



Office of
Representative Hannah E. Kane
Commonwealth of Massachusetts

For Immediate Release

Contact: Anna Darrow, 617-722-2810, Anna.Darrow@mahouse.gov

July 9, 2021

Rep. Kane awarded 2021 NORD Rare Impact Award

BOSTON – State Representative Hannah Kane (R-Shrewsbury) was honored by the National Organization of Rare Disorders (NORD) with a Rare Impact Award in a virtual ceremony on June 28, 2021. With this recognition, Representative Kane joined patients, caregivers, innovators, advocates, legislators, and other leaders whom NORD has honored every year for more than 30 years for the positive impact each has made to advance the fight against rare diseases.

Representative Kane has a daughter with two chronic diseases and is a long-time advocate for the rare disease community. She partnered with her colleague Representative Joseph McKenna (R-Webster) to sponsor and pass legislation into law this past winter that created a Rare Disease Advisory Council (RDAC) in Massachusetts. The RDAC will be a powerful tool in creating a comprehensive rare disease network and bolstering education and attention to the cumulative mass and prevalence of rare diseases. The mission of the RDAC is to advise the Governor, General Court, and Department of Public Health on the incidence and status of rare disease in Massachusetts. Representative Kane was the first member appointed to the Council.

“I am thrilled to be recognized as a 2021 NORD Rare Impact honoree and I am grateful to the people, partners, legislators, and advocates in Massachusetts who worked alongside Rep. McKenna and I to get our Rare Disease Advisory Council legislation signed into law. As parent of a daughter with two chronic diseases, I recognize how challenging it can be to navigate getting a diagnosis and accessing care for a non-rare disease – and I have learned from advocates, caregivers, and patients themselves just how much more difficult it is with a rare disease. With the tremendous advocacy work of NORD and partner organizations, with the ongoing establishment of additional Rare Disease Advisory Councils in states across the country, and with the united strength of the rare disease community, I am hopeful that no rare disease patient will ever feel alone, or without hope for a bright future, and I am committed to doing all I can to make it so,” remarked Representative Kane in her recorded acceptance of the award.

NORD is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. Learn more about NORD and Project RDAC [here](#).

###