



The Commonwealth of Massachusetts

HOUSE OF REPRESENTATIVES
STATE HOUSE, BOSTON 02133-1054

PAUL HEROUX
STATE REPRESENTATIVE
2ND BRISTOL DISTRICT

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RE: H1977 An Act to Create a Massachusetts Rare Disease Advisory Council
DT: 5 May 2015

Dear Honorable Chairs and Members of the Joint Committee on Public Health,

Thank you for considering my bill *H1977 An Act to Create a Massachusetts Rare Disease Advisory Council* before your committee today. This bill has a dozen co-sponsors from both the House and Senate. I respectfully request that you report out favorably *H1977*.

This bill would direct the Department of Public Health to create an advisory council, membership of this council outlined in the bill, to monitor the incidences of rare diseases throughout the Commonwealth and the status of the rare disease community, with the purpose of the council creating a profile of the social and economic burden of rare disease in the commonwealth. The bill defines a rare disease as: "any disease which affects fewer than 200,000 people in the United States, which 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."

Thank you for your time and attention to this matter. Once again, I urge you to report out favorably *H1977 An Act to Create a Massachusetts Rare Disease Advisory Council*.

Sincerely,

A handwritten signature in cursive script that reads "Paul Heroux".

Paul Heroux