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PRESIDENT’S LETTER

In my last report to you in December 2020, we were in the throes of the COVID pandemic wondering what changes CHEST would have to make to meet the needs of our members and our patients. The good news is that with vaccination programs underway, we are seeing relaxation of some of the restrictions, although we remain cautious about our face-to-face interactions.

Looking to a more hopeful 2021, we begin by celebrating the CHEST Foundation’s 25th anniversary! Our theme throughout this year will be “Leaders of the past. Trailblazers of the future.” In light of this, I want to update you on two important initiatives of the CHEST Foundation, namely, the Listening Tour and our fundraising efforts.

First, the CHEST Foundation conducted Listening Tour stops in Jackson, MS; New York, NY; Chicago, IL; South Texas; and the Southwest (CA, AZ, and New Mexico). At each of these stops, we invited clinicians and patients to share with us their experiences related to obtaining health care access. We heard story after story of patients who experienced difficulties obtaining the care they needed because of inability to pay for medications, poor communication with physicians, or difficulty navigating the health care system. In addition, patients consistently told us that they faced obstacles to care based on their race, ethnicity, or financial status. The findings of the Listening Tour have prompted us to explore new ways to address health care disparities encountered by patients suffering from pulmonary disorders. We are considering how the CHEST Foundation can develop educational and financial support programs to obtain medications. In addition, we are exploring ways to create a more meaningful “first five minutes” of a conversation between patients and clinicians. We know that understanding the social determinants of our patient’s health is one way to positively affect the management of their pulmonary condition.

Second, I am delighted to report that we are on target to meet our 18-month fundraising goals. The CHEST Foundation’s staff has done a superb job of creating virtual fund-raising events focused on the Feldman poker tournament and wine tastings. They are currently planning creative ways to ensure that the Belmont gala scheduled for June 5, 2021, in New York, is a success. Kudos go to Rudy Anderson, Angela Perillo, Caitlin Moroney, and Andrew Gillen. The CHEST Foundation remains committed to finding ways to “crush lung disease” by building on past successes and tackling new challenges. The Board of Trustees and the entire CHEST Foundation staff thank you for your continued support to reach these goals.

Sincerely,

Ian T. Nathanson, MD, FCCP
For a long time, the CHEST Foundation was identified by what we did — give grants. Then, we were described by who we were — patient educators, community event planners, and clinical researchers.

Now, as we mark 25 years of stewardship, in a moment when racial disparities become more evident in our underserved communities, and a lung health crisis threatens every aspect of our lives, we know exactly who we are being called to be.

AN IDENTITY SHIFT

Like many philanthropic arms of medical societies, the CHEST Foundation was founded on the premise of delivering grants to its members, and we awarded more than 30 in our inaugural year. Funding clinical research, world health partnerships, and lectureships constituted our identity for a very long time. It served us well in supporting the overall mission of CHEST, which is an organization that invests in community research.

Our first evolution was prompted several years ago when CHEST decided to prioritize patient education, supporting new community-centric initiatives that would be spearheaded by the Foundation. Within a short amount of time, we began to develop patient and caregiver resources that were previously outside our realm, becoming true advocates by:

• Creating engaging tobacco cessation and educational programming to help eliminate tobacco use
• Founding the Critical Care Family Assistance Program (CCFAP) to provide for the unmet needs of families of critically ill patients in hospital ICUs
• Launching the “Beyond Our Walls” campaign to support CHEST’s Simulation Center to train to patient-centered care
• Partnering with the Popovich family to secure a substantial ILD endowment
• Funding COVID-19 microgrants aimed at community outreach supplying food, masks, oximeters, and supplies
• Launching a Listening Tour campaign to address health disparities in underserved communities
• Producing a complimentary oxygen toolkit enabling patients to have informed conversations with their clinicians
WHO ARE WE NOW?

After 25 years of listening and learning, we’re proud to say that we’ve evolved into conversation starters, access granters, community activists, and change makers.

We’ve changed a lot over the past 2 decades and so has lung disease awareness. That’s why this anniversary is so important. It’s not just to celebrate the past or say “well done.” It’s to take this opportunity to highlight all our past accomplishments, what we call our building blocks, to create a solid foundation and vision for the future.

What we learn when delivering care packages during a pandemic, what we hear patients say during a listening tour, and what caregivers look for when visiting our patient hub – this is how we will gather the knowledge we need to define who we are moving forward.

TRAILBLAZING INTO THE FUTURE

Our anniversary theme is “Leaders of the past. Trailblazers of the future.” It may sound like a snappy phrase, but we take it very seriously.

“Without the vision, guidance, and support of our leaders, much of the work we’ve done wouldn’t have been possible. They are our champions and carried our torch for a very long time. Looking to the future, we’re excited to welcome new torch carriers who we can partner with to propel us into a new era of philanthropic work,” stated Rudy Anderson, CAE, Executive Director of the CHEST Foundation.

AWARDING $200,000 annually in collaborative diversity grants and community-focused programming

ESTABLISHING “Rita’s Fund,” an initiative to support marginalized patients who can’t afford proper care

EXPANDING access to oxygen therapy and pulmonary rehab through a telemedicine pilot program

PARTICIPATING in more advocacy efforts by developing policy statements from our tobacco experts

It’s time to remember the past. It’s time to celebrate the present. And it’s time to blaze into the future. We hope you’ll join us.

Visit chestfoundation.org/25th-anniversary to discover all the ways we’re marking this historic occasion.
IT’S TIME TO CELEBRATE!

To celebrate our 25th Anniversary, we’re hosting a variety of fun and entertaining virtual events. Remember, the funds raised from our events go directly toward advancing our programming, so you won’t only be enjoying a unique activity, you’ll also be helping fight lung disease! To register, visit chestfoundation.org/news-and-events/.

EVENTS

Margaritas and Guacamole Lesson  |  April 28
Wine Tasting  |  May 14
Irv’s Spring Splash Poker Tournament  |  May 20
Belmont Stakes  |  June 5
Irv’s Spring Splash Poker Tournament  |  June 18
Wine Tasting  |  June 24
Trivia Night  |  July 21
Wine Tasting  |  August 12
Virtual Painting  |  September 8

GET INVOLVED ON SOCIAL MEDIA

It’s because of our generous donors that we’ve been able to fulfill our mission for over 2 decades. That’s why we want you to be a huge part of our anniversary by getting involved on social media. Be sure to follow the hashtag #CHESTFoundation25 on Twitter, Instagram, and Facebook. We’ll be asking questions every month, and we would love to hear your answers!

Visit foundation.chestnet.org/25th-anniversary to learn more about our anniversary!
WHAT WE LEARN FROM LISTENING
INSIGHTS FROM THE CHEST FOUNDATION LISTENING TOUR

A year after the start of the COVID-19 pandemic and more than 550,000 US deaths later, the picture of lung health is forever changed with COVID survivors at an increased potential for long-term effects from the virus.

What didn’t change was the impact long-standing systemic health and social inequities are having on our disadvantaged populations. Black, Indigenous, Latinx, and other people of color are losing their lives at a higher rate than their White counterparts. Nationwide, Black people died at 1.4 times the rate of White people, accounting for 15% of all known COVID deaths.

The numbers are grim. The people behind these numbers are families, friends, and neighbors who make up the heartbeat of a community. So many of them are our community—the people with chronic lung disease who we fight for every day.

Learning about the circumstances that exist for those with lung disease who live in different regions is critical to understanding how some of our communities are fighting for their health from a disadvantaged position. We visited five communities across the United States as part of a year-long virtual Listening Tour. The communities were Jackson, Mississippi; Chicago; New York City; South Texas; and the Southwest (California, Arizona, and New Mexico).

This is the state of health care in these regions—all share commonalities, including limited access to care due to proximity or adequate health insurance coverage and environmental health factors. This results in a decreased quality of life and increased loss of life for our patients, especially those living in lower income communities.

These are conditions we can’t change, but there are actions we can take to support people living with lung disease.

New York City’s poorest neighborhoods have mortality rates that are 30% higher than those in wealthier neighborhoods for virtually every health indicator.

Mississippi has the LOWEST NUMBER OF PHYSICIANS per capita of any state, with nearly half of Mississippi’s rural hospitals in risk of closure and having the THIRD HIGHEST MORTALITY RATE nationwide for lung disease.

Texas has the highest percentage of uninsured people in the country, with communities like Corpus Christi and San Antonio more than double the national average and more than 1.6 MILLION RESIDENTS with ASTHMA.

Air quality in Phoenix received an “F” for both particle pollution and ozone quality, the lowest quality grade a city can receive, and nearly 30% of patients with lung cancer diagnoses in Arizona receive no treatment, the worst such rate in the country.
IN THEIR OWN VOICES

When conditions that don’t support health care exist, people are forced to make decisions that can cost them their lives. Real people. Patients and caregivers joined the conversation sharing with clinicians and community leaders alike what real life is like for them.

“When you need the doctor most, that’s when you’re turned away,” said Challise Burciago of Jackson, who is a patient and caregiver. Challise kept her symptoms well managed until she caught COVID-19. She couldn’t get an inhaler because she couldn’t see a doctor due to her COVID diagnosis.

When Elizabeth Ortiz showed up for her appointment to address her asthma, she was nearly turned away. The doctor’s office didn’t have documentation of the appointment scheduled from a NYC hospital emergency department referral. “I was extremely upset. I couldn’t breathe. I didn’t feel well, and the nurses told me I’m not going to be seen,” she said.

Rita Castro is legally blind with limited mobility. Getting to an office visit at any one of her 17 different doctors can be a lengthy test of her will. She didn’t notice when her asthma had worsened, and her breathing became impaired. “Every day, there are just a number of things that I need help with, and there is no one here to help me. And so, I will sit and wait,” said Rita, who lives in South Texas. “I know it’s inevitable that eventually, at some point, there will be no coming back from this (loss of vision). And so, I feel my world is getting smaller and darker.”

Marciano Gutierrez and his wife, who is his primary caregiver, speak primarily Spanish. They struggle to find a doctor who understands their language, their culture, and their everyday experience. A decade ago, Marciano worked in a frozen food warehouse where cold air blasted into his lungs for hours a day, exacerbating his asthma and COPD.

When he had a heart attack and lost his job, his wife’s insurance provided coverage until she lost her job during the COVID-19 pandemic. Paying for the asthma medications went from difficult to impossible. “We have been getting by with samples for the inhaler,” he said through a translator.
Less than 3 weeks after participating in the Listening Tour, Marciano Gutiérrez, age 68, died in a Chicago hospital after testing positive for COVID-19.

Access. Insurance. Poverty. Disability. These are all factors that play into the availability of quality health care for millions of US residents every year.

When our people are marginalized and then encounter failing health systems, health conditions go unrecognized, undiagnosed, and untreated. Through efforts like the Listening Tour, we can elevate people's voices. But actions that change lives can’t happen without personal commitment and financial support.

How can we act to make a difference in the quality of lives for those affected by these conditions? One way is by acting to remove barriers.

**Access. Insurance. Poverty. Disability. These are all factors that play into the availability of quality health care for millions of US residents every year.**

**FINDING THEIR OWN WAY**

Overcoming this divide has been on the shoulders of the patients who are too often ill-equipped to advocate for their needs. They are expected to take on government systems that make getting assistance nearly impossible. Language barriers keep vital lifesaving details from being heard and understood by both clinicians and patients. Lack of transportation can prevent the most determined of patients from getting to inaccessible or far away medical centers. Then there are the ever-rising medical costs.

Maria del Carmen Agudelo was born in Colombia and lives in NYC. She doesn't speak English. At most of her appointments, she relied on translators. Details got lost in translation and made her hesitant to ask questions. Then, she found a Spanish-speaking pulmonologist. “He has explained my condition to me. I have had translators and doctors who have treated me, but communication was not good when it is not in your same language. It is a great barrier to understanding and asking questions confidently,” she said.
Busy mom Constance Baker is the primary caretaker of her father, James, who can't read or write. When his breathing became labored, repeated trips to the ED weren't solving the problem. Originally thought to be a cardiovascular problem, Constance and James were referred to Jackson pulmonologist Dr. Demondes Haynes when the condition wasn't improving. James, who has pulmonary hypertension, was diagnosed with scleroderma, a rare disease that hardens patches of skin and created scarring of his lung tissue.

A specialized nursing team trained Constance in preparing her father's medication. Throughout the process, Dr. Haynes patiently explained complex medical concerns and answered questions. “Patients don't care how much you know about the disease until they know how much you care,” said Dr. Haynes.

“Patients don’t care how much you know about the disease until they know how much you care,” said Dr. Haynes.

Nobody likes a visit to the intensive care unit. Shirley Van Buren has severe asthma episodes that regularly sent her to a Chicago hospital where she was steered directly to the ICU. When she had to take medical leave from her job, she lost her insurance coverage, which led to some tough choices – stop providing for the grandchildren she helps raise, pay for asthma or diabetes medications, or cover her heart medication.

“I really had to hustle to figure out how to get the money in the door,” said Shirley, who started a side business selling baked goods. She was able to get health coverage through an assistance program but finding a doctor who accepted her public health care and treated her with compassion wasn't easy. It eventually happened. “Ever since I became her [Dr. Sunita Kumar] patient, she was right there. No matter what. She reminds me of my mother, always on me,” she said. “Trust for me was really critical in my willingness to follow (doctors') instructions.”

Orlando Rivera found a medication that got his asthma under control, but the allergist who prescribed it to him increased the cost of office visits as often as four times a year. When the office administrator failed to file the right paperwork for a grant that had covered his copayments, Orlando had to find a different doctor. His trust in the system was low.

“Trust, I think for me, has to be built on the consistency of a caring clinician who takes the time to listen and respond accordingly.”

Rivera was pleased to find Dr. Diego Maselli, who was able to accurately diagnose his condition and prescribe medication that substantially lessened his symptoms at a price he could afford. “Trust, I think for me, has to be built on the consistency of a caring clinician who takes the time to listen and respond accordingly,” Orlando said, who found that in Dr. Maselli.
Patients and caregivers struggling to afford medications or be understood by their clinicians need advocates to stand with them in the struggle. With the support of our donors, we are those advocates.

WHERE CHANGE CAN BEGIN

Every patient needs to be their own advocate, but for some, the social and racial systems in place create such thick barriers that being heard is nearly impossible. Overcoming the systems and culture that support these inequities can only happen when all the parties involved are willing to look at their role in the problem. Some of the barriers include:

1. Attentiveness and care can be inconsistent, and providers can appear to lack empathy.
2. Not understanding the circumstances that make medications unaffordable keeps patients from returning for care.
3. Billing and costs are seen as point of contention between staff and patients; patients can feel shamed and believe doctors are only focused on money.
4. Overwhelmed with busy schedules, doctors feel limited in the time they have to form connections with their patients.
5. Language barriers and racial and ethnic difference can hinder understanding and make a patient hesitate to share crucial information.

This is just the tip of the problem underlying the health disparities crisis in America. In the next months, we will reveal our plan to begin addressing and funding programs that target the core of these issues. Keep listening and watching.

Sources: All sources can be referenced on the CHEST Foundation website under the Listening Tour.

HELP US TURN LISTENING INTO ACTION

The Foundation’s Listening Tour provided patients a platform from which to speak to civic leaders, clinicians, and specialists responsible for changing and improving the conditions and quality of life for them and their communities.

People who, with the onset of COVID-19, are more vulnerable than ever with their lung conditions need our help. Because of your support, people who are compromised by lung disease have a voice.

Help us continue to turn words into action.
LONG ROAD TO BREAKING DOWN BARRIERS

When Alvin V. Thomas Jr., MD, FCCP, accepted the CHEST presidency in 2007, he had a mission in mind, one that he had been formulating for a long time. His goal was to highlight health care disparities and raise the consciousness of his colleagues to an issue that was affecting large communities of people suffering with lung disease.

Dr. Thomas, who is currently Emeritus Chief of Pulmonary and Critical Care Medicine at Howard University Hospital, and his wife Zorita, recently took the time to talk with us about their involvement in equity issues and working with underrepresented communities. This conversation was sparked by a letter sent last year by Dr. Thomas; Dr. David Gutterman, Master FCCP; and Dr. John Studdard, FCCP, calling on CHEST to be leaders in the area of equity for people of color. This topic is also the current focus of the CHEST Foundation Listening Tour.

Dr. Thomas saw how issues of health equity and access impacted health care throughout his education and early medical career. In addition to working extensively in underserved communities, Dr. Thomas has been a principal investigator or participant in several studies on preventive care in Black men. Dr. Thomas notes that when he joined CHEST in the early 1980s, “the problem of disparities in health and health care were just beginning to be major topics of discussion at a national level.”

“The medical profession is one of the last areas to really have to deal with the issues of equity and diversity. I’ve seen pushback on this issue, even though diversity and inclusion are essential.”

He began laying the groundwork for a call to action. By the time he became the first (and only so far) African American President of CHEST, Dr. Thomas felt the college should take an active role in addressing barriers to care and aggressively mentor minority clinicians into leadership roles.

“It was clear that a lot needed to be done, and people didn’t really have an organized way to try to do it. You highlighted the disparities in health. You highlighted disparities in care. But there weren’t a whole lot of easy solutions because it really dealt with deeper issues,” explained Dr. Thomas. There was little impetus for change by the medical community at large.
One change Dr. Thomas focused on was the inclusion of annual meeting sessions related to disparities in health care. “But of course, there was a barrier there, too, and not from the college,” said Dr. Thomas. “People just didn’t attend.”

Then and today, Dr. Thomas stressed the need to integrate discussion of health issues in diverse populations into every learning opportunity to increase awareness for all clinicians. This as a step CHEST has already begun incorporating.

When President, Dr. Thomas stated that addressing disparities should be part of the “cultural fabric” of all CHEST programs. He noted the need to seek funding for patient transportation programs, community-based interventions, and training in cultural competencies for physicians—issues currently highlighted in the Foundation’s Listening Tour. As Dr. Thomas’ time in leadership came to an end, attention eventually shifted away from actively pursuing diversity issues.

“The medical profession is one of the last areas to really have to deal with the issues of equity and diversity. I’ve seen pushback on this issue, even though diversity and inclusion are essential,” noted Dr. Thomas. He believes problems of diversity and inclusion in medicine will improve when there is greater commitment and success in increasing the number of Black and Brown persons as medical students, medical faculty, and practicing medical care providers.

Last year, with the rise of the COVID-19 pandemic and the social unrest resulting from the death of George Floyd, CHEST was asked once again where it stood on the issues of health care disparities. “We can and should be a thought leader in the pulmonary and critical care community on this issue,” said Dr. Thomas both in 2007 and today.

Some visions might take longer, but they are not forgotten. We are all challenged to take up that vision through our actions in whatever form they take—mentoring, advocating, donating, or leading.

WORK WITHIN COMMUNITIES

While her husband may be the physician in the family, Zorita Thomas is the activist focused on community-based service. Ms. Thomas participated in and led the CHEST Foundation community-based service program, the Ambassador Group. The members coordinated lung health education events and outreach to underserved communities internationally. At one point, the program was so extensive that the members were regular attendees of the CHEST annual meeting, holding their own sessions and programs.

“This program was started by two women who went out into the communities in San Francisco, to the schools, to talk about asthma. Then it opened up, and [the program] kept getting bigger,” explained Ms. Thomas. “The focus was on what each of us can do in our own communities.” Together, Dr. and Ms. Thomas believe the best way to help is to work within the community.

In this way, the CHEST Foundation Listening Tour is right on track by bringing patients, caregivers, community leaders, and community physicians together. The Foundation’s community service microgrants for clinicians who want to help at-risk populations during the pandemic provided food and supplies, health-care quality masks, and oximeters.

“Get in the communities, identify the people in the community who the people trust, and then work with them,” said Dr. Thomas. “Finding community workers who people know and trust, that’s what it takes to really get things done. It takes time, but that’s the kind of granularity that’s necessary.”

Alvin and Zorita Thomas have actively supported the CHEST Foundation’s efforts in diversity and health equity as Lifetime Members and community leaders.
The Champion’s Circle is the CHEST Foundation’s annual giving club that recognizes our most committed donors in a calendar year. Last year was an especially difficult year, and we are truly grateful for the commitment and sacrifice from our physicians and donors. To everyone who gave in 2020, we sincerely thank you.

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