



The Commonwealth of Massachusetts
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Representative Kane appointed to Rare Disease Advisory Council

BOSTON – House Minority Leader Bradley H. Jones, Jr. (R-North Reading) has appointed State Representative Hannah Kane (R-Shrewsbury) to serve as his designee on the newly-established Rare Disease Advisory Council.

During the 2019-2020 legislative session, Representative Kane was the lead co-sponsor, along with Representative Joseph McKenna (R-Webster), of legislation calling for the creation of the Council, which will advise the Governor, the Legislature and the Department of Public Health on the incidence of rare disease in Massachusetts. She also sponsored an amendment based on the legislation she filed that was adopted as part of an omnibus health care reform bill that was signed into law on January 1.

“Hannah has been at the forefront of this issue and has spearheaded the effort to create a permanent state entity devoted to addressing the needs of the rare disease community in Massachusetts,” said Representative Jones. “I am confident she will help make the Council an effective voice for improving access to research, diagnosis and treatment for those individuals who are living with a rare disease.”

The new law defines rare diseases as any condition that “affects fewer than 200,000 people in the United States, has status as an orphan disease for research purposes, or is known to be substantially under diagnosed and unrecognized as a result of lack of adequate diagnostic and research information.”

The 29-member Council will be chaired by Dr. Monica Bharel, the state’s Commissioner of Public Health. It will be responsible for developing and maintaining a comprehensive rare disease plan for the Commonwealth, and will be required to file an annual report by December 31.

Later this month, Representative Kane is scheduled to speak virtually about the creation of the state’s Rare Disease Advisory Council as part of Biogen’s Lunch N’Learn program and at the NORD (National Organization for Rare Disorders) Rare Action Network of MA virtual lunchtime event.

“The Massachusetts Rare Disease Advisory Council will ensure that a framework for tackling rare disease is in place in the Commonwealth, it will bolster education around rare disease and it will ensure that the rare disease community is being championed here,” said Representative Kane. “I am honored to be a member of the initial

Council and grateful to the Minority Leader for appointing me as his designee. Massachusetts life science companies are at the forefront of discovery in treatments for rare diseases and our health care institutions lead the world in break-through treatments. Massachusetts can and will lead a coordinated effort to confront rare diseases head-on and provide life-saving treatments to residents suffering from these diseases.”

In addition to the Rare Disease Advisory Council, Representative Kane is also serving as the House Minority Leader’s designee on the Massachusetts Food Policy Council and the Massachusetts Commission on Unaccompanied Homeless Youth. From 2016-2018, she served on the Special Commission on Local and Regional Public Health, and on the Regional Transit Authority Task Force from 2018-2019.

Representative Kane is the Founder and Co-chair of the first in the nation Food System Caucus, which is the second largest caucus in the Massachusetts Legislature. She currently serves as a member of Governor Charlie Baker’s Food Security Task Force, which was created in response to the challenges to the food production and distribution system created by COVID-19 that has led to increased food insecurity. Governor Baker also appointed her in February of 2020 to serve on the Special Commission on Family Care and Child Care Services.

First elected to the Legislature in 2015, Representative Kane is now the Ranking Minority Member of both the Joint Committee on Public Health and the Joint Committee on Health Care Financing. She is also serving as a member of the Joint Committee on Mental Health, Substance Use and Recovery, as well as the newly-formed Joint Committee on Racial Equity, Civil Rights and Inclusion.

Representative Kane represents the Eleventh Worcester District, which is comprised of the town of Shrewsbury and precincts 4 and 5 in Westborough.

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