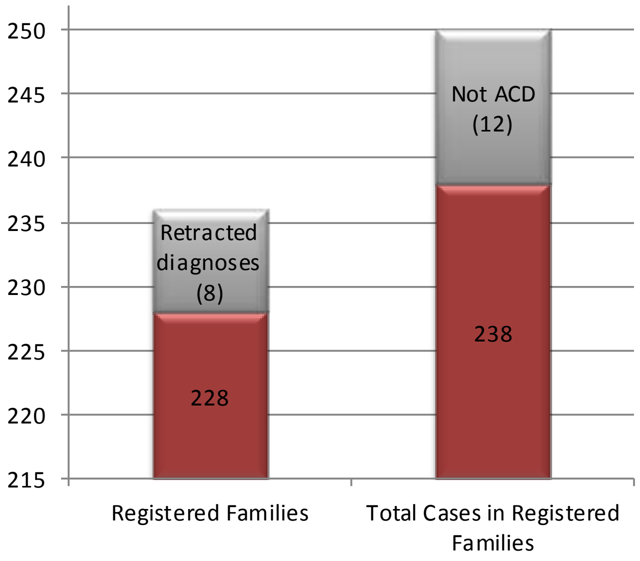
ACDA NOTES

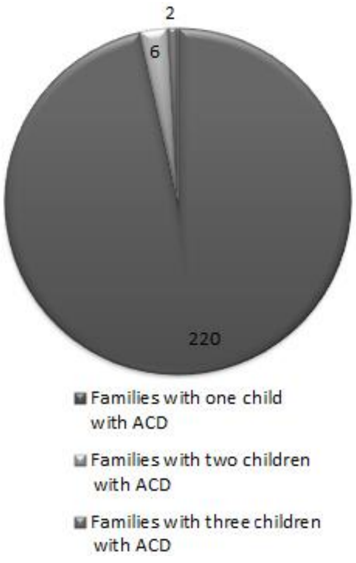
FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

How many children with ACDMPV have been reported to the ACDA*?

As of July 2018, 236 families are registered in the ACDA database with a total of 250 cases. Eight families subsequently confirmed to the ACDA after registration that their original diagnosis was later retracted by their medical professionals, which results in 228 families with a total of 238 confirmed or suspected ACDMPV cases registered with the ACDA. Please note this data is only with respect to families that have registered with the ACDA and DOES NOT include all reported or known cases of ACDMPV. In addition, the known case reports almost certainly underestimate the true prevalence of ACDMPV. Regards, Eliza Rista, President





**The above data is intended to be accurate but please know some information may not be current or precise as the ACDA has lost contact with certain families over the years. Please always consult with your qualified medical professionals. A Family is defined as children from the same parents (i.e. re-marrying would be another family). The recurrence chart does not contemplate a small number of other families that did not attempt a subsequent pregnancy after genetic testing revealed a familial connection.*

RESEARCH NEWS

2018 NORD Grant:

As referenced in Issue #63 of ACDA Notes, it is the great pleasure of the ACDA and The David Ashwell Foundation to officially announce a **$50,000 grant will be issued in 2018 for ACDMPV research.** NORD announced the Request for Proposals (RFPs) on May 24, 2018 (see the box to the right for additional RFP information).

As background, ten grants for ACDMPV research have been issued through NORD since 2005, including 2005, 2008, 2012 (two grants), 2014 (two grants), 2015, 2016, 2017 and 2018. Please visit our website HERE to read a full history of NORD grants for ACDMPV research.

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

NORD Request for Proposals ("RFP") – 2018 Research Grant:

NORD, with funding from The David Ashwell Foundation and the Alveolar Capillary Dysplasia Association (ACDA), **is accepting applications for a total of $50,000**, for scientific research studies and/or clinical research studies related to Alveolar Capillary Dysplasia/misalignment of the pulmonary veins (ACDMPV). NORD encourages all U.S. and international researchers interested in studying ACDMPV to consider applying for 2018 funding. The Abstract Submission Deadline for ACDMPV will **remain open** even after the listed July 16 date. See the full RFP and abstract template HERE.

AWARENESS NEWS

Half Marathon (Amelia Weaver):

On April 28, 2018, Adam Weaver, ACDA father to Amelia (May 24, 2015 - June 19, 2015), participated in the Kentucky Derby Festival Mini Marathon while raising awareness for the ACDA! Thank you, Adam!

Living with ACDMPV without transplant:

As background, ACDMPV classically presents in the neonatal period with irreversible respiratory failure. A small number of ACDMPV patients with atypical presentations have undergone successful bilateral lung transplantation. The ACDA includes registered families of four ACDMPV affected children in receipt of a bilateral lung transplant with three survivors (currently 6 years old, 2.5 years old and 2 years old after receiving their transplants at 9 months old, 5 months old and 4.5 months old, respectively). There are several other successful lung transplants for ACDMPV patients discussed in medical research journal articles but not all recipient families have contacted the ACDA.

Within the past year, **the ACDA has also registered four families with children living with a presumptive or confirmed ACDMPV diagnosis without a bilateral lung transplant.** Genetic testing identified abnormalities affecting FOXF1 in all four cases. Please meet the following four children in our ACDA community:

Joaquin Williams – One year old in Texas, USA under the out-patient care of **Texas Children's Hospital (TCH)** with a presumptive ACDMPV diagnosis based on genetic testing and clinical symptoms but without lung biopsy. Joaquin was diagnosed with Pulmonary Hypertension when he was 24 hours old. At three months old, he was transferred from his local hospital in California to Texas where he was evaluated for lung transplant by medical professionals familiar with ACDMPV. After several months, his new doctors ultimately decided not to proceed with lung transplant because Joaquin was increasingly stable. He was discharged at approximately six months old and remains under the out-patient care of TCH. Please read a case study about Joaquin HERE.

David Williams – Twelve year old in **North Carolina, USA** under out-patient care with a presumptive ACDMPV diagnosis based on genetic testing and clinical symptoms but without lung biopsy. David was born with Idiopathic Pulmonary Hypertension and even supported at one point by ECMO. He was discharged from the hospital and the family recently started seeing a pulmonologist for recurring pneumonia. Genetic testing was recently performed to find the cause of his Pulmonary Hypertension and a FOXF1 mutation was determined.

Tom Schnierle – Almost two year old under the in-patient care of a **German** hospital with a presumptive ACDMPV diagnosis based on genetic testing and clinical symptoms. A lung biopsy has been performed and sent to Baylor College of Medicine for confirmation. Tom has been in the intensive care unit since birth. His family's current goal is to finally bring Tom home with nitric oxide. The family is also considering possible lung transplantation pending discussions and review with Tom's medical professionals, which is complicated by limited organ availability and the fact that lung transplants are not currently performed on small children in Germany.

Larissa Brooks – Seven month old in California, USA under the in-patient care of **University of California, San Francisco (UCSF) Benioff Children's Hospital** with an ACDMPV diagnosis based on genetic testing and clinical symptoms as further confirmed by lung biopsy. Larissa was initially admitted to the hospital at four weeks old after presenting with low oxygen saturation. Since that time Larissa spent time at home with her family but was readmitted in June 2018 for further treatment. You can follow Larissa's story HERE.

7,000 RARE DISEASES exist

RareDiseaseFacts™

What is a RARE DISEASE ?

Any disease, disorder, illness or condition affecting **fewer than 200,000** people in the United States is considered RARE.

NORD® National Organization for Rare Disorders

Upcoming Date:

August 19, 2018 – 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, tax-exempt organization as designated by the Internal Revenue Code of the United States.

Balance of ACDA account:

The balance of the ACDA bank account as of July 23, 2018 is $[redacted].

Update from AmazonSmile:

The ACDA was issued a $[redacted] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between January 1 and March 31, 2018. 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:

The accrued commission payment from Spreadshirt between April 26, 2018 and July 23, 2018 is $[redacted]. Our Spreadshirt store featuring the ACDA logo has sold 160 items since opening in September 2015! Items with the ACDA logo are available for purchase in our Spreadshirt store HERE. The ACDA earns a commission equal to **20% of every product sold**. **Look for 15% off everything from August 2 – 6, 2018!** (Use code: SUMMERSUN)

Update from NORD (2018 Grant):

The NORD balance of the Research Fund (ACD) is $[redacted] as of May 8, 2018.

The ACDA and The David Ashwell Foundation are pleased to announce the above balance exceeds the required minimum amount ($35,000) for the issuance of a 2018 grant! **Please see page 2 for detailed information about the 2018 NORD grant**.

Let's continue working towards a 2019 grant!

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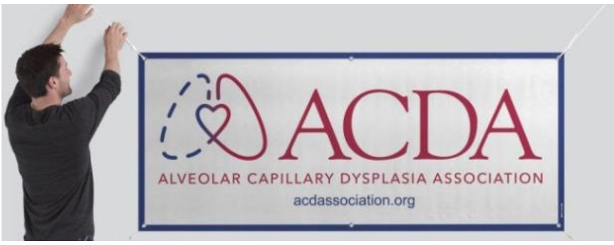
**We are sorry we do not know the child for whom the honorary contribution was made. Please contact us to let us know.*

FJNortheasters (Fallon Rilling):

Once again, it's fundraising season for the Toyota off road club, the **FJNortheasters**.

The FJNortheasters held their **11th Annual Northeast Run** in April 2018. Each year, this awesome family of "Off Road" enthusiasts gets together for a huge charity off-roading event. Bob Rilling, ACDA father to Fallon (October 10, 2013 – October 21, 2013), was recently elected President of the FJNortheasters and continued the club's tradition of generously supporting the ACDA (see Issues #56 and #59 of ACDA Notes). **An incredible total of $5,444 was donated to the ACDA in honor of Fallon Jade Rilling**. A huge thanks to the FJNortheasters and the staff, sponsors and members for funding ACDMPV research in such a significant way each year.

Banners:



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

Brochures:

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

Rack Cards:

Order an ACDA "rack card" with key facts about ACDMPV; click for **ENGLISH**.

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**." Please see highlights below:

Amsterdam Photography Exposition (June 16-17, 2018):

Photographer Eelko Bouma followed Mathijs for six months and dedicated his final project Visions "The world through our eyes" to Stichting ACD. The photography exposition was held in the center of Amsterdam on June 16-17, 2018.

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.

Roelove blog:

In a special connection between two Dutch ACDA families, Roelina Jut, ACDA mother to Jasmijn (February 8, 2013 – February 23, 2013), recently interviewed Mathijs for a two part article about Mathijs' ACDMPV efforts. Read Part I and Part II (in Dutch).

Cologne, Germany Marathon (October 7, 2018):

Mathijs is officially expanding his marathon adventure across the border! For his first foreign marathon, he will be running the upcoming **marathon in Cologne, Germany on October 7, 2018** to raise ACDMPV awareness in Germany. Mathijs completed the Rotterdam Marathon (April 2017 and April 2018) and the Amsterdam Marathon (October 2017) and plans to run marathons for ACDMPV awareness in Europe and then worldwide. For additional information, please visit Run4ACD on Stichting ACD's website and the RheinEnergieMarathon Köln page. **Please contact Mathijs if you are interested in participating or cheering on his upcoming plans!**

REPORT FROM THE DAVID ASHWELL FOUNDATION (UK):

If you live in the UK and would like to fundraise for ACDMPV research or have a fundraising idea please get in touch!

The David Ashwell Foundation is run by Simon and myself (Amelia), we are so very grateful to anyone who uses the charity or donates to the 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).

On my to-do list for September 2018 is to enrol local schools and universities to take part in Rare Disease Day 2019 to make sure we get it into school calendars.

In May we transferred £16,221 ($21,332) to the ACD research fund at NORD.

Since March 2011 **£197,895 ($260,249)** has been raised for ACDPV Research by families in the UK and Europe. This has contributed to the funding raised internationally to the ACDA. Since we made the donation to NORD in May 2018, we have raised £406 but we are always keen to raise more money and would appreciate any help!

In June for our exam boards a wonderful colleague organized a 'board bake' where we baked for the meetings and people made a donation – this raised £107 in total.

https://www.thegivingmachine.co.uk/causes/the-david-ashwell-foundation/support/

As ever, can I plea with all UK families to use the **Giving Machine** 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!

UK families you can set up direct debits to The David Ashwell Bank Account (we have a number of people who do this).

Additionally we have a Virgin Money Giving account where you can set up a page in memory of your child or for special occasions (such as birthdays or Christmas).

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. http://David Ashwell Foundation
2. Fundraise while you online shop (The Giving Machine) (a percentage of what you spend is donated)
3. Collect postage stamps http://David Ashwell Foundation

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, please contact Simon and Amelia.

Website: http://David Ashwell Foundation
Email: davidashwellfoundation@yahoo.co.uk
Twitter: @TDavidAshwellF
Mobile (Amelia): 07855473686

Remembering Our Babies

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Welcome to New Families

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

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

(continued on following page)

- [redacted]

[redacted]

- [redacted]

Safe Arrivals!

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

[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)