INVESTIGATIONS

Oregon Hospitals Didn't Have Shortages. So Why Were Disabled People Denied Care?

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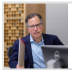
JOSEPH SHAPIRO

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Masks hang from an IV pole at a hospital.

Jenny Kane/AP

At the start of the coronavirus pandemic, a small group of disability rights advocates found itself in a race against time to save the life of a woman with an intellectual disability.

The woman was taken to the hospital with COVID-19. But the hospital, in a small Oregon town, denied the ventilator she needed. Instead, a doctor, citing her "low quality of life," wanted her to sign a legal form to allow the hospital to deny her care.

Out of that quiet fight in early spring, the advocates — staff at a disability rights legal group, a state lawmaker and a few others — discovered something disturbing: There were many cases in Oregon of health care being rationed to people with disabilities.

At the same moment, across the United States, disability groups and even a civil rights office of the U.S. government were raising a similar warning: that behind closed doors, people with disabilities, as well as elderly people, were in danger of being denied health care.

NPR was looking for cases, too, and heard about the woman in Pendleton while she was in the hospital.

There's no reason that these examples would occur more frequently in Oregon than in other states. But the fight for that anonymous woman with an intellectual disability peeled back the curtain on health care decision-making in Oregon in a way that did not happen in other states.

That activism led to change in Oregon — including anti-discrimination legislation and new statewide policies.

It was late March when the woman with an intellectual disability contracted COVID-19. She struggled to breathe.

INVESTIGATIONS

As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?

THE CORONAVIRUS CRISIS

One Man's COVID-19 Death Raises The Worst Fears Of Many People With Disabilities

In the hospital, a medical provider wrote do-not-resuscitate (DNR) and do-not-intubate orders for the woman. Those are medical instructions to health care providers to withhold potentially painful interventions, like a ventilator or CPR, if a patient stops breathing or the patient's heart stops. The woman was alone in the hospital and did not understand what the doctor and medical staff wanted her to agree to.

In addition, the hospital staff sent word to the woman's group home: Fill out DNRs in advance for your other residents, in case one of them comes to the hospital.

People who worked with the woman were angry that the doctor and the hospital seemed to be discounting the lives of people with disabilities.

Someone tracked down lawyers for help.

The lawyers work for Disability Rights Oregon (DRO), a federally funded legal group that protects the rights of people with disabilities. State Sen. Sara Gelser, who chairs Oregon's Senate Committee on Human Services, was notified too.

NPR knows some details of the case in Pendleton based on interviews with state officials, lawyers and others in Oregon, as well as from documents obtained through a public records request.

Because of privacy laws, those we spoke to could talk only generally of the case and the person involved. They couldn't confirm the gender of the person. NPR knows the person was a woman because of references in the state documents we obtained. Officials at DRO said they cannot confirm the place where the case happened. State documents show it was in Pendleton, a town with one small, 25-bed hospital.

The report from Pendleton alarmed staff at DRO. "We investigated and substantiated it," Jake Cornett, executive director of DRO, told NPR. A person with an intellectual disability was "being inappropriately influenced about life-sustaining treatment. And the physician in that case talked about the quote 'low quality of life' of a person with a disability." Cornett made the same points, briefly, in testimony to the state legislature.

"It would be one thing if these were isolated incidents," says Jake Cornett of Disability Rights Oregon, but care was being denied to people across the state and that "should raise the alarm bell."

Ramsey Cox

At the hospital, the intellectually disabled woman needed to be on a ventilator immediately.

Emily Cooper, the legal director at DRO, threatened to sue the hospital. The woman was moved to another hospital, where she was placed in the intensive care unit and on a ventilator.

Her condition was dire. There was fear, according to a letter that state Senator Gelser sent to the governor's office and state health officials, that the woman had been left "without appropriate and necessary care for two days" and that the time without a ventilator had put her life at risk.

The woman's advocates worried that she might die. But after several days in the new hospital, the woman recovered. She returned to her group home.

Still, even that success left Cooper worried.

"The threat of litigation and the threat of exposing the depth and the whiff of discrimination in our state, I think, was enough to get people to do the right thing," says Cooper. "But what that meant is you needed to have a lawyer call or you needed to have someone that had the gravitas to push for that."

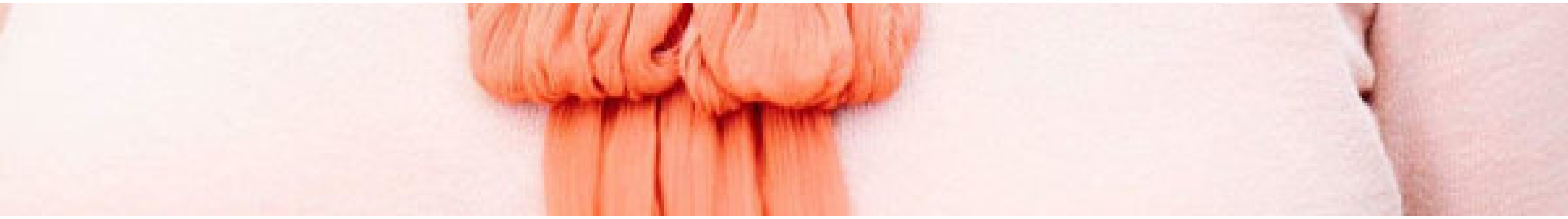
Most people with disabilities and their families don't have lawyers working for them. And DRO and state officials were getting more reports from around the state of health care being denied.

Gelser urged the governor and state officials to make it clear that doctors could not write blanket DNRs for patients with disabilities.

"I remain deeply concerned about the situation in Pendleton," Gelser wrote on April 10 in an email to state officials. "We only know about it because someone knew to call for help. If that call had not happened and DRO had not engaged, it is not hard to imagine the person would have died."

Gelser, in the email obtained by NPR in its records request, urged state officials to sanction the hospital. "The providers, as far as I can tell, have been given no clear signal that what they did was wrong and should not occur again," she wrote. "A strong, pointed statement about the rights of elderly and disabled people is desperately needed at this time."

The Oregon Health Authority "received a complaint in April 2020 related to patients' rights," a spokesperson told NPR. But it concluded "that we would not be able to investigate." The main allegation was against the doctor, and the health authority does not have "jurisdiction over individual health care providers."



When Emily Cooper at Disability Rights Oregon learned of the disabled woman who needed a ventilator but couldn't get one, she threatened the hospital with a lawsuit.

Kelly Robbins

It was up to the organization that accredits the hospital, the health authority concluded.

NPR checked with the Joint Commission, the accrediting body. A spokesperson said it had not received a complaint. But as a result of NPR's inquiry, the spokesperson said, it had opened a review of the incident.

"Nothing happened to that hospital. Nothing happened to that physician," Gelser told NPR. "The health authority confirmed that, in fact, that was a coerced do-not-intubate order, that they confirmed it happened ... but there was no sanction. So there was no remedy."

Adds Gelser: "This is immoral. We do not respond to disability discrimination in the way that we should."

CHI St. Anthony is the one hospital in Pendleton. In a statement to NPR, the hospital said: "For reasons of patient confidentiality, we are not able to comment on any specific situation or patient. We are committed to providing compassionate and high quality care to every patient, without regard to anyone's ability or disability. St. Anthony Hospital categorically denies any allegations to the contrary. We are unaware of any complaint to the Oregon Health Authority such as you have described."

NPR reached out to the disabled woman who survived COVID-19. But the woman, traumatized and confused by her time in the hospital, does not speak about it.

Federal laws, notably the Americans with Disabilities Act and the Affordable Care Act, prohibit health care discrimination — including denial of care — based solely on a person's disability.

The Office for Civil Rights at the U.S. Department of Health and Human Services explained the law in guidance at the start of the pandemic. When care is scarce, doctors are allowed to decide who gets it and who doesn't. They can decide who is most likely to do best with that treatment by making an "individualized assessment of the patient" based on objective medical evidence.

But doctors can't rule out people because they have a specific disability — for example, dementia or using portable ventilators every day to help themselves breathe. "Persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age," the civil rights office explained.

OCR issued those guidelines on March 28 after national and state disability groups raised alarm that states had issued rationing plans that allowed discrimination against elderly and disabled people. Oregon was one of 29 states that issued "crisis standards of care" guidelines to doctors and health care systems about how to allot scarce medical care in case of a crisis — like a terrorism event, a natural disaster or a pandemic. In early May, Disability Rights Oregon led a coalition of 21 state and national disability and civil rights groups and filed a complaint about Oregon's standards with OCR.

The near death in Pendleton spurred the advocates to watch for other cases. One state official, who handled complaints at residential facilities, wrote to Gelser in April that her office had received and investigated complaints of hospitals and physicians "inappropriately" asking people with disabilities to fill out a legal form to limit care, according to the documents obtained by NPR.

Gelser heard reports of disabled and elderly people who had symptoms of COVID-19, went to the hospital and were denied tests, treatment or even lifesaving care. "We had hospitals that were trying to immediately discharge people and saying that they needed to go home for palliative or comfort care, instead of actual treatment," she says.

There are additional cases in the public documents that NPR collected. In April, a health care system in Salem, Ore., sent an "urgent message" to area group homes for people with disabilities, telling them not to bring residents with symptoms of COVID-19 to the emergency room unless "they are so sick they require hospitalization," according to the letter.

That was alarming, Gelser says, because it "discouraged people from bringing in clients that needed care. It also indicated people would be discharged prematurely — and into group homes that didn't have the capacity to provide appropriate care."

A spokesperson for Salem Health said it had focused in early spring on being prepared to handle a large number of coronavirus cases. "During the unknowns of the spring surge, this meant preserving hospital capacity for those who truly required hospital-level care," the spokesperson said, adding that the system followed state and federal guidelines for best practices and has changed its policies as those standards have changed.

The state records that NPR obtained show other people with disabilities were denied coronavirus tests or treatment when they showed up at hospitals with symptoms.

Sarah Frazzini, the executive director of Benco, a nonprofit agency that provides housing and other services to people with disabilities, points to the story of one of her residents.

On April 2, the 64-year-old man was running a high fever, and staff at his group home worried that he'd contracted COVID-19. They took him to the emergency room at Good Samaritan Regional Medical Center in Corvallis.

The man has a significant intellectual disability. He doesn't speak words. He's quadriplegic. He can't swallow and is fed through a tube.

Medical staff in the emergency room refused to test him for the coronavirus. Frazzini told the story to NPR, as well as to state lawmakers in a June hearing. It would be a "waste of valuable PPE," or personal protective equipment, a member of the medical team said, angrily, in front of the man, according to Frazzini. At the time, there were shortages of PPE in Oregon and nationwide.

He was eventually tested after a staff worker for the agency that ran the man's group house insisted, Frazzini told NPR. The man was admitted to the hospital. It turned out he had pneumonia, not COVID-19.

When, after six days, he was discharged, Frazzini said in the hearing and to NPR, a physician in an online call made a recommendation: The group home should stop the man's care and nutrition and begin end-of-life hospice care. According to Frazzini, the doctor said the man, with his multiple disabilities, had a "low quality of life."

The staff member who worked for him was furious. The man was not dying. His condition was the same as before he'd entered the hospital. He'd lived this way for years. Frazzini says her staff felt the doctor had seen a man with significant disabilities and had made a judgment that his life didn't matter.

The man is in good health today. He lives in his group home and spends days in his favorite recliner, watching his favorite superhero movies and enjoying the brightly colored tropical fish in his large aquarium.

The man "lives a dignified and fulfilled life," Frazzini told lawmakers. "To have to fight so hard for the COVID test, to hear statements about giving the test being a 'waste of valuable PPE' and to have the physician recommend at discharge to end his life is absolutely appalling," she said at the hearing.

A spokesperson for Samaritan Health Services said that he could not comment on the care of a specific patient but that the hospital's policies have evolved since the spring based on changes in state recommendations.

In the documents obtained by NPR, there are other reports of people with intellectual disabilities being told to sign a do-not-resuscitate order as a condition before being admitted. At other hospitals, they were separated from their caregivers and pressured to sign a document they did not understand.

Or, as in Sarah McSweeney's case, her guardians felt pressured.

Before she went to the hospital, McSweeney loved it when staff at her group home took her to the shopping mall to get her hair done and to country music concerts. The 45-year-old woman had multiple disabilities. She was quadriplegic, so staff at her group home in Oregon City pushed her in her bright pink wheelchair. She couldn't swallow, so the direct service professionals — the caregivers at the group home — fed her through a gastrostomy tube that sent nutrition directly to her stomach. She couldn't speak words, but the people who worked for her could understand her by her sounds and facial expressions.

Sarah McSweeney had a big personality and loved going shopping with friends. But at the hospital, doctors questioned why she wanted full care.

Joshua Peyton

"And even though she had these medical issues, she was vivacious. She just lived her life," says Heidi Barnett, who worked with her. "She had a pretty full life. And you were blessed if you got to meet her."

NPR told McSweeney's story earlier this month.

Barnett works for the Arc Oregon in its guardianship program. She helped McSweeney make decisions about her life and health care. She helped McSweeney draft the legal document that went with her to the hospital: It said that she wanted full medical care.

But after McSweeney went to the hospital on April 21 with a high fever, doctors and social workers called Barnett — who wrote up detailed notes of these calls — and tried to get her to accept a do-not-resuscitate order for McSweeney.

Tests showed McSweeney did not have COVID-19. But in the hospital she had episodes of aspiration pneumonia, when fluid backed up into her lungs.

In the hospital, a doctor told Kimberly Conger, the nurse manager from Community Access Services, which ran the group house where McSweeney lived, that she needed to be on a ventilator. "We discussed the possibility of her being intubated and letting the lung rest, giving her time to heal and letting the antibiotics do their magic," says Conger.

But then the doctor questioned whether it was worth doing, citing McSweeney's "quality of life." Conger says she objected to that. "And he looked at me and goes: 'Oh, she can walk? And talk?' " she says the doctor asked, moving his fingers in the air in a walking motion.

Conger replied: "There's a lot of people who don't walk who have full quality of life."

McSweeney was not moved back to the ICU and was not put on a ventilator. She died on May 10 of severe sepsis because of aspiration pneumonia.

"We believe there was bias and discrimination in the care provided," Anna Keenan-Mudrick, executive director of Community Access Services, told Gelser's committee in June.

A spokeswoman for the hospital, Providence Willamette Falls Medical Center, says: "While we have conversations with patients, family and/or guardians about care options, we do not pressure or force anyone to sign a DNR order, and we are unaware of any evidence to the contrary."

"I just think she could have gone out better," says Barnett. "They owed her more respect than she got."

After McSweeney's death, Barnett says she dealt with a similar case with another client. A 77-year-old man with an intellectual disability contracted COVID-19 and went to another Oregon hospital for treatment. But she says a doctor there, acting unilaterally, reversed the man's legal order for full treatment.

When Barnett and the man's advocates objected, she says the doctor stood firm, saying the man — who is diabetic and intellectually disabled — was "too difficult to treat." Says Barnett: "It was absolutely flooring to me." The man survived and returned home.

One of the most common causes of poor care occurred when someone who had difficulty communicating or had dementia went to the hospital alone. Family and advocates were barred, for the most part, from visiting — even when the person depended on them to communicate.

One Oregon doctor, who asked to remain anonymous in order to speak freely, told NPR about a teenage girl with significant disabilities who was on a ventilator with COVID-19 in the ICU at his hospital.

She had difficulty speaking and, typically, relied on her mother to communicate for her. The hospital arranged a videoconference with the girl and her mother to talk about ongoing care. But when the young woman saw her mother's face on the computer screen, she sobbed uncontrollably. "It was heart wrenching," the doctor told NPR. Eventually, the mother was allowed to visit.

Oregon lawmaker Sara Gelser — here on the floor of the state Senate — introduced a bill to guarantee that people with disabilities get equal care in hospitals during the coronavirus pandemic.

Oregon state Sen. James Manning

In late June, Gelser wrote and co-sponsored an anti-discrimination bill: Senate Bill 1606. It bars doctors from forcing a do-not-resuscitate or do-not-intubate order on disabled or elderly patients, either as a condition of being admitted to the hospital or as a condition for treatment. It requires doctors to honor a person's medical orders for care.

It allows people with certain disabilities to have a family member or other support person with them during a hospital stay to help explain their medical choices.

That legislation passed the legislature, and Oregon Gov. Kate Brown signed it into law on July 7.

Gelser was surprised that one section of the bill turned out to be controversial. Language that said doctors and health care providers could not discriminate on the basis of disability was stripped from the bill. Health officials worried that the language was too vague and would interfere with individual decision-making.

The debate over denial of care to people with disabilities was a quiet one in Oregon. It was a conversation largely among advocates in the disability and aging communities, medical officials and state officials.

But it resulted in positive change.

- Officials in state health agencies played a role. The Oregon Association of Hospitals and Health Systems started trainings.

- In September, the Oregon Health Authority withdrew the disputed state crisis standards of care. Those are the rules that doctors and hospitals can apply to ration care when it gets scarce. The drafters had failed to adequately reach out to "communities of color, tribal communities, or people with disabilities," the authority said in a letter to Gelser, and as a result the guidelines "have the potential to perpetuate discrimination on the basis of race, age or disability."

Leann Johnson, the health authority's chief equity and inclusion officer, told NPR that the move reflected the agency's plan, announced at the start of 2020, to end health care disparities by 2030.

- In October, Gelser objected that people with intellectual disabilities who lived in group homes and their direct service professionals had been left off the state's priority list to get the COVID-19 vaccine. In November, the state amended its list and they were added. That made Oregon one of the first states — and likely the first, but there is no comprehensive comparison of every state's plan — in the country to prioritize group home residents.

Frazzini reports that the man who back in April had difficulty getting a coronavirus test ran a high fever again in October and returned to the hospital ER. This time he got tested quickly and respectfully.

Frazzini gives the hospital credit for changing. "They really listened," she says.

Frazzini was asked to join the hospital's ethics committee — her first meeting is scheduled for January — to give the hospital perspective about disability.

And on Dec. 8, Oregon announced new "crisis care principles" for health care providers, who were then facing a surge of new COVID-19 patients. Once again, there was fear of needing to ration scarce care. This time, the guidance from the Oregon Health Authority focused on the responsibility of doctors and hospitals to provide care in ways that did not discriminate against people on the basis of disability, race and other categories protected by civil rights law.

"Any approach to triaging care," the new guidance said, cannot "exclude" someone on the basis of an underlying medical condition or a disability. Dana Hargunani, the Oregon Health Authority's chief medical officer, told NPR that the agency is asking doctors and hospitals "to really consider the role that implicit bias has played."

When the Oregon Health Authority announced the new equity principles, officials highlighted the advocacy of DRO and Gelser and thanked them for helping to shape the new plan.

The changes in Oregon echoed the evolution of guidelines in other states. State and national disability groups had brought complaints to the Office for Civil Rights at the federal Department of Health and Human Services, the agency that enforces anti-discrimination laws in health care.

The Office for Civil Rights has announced its own settlements with several states to rewrite their crisis standards of care. Tennessee and Pennsylvania agreed to quit letting doctors use "quality of life" scores to determine who gets scarce care. Connecticut agreed to let family members into hospitals to help people with disabilities who have difficulty communicating. And Utah agreed to bar doctors from issuing blanket do-not-resuscitate orders.

There was one lingering question in all of these cases: Why was care rationed to people with disabilities at a time when Oregon's hospitals were not overcrowded, when there were no shortages of treatment?

In early April, Governor Brown announced that Oregon was sending 140 ventilators to hard-hit New York. "We are all in this together," she said.

So, if there was no shortage, why were McSweeney and the woman in Pendleton denied ventilators?

Gelser — who has an adult son with an intellectual disability — thinks she has an answer.

There has always been a bias against people with disabilities in the health care system, she says. It was largely hidden.

The coronavirus made it visible — and then the virus made it worse.

"COVID has put a giant magnifying glass on inequities in health care delivery" for people with disabilities, Gelser says. "For the first time, we see in a more pressing and public way how deadly that can be."

In the pandemic, doctors — worried about potential shortages for some — made decisions to deny care to others. "So before we even needed to triage," Gelser says, "medical systems were deciding on reserving resources for nondisabled people that the system valued more, in case they ran out of resources later."

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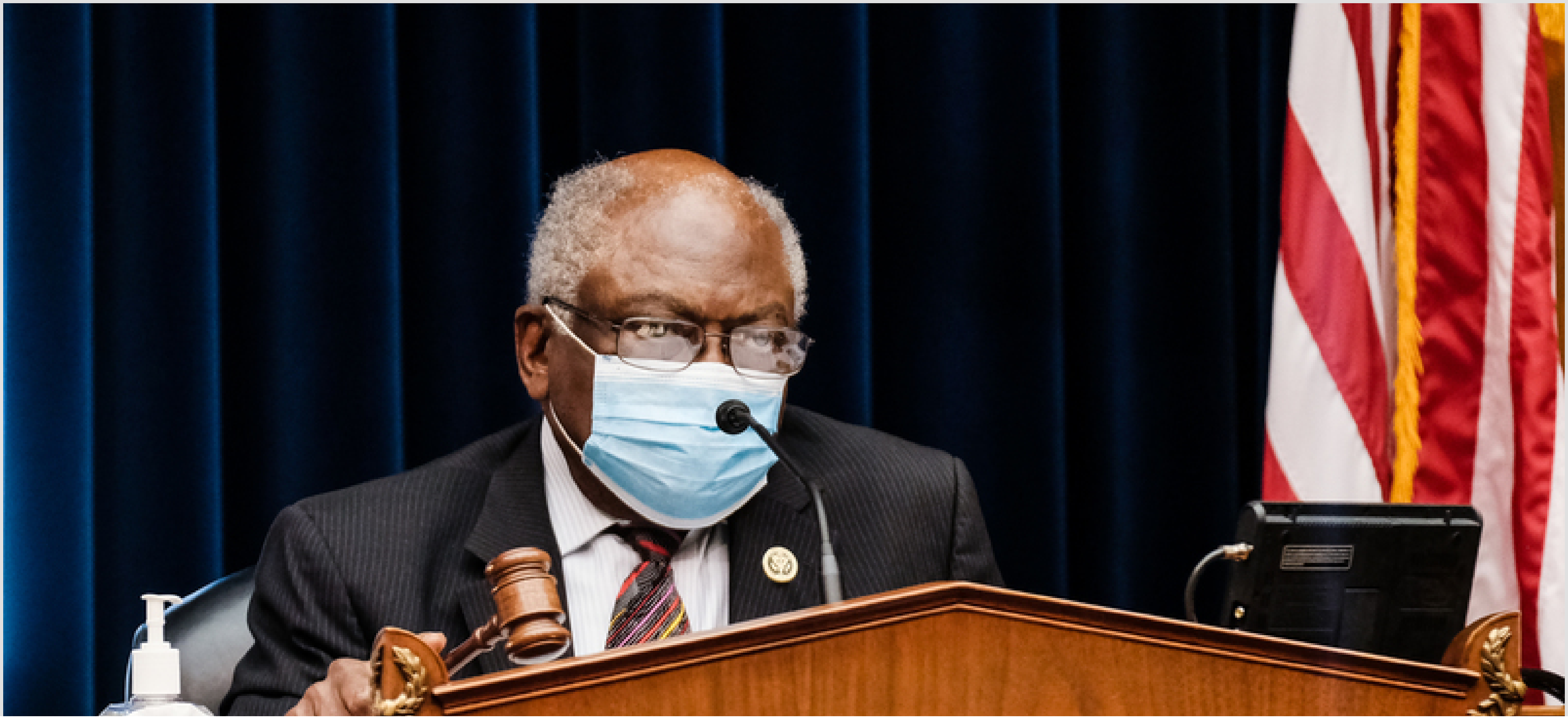

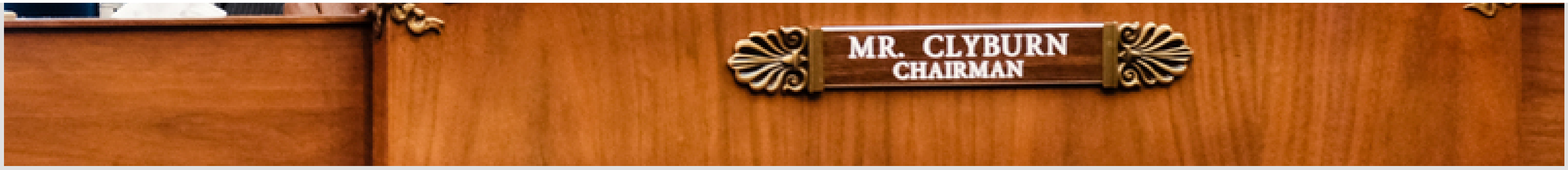

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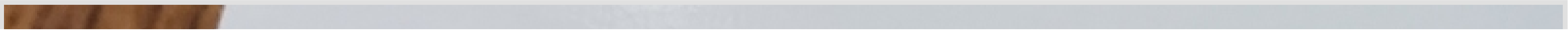

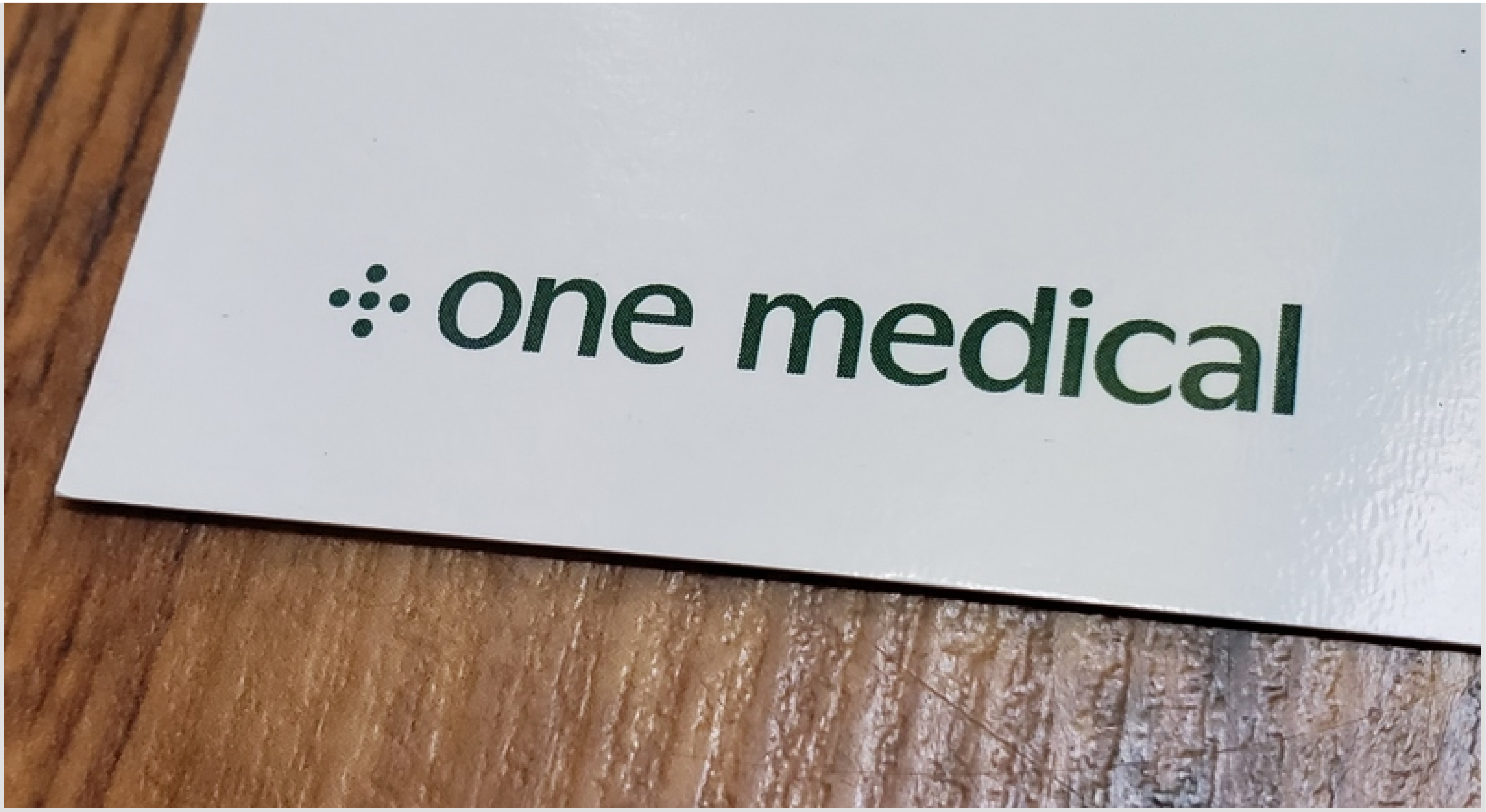

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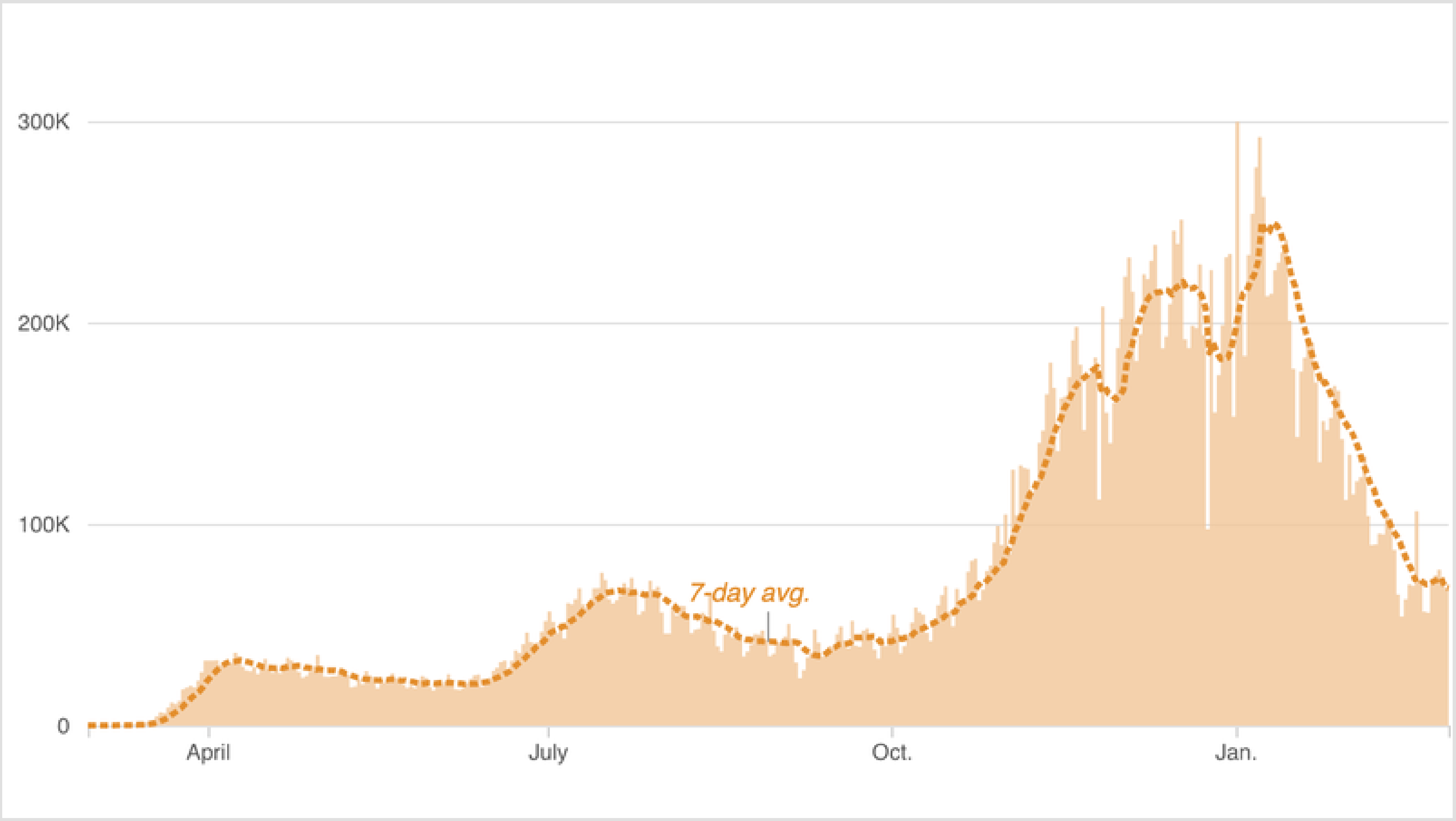

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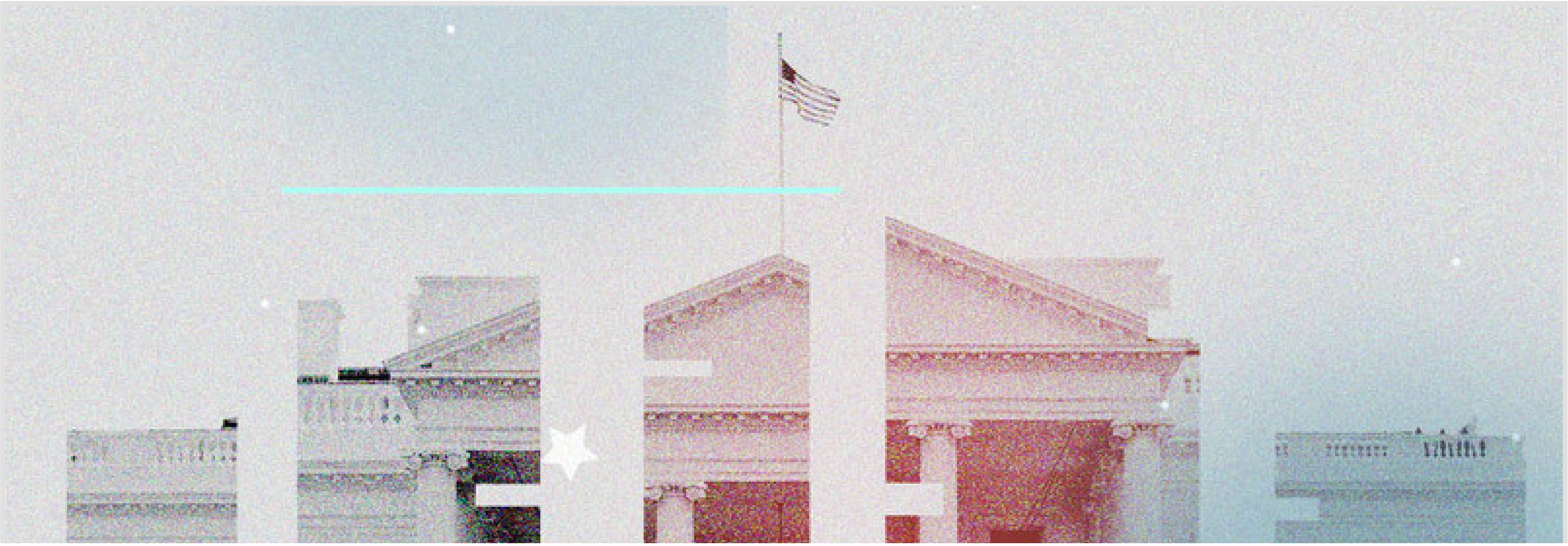

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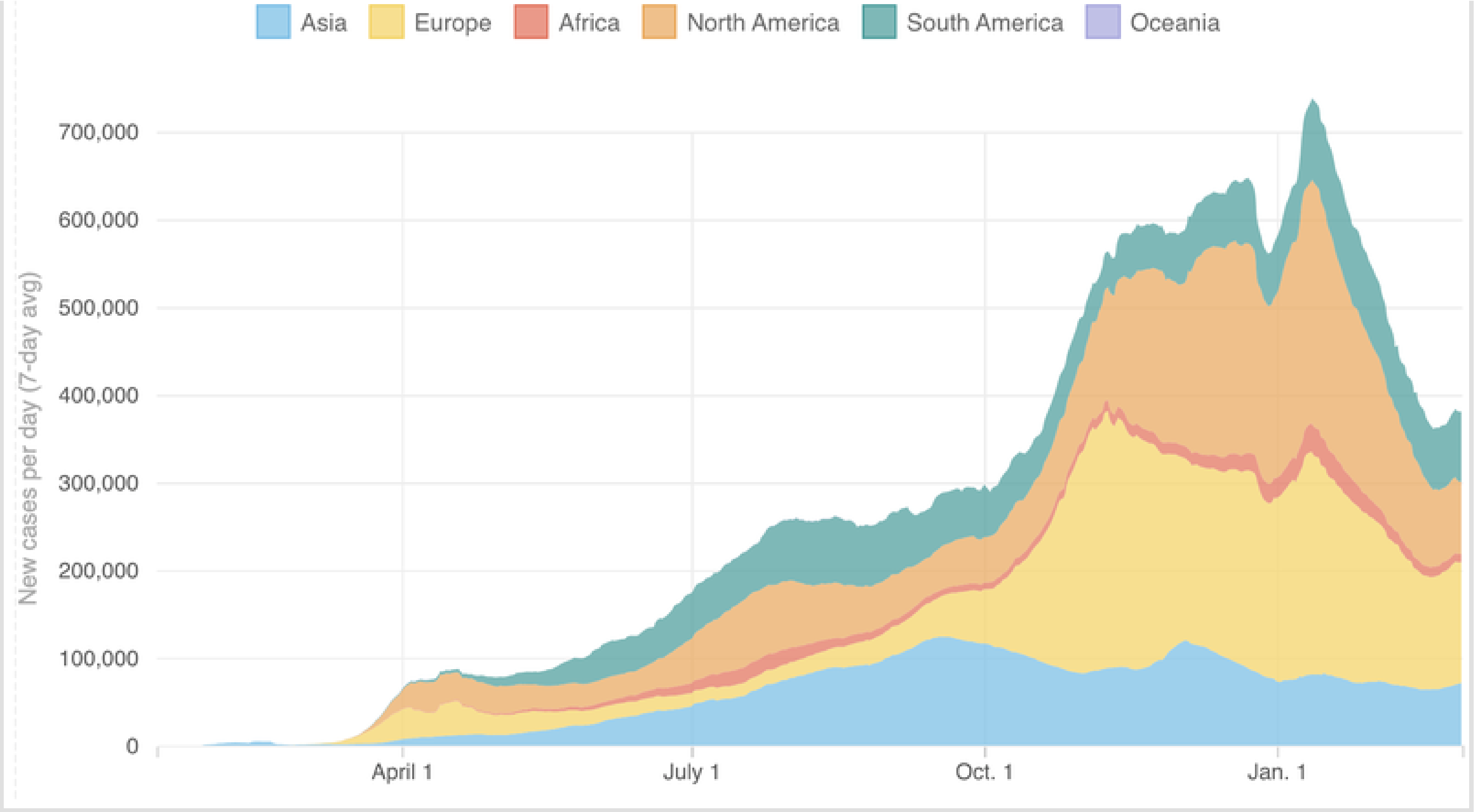

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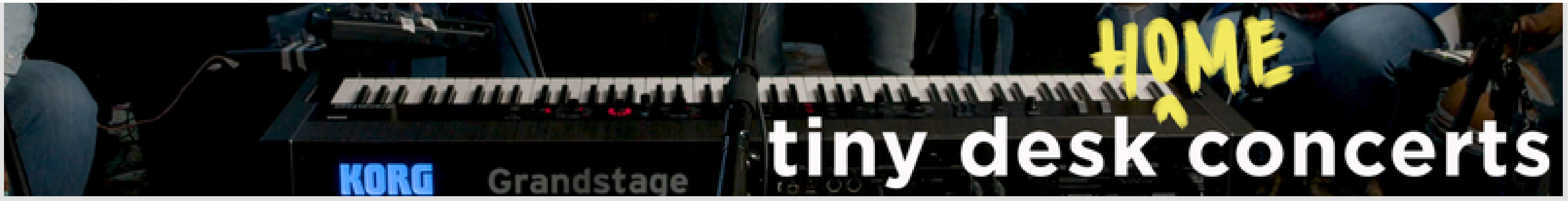

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