The State of Pulmonary Health in Jackson, Mississippi

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

With few specialists to treat people from marginalized communities, a level of mistrust based on limited understanding and access to healthcare has taken hold. Awareness of this barrier to providing care is necessary for eliminating health disparities among underrepresented and vulnerable groups. Working in partnership, clinicians, patients, and caregivers must find creative solutions to repair the damage that exists and eliminate disparities.

Lung disease is incurable. Existing tools treat symptoms and work to delay its progression. There is nothing to eradicate the illness. Chronic lung disease affects an estimated 14 percent of adults in the metro area. Those are only the numbers for people diagnosed with the disease. COPD, asthma and interstitial lung disease and other pulmonary diseases often go undiagnosed, especially in those without easy access to health care. In Jackson, that describes more people than it should. Poverty levels and the percentage of people without health insurance are double the national average according to recent U.S. Census estimates.

The spread of COVID-19 in Mississippi complicated the already murky future, creating a new reality we are only beginning to see. The potential for lasting health complications from COVID-19 could add even more patients to the roster of those needing care. The pandemic’s spread has also deepened social divides, sunk many people into economic distress, and strained our health systems.

Both long suffering patients and those who developed new diagnosises post-COVID have one commonality — they are disproportionately made up of our most vulnerable populations. It creates a harsh disparity in health outcomes for people of color or without financial resources.

In Jackson, we are fortunate to be part of a coast-to-coast search for answers.

The CHEST Foundation launched a nationwide listening tour in Jackson. The virtual event brought together civic leaders, clinicians, specialists and provided a platform on which 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 directly support those who need help most.

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 introduce one change that has been desperately needed. In the absence of a cure for lung disease, the ability to remove barriers to care and treat everyone, regardless of who they are, would be a victory.
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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. They try to find a health care provider who takes their form of payment and insurance, whom they trust and who demonstrates concern. Getting the appropriate medications and medical equipment strains their resources or, in some cases, is beyond their ability.

With no long-term cure for lung disease, the problem persists through these people’s lifetimes. The roster of patients without solutions threatens to grow, as some survivors of COVID-19 develop lasting lung conditions.

On September 17, 2020, The CHEST Foundation hosted a virtual event as part of a national listening tour focusing on lung health care. This event, based in Jackson, Mississippi, was the first of five planned community conversations that will take place in cities identified for their incidence of lung disease, racial disparities, and COVID-19 infection rates.

People in Jackson suffer from low overall lung health and are twice as likely as the average American to be uninsured and in poverty. Studies estimate 14 percent of people in the city experience chronic lung disease. Despite this prevalence, there are just 26 pulmonologists practicing in the city. The rate of deaths related to lung disease and asthma in Mississippi is among the highest in the country, driven by a concentration in Jackson.

The discussion focused on identifying barriers to medical care access and finding trust breakdowns between patients and caregivers. It also examined how to reach equity in treatment for people of color and disenfranchised communities.

The listening tour was launched in part to prepare communities for the rise of patients with chronic lung issues, as some COVID-19 survivors develop lasting lung complications from the virus. 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 cannot afford needed medical devices and medication.
Participants

Invitations were extended to area physicians, patients, caregivers, and community leaders. Twenty-seven Jackson residents participated in the virtual event. They included the following:

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<tr>
<th>PHYSICIANS &amp; PROVIDERS</th>
<th>PATIENTS &amp; CAREGIVERS</th>
<th>COMMUNITY LEADERS</th>
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<tr>
<td>Demondes Haynes, MD, FCCP&lt;br&gt;The University of Mississippi Medical Center&lt;br&gt;Member, Training &amp; Transitions Committee&lt;br&gt;Member, Diversity/Inclusion Roundtable&lt;br&gt;Member, Scientific Program Committee</td>
<td>James Lindsey&lt;br&gt;Patient</td>
<td>Chokwe Antar Lumumba&lt;br&gt;Mayor, City of Jackson</td>
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<td>John Studdard, MD, FCCP&lt;br&gt;Jackson Pulmonary Associates&lt;br&gt;CHEST Past President (2017-2018)&lt;br&gt;Member, Health Policy and Advocacy Committee</td>
<td>Constance Baker&lt;br&gt;Caregiver</td>
<td>Senator John Horhn&lt;br&gt;Mississippi State Senate&lt;br&gt;District 26</td>
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<td>Justin Turner, MD&lt;br&gt;Turner Care, LLC</td>
<td>Challise Burciaga&lt;br&gt;Patient and Caregiver</td>
<td>Von Gordon&lt;br&gt;The Winter Institute</td>
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<td>Keith Mansel, MD&lt;br&gt;The University of Mississippi Medical Center</td>
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<td>Robert Langford&lt;br&gt;Operation Shoestring</td>
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<td>Raymond Portis, MD, FCCP&lt;br&gt;Jackson Pulmonary Associates</td>
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<td>Victoria Gholar, MSN, RN-BC&lt;br&gt;Myrlie Evers-Williams Institute for the Elimination of Health Disparities at University of Mississippi Medical Center</td>
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<td>Jasmin Chapman, DDS&lt;br&gt;Jackson Hinds Comprehensive Health Center</td>
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<td>Penney Ainsworth, MSW&lt;br&gt;Boys &amp; Girls Clubs of Central Mississippi</td>
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<td></td>
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<td>Staci McNinch&lt;br&gt;Junior League of Jackson</td>
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<td>Primus Wheeler Jr.&lt;br&gt;Jackson Medical Mall</td>
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Patients with lung conditions face an uphill battle to get a diagnosis, receive treatment, and maintain a supply of medication or equipment. In some cases, they are not aware of lung disease’s warning signs or informed about its severity. Often, patients need an advocate to help them get the treatment they need.

Even when patients are insured, they may not have a relationship with a primary caregiver. Rotating emergency room doctors and physicians at clinics oversee their health. Appointments with specialists can be more difficult to get because of insurance requirements for referrals and cost-prohibitive because of high deductibles and the burden on patients to pay for two visits.

Once they make it to a doctor’s office, a new concern emerges. Providers can destroy any chance of trust if they act dismissive of both social and medical concerns, fail to explain diagnoses clearly, or treat low-income patients with bias.

Maintaining lung health once a lung disease is diagnosed has its own barriers. Insurance changes can require patients to find a new doctor and reestablish trust. Renewing prescriptions they need annually carries a double burden of the doctor’s visit expenses and the cost of the medication.

The struggles patients with lung disease face are part of a larger puzzle with complex, moving parts. Poverty, prejudices, and toxic stress compounds the problems patients face accessing quality health care. Patchwork solutions address some issues, but there is a lack of awareness about what resources are available.

Moving forward, a need for public awareness about indications of serious lung disease and available resources would be beneficial. Clinicians need awareness about tactics to establish and build trust, training on addressing medication access with patients and a network of community resources offering support.
Patients and caregivers expressed the most difficulties with accessing health care. Obstacles blocked their access when they needed to see doctors and specialists and to get medication. Sometimes those barriers are logistical. Not all practices accept low-income insurance, and health care plans may require referrals to see specialists, doubling the logistical problems and expense of visits.

It’s a lack of resources that prevents other patients from accessing health care. If they don’t have an advocate fighting for them, they may try to suffer with their symptoms on their own. The cost of repeated doctor visits accumulates. Without a consistent insurance plan, establishing a long-term relationship with a primary provider can be difficult to do.

Patient Challise Burciaga has had asthma since childhood, but when off her parents’ insurance, she relied on clinics for treatment. These providers treated only surface-level problems. With a daughter who has asthma as well, she faces difficulty finding doctors who will accept the state children’s health insurance program and is financially burdened by the cost of multiple office visits and medications.

Identified barriers included these:

- Insurance not accepted by desired doctors
- Referral needed for a specialist
- Doctors/clinics unwilling to treat COVID–19 positive patients
- Expense of doctor visits for patients without insurance and those with high deductibles
- Cost of medication
- Need for patient caregivers or health advocates for those who do not have the ability to advocate for themselves
- Patients without primary care doctors being treated for surface-level problems only in clinic/emergency department visits

"You have to go through so much and it causes so many extra expenses, just to get an inhaler," she said.

Her daughter has asthma as well. She doesn’t have an inhaler, because her primary doctor who diagnosed her said she needed to see an allergy and asthma doctor to determine the best course of action. Then red tape interfered with getting a referral for the specialist.

"You have to go through so much and it causes so many extra expenses, just to get an inhaler."

—Challise Burciaga, patient and caregiver
Challise Burciaga

*Patient, Caregiver*

Challise kept her symptoms well managed until she caught COVID-19. She didn't have an inhaler and when she tried to get an appointment to see a doctor, they refused to see her. They didn't want any COVID–19–positive patients in the office.

"When you need the doctor most, that's when you're turned away," she said.

She fought the virus with a mix of home remedies. Now she's experiencing breathing troubles and her once well-managed asthma gives her chest pains like she had as a child.

"When they say you still have symptoms, or that it does cause problems after the fact, you have lingering problems, they are telling the truth," she said.

Challise's daughter has asthma as well. She has insurance through the state child health insurance plan, but Challise sometimes feels stigmatized by health care providers for that and because she's a single mother on state-funded insurance.

"I can take care of myself. I know how to handle myself," she said. "But when it comes to my kids and to just witness, how sometimes they have been treated ... there is a prejudgment on them based on their insurance."

Not many quality providers accept the state-funded insurance. Challise pays for visits out of pocket instead.

"I go on with our life, sometimes putting stuff on the back burner, just to make sure that (my) children can get quality health care," she said.
"Health care shouldn't be a luxury or a profit-based decision."
—Jackson Mayor Chokwe Antar Lumumba

The health care industry in Jackson is not unpolluted by systemic racial divides. Perceptions that providers treat African-American patients and low-income patients differently prevail. The city is sharply divided between who can afford health care and those who cannot. A lack of education about health care terms and lung disease symptoms causes some patients to be unaware of serious complications. Without the benefit of a health advocate, or proficiency in health issues, low-income patients may not have the ability to seek care or maintain treatment.

Barriers include the following:

- Low percentage of African-American doctors compared with the state population
- Deepening of wealth disparities because of COVID-19 economic fallout
- Lack of in-depth knowledge in health areas
- Cost prohibitive medication leading low-income patients to rely on home remedies or over-the-counter medication
Constance Baker
Caregiver

Constance Baker was juggling the dual stresses of mothering a newborn and a teenager when she noticed a patch of her father’s skin looked discolored. There were other seemingly unrelated problems she detected in her father, James Lindsey. His breathing became labored. The skin on his hands appeared calloused. Then he passed out. Initially, doctors thought his problems were cardiovascular.

James can't read or write and had no primary doctor. Repeated visits to the same emergency room attracted the attention of a medical intern. He ordered tests and asked James to go to a specialist.

It was more than half a year and dozens of doctor visits until Constance and James met pulmonologist Dr. Demondes Haynes and learned the cause of James' troubled breathing. James has a rare disease called scleroderma, which hardens patches of skin and created scarring of his lung tissue. He also had pulmonary hypertension. James needed rapid intervention with a complicated regime of medication.
Providers must establish trust by showing patients their concern for them extends beyond their health issues. Education is needed to ensure physicians enable patients understand diagnoses and address barriers patients may encounter in carrying out recommended treatment.

Identified barriers included the following:

- Patients perceive dismissive attitudes and/or mistreatment based on their race, income level or use of state-funded insurance
- Technical medical language used by physicians can intimidate patients and make them reluctant to ask questions
- Clinicians can be oblivious to obstacles patients face affording medication, returning for follow-up visits or administering complicated treatment plan
- Misdiagnoses and related unnecessary expenses lead patients to believe providers do not understand the cost burden of medical care
- Ideology that patients must "pull themselves up by their bootstraps" doesn't address reality or the roadblocks patients face carrying out health plans

Demographics of Jackson

82% African American
16% Non-Hispanic White
1% Hispanic
1% Other

A specialized nursing team came to Jackson to train Constance in preparing her father’s medication. It involved a complex process of sterilizing equipment, mixing medications, ensuring no air bubbles contaminated it, preparing syringes and measuring dosages.

"I was nervous and scared. They were basically telling me if this wasn’t done correctly, he could die. I had to step it up. I had to pay attention. I had to be dedicated because I didn’t want to lose the one I love," she said.

Preparing the daily medication dosages took half an hour. Constance had already been caring for her infant son when her father’s issues emerged. Then her mother had a stroke, adding to her burden.

Throughout the process, Dr. Haynes patiently explained complex medical concerns and answered questions.

Baker still helps her father manage his disease, but after seven years of treatment he can now treat the illness with pills instead of the medicine that required such intricate preparation.

"The patients don’t care how much you know about the disease until they know how much you care."

—Dr. Demondes Haynes
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.

- Teach clinicians to ensure patients can afford medication when they prescribe it
- Develop a way for patients to renew established prescriptions cost effectively
- Ensure easily accessible information about doctors who accept Children's Health Insurance Program (CHIP) or low-income health insurance
- Educate clinicians to identify and understand barriers to access; treat everyone as deserving of care
- Raise awareness of all social resources to help secondary issues that develop as a result of health issues. Ex: Long-term stress management, help with other expenses
- Raise Awareness of signs of serious lung problems that necessitate specialist care

“They have to make those day-to-day decisions. Is it food or is it medicine? Is it keep the lights on or is it keeping the direct pay of the mortgage paid?” he said.

“COVID has not only shone a light and exposed underlying health conditions. It has exposed the underlying conditions of our nation” he said.

COMMUNITY ACTION

State Senator John Horhn sees two facets of Jackson, but they might as well be two different worlds. The city—and society—is divided into those who can afford health care and for whom accessing a doctor is as easy as calling to make an appointment and those for whom each step in a health journey is a struggle.

“They have to make those day-to-day decisions. Is it food or is it medicine? Is it keep the lights on or is it keeping the direct pay of the mortgage paid?” he said.

“That needs to change. Health care shouldn’t be a luxury or a profit-based decision,” Jackson Mayor Chockwe Lumumba said.

He perceives few differences between a society that lacks medical advances and one that has the ability to provide care but doesn’t. Making sure that Jackson has the resources to provide health care—and does so for everyone—requires a communitywide effort.

The COVID-19 pandemic created horrible situations for many people, but it also presents an incredible opportunity to solve problems that have existed and been ignored.

“COVID has not only shone a light and exposed underlying health conditions. It has exposed the underlying conditions of our nation” he said.
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 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, becoming a facilitator between clinicians and patients for the myriad of burdens that patients and families encounter from their initial diagnosis to their 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