



3300 Ponce de Leon Blvd.
Coral Gables, Florida 33134
Toll Free: (877) 228-7321
Tel: (305) 567-9888
www.alpha1.org

BOARD OF DIRECTORS

Executive Committee

Jeanine M. D'Armiento, MD, PhD
Chair
New York

Elizabeth Johnson*
Vice Chair
Massachusetts

Gordon E. Cadwgan, PhD*
Immediate Past Chair
Florida

Jennifer Jopp*
Secretary
Minnesota

Fred Walsh*
Treasurer
Massachusetts

Martin R. Zamora, MD
Physician-Director
Colorado

Members

Virginia Clark, MD
Florida

Kenneth Irvine +
Connecticut

Peg Iverson*
Iowa

Ann Knebel, PhD, RN
Maryland

Noel G. McElvaney, MD, MCh, BAO,
FRCP, FRCPC
Dublin, Ireland

James K. Stoller, MD, MS (Org. Dev.)
Ohio

Frank Willersinn, MD*
Brussels, Belgium

EXECUTIVE STAFF

President & CEO
Miriam O'Day

Chief Financial Officer
Mark B. Delvaux

Interim Scientific Director
Mark Brantly, MD

Clinical Director
Robert A. Sandhaus, MD, PhD

* Diagnosed Alpha-1
Antitrypsin deficient
+ Diagnosed family member

March 11, 2020

To whom it may concern,

On behalf of the Alpha-1 Foundation, please accept this communication regarding the current outbreak of the 2019 novel coronavirus (COVID-19). Our patient population suffers from a rare disease called Alpha-1 Antitrypsin Deficiency (Alpha-1) and are one of the most vulnerable populations to the COVID-19 virus. Alpha-1 is a rare genetic disorder that affects the lungs and/or the liver; the lung disease is commonly called "genetic COPD".

Since COVID-19 causes primarily fever and respiratory symptoms, often leading to pneumonia in susceptible individuals, people with Alpha-1 are likely to be particularly vulnerable to the effects of this coronavirus infection. Alphas-1 patients with lung disease or those who have had a lung transplant are among the groups considered most susceptible to serious complications if they become infected.

On March 8, 2020 individuals from the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) suggested that individuals in susceptible groups should avoid air travel and cruise ship travel. "Susceptible groups" include those with chronic cardiac, kidney, and lung conditions. Some presentations have suggested that anyone over 60 years of age should be considered within the susceptible group category as well.

The Alpha-1 Foundation advocates for the best health of these patients and we strongly recommend that they suspend travel due to the risk of potentially exposing them to this deadly virus. We hope that no financial penalties will be assessed if the travel plans of patients with Alpha-1 need to be changed or cancelled due to COVID-19 precautions.

Sincerely,

Dr. Robert Sandhaus
Clinical Director, Alpha-1 Foundation