



March 21, 2020

Haystack Project, an umbrella group of almost 70 rare, ultra-rare patient groups, including rare cancers in the Rare Cancer Policy Coalition, write to you as patients, parents, and caregivers, standing in the wake of the COVID-19 pandemic with the realization that the actions you take in the coming days and weeks will drastically impact our care. We appreciate all that Congress is doing during this pandemic to aid access to medications for conditions such as ours.

We write in urgent support of a provision under consideration that would provide immediately needed relief for patients who typically rely on Medicare Part B settings of care for their infusion treatments. Our community is confronted with impossible choice between the risk of COVID-19 exposure and the known, potentially catastrophic consequences of delaying or stopping treatments for a rare cancer or other rare/ultra-rare condition. We desperately need your help, and urge you to include in your COVID-19 legislation **an immediately effective provision that lets patients receive Medicare-covered Part B infused medications from qualified practitioners in the safety of their homes.**

We also just recently became aware of a provision under consideration for the Corona virus package that in fact has nothing to do with the pandemic. We would like to have more time to consider the provision, but as it reads now, Sec. 4144 of the Senate package appears to put the breakthrough therapies, gene therapies, and regenerative medicine products that predominate in the rare and ultra-rare disease space on a separate track from other innovations. We are deeply concerned that this provision makes national coverage decisions mandatory for products with breakthrough status and RMAT designations. Congress developed these designations so patients like the ones we represent would have timely access to new treatments. **Section 4144 would thwart that very goal, delaying access, confusing providers, etc. We are very disappointed that a policy change with such far-reaching implications for patients with few or no treatment options would be hastily incorporated into a COVID-19 relief bill. Haystack and RCPC strongly urge you to remove the "Novel Medical Products" provisions of the draft bill.**

Please let us know how we can support your efforts on both the issues outlined above. Please contact our consultant, Saira Sultan at saira.sultan@connect4strategies.com, with any questions or request for any patient information we can provide.