

From Survival to a Paradigm Shift

Patients Driving the CF Senior Agenda



INTRODUCTION

The CF Seniors Project Group is a patient-driven initiative, established with the support of Halite Solutions Group (HSG), a nonprofit organization committed to enhancing the quality of life for individuals affected by cystic fibrosis (CF). Operating within HSG's strategic framework, Pathways to Impact, the group prioritizes advancing collaboration, education, and advocacy to meet the specific needs of older adults with CF. This work has received recognition and endorsement from the Aging with CF Special Interest Group.



DEFYING PERCEPTIONS DEFINING OUR FUTURE®

WHO WE ARE

CF Seniors Project Group

We represent a cohort of individuals with cystic fibrosis who are reaching beyond the 5th decade of life — a milestone previously considered unattainable. Our experiences exemplify unprecedented medical breakthroughs, tireless advocacy efforts, and resilience in the face of adversity. Through advanced and intensive therapies (e.g., clinical trial treatments) and the continual challenge of uncertainty, we now serve as living proof of progress in cystic fibrosis care.

As senior members of the CF community, we offer notable perspectives with the power to shape future CF healthcare initiatives. It is essential that our contributions are not only acknowledged, but that CF seniors are a priority in funding, clinical practice, biomedical research, and healthcare policy development. This monumental step would foster the change that is desperately needed to propel the CF community to the forefront of a paradigm shift in healthcare.

THE PROBLEM

We are living decades longer than previously anticipated by medical professionals, and healthcare systems have not fully adapted to this demographic shift. Existing policies, research priorities, and care models provide insufficient attention to medical issues that are more prevalent in the older CF population, such as osteoporosis, arthritis, altered pharmacokinetics, mobility limitations, and evolving social support structures. Consequently, there is a notable deficiency in programs, research, and policy initiatives designed to meet the complex needs of seniors with cystic fibrosis.





OUR STORY

The continued survival of patients with CF exemplifies the advancements aimed at optimizing CF care. In 1987, New York State inaugurated the country's 30th adult program for those over 21 with CF, marking a significant achievement (Galdi et al., 1988). Today, a substantial proportion of individuals who were young adults at that time have reached nearly 60 years of age. Currently, more than one-quarter of the CF population is older than 40 years old (Ostrenga et al., 2025).

Despite the increasing longevity of CF individuals, survival alone is not enough. The current CF healthcare infrastructure was designed for younger patients, and has not sufficiently evolved to address the increasingly complex needs of a continuously growing and aging population. The current healthcare system is missing critical foundational elements needed to support senior patients living with CF. Such a population needs dedicated senior programs, geriatric research, and policy frameworks that recognize the lived experiences of aging CF adults.

This story is one of resilience and persistent challenges. It is imperative that every additional year lived is epitomized by dignity, independence, a sense of belonging, empowerment and health. The progress we celebrate was made possible by decades of advocacy and sustained community investment, which enabled medical milestones. Now, the system must evolve to reflect this progress. Prioritizing CF seniors in data collection, research, and policy will help ensure comprehensive support throughout each person's lifespan and further improve quality of life and longevity.

WHAT DRIVES THIS

We remain underrecognized and insufficiently supported in medicine. According to the Cystic Fibrosis Foundation (2025), median survival for those born 2020–2024 is estimated at 65, but many of us born in the 1960's and earlier have already surpassed this age. Advances in diagnoses and treatment have evidently outpaced the system's ability to adapt and comprehensively support CF seniors in today's age.

A publicly accessible, centralized, and verifiable database on the quantity and location of physicians within the CF care network, and on CF-specialized researchers does not exist. Despite the involvement of multidisciplinary teams in care and research, there remains a gap in transparent, publicly accessible reporting on the presence of qualified specialists and the allocation of resources for older adults with CF. These data gaps have significant implications, prohibiting the CF system from being properly assessed and from being tailored to address our multifaceted requirements as we age. Issues such as increasing comorbidities, evolving medication needs, and complexities in social/emotional support requirements demand specific focus that differs from those encountered by younger adults.

We are both a success story and a call to action. Our existence underscores the importance of strengthening healthcare, advancing research, and developing a workforce for aging, home, and assistive care so that every additional year of life for CF seniors is supported holistically.



What We Are Asking For

Top Five Calls to Action



1 Recognize CF Seniors as a Distinct At-risk Population

We face unique health challenges — age-related degenerative lung changes, comorbidities, and age-related changes in medication metabolism. Policies, care guidelines, and funding should explicitly prioritize CF seniors to ensure our needs are addressed expeditiously.

2 Guarantee Equitable Access to Geriatric-Centered, Interdisciplinary Care

CF care teams must include or collaborate with specialists in primary care, geriatrics, cardiology and mental health; support home visits, telehealth, and mobile testing; ensure coordinated and seamless care through health homes and care navigators who can assist us with transitions like Medicare, retirement, or assisted living.

3 Implement Practice-Based Designs and Strategies to Guide Real-Time Improvements

While pre-clinical and clinical research are of utmost importance, policy and program evaluation research in real-world settings can provide actionable insights often within the appropriate time frame. To shape evidence-based medical breakthroughs for the aging CF community impacted by decades of cumulative disease burden, adequate tracking of health outcome variables such as pharmacological adverse effects, mobility decline, psychosocial adversity, and quality of life must be executed and recorded for proper analysis.

4 Strengthen Home, Long-Term, and Assistive Care

New and expanded community care models that include expanded virtual visits and remote medical monitoring will be needed. Additionally, specialized visiting nurses, home health and long-term care workers will be needed to treat the aging CF population. Integrating care for symptom management, stress reduction, emotional and mental wellbeing and coordination between primary care and specialists will preserve the very qualities that define a dignified life well into its latter decades.

5 Support for Social and Financial Well-Being

The expansion of access for CF patients to disability benefits, Medicare coverage, affordable housing, and in-home assistance serves as a priority in today's economic climate. Promoting social connection and community engagement through peer networks, senior-focused fitness groups, and wellness programs can reduce isolation and enhance our quality of life. Long-term this prioritizes CF seniors as a whole, thus optimizing their experiences as life expectancies are extending beyond prior projections.

THE IMPACT OF YOUR ACTION

Your support plays a vital role in driving this crucial transformation. By acknowledging and addressing the distinct needs of CF seniors, expanding access to geriatric-informed care, and integrating real-world evidence into practice, the CF community, with your support, can transform survival into thriving. Your support will directly enhance quality of life, protect independence, and ensure that every additional year of life is lived with dignity, inclusivity, and robust health.

The time to act is now – CF seniors cannot wait.

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Kristina Robinson, President & Founder, Halite Solutions Group
Bre’anca Sanders, MMS, TGen Helios Scholar 2020, MD Candidate, Class of 2027, The University of Arizona College of Medicine-Phoenix



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