

ACDA NOTES

FROM THE ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

What's INSIDE

- 1 Greeting
- 2 Pregnancy and Infant Loss Awareness Month
- 3 Audio Project 2021 and Awareness News
- 5 Fundraising News
- 7 Report from Stichting ACD (Netherlands)
- 8 Report from The David Ashwell Foundation (UK)
- 9 Remembering Our Babies and Welcome to New Families
- 10 Safe Arrivals, Committee Positions and Connect With Us



In October 2021, the ACDA created an **audio project** in observance of Pregnancy and Infant Loss Awareness month. Please see **page 3** 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 Friday, October 15 at 7:00 p. m. in your respective time zone, please share a photo of your candle** on the ACDA Facebook or Instagram 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 follow us on
FACEBOOK or
INSTAGRAM
and join the ACDA
Wave of Light.

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, 2021 – 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 Audio Project: October 2021



Press Play to Listen

In October 2021, the ACDA created an audio project for Pregnancy and Infant Loss Awareness Month. Projects in prior years have included collages of our babies, a photo project of bereaved parents, a memorial wall, luminaries, calligraphy and a written word project about grief over time.

This year we wanted to hear your child's name. The purpose of this project was to compile a seamless audio file of names recorded by our ACDA families; we know **saying and hearing your child's name spoken aloud is often a welcome expression of love.** It is our hope that hearing your loved one's name along with the names of other children affected by ACDMPV will provide a sense of comfort and community within our ACDA families. A suggested idea is to listen to the final audio recording while lighting your candle on October 15 during the ACDA Wave of Light. We encourage you to take a moment to listen to the recording and reflect on the lives of these precious children and the heartbreaking loss endured by their respective families, friends and loved ones. [Listen Here](#)

Please go [HERE](#) to learn how to participate in the ACDA Wave of Light on October 15, 2021. #WaveofLight #ACDAWaveofLight

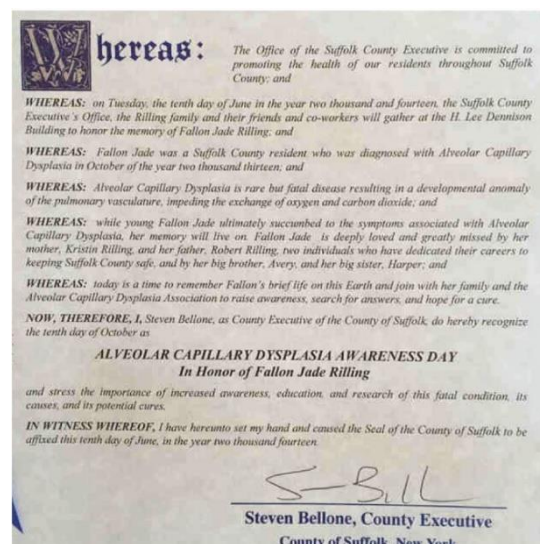


Lights in Suffolk County (Fallon Rilling):



On October 10, 2021, 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 eighth 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 will always be grateful to the Rilling family for their incredible awareness and fundraising efforts throughout the years. We look forward to the purple Denison building and tree each year, in honor of Fallon. 💜🦋



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

Families in the News (Miller Jacob):



In September 2021, Jakalah and Chad Jacobs, ACDA parents to Miller (April 19, 2021 – May 5, 2021), shared their story about their precious Miller and what they are doing to raise funds for ECMO machines and other hospital resources in New Zealand via “Miller’s Movement.” Please read their touching story below:

[Parents of baby who died of rare condition launch campaign to help others](#)



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 balance of the ACDA bank accounts as of October 13, 2021 is [REDACTED] (which includes funding allocated to the 2021 grant recipient in the amount of [REDACTED], together with [REDACTED] originally deferred due to the COVID-19 emergency to be reapplied to 2022 grant issuance).

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, 2021. 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 August 30, 2021 and October 13, 2021 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 free standard shipping from October 26-31, 2021!**

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]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	[REDACTED]
[REDACTED]	*

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

Brochures:

View, save, email or print your own copies of the ACDA brochure; click for [ENGLISH](#), [DUTCH](#) or [ITALIAN](#).



Fundraising Idea (SO EASY!!):



Please consider participating in the ACDA's **seventh 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" and paperless express 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 or paperless express sales. **Please contact us to get involved!**

Matching Gifts:

MATCHING GIFTS

1. YOU DONATE.
2. THEY MATCH.
3. DOUBLE THE IMPACT.

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, Schneider Electric, Tokyo Electron and Verisk Analytics** for their matching gifts for ACDMPV research!

#GIVINGTUESDAY

November 30, 2021

DONATE

ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

GivingTuesday is a global generosity movement unleashing the power of people and organizations to transform their communities and the world. GivingTuesday was created in 2012 as a simple idea: a day that encourages people to do good. Over the past seven years, it has grown into a global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity. The ACDA raised \$1,600 (2017), \$2,630 (2018), \$2,500 (2019) \$2,300 (2020) on this one day alone!

- **What:** A global day of giving
- **When:** The Tuesday following Black Friday (November 30, 2021)
- **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 giving season by promoting the #GivingTuesday campaign on November 30, 2021 in support of the ACDA.**

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 Rotterdam Marathon (April 2017, 2018 and 2019), Amsterdam Marathon (October 2016 (*half*), 2017, 2018 (*Kids Run*), 2019 (*Kids Run*)), Berlin Marathon (September 2019), Stichting Marathon #1 (October 2020), Stichting Marathon #2 (April 2021) 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.

TCS Amsterdam Marathon Kids Run (October 17, 2021):



Upcoming Event: Mathijs and **kids** from team Stichting ACD will run the **TCS Amsterdam Marathon Kids Run on October 17, 2021** to raise ACDMPV awareness! The Kids Run is a children's run that takes place during the TCS Amsterdam Marathon. Children aged 4 to 13 can participate in the 700-metre run, which starts behind the stadium and finishes in the stadium itself.



Good luck to these amazing team of **TWENTY kids** running for ACDMPV awareness and in honor of Myla, we cannot wait for pictures!



Erasmus MC-Sophia Kinderziekenhuis (September 24, 2021):

Programma	
08.45 uur	Registratie en ontvangst
09.30 uur	Welkom en korte inleiding
09.35 uur	• Dr. Chao Shengdong, gynaecoloog
09.50 uur	"Gelukkig heeft hij niet geleefd..."
10.00 uur	• Wieke Kalkman, verloskundige en moeder
10.10 uur	Psychological impact of perinatal loss and experience of subsequent pregnancy
10.15 uur	• Dr. Angel Borchi, kinderpsycholoog en onderzoeker
10.30 uur	Pause
10.35 uur	Kan je iemand missen die er nooit is geweest?
10.40 uur	• Dr. Kalkman en wieke Kalkman en wieke Kalkman
10.45 uur	• Wieke Kalkman, verloskundige en moeder
10.50 uur	Wat doet Stichting ACD?
10.55 uur	• Mathijs Lourens, vader van Myla, Kalkman en wieke Kalkman
11.00 uur	Lunch
11.15 uur	Zwangerschapstherapie en/of doorgaande - de begeleiding van 'second victim'
11.20 uur	• Hildegarde Kalkman, stichtingsvoorzitter en wieke Kalkman
11.25 uur	• Wieke Kalkman, verloskundige en moeder
11.30 uur	• Wieke Kalkman, verloskundige en moeder
11.35 uur	• Wieke Kalkman, verloskundige en moeder
11.40 uur	• Wieke Kalkman, verloskundige en moeder
11.45 uur	• Wieke Kalkman, verloskundige en moeder
11.50 uur	• Wieke Kalkman, verloskundige en moeder
11.55 uur	• Wieke Kalkman, verloskundige en moeder
12.00 uur	Afsluiting

On September 24, 2021, Mathijs participated in a symposium at Erasmus MC-Sophia Kinderziekenhuis. In Mathijs' own words the day before the event, "Tomorrow I can close the Symposium 'Loss in obstetrics' together with pediatrician Patricia Kalkman within the theme '*guidance of parents in the NICU*'. In addition to providing insight and sharing my experience, it is always fun to tell about Myla and Stichting ACD, of course. Tomorrow will be another beautiful day!"



REPORT FROM THE DAVID ASHWELL FOUNDATION (UK):

March 2021 will be 11 years since David was born and we became part of the ACDMPV family. I am always open to suggestions of what is a good way to fundraise for ACDMPV research so please get in touch, particularly ideas that are automated – like The Giving Machine.

Thank you to those families who have set up direct debits for the charity and whose families fundraise at work for us. Looking back since March 2011 over **£200,000** 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!



At the moment not many people are using The Giving Machine.

Please, UK families can you use The Giving Machine ([GO HERE](#)) 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! 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.

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. UK families you can set up direct debits to The David Ashwell Bank Account (we have a number of people who do this – just ask me for bank details.)
2. Through the Virgin Money Giving account you can set up a page in memory of your child or for special occasions (e.g. birthdays or Christmas).
3. You can make a donation directly, using the [Virgin Money Giving](#) website.
4. Fundraise while you online shop ([The Giving Machine](#)) (a percentage of what you spend is donated)
5. Collect [postage stamps](#)



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 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, contact Simon and Amelia.

Website: <http://David Ashwell Foundation>

Email: davidashwellfoundation@yahoo.co.uk

Twitter: [@TDavidAshwellF](#)

Mobile (Amelia): 07855473686

REMEMBERING OUR BABIES

[REDACTED]

[REDACTED]

Welcome to New Families

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

- [REDACTED]
- [REDACTED]



Safe Arrivals!

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

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

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)

