

Issue
60

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

- 1 Greeting
- 2 Research News
- 3 Dean Grant
- 4 Upcoming Date
- 5 Fundraising News
- 7 Report from The David Ashwell Foundation
- 8 Update from Stichting ACD
- 9 Remembering Our Babies and Welcome to New Families
- 10 Safe Arrivals and Connect With Us

NIH GRANT ANNOUNCEMENT



Grant Budget:
Awardee Organization:
Project Leader:
Project Start & End Dates:
Title:

\$1,952,000
Baylor College of Medicine
Pawel Stankiewicz, MD, PhD
May 22, 2017 - April 30, 2021
ACDMPV - Epigenomic Dysfunction at 16Q24.1 Vascular Defects and Perinatal Consequences



The ACDA is absolutely thrilled to announce Baylor College of Medicine in Houston, Texas, USA has recently been awarded a very substantial government grant for ACDMPV research. Please read the details on page 2!

Regards, Eliza Rista, President

RESEARCH NEWS

2017 NIH Grant:

It is the great pleasure of the ACDA to announce Baylor College of Medicine in Houston, Texas, USA was recently awarded a **NIH R01 grant** in the amount of **\$1,952,000** for ACDMPV research over the course of four years. This multi-year study at Baylor hopes to explain how enhancers in chromosome 16q24.1, including long noncoding RNAs (lncRNAs), regulate expression of the FOXF1 gene responsible for ACDMPV. Baylor will study the role of lncRNAs in genomic imprinting of the FOXF1 locus and will also study the function of a specific lncRNA in the development of lungs and other organs. lncRNAs are considered promising therapeutic targets and Baylor believes that by manipulating their expression, we may have the potential to correct the lethal phenotype of ACDMPV in the future.



The National Institutes of Health (NIH) is an agency of the United States Department of Health and Human Services and is responsible for biomedical and public health research. The **ACDA extends our heartfelt thanks to Dr. Pawel Stankiewicz (Project Leader for the 2017 NIH grant) and Dr. Przemyslaw Szafranski** at Baylor College of Medicine for their tireless efforts to secure substantial NIH funding. As background, R01 grants from the NIH are highly competitive and are known as the gold standard due to it being one of the most respected mechanisms of financial support in the medical research world.

We look forward to providing updates on the results of the research through this NIH grant as we continue our steadfast mission to find the cause of and cure for ACDMPV.



AT A GLANCE

Grant Budget:

\$1,952,000



Awardee Organization:

Baylor College of Medicine

Project Leader:

Pawel Stankiewicz, MD, PhD

Project Start & End Dates:

May 22, 2017 - April 30, 2021

Title:

Epigenomic Dysfunction at 16Q24.1 Vascular Defects and Perinatal Consequences (Click [HERE](#) to read more from the NIH)

This would not be possible without the ongoing seed grants raised by families and friends affected by ACDMPV. Among other objectives, prior seed grants have helped Baylor to accumulate and maintain the largest collection of DNA and tissue samples related to ACDMPV in the world and to detect mutations and deletions therein. The smaller seed grants (approx \$50,000) issued each of the past few years through money raised by families and friends affected by ACDMPV has helped to collect data for use in this larger multi-year government grant. The ACDA will continue to focus on raising funds for annual seed grants with the purpose of investigating ACDMPV from all perspectives, including genetic, biological, clinical, etc.

Our thanks, always, to the numerous individuals and organizations who continue to support our very important mission from the ground up.

DEAN JESSE GRANT:

In June 2017, I messaged with Ashley Grant, ACDA mother to baby Dean, to ask her if I could prepare a write-up for this newsletter to introduce Dean to the broader ACDA community. Dean was nine months old at the time of our messages, and thankfully, had recently been listed on the lung transplant list.



The **ACDA first met Dean in November 2016** when Ashley registered her then two month old baby boy who had been diagnosed with ACDMPV. Ashley became active in the Facebook ACD Parent Group and Dean quickly became a beloved extended member of

many of our families. We looked forward to pictures and updates and watched as 'our' little jellybean (as his parents lovingly referred to him) grew up into a handsome and precious little boy.

During this time, his parents, Ashley and Derek, packed everything and moved from their home in Wisconsin to transfer Dean to Children's Hospital of Philadelphia (CHOP) in Pennsylvania, USA. CHOP is ranked as the #1 pulmonary pediatric hospital in the country and may sound familiar because it is the facility that successfully performed the lung transplant on Luca Palmisano in November 2016 (see Issues #57, #58 and #59 of ACDA Notes). The Grant and Palmisano families quickly became like family to each other as they braved life together as ACDMPV lung transplant and pre-transplant families.

Ashley lived in temporary

housing near CHOP for several months while Dean was evaluated and ultimately approved to be listed for transplant. While we all anxiously waited for news of 'the call,' Derek arrived with the U-Haul and together he and Ashley rented an apartment in June, prepared to make life near CHOP their new permanent home. The plans were all designed and implemented due to the tremendous love the Grant family shares and their absolute unyielding commitment to do whatever it took for their son.



And this is where the story changes from everything I was prepared to write about the Grant family to words that I can barely make my fingers type.

It is with the heaviest of hearts and most reverent of words that I share our sweet Dean passed away at ten months old on July 27, 2017 due to heart failure.

The Grants openly shared their dearly loved little boy with our ACDA community of grieving parents over the course of the past year. We smiled and laughed at the videos of him laughing or playing with his toys. Our



hearts melted at the adorableness of his chubby cheeks or the picture of him sleeping like a five pointed starfish. We frequently talked about him with our friends and family outside of the Facebook group. He truly was growing up with a community of adoring virtual parents spread throughout the world.

The anguish of losing 'our' Dean is met with the devastating heartbreak of knowing the difficult days ahead for Ashley and Derek. It was always the hope they would be shielded from this pain.

Ashley and Derek are two of the most considerate and courageous souls that I know and every communication with them is always full of gratitude and kindness. I am certain Dean received these traits from them and he will be fiercely loved and missed by his parents, grandparents, aunts, uncles, family, friends and our ACDA community, **always and forever**. Rest in peace, jellybean.

Love,
Eliza Rista



To read more about Dean, please visit [Dean's Lung Transplant Journey](#) or [GoFundMe](#)

Upcoming Date:

August 19, 2017 – 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)



Donations:

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.

The balance of the ACDA bank accounts as of July 31, 2017 is [REDACTED].

The ACDA was issued a [REDACTED] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between January 1 and March 31, 2017. 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>

The accrued commission payment from Spreadshirt between May 4, 2017 and July 31, 2017 is [REDACTED]. Items with the ACDA logo are available for purchase in our Spreadshirt store [HERE](#).



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.

In July 2017, the ACDA would sincerely like to thank **AMC Theaters for matching \$1,000 in honor of Finley Smith!**

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

[illegible]

[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]

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

2nd Annual Finley Kathleen Memorial Wiffleball Tournament and Raffle (Finley Smith):

On June 17th, in honor of our daughter Finley Kathleen Smith, we hosted the 2nd Annual Finley Kathleen Memorial Wiffleball Tournament and Raffle at Finley Park (our backyard). While the weather was hot with the temperatures well into the nineties, the turnout and participation was unbelievable. Once again, over 100 people were in attendance to either play or cheer the teams on. The double elimination tournament consisted of 10 teams and great fun was had by all.

We were truly amazed by the impact that our special little girl continues to have in the efforts to raise awareness and money for research into ACDMPV! **The most touching part of the day was when students of my first grade class**

presented me a check for the ACDA that was well over three hundred dollars. This was money that they themselves donated. It melted our hearts. Through Finley, these children have learned of the spirit of giving to help

others. We believe that these lessons will continue to live on in these children as they grow into teenagers and young adults because of their being a part of this experience. What an incredible legacy for Finley!

While there were a lot of home runs hit and great plays made in the field, as always the star of the day was most definitely Finley

Kathleen. At times, we looked out over Finley Park and could see all these people playing and just generally having fun to honor Finley and to help other babies



through their donations and participation and we were humbled and proud of our little girl. This year, through the generosity of these wonderful people, **Finley raised over \$4,700 for the ACDA!!** She brought together so many people who shared in an experience none will soon forget. Way to go Miss Finley!!!



REPORT FROM THE DAVID ASHWELL FOUNDATION:

I haven't written an update since Jan 2017 and a lot has happened in that time!

We made a large transfer to NORD in April 2017 of £17,877 (approximately \$23,132).

Since that large transfer in April we have raised **£7,166 (\$9,208)** and I have a number of people to thank for that amount. In particular those families who have a standing order putting money into the charity bank account each month (ACD and non ACD families) and individuals who chose to donate to the charity in memory of a loved one.

Our love and condolences to the Hardisty family on the loss of Alison's father Randall Miles in whose memory donations have been made. Also to the family of Nathan and Ellie Flores who have donated in the memory of their loved one Mrs Kit Fastiggi, Nathan's grandmother.



Ceilidh for David – Simon and Amelia Ashwell, founders of The David Ashwell Foundation and ACDA parents to David (Mar 4, 2011 - Mar 19, 2011), together with Jo Taylor and Chris Coe, ACDA parents to Alex (May 8, 2011 - May 17, 2011)

On David's 6th birthday I held the second 'Ceilidh for David' in Stokesley (the small town where we live). Once again I was overwhelmed with the

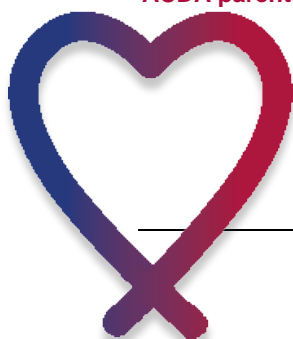
incredible support we were given and people's kindness. We raised £3,611 (\$4,672) through that event. It was hard work but so much fun and this year Jo Taylor and Chris Coe (parents of Alex) came to be part of it. We honestly couldn't have done it without them both and their hard work! Plus our rainbow babies had such an amazing time together – what an incredible bond they have!



Chris Dunne raised £2,256 (\$2,919) through his fundraising by running the Edinburgh Marathon. Chris lost his son Fraser to ACD in 2014 and we are so grateful to him and his family for raising money for our small charity.

I am continually amazed by the kindness of people. Some amazing ladies who work in my local shop organized a charity walk for David and raised £435 (\$562).

We have also had a lot of Rapha cycling kit donated to sell for the charity... so any keen cyclists please contact me!



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!

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

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. Fundraise when you ebay ([ebay for Charity](#)).
4. 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 ACD/MPV 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: [@TDAshwellF](https://twitter.com/TDAshwellF)

Mobile (Amelia): 07855473686

UPDATE FROM “STICHTING ACD” IN THE NETHERLANDS:



We introduced you to Mathijs Lourens, ACDA father to Myla (November 20, 2015 - December 17, 2015) in Issues #58 and #59 of ACDA Notes. As background, Mathijs has established a Dutch ACD foundation called “[Stichting ACD](#),” written a [book](#) describing his experience of being Myla’s father, coordinated various fundraising events and trained for and participated in several marathons, including marathons in Amsterdam (October 2016 and upcoming October 2017) and Rotterdam (April 2017).

Please contact Mathijs through Stichting ACD if you would like to join him for the Amsterdam marathon in October 2017 to raise awareness for ACDMPV!

Please also read a touching tribute to Myla [HERE](#) (in Dutch), published July 19, 2017 in LINDAnieuws.



Remembering Our Babies

[REDACTED]

[REDACTED]

Welcome to New Families

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

[REDACTED]



Safe Arrivals!

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

- [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
- [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

- [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
- [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)

