April 24, 2020

Senator Gustavo Rivera
502 CAP
Albany, NY 12247

Assemblyman Richard Gottfried
822 Legislative Office Building
Albany, NY 12248

Dear Chairmen Gottfried and Rivera:

The American Plasma Users Coalition (APLUS) appreciates your leadership in sponsoring S.7811 and A.9915, respectively, which will hopefully lead to increased source plasma donation in New York. This is very important as there is a growing clinical need for plasma-derived medicines, which are made from donated source plasma.

APLUS is a coalition of national patient organizations created to address the unique needs of patients with rare diseases who use life-saving plasma protein therapies created from source plasma. APLUS member organizations share a common desire to ensure that the patient voice is heard when relevant public policies, regulations, directives, guidelines, and recommendations affecting access to safe and effective therapy and treatment are considered. Together, our coalition represents more than 125,000 Americans living with chronic disorders dependent upon plasma protein therapies for their daily living. Safety is of utmost concern to APLUS: we believe that plasma collection regulations should always prioritize the safety of the donor and the safety of the eventual plasma user.

The passage of your legislation will support plasma users’ access to the life-saving therapies they need. Source plasma is donated in source plasma donation centers. There are currently more than 840 source plasma donation centers in the United States, yet New York has only 12. This places New York on a par with states such as Nevada and Idaho. For comparison, Pennsylvania has 24, Illinois has 35, and Ohio has 41 plasma donation centers. This disparity seems to be attributable to New York state regulations that go beyond the federal guidelines for plasma collection, creating obstacles to the operation of plasma donation centers within the state.

The passage of your legislation will harmonize the requirements applicable to plasma donation centers and staff with federal standards. We are hopeful that this harmonization will result in the opening of more plasma donation centers in New York, helping to meet the need for source plasma and life-saving plasma-derived medications.

Thank you for your leadership in changing policies in New York and please consider APLUS a resource in this regard.

Signed,

APLUS Members

GBS|CIDP Foundation International
Hemophilia Federation of America
US Hereditary Angioedema Association

Jeffrey Modell Foundation
Platelet Disorder Support Assoc.
National Hemophilia Foundation