

Steven Sepe

From: troy peck <peck.troy@gmail.com>
Sent: Tuesday, February 6, 2024 1:20 PM
To: House Health and Human Services Committee
Subject: H 7363 | Rare Disease Advisory Council

Dear Chair Donovan, Vice Chairs Giraldo and Potter, and Members of the Committee:

My name is Troy Peck, and I currently reside in Cranston with my wife, Ashley, and two children, Aspen (4) and Elliott (6). Today, I am writing to you to express my support for H 7363 to establish a Rare Disease Advisory Council (RDAC). As the parent of a child who has a rare disease, the lack of an RDAC in Rhode Island is clear, and could have been a vital resource when my family was thrust into the world of rare diseases on January 15, 2021, when Aspen was diagnosed with acute myeloid leukemia (AML), RAM phenotype with a CBFA2T3: GLIS-2 fusion. Aspen's particular flavor of AML has a 20% five-year survival rate with *no known cure*. Since 2016, when the disease was first discovered, there have been approximately 20 cases diagnosed. To have any chance of beating this disease, Aspen had to go through months of experimental chemotherapy and a bone marrow transplant. When Aspen relapsed 8-months post-transplant we turned to an investigational drug that had only been used in eight children prior to Aspen. Nearly two years post-relapse and 4-months off-treatment, Aspen is in remission.

From the day Aspen was diagnosed, Ashley and I researched everything about Aspen's disease, established a relationship with the only researcher working on the disease, and fought for access to every experimental treatment we could find. Again, there's no known cure and all existing FDA-approved treatment options have a 0% efficacy rate. We were in the "fortunate" position to wade through the rare disease world due to my background in Medicaid policy, family experts, and an insatiable desire to advocate for our daughter, family, and those similarly situated. With Aspen's remission we are active with the Leukemia & Lymphoma Society and the National Marrow Donor Program, where we volunteer our time to advocate on issues related to research funding, labor law changes (e.g. FMLA), access to care (Medicaid Provider Screening), and other relevant issues.

If Ashley (cc'd hereto) and/or I can provide any support to the Committee to help with the passage of this important piece of legislation, please do not hesitate to contact us. Thank you for your time.

Be well,

Troy Peck
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