2020
The State of Pulmonary Health in Chicago

Listening to Your Voice.
Fighting for Your Every Breath.
The Fund for Trust, Access, and Equity.
Chicago faces a pulmonary health crisis.

Despite superior medical facilities, the city has dramatic health disparities created by pronounced wealth gaps. The city needs solidarity and creative problem solving to repair damage and to find a solution.

Lung disease is often incurable. Existing tools treat symptoms and work to delay its progression. There is nothing to eradicate the illness itself. Chronic lung disease plagues an estimated 12 percent of adults in Chicago. Chronic obstructive pulmonary disease (COPD), asthma, and other pulmonary conditions often go undiagnosed, especially by those with limited access to health care. In Chicago, that describes more people than it should. Poverty levels and the percentage of people without health insurance are well above the national average—according to recent Census estimates.

The outbreak of COVID-19 in Chicago amplified the problem. The lasting health complications of COVID-19 infections may add more patients to the roster of those needing lung care. The pandemic has also deepened social divides, sunk many people into economic distress, and strained our health systems.

Both long-suffering patients and those who developed post-COVID diagnoses have one commonality — they disproportionately represent our most vulnerable populations. We face a harsh disparity in health outcomes for people of color and others who lack financial resources.

Chicago is part of a coast-to-coast search for answers.

The CHEST Foundation held a virtual event November 11, focused on Chicago, that was part of a nationwide listening tour. The event brought together civic leaders, clinicians, specialists, and patients. It provided a platform for these patients who have fought for access to care to share their stories.

This summary explains specifics to be addressed by a newly launched CHEST Foundation fund that will support those who need help.

The pandemic introduced changes to countless aspects of our lives, most of which were unwelcome. Through this new initiative and an increased awareness of lung health, we can accomplish change that is desperately needed. In the absence of a cure for lung disease, the ability to treat everyone, regardless of who they are, would be a victory.
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On November 11, 2020, The CHEST Foundation hosted a virtual event in Chicago as part of a national listening tour focusing on lung health care. The conversation united health-care providers, patients, and community organizations. It was the third event of its kind, with more planned across the country in cities identified for their incidence of lung disease, racial disparities, and COVID-19 infection rates.

People in Chicago suffer from low overall lung health and are more likely than the average American to be uninsured and in poverty. Studies estimate 12 percent of the city suffers from chronic lung disease.

The city has documented persistently worse conditions for people of color and those living in low-income neighborhoods. Asthma rates in the city’s low-income neighborhoods are nearly double what they are elsewhere. As many as 28 percent of people in low-income neighborhoods have prescriptions they cannot fill because of cost. When COVID-19 spread to Chicago, the city saw Black and Hispanic people nearly twice as likely to be hospitalized or die from the disease as their white neighbors.

The discussion focused on identifying barriers to accessing medical care, breakdowns in trust between patients and caregivers, and how to achieve equity in treatment for people of color and disenfranchised communities. Providers shared what resources they need to properly treat patients and the logistical roadblocks to providing the best care.

The listening tour was launched to prepare communities nationwide for more patients with chronic lung issues. Both Americans living with chronic lung disease and those diagnosed with COVID-19 are disproportionately made up of vulnerable populations, who often do not have resources to seek medical treatment or afford needed medical devices and medication.

The COVID-19 pandemic worsened an already dramatic disparity in Chicago between those who can afford health care and those who cannot.

The time to find solutions is now.

In Chicago, Blacks were twice as likely to die from COVID-19 as white people.
Participants

**PHYSICIANS & PROVIDERS**

- Deji Adegunsoye, MD, MS, FACP, FCCP  
  *The University of Chicago Medicine*

- Ada Arias, MD  
  *Presence Saints Mary and Elizabeth Medical Center*

- Neeraj R. Desai, MD, MBA, FCCP, FACP  
  *University of Illinois College of Medicine, AMITA Health*

- Edward Diamond, MD, MBA, FCCP  
  *AMITA Health, Immediate Past President of the CHEST Foundation*

- Brenda Louise Giles, MD  
  *The University of Chicago Medicine*

- Sunita Kumar, MD, FCCP, FAASM  
  *Loyola University Medical Center*

- Jay Shannon, MD  
  *Illinois Emergency Management Agency*

**PATIENTS & INTERPRETER**

- Marciano Gutiérrez  
  *Patient*

- Aldophus Kindle  
  *Patient*

- Shirley Van Buren  
  *Patient*

**COMMUNITY LEADERS**

- Miriam Barger  
  *Community Health*

- Kiana Courtney  
  *Environmental Law & Policy Center*

- Robert Dahl  
  *AMITA Health*

- Sydney Edmond  
  *Illinois Public Health Institute*

- La Tisa Foscett-Gonzalez  
  *Resurrection University*

- Kim French  
  *AMITA Health*

- Atrician Lumumba  
  *MAP Corps*

- Pamela Mitchell-Boyd  
  *AMITA Health*

- Matt Siemer  
  *Mobile Care Chicago*

- Renuka Sharma, M.Ed  
  *Chicago Citywide Literacy Coalition*

- Vickie Thornley  
  *Resurrection University*

- Patti Toumey  
  *Josephinum Academy, Past Trustee of the CHEST Foundation*
People battling lung disease fight for every breath. For many of them, the struggles aren’t isolated to the physical limits of their lungs. They search for answers and struggle to validate their diagnosis. They try to find a health-care provider who takes their form of payment and insurance, who they trust, and who demonstrates concern. Getting the appropriate medications and medical equipment strains their resources or, in some cases, is beyond their ability. Many of these people cope with poverty, unemployment, and systemic racism, and have not found their voice to advocate for a better standard of care for themselves.

Meanwhile, doctors struggle to establish relationships with patients due to limited time, when they must also give them the crucial information they need and understand the contributing factors that impede their health. Educating patients on complicated health issues can take years. They don't always know how to help patients navigate social assistance programs or identify one that might be appropriate for their patient's needs.

With no long-term cure for lung disease, the problem persists through their lifetime. The roster of patients looking for these solutions grows.

"The CHEST Foundation is truly a 'breath of fresh air' for the estimated 12 percent of adults in Chicago suffering from chronic lung disease. I am thoroughly impressed by its dedicated work to identify barriers to pulmonary care, and the many disparities that have been further exacerbated by the COVID-19 pandemic. As evidenced by its State of Pulmonary Health in Chicago report, the CHEST Foundation's virtual listening tour provided much-needed insight into the importance of trust in the patient-provider relationship, as well as clarity into the role that providers must play in broadening access and ensuring equal treatment for all patients regardless of their backgrounds and financial status. Even with the clear challenges that must be overcome, I am encouraged by the key insights and data this report has uncovered, and I am eager to work more with the CHEST Foundation in developing meaningful strategies to help more people get the critical and preventative care they need moving forward."

—Congressman Raja Krishnamoorthi (IL-08)
Aldophus Kindle

Patient

Aldophus Kindle may not look the part anymore, but there was a time he was fighting just to survive the tough streets of Chicago's South Side.

Back then, taking care of his health meant simply surviving. He went to the doctor only in emergencies and never considered visiting a specialist.

"I was using the emergency room as my doctor," he said. "I don't have the money or the willingness (to see a specialist)."

Then he had a wakeup call. What started as concerns about his blood pressure and heart prompted tests, which revealed that he had developed sarcoidosis. Kindle didn't even notice he was having trouble breathing.

"You could have told me that perhaps I had pulmonary issues and I wouldn't have believed you," he said. His doctor looked at his list of conditions on his medical chart and didn't mince words. "He asked me, 'Do you have a death wish? Are you trying to live?'" he recalled. "He was trying to introduce a medical intervention."

Kindle wised up around the same time he got a job that offered premium health care coverage. After years of being uninsured, felt like a received a golden ticket to better health. He even started routinely dressing in a suit on days he visited a doctor.

"If I wear a suit to a doctor's appointment, I get a different level of respect from the nurses and from the other people as I walk into the room and as I interact with them," he said. He manages his health conditions well now, but he said he likely wouldn't have survived without the doctor's intervention.

Cultural attitudes contributed to his years of inattention, he said. "It was a combination of...some cultural thought processes and not having the money at that time," he said. "I didn't have a relationship with a doctor. And then, as a consequence, (I) really don't know the other issues that (I'm) having."
The cost of health care prevents many patients from treating their conditions or engaging in preventative health. Without established primary care providers, patients can go years without recognizing signs that lung health problems are emerging. By the time they are treated, their conditions have deteriorated to a chronic level. For these patients, treatment from a specialist can be out of reach.

A job that offers premium insurance can provide better access. Without it, health care is a luxury and lung conditions are only treated when they reach a critical state. Without a job, patients lose both the insurance network that helped them access care and their ability to pay for visits out of pocket. Often, this problem is exacerbated when poor health prevents people with chronic lung conditions from working or performing their work well, leading to increased financial strain.

Instead of incurring the expenses associated with specialists, uninsured patients rely on emergency care. If a lung condition is diagnosed, many have no hope of filling prescriptions as often as needed and instead survive on samples provided by hospitals.

Identified barriers included:

- Lack of preventive care or an established primary care provider leads to worsening conditions that go undiagnosed until they reach a chronic state.
- People who lose jobs due to health reasons can no longer treat their conditions or afford medications.
- High copayments can lead insured patients to defer treatment.
- Expensive medication leads patients to ration out their supplies because they can't afford to buy more or rely on samples from providers.
- The costs of health care is compounded by the secondary costs of missing work and paying for follow-up appointments and medications.
- Multiple medical problem forces some patients to choose which medications to purchase and which ailment to treat because of financial limits.
- High costs lead some patients to resort to side jobs to earn extra income to pay for treatment. For those without the ability to earn extra income, there is no option to pay for needed medication or expenses.

In Chicago's low-income neighborhoods, up to 28 percent of residents have prescriptions they don't fill because of cost.
Shirley Van Buren
Patient

Shirley Van Buren has seen the inside of an intensive care unit more times than she can count. It seems to her that almost anything can set off an extreme asthma episode, leading to a hospital visit where she's steered directly to ICU.

Not long ago she led an active life. Her worsening, severe asthma put a stop to that. A year ago, she worked as a retail store manager, standing on her feet and pushing shopping carts around a parking lot.

It was difficult to keep up with the job and her complaints went disregarded. Van Buren went on a medical leave that has stretched on for more than a year, causing her to lose her insurance coverage. She had to make tough choices. Should she stop providing for the grandchildren she raises? Pay for her diabetes medication or her heart medication?

She began a side business selling baked goods.

"I really had to hustle to figure out how to get the money in the door," she said. Van Buren was able to get health coverage through an assistance program. The new program doesn't cover the medications she needs that she previously was able to purchase. She goes into every doctor visit focused on what it will cost and if it will be worth it.

When she found a doctor who accepted her public health care and treated her with compassion and not pity or disdain, her hope was renewed.

"Ever since I became a 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."
Insurance coverage grants its holders more than just access to quality providers and help paying the bills—It translates into an unspoken measure of worth. Patients who previously had insurance and lost it, as well as those who went years without coverage before getting insurance, attested to this. Patients with a PPO are treated like more deserving of care.

The division between people who can afford health care and those who cannot creates health disparities. These gaps follow patterns of historic racial inequalities, and the community’s health reveals these racial divides. In Chicago, black patients suffer the most, which is compounded by a cultural aversion to medical treatment.

A lack of education about health-care terms and serious lung disease symptoms causes some patients to be unaware how serious their conditions are. Without the benefit of a health advocate, the wherewithal to advocate for themselves, or proficiency in health issues, patients may not have the ability to seek care or maintain treatment.

Identified barriers include:

- Providers know which patients have premium insurance and can present more options to them on their health care, which can imply these patients are more deserving of care.
- Physical appearance, such as grooming and attire, can influence how providers perceive and treat patients.
- Clinicians may assume, or seem to imply, that black and Hispanic patients are uneducated.
- Language barriers prevent Spanish-speaking patients from completely understanding their conditions and asking questions.
- A cultural attitude among black men doesn’t prioritize health care.

"The best medication is the one that not only works for the patient but also the patient can afford."
—Dr. Ada Arias

Blacks are twice as likely to visit emergency departments for health conditions that a primary provider could treat.
Marciano Gutiérrez  
Patient  

A decade ago, Marciano Gutiérrez worked in a frozen food warehouse. Cold air blasted into his lungs for hours a day.

He knew those conditions exacerbated his asthma and his COPD. He began getting sick more often and respiratory infections were harder to shake. Then he had a heart attack. Gutiérrez missed so many days of work from illnesses that he lost his job.

Luckily, he still had health insurance coverage through his wife. But without the extra income from his job and the worsening of his health, he couldn't pay for the growing medical expenses. His wife started making sandwiches and snacks to sell to her coworkers to pay the copays and medical bills.

During the COVID-19 pandemic, his wife lost her job. 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. Gutiérrez participated in the Listening Tour call on November 11. A few weeks later, Gutiérrez was admitted to a Chicago hospital and tested positive for a COVID-19 infection.

He passed away on December 1, at the age of 68, from complications from the COVID-19 infection.
Providers must establish trust with their patients if they expect them to carry out their instructions. Building a relationship in a short visit begins by establishing a human connection and demonstrating concern for the patient that is beyond their health issues.

Identified barriers included:

• A cultural aversion to visiting doctors' offices or specialists stemming from poverty and costs associated with medical care.
• A need for providers to speak frankly with patients about the severity of their conditions if they seem unconcerned or oblivious.
• Availability of doctors to provide means of contact for follow-up questions without requiring another office visit.
• Perceived inattention from providers leading to feeling as if the patient is only a case number and not a person.
• Time constraints of office visits bleeding over into provider attitude that they are in a hurry and need to get away from the patient and onto the next appointment.
• Medical advice given is treated like a mandate without input from patient.

“Really take a moment to pay attention to me and not just, you know, give me my five minutes and send me out the door.”
—Aldophus Kindle, Patient

Every 15 minutes of a doctor’s day are seen as slots to see another patient. In that window, they have to examine, diagnose, and develop a treatment plan. While they know in their hearts every patient deserves good health care and treatment, in that rushed schedule, it can be difficult to demonstrate. Dr. Ada Arias does this with a list of questions that indicates she sees the patient as a whole.

• Who takes care of you at home?
• Who do you live with?
• Who takes care of you when you’re sick?
• Do you understand your disease?
• If you get sick and an emergency happens, who brings you your medication? Do you remember to take it on your own?

Demographics of Chicago

- 32 percent Non-Hispanic White
- 30 percent Black
- 29 percent Hispanic
- 6 percent Asian
- 3 percent Other
Recommendations

The problems surrounding trust, access, and equity can't be eradicated until the community acknowledges them and works together toward a solution. Health care expenses, even for the insured, can deter treatment. Providers must be a partner in assisting patients with accessing their medication and be sensitive to perceptions of unequal treatment. Patients need education and engagement from their medical team. Physicians need partners in their fight to provide better care.

ACCESS
• Emergency coverage for people who have recently lost their jobs due to a health issue.
• Low-cost options for uninsured patients to consult with specialists.
• Routine screening for pulmonary conditions in general clinical care to identify conditions before they worsen.
• Public education about signs of lung disease before they reach chronic conditions.
• Clinics that treat patients after working hours to avoid missing work to seek medical care.
• Assistance with costs of copayments, out-of-pocket doctors’ visit expenses, and medication.

TRUST
• Clear communication of full costs so patients aren’t wary of hidden expenses or bills.
• Provide a phone number or email address for patients to ask follow-up questions and receive timely answers.
• Patients and doctors to approach a treatment plan as a collaborative decision.
• Placing emphasis on providers learning more about patients’ backgrounds and living situations to prescribe medications they can afford and a treatment plan they will be able to follow.
• Emboldening doctors and care teams to educate patients on conditions in a forthright manner.

EQUITY
• Emphasis to providers to treat all patients equally, regardless of their backgrounds, appearance, or financial status.
• Diversity in medical staff at all hospitals in all areas of the city to ensure that patients feel comfortable.
• Fluent speaking providers and translators to erase any language barriers.
• Public education on importance of preventative health care.

“I really wasn't paying attention to my health, and I was living my life through the emergency ward.”
—Aldophus Kindle, Patient

“A patient-clinician relationship is just like any other relationship. You have to put in time and get to know them.”
—Dr. Neeraj Desai
About the CHEST Foundation

The CHEST Foundation, the charitable arm of the American College of Chest Physicians, champions lung health by supporting clinical research, community service, and patient education. Through CHEST Foundation-supported programs, CHEST’s 19,000+ members engage in advancing the lung health of millions of patients in local communities around the world. More than 95 cents of every dollar raised goes toward advancing the foundation’s mission-based programming. Since its inception, the foundation has provided more than $10 million in funding for clinical research and community service, with a reach that spans more than 60 countries.

For more information about the CHEST Foundation, visit chestfoundation.org.

About the Erin Popovich Endowment

The Erin Popovich Endowment, established with the CHEST Foundation, is changing what it means to live with interstitial lung disease (ILD) by increasing access to information and treatment, improving patient independence and supporting clinical research. The mission of the Erin Popovich Endowment focuses on improving the quality of life of patients with ILD and their families through education, and becoming a facilitator between clinicians and patients for the myriad of burdens that patients and families encounter from their initial diagnosis to the end of life. To learn more about the Erin Popovich Endowment, visit chestfoundation.org/popovich.

We Can Heal Together.

It Starts by Listening.

To learn more about the Listening Tour, visit chestfoundation.org/tour.