January 29, 2014

House Committee on Health, Education & Welfare
Room 135, State House
Providence, RI 02903

RE: Support of House Bill 7094

Dear Chairman McNamara and Members of the House Committee on Health Education and Welfare,

The Immune Deficiency Foundation (IDF), the national nonprofit organization dedicated to improving the quality of life for patients with primary immunodeficiency diseases, writes in support of HB 7094, Rare Disease Community Support, Resource Coordination, and Quality of Life Act of 2014.

This bill would establish a Rhode Island rare disease community advisory council within the Department of Human Services in order to aid the state in developing an action plan that addresses the coordination of resources to efficiently provide care for Rhode Islanders living with rare diseases.

Primary Immunodeficiency (PI) represents a group of more than 185 related, rare genetic diseases. The defining characteristic throughout each of the 185 different PI conditions is that the immune system is malfunctioning resulting in a decreased ability to fight off infection. Infections can affect organ function, and autoimmune diseases are common. Throughout their lives, people with PI are more susceptible to infections, endure chronic diverse health problems and often develop serious and debilitating illnesses.

There are approximately 250,000 people diagnosed with primary immunodeficiency diseases in the United States. Treatments are diverse and can include regular infusions of immunoglobulin replacement therapy, prophylactic antibiotic therapy, bone marrow transplantation, enzyme replacement, interferon gamma and antifungals.

IDF recommends the inclusion of an immunologist among those specialists on the advisory council, or at the least a less restrictive listing of specialists to achieve a greater diversity of rare disease perspectives on the council. We also ask for a greater emphasis on patient representation on the advisory council. With only one patient and one caregiver represented, the patient voice is threatened.

The establishment of a Rhode Island rare disease advisory council assures that the unique needs and challenges of working with rare disease and small patient populations are considered. The expertise that participants in the advisory council can bring to the Department of Human Services will be critical in the success of these patient populations. The Immune Deficiency Foundation supports HB 7094 and asks for the inclusion of additional patient and physician representation on the proposed rare disease advisory council.

Should you have any questions please contact me at 410-632-2552 or at llamotte@primaryimmune.org.

Regards,

Larry LaMotte
Vice President, Public Policy