

December 2, 2022

The Honorable Kathy Hochul
Governor of New York State
NYS State Capitol Building
Albany, New York 12224

Re: S2121-C (Rivera) /A289-C (Gottfried)

AN ACT to amend the public health law and the insurance law, in relation to enhancing coverage and care for medically fragile children

Dear Governor Hochul,

The undersigned organizations, which together represent tens of thousands of physicians across the State of New York delivering care to millions of patients each year, **strongly support** the enactment of the above referenced legislation, which is critically important in requiring insurers and health plans have proper protocols and standards in determining coverage for treatments and services for medically fragile children.

This legislation, which passed the Senate and Assembly with near unanimous support, amends to the Insurance and Public Health Laws to include important protections with respect to coverage and appeal mechanisms for medically fragile children. The bill establishes a definition of medically fragile child as:

“... means an individual who is under twenty-one years of age and has a chronic debilitating condition or conditions, who may or may not be hospitalized or institutionalized, and meets one or more of the following criteria (a) is technologically dependent for life or health sustaining functions, (b) requires a complex medication regimen or medical interventions to maintain or to improve their health status, or (c) is in need of ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health or development at risk.”

Codifying this definition is extremely important as it will provide a clear understanding for insurers, health plans, public health programs and most importantly for families. The legislation cites several examples of chronic debilitating conditions and empowers the Commissioner of Health to issue written guidance that provides further detail on conditions that qualify. As part of this written guidance and listing the type of patient care needs which are deemed to meet this definition, the above organizations urge the Commissioner to include congenital anomalies including cleft lip and palate, facial clefts, craniofacial microsomia, and craniosynostosis.

One of the most important provisions of the bill requires a health plan reviewer for an internal appeal or external appeal to be a physician with expertise in pediatric rehabilitation, pediatric critical care, neonatology, or pediatric subspecialty directly relevant to the medically fragile child's condition. Furthermore, the legislation requires the clinical standards used by utilization review agents to make medical necessity determinations must consider the special needs and accommodations of this population including “... health care services that are necessary to promote normal growth and development and prevent, diagnose,

treat, ameliorate or palliate the effects of a physical, mental, behavioral, genetic, or congenital condition, injury or disability." This includes accommodation for "unusual stabilization and prolonged discharge plans."

According to the New York State Department of Health's Bureau of Environmental and Occupational Epidemiology, 1 in 38 babies in New York State are born with a congenital anomaly as compared to 1 in 33 babies nationally according to the Centers for Disease Control and Prevention. Currently, there are 13,200 medically fragile children in New York State under the age of 21, a population that will grow as these children live longer thanks to new developments in treatments and technologies. ¹ As it stands, there have been instances where coverage for necessary follow up reconstructive surgeries and therapies are denied as the child continues to grow older and erroneously classified as "dental" or "cosmetic."

For the aforementioned reasons, the undersigned organizations **strongly urge** you to sign this critically needed legislation into law.

Sincerely,

MEDICAL SOCIETY OF THE STATE OF NEW YORK
NEW YORK CHAPTER AMERICAN COLLEGE OF PHYSICIAN SERVICES INC.
NEW YORK STATE ACADEMY OF FAMILY PHYSICIANS
NEW YORK STATE ACADEMY OF PEDIATRICS – CHAPTERS 1, 2 & 3
NEW YORK STATE NEUROLOGICAL SOCIETY
NEW YORK STATE OPHTHALMOLOGICAL SOCIETY
NEW YORK STATE PSYCHIATRIC ASSOCIATION
NEW YORK STATE SOCIETY OF ANESTHESIOLOGISTS
NEW YORK STATE SOCIETY OF OTOLARYNGOLOGY-HEAD AND NECK SURGERY
NEW YORK STATE SOCIETY OF PLASTIC SURGEONS

¹ <https://www.globenewswire.com/news-release/2015/12/02/1134055/0/en/Healthcare-Summit-Highlights-Expanding-Population-of-Children-and-Young-Adults-With-Complex-Medical-Conditions-Aging-Out-of-Residential-Treatment-Options.html>