

Issue
80

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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THERE IS A STORY
BEHIND EVERY
CHILD'S NAME.

TELL US YOURS.

The ACDA is undertaking a story telling project for Pregnancy and Infant Loss Awareness Month in October 2022. Projects in prior years have included collages of our babies, a photo project of bereaved parents, memorial wall, luminaries, calligraphy, written word project about grief over time and an audio compilation of spoken names.

This year we want to hear the story of your baby's name, please
[submit your response here.](#)

Bereaved parents often have limited opportunities to hear or say their beloved child's name, with even fewer chances to talk about its meaning. We want to hear those stories. It is our hope that sharing the story of your loved one's name along with reading the names and stories of other children affected by ACDMPV will provide a sense of comfort and community within our ACDA families. If you would like to participate, please visit the [link above](#) and submit your response by **SUNDAY, OCTOBER 2.**

All responses will then be organized and presented by the ACDA on October 15, 2022. We hope you will participate and look forward to sharing the final version of this special story telling project for Pregnancy and Infant Loss Awareness month.

Regards, Eliza Rista, President

RESEARCH NEWS

2022 Grant Update:



As shared via social media in July 2022, it is the great pleasure of the ACDA and The David Ashwell Foundation to announce a **\$50,000 grant will be issued in 2022 for ACDMPV research**. The ACDA is partnering with the **American Thoracic Society (ATS)** and its excellent research program for this grant cycle. The ATS, with funding from the ACDA and The David Ashwell Foundation, is accepting applications for a total of \$50,000 for scientific research studies and/or clinical research studies related to ACDMPV (see the box to the right for additional application information).

As background, **over \$700,000 has been issued for ACDMPV research with a total of thirteen grants since 2005**. Thank you for keeping the momentum going with annual research grants the **last nine years in a row**, other than a one year deferral due to COVID-19 impacts.

Every single dollar matters in rare disease research, perhaps more than ever as significant research developments regarding possible therapeutic approaches for ACDMPV are emerging, pending the development of clinical trials. The smaller seed grants issued in recent years through money raised by

ACDMPV affected families and friends has collected data for use in larger multi-year government grants, including the \$1,900,000+ grant awarded to Baylor College of Medicine from the NIH in 2017 for a four-year study. The seed grants also sustain ACDMPV research during the very difficult NIH or FDA application processes. It can take research institutions a few years (and rejections) to finally have enough research material for NIH or FDA approval. **Larger governmental grants and approvals would simply be inaccessible without the ongoing seed grants raised by families and friends affected by ACDMPV.** So please keep up those birthday fundraisers, restaurant nights, off-roading events, marathon pledges and all the other amazing ways you raise money for ACDMPV research! Progress is being made each year and we are thankful for every donation. Please visit our website [HERE](#) to read a full history of 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.

ATS Request for Letter of Intent – 2022 Research Grant:

The American Thoracic Society (ATS), with funding from the Alveolar Capillary Dysplasia Association (ACDA) and The David Ashwell Foundation, is **currently accepting applications for up to \$50,000** for scientific research studies and/or clinical research studies related to Alveolar Capillary Dysplasia/misalignment of the pulmonary veins (ACDMPV). The ATS encourages all U.S. and international researchers interested in studying ACDMPV to consider applying for 2022 funding. **The Letter of Intent Submission Deadline is September 26, 2022.** See full information [HERE](#).



AWARENESS NEWS

ACDA Tattoo (Maryann Blehr):

In May 2022, **Maryann Blehr**, ACDA mother to Bella (December 21, 2009 – January 12, 2010), got a tattoo of the ACDA logo. In Maryann's own words, "I've been wanting the ACD logo tattoo since it was designed...finally got it yesterday and I love it 🥰. In the future I plan to add a white butterfly, cherry blossoms, and Bella 💙💜💖"



The ACDA is now aware of a total of **fifteen tattoos** featuring the **ACDA logo**!

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



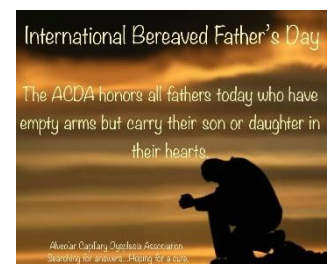
ACDA parents, Candice and Bryan from the USA, meet up with Amelia and Jo, in the UK!

In August 2022, **Candice and Bryan McCasland**, ACDA parents to Sadie (February 4, 2014 – February 19, 2014), **traveled to England** and **met up with Amelia Ashwell**, ACDA mother to David (March 4, 2011 – March 19, 2011) and **Jo Taylor**, ACDA mother to Alex (May 8, 2011 – May 11, 2011). Amelia is the co-founder of the David Ashwell Foundation, our sister organization in the UK, and Jo has contributed extensively to The David Ashwell Foundation.

This visit follows up on their initial in-person meeting in 2019 (see ACDA Notes #69). In Candace's own words: "This group has been life changing in so many ways but it's special to see **friendships forged in grief come full circle**. Yesterday I was lucky enough to get to spend the day with Amelia and Jo and **watching my older girls and our rainbow babies play together like the best of friends** was truly special. ❤️ till next time!!"

International Bereaved Father's Day (August 28, 2022):

Love and light to our bereaved ACDA fathers this past International Bereaved Father's Day, which is observed annually on the last Sunday in August.



LUNG TRANSPLANT UPDATES

Ten Year Anniversary (Eleni "Ellie" Scott):



Eleni "Ellie" Scott (see Issues #57, #68 and #75 of ACDA Notes), a lung transplant recipient and daughter of ACDA parents Karen and Nick Scott, **celebrated ten years post-transplant in June 2022!** In Karen's own words, "Today is a day to celebrate. We are so amazed by our daughter Ellie and her strength. Today she is 10 years post double lung transplant. ACD is such a horrible rare disease that takes too many babies too soon. Our hope is always that her story may just help find a way for early diagnosis or transplantation be a viable option for more babies. To each and everyone of you thank you for always supporting us on this journey."

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 celebrated her 11th birthday on August 26, 2022!



Six Year Anniversary and 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 at the time of transplant (see Issues #56, #58, #61, #65, #68, #73 and #75 of ACDA Notes). **On May 12, 2022, Imogen celebrated six years ([watch the video here!](#)) post bilateral lung transplantation and her family has been busy spreading her story throughout the UK and raising awareness for ACDMPV and organ donation.** For a listing of articles featuring Imogen, please click [HERE](#) and also follow Imogen's story on Facebook [HERE](#).



Gold and Bronze medals in the British Transplant Games! Way to go Imogen!

Imogen will celebrate her seventh birthday in November 2022!

In July 2022, Imogen also participated for the third time in the **British Transplant Games**, this year in Leeds. Imogen competed for GOSH

Heart and Lungs and a few years ago was the youngest participant in the entire competition. Imogen was sponsored this year for her efforts in football (gold medal!) and cup stacking (bronze medal!) 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

Moving "Forward" with Grief:



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.

<http://acdassociation.org/board-members>

At the quarterly ACDA Board of Directors meeting in August 2022, 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 2023

Reports from **Stichting ACD** (The Netherlands) and **The David Ashwell Foundation** (UK) will return in a following edition of ACDA Notes.

STICHTING ACD 



FUNDRAISING NEWS

Donations:

To make a secure tax deductible donation to the ACDA, please visit our website.



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 unallocated balance of the ACDA bank accounts as of August 16, 2022 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, 2022. 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:



Items with the ACDA logo are available for purchase in our Spreadshirt store [HERE](#). The accrued commission payment from Spreadshirt

between February 25 and May 16, 2022 is [REDACTED]. Please continue to shop at our store as new items and new features are added regularly. You have the option to customize your products by choosing "Create," including adding your child's name or picture to most items featuring the ACDA logo. Don't forget the ACDA earns a commission equal to **20% of every product sold!** **Look for 20% off everything from September 23-26, 2022! No code needed!**

Donations Received:

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

Donor	In Memory Of
[REDACTED]	[REDACTED]
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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):



Thank you FJNortheasters for raising \$1,040 at this year's off-roading event and your continued support of the ACDA in honor of Fallon Riling!

Once again, it's fundraising season for the Toyota off road club, the **FJNortheasters**! The FJNortheasters held their **Annual Northeast Run** in May 2022. 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) helped to coordinate the FJNortheasters tradition of generously supporting the ACDA (see Issues #56 #59, #64, #68 of ACDA Notes). **An incredible total of \$1,040 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 on a continued basis.



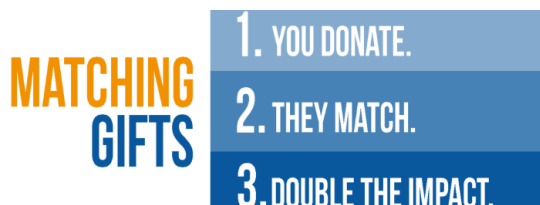
Wear Jeans to School (James Perrella):



Thank you Merrick UFSD Faculty at Birch, Chatterton and Lakeside Schools for raising \$420 from school jeans days in honor of baby James Perrella!

Received in May 2022, **Maria and Jimmy Perrella**, ACDA parents to James (January 23, 2019 – February 15, 2019), helped coordinate an awareness and fundraising jeans day for **ACDMPV research in honor of Baby James Perrella**. Our sincere gratitude to **Merrick UFSD Faculty at Birch, Chatterton and Lakeside Schools!** We are so grateful for your support!

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 **AMC Theaters, Bank of America, Chevron, Goldman Sachs, Google, Humana, Schneider Electric, Tokyo Electron and Verisk Analytics** for their matching gifts for ACDMPV research!



Bags Tournament (Barrett Bone):



An outstanding \$8,500 was raised by Katy and Tyler Bone in honor of their son Barrett at their 1st Annual Barrett's Bags Tournament! Thank you Katy and Tyler! Click the photo above for a slideshow!

In August 2022, Katy and Tyler Bone, ACDA parents to Barrett (June 14, 2019 – July 12, 2019) organized a bags tournament in honor of Barrett Bone. In Katy's own words, "Thank YOU to every single person who made our 1st Annual **Barrett's Bags Tournament Fundraiser a HUGE success**. To each sponsor, each person who donated a basket, donated their time, donated money, and those who helped set up and prepare for this event. We THANK you! We are beyond grateful for how well this turned out for it being our first year. And thank you for braving the heat.

It was a beautiful day to honor our son Barrett. Thank you for keeping his legacy strong. He deserves it. Because of Barrett We Love Harder! 🐝🐝🐝

Here are some photos of the day. We had hundreds show up! In the past years we did a BBQ around Barrett's Birthday and Tyler had the idea of a bags tournament for this year which turned out to be a fabulous idea. 😊"

REMEMBERING OUR BABIES

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

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 siblings 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](#).

Instagram:

- Follow us [alveolar_capillary_dysplasia](#)

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)

