



July 27, 2021

The Honorable Brendan P. Crighton
Chair
Joint Committee on Financial Services
24 Beacon Street
Room 520
Boston, MA 02133

The Honorable James M. Murphy
Chair
Joint Committee on Financial Services
24 Beacon Street
Room 254
Boston, MA 02133

Re: Support for House Bill 1153 (H.1153)

Dear Chair Crighton, Chair Murphy, and Members of the Joint Committee on Financial Services:

On behalf of the 1-in-10 individuals living in Massachusetts with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for adding House Bill 1153 (H.1153) to the Joint Committee on Financial Services' meeting agenda. H.1153 would require health insurance coverage for certain medically necessary services related to functional repair or restoration of craniofacial disorders.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD believes strongly that all patients deserve the medical care that is best suited for their medical situation and will give them the best results.

Several rare diseases require medically necessary services for craniofacial disorders; however, it is common for insurance companies to deny and delay coverage for these procedures, which places an enormous burden on rare disease patients who are then required to pay high out-of-pocket costs for medically necessary treatments. H.1153 will ensure that medically necessary care for craniofacial disorders is covered by insurance to the same extent as other medically necessary procedures.

Craniofacial disorders are complex medical conditions that have widespread effects on the entire body, not just oral health. Without proper treatment, these conditions can lead to serious health complications such as infections which can travel to other parts of the body, bone loss in the face and jaw, nutritional deficiencies, and severe pain in other affected areas of the body. Additionally,



the cumulative effect of these problems often leads to mental health issues and difficulty maintaining employment. This legislation will allow patients better access to the most appropriate treatments to relieve the symptoms that rare disease patients with craniofacial disorders frequently endure.

Once again, on behalf of the Massachusetts rare disease community, we thank you for bringing H.1153 before your Committee for consideration and urge its swift passage. For any questions, please feel free to reach out to Annissa Reed at AREed@rarediseases.org. Thank you for your consideration.

Sincerely,

Heidi Ross
Director of Policy
National Organization for Rare Disorders

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC: Members of the Joint Committee on Financial Services