Legislation to Establish a Michigan Rare Disease Advisory Council to be Introduced on Rare Disease Day

Giving a voice to the one million Michiganders with a rare disease.

ANN ARBOR, MICHIGAN, UNITED STATES, February 27, 2023 /EINPresswire.com/ -- Representative Jason Morgan (D) Ann Arbor to introduce legislation to establish a Rare Disease Advisory Council (RDAC) in Michigan. The council will gather stakeholders from the patient community, the life sciences industry, health insurance, provider groups, advocacy organizations and other interested parties to provide decisionmakers with information on the unique needs and challenges faced by the rare disease community.

> The proposed bill is an important step in creating discourse between patients and policy-makers that enables policy decisions with the greatest benefit to patients and their families, and caregivers.”
>
> *Stephen Rapundalo, PhD, President and CEO of MichBio*

Patients and advocates from around the state will gather in Lansing on Tuesday, February 28th – Rare Disease Day - to join Rep. Morgan in the announcement of the bill and to celebrate Michiganders who are currently living with a rare disease.

“As many as a million of our friends and family members live with a rare disease in Michigan, and they deserve a voice in Lansing,” says Kira Mann, CEO of MitoAction. “We’re incredibly excited about this important legislation because it brings patients to the table on public policy in a way they’ve never been invited before.”

Rep. Morgan is one of those Michiganders living with a rare disease – Burton Muscular Dystrophy – and has a personal understanding of the impact these disorders can have on one’s health, well-being, and livelihood.

“We know so little about the challenges that those with rare diseases in our state face. We need to gain a better understanding of what support they need and how best to deliver it to them,” Morgan said. “The Rare Disease Advisory Council will help us achieve that goal, so patients receive better treatment, doctors are better informed, and families can better support their loved ones.”

Sarah Procario, Advocacy Director at the Hemophilia Foundation of Michigan addresses why it can be so challenging for policymakers to enact meaningful legislation for the rare disease community. “There are more than 7,000 rare diseases impacting Michiganders. The truth is, it’s impossible for even the most caring policymakers to have in-depth knowledge about all of them. Creating a council to help educate decision makers on the sometimes-complicated issues surrounding treatment and the impact their policies have on real people couldn’t be more important.”

Laura Bonnell, Founder of the Bonnell Foundation: Living with Cystic Fibrosis adds, "while lawmakers make decisions that will directly impact the cystic fibrosis (CF) and rare disease communities in Michigan, we have no official voice at the state level. Our communities share common concerns including continued access to telehealth, newborn screening, prior authorization, improved diagnostics, step therapy, and more. The RDAC ensures patient voices are included in decision-making on these important topics."

An incomplete understanding of the needs of the rare disease community contributes to obstacles faced by patients, including delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs, limited access to specialists and more.

“Public policy has a real impact on patients like me,” says Sharon L. Harris, who lives with systemic and discoid lupus and is the Executive Director of Lupus Detroit “Lupus is a chronic autoimmune disease and meds are extremely costly. Insurance companies are now using step therapy, a process that has patients – when prescribed an expensive drug - try a less expensive drug first, and if that fails to help them, only then will the insurance company allow the patient to take what their doctor prescribed. This practice prolongs treatment, undermines providers, and impacts quality of life. I’m so grateful Representative Morgan is the RDAC sponsor.”

Dr. Wanda Whitten-Shurney, CEO and Medical Director of the Sickle Cell Disease Association of America, Michigan Chapter and Kym Worthy, Wayne County Prosecutor and Parent of a Sickle Cell Warrior, expand on the need for public policy targeted at the challenges faced by the rare disease community. “There are approximately 4,000 individuals in Michigan living with sickle cell disease – a condition that creates unpredictable episodes of excruciating pain and life-shortening organ damage. There are more medications in the pipeline and even the potential for a genetic cure, and it is essential that patients have a voice in the development of policies that can ensure access to care and clinical trials that could have a dramatic impact on their quality of life.”

If the bill passes, Michigan will join twenty-four other states that have established RDAC’s to help lawmakers better explore challenges faced by patients.
"An RDAC in Michigan will give all stakeholders in the rare disease community an opportunity to make recommendations to Michigan lawmakers on ways to improve the lives of those impacted by a rare disease,” says Heidi Ross, Vice President of Policy and Regulatory Affairs, National

Organization for Rare Disorders (NORD). “NORD is grateful to Rep. Morgan for his leadership and looks forward to working with him and numerous advocates across Michigan to get this RDAC legislation signed into law.”

Tara Britt, Founder and President of the Rare Disease Innovations Institute adds, “we are thrilled for those who will benefit from this legislation - rare disease is a public health disparity and congratulations to Michigan for addressing this through strategic legislation.”

The rapidly growing coalition of organizations supporting Rep. Morgan extends to industry groups and research organizations.

“Our role as the Michigan Biosciences Industry Association puts us at the intersection of patients and of the life sciences industry that works to develop life-changing products and treatments,” says Stephen Rapundalo, PhD, President and CEO of MichBio. “Those products and treatments are only effective if patients can access them affordably and without unnecessary barriers. Legislation such as the proposed bill is an important step in creating discourse between patients and policy-makers that enables informed policy decisions which can have the greatest benefit to patients and their families, and caregivers.”

Organizations that wish to join the coalition in support of the creation of a Rare Disease Advisory Council in Michigan are encouraged to contact Laura Bonnell at thebonnellfoundation@gmail.com or Stephen Rapundalo at stephen@michbio.org.

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