



## **The Patient Protection and Affordable Care Act and its Impact on Children and Young Adults with Cancer and Blood Disorders**

**Chicago, October 2020:** In September, [\*The Patient Protection and Affordable Care Act and its Impact on Children and Young Adults with Cancer and Blood Disorders\*](#) was published in the American Society of Pediatric Hematology/Oncology's (ASPHO) *Advocacy Brief*. This was written by ASPHO Advocacy Committee members and articulates a balanced perspective on the importance of the Affordable Care Act (ACA), which aligns with ASPHO's advocacy priorities of improving access to care and supporting adequate payment for the care of children by PHO subspecialists. The ACA helps protect access to care and payment for care in a variety of ways, including covering patients with pre-existing conditions. ASPHO encourages individuals to contact their [representatives](#) and [senators](#) to support the ACA.

Only ten years ago 46 million nonelderly Americans, roughly 18% of the population, were uninsured while health care expenditures had heightened to 17.4% of the GDP. This unstable balance between diminishing coverage and growing costs necessitated a law aimed to increase the affordability, accessibility and quality of health care across the entire system. In 2010, the ACA was enacted into law and progress began.

Payment and delivery reforms were created to decrease expenses such as reduced Medicare payments, value-based payment models, individual and employee mandates, maximum out of pocket payments and subsidies. Coverage and access provisions designed to insure and improve the health of more Americans included Medicaid expansion, the creation of essential health benefits, the elimination of lifetime or annual limits, the banning of pre-existing condition exclusions

("guaranteed issue") and premium adjustments ("community rating"), as well as dependent coverage to the age of twenty-six years. The ACA introduced additional vital patient protections highly relevant to children and young adults with cancer and blood disorders, including coverage for routine costs of care for individuals participating in approved clinical trials, concurrent hospice/curative care coverage, and insurance claims and appeals, and external review processes.

Demonstrable improvements in some measurable aims of the ACA have occurred over the last decade. The percentage of uninsured nonelderly Americans dropped to a low of 10.6% by 2016. The percentage of uninsured young adults aged 19-25 years dropped by about half. Total Medicare expenditures are 200 billion dollars less than projected pre-ACA. Nationally, hospital acquired conditions have steadily declined and Medicaid expansion states have seen reductions in mortality from cardiovascular and end-stage renal disease. Notwithstanding, the ACA's ideologic and financial underpinnings have generated numerous legal, constitutional and economic challenges which have begun to pull the threads on the ACA. The tax penalty for individual mandate noncompliance has been repealed, correlating with a recent increase in uninsured Americans by about 3% from its nadir. Cost-sharing reduction payments to insurers are now eliminated, leading to a ~20% increase in premiums. Market exchange marketing support has been cut by 90% and enrollment periods have been reduced in half, making it harder for people to sign up for ACA coverage. With the fundamental building blocks of this policy systematically removed, the ACA is already collapsing.

Perhaps it is easier to understand the importance of the protective elements of the ACA by envisioning patient care conversely, as if the policy were either functionally dismantled or entirely repealed. Imagine the uninsured population rising by at least 20 million at a time when hospitals are managing the financial crises ensuing from the current COVID-19 crises. Moreover, as the unemployment rates are in excess of 2010 levels at the time of writing this article (September 2020), non-employer-based insurance coverage could be even more necessary. Envision twice as many adolescent and young adults choosing to avoid medical care because they are uninsured, and the downstream impact on young adult cancer care, as well as the near half million Americans in need of childhood cancer survivorship care. Imagine consenting a family to a clinical trial, informing them that their medical costs may not be covered if they choose to enroll, with no recourse to appeal (as anathematic a task it is). What consequence would that have on clinical trial enrollment, progress in cancer care and health care disparities? Think of the patient with hemophilia who has annual and/or lifetime caps enforced for their product. Recall the time when enrollment onto hospice required foregoing any coverage for treatments deemed

curative. Volumes of congressional testimony and countless hard-fought battles occurred in the late 2000's to earn the oft omitted prefix to the actual name of the law, the Patient Protection and Affordable Care Act (PPACA).

Legal, political and economic scholars will continue to debate the merits and flaws respective to their areas of expertise. It is incumbent upon health care professionals, particularly pediatricians and patient advocacy groups, to contribute our part by reminding policymakers why patient protection was required in the first place. Partnership with one's institutional government relations officers can both help harmonize one's message with community members and connect with representatives. Collaborating with institutional colleagues and local patient advocates can strengthen one's message. ASPHO offers resources to enhance one's advocacy skills, build relationships with representatives as well as partner with a variety of other professional societies and coalitions. Through ASPHO involvement, the voices of pediatric hematologists/oncologists and the patients they represent can be amplified through meetings with and letters to Congress, the Department of Health and Human Services, the Centers for Medicare & Medicaid Services, and other agencies.

Advocacy of this magnitude is a time-consuming, non-revenue generating activity with unquantifiable rewards as it may be essential for increasing access and improving health outcomes. The time as well as emotional and professional investments required to have an impact in this space could pale in comparison to what ensues if the elements of patient protection in the PPACA are lost.

*As the primary organization dedicated to supporting pediatric hematologists and oncologists, ASPHO plays a unique role in impacting care of children, adolescents, and young adults with blood disorders and cancer. Founded in 1981, the Society supports member physicians and other healthcare professionals by advancing research, education, treatment, and professional practice. ASPHO sponsors a range of program and co-sponsors Pediatric Blood & Cancer. For more information, visit [www.aspho.org](http://www.aspho.org), or contact ASPHO at [info@aspho.org](mailto:info@aspho.org) or 847-375-4716. Follow ASPHO at [@aspho\\_hq](https://twitter.com/aspho_hq) and [www.Facebook.com/aspho.org](https://www.facebook.com/aspho.org).*

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