ACDA
ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION
acdassociation.org
FALL 2019
Issue 69

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

In October 2019, the ACDA created a **memorial wall** dedicated to the memory of our children in observance of Pregnancy and Infant Loss Awareness month. Please see **page 4** for the completed project and view it **online** [here](#).

In addition, we invite all of our ACDA families to participate in the **ACDA Wave of Light** on Pregnancy and Infant Loss Remembrance Day. **On Tuesday, October 15 at 7:00 p. m. in your respective time zone**, **please share a photo of your candle** on the ACDA Facebook page to create an ACDA Wave of Light. Please also use the public forum to share your child's name or special memory in the comments. The ACDA Wave of Light provides a time for quiet remembrance and reflection and is a powerful worldwide experience in honor of our loved ones. #WaveofLight #ACDAWaveofLight

Regards, Eliza Rista, President

Please click HERE to "Like" our public Facebook page and join the ACDA Wave of Light.

RESEARCH NEWS

Cincinnati Children's Hospital:

In September 2019, the ACDA corresponded with the developmental biology research group at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, USA (see Issues #57, #62, #63 and #68 of ACDA Notes) regarding **Dr. Kalinichenko's hope to provide a compassionate use trial of PEI/PEG nanoparticles for delivery of therapeutic angiogenesis stimulating genes for the treatment of ACDMPV**. As stated by Cincinnati Children's, the published work, "*The S52F FOXF1 Mutation Inhibits STAT3 Signaling and Causes Alveolar Capillary Dysplasia*" (discussed in Issue #68 of ACDA Notes), shows promise in animal models of ACDMPV. Further, they explained they are in communication with the FDA to potentially make it available to patients with ACDMPV for two reasons: (1) there is neither cure nor effective treatment for patients with ACDMPV, and (2) this genes restorative technique rescues pulmonary structure and function in patients with ACDMPV according to Cincinnati Children's research. Dr. Kalinichenko's therapy targets the FOXF1 gene and/or its significant downstream gene targets.

Please see the related journal article in the next subsection for further discussion on this possible therapeutic approach. **The ACDA extends its sincerest thanks to Cincinnati Children's for its significant developments and advancements in ACDMPV research.**

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):

Dr. Jennifer Wambach, an ACDMPV expert at St. Louis Children's Hospital in Missouri, USA, and Dr. Lawrence Nogee at Johns Hopkins University School of Medicine, recently published a discussion article about Dr. Kalinichenko and his colleagues' recent research developments, entitled "*A Step Towards Treating a Lethal Neonatal Lung Disease: STAT3 and Alveolar Capillary Dysplasia*," which can be found HERE (full text HERE).

The article contemplates the question "**Could delivery of STAT3 cDNA using nanoparticles, which are being used in clinical trials for human malignancies, be used to treat human infants with ACDMPV?**" and explains the process while setting forth any potential limitations or barriers. Despite the practical limitations set forth therein, the authors conclude Dr. Kalinichenko and his colleagues have "**generated an important animal model of and made an important advance in understanding the molecular pathogenesis of ACDMPV, and suggest a path forward for the treatment of this devastating disorder.**"

October is Pregnancy and Infant Loss Awareness Month

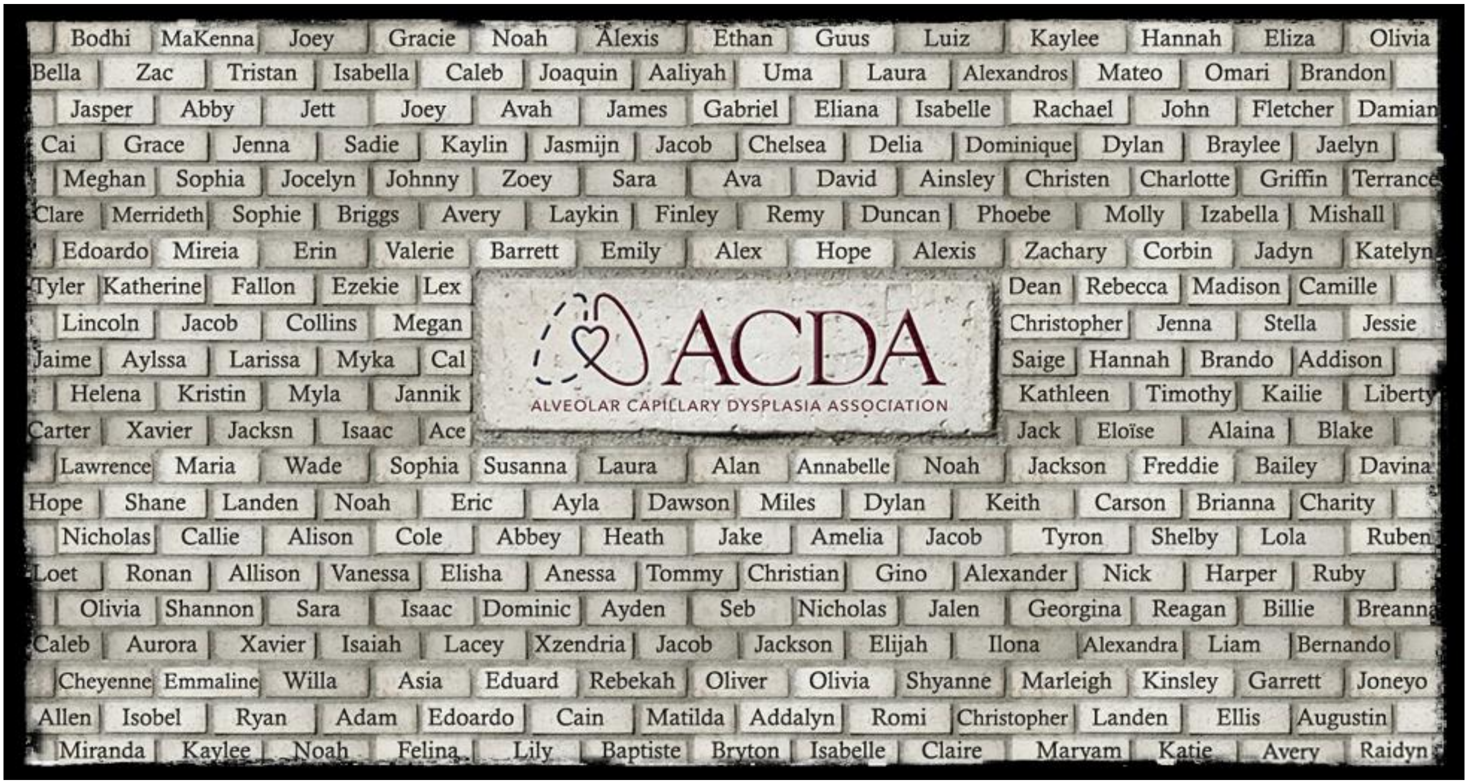
In October 1988, President Ronald Reagan of the United States proclaimed **October as National Pregnancy and Infant Loss Awareness Month** saying, “When a child loses his parent, they are called an orphan. When a spouse loses her or his partner, they are called a widow or widower. When parents lose their child, there isn’t a word to describe them. This month recognizes the loss so many parents experience across the United States and around the world.”

October 15, 2019 – Pregnancy and Infant Loss Remembrance Day

October 15 is Pregnancy and Infant Loss Remembrance Day. The day is observed with ceremonies and candle-lighting vigils, concluding with the International Wave of Light; a worldwide lighting of candles. **The International Wave of Light invites participants from around the world to light a candle at 7:00 p.m. on October 15 in their respective time zones, and to leave the candle burning for at least an hour. The result is a continuous chain of light spanning the globe for a 24 hour period in honor and remembrance of our babies we have lost.**

AWARENESS NEWS

ACDA Memorial Wall: October 2019



"Remembering you is easy, I do it every day;
missing you is a heartache that never goes away."

In October 2019, the ACDA created a memorial wall in honor of Pregnancy and Infant Loss Awareness month. Projects in prior years have included collages of our babies, a photo project of bereaved parents, luminaries and calligraphy.

This year a memorial wall is dedicated to the memory of our children. The names commemorate children registered with the ACDA that have sadly passed away. So many names and so many stories with so much love and so much heartbreak. We encourage you to take a moment to look through the names and reflect on the lives of these precious children and the loss endured by their respective families, friends and loved ones.

Please go HERE to learn how to participate in the ACDA Wave of Light on October 15, 2019. #WaveofLight #ACDAWaveofLight #infantloss #PAIL

University of Florida College of Medicine presentation (Christopher Locke):

Diana Locke, a Registered Nurse and ACDA mom to Christopher (November 7, 2006 - December 17, 2006) gave her annual presentation to 142 first year medical students (and even some returning second and third year students that had attended prior presentations!) at the University of Florida College of Medicine in Gainesville, Florida, USA on August 21, 2019. The presentation focused on ACDMPV, Christopher's case and other ACDMPV babies. With this program, future doctors now know about ACDMPV.

Diana shared that the medical students were wonderful again this year with so many good questions! She said a PICU nurse now enrolled in medical school said they have observed symptoms similar to possible ACDMPV cases in the PICU for years without affirmative diagnosis. The ACDA sincerely appreciates Diana's teaching presentations to these future medical professionals.

Lights in Suffolk County (Fallon Rilling):

On October 10, 2019, the H. Lee Dennison Building in Suffolk County, New York, USA was once again lit purple to raise awareness for ACDMPV in honor of the sixth birthday of Fallon Rilling (October 10, 2013 – October 21, 2013). In 2014, Suffolk County officials declared every October 10th as "ACD Awareness Day" in Suffolk County, New York in honor of Fallon. As such, the county executive building has been lit each year to promote ACDMPV awareness.

The ACDA is infinitely grateful to the Rilling family for their incredible awareness and fundraising efforts throughout the years.

Whereas: *The Office of the Suffolk County Executive is committed to promoting the health of our residents throughout Suffolk County; and*

WHEREAS: *on Tuesday, the tenth day of June in the year two thousand and fourteen, the Suffolk County Executive's Office, the Rilling family and their friends and co-workers will gather at the H. Lee Dennison Building to honor the memory of Fallon Jade Rilling; and*

WHEREAS: *Fallon Jade was a Suffolk County resident who was diagnosed with Alveolar Capillary Dysplasia in October of the year two thousand thirteen; and*

WHEREAS: *Alveolar Capillary Dysplasia is rare but fatal disease resulting in a developmental anomaly of the pulmonary vasculature, impeding the exchange of oxygen and carbon dioxide; and*

WHEREAS: *while young Fallon Jade ultimately succumbed to the symptoms associated with Alveolar Capillary Dysplasia, her memory will live on. Fallon Jade is deeply loved and greatly missed by her mother, Kristin Rilling, and her father, Robert Rilling, two individuals who have dedicated their careers to keeping Suffolk County safe, and by her big brother, Avery, and her big sister, Harper; and*

WHEREAS: *today is a time to remember Fallon's brief life on this Earth and join with her family and the Alveolar Capillary Dysplasia Association to raise awareness, search for answers, and hope for a cure.*

NOW, THEREFORE, I, *Steven Bellone, as County Executive of the County of Suffolk, do hereby recognize the tenth day of October as*

ALVEOLAR CAPILLARY DYSPLASIA AWARENESS DAY
In Honor of Fallon Jade Rilling

and stress the importance of increased awareness, education, and research of this fatal condition, its causes, and its potential cures.

IN WITNESS WHEREOF, *I have hereunto set my hand and caused the Seal of the County of Suffolk to be affixed this tenth day of June, in the year two thousand fourteen.*

Steven Bellone, County Executive
County of Suffolk, New York

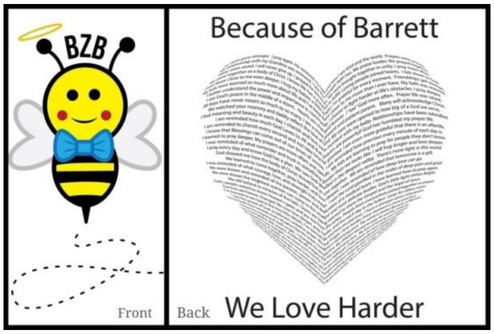
Proclamation in 2014 declaring every October 10th as ACD Awareness Day in Suffolk County, New York

Families in the News (Barrett Bone):

Katy and Tyler Bone, ACDA parents to Barrett (June 14, 2019 – July 12, 2019), recently shared Barrett's experience with ACDMPV and their generous gift of donor milk to other NICU babies with KMOV4 in St. Louis, Missouri. Please read their poignant story below:

St. Charles Co. mom lost her infant and is now on a mission to help other moms and newborns

Be sure to watch the touching video that accompanies the story to enter Barrett's nursery with Katy and Tyler and hear their loving description of Barrett in their own words.



**Shirts in honor of Barrett Bone -
the heart is comprised of personal responses
as to how Barrett changed lives**

In addition to their awareness efforts, Katy and Tyler are also **raising funds for ACDMPV research in Barrett's honor**. They worked with a designer to create shirts for Barrett and proceeds from the sales will be contributed to the ACDA. **Thank you Bone family!**

ACDA connections (Sadie McCasland, David Ashwell and Alex Taylor Coe):

ACDA moms, Candice and Amelia, in the UK!

Candice McCasland, ACDA mother to Sadie (February 4, 2014 – February 19, 2014), **recently traveled to England** for vacation and **met Amelia Ashwell**, ACDA mother to David (March 4, 2011 – March 19, 2011) for tea. Four of their daughters also got the opportunity to meet and play! Amelia is the co-founder of the David Ashwell Foundation, our sister organization in the UK.

Candice also had the opportunity to meet **Jo Taylor**, ACDA mother to Alex (May 8, 2011 – May 11, 2011) the next day! Their kids had a fun time together in the gardens and quickly became fast friends. Jo has contributed extensively to The David Ashwell Foundation.

ACDA moms, Jo and Candice, in the UK!

Candice is a member of the ACDA Communications Committee and she has now met **eight ACDA families** in-person worldwide! Thanks for being such a fantastic ACDA ambassador to our families, Candice!

LUNG TRANSPLANT UPDATES

Lung Transplant Update (Tom Schnierle):

In December 2018, Tom received a lung transplant at 2.5 years old in Germany, which was complicated by limited organ availability and the fact that lung transplants were not performed on small children in Germany. Prior to his lung transplant, Tom had been in the intensive care unit since birth (See Issues #64, #66 and #67 of ACDA Notes). On August 10, 2019, **Tom celebrated his birthday at home** for the first time ever! Happy 3rd birthday, Tom! #acdwarriors

Tom, age 3, a lung transplant recipient and hospitalized from birth for 2+ years until transplant, celebrated a birthday at home for the first time in August 2019!

Lung Transplant Update (Luca Palmisano):

Luca, age 3, a lung transplant recipient and new preschooler!

Look who started preschool in Fall 2019! We introduced you to Luca Palmisano in Issues #57-59, #61, #66 and #67 of ACDA Notes.

November 3, 2019 is the annual Team Luca 5k Run/Walk if you would like to register!

In November 2016, Luca received a lung transplant at 4.5 months old at Children's Hospital of Philadelphia in the USA.

You can follow Luca's Lung Transplant Story HERE. #teamluca #GiftofLife #acdwarriors

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 October 11, 2019 is **$**[redacted]**,** which amount does not include an additional $[redacted] in known pending distributions to the ACDA.

Update from AmazonSmile:

The ACDA was issued a **$**[redacted] donation from the AmazonSmile Foundation as a result of AmazonSmile program activity between April 1 and June 30, 2019. To date, AmazonSmile has donated a total of $[redacted] to the ACDA. 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 July 31, 2019 and October 11, 2019 is **$**[redacted]. Items with the ACDA logo are available for purchase in our Spreadshirt store HERE. 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 FREE SHIPPING from October 23-25, 2019!**

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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Fundraising Idea (SO EASY!!):

Please consider participating in the ACDA's **fifth annual coffee fundraiser** this holiday season through [Giving Bean](). In addition to "online" purchases with **25%** of every bag sold online donated to the ACDA, "in-person" sales can also easily be organized with **40%** of such in-person sales contributed to the ACDA! Additionally, the ACDA logo is printed directly on the coffee bag label if more than 50 bags are ordered through such in-person sales. **Please contact us to get involved!**

#GIVINGTUESDAY

December 3, 2019

DONATE

It seems the holiday season begins earlier every year, but the frenzy of shopping truly launches the day after Thanksgiving, commonly known as #BlackFriday. As more and more people began to turn to online shopping, #CyberMonday emerged too. Although all this shopping is done in the name of giving gifts to loved ones, it sometimes feels like the goodwill of the holiday season fades into the background. In 2012, a few nonprofit professionals decided to do something about it and raised over $10 million in the inaugural event. But Giving Tuesday was just getting started. By 2016, the giving day raised over $177 million online and over $400 million online in 2018!

- **What:** A global day of giving
- **When:** The Tuesday following Black Friday
- **Where:** Everywhere. Organizations all over the world participate

The biggest giving month of the year is right around the corner. In fact, about a third of all charitable giving happens in December. Please help us successfully kick off the holiday giving season by promoting the #GivingTuesday campaign on December 3, 2019 in support of the ACDA.

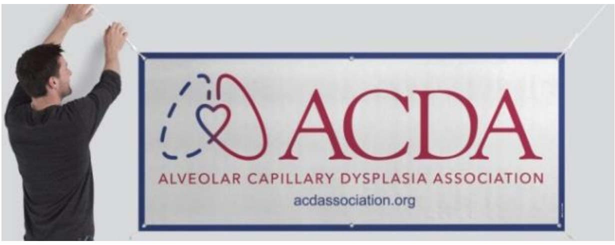
In Memoriam Donations (Madison Arias):

Rebecca and Jonathan Arias, ACDA parents to Madison (August 12, 2019 - September 1, 2019), have raised an outstanding $17,107 for ACDMPV research. The ACDA is grateful for this incredible contribution in honor of Madison.

Madison Georgann Arias was born on **August 12, 2019** at 10:52 AM. She was 40 weeks and 3 days and by all measures was a normal, healthy baby. She was born with a head of full, beautiful, jet black hair, full pouty lips and she loved to be held. Everything was going fine, she was latching and feeding with no problems and had just finished her first bath. It was after her bath, approximately 21 hours into her life, that we noticed her rosy pink complexion turn purple, her pouty lips turn blue. She was rushed to the NICU at Brigham & Women's Hospital. It was at the NICU where our unwanted education on oxygen saturation, pulmonary hypertension and PDA shunting began. At first the diagnosis was benign, her x-rays and echo cardiograms showed no major issues, just some pressure in the right ventricle which pointed to PPHN, a disorder that could be solved with extra oxygen and time. However, as the hours passed, the amount of oxygen increased along with the size of the machines being used to support her. We went from oxygen hoods to ventilators, from no medication to nitric oxide. When we went to bed that night we hoped for the best, but the morning had different plans. The nurses at the NICU were having difficulty keeping her oxygen saturation up with just a ventilator and we were informed that we would need to transfer her to **Boston Childrens** so that she could be put on ECMO. Luckily, Boston Childrens was right next door and was just a short bridge walk over. At Boston Children's they were able to stabilize her using ECMO. The staff at Childrens were excellent and really became an extended family for Madison. They adored her beautiful hair, were impressed by her strength during all the tests and loved her **signature pink bow**, a gift from her loving aunts. She showed a lot of improvement in the tests over the next few days. So much so that after 5 days on ECMO, we were confident about taking her off. She was de-cannulized and remained stable for 24 hours and we rejoiced over the little wins like her **opening her eyes and squeezing our fingers with her tiny hands.** But eventually her pulmonary pressures had once again risen, causing her stats to drop and ultimately needing to return to ECMO. It was at this time that the word Alveolar Capillary Dysplasia began increasing in the medical staffs' vocabulary. They performed some additional tests using a cardiac catheter and a lung biopsy. After the biopsy she was diagnosed with ACD. We knew our options were limited, our next course of action was to try Remodulin to see if it would help. The staff began giving her the medicine, hoping to improve her condition enough to at least be taken off ECMO. However, we didn't get the chance. She began bleeding from her brain, which started the downward spiral to her final hours. Her father and I were able to spend her last hours of life holding her, with no tubes or machines, just like we did when she was born 3 weeks earlier. She passed away on September 1st and 12:45 AM, in our arms. We take comfort in the knowledge that **she knows we were with her throughout her whole journey, every night, reading her stories and singing her songs.** And we take pride in **how hard she fought** for her life. In an effort to continue her fighting spirit, we are dedicated to doing whatever we can, to ensure future families don't have to experience such a devastating loss. **That includes contributing whatever resources we can to the important research being conducted by the ACDA.**

Thanks,
Rebecca & Jonathan

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.

Rack Cards:

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

Birthday Fundraiser (Griffin Brady):

[redacted] **Laken's Birthday Fundraiser**
Fundraiser for Alveolar Capillary Dysplasia Association by [redacted]

$406 raised of $200 Ended

Laken and Josh celebrated their birthdays in August 2019 and together raised over $1,000 for ACDMPV research in honor of their son, Griffin Brady. Thank you for your amazing support, Brady family!

In August 2019, Laken and Josh Brady, ACDA parents to Griffin (March 7, 2019 – March 24, 2019), organized birthday fundraisers for **ACDMPV research in honor of Griffin**. In Laken's own words, "My husband and I celebrated both of our birthdays this weekend and together with the help of friends and family raised over $1000 for the ACDA! Nothing will ever replace my sweet boy, but it makes my heart so happy that we could do something in memory of him.❤"

Brochures:

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

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 the Rotterdam Marathon (April 2017, 2018 and 2019), the Amsterdam Marathon (October 2016 (*half*), 2017 and 2018 (*Kids Run*)), the Berlin Marathon (September 2019) 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 and TCS Amsterdam Marathon Kids Run.

TCS Amsterdam Marathon Kids Run (October 20, 2019):

TCS AMSTERDAM MARATHON 2019
TATA CONSULTANCY SERVICES

Upcoming Event: Mathijs and **kids** from team Stichting ACD plan to run the **TCS Amsterdam Marathon Kids Run on October 20, 2019** to raise ACDMPV awareness! The Kids Run is a children's run that takes place during the TCS Amsterdam Marathon. Children aged 4 to 12 can participate in the 700-metre run, which starts behind the stadium and finishes in the stadium itself.

Dam tot Damloop (September 22, 2019):

On September 22, 2019, Mathijs and team Stichting ACD ran the **Dam tot Damloop** (Dam to Dam Run in English), which is an annual road running competition held in North Holland in the Netherlands. It is a ten mile race from Amsterdam to Zaandam.

In Mathijs' own words, "**We are still here. Fighting ACD in our own way, with so much love**. I am still running more than three years after our daughter Myla died of ACDMPV. And, maybe even more precious, **more and more people** start running with us. Life is like a marathon and never goes in one straight way. Eventually we will reach our goal. Today was the Damloop in Amsterdam and it was a wonderful day. Smiling faces and nice weather. Old friends and new friends running with the amazing Myla shirt in the streets of Amsterdam and Zaandam. Next week I will be running Berlin marathon and I cannot do that without our special team of dear friends supporting me."

BMW Berlin Marathon (September 29, 2019):

On September 29, 2019, Mathijs and team Stichting ACD ran the **BMW Berlin Marathon in Berlin, Germany.** After illness forced Mathijs to sit out his first attempt last year (see Issues #65-#68 of ACDA Notes), he achieved his goal in September 2019 of running his **first foreign marathon** and expanded his marathon adventure across the border!

In Mathijs' own words, "After another long journey of hard work, discipline and dedication, our first international adventure was about to happen. Last weekend we went to Berlin together for the Berlin Marathon and of course Myla was with us. It was amazing and of course I couldn't have done it without the help of Jessica and amazing friends.

Wearing the special Myla shirt always makes me happy. **We will continue searching for answers! We are always stronger together!"**

Check out (and share!) this **awesome** high definition **[VIDEO](#)** of the Berlin marathon adventure! English subtitles included.

HD Video of the Berlin marathon adventure!
English subtitles included.

Eindhoven Marathon (October 13, 2019):

On **October 13, 2019**, a runner from team Stichting ACD raised ACDMPV awareness while running the **Eindhoven Marathon**!

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. To be added, please contact Mathijs at contact@stichtingacd.nl and send him a picture with name, birth date and angel date.

REPORT FROM THE DAVID ASHWELL FOUNDATION:

If you are going to give gifts this holiday season **please, please use The Giving Machine** (see below for more info)!

In your workplace you could suggest donating to The David Ashwell Foundation rather than giving gifts or Christmas cards. On our Virgin Money Giving pages (see below), set up a page in for your precious baby/child and encourage people to donate there.

Still, on my (very long) to-do list for autumn is to enroll local schools and universities to take part in Rare Disease Day 2020 to make sure we get it into school calendars.

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 families:

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

[redacted]

[redacted]

Safe Arrivals!

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

[redacted]

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

At the quarterly ACDA Board of Directors meeting in August 2019, Eliza Rista, Renee Murray and John Rista were unanimously reelected to serve as President, Secretary and Treasurer, respectively, of the ACDA Board of Directors until August 2020.

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)