Foreword

Since 2001, the ATS Public Advisory Roundtable (PAR) has helped to highlight the patient experience and to weave patients into the fabric of the American Thoracic Society. Along with PAR partners, comprised of various patient advocacy groups, PAR has opened up the Society to include those most personally affected by the diseases we research and treat: patients and their caregivers.

Throughout the year, PAR and PAR partners promote awareness, public education, advocacy, and research. The outcomes of those presentations are expansive and stretch from inspiring investigators to shaping ATS advocacy programs.

Patient Voices is a particularly important part of this effort. In this edition, you’ll hear from patients and caregivers in their own words, not just about the disease and its treatment, but about their reactions to diagnoses, their fears, and in some cases, their recoveries. This special edition takes on another element of the fight against respiratory disease – health care access inequalities and disparities in care.

In 2014, the ATS defined respiratory health disparities as “significant differences in respiratory health that are closely linked to racial ancestry, social, economic, and/or environmental differences.” Such disparities adversely affect groups of people who have experienced greater obstacles to health based on characteristics historically linked to discrimination or exclusion, such as race or ethnicity, geographic location, and socioeconomic status. Patient stories are always sobering to read, and this year, the added element of disparities may be particularly disturbing to some readers, as the stories contain descriptions of discriminatory treatment and lack of access to life-saving care, as well as suicide.

The stories, while challenging to read, are even more so to tell, and we’re grateful to the contributors for sharing their experiences. We also share in their hope that this edition will raise awareness about lung disease, as well as serving as a step toward respiratory health equality, an ideal strongly supported by the American Thoracic Society.

Thank you for making Patient Voices possible as we work together toward ever more treatments, therapies, and ultimately, cures.