

23 June 2017

The Honorable Susan M. Collins  
Ms Elizabeth P. Allen  
G31 Dirksen Senate Office Building  
Washington DC 20510  
(delivered via email: Elizabeth\_allen@aging.senate.gov)

Dear Senator Collins and Ms Allen:

Now that the Better Care Reconciliation Act (BCRA) is public, I am writing to arm you with more information about the impact of the bill on the hemophilia community, ask for your help, and offer my help to you as you study the BCRA. *I am deeply concerned about how this bill will affect my son, William with severe hemophilia and his peers in the bleeding disorders community in Maine and throughout the US -- as well as those with cystic fibrosis, cancer, rheumatoid arthritis, Huntington's disease and other rare/expensive diseases.*

Based on my read of the bill, below are my five fears:

1. I believe this bill will increase premiums and out-of-pocket costs to individuals and health insurance plans will provide poorer benefits coverage.
2. Permitting states to define essential health benefits (EHBs) erodes the bans on annual and lifetime caps as well as annual maximum on out-of-pocket expenses.
3. Repealing Medicaid expansion, MaineCare in Maine, will hurt many people in the bleeding disorders community where



William at the head of the 100 Mile Wilderness on Appalachian Trail (one of my favorite pictures!)

you and I live in the state we love. When we met with you in March, you may remember a Mom in our group from Wiscasset whose adult son with hemophilia relies on MaineCare for his factor medication and other health care needs. Her daughter, also a

Mom, lives in Dexter, has a son with hemophilia on MaineCare/Katie Beckett. [I could keep going with Maine stories; the point is that eligible Maine families with hemophilia and other bleeding disorders need to know that MaineCare is a viable option.]

4. Making tax credits linked to plans with less generous coverage is completely counterintuitive. The factor medications, the ambulatory care visits, emergency room visits, and so on are necessary medical care for people with bleeding disorders; *no one in our community is using the health care system for frivolous health care services.*
5. Allowing states to change medical loss ratios creates inconsistency in our health care system with health insurance costing more yet providing fewer benefits.

I am counting on you. William is counting on you. Grace is counting on you. David is counting on you.

Please consider me as a resource to you and your team. *Call on me or email me.* Your NO vote is super critical to William's and my family's health.

I look forward to hearing from you.

Best wishes,



Victoria Kuhn

---