LEGISLATOR

OFFICIAL MAGAZINE OF THE NATIONAL BLACK CAUCUS OF STATE LEGISLATORS



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THE LEGISLATOR -**SUMMER 2023 -**

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TO OUR READERS:

This summer's online edition of *The Legislator* is informative, and, we hope, helpful to your work and life. As always, the topics and articles are specific to the interests of African Americans and highlight the work of policymakers, advocates, individuals, and companies.

Our articles cover a range of issues from gun reform, employment disability, healthcare, rare diseases, access to healthcare, mental health, and education. They include policy recommendations, successes, challenges, and legislative proposals.

Authors include Florida State Representative Daryl Campbell, who is working on legislation around sickle cell, which disproportionately affects African Americans.

NBA Hall of Famer, Alonzo Mourning, shares his lifelong journey with focal segmental glomerulosclerosis (FSGS), a rare and potentially fatal disease that scars the filters in the kidney.

Also included is a piece on the cross section of the civil rights movement and disability movement, penned by the Department of Labor's Assistant Secretary of Labor for Disability Employment Policy, Taryn Williams.

Wishing you a great summer!

Best,

The Editorial Team

FROM THE PRESIDENT



DEAR READER,
WELCOME TO THE SUMMER EDITION OF THE LEGISLATOR,
THE OFFICIAL MAGAZINE OF THE NATIONAL BLACK
CAUCUS OF STATE LEGISLATORS (NBCSL).

For 47 years, the NBCSL has been consistent in voicing the concerns of our constituents. Today, our voices are needed more than ever. This year, as of this writing, there have been 263 mass shootings. By the time of our publication, the stark reality is that number will have increased. Shootings at a Kentucky bank and at a 16-year-old's birthday party in my home state, Alabama, shine a light on a growing problem in America.

As an educator, the safety of our children and educators in our schools is of utmost importance to me. The Nashville, Tennessee school shooting, where three children and three adults were killed, was a devastation to us all, demonstrating the severity of the issue and the challenges many of us face in our state legislatures.

Our Executive Committee and Regional Chairs recognize that, by working together, we can address and make meaningful change possible. Representatives Justin J. Pearson and Justin Jones recently spoke out on the need for reforming their state's gun laws. In April, to show our support, some of our Executive Committee and members joined the Tennessee Legislative Black Caucus in Nashville. The NBCSL stands with them, sounding the alarm for the need to pass meaningful policy reforms in our state legislatures.

I would be remiss if I didn't say that mass shootings are not the only issue. The shooting of 16-year-old, Ralph Yarl, who went to the wrong address to pick up his twin brother reminds us that racism is still very alive today. And, the murder of 20-yearold Kaylin Gillis, shot in a friend's car after turning into the wrong driveway, pinpoints a simple fact: America has a gun epidemic. It is a health crisis affecting families, hospitals, and law enforcement.

In 1977, the NBCSL founders recognized their voices were suppressed in their state legislatures and on a national scale. Collectively, they realized that in their state legislatures they had small numbers but by uniting nationally, their voices were amplified. This way forward is still in our best interest.

As President, this is my goal and focus. It is one of many reasons why our magazine is important. *The Legislator* allows us to keep our members and member companies, past and present, as well as others informed of the important work and tasks in front of us.

Thank you to all our members and corporate partners who highlight and inform us daily of policy issues, trends, challenges and successes.

Best,

Representative Laura Hall (AL)

President

The National Black Caucus of State Legislators (NBCSL)



FROM THE CHIEF EXECUTIVE OFFICER



GREETINGS,

IN 1977, A GROUP OF 18 BLACK STATE LEGISLATORS ATTENDED THE ANNUAL MEETING OF THE NATIONAL CONFERENCE OF STATE LEGISLATURES (NCSL).

From that meeting, they gathered that NCSL was still "racially exclusive" of issues impacting their constituents. And so, they held their own national conference in Nashville, Tennessee, which we know today as the first conference of the National Black Caucus of State Legislators (NBCSL).

Since then, legislators have continued to increase in number, meeting annually to collaborate and share best practices. Recognizing the challenges in their respective state chambers, both politically and culturally, over the years they have come to understand the power of working together.

Today, under the leadership of President Laura Hall (AL), our members recognize, like those who served before them, the power of working together; a power that works for us all. We are experiencing an increased political and cultural divide today, unlike anything this country has seen before. Police reform, social justice, voting rights, women's rights, and gun reform are just a few issues facing America today. Tackling these issues and championing the necessary reforms is at the forefront of our agenda.

Our members stand ready and prepared. We have a generation of leaders carrying forward the legacy of past members, recognizing, like they did, the strength and power of working together.

"Together. Everyone. Achieves. More."

Paula & Hoisington

Sincerely,

Paula J. Hoisington

Chief Executive Officer

The National Black Caucus of State Legislators (NBCSL)

NBCSL HIGHLIGHTS: LEGISLATORS ON THE MOVE



Legislators with guest speaker, Actress Dr. Tommie "Tonea" Stewart at The NBCSL Regional Summit in Selma, Alabama during Selma Jubilee Weekend 2023.



Legislators attending White House Christmas Party.



President Laura Hall (AL), Ambassador-Elect Calvin Smyre, and President Emeritus Billy Mitchell (GA) packing backpacks with school supplies for Selma area children.



Legislators participate in Linking Arms for a Change along with Voice of a Safer Tennessee in response to Covenant School Shooting in Nashville, Tennessee.

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Legislators at community service event in Selma, Alabama.



Legislators with U.S. House of Representative Terri Sewell (AL-07).



President Laura Hall (AL) speaking with Selma Mayor James Perkins, Jr.



Legislators with Selma Mayor James Perkins, Jr.



Representative Toni Rose (TX) also packing backpacks.



Representative Prince Chestnut (AL), Representative Anthony Daniels (AL), President Laura Hall (AL), Senator Merika Coleman (AL), and Representative Penni McClammy (AL).



Senator Raumesh Akbari (TN), Representative Toni Rose (TX), and Representative Cherrish Pryor (IN) at Selma City Hall.

HISTORIC FIRSTS FROM THE NBCSL MEMBERS

THE NBCSL/AFRICAN AMERICAN STATE LEGISLATOR HISTORIC FIRSTS



Indiana Representative William (Bill) A. Crawford (January 28, 1936–September 25, 2015) served forty years in the Indiana House of Representatives from 1972 in 2002. He became the first African American lawmaker to serve as chairman of Ways and Means and played a significant role in establishing the Indiana Legislative Black Caucus and the NBCSL. Crawford helped create the Indiana Black Expo. Beginning in the late 1970's, he played a key role in shaping

Indianapolis' reputation as a sports destination on the "city committee", which worked to attract opportunities to spur the city's growth as a sports destination. Crawford was the only African American on the committee whose membership included many of the city's elite.



Speaker Adrienne A. Jones – Speaker of the Maryland House of Delegates, first African American and first woman to serve in that position in Maryland.

Member of Maryland House of Delegates (1997–Present)



Speaker Joanna McClinton – Speaker of the Pennsylvania House of Representatives since February 28, 2023. The first woman to serve as Speaker. Member of the

Pennsylvania House of Representatives (2015–Present).



Senate President Bobby Joe Champion is Minnesota's first African American Senate President. He worked as an assistant Minnesota attorney general and as an attorney for a legal rights center. Champion was elected to the House in 2008, and to the Senate in 2012. In 2022, he was elected Senate President. He has also worked with Flyte Tyme Productions and was co-founder and director of the Grammy nominated Excelsior Choir. He was executive director of the

Midwest chapter of the National Association of Minority Contractors and program director for Social Spaces with Stairstep Initiative.

FIRST AFRICAN AMERICANS IN THEIR RESPECTIVE STATE LEGISLATURES AND OR CHAMBERS



Juanita W. Goggins (May 11, 1934–February 20, 2010) was the first African American woman to serve in the South Carolina House of Representatives. Motivated by her interest in education, Goggins became active in the civil rights movement and politics. Rock Hill, SC was the site of civil rights demonstrations in the 1960s to end segregation in public facilities. In 1972, she was elected as a delegate to the Democratic National Convention, where she was the first

black woman to represent the state of South Carolina. Defeating a white man, Goggins was elected in 1974 to represent Rock Hill in the state House of Representatives and re-elected to serve a total of three terms. Among her accomplishments as legislator were securing funding for sickle-cell anemia testing in county health departments; the disease affects primarily African Americans, whose health programs had been underfunded during the decades of segregation and disenfranchisement.



Dorothy Lavinia Brown (January 7, 1919–June 13, 2004) also known as "Dr. D.", was an African American surgeon, legislator, and teacher. She was the first female surgeon of African American ancestry from the Southeastern United States. In 1966, she became the first African American female to be elected to the Tennessee General Assembly (known also as the Tennessee State Legislature), a position that she held for two years. She worked tirelessly to have

abortions legalized in cases of rape or incest, and in expanding the already existing legally permitted abortions in cases when the "mother's life was in danger". During her career as a politician, Brown also became involved in the passing of the Negro History Act, which required public schools in Tennessee to "conduct special programs during Negro History Week to recognize accomplishments made by African Americans".



Sampson W. Keeble (May 18, 1833–June 19, 1887) Born into slavery, Keeble became a barber and was also a Davidson County magistrate from 1877-1882. A businessman

and politician in Tennessee during the Reconstruction era, in 1872, he was the first African American elected to the Tennessee House of Representatives, serving from 1873 to 1875 representing Davidson County.



Charniele LeRhonda Herring
has served in the Virginia
House of Delegates since
2009. She has been the House
Democratic Caucus Chair
since 2015 and in December

2012, she was the first African American to be elected chair of the Democratic Party of Virginia. In 2020, she was elected to be the Majority Leader of the Virginia House of Delegates, making her the first woman and the first African American to hold the position.

LEGISLATIVE CONFERENCE RECAP

Last year, the NBCSL's Annual Conference was historic. We convened several sessions with the Quad Caucus, made up of The National Hispanic Caucus of State Legislators (NHCSL), The National Caucus of Native American State Legislators (NCNASL), and The National Asian Pacific Islander Caucus of State Legislators (NAPACSL).

We also had a dynamic array of speakers and policy sessions that focused on issues concerning our collective communities. This year, we are excited to be meeting in the city that hosted our inaugural conference in 1977!

Here is a glimpse into some of last year's conference in Las Vegas. We invite you to be a part of our national conference this year in Nashville, Tennessee!























NBCSL, "the Voice for the States" understands the importance of partnering with other legislative, civil, community, and corporate organizations to leverage combined power for greater impact to move forward with legislation for change.































- Participate in educational sessions on a range of policy issues.
- Voice the educational, political, economic, and social impact your company/ organization can offer to policymakers and their constituents.
- Hear powerful speakers and distinctive leaders of the African American community.
- Meet, network, exchange ideas, and forge new bonds with legislators, community and corporate partners.

REGISTRATION INFORMATION

EARLY BIRD BEGINS: AUG. 31 **ENDS: SEPT. 25**

For more information call 202-624-5457 or for the latest conference updates, visit us at www.nbcsl.org



National Black Caucus of State Legislators (NBCSL) is the nation's premier organization exclusively representing and serving the interests of African-American state legislators. With more than 700 members collectively representing over 60 million Americans, NBCSL serves as a national network, advocate and catalyst for public policy innovation, information exchange, and joint action on critical issues.



By Carl V. Hill, Ph.D., MPH Alzheimer's Association Chief Diversity, Equity and Inclusion Officer



It's an exciting time for the Alzheimer's and dementia community. The Food and Drug Administration (FDA) has approved two Alzheimer's treatments, and a pipeline of potential new treatments offer hope for those impacted by this devastating disease. As new treatments are approved, early detection and diagnosis are even more critical so individuals receive the most benefit at the earliest point possible. Now more than ever before, we must focus on health equity by increasing early detection and diagnosis of dementia in disproportionately affected and underserved communities and ensuring that FDA-approved Alzheimer's treatments are effective, accessible, and affordable for all people.

Currently, there are more than 6 million Americans living with Alzheimer's. By 2050, this number is

expected to rise to nearly 13 million. Alzheimer's disproportionately affects underserved and underrepresented populations in the United States, with older Black Americans about twice as likely to have Alzheimer's or other dementia as older White Americans. In fact, among Black Americans ages 70 and older, 21% percent are living with Alzheimer's. Despite the disproportionate impact, these populations are less likely to be diagnosed, recruited to participate in research, or have access to care and support services. This must change.

State lawmakers are on the front lines of the Alzheimer's public health crisis. By advancing policies that improve risk reduction, early detection and diagnosis, and support a coordinated statewide response to Alzheimer's and other dementia, states throughout the nation can address these challenges and advance health equity.

An early and accurate diagnosis of Alzheimer's can improve access to care and treatment, enhance quality of life and reduce the financial impact of the disease. By expanding efforts to educate

health care providers and the public about the importance of early detection and diagnosis, state public health departments can improve access to and increase awareness of available resources. States can also increase access to resources in diverse and underserved communities by working together with community partners. These efforts will not only increase risk reduction, early detection and diagnosis, but will also reduce the stigma of Alzheimer's and other dementia in these communities.

An example of a collaboration to increase early detection and diagnosis in underserved communities, Gdavis Productions and Films, LLC and the Alzheimer's Association are working together to bring the production of *Unforgettable* to communities across the nation. *Unforgettable* is a dynamic and emotional stage play that showcases the effects of caring for a loved one with Alzheimer's. The play sheds light on the importance of early detection, recognizing the early warning signs of Alzheimer's and other dementia, and highlighting the need for more racial/ethnic representative recruitment and participation in clinical trials.

As Alzheimer's treatments receive FDA approval and other treatments are being developed, we must ensure they are safe and effective for all populations. Currently, there is a lack of adequate representation in Alzheimer's clinical trials. The underrepresentation of these populations not only hinders the ability of researchers to understand health disparities, it also restricts their knowledge of how an approved therapy or diagnostic may affect the populations most likely to need the treatment.

The Alzheimer's Association is working with policymakers at the federal level to advance equity in access to clinical trials through legislation like the bipartisan Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act, key provisions of which were enacted into law in December 2022. The ENACT Act is working to increase education and outreach to underserved and underrepresented

communities, encourage diversity of clinical trial staff, and make it easier for underrepresented groups to participate in research.

New and better treatments are urgently needed, but we are seeing progress. There are now two FDA-approved treatments (aducanumab and lecanemab) that treat one of the underlying causes of Alzheimer's. Despite this, the Center for Medicare & Medicaid Services (CMS) is blocking equitable access to these Alzheimer's treatments. Additional clinical trials are underway and offer the hope of additional treatments.

State lawmakers in Georgia recently increased funding for the Georgia Memory Net program from \$4 million to more than \$7 million annually, to increase access to early diagnosis and treatment of Alzheimer's disease and other dementias. Illinois enacted comprehensive legislation to ensure clinicians receive adequate education in the early detection and diagnosis of Alzheimer's.

While we have much more yet to accomplish, we remain deeply committed to ensuring that no one is left behind, especially communities most affected by Alzheimer's and dementia. We look forward to working closely with state lawmakers from across the nation to take action in the fight against Alzheimer's and other dementia and advance health equity in our communities.

Carl V. Hill, Ph.D., MPH, is the Chief Diversity, Equity and Inclusion Officer for the Alzheimer's Association, overseeing strategic initiatives to strengthen the Association's outreach to all populations, and providing communities with resources and support to address the Alzheimer's crisis.

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By Tammy ThiemanDirector of Career Development
Programs, Amazon



Over the past three years, the global workforce has changed drastically. The pandemic caused widespread job loss and furloughs for many in the workforce. The unemployment rate for Black Americans, particularly, soared to 16.8 percent according to the **U.S. Department of Labor**—notably higher than the overall unemployment rate that peaked at 14.7 percent during the height of COVID-19. As we are now in the midst of a post-pandemic economy, companies around the globe have to reimagine workforce needs and labor demand—not only to keep pace with fast-changing technology shifts, but to also support an evolving workforce whose needs and career aspirations may not look the same as they did in 2020.

Despite varying levels of economic turmoil, one fact remains true: the more skills a person has developed, the higher their earning potential and the less likely they are to experience unemployment. The U.S. Bureau of Labor

Statistics finds that there is a 6.3 percent unemployment rate for those with less than a high school diploma and nearly 2 percent unemployment for those who hold a Bachelor's degree or higher. Additionally, many employees believe that developing their skills and climbing the career ladder can also lead to better worklife balance and a sense of purpose, according to a **recent study** by Workplace Intelligence in partnership with Amazon.

Simply put, upskilling is critical to remaining competitive in an evolving economy and finding satisfaction in the workplace. We should all find opportunities to learn new skills, and perhaps even identify new passions, to continue to learn, grow, and re-invent our careers.

Companies like Amazon are taking action. We recently launched our <u>Upskilling 2025 pledge</u>: a \$1.2 billion commitment to provide 300,000 employees with access to education and skills training programs—including prepaid tuition for college and certificate programs for hourly employees through our largest skills training program, Career Choice. Since launching the program, Career Choice has seen more than 130,000 employees participate at over 300

UP SKILLING IN AN UNCERTAIN ECONOMY: HOW SKILLS TRAINING CAN HELP FUTURE-PROOF THE WORKFORCE

education providers across the U.S., several of which are historically black colleges and universities (HBCUs). Looking at job growth over the next decade, the U.S. Bureau of Labor Statistics anticipates that some of the fastest growing job areas are increasingly in more skilled areas, including software developers and statisticians. Programs like Career Choice are creating pathways to careers in areas that will continue growing for years to come, enabling employees to ideally move into higher paying, indemand jobs at Amazon or elsewhere.

In addition to helping employees future-proof their careers, upskilling programs have significant implications for employers as well. **Data** shows that 88 percent of employees are motivated to improve their skills and 83 percent say it's among their top priorities. Whether employees are looking to move upward, leverage transferable skills, or build a career in an entirely new industry, companies should commit to providing growth opportunities that will equip employees to succeed within the organization or elsewhere.

Amazon is proud to lean in on this effort and we applaud our peers, large and small, who are also doing their part to upskill working adults. For those who are considering expanding skills training opportunities for their workforce, I hope that these insights inspire you or your organization to take action.

I'll close with a final rallying cry and one of Amazon's leadership principles. Always learn and be curious.

Tammy Thieman is the Director of Career Development at Amazon. During her sixyear tenure at Amazon, Tammy has focused on upskilling initiatives including launching Amazon's first Department of Labor registered Apprenticeship program which builds technical skills for Amazon Web Services (AWS), and initiatives to support veteran hiring in tech. She currently leads Career Choice, which is just one of our ten upskilling programs under our the Upskilling 2025 pledge.

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CONFRONTING BIRMINGHAM'S PAST BY

INVESTING

IN OUR FUTURE

By Wardine Alexander

President, Birmingham City Council, Regional Director for the National Black Caucus of Local Elected Officials



Birmingham, Alabama has changed a lot in my lifetime, not through the efforts of one person or group, but rather through an innumerable amount of seemingly small steps taken by the people who live here.

THE LEGISLATOR — SUMMER 2023

That march toward progress is made very evident here at City Hall, where I am writing this now, down the hall from where Bull Connor once launched his campaign of oppression against people who looked like me. Nearly 60 years later, our local government is truly reflective of the people who call the Magic City home and who have elected us to be their representatives.

Having said that, over the years we've made a concerted effort to continue to invest in our young people and provide them with opportunities and resources they need to continue building on the progress our city has made in recent decades.

Creating workforce development opportunities is crucial for our communities because it can help break the cycle of poverty and provide pathways to economic mobility. Time has shown us that dismantling systemic mechanisms of prejudice and inequality takes a collective effort, and cannot be accomplished overnight.

The Birmingham Promise Program is a workforce development and education initiative launched in 2019 by the City of Birmingham. The program aims to provide eligible high school graduates with access to tuition-free education and career training opportunities in the city, with the goal of preparing them for the workforce and increasing economic mobility. It has been, by all accounts, a tremendous success.

This initiative is funded through a public-private partnership, with the City of Birmingham contributing \$10 million in funds from the city's general fund over five years, and local businesses and philanthropic organizations contributing additional funds to support the program.

It fills me with joy to know that a student from my alma mater, Wenonah High School, was one of the first recipients of this program in 2019. She went on to graduate from Alabama State University a year early as Summa Cum Laude. She's now returned to the community to begin her professional career. This is just one real-world example of how these kinds of investments can pay dividends for generations to come.

An initiative that I've taken great pride in being a part of recently is helping to create a workforce development pipeline between Lawson State Community College (LSCC) and Buffalo Rock, a company that is now providing specialized training to fill jobs in my district. I was lucky enough to be selected as one of the 13 fellows with the organization E Pluribus Unum, and was awarded a \$75,000 grant to address racial inequalities in my community.

That grant funded the program and partnership between LSCC and Buffalo Rock. Over the last couple of years, we have felt the impact of this program as it has helped strengthen our local workforce by providing people with the tools they need to fill positions with one of Birmingham's oldest companies.

Lastly, I've been very encouraged by the work being done with the leadership of Birmingham City Schools and the Birmingham Business Alliance to connect students with internships, workforce training and job opportunities. Fostering these kinds of public-private partnerships is crucial for Birmingham's continued success.

I believe that the measurement of success in any society should be "are we leaving a better future for our children?" Birmingham is no stranger to the struggle for equality and the ways in which systemic injustice still impacts our communities. However, instead of trying to run from this history, we've faced those challenges head on so that we can show the rest of the world what can be accomplished when citizens, elected officials, and the private sector come together with a shared vision for the future.

Councilor Alexander is the Chair of the Birmingham City Council's Utilities/ Technology Committee, a member of the Administration Committee, and the Budget and Finance Committee. She works to improve public safety, economic opportunity, and the quality of life for all residents within District 7 by way of workforce development and community revitalization programs.



By Joseph M. Grant, Ph.D.



It is no accident that constitutions of every American state or political subdivision recognize their Legislative branch as the 'first among equals' of the three branches of government. The legislative branch is awarded the authority by the state, county, city or town constitution, or charter. The responsibility of the legislative branch is to set the parameters within which their co-equal branches of government will operate.

While the research on federal legislators and their efforts on behalf of Black citizens is important, "the states are laboratories of democracy" and provide greater opportunities for interaction, creativity and influence. King-Meadows says it best in his book Devolution and Black State Legislators: The type of representation a constituent receives is determined by the constituent base. "Given that there are nearly 600 Black state legislators nationwide and formal caucuses in 28 states. a preoccupation with the effectiveness of the relatively small Congressional Black Caucus (CBC) therefore seems inadequate at best and misfocused at worst." Written in 2006, King-Meadows' book, if updated, would show almost 800 Black state legislators currently serving.

Equally important is the fact that Black state legislators have been largely absent from the

public policy development arena. It was almost a century after Reconstruction that Black state legislators re-emerged in the public policy making chambers of states, counties, cities, and towns. Their absence was not voluntary: Blacks and women were prevented from service due to their inability to get elected to such posts. Of course this changed dramatically for Blacks after the passage of the Voting Rights Act of 1965.

Today, The NBCSL pauses to acknowledge and congratulate Black state legislators who hold positions of leadership in their respective legislatures across the country. With rare exception, the individual legislator rose to the position of leadership through the vote of their legislative colleague.

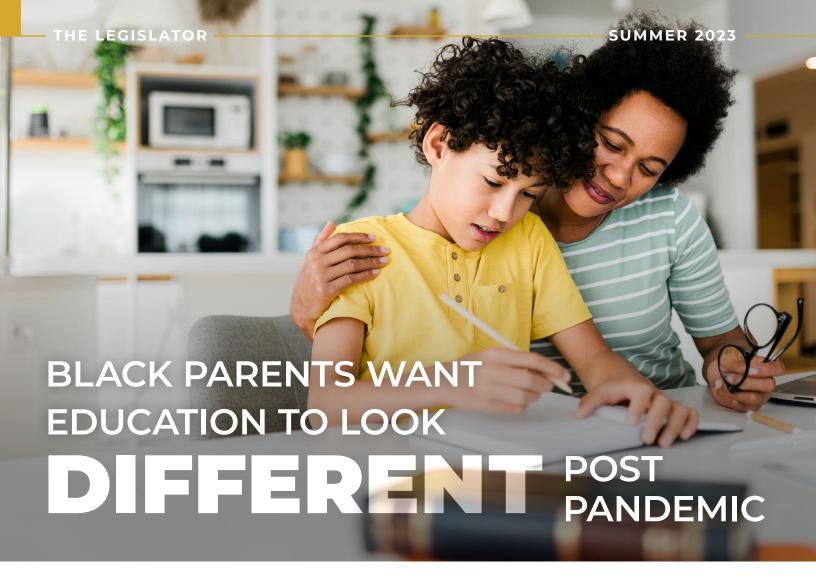
This vote of support is a testament to the Black state legislative leaders' knowledge of the legislative process, their ability to work across the political aisle, and to navigate the political minefields that are often present in developing sound public policy. From the Senate to the House, Black state legislators now occupy positions of leadership that give them the clout and the opportunities to influence public policy in ways that recognize the needs of communities of color in their respective state and individual legislative district.

Dr. Joseph M. Grant is the Chief Operating Officer at The National Black Caucus of State Legislators.



Across the country, from small towns to big cities and across racial differences, we are coming together to care for each other, to organize together and to set a vision of the future that includes all of us—no exceptions.

For more information visit NEA EdJustice at neaedjustice.org



By Emory Edwards and Robert C. Enlow EdChoice





The Covid-19 pandemic may be fading into memory for some, but when it comes to post-pandemic learning, parents of Black students are saying, "not so fast."

The message comes via a nationally representative survey of Black parents conducted earlier this year by EdChoice, in partnership with Morning Consult. In it, only a quarter of respondents say education should return to the way it was pre-2020. Parents cite the heightened attention on mental health, the shift toward hybrid and remote learning, and the increased use of technology as some of the positive changes made that should continue.

Importantly, Black parents want more choices and control over their students' academic futures.

"From the pandemic, we've learned how powerful it is to actually be in a space to have a choice," Jay Artis-Wright, executive director of The Freedom Coalition for Charter Schools, said recently during a panel discussion about the findings at SXSWEDU. "A lot of what was revealed about the work happening in our schools is that our students weren't being taught what we thought they were being taught. And now at home, we have more resources...Why would (we) ever send them back to the environment that wasn't good for them in the first place?"

More than two-thirds of Black parents say remote learning during the pandemic led them to be more involved in their child's education, and for many, it caused them to reevaluate what learning should entail. More than three-infour respondents support educational choice

policies—including education savings accounts, vouchers, charter schools, and open enrollment—when provided a definition.

To better understand the unique experiences of Black students and inform the national survey, EdChoice partnered with Phoenix Lifestyle Marketing Group to conduct three in-person focus groups with Black parents, educators and advocates—including the National Black Caucus State Legislators Chief Executive Officer Paula Hoisington.

Constance Lindsay, Ph.D., an assistant professor at University of North Carolina at Chapel Hill, commented about the survey saying that solutions must be informed by the lived experiences of diverse communities.

"What I think is so cool about this particular study is that it really is elevating that Black parent voice which is usually missing in these conversations," she said.

The conversations revealed parents seek a more holistic education for their children that is both academically rigorous and prepares students for life.

"This survey confirms what so many of us believe as parents, policy makers and educators, that black parents want our children to attend schools that are emotionally and physically safe, offer a well-rounded education where our children are developed into critical thinkers, and a place where they feel welcomed," Alisha Thomas Searcy, former state legislator and education systems leader, said of the findings.

Parents and educators say students are not currently receiving sufficient development when it comes to life skills and that schools should integrate such instruction into their curriculum. They want to see children become critical thinkers, inquisitive, and capable of challenging ideas.

"Take the village approach," one educator said, "Everyone in the child's life has the same vision, speaking positively and building up the child. We can't forget that parents are educators too."

Like parents who participated in the national survey, focus group participants favor school choice policies, especially homeschooling.

"(The pandemic) pushed me to encourage my kids that they have autonomy over their education and what they need," one parent shared, "Now I'm teaching them how to advocate for themselves and question with respect. I was always involved but it changed how I engaged with my kids. My kids now know they can come to me as their mom and say something. They take education more seriously now. Both they and I are more engaged."

Parents want to learn more about microschools, which they describe as "mysterious." Meanwhile, educators report switching to microschools, where they have the autonomy to teach what they know students need to learn, and experience fewer discipline issues because children are safe and supported.

Like parents and educators, education advocates envision a system that instills a love of learning in students and prepares them to be lifelong learners.

"It is also clear that regardless of socioeconomic status, black parents know the 'what' when it comes to what children deserve," Thomas Searcy added, "Now it is time for us to ensure they can choose the 'where'. Black parents know that having options is the key to obtaining the things they want for their children. It's up to us as advocates and policy makers to create the environment for them to have those choices."

EdChoice is a 501(c)(3) nonprofit, nonpartisan organization working to advance educational freedom and choice for all students as a pathway to successful lives and a stronger society. Emory Edwards is Vice President of Outreach there, and Robert C. Enlow is President and CEO.



THE LEGISLATOR — SUMMER 2023

By Cornelius Fletcher Everytown for Gun Safety



It takes all of us. This is the dawning realization of Americans who wake up to yet another rash of gun violence across this country. We believe that our government representatives should be working to protect our communities from the gun violence epidemic. The life-long collective cost of anguish and fear borne by individuals, families, and neighborhoods due to constant gun violence is destroying our sense of freedom, compromising the joy of gathering in public spaces and shredding the very fabric of the American experience. We should not have to reside in fear that gun violence can ring out at any moment—no other high-income country on the Earth lives like this.

Gun violence, including tragedies like suicides, homicides, mass shootings, domestic violence, city gun violence and unintentional shootings, costs the United States \$557 billion each year. Nationally, employers lose an average of \$1.47 million on a daily basis in productivity, revenue and costs required to recruit and train replacements for victims of gun violence. While no number could ever fully reflect the toll of gun violence on families and survivors, our society loses \$1.34 billion daily in quality-of-life costs from their suffering and lost well-being.

In stark relief to other high-income countries, firearms are the leading cause of death for children and teens in the United States.

Compounding that tragic fact, the psychological and mental well-being of our children and teens is harmed when a friend or family member is killed with a gun, when someone they know is shot, and when they witness and hear gunshots; when homes, neighborhoods, and schools are not safe from gun violence, entire generations of American children are affected.

Research shows that stronger gun laws equate to less gun violence. States with background checks, red-flag laws, secure storage measures, and firearm permitting and training requirements have lower levels of gun violence. Investing in the environment and buttressing the leadership of residents living in longneglected, once red-lined districts can also have a significant impact on reducing gun violence.

Everytown for Gun Safety is the largest gun violence prevention organization in the nation and offers a vast array of opportunities for individuals to participate in reducing the daily threat of gun violence. In the wake of multiple tragedies, residents in every state are joining its non-partisan fight for public safety measures that can protect us. We encourage legislators throughout the country to file common sense gun violence prevention measures that we know will keep their constituents safe. Legislators should be supporting city violence interruption initiatives, building community awareness about the importance of secure gun storage, and acting as persistent, determined, advocates for evidence-based gun safety laws in their state.

From school boards to Congress and every city and state-elected position in-between, it is imperative that voters support lawmakers and officials who promote gun safety as well as "gun sense" candidates running for office who will build a policy infrastructure to protect the public from gun violence.

It takes all of us to prevent the scourge of gun violence in our communities.

Cornelius Fletcher serves as Associate Regional Director for State Government Affairs at Everytown for Gun Safety, the nation's largest gun violence prevention organization.



ITI and Morehouse College's National Initiative to Increase Diversity in Technology

Learn more about ITI
and Morehouse College's
Innovation Advisory Board,
a first-of-its-kind partnership
to diversify the tech sector.



itic.org/advocacy/innovation-advisory-board



By Jennifer Thomas

Vice President and Business Unit Lead of Corporate Affairs American Honda Motor Co., Inc.



Honda's founders structured the philosophy of our company around the belief that diversity and inclusion make us stronger. All Honda associates are asked to truly live our values in action to make Honda a company that society wants to exist and our world a better place to live.

Our special relationship with Historically Black Colleges and Universities (HBCUs) is an important part of how we can do this. This relationship represents more than 30 years of collaboration on programs that support the success and dreams of HBCU students as the next generation of leaders.

Through Honda Battle of the Bands, Honda Campus All-Star Challenge and other HBCU-related initiatives, Honda has provided more than \$14 million in grants to HBCUs and touched the lives of nearly 300,000 students over the past three decades. We are proud to make contributions to these institutions because when we invest in HBCUs, we are investing in the future.

30+ Years of Celebrating and Supporting HBCU Excellence

We believe HBCUs play a unique and critical role in providing higher education and opportunities for advancement to Black students.

Since its inception in 1989, Honda Campus All-Star Challenge (HCASC) has been the cornerstone of Honda's partnership with HBCUs. This year-round program showcases the academic talents of top HBCU students from across the country.

Beyond gameplay, HCASC is about creating real connections—or as we like to say—friends for life. As part of the program, we encourage participating students to take time to meet and network with their peers from other HBCUs as well as our Honda associates.

We recently hosted another of our HBCU initiatives, the 18th Honda Battle of the Bands (HBOB), the nation's premiere marching band showcase for HBCU marching bands and dance teams. For all of us at Honda, HBOB isn't just about entertainment. It's a chance for us to celebrate and share HBCU culture and traditions on a national stage.



HBOB continues to evolve into a platform built for and by the HBCU community. This is the first year we tried a new approach of bringing HBOB to an HBCU campus.

Investing in Future Leaders

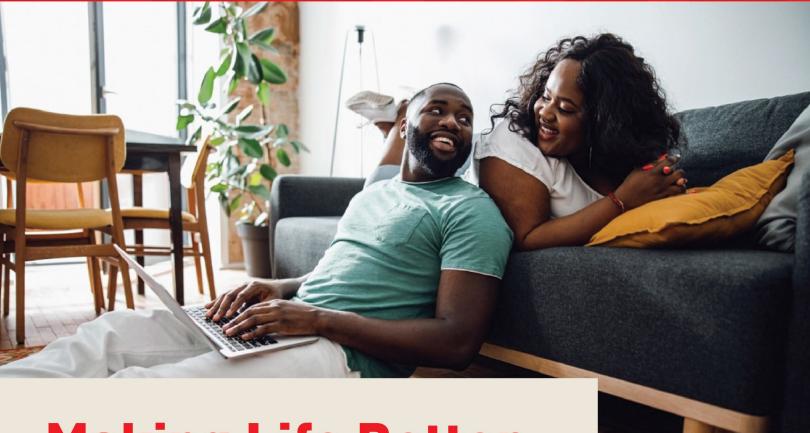
Honda has been a partner of UNCF since 1984, supporting efforts to increase the total annual number of Black college graduates by focusing on activities that ensure more students are college-ready, enroll in college and persist to graduation.

Through the Thurgood Marshall College Fund, we support HBCU students in fields that are critical to our future—engineering, supply chain management and manufacturing. With this partnership, we are creating scholarships, internships and co-op positions for HBCU scholars, with the hope that some of them might want to become Honda associates in the future.

We've continued to grow these relationships into something that not only supports HBCU students but also will serve as a source of talent to power the future of Honda. And we encourage other companies to do the same.

Our relationship with the HBCU community will not only make Honda a more diverse and inclusive company, but it will make us a stronger company. That's why we remain committed to driving the legacy of HBCUs and supporting the dreams of so many talented students.

Jennifer Thomas is the vice president of Corporate Affairs of American Honda Motor Co., Inc., where she oversees Government & Industry Relations, North American Corporate Communications, Corporate Social Responsibility and Inclusion & Diversity. Thomas also serves as Honda's top liaison to the White House, as well as Honda's lead representative to the company's major trade associations, including the Alliance for Automotive Innovation, Autos Drive America and the Outdoor Power Equipment Institute.



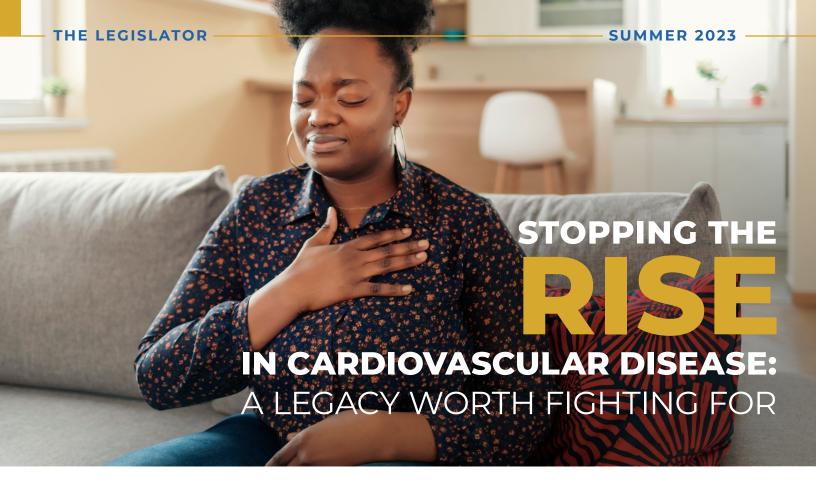
Making Life Better for People with Type 2 Diabetes

Despite the many treatment advancements in recent years, only half of the people living with type 2 diabetes are meeting their goal of lowering their blood glucose levels.

We're driven by our purpose: uniting caring and discovery to create medicines that make life better for people with type 2 diabetes.

Learn more about the latest in diabetes care and treatment at lilly.com/diabetes.





By Millard D. Collins

Family Medicine Section National Medical Association (NMA)



Scientific progress has facilitated numerous advances in treating heart disease. As a nation, we achieved a consistent long-term decline in cardiovascular deaths between 1981 and 2010 by unlocking new approaches to care and innovative treatments to improve heart health. However, this trend has reversed over the past decade and is now on the rise—threatening decades worth of progress against cardiovascular disease, the number one killer of Americans.

The burden of cardiovascular disease falls disproportionately on underserved groups; Black and Brown Americans, women, and rural populations bear an outsized portion of poor cardiovascular outcomes, stemming from disparities in access to care and treatment and in the social determinants of health. As a family doctor, I've seen firsthand the devastating—and often preventable—impact of cardiovascular disease.

That's why my organization, the National Medical Association, has teamed up with the Foundation of the National Lipid Association to launch <u>Take</u> <u>Health to Heart</u>, an advocacy and education initiative that seeks to educate our elected officials on the risk factors that lead to the development and progression of atherosclerotic cardiovascular disease (ASCVD), the most common and deadliest form of cardiovascular disease.

To help elected officials understand the magnitude of the problem among their own constituencies, we developed the **State of the Heart,** a new resource that quantifies the massive burden of ASCVD at the state and national levels. It found that nearly 22.3 million Americans have ASCVD, or eight percent of all adults. In 2020, ASCVD was an underlying cause of death for 416,096 Americans, killing more people than COVID-19. Black Americans experienced the highest death rate from ASCVD among all races and ethnicities, at a rate more than twice as high as Asian Americans.

State of the Heart also includes a first-of-its-kind analysis that graded the nation and each state against the expert-recommended **Healthy**

People 2030 targets for two key measures of cardiovascular deaths. It paints a stark picture of alarmingly poor heart health across our country; the U.S. received a D grade, meaning it lags behind targets by more than 20 percent. More than half of the states and the District of Columbia received Ds and Fs.

Through this resource, we hope to raise awareness of ASCVD and its risk factors, but we know that addressing the rise in cardiovascular disease will require action. While health behaviors can contribute to poor cardiovascular outcomes, these are often shaped by a complex set of societal barriers—many of which are themselves rooted in structural inequities that contribute to the wide disparities that Black Americans and other communities face today. This underscores the importance of identifying ASCVD risk and reaching patients as far upstream as possible. Targeted interventions like the **CDC's** WISEWOMAN program, which provides lowincome, uninsured, and underinsured women ages 40-64 years with risk factor screenings and services that promote healthy behaviors to reduce the risk for heart disease and stroke, can help dismantle these social and economic barriers.

Once diagnosed, many individuals with ASCVD continue to face access barriers that can prevent them from properly managing their disease. For example, as a physician, I deal every day with the growing burden of prior authorization—requirements from insurers to fill out complex paperwork before patients can access the medicines that their providers have prescribed. This takes my time away from where it is best spent in my practice: delivering high-quality patient care. For cholesterol management therapies that are needed to treat ASCVD, this disproportionately burdens populations who are already at risk for poor ASCVD outcomes, including Black patients, who face higher

rejection rates for their prior authorization requests than white patients.¹

Overcoming socioeconomic and insurance obstacles to better cardiovascular care is not something patients can do on their own. Policy change is needed to combat these disparities before we can turn the rising tide of cardiovascular deaths happening in our communities today. A few actions we encourage elected officials to consider include:

- Establishing or updating your state's action plan on cardiovascular disease;
- Raising awareness of cardiovascular disease through legislative resolutions;
- Reforming state laws that regulate prior authorization policies implemented by insurance companies to remove unnecessary barriers to patient access; and
- 4. Implementing or expanding a WISEWOMAN program in your state through funding from the CDC.

On behalf of Take Health to Heart, I urge you to prioritize your state's cardiovascular health to improve the well-being of our communities.

Dr. Millard D. Collins is the Family Medicine
Section Chair at the National Medical
Association (NMA) and a primary care provider
who specializes in family medicine at Meharry
Medical Group. He provides services such as
adult and children's care, preventative care and
women's health services, along with urgent
and elder care at both the Meharry Clinic and
Meharry Family Medicine at Skyline. Dr. Collins
is an Associate Professor and Chair of the
Department of Family and Community Medicine
at Meharry Medical College in Nashville, TN.

Partnership to Advance Cardiovascular Health. Rejected: How Life-Saving Heart Medication Eludes Women, Southerners & People of Color. 2022. https://staticl.squarespace.com/static/56e6efdb5559866c54beb696/t/62ded03d9b0e0a253a1c1c
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By Patty Nece, JD
Obesity Action Coalition
Board Chair
And Chrystal Jones, MPA
Obesity Action Coalition
Advocacy Manager





Penny has struggled with her weight, but finally found a glimmer of hope after a successful seven months on anti-obesity medication. Her insurance is now denying her medication.

Teneisha worked hard to successfully complete a one-year weight loss program that was required by insurance for bariatric surgery. Her surgery was denied due to coverage changes within that year.

Karen went to the ER three times for back pain but her symptoms were dismissed as weight-related each time. When she lost the ability to walk, she was transported via ambulance and the appropriate tests were finally conducted. They found that she had an epidural abscess compressing her spinal cord. The delay in treatment caused neurological symptoms that persist to this day.

Devin wants his employees to have insurance coverage for obesity treatments, but he can't find a plan that will include the coverage.

Stories like these arrive daily at the Obesity Action Coalition, the nation's leading obesity patient advocacy nonprofit organization.

Nearly every person in this country is either affected personally with overweight or obesity, or knows someone who is. Over 30% of US adults are overweight, over 40% have obesity, and over 19% of youth have obesity. Obesity rates also vary widely by race and ethnicity: Black Americans have the highest rate of obesity at 49.9%, Latino at 45.6%, white at 41.1%, and Asian at 16.1%.

The American Medical Association recognized obesity as a disease in 2013. In 2022, six leading US organizations (Academy of Nutrition and Dietetics, American Society for Metabolic & Bariatric Surgery, Obesity Action Coalition, Obesity Medicine Association, STOP Obesity Alliance, The Obesity Society) with a primary focus on obesity released a consensus statement:

- Obesity is a highly prevalent chronic disease characterized by excessive fat accumulation or distribution that presents a risk to health and requires lifelong care. Virtually every system in the body is affected by obesity.
 Major chronic diseases associated with obesity include diabetes, heart disease, and cancer.
- The body mass index is used to screen for obesity, but it does not displace clinical judgment. BMI is not a measure of body fat.
 Social determinants, race, ethnicity, and age may modify the risk associated with a given BMI.
- Bias and stigmatization directed at people with obesity contributes to poor health and impairs treatment.
- Every person with obesity should have access to evidence-based treatment.

Yet, we don't treat obesity as a disease. How did we get here? Every part of the system is broken. Patients with obesity are hesitant to seek care—and who can blame them with the rampant weight bias and lack of coverage for treatments? Many are getting sicker by the day while America collectively turns a blind eye to this noxious stew of bias and misinformation. Many are significantly harmed by the blatant, systematic neglect.

Contrary to popular belief, pharmaceutical and surgical treatments are not a first choice (or even a second, third... tenth choice) for people who struggle with obesity. They often spend a lifetime trying self-care and following dated, harmful, and unscientific dieting approaches. People seeking obesity care should be celebrated because they have finally broken through the stigma society puts on needing help to address obesity.

There are evidence-based, FDA-approved treatments that mitigate the impacts of obesity and improve health outcomes. But our system remains fractured and coverage options for obesity treatments are only available for a lucky few who live in the right zip code or work for the right employer.

Dear Legislators: it's time to treat obesity as the disease that it is and provide treatment options in the same manner as other diseases, such as diabetes and hypertension. NOW is the time to review coverage of evidence-based obesity treatment options in each state and federal health plan, including Medicare, Medicaid, plans offered under the Affordable Care Act, SCHIP, and state employee plans. Each of these plans should cover behavioral, nutrition and mental health counseling, FDA approved anti-obesity medications, and bariatric surgery. It is equally important that these services are offered without significant barriers. Comprehensive care is the key to success in addressing obesity.

Dear Constituents: It's the fight of our lives, and we need your help! Email advocacy@obesityaction.org to help OAC in its fight to stop weight bias and expand access to obesity care.

For more information, visit <u>ObesityAction.org</u> and for state-specific obesity data, visit <u>ObesityAction.org/StateFactSheets</u>.

Patty Nece, JD, is an OAC member and serves as the OAC Chair of the OAC National Board of Directors. An avid advocate for sound obesity treatments and eradication of weight-based bias, Patty encourages change by sharing her own experiences of living with lifelong obesity with legislators, health-care providers, government officials, medical school students, and others.

Chrystal Jones, MPA, is the Advocacy Manager at Obesity Action Coalition, engaging OAC's 75,000 to members to help change the way we care for obesity through advocacy. Chrystal has dedicated 19 years to working in nonprofit organizations with a background in issue advocacy and volunteer management. Chrystal graduated from Eckerd College with a BA in Political Science and minor in International Relations, and Norwich University with a Master's Degree in Public Administration.



By Andrew DukeOnline Lenders Alliance

At the end of last year, nearly two-thirds of Americans were living paycheck to paycheck—a staggering number that is part of an increasing trend. When you couple the growing number of those who have little savings with the nearly 20% of American households that are unbanked or underbanked, the dilemma many Americans face every day becomes quite clear: accessing credit is paramount, but it can also be hard to find.

Financial data shows that many of these credit needs are for smaller amounts—nearly 20 percent of installment loans from alternative financial services lenders are for less than \$500 and more than half are for less than \$1,000. Fortunately, fintech companies have emerged to provide these consumers with credit access and options. With the click of a button using the internet or an app, consumers can have multiple lenders to choose

from, many of whom provide small-dollar loans with the speed and privacy that consumers want.

In other words, thanks to modern technology, access to a phone or the internet means you have access to fintech-powered credit options. More than 90 percent of consumers—regardless of race—enjoy access to the internet through their smartphone or computer. Fintech companies and their use of data analytics have brought the development of new and innovative products, resulting in an array of companies offering them.

We often hear about credit deserts—
neighborhoods and communities with little to no
bank or credit union presence. These traditional
financial institutions increasingly view branches
as cost burdens to their bottom line, and therefore
they are reluctant to build more of them. Fintech,
however, provides a wide-ranging, competitive
market to everyone who can access the internet.

With loans, not every consumer qualifies for every product or offering. Some borrowers' financial situation and history can make them too high of a risk for certain lenders—and with



small dollar credit, banks and credit unions are among the first to turn these customers away. Alternative credit providers often fill this need, and fintech options increasingly reach more customers with more options by using their advanced underwriting technology to provide risk-priced credit options. Sometimes the fintech company provides technology services to a bank so that they can reach these borrowers.

Consumers want solutions when they run into financial difficulty, and a recent academic study and survey offers us insight into what happens when their options are limited by policymakers. Following the enactment of Illinois' 36 percent APR cap on loans, the number of loans to subprime borrowers decreased by 44 percent while the average loan size to subprime borrowers grew by 40 percent (leaving them with a bigger loan than they likely wanted).

The study also included survey data from previous users of loans with APRs exceeding 36 percent, which showed that most of those Illinois borrowers are unable to borrow money when they need it, they struggle to pay bills, and most of them

would like the option to return to their previous lender. Furthermore, one year after the rate cap took effect, the number of licenses held by Illinois installment lenders fell by 45 percent, leaving consumers with even fewer options than before.

Earlier this year, a researcher documented that banks are not filling this void, and the number of small dollar loans from credit unions has actually declined over the past few years. Some activists insist consumers can simply beg for mercy, sell their bodily fluids, or work themselves to exhaustion. Those aren't solutions; they're merely empty rhetoric. Financial inclusion requires financial options, and fintech providers are working every day to provide more consumers with the solutions they need to enhance their financial well-being.

The Online Lenders Alliance (OLA) is the center for lending, technology, and innovation and represents the growing online lending industry. OLA members abide by industry best practices and a code of conduct to ensure their customers are fully informed and fairly treated.



By Debra Barrett Vice President, Corporate Affairs Otsuka America Pharmaceutical, Inc.



Post-traumatic stress disorder (PTSD), a mental health condition that develops in individuals after experiencing a life-threatening or traumatic event(s), is not primarily a veteran's disease. In fact, **86 percent** of those diagnosed with PTSD are non-military individuals.¹ Yet, many in the U.S. remain unaware that PTSD can occur in diverse populations after any of these experiences (among others): abuse, bullying, historical trauma, intimate partner violence, natural disasters, serious accidents, terrorist acts, and sexual assault. In addition, the following facts are not widely known even though approximately 16 million adults in the U.S. experience PTSD in any given year²:

- Lifetime PTSD prevalence and conditional risk for PTSD is higher among Black/African Americans compared to White, Latino and Asian individuals.³
- Women are twice as likely as men to experience PTSD.⁴
- Those who experience PTSD are 2.7x more likely to attempt suicide.⁵

Despite its prevalence, many people who live with PTSD may not be appropriately treated or may be misdiagnosed. It's estimated that only **23 percent** of people living with PTSD have received a diagnosis and at least half of PTSD cases are undiagnosed in primary care,⁶ which may result from common misperceptions about the condition. Lack of access to adequate mental healthcare services is also a major contributor—a topic on which there is growing focus from a policymaker standpoint.

On that topic, Otsuka recently invested in a study to help uncover how systemic health inequities impact those living with mental illness. Conducted by The Satcher Health Leadership Institute at the Morehouse School of Medicine, researchers found that between 2016-2020, at minimum, more than 116,000 lives and approximately \$278 billion could have been saved by investing in proper mental healthcare for minority populations.

While nearly half of the U.S. population (47%) lives in a mental health workforce shortage area⁷, the report provided tangible evidence that historically underserved populations and minority populations face **significantly worse access to mental healthcare**, which has led to generations of poor health outcomes.

Amid this staggering reality, a distinct moment in time beams: today, we have an opportunity to work collaboratively to create a more equitable future for our communities. Based on the findings, the report offers a roadmap in three pillars to guide, and ultimately impact, policy decision making: make sustainable long-term investments in the mental health system, adopt a culturally centered mindset when evaluating options and lastly, recognize the importance of the impact of political and social determinants of health. Policy solutions anchored in those pillars are critical and some examples include:

- Strengthen enforcement mechanisms on mental health parity to ensure health plans reflect the same offerings between physical and mental health.
- Create opportunities to extend Medicaid benefits as individuals transition in and out of the criminal justice system to ensure continuity of access to care.
- Evaluate how social determinants of health impact patient outcomes and adopt reimbursement systems that reflect those considerations.

No one entity can successfully rebuild and reimagine our mental healthcare system. At Otsuka, we are committed to bringing together

a coalition of stakeholders to address the pressing issues needed to transform our mental healthcare system into one that anticipates and responds to individual needs in every community. We will continue to build awareness about conditions like PTSD, and correct misinformation that

prevents people from seeking treatment. We applaud existing efforts of policymakers to both recognize and correct areas of health disparities and are committed to continue the conversation on driving policies that will provide improved and equitable access to all.



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ViiV Healthcare's commitment to supporting community-driven activities that strengthen the health and well-being of Black gay, bisexual, queer, and trans men.

Follow us:

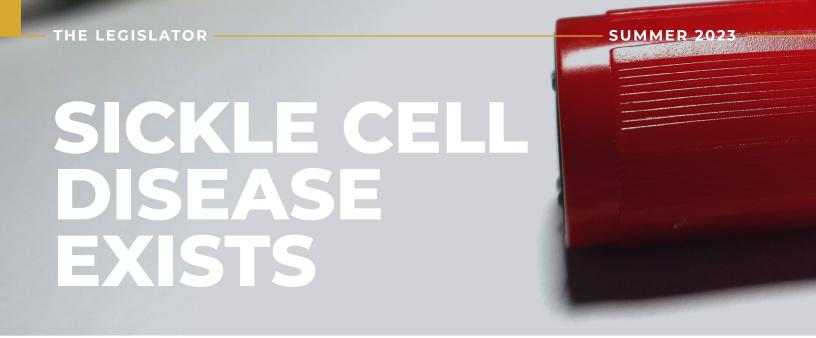












By Representative Daryl Campbell (FL-99)



"You know, we're not a pain clinic" was the response Amy Mason received from a nurse when she regained consciousness after enduring hours of pain while waiting for care in an emergency room (ER) triage. After going to the ER in extreme pain due to sickle cell disease (SCD), Amy faced accusations of being a drug addict faking her pain.

"Every time it's a battle," Amy says. "Nobody cares about sickle cell."

Sickle cell disease is the most commonly inherited genetic disorder in the world. When in a healthy state, red blood cells are typically round in shape. SCD causes blood cells to become rigid and morph into a C-shape like a sickle. These cells die quickly, which leads to a constant shortage in red blood cells found in the bloodstream causing blood clots, intense pain, a heightened risk for developing infections, acute chest syndrome, and stroke. An estimated 100,000 Americans suffer from the disease according to the U.S. Department of Health and Human Services. Yet, despite the gravity and prevalence of SCD, it is not well understood by medical professionals, the government, or society.

Instances of SCD are highest in the Black community. One out of every 13 births in our community have the trait and 1 out of ever 365 have the disease. With such a high prevalence in our community, it is no surprise racial discrimination in healthcare extends to SCD patients. Black SCD patients wait 25% longer than other ER patients before receiving care; in the general population Black patients are 22% less likely than White patients to receive the medication they need. In a healthcare system embedded with racial discrimination in every fiber of its being, Black SCD patients are left at its mercy. It is extremely crucial that we both understand and provide the services missing in treating sickle cell disease if we want to alleviate the pain for those afflicted with SCD.

As of now, no national data registry exists for sickle cell disease. According to the Centers for Disease Control and Prevention (CDC), this means "we don't have basic information, like how many people in the U.S. have sickle cell disease. Where are they getting their healthcare? Or, what their healthcare utilization looks like."

In collaboration with Florida House Democratic Leader Fentrice Driskell, we are pushing to fill this knowledge gap in our state with House Bill 1481: Sickle Cell Disease Medications, Treatment, and Screening. This bill will direct the Florida Agency for Health Care Administration to perform a study on the available covered medications, treatment, and services for those living with SCD and how additional provisions can lead to better outcomes



for patients. In addition, it directs the Florida Department of Health to create and maintain a registry of sickle cell disease and trait patients in the state, allowing for medical professional verification and outreach to individuals suffering from the disease

While a study provides us a better understanding of sickle cell disease in Florida, specialized care is lacking. For this reason, I am also requesting \$5,000,000 in funding for the creation of ten community-based sickle cell treatment centers throughout the state modeled after The Foundation for Sickle Disease Research in Hollywood, Florida. These centers provide over a dozen different services treating sickle cell, under the direction of Dr. Bronte Hall, and are a welcome alternative to traditional hospitals where individuals with SCD are often mistreated or viewed with suspicion.

Sickle cell disease holds a deeply personal significance for me, my district, and our community. During the course of drafting House Bill 1481, I discovered that a mentee, with whom I have mentored since middle school, is living with this disease, and unfortunately, this is an all-too-common occurrence in our region. In fact, it is worth noting that eight percent of all individuals afflicted with SCD across the nation are located in the state of Florida, with South Florida serving as a prominent hub for this medical condition.

Sickle cell disease is a painful and prevalent genetic disorder that disproportionately affects our

Black communities. Unfortunately, discrimination and lack of understanding within the healthcare system often leaves patients without the proper care and compassion they need. While we work towards greater understanding and support for those with sickle cell disease, as members of the National Black Caucus of State Legislators (NBCSL), we must remember that it is our responsibility to ensure that those suffering from sickle cell disease are not left behind in any of our communities.

Representative Daryl Campbell is one of the newest and youngest members to serve in the Florida State House, currently representing District 99, serving the cities of Ft. Lauderdale, Lauderhill, Lauderdale Lakes, Wilton Manors, and Plantation. As a licensed clinical social worker, Representative Campbell focuses his legislative efforts on improving the mental health of Floridians. After his first Legislative Session, Representative Campbell earned a 94% "people first" rating for voting on issues that matter to everyday Floridians and is currently continuing his advocacy in his first term of 2022–2024.

Florida State Representative Daryl Campbell— District 99 Florida House of Representatives 405 Northwest 7th Avenue Fort Lauderdale, FL 33311-8134 (954)-937-9684



By Michelle LeBlanc, MPH

Senior Health Policy Analyst, National Governors Association

Despite their name, when considered altogether, rare diseases are not that rare. They affect 25 to 30 million Americans and have an extensive impact on public health policy and delivery. There are more than 7,000 rare diseases, including Cystic Fibrosis, Huntington's Disease, Meningitis, Sickle Cell Disease, Juvenile Pilocytic Astrocytoma and all pediatric cancers. In the U.S., conditions are categorized as "rare" if they each affect less than 200,000 people. Many of these diseases are serious or life-threatening; studies estimate half affect children, adolescents and young adults, and 72 percent are genetic conditions. On average, a person living with a rare disease may face health care costs between **\$4,000-\$140,000** depending on the condition and their insurance coverage.

Given the small population of those with an individual rare disease, patients can often face

barriers accessing appropriate care. Patients frequently encounter providers who know little about their condition, limited care options and high treatment costs. Additionally, receiving a correct diagnosis can take an average of **five years**.

The Orphan Drug Act of 1983 (ODA) was created to incentivize pharmaceutical companies to develop treatments for rare diseases. Since 1983, the Food and Drug Administration has approved over 550 unique drugs and biologics for more than 1,100 rare diseases, compared with just ten orphan drug approvals in the decade before passage of the ODA. Significant progress has been made in identifying and treating rare diseases, but given the scientific complexity and challenges with drug development, most rare conditions do not have approved treatments.

Enhanced <u>newborn screening and affordable</u> <u>genetic testing</u> can lead to an earlier diagnosis and quicker treatment for some genetic diseases. According to the CDC, through newborn screening programs, each year more than 13,000 newborn babies are identified with conditions such as sickle cell disease and cystic fibrosis. Early intervention for these and other diseases,

including those with a fast disease progression, is critical to change their course and enhance quality of life for those with rare diseases and their families. Early intervention is also linked to reduced costs for the health system. Although the federal government recommends screening for 35 conditions, states have the power to regulate their newborn screening program's screening options, the diseases that are screened and how funding is allocated. For example, Idaho screens for all federally recommended conditions and several secondary conditions, has a newborn screening advisory committee, and funds ongoing actives of the program for sustainable impact.

Policies that aid in supporting rare disease patient engagement are also effective. There are more than 20 states with a rare disease advisory council (RDAC), an advisory body providing a platform for the rare disease community to have a stronger voice in state government. RDACs are made up of patients, caregivers, providers, insurers, biotech industry representatives, researchers, patient advocacy organizations, and state government officials. This diverse group meets the needs of patients and families by providing recommendations to state leaders on critical issues. For example, the North Carolina RDAC worked with state leaders to expand newborn screening to include two additional disorders as of February 2023.

A recent discussion at the 2023 NGA Winter Meeting highlighted rare diseases, where attendees heard from experts with lived experiences. The panel included Derek Robertson from Maryland Sickle Cell Disease Association, Teonna Woolford from the Sickle Cell Reproductive Health Education Directive, Kristen Wheeden of the United Porphyrias Association, and Dr. Dominique Pichard from the International Rett Syndrome Foundation. The panel underscored that patients are often the experts when it comes to rare diseases, and their voices must be central in any rare disease policy or program.

Teonna Woolford, Co-founder and CEO of Sickle Cell Reproductive Health Education Directive, highlighted that her organization is the only Sickle Cell Disease (SCD) organization with a mission to support reproductive health. Teonna shared, "I am hopeful that the rare disease community will see significant advancements, particularly concerning high-quality sexual, maternal, and reproductive health care. Tackling reproductive health means addressing a disparity within a disparity. For women and men with SCD, the disparities are overwhelming. For pregnant women with SCD, the maternal mortality rate is 27 times higher than the national average. Currently, there are no FDAapproved treatments that have been proven safe to take during pregnancy or while breastfeeding. There is also no collective access to fertility services or genetic counseling. I am hopeful that collaborative efforts with patients, policymakers, researchers, caregivers, and providers will lead to further advancements for the rare disease community."

As noted during Rare Disease Day 2023, the community's long-term goals are "to achieve equitable access to diagnosis, treatment, health and social care and social opportunity for people affected by a rare disease."

Addressing rare diseases requires a multifaceted approach involving collaboration between health care providers, researchers, policymakers, patients and families. Working together can improve outcomes for patients with rare diseases and promote better overall public health. Policy changes and general standardizations can do this by improving affordability and accessibility to quality health care, supporting treatment development, championing research efforts and ensuring the rare disease community is engaged in the progress of diagnosis and treatments.

This article was developed by Michelle LeBlanc, MPH, Senior Health Policy Analyst, National Governors Association. For more information on Governors' health efforts please contact communications@nga.org.

By Representative Toni Rose (TX-110)



It's often said that 'everything's bigger in Texas.'

Sadly, that sentiment includes the state's maternal mortality rate.

In 2021, the national rate climbed to its highest level in nearly 60 years at 20.1 deaths per 100,000 births, according to the Centers for Disease Control. Enter Texas into the statistical fray. That same year, maternal mortality rates for the Lone Star state were 32.9 deaths per 100,000 births.

It's not a good look when your state's maternal mortality rate surpasses the national number.

Surely, Texas has a plan, right? That would be a resounding 'Yes' if the Texas Legislature wraps its lawmaking hands around House Bill 12. Under this proposal, post-partum Medicaid benefits for eligible women would be extended to a full 12 months of coverage. Moreover, the bill enables a new mom to continue to see her same physician and mental health professional, as well as a specialist to manage issues related to post-partum before they worsen. With this expanded level of comprehensive coverage, more lives will be saved and Texas children will benefit immensely because they will get to bloom under the protective eyes of their loving mothers.

On April 21, 2023, HB 12 successfully jumped one hurdle when the Texas House approved the measure. The proposal was a key legislative priority for Speaker of the House Dade Phelan. Now all eyes are on the other chamber, the Texas Senate.

I can't underscore enough how important it is that HB 12 remain in tack, as written. The reason for this is that HB 12 aligns with federal statute. Consequently, the sooner the Centers for Medicare & Medicaid Study approve the plan, the quicker we can start saving the lives of our Texas moms.

And given that time waits for no one, the need to pass this critical piece of legislation is taking on a renewed sense of urgency. Texas moms are covered for post-partum benefits under the federal public health emergency declaration, implemented due to the COVID-19 Pandemic, but the caveat is the PHE declaration will end on May 11, 2023, thus terminating coverage after 60 days.

Legislative action on this issue was needed after information about the alarming rates of pregnancy-related maternal deaths, particularly among Black women, was released in a 2022 report from the Texas Maternal Mortality and Morbidity Review Committee. I was taken aback by the fact that 90 percent of the deaths for Texas women in 2019 were preventable and only 44 percent of these deaths were pregnancy related.

Given we live in a first-world nation and in a state as prosperous as Texas, these statistics are beyond shocking. This legislation will stem the tide of unnecessary deaths of Texas moms.

Representative Toni Rose is the author of House Bill 12. Elected to the Texas House of Representatives in 2012, she represents District 110.

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By Alex RandolphDirector of Government
Affairs, Target



Target employs over 400,000 team members with more than 1900 stores across 50 U.S. states and the District of Columbia. We have a responsibility to continue to build trust and resilience in the communities that deeply interconnect us. With 75% of the U.S. population living within 10 miles of a Target store, we recognize our footprint is significant and the impact we have through efforts to create a more inclusive economy is essential for systemic change.

That is why we established the Racial Equity Action and Change (REACH) committee to accelerate our diversity, equity and inclusion strategy for our Black team members, guests and communities. We are committed to invest more than \$2 billion with Black-owned businesses by the end of 2025. We have increased investments with Black-owned brands, companies and suppliers by more than 50% compared to 2020 and more than doubled Black-owned brand product offerings, with representation across

every major product category. A 2021 McKinsey survey found that two out of three Americans said their social values shape their shopping habits. And nearly half of respondents, likely representing over a hundred million consumers, believe retailers should actively support Blackowned businesses and brands

At Target, our commitment to supporting Black-owned companies and advocating for racial equity touches every aspect of our business—including investing in underrepresented entrepreneurs, launching Black-owned brands at Target, working with Black designers and suppliers and increasing visibility through our marketing. That means leveraging what makes us unique: (i) our brick-and-mortar footprint that deeply roots us within neighborhoods and communities, (ii) our team members in stores and supply chain facilities that reflect diverse communities across the nation, and (iii) our wide-ranging partnerships with vendors, entrepreneurs, and brands that guests love.

Target is supporting the next generation of Black talent with partnerships, programs, and resources that provide opportunities for students to create meaningful careers and build their professional networks. That is why in 2021, THE LEGISLATOR — SUMMER 2023

we launched the Target Scholars Program in partnership with the United Negro College Fund, to provide 1,000 first-year students at historically Black colleges and universities (HBCUs) with \$5,000 scholarships. Last year, we doubled down on our commitment and offered each student an additional \$10,000 over the next three years to support the completion of their degree, plus continued access to resources like coaching, mentoring, internships and more.

Target leverages our unique expertise across multiple skill areas to be part of institutional change. We are a founding supporter of the PENSOLE Lewis College of Business & Design (PLC), the country's first design-focused HBCU, which offers free tuition to aspiring Black designers, engineers, and leaders, and bolstering these efforts by supporting PLC's operations and its students. We are also a proud co-founder of RISE Up, the National Retail Federation's (NRF) training and credentialing program that provides foundational and life-long skills to help people land jobs and build meaningful careers in retail and beyond. More than 500,000 people have now earned RISE Up credentials.

To achieve success, and to maximize the impact of our efforts at scale, we must rely on deep collaboration with a diverse set of stakeholders. We call our sustainability strategy Target Forward, which hinges on the input and

participation from hundreds of Target vendors and suppliers, plus countless organizations we partner with in the communities we serve. This community-centric, holistic approach is especially important in achieving DE&I and driving our REACH strategy within our enterprise, and within the community at large.

However, none of this can be accomplished without strong partnership and engagement with policy makers. Multifaceted partnerships are the linchpins to building a better future for generations to come. We are proud to support the National Black Caucus of State Legislators where we can have that important dialogue and exchange of ideas. Thank you for your service to our communities and for the opportunity to create an equitable future together.

Alex Randolph is the Director of Government Affairs for Target in Alaska, California, Hawaii, and Nevada. As a first-generation college graduate and a proud Urban League of San Diego scholar, he is excited to help fulfill Target's commitment to diversity, equity and inclusion on NBCSL's Corporate Round Table Board.

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By Taryn Williams

Assistant Secretary of Labor for Disability Employment Policy U.S. Department of Labor



This past March was a special time for me, both personally and professionally. It brought me from Washington, D.C. to the great State of Alabama to celebrate the Selma Bridge Crossing's Jubilee and meet with NBCSL's esteemed members.

I'm always humbled by trips to Alabama, the backdrop for so many pivotal moments in the

Civil Rights Movement. And I get awestruck because not only am I a proud Black woman, but also a person with a disability who understands the seminal role the Civil Rights Movement played in sparking the disability rights movement.

When the disability rights movement was just emerging in the 1960s and 70s, its leaders looked to the civil rights leaders—those who marched in Selma and took action across the South—to advance the cause. Inspired by their passion and commitment, these leaders made disability rights the next step in America's ongoing progress, demanding that we live up to the ideal that we are all created equal.

While there were many people who brought the disability rights movement to the forefront, one has been top of mind lately—my friend and mentor Judith (Judy) Heumann, who passed away the very day I was in Selma. As just one of so many examples of her impact, Judy helped lead the historic 1977 "504 sit-in" at the San Francisco Federal Building. This demonstration resulted in the long-awaited signing of regulations implementing Section 504 of the Rehabilitation Act of 1973—the 50th anniversary of which we are observing this year. Section 504 was actually modeled on the Civil Rights Act of 1964. and was the first federal legislation to address the notions of access and equity for people with disabilities. And, it laid the foundation for more comprehensive legislation to come—the Americans with Disabilities Act (ADA).

The ADA prohibits discrimination on the basis of disability in so many respects, including employment, which is the focus of my work at the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). Unfortunately, people with disabilities still face stark employment inequities compared to people without disabilities. In addition, we know there are significant racial disparities, with Black Americans with disabilities employed at lower rates than white Americans with disabilities.

However, these same people represent a diverse talent pool that can help fill workforce gaps and be part of the jobs solution—and our nation's success going forward. In fact, a growing body of evidence demonstrates that diverse, equitable, inclusive and accessible workplaces yield higher-performing organizations. So, inclusion is not just a moral imperative, but a way to bolster our economy and build a stronger American workforce.

The late great Congressman John Lewis once said, "Freedom is not a state; it is an act. It is not some enchanted garden perched high on a distant plateau where we can finally sit down and rest. Freedom is the continuous action we all must take, and each generation must do its part

to create an even more fair, more just society." I share his view that we cannot achieve freedom, equity or full inclusion without action.

So, what can NBCSL members do to advance disability inclusion? You can remember to include people with disabilities in the policies you introduce and ensure that disabled people have support in the areas of workforce development and employment. This starts by making sure your state government is inclusive of people with disabilities, serving as a model employer and accessing this untapped labor pool.

To help on this front, ODEP offers state policymakers a tremendous resource—the **State** Exchange on Employment and Disability (SEED). SEED is a unique state-federal collaboration that supports state and local governments in adopting and implementing inclusive policies and best practices that lead to increased employment opportunities for people with disabilities. We are thrilled to call NBCSL a partner in SEED and are available to assist individual states and localities. as well. Acting as an educator and hands-on policy guide, SEED offers background on disability employment-related policy practices, shows you where inclusion intersects with your own policy agenda, and, if needed, can help you shape your own effective policies and put them into practice.

America deserves a workforce that reflects the diversity and talents of all its citizens, including people with disabilities from all backgrounds. With your help, we can make that vision a reality, because, as countless champions of civil rights have taught us, when we advance inclusion for any underrepresented community, it lifts *all* of us a little higher.

Taryn Williams
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By Alonzo MourningVertex Pharmaceuticals



It was 2000 and I had just come off the thrill of winning gold at the Olympics in Sydney. I was the consummate professional athlete who put my body through hours in the gym, played intense basketball games and was meticulous about what I ate—I was in the best shape of my life—or so I thought.

There were days I was downright exhausted and had swollen legs, but I ignored them. Because what did I, a "healthy" 30-year-old professional athlete at the top of my game, need to worry about?

A mandatory team physical marked the beginning of a lifelong journey with a new opponent tougher than any of those I've had on the court—focal segmental glomerulosclerosis, also known as FSGS. I found out it's a rare and potentially fatal disease that slowly scars the filters in the kidney, eventually rendering them irreversibly damaged.

Terrified doesn't even begin to describe how I felt, but basketball taught me to study my opponent and come up with a game plan. I was eager to learn everything I could about what was going on inside my body.

After more testing, doctors told me I had what is now known as APOL1-mediated kidney disease, or AMKD. Everyone has the APOL1 gene, however, for people like me, having two variants of the APOL1 gene comes with an increased risk of this rapidly progressive form of kidney disease. Over time, the DNA of people of sub-Saharan African ancestry evolved, resulting in a greater likelihood that they may carry these genetic variants; in the U.S., this includes people who identify as Black, African American, Afro-Caribbean, and Latino/ Latina. The APOLI gene is a part of our body's immune system. It lives in our tissues, including the kidneys. For a while, these variants stayed dormant in my body, but then, as can happen to those who have these two variants, for reasons the medical community is still working to understand, they woke up and went on the attack.

Looking back, I wish I had recognized some of those warning signs earlier and sought medical advice. Today, I'm so grateful for that mandatory team physical, as it resulted in connecting my symptoms with an eventual diagnosis. AMKD is a serious genetic disorder and can lead to kidney failure; however, for many people it can be more effectively managed if detected early. Because of how advanced the disease was for me, I needed

a kidney transplant. Three years after my diagnosis, I was lucky to be able to receive a kidney from my cousin. After recovering from surgery, and with strong support of my medical team and those around me, I worked hard to return to the court and helped the Miami Heat win the NBA championship in 2006.

I'm sharing my story in hopes of inspiring you to take charge of your health.

Knowledge is power. More people need to know what's going on in their bodies, and legislators can help encourage this. Have conversations with your community about taking charge of your health, which can include knowing family history of kidney disease, and the importance of speaking to your doctor about your individual risk level, which may include getting a genetic test to find out if you have the APOL1 risk variants. For resources on how to begin these conversations with your doctor and your family members, visit PowerForwardTogether.com, which I helped launch in partnership with Vertex Pharmaceuticals to increase awareness of AMKD.

To people battling the disease and/or advocating for communities impacted—don't give up. It's vitally important and essential to Black health.

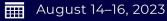
Keep powering forward.

Alonzo Mourning is best known for his legendary basketball career in the 1990s and early 2000s. Among his many achievements are National Collegiate Athletic Association (NCAA) records at Georgetown, seven NBA All-Star recognitions, and NBA championship, an Olympic gold medal, and his induction into the Basketball Hall of Fame. Mr. Mourning is now an advocate for kidney health and encourages others to be proactive as well.

Alonzo Mourning is a paid spokesperson for Vertex Pharmaceuticals.

UPCOMING NBCSL EVENTS

JOINT NBCSL & CRT MEETING



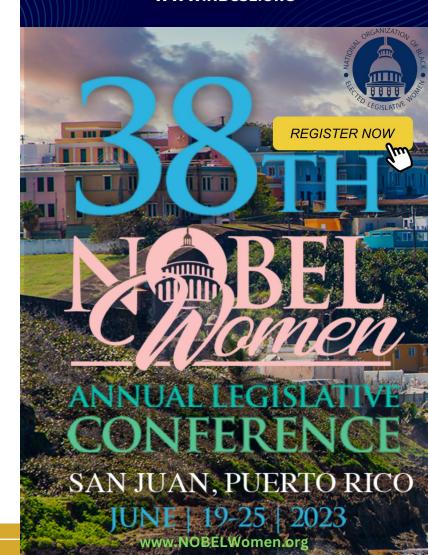
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By Catherine PughFormer State Legislator,
Maryland



In every state, there are laws that should be modified and or repealed. Some are outdated, while others don't make sense. They are not enforceable, not justly applied and can be discriminatory. One such law in Tennessee was recently used in April to expel two African American state legislators from the legislature.

"What happened to Representatives Justin Jones from Nashville, Tennessee and Justin Pearson from Memphis, Tennessee should never happen again." said The National Black Caucus State Legislators President Laura Hall.

Not only is she right, the NBCSL members like them are on the front line to ensure that instances like this don't occur again. Some members traveled after the expulsion to Nashville, Tennessee from around the country to show their support.

Yet, the question for legislators is not just about repealing or even modifying laws that don't make sense. There is also the question of how to apply or enforce laws fairly and without prejudice at all levels.

Prejudice was on display in Tennessee. The action taken by the Tennessee Legislature resulted in

the removal of two members, Jones and Pearson, and spared one who committed the same act, Representative Gloria Johnson.

In her own words, Johnson exclaimed what we all know to be true, because of her race, she was not given the same punishment as her peers. The votes by a legislature of Republicans who outnumber Democrats three to one, voted to expel Jones 75-25, Pearson 69-29 and Johnson 65-30. The expulsions were carried out under a Tennessee law, Article 11, Section 12 of the Tennessee Constitution. It states, the House can "punish its members for disorderly behavior, and with the concurrence of two thirds expel a member."

For a minute, let's look at laws in some other states, and you decide if like this one, they are necessary.

In Kentucky, their Constitution states, every legislator, public officer, and lawyer must take an oath that they have not fought a duel with deadly weapons. It was voted into law in 1849, to keep men seeking public office from engaging in the once popular southern tradition.

In Michigan, adultery is a felony. How many people break that law daily? While in Nebraska, a law that is hardly enforceable, states that no one with a sexually transmitted disease can marry. Did anyone of the 9,700 reported cases of chlamydia or gonorrhea reported in 2015 to the Nebraska Department of Health and Human Services marry?

What about laws that forbid certain actions of its citizens and, all the while, lawmakers themselves are not adhering to those laws? In Hawaii, billboards are outlawed, yet, legislators use them for their political campaigns.

The resolution to expel is outdated and in this instance was used with prejudice. Three Democratic members — Jones, Pearson, and Johnson — joined with citizens who were protesting in the Tennessee legislative chamber over guncontrol. When the Republican-led legislature refused to hear the three Democrats, they voiced their opposition, and were ruled out of order.

Why did they voice opposition?

Representative Pearson represents the city of Memphis, where on February 19, 11 people were shot and one was killed. On March 27, in Representative Jones' district, three children and three adults at a Christian School were shot to death. To say emotions were high is an understatement. Parents and community members present at the Capitol demanded that legislators take some sort of action. Jones, Pearson, and Johnson were doing just that.

What lawmakers in Tennessee and in Congress ignore is simple and true. Since 1968, 1.5 million people have died in gun-related deaths in the United States. By comparison, in US history, 1.2 million service members in all wars combined have been killed. This is according to estimates from the Department of Veterans Affairs and iCausualties. org, a website that maintains an ongoing database of casualties from the wars in Iraq and Afghanistan. Mass shootings should cause legislators to pause, debate, and find bipartisan support to reform gun laws, instead of using a discriminatory law to expel members who simply want to save lives.

It is time to replace outdated laws with responsible gun laws and hold elected officials who stand in the way accountable. This will save lives. Laws should not be discriminatory. They should not be applied differently for one race, gender or political party against another.

Representatives Jones and Pearson were reinstated, but the red flag in Tennessee is raised. Correcting injustices in our local, state, and federal constitutions is an obligation all legislative bodies should undertake. Our nation is at a crossroad. Tennessee shined a light on the reason why, as NBCSL President Hall said, "We cannot let this happen again."

Catherine Pugh is a former state legislator in Maryland General Assembly having served in House of Delegates and State Senate.



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