ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

acdassociation.org SUMMER 2019

Issue
68

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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Please see pages 2-4 for information about recent significant developments in ACDMPV research. The two research institutions discussed in the articles, Cincinnati and Baylor, are both recent NORD grant recipients. Thank you for supporting the ACDA and making research developments possible.

Regards,
Eliza Rista, President

RESEARCH NEWS

NORD GRANT UPDATES:

2018 NORD Grant:

The previously announced 2018 NORD grant (see Issues #63 and #64 of ACDA Notes) in the amount of $50,000 for ACDMPV research was recently awarded in June 2019 to **Dr. Csaba Galambos** at **University of Colorado Denver** in Aurora, Colorado, USA for the study entitled, "*The role of serotonin signaling in the pathogenesis of alveolar capillary dysplasia.*"

The ACDA initially presented Dr. Galambos' theory about the possible role of serotonin in ACDMPV patients in Issue #63 of ACDA Notes, stating his prior study "contemplates a new area of exploration in both the pathogenesis of and possible future development of new therapeutic strategies for ACDMPV. In the meantime, the next proposed step of this research is to confirm whether or not ACDMPV patients display elevated serotonin levels." The ACDA will support Dr. Galambos' current research by facilitating the collection of 24-hour urine samples of approved ACDMPV patients.

Dr. Galambos is a pediatric pathologist and prior NORD grant recipient for ACDMPV research in 2014. He has maintained a close working relationship with other key ACDMPV research institutions, including Baylor College of Medicine.

2019 NORD Grant:

The abstract submission deadline for the previously announced 2019 NORD grant (see Issue #67 of ACDA Notes) in the amount of $50,000 for ACDMPV research closed on June 18, 2019. NORD has begun the review of all submitted applications and will move forward with the selection process for the 2019 recipient.

2020 NORD Grant:

The ACDA is in the process of raising funds for a potential 2020 NORD grant. Please note the minimum amount required for a NORD grant for ACDMPV research is $35,000. Please click HERE to donate.

AT A GLANCE

Two possible therapeutic approaches for ACDMPV (pending the development of clinical trials):

- ➢ **Nanoparticle technology** delivering a STAT3 protein to the lungs of ACDMPV babies, which could trigger the development of blood vessels in the lungs
    - Science Daily (June 19, 2019)
    - Medical Daily (June 20, 2019)
- ➢ **Cell transplantation** of c-KIT-positive endothelial progenitor cells from donor lungs, to increase the development of pulmonary capillaries in ACDMPV babies

Please read additional information (see pages 3- 4) about each of the above possible therapeutic approaches. Note: The two research institutions discussed in the articles, Cincinnati and Baylor, are both recent NORD grant recipients. Thank you for supporting the ACDA and making significant research developments possible.

Journal Article (AJRCCM) (Nanoparticle Technology):

American Journal of
RESPIRATORY AND CRITICAL CARE MEDICINE®
An official journal of the American Thoracic Society / Advancing Pulmonary, Critical Care and Sleep Medicine
ATS
We help the world breathe
PULMONARY · CRITICAL CARE · SLEEP
www.thoracic.org
Vol 200 | No 3 | August 1 2019

Illustration depicting alveoli of the lung. Image from Carol and Mike Werner/Science Photo Library.

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Spatial Network Mapping of Pulmonary Multidrug-Resistant Tuberculosis Cavities Using RNA Sequencing (See page 370)

The developmental biology research group at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, USA (see Issues #57, #62 and #63 of ACDA Notes), recently collaborated with the genetic research team at Baylor College of Medicine in Houston, Texas, USA to publish a manuscript entitled "*The S52F FOXF1 Mutation Inhibits STAT3 Signaling and Causes Alveolar Capillary Dysplasia"* in the American Journal of Respiratory and Critical Care Medicine, which can be found HERE.

Pending the development of a clinical trial, nanoparticle technology delivering a STAT3 protein to the lungs of ACDMPV babies may be a future possible therapeutic approach for ACDMPV, to trigger the development of blood vessels in the lungs. Please read news articles published in Science Daily (June 19, 2019) and Medical Daily (June 20, 2019) for further details. From the Science Daily article:

"There are no effective treatments other than a lung transplant, so the need for new therapeutics is urgent," said Vlad Kalinichenko, MD, PhD, at the **Cincinnati** Children's Perinatal Institute Center for Lung Regenerative Medicine and lead study investigator. "We identified a nanoparticle therapeutic strategy to increase the number of alveolar capillaries and help preserve respiratory function for at least a subset of the babies with this congenital lung disease."

"In collaboration with the team of Pawel Stankiewicz, MD, at the **Baylor** College of Medicine in Houston, the Kalinichenko lab analyzed genetic information from human ACDMPV cases to **generate the first clinically relevant animal model of ACDMPV**. Scientists used a gene editing method called CRISPR/Cas9 to generate mice that faithfully mimic ACDMPV. The new laboratory model allowed researchers to pinpoint the ailment's cause and develop a potential and desperately needed nanoparticle-based treatment.

The authors theorized that treating newborn mice with STAT3 would stimulate blood vessel development in the lungs, but they had to figure out how to get the protein to the lungs…Researchers turned to nanoparticle technology to deliver a STAT3 mini-gene to lungs of newborn mice. They created a novel formulation for what are known as polyethylenimine (PEI) nanoparticles.

The gelatin-like PEI nanoparticles can carry therapeutic genetic material to different parts of the body by administering them to **patients intravenously**. Different formulations of PEI nanoparticles are currently being tested in clinical trials for adult cancer at other institutions, according to study authors…This stimulated blood vessel growth in the animals and the formation of air sacs called alveolar."

"If the efficacy of PEI nanoparticles is confirmed in the clinical trials under way for adult cancer, **PEI could be considered for STAT3 gene therapy in infants with ACDMPV**," Kalinichenko said. "Considering that ACDMPV is a rare disease, a multicenter clinical trial would be needed to assess the efficacy of STAT3 gene therapy in ACDMPV newborns and infants."

As background, the Kalinichenko Research Lab at Cincinnati was the winner of the 2017 NORD grant for ACDMPV research. The long-term goal of the Kalinichenko Research Lab is "to discover novel therapeutic approaches and generate novel FDA-approved drugs for treatment of these severe respiratory disorders." To learn more about the Kalinichenko Research Lab, please click HERE and read about their current projects.

Journal Article (AJRCCM) (Cell Transplantation):


American Journal of
RESPIRATORY AND CRITICAL CARE MEDICINE®
Vol 200 | No 3 | August 1 2019

The developmental biology research group discussed above at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, USA also recently collaborated on another manuscript entitled "*Postnatal Alveologenesis Depends on FOXF1 Signaling in c-KIT+ Endothelial Progenitor Cells*" in the American Journal of Respiratory and Critical Care Medicine, which can be found HERE.

The article focused on a severe pediatric lung disorder called Bronchopulmonary Dysplasia (BPD) with an objective to determine whether c-KIT+ EC progenitor cells stimulate alveologenesis (the formation of the alveoli) in the neonatal lung. The conclusion of the study was that cell therapy involving c-KIT+ EC progenitors can be beneficial for treatment of BPD.

In July 2019, the ACDA corresponded with Dr. Kalinichenko at Cincinnati (discussed above) to further understand the significance of this important research and how it applies to ACDMPV. **Pending the development of a clinical trial, cell transplantation of c-KIT-positive endothelial progenitor cells from donor lungs may be a future possible therapeutic approach for ACDMPV, to increase the development of pulmonary capillaries in ACDMPV babies.**

Journal Article (AJRCCM) (Diagnostics):


American Journal of
RESPIRATORY AND CRITICAL CARE MEDICINE®
Vol 200 | No 3 | August 1 2019

The genetic research team at Baylor College of Medicine in Houston, Texas, USA recently collaborated with an international team to publish a manuscript entitled "*Clinical, Histopathological, and Molecular Diagnostics in Lethal Lung Developmental Disorders*" in the American Journal of Respiratory and Critical Care Medicine, which can be found HERE.

The research team examined a series of pediatric lethal lung developmental disorders, including (1) ACDMPV, (2) acinar dysplasia (AcDys), (3) congenital alveolar dysplasia (CAD), and (4) other unspecified primary pulmonary hypoplasias. The team reviewed histopathological samples from lung biopsy or autopsy.

"The histopathological continuum in these lethal developmental disorders has made accurate diagnosis challenging. Over the past decade, genetic studies have revealed the causative role of the FOXF1 gene or other nearby variants in chromosome 16 for ACDMPV patients. In contrast, the molecular bases of two of the other lethal lung development disorders, AcDys and CAD, have remained poorly understood but the article discusses recent progress for these other disorders, including disruption of the TBX4-FGF10-FGFR2 pathway. The team proposes that for a more precise diagnosis of lethal lung developmental disorders such as AcDys and CAD, a diagnostic pathway including whole genome sequencing should be implemented."

AWARENESS NEWS

Sci Foo Conference (David Ashwell):

Amelia Ashwell, ACDA mother to David Ashwell (March 4, 2011 – March 19, 2011), recently traveled from the UK to attend a science conference, Sci Foo, at Google X in Palo Alto, California, USA. In Amelia's own words:

"Those of you who follow me on social media will know that early in July I made a trip to California to attend **Sci Foo**. They invite scientists from all over the world. As an attendee, I heard about some new innovations which could have an impact on ACDMPV and other diseases requiring transplants.

One incredible woman I met was **Professor Doris Taylor who works at the Texas Heart Institute and is a pioneer in regenerative medicine**. Basically, she builds hearts and other organs, including lungs, from unusable organs. This could be a complete game changer in the future for babies waiting for transplants, not just for lungs but many other organs.

However the team at Texas are not alone, in Harvard they are also developing technologies that means we are less reliant on donor organs. I met Professor Kit Parker who is also working in this field.

I wanted to share with you that there are developments in these broader fields that could make a difference to ACDMPV outcomes in the future."

Upcoming Date:

August 19, 2019 – 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)

LUNG TRANSPLANT UPDATES

Seven Year Anniversary (Eleni "Ellie" Scott):

Ellie, age 7, a lung transplant recipient, celebrated seven years post-transplant in June 2019!

Eleni "Ellie" Scott (see Issue #57 of ACDA Notes), a lung transplant recipient and daughter of ACDA parents Karen and Nick Scott, recently celebrated seven years post-transplant in June 2019 and is doing very well! Eleni was diagnosed with ACDMPV at eight months old and received a double lung transplant at nine months old at St. Louis Children's Hospital in St. Louis, Missouri, USA. She will celebrate her 8th birthday on August 26, 2019!

In addition, please read this touching article recently posted by St. Louis Children's Hospital about Ellie's experience with atypical ACDMPV and bilateral lung transplantation:

Ellie Scott: A Gifted Life

Excerpt: "For all of the successful pediatric transplants performed at St. Louis Children's Hospital, Dr. Sweet first credits the commitment of patient's families like Ellie's, who do whatever is needed to ensure the health of their children. "We also rely on the foundation of people who don't lose track of the details – our transplant coordinators, social workers, child life specialists, dietitians, and physical therapists, as well as the physicians and nurse practitioners overseeing the children's care," he says. "**For Eleni, we were pushing the envelope in terms of a strategy to bridge her to successful transplantation. We are all delighted that she has succeeded in becoming such an extraordinary little girl.**""

British Transplant Games (Imogen Bolton):

Imogen Bolton's story remains in the headlines in the UK and beyond! We introduced you to Imogen as an ACDMPV survivor in the UK and Europe's smallest lung transplant recipient (see Issues #56, #58, #61 and #65 of ACDA Notes). For a listing of articles featuring Imogen, please click HERE and also click HERE to follow Imogen's story on Facebook. **Imogen will**

celebrate her fourth birthday in November 2019!

For the second year in a row, Imogen participated in the **British Transplant Games**, this year in Newport. Imogen competed for GOSH Heart and Lungs and last year was the youngest participant in the entire competition. Imogen was sponsored this year for her efforts in the long jump (silver medal!), ball throw, beanbag archery (bronze medal!) and 25m track competitions and raised a substantial sum of money directly for the heart and lung transplant team at GOSH that saved her life in 2016.

The British Transplant Games are the largest national charity in England promoting active recovery for transplant recipients and increasing awareness of the benefits of organ donation. Their aim is to raise awareness of the need for organ donation, encourage transplant recipients to lead active lifestyles, and show appreciation for and remember donors and their families. #DonateLife

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Moving “Forward” with Grief:

As shared in the ACD Parent Group on Facebook, **WATCH** a TED talk about grief by writer and podcaster Nora McInerny. “Grief is kind of one of those things…where you don't get it until you get it, until you do it. And once you do it…once it's your grief and your front row at the funeral, you get it. You understand what you're experiencing is not a moment in time…What can we do other than try to remind one another that some things can't be fixed, and not all wounds are meant to heal? We need each other to remember, to help each other remember, that grief is this multitasking emotion. That you can and will be sad, and happy; you'll be grieving, and able to love in the same year or week, the same breath...A grieving person is going to laugh again and smile again," she says. "They're going to move forward. But that doesn't mean that they've moved on."

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 prior to the Q3 ACDA Board Meeting in August 2019.

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 2020 NORD grant is $35,000.

Balance of ACDA account:

The balance of the ACDA bank accounts as of August 1, 2019 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, 2019. 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 May 15, 2019 and July 30, 2019 is $[redacted]. Items with the ACDA logo are available for purchase in our Spreadshirt store HERE. Don't forget the ACDA earns a commission equal to **20% of every product sold**! **Look for 15% off everything through Aug 4, 2019!** (Use code: SUMMERSUN15)

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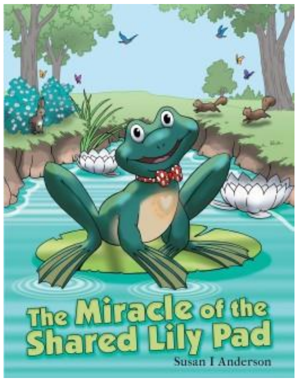
**We are sorry we do not know the child for whom the memorial contribution was made. Please contact us to let us know.*

FJNortheasters (Fallon Rilling):

Once again, it's fundraising season for the Toyota off road club, the **FJNortheasters**! The FJNortheasters held their **12th Annual Northeast Run** in April 2019. 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) and President of the FJNortheasters, continued the club's tradition of generously supporting the ACDA (see Issues #56 #59 and #64 of ACDA Notes). **An incredible total of $4,444 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. Please read the summary below in Bob's own words:

"A successful Northeast Run has come and gone. The bills have been paid. The food has been eaten. The prizes have been raffled off. The merchandise has been sold. Thanks to all of you, the @fjnortheasters 12th Annual Northeast Run has raised a total of $4,144.00 to donate to the #acda for #alveolarcapillarydysplasia research. We will again donate in honor of Fallon Jade Rilling, the daughter of one of our long time members and current club president, who passed away in 2013 from ACD/MPV. Thanks to all of our members that attended the event, thanks to the ones that couldn't come but still found a way to donate, thanks to our sponsors for donating such amazing prizes and thank you to our staff for making it all come together all year long. Thanks to @rauschcreek and Twin Grove camp ground fo allowing us to use your facilities. FJNE number 12 just ended but our volunteer staff is already prepping to make number 13 even better! A special thanks to Zach @zd.photo for being on hand to capture the event. See you all next year!! #fjnortheasters #toyota #fjcruiser #overland #rauschcreekoffroadpark #landcruiser #4runner #tacoma #jeep #wheelingforareason #raredisease"

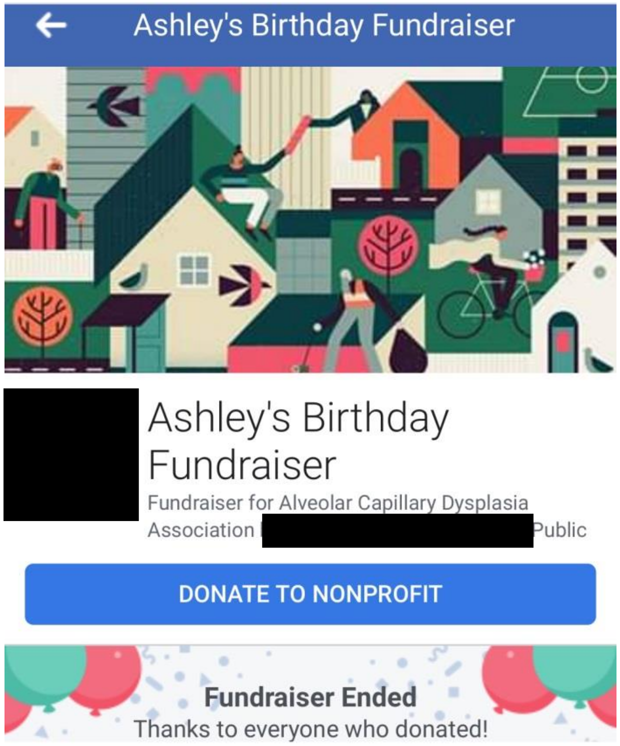
The Miracle of the Shared Lily Pad:



Susan Anderson, mother to ACDA mom Kim Anderson Bush and grandmother to Phoebe (March 21, 2010 – April 21, 2010) and Ronan (April 27, 2011 – July 16, 2011), published a book entitled, "The Miracle of the Shared Lily Pad." Ms. Anderson is generously donating all profits after taxes and expenses from the sale of her book to ACDMPV research. If you would like to order a copy, the website for the book is www.writinggrammy.com. It is also available through Amazon.com, christianbook.com and barnesandnoble.com.

Many of our ACDA families previously chose to have their child's name(s) included, which are placed in alphabetical order throughout the book. As described by Ms. Anderson, "This children's storybook follows the adventures of Freddie the frog who is given a special gift from God, a beautiful place to live. Freddie learns to share his gift and subsequently grows in his love for God's other creatures. Every time he shares, God expands his pond. The biggest surprise for Freddie is how his heart grows with God's love."

Birthday Fundraiser (Braylee Speed):



[redacted] Ashley's Birthday Fundraiser

Fundraiser for Alveolar Capillary Dysplasia Association [redacted] Public

Fundraiser Ended

Thanks to everyone who donated!

Ashley organized a Facebook birthday fundraiser in honor of her daughter, Braylee Speed. Thank you Ashley!!

In June 2019, Ashley Speed, ACDA mother to Braylee (February 13, 2014 – February 26, 2014), organized a birthday fundraiser **for ACDMPV research in honor of Braylee**. In Ashley's own words, "For my birthday this year, I'm asking for donations to the 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."

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 2018 for the ACDA. *Please let us know if similar volunteer grants are offered through your employer!*

Matching Gifts:

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 **Schneider Electric, Bank of America, Chevron and Goldman Sachs** for their recent 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**." Mathijs plans to continue running marathons for ACDMPV awareness in Europe and then worldwide! He previously completed the Rotterdam Marathon (April 2017, 2018 and 2019), the Amsterdam Marathon (October 2016 (*half*), 2017 and 2018 (*Kids Run*)) 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, Germany or beyond!** For additional information about the upcoming runs highlighted below, please visit Run4ACD on Stichting ACD's website, Dam tot Damloop and BMW Berlin Marathon.

Dam tot Damloop (September 22, 2019):

Upcoming Event: Dam tot Damloop (Dam to Dam Run in English) is an annual road running competition held in North Holland in the Netherlands. It is a ten mile race from Amsterdam to Zaandam. Mathijs plans to participate in the **Dam tot Damloop on September 22, 2019!**

BMW Berlin Marathon (September 29, 2019):

Upcoming Event: Chasing the dream to cross the world with Myla! Mathijs trained hard with focus and determination for many months in order to expand his marathon adventure across the border in October 2018 (see Issues #65 and #66 of ACDA Notes). For his first foreign marathon, he planned to run the marathon in Cologne, Germany on October 7, 2018 to raise ACDMPV awareness in Germany. Despite his best efforts and tremendous optimism, a significant cold mandated that Mathijs sit out his first foreign marathon attempt. But Mathijs never gives up and is already planning his next marathon adventure in Germany! Mathijs plans to participate in the **BMW Berlin Marathon in Berlin, Germany on September 29, 2019!**

Book:

In addition to his work on the marathons, Mathijs has written a book. If you would like to order a copy of Mathijs' book describing his experience of being Myla's father, the book is for sale and the proceeds benefit Stichting ACD.

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.

REPORT FROM THE DAVID ASHWELL FOUNDATION (UK):

I am always open to suggestions of what is a good way to fundraise for ACDMPV research so please get in touch! On my to-do-list is to make an 'Amazon Smiles' account for The David Ashwell Foundation.

After we have made a payment to NORD, which we did in April 2019, the bank balance goes to zero which is always daunting! But now **it's back up to over £1000 – so lots more fundraising to do**!

Looking back since March 2011, **£208,414 ($258,100)** has been raised for ACDMPV research by families in the UK and Europe. This has contributed to the funding raised internationally to the ACDA. We are always very enthusiastic to raise more money for ACDMPV research and would appreciate any help! **Thank you to those families who have set up direct debits for the charity and whose families fundraise at work for us.**

Another plea for everyone in the UK online shopping – please use The Giving Machine (GO HERE) **to generate income from online shopping (for free!).** 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 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 ACDMPV 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).

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.
2. Fundraise while you online shop (The Giving Machine) (a percentage of what you spend is donated)
3. Collect postage stamps
4.

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 family:

[redacted]

SAFE ARRIVALS!

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

[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)