

January 25, 2016

The Honorable Orrin Hatch  
Chairman  
Senate Finance Committee  
219 Dirksen Senate Building  
Washington, D.C. 20510

The Honorable Ron Wyden  
Ranking Member  
Senate Finance Committee  
219 Dirksen Senate Building  
Washington, D.C. 20510

The Honorable Johnny Isakson  
Co-Chair, Chronic Care Working Group  
131 Russell Senate Building  
Washington, D.C. 20510

The Honorable Mark Warner  
Co-Chair, Chronic Care Working Group  
475 Russell Senate Building  
Washington, D.C. 20510

Re: Response to *Bipartisan Chronic Care Working Group Policy Options Document*  
Submitted electronically via [chronic\\_care@finance.senate.gov](mailto:chronic_care@finance.senate.gov)

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson and Senator Warner:

On behalf of the Children's Cause for Cancer Advocacy (CCCCA), we appreciate the opportunity to provide input on the Bipartisan Chronic Care Working Group Policy Options Document. The Children's Cause for Cancer Advocacy (Children's Cause), established in 1999, was founded to ensure the needs and perspectives of children with cancer and survivors are integrated into federal health care, research and cancer policy.

***Integration of Cancer Survivorship Care***

The working group is considering policies that improve the integration of care for individuals with a chronic disease and with a behavioral health disorder. Policies would encourage care integration whether the beneficiary elects enrollment in traditional Medicare fee for service (FFS), a Medicare FFS Alternative Payment Model, or a Medicare Advantage plan.

We recommend that models that integrate care also include the delivery of comprehensive cancer survivorship care. Individuals who have been diagnosed with cancer and received

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treatment that might include surgery, radiation, and chemotherapy are often “lost in transition” as they move from active treatment to long-term survivorship.

We believe the essential components of survivorship care are:

- Prevention of recurrent and new cancers and the prevention of other late effects;
- Surveillance for cancer spread, recurrence, and second cancers, as well as the assessment of medical and psychosocial late effects;
- Intervention for the consequences of cancer and its treatment. These consequences might include cardiac damage, stroke and growth impairment; infertility, pain, fatigue, depression, psychological distress, neuropsychological impairments, and concerns related to employment, insurance, and disability; and
- Coordination between primary care providers and specialists to ensure that survivors’ health needs, as described above, are addressed.

A chronic care benefit that includes providers caring for cancer survivors holds great promise for addressing the serious and complex chronic health care needs of many cancer survivors and fairly compensating cancer care professionals providing this complex care. The need for a system of this sort is clear. There will be a 30% increase in the number of cancer survivors by 2022 and a 45% increase in cancer incidence by 2030. The burden of cancer and cancer survivorship on individuals, families, and the nation is significant. Medicare beneficiaries and the Medicare program bear significant financial responsibility for the cancer care system simply because of the incidence of cancer and the number of cancer survivors in this population. A chronic care benefit might focus initially on Medicare beneficiaries who are cancer survivors and be expanded to other populations of cancer survivors. Medicare regulations have important implications for coverage for children under Medicaid, CHIP and private insurance.

### ***Transitions of Care***

CCCA remains focused on the issue of transitions of care, whether in public or private plans. Since transitions in care are more complex for children with cancer. For this reason, the Working Group should consider several items as they further develop policy:

- Should pediatric oncologists continue to follow children with cancer to provide chronic care or primary care services?

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- How should transitions from pediatric to adult providers be managed? Should oncologists provide both primary care and survivorship care for childhood cancer survivors? What are the reimbursement implications of these alternatives?
  - For children who do survive, only to experience recurrent or refractory disease, who should deliver palliative care to meet the needs of these survivors?

We look forward to working with you as you further develop your proposal. If you should have questions, please contact George Dahlman at [GDahlman@childrenscause.org](mailto:GDahlman@childrenscause.org) at the CCCA.

Sincerely,

/s/

Susan L. Weiner, Ph.D.  
President  
Children's Cause for Cancer Advocacy