May 3, 2017

Committee on Appropriations  
House of Representatives  
Room H-305  
The Capitol  
Washington, DC 20515

Committee on Appropriations  
Room S-128  
The Capitol  
Washington, DC 20510

Dear Representative/Senator:

We are writing to urge both Congressional Committees on Appropriations to ensure adequate funding for the Health Resources Services Administration (HRSA), Maternal and Child Health Block Grant, Special Projects of National Significance (SPRANS) program for fiscal Year 2017. The SPRANS program has included funding for the national network of hemophilia diagnostic and treatment centers since 1974. These funds help cover the cost of essential non-reimbursable services provided to patients with severe, high-cost bleeding disorders. We are concerned that the proposed budget cuts would eliminate or significantly reduce funding for the SPRANS hemophilia program and as a result negatively affect HTCs’ abilities to properly care for patients with complex bleeding disorders. We respectfully request that the Congressional Appropriations Committees maintain vital funding the SPRANS hemophilia program for fiscal year 2017.

Aptevo Therapeutics is a biotechnology company focused on novel oncology and hematology therapeutics to meaningfully improve patients’ lives. In particular, we take pride in our products that treat rare bleeding disorders. This feeling comes not only from creating and offering various therapeutic drug treatments. We have a deep understanding of the rare bleeding disorder patient communities that we serve and their unmet patient care needs.

We launched IXINITY, a medicine used to replace clotting factor (factor IX) that is missing in adults and children at least 12 years of age with hemophilia B, during the summer of 2015. Over the past two years, we have closely collaborated with the hemophilia community gaining a full understanding of the daily challenges faced by patients with hemophilia B. Our patients are tremendous individuals with unique stories of challenge and triumph. Working closely with the hemophilia community, we understand how Hemophilia Treatment Centers (HTC) play an extremely important role in patients’ lives. HTCs are comprised of a multi-disciplinary team of providers – hematologists, nurses, physical therapists, social workers, and pharmacists. HTCs provide critical, comprehensive, multi-disciplinary services not typically covered by insurance, such as physical therapy assessments, social work, and case management services. This integrated care model is supported by the recent NHF-McMaster Guideline on Care Models for Hemophilia Management.1 CDC studies show that mortality and hospitalization rates are 40% lower in people who use HTCs compared with those who do not, even though more severely affected patients are more likely to be seen in HTCs.2 Managing hemophilia is extremely expensive and many individuals and families do not have the financial means to treat their bleeding disorder
effectively. Expert, integrated medical care provided by HTCs is recognized as the model paradigm to manage this expensive, difficult to treat patient population.

At Aptevo Therapeutics, we hope that individuals with bleeding disorders have full access to the treatments and specialists they need to lead healthy and productive lives. We strongly urge that Congress continue to fund the SPRANS program and maintain funding for SPRANS in fiscal year 2017.

Sincerely,

Michael D. Adelman
VP, Commercial Operations

References: