



Debbie Drell **Director of Membership**

Debbie is the Director of Membership for the National Organization for Rare Disorders (NORD). She oversees NORD's Membership programs, which support the collective and individual needs of rare disease patient organizations, patients, and patient advocates through education, research, advocacy, and mentorship. Ms. Drell coordinates the participation of 270 patient organizations — including PHA — and nearly 700 executive directors, founders, chief scientific officers and others.

Ms. Drell has 18 years of leadership in nonprofit public health education, awareness and advocacy. Most recently, she spent 13 years as a Senior Director for the Pulmonary Hypertension Association, a NORD member organization. During that time, she helped to grow the organization's network of support groups from 80 to nearly 300; to develop new services tailored for patients of all ages; and to convene the largest gathering of PH patients in history. Debbie was inspired to enter the field after her sister, Alex, was diagnosed with pulmonary hypertension.

Debbie has spoken on a thousand colleges and universities on women's health issues; delivered speeches on caregiving across the country, including at Johns Hopkins University events; and has moderated panels at the World Orphan Drug Congress European meeting.

Debbie has represented the patient voice on several national platforms, including as a member of the Board of Trustees of the American Thoracic Society, a 112-year old medical society boasting global membership of 16,000 pulmonologists, critical care and sleep disorder researchers, clinicians and medical professionals. She has brought the rare disease patient voice to a panel on NPR's Kojo Nnamdi Show, and was featured in a cover story for Community, the quarterly publication of Caring Voice Coalition, a nonprofit group that provides financial support to people with rare diseases.