Congress of the United States
Washington, DC 20515

July 11, 2017

Ms. Emma Walmsley
Chief Executive Officer
GlaxoSmithKline
980 Great West Road
Brentford
Middlesex
TW8 9GS
United Kingdom

Dear Ms. Walmsley:

We are writing with strong concerns about GlaxoSmithKline (GSK)'s discontinuation of POTIGA®. While we appreciate GSK's advance announcement and that healthcare providers were advised to seek alternative treatments for patients a year ago, for many patients there is no acceptable alternative to preserve the quality of life they have been able to achieve using POTIGA®. In statements, GSK admitted the discontinuation of the drug was not due to any efficacy or safety concerns, but rather its small user population. We urge GSK to reconsider and commit to finding a way to continue to provide POTIGA® for the patients who don't have other options.

There is a family in Connecticut who is asking for GSK's help in keeping POTIGA® available for their young son, Christian Mumm (age one). Christian suffers from a rare mutation of the KCNQ2 gene that regulates the potassium channels in his brain. Before his family was prescribed POTIGA®, Christian suffered from severe seizures every hour that greatly impaired his physical and cognitive development, and his quality of life. Each seizure put his life at risk and when his doctors began to decrease his dosage to prepare for POTIGA®'s discontinuation, his condition worsened immediately.

We have enclosed a letter from his mother, Erica Mumm, who wrote to GSK in November 2016 on behalf of her son. While the U.S. Food and Drug Administration's (FDA) approval of POTIGA® for market in June 2011 was not specific to pediatric care, her letter makes clear that is has been shown to be an effective treatment in Christian's case. For Christian, POTIGA® remains his only viable option for preserving quality of life. We join with his parents, Erica and Edward, and his four siblings to urge GSK to work with his medical team to find a compassionate solution.

Additionally, it has come to our attention that GSK has begun sending out notices to wholesalers and pharmacies asking them to immediately stop further distribution of the

POTIGA® and return all existing inventory to one of their facilities. We are concerned that patients still using POTIGA® will be denied access to even the remaining supplies of the drug. We are writing to ask what will happen to the remaining supplies once they are returned to GSK facilities and if GSK plans on making them available to patients like Christian on a limited basis.

The gene mutation Christian suffers from is both life threatening and seriously debilitating. His physicians agree there is no comparable or satisfactory alternative available, and its prior FDA approval and current success as a part of Christian's care greatly outweighs the potential risk of continued off-label use. We urge GSK to work with the family and his physicians to ensure that Christian will have continued access to this life-saving treatment.

Please know we stand ready to offer any assistance we can to help GSK and help Christian in his fight. Thank you for your consideration.

Sincerely,

JOHN B. LARSON
Member of Congress

RICHARD BLUMENTHAL
United States Senator

CHRISTOPHER S. MURPHY
United States Senator

ROSA L. DELAURO
Member of Congress

JOE COURTNEY
Member of Congress

JIM HIMES
Member of Congress

ELIZABETH H. ESTY
Member of Congress