



WE'RE FIGHTING FOR EVERY BREATH

ARDS Foundation
3330 Dundee Rd. Suite C4
Northbrook, IL 60062
Phone: (312)749-7047
Email: erubin@ardsglobal.org
Web: <https://ardsglobal.org>

By: Michael Hurley, PAR Liaison
ARDS Foundation
ARDS Diagnosis: July, 2001 (Age 17)

Who We Are

- **Eileen Rubin, J.D., Founder**

- Diagnosed abruptly with ARDS at age 33, Eileen's initial efforts to seek treatment were dismissed by emergency room medical staff. After relentless advocacy by her and her mother, doctors were convinced that something more dire was affecting Eileen. Her experience derailed a prominent legal career as a prosecuting attorney in Chicago. However, tired of feeling isolated and unheard by the world and medical community, she, along with other survivors, formed the ARDS Foundation.
- Eileen has been a force to be reckoned with and fierce advocate for the ARDS Community through her countless, global fundraising and speaking engagements since the inception of the foundation. She also moderates various Facebook groups welcoming recovering ARDS survivors, family members, and caretakers alike.

- **Michael Hurley, ARDS Foundation Board Member & ATS PAR Liaison**

- Newest member of the ARDS Foundation and recent PAR inductee (First meeting: June 2020)
- Diagnosed with ARDS in July 2001 at age 17. Treatment included, nearly two months on mechanical ventilation, two months in PICU, twenty-five days on ECMO, and thirty-one days under deep sedation. First clear memories once brought out of sedation were watching 9/11 news coverage from my PICU bed.
- Nineteen years later and I am a Technical Product Manager with an IT Security Firm in Las Vegas, met the love of my life and got married, lived in Indianapolis, Tampa, Seattle, Austin and now Vegas, purchased my first home February of this year, traveled the world to destinations including Hong Kong and Australia, become a highly-seeded amateur photographer.
- Panel Speaker at ATS 2019 in Dallas
- Looking forward to serving the ARDS community in this new role.

Our Mission

- To support and advocate for those who are affected by Acute Respiratory Distress Syndrome.
 - Since our inception, we have worked to produce information in plain English to patients and families about ARDS so that they could understand what was happening during those hectic days in the Intensive care unit. In addition to creating plain English brochures, we also wanted to be a source of continuing education to those in the ARDS Community. We offer the most up to date medical research that has been published as well as offering from time to time, webinars for patients to gain knowledge and engage in.
- Promote public awareness of ARDS and its devastating effects
 - Too many people are unaware of this deadly syndrome that strikes without warning, suddenly and quickly. Increasing public awareness is instrumental in raising funds for ARDS foundation so that we can continue to support this community vigorously. We also partner with medical professions to facilitate research projects, offering travel grants, previously offering nursing scholarships and also by partnering in medical research grants, as well as sponsoring medical conferences. ARDS Foundation is instrumental in helping physicians with their research projects by locating subjects to participate in medical research studies. We consider working with industry an important component of our mission.
 - Patients and families want to know that those who are in industry have a vested interest in the well-being of patients and families dealing with an ARDS diagnosis and the crisis that follows.

Our Vision

We seek a world where ARDS is no longer an unknown medical issue and people survive and thrive after being afflicted by ARDS.

The ARDS Foundation will be a global force and a partner of choice within a worldwide movement dedicated to ending ARDS. We will be known everywhere for our unshakable commitment to the dignity of people.

“At age seventeen, I experienced a trauma so consuming and disruptive that my life was split into two components: the before, and the after. ARDS destroyed my adolescence, young adulthood, freedom, family, and my general ability to feel comfortable and safe. I hope that nobody ever need endure the excruciating pain of ARDS, nor its devastating effects on a survivor’s relationships, physical, mental and emotional health. It leaves it’s survivors with lifelong struggles that make it difficult to think of anything but the worst thing that ever happened to you. We can do better. So, please, let’s start.”

Michael Hurley, ARDS Foundation

ARDS Diagnosis: July, 2001

Surviving and Thriving against the Odds for Nineteen Years



Cystic Fibrosis Research, Inc: Your Partner in Living

CFRI exists to fund research, to provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.



Research for Living ~ Partners for Life

Siri Vaeth, MSW
Executive Director
cfri@cfri.org



CFRI FUNDED RESEARCH

CFRI supports cystic fibrosis research projects at academic and medical institutions across the U.S. that pioneer a new approach to a CF therapy or cure.

**Elizabeth Nash Memorial Fellowship: Post-Doctoral Fellows
(\$60K/Year)**

New Horizons: Principal Investigators (\$70K/Year)

CFRI FUNDED RESEARCH



CFRI–Funded Research Topics: *A Small Sampling*

Phage Therapy & Cystic Fibrosis

CF Respiratory & Intestinal Microbiome

CFTR Function & Calcium–Activated Chloride Channels

Inhibiting *Pseudomonas* & *Staphylococcus Aureus*

Cystic Fibrosis SubMucosal Gland Dysfunction

Bacterial Biofilm Studies

Metagenomic Analyses of Viral Communities in CF Lungs

Studies on CF Airway Epithelia Innate Hyperinflammatory

Immune Response

CFRI research awards often act as seed funding for young researchers that ultimately attracts larger funding from the CFF and NIH.



**For more
information:**

cfri@cfri.org

www.cfri.org

JENNIFER MEFFORD
SENIOR DIRECTOR, CORPORATE RELATIONS

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live, longer, healthier lives.

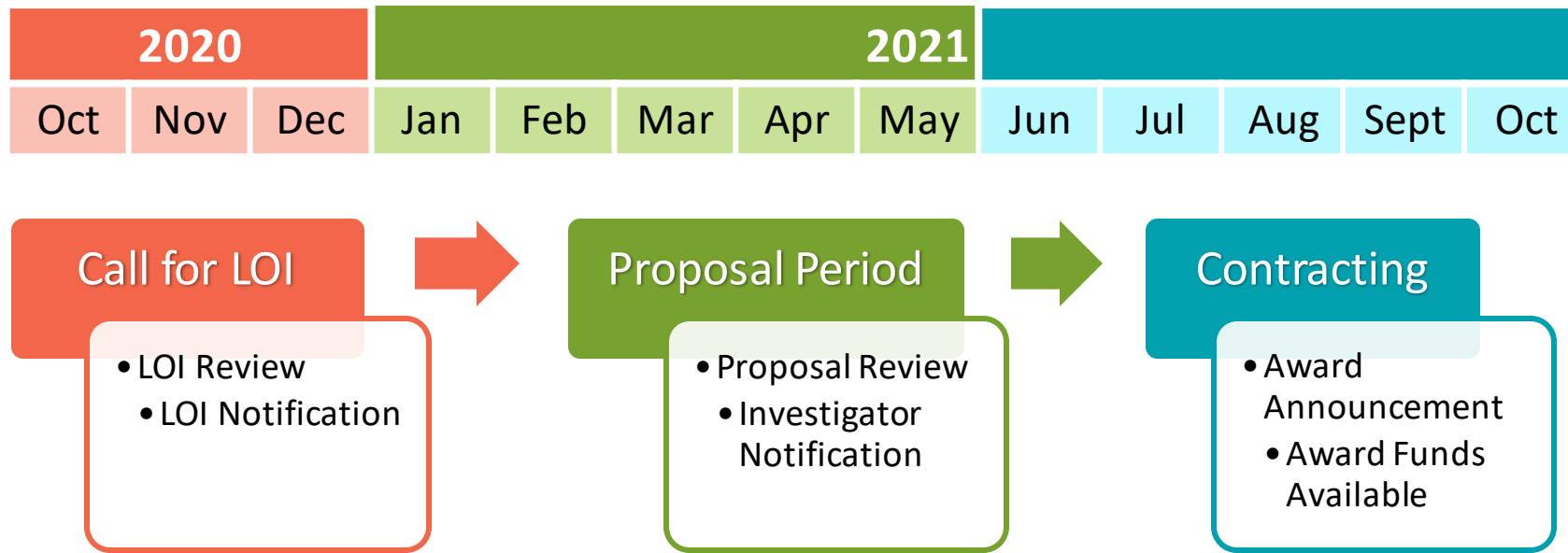
For more information visit pulmonaryfibrosis.org

THE PFF SCHOLARS PROGRAM

- Engages early-career investigators in their emerging research in the field of pulmonary fibrosis.
- PFF Scholars receive up to \$50,000 over a two-year period.
- Upcoming Grant Cycle starts Oct 2020.
- Total of 6 awards available.



TIMELINE & REQUIREMENTS



Eligibility Requirements

- MD, DO, RN, PhD, or other doctoral level or professional degree
- Post-doctoral fellow, Instructor, or Assistant Professor for less than 7 years
- Clinical degree candidates must have completed their clinical fellowship training.

See **PFF Scholars Guidelines** for more detailed requirements.

FOR MORE INFORMATION...

Contact Jennifer Mefford

jmefford@pulmonaryfibrosis.org

PFF Research Funds Information

www.pulmonaryfibrosis.org/PFFResearch

For people with PCD, every breath is a challenge.

That's why we've made it our mission to...

CLEAR THE WAY

- to improve patient quality of life ■**
- to help patients find clinical centers ■**
- to create a patient registry ■**
- to support research ■**
- to increase funding ■**
- to find a cure ■**



What is Primary Ciliary Dyskinesia (PCD—aka ‘Kartagener Syndrome’)

Primary ciliary dyskinesia (PCD) is a genetic disorder of mucociliary clearance primarily affecting the upper and lower airways. Individuals with PCD have chronic infections of the sinuses, ears and lungs, leading to hearing loss, bronchiectasis and for some adults, respiratory failure and the need for lung transplant

Genetic defects of ciliary function also affect organ placement and development. Situs anomalies including heterotaxy affect 50% of the patient population, and individuals with PCD have a 200x increased risk of congenital cardiac defects

Individuals with PCD often experience reproductive health issues with infertility/subfertility

Potentially hundreds of proteins are required for adequate ciliary function, to date more than 50 PCD genes have been identified. Most are autosomal recessive, but opportunities for genetic discovery are abundant

There are currently no approved therapies for PCD



The PCD Foundation: Progress Through Partnership

The PCD Foundation is a 501(c)3 tax-exempt patient advocacy organization focused on accelerating both basic science and clinical research in PCD through:

- The Path to Clinical Trials* program, consisting of 30+ clinical & research sites in the US and Canada and a PCD registry
- Partnering with the NIH-sponsored *Genetic Disorders of Mucociliary Clearance Consortium*
- Partnering with the *ATS, Gordon Conference, FASEB* and other professional societies that share our mission to expand knowledge of cilia in health and disease and improve the lung health and quality of life for individuals with PCD
- Collaborating with international groups and scientists, like the *European BestCilia* group working on PCD
- Providing *grant support for conferences and for individual investigators*



ALLERGY & ASTHMA NETWORK

BREATHE BETTER TOGETHER



ALLERGY & ASTHMA NETWORK



Outreach

Education

Advocacy

Research

What We Believe:

- Together, we can work to end the needless death and suffering due to asthma, allergies and related conditions

We are here to help.

OUTREACH

Volunteer Outreach Service Coordinators

Community Asthma Experts

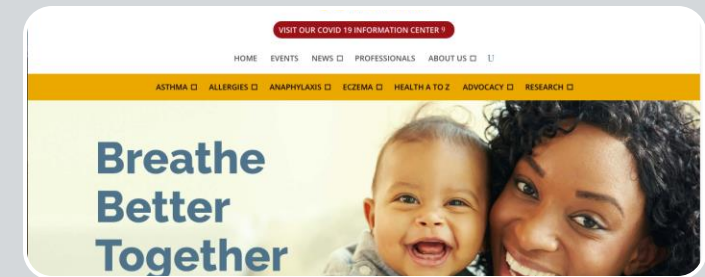
HealthUnlocked – Online Support Communities

- Asthma
- Allergies
- Anaphylaxis
- Spanish

Asthma Storylines App



EDUCATION



Print Publications

- Allergy & Asthma Today
- Monthly eNewsletter
- Understanding Guides
- Posters and Infographics

Digital Education

- 3 Webinar Series
- Patient Learning Pathways
- Online Learning Center

Website

- COVID-19 Information Center
- Patient Medication Assistance

ADVOCACY

Allergy
& Asthma
NETWORK
35TH ANNIVERSARY



American
College
of Allergy, Asthma
& Immunology

Allergy & Asthma Day

Capitol Hill



Legislative Priorities

- Access to Care
- Affordable Medications & Treatments
- Asthma & Allergy Federal Funding
- Health Equity
- Food Product Labeling

School Issues

- Stock Epinephrine Implementation
- Stock Albuterol

RESEARCH



- PCORI Disparities Work
- Telehealth
- OCS Overexposed
- Clinical Trials
- Surveys
- Decision Mapping
- PAR Study



1 IN 12

Americans have
asthma.

We are here to help.

ALLERGY & ASTHMA NETWORK

ALLERGYASTHMANETWORK.ORG

Sally Schoessler
Director of Education

Phaware global association®

phaware global association® is a 501(c)3 organization dedicated to raising global awareness & creating innovative technology for research.

phaware® educates the public about pulmonary hypertension. We create global PH awareness engagement on behalf of families, caregivers and medical professionals and support PH research efforts to find a cure for this deadly disease.

Our goal is to capture, engage and enable misdiagnosed and undiagnosed PH patients, because early diagnosis and treatment can mean the difference between life and death.

Learn more: www.phaware.global

Contact: marie@phaware.global

www.phaware.global/covid19

Phaware research network

What is the walk.talk.track. platform?

Mobile and Wearable Health Data Collection
System

Adult and Pediatric emphasis

DynAMITE PAH Study (Stanford)

QoL/WHO Study (Children's Colorado)

Full Data Privacy Protection

Multi Facility Multi Study Capabilities

Supports Qualitative and Quantitative Patient
Data Collection

Allows for Out-of-Clinic Research Studies or
In/Out Clinical Hybrid



WTT KEY FEATURES

- Support for both iPhone & Android based patient data collection
- Augmented Actigraphy Data Collection from select iOS and android Powered Watches
- Core Researcher Web-Based Interface for Data Access & Patient Management
- Complete Data Security Solution for Research partners
- Full Application Audit Tracking
- 6 Minute Walk Test Execution & Data Collection
- Fully Configurable Patient Survey System
- Participant Metrics Dashboard
- Participant Feedback System

WTT Collectible data

HR

HR Recovery

HR Variability

Chronotropic Index

Heart Rate Recovery at One Minute

Gait Walking Style Modification

Respiratory Rate

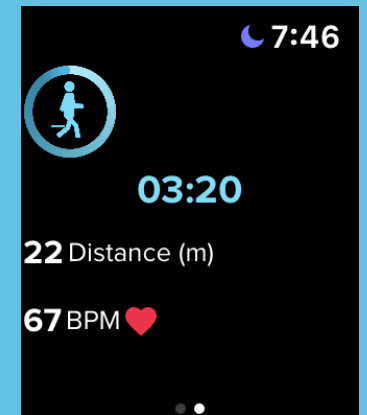
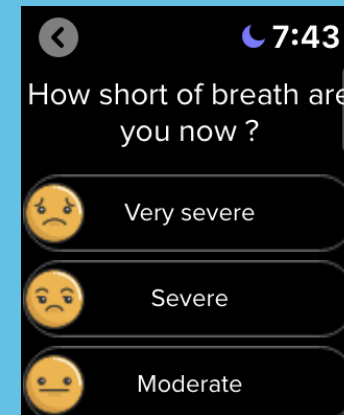
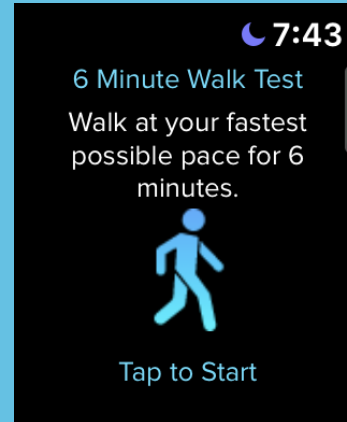
Incline

Altitude

Humidity

EKG

WALK.TALK.TRACK. APPLE WATCH SCREEN SHOTS



global outreach

I'm Aware That I'm Rare: the PHAWARE® podcast

The phaware® podcast is devoted to raising global pulmonary hypertension and related rare disease awareness with dynamic stories from patients, caregivers, medical professionals and thought leaders from around the world.

If you are a Pulmonologist, Cardiologist, Critical Care Physician, Advance Practice Nurse, Researcher, or PhD, we would love to interview you! We can record anyone... from anywhere... anytime.

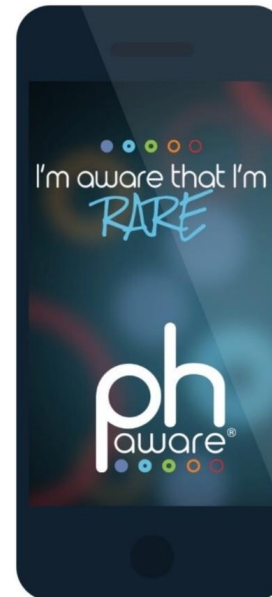
[Contact us](mailto:info@phaware.global) to share YOUR story.
info@phaware.global



335+ EPS

110+
COUNTRIES

250K UNIQUE
DOWNLOADS



THE PHAWARE® PODCAST





Lung Transplant
FOUNDATION