THE ACDA OFFERS THE FOLLOWING:

- ACDA website
- Compassionate support for diagnosed or bereaved families
- Quarterly newsletter
- Directory of registered families
- Referrals to private Facebook support groups
- Fundraising support
- Comprehensive library of medical articles
- Guidance through the genetic testing process
- Contact with physicians, researchers and pathologists
- Referrals to medical professionals familiar with lung transplantation options for ACDMPV patients

The ACDA does not offer medical advice but does try to provide access to as much information as each family requires.

In the years since the ACDA has been established, we have talked with physicians, researchers and families about how we might make a difference. We believe we have begun this task, but there is still much we can do. We have learned one very important thing – as our numbers grow, our voice in the medical community gets louder. It is that voice that will lead to the answers we all long for. Please contact us and join the growing number of families who search for answers.

CONNECT WITH US:

Please visit the ACDA website for comprehensive information about ACDMPV, including current genetic summaries, research studies, FAQs, grant history, newsletters, grief resources, community resources and links for medical professionals. Also connect with the ACDA on Facebook and Twitter or send us an email.

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.

acdassociation.org/donate

ACDA

ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

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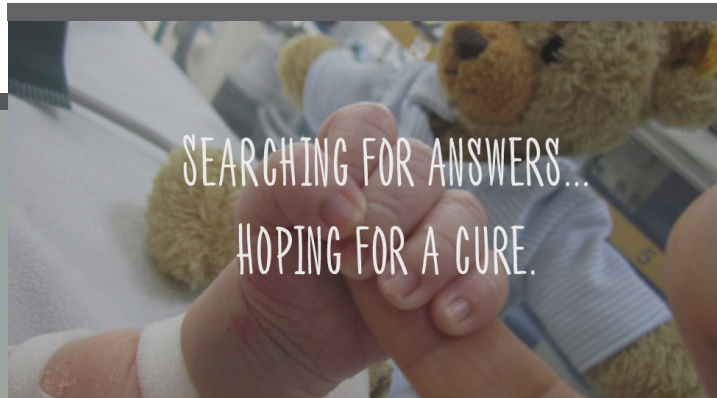

MISSION

The ACDA represents a group of parents throughout the world who have experienced a common tragedy - the diagnosis or death of a child from Alveolar Capillary Dysplasia with Misalignment of Pulmonary Veins (ACDMPV). The ultimate goal of the ACDA is to support the efforts of the medical community to find the cause of and cure for ACDMPV.

The ACDA is dedicated to increasing ACDMPV awareness and funding ACDMPV research in the medical community while simultaneously providing a supportive environment for families affected by ACDMPV.

FACTS

- ACDMPV is a rare disease. Worldwide, there are only a few hundred cases of ACDMPV reported formally in the medical literature since first identified in 1948. The incidence or prevalence of ACDMPV is not yet known but there are almost certainly more cases than those officially reported.
- The ACDA has grown to over 200 registered families from around the world since its formation in 1996.
- While the microscopic details of ACDMPV are now recognizable, it is not known what causes the disease in many confirmed cases. Researchers are getting closer to answers but more research is needed.
- Research into ACDMPV is ongoing at several medical research facilities worldwide, including Baylor College of Medicine in Houston, Texas, USA. Baylor has accumulated the largest collection of ACDMPV samples in the world and families may request genetic testing through the research study at Baylor free of charge.

WHAT IS ACDMPV?

ACDMPV is a rare anomaly of the newborn lung that results in an infant fatality in almost every occurrence due to the inability of the lungs to effectively deliver oxygen to the bloodstream. It is caused by abnormal development of the blood vessels (small arteries and capillaries) in the airspaces of the lungs (alveoli).

ACDMPV infants are usually born at term from uncomplicated pregnancies. Most reported cases present within the first days of life and commonly have an initial diagnosis of Primary Pulmonary Hypertension of the Newborn (PPHN). Respiratory distress and further complications quickly develop in these newborns because of their inability to shift from fetal circulation to newborn circulation, resulting in extremely high blood pressure in the lung vessels.

There are several characteristics that ACDMPV infants have in common, such as low oxygen levels, cyanosis (turning blue), pulmonary hypertension (high lung blood pressure) and respiratory distress.

Newborns frequently undergo a protracted course of Extracorporeal Membrane Oxygenation (ECMO), Nitric Oxide (iNO), Prostacyclin Vasodilators, Sildenafil or a combination thereof. Lung transplantation is available in extremely limited circumstances and there is otherwise no known cure, supportive therapy or treatment for ACDMPV.

Definitive diagnosis of ACDMPV is made by lung biopsy or autopsy. The lungs of ACDMPV patients are described as having Misalignment (malpositioned) of the Pulmonary Veins (MPV). The disease can have a variable severity according to the degree of lung blood vessel maldevelopment. Limited reports have begun to emerge in the medical literature of presentation of ACDMPV beyond the neonatal period.

Two broad types of genetic abnormality have been found to cause ACDMPV: (x) a mutation of the FOXF1 gene on chromosome 16, or (y) other genetic abnormalities such as deletions in areas of chromosome 16 that regulate the expression of the FOXF1 gene. At present, around 80-90% of infants with confirmed ACDMPV can be found to have one of these abnormalities. In approximately 90% of such cases with a confirmed genetic abnormality, the genetic abnormality appears to have arisen *de novo* and is not present in either parent. Please visit the ACDA website to review additional genetic information: **acdassociation.org/genetics**

Participate in Research

The ACDA encourages families to donate DNA and tissue samples to the ACDMPV research team at Baylor College of Medicine in Houston, Texas, USA.

To request genetic testing through the research study at Baylor, please contact Dr. Pawel Stankiewicz at pawels@bcm.edu or (713) 798-5370.

ACDA

ALVEOLAR CAPILLARY DYSPLASIA ASSOCIATION

Searching for Answers...Hoping for a Cure.