



September 8, 2021

The Honorable Cedric Richmond  
Director of the White House Office of Public Engagement  
The White House  
1600 Pennsylvania Avenue, N.W.  
Washington, DC 20500

Dear Rep. Richmond:

My name is Daniel E. Smith, and I am the Executive Director for the Alliance for Proton Therapy Access. We are based in the Washington, DC area but work closely with patients all over the country. The Alliance was started at the end of 2016 when concerned patients, physicians, clinicians, family caregivers, employers and other stakeholders came together in response to reports from across the country that insurance companies were unfairly restricting or delaying access to proton therapy, a proven targeted weapon in the fight against cancer. In the time since we launched the organization, we have gotten to know hundreds of patients, many of whom come to us because their doctor is saying they need proton therapy for the best outcomes only to turn around and find out that their insurance company will not cover the treatment. We work alongside these advocates to put a stop to these improper denials.

President Biden has committed to make cancer a priority in his Administration and end this disease as we know it. One critical step on the path to ending cancer is making sure that advanced cancer treatments such as proton beam therapy - the most advanced radiation oncology modality - are readily available to the patients who will greatly benefit from them. When President Biden met with doctors at the James Comprehensive Cancer Center at Ohio State University, his enthusiasm about cancer research and proton therapy was unequivocal. As he effusively described the innovation taking place there as "a source of hope," he encouraged a continued "focus on proton therapy."

Part of that hope comes from the innovative and groundbreaking research on, and utilization of, proton therapy. Proton beam therapy has a long clinical history, cleared by the Food and Drug Administration (FDA) for use in patients thirty-three years ago. A critical clinical benefit of proton beam therapy is the elimination of excess radiation to healthy tissues and organs, minimizing debilitating and costly side effects. By sparing healthy tissue, proton therapy leads to a decrease in complications, better preservation of quality of life, and for some cancers, higher disease control and overall survival. I am attaching an op-ed that I recently published in *Morning Consult* about this issue.

The Center for Medicare and Medicaid Innovation (CMMI) has ignored the voice of physicians, patients, and the cancer research community as evident by the recently released RO APM. The RO APM undervalues proton therapy by establishing the same payment rates for all radiation treatment modalities without regard for the investment required to deliver this type of radiation. It sets complex adjustments and methodology that is intended to provide a glidepath to equal reimbursement for drastically different priced modalities. These substantial cuts in reimbursement put financial pressure on institutions already burdened by the impact of the ongoing pandemic, thus, straining their ability to ensure quality care and participate in clinical research. **CMMI should exclude proton therapy from the RO Model just as they have proposed to exclude brachytherapy due to its unique and complicated concerns over patient access to specialized care.**

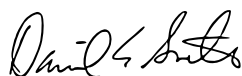
With only 38 cancer centers providing proton therapy, access for patients will be even more limited, leading to an **even wider gap in disparities for cancer patients seeking advanced and specialized treatment**. While other countries are actively expanding access to proton therapy, the RO APM will discourage the use and adoption of this cancer treatment in the United States. This technology and other advanced treatments should not be restricted but should be nurtured and encouraged to be accessible to physicians delivering care and patients who receive it. This is a misguided policy that undermines President Biden's commitment to end cancer by jeopardizing innovation and research, the very concepts that are critical in the fight to end cancer as we know it.

I urge you to support cancer innovation by asking President Biden to instruct CMS to exclude proton therapy from a value-based model that fails to take into account its unique, innovative nature and value to Medicare patients.

Please contact me by phone at 202-999-8923 or by email at [dsmith@allianceforprotontherapy.org](mailto:dsmith@allianceforprotontherapy.org) if you have any questions or would like to additional discussion on this topic.

I appreciate your thoughtful consideration of this very important issue.

Sincerely,

A handwritten signature in black ink, appearing to read "Daniel E. Smith".

Daniel E. Smith  
Executive Director  
Alliance for Proton Therapy Access  
4515 Drummond Ave  
Chevy Chase, MD 20815

 **MORNING CONSULT****Biden Must Push to Make Proton Therapy Accessible to All Cancer Patients (Opinion)**

By Daniel E. Smith | July 7, 2021

In a March tour of the [James Comprehensive Cancer Center](#) at Ohio State University, President Joe Biden's enthusiasm about cancer research and a treatment called proton therapy was unequivocal. Now his administration is weeks away from enacting a controversial Trump-era rule change that could make this cutting-edge cancer treatment inaccessible for many.

Unlike conventional X-ray radiation, proton therapy has the unique ability to precisely target cancerous cells with minimal damage to healthy tissues. Patients treated with traditional radiation often face long-term side effects, and the risk of secondary cancers later in life. Proton therapy minimizes these risks. During his tour, Biden enthusiastically described the innovation taking place there as "a source of hope," and encouraged a continued "focus on proton therapy."

Yet the administration may be about to take a step that would drastically limit patient's access to the amazing benefits of proton therapy. At any moment, the Centers for Medicare & Medicaid Services could implement a devastating policy shift that would effectively deny Medicare patients access to this treatment option.

CMS's move to [change the policy](#), known as the proposed Radiation Oncology Alternative Payment Model (RO-APM), began under the Trump administration. With the rulemaking process nearing completion, Biden must step in by removing this innovative treatment from the proposed model.

If CMS' new policy is implemented as written, many cancer institutions would be in the difficult position of not being able to offer their patients proton therapy, as the reimbursement rate would not adequately cover the costs for delivering this sophisticated technology. Many proton centers may be forced to make the difficult decision to close their doors.

With only [38 cancer centers](#) currently providing the treatment in the United States, access for patients will become even more limited. This will lead to an even wider gap in disparities for cancer patients seeking advanced and specialized treatment. For those unable to afford the treatment they'll be forced to pursue other options—many that lead to unnecessary and permanent side effects—or resort to paying out-of-pocket, a luxury that low and moderate-income Americans are not afforded.

Almost every day, my organization works with patients like [Randy Speed](#) who are seeking access to this groundbreaking cancer treatment. Randy is an American Airlines pilot who once was told that his stage-four esophageal cancer was terminal. For many in Randy's situation, traditional radiation often means lifelong side effects, potentially impacting an individual's ability to swallow or even requiring the use of a feeding tube. But thanks to proton therapy, Randy is now cancer-free and is likely one of the only commercial pilots still flying after such a devastating diagnosis.

If the RO-APM doesn't exclude proton therapy, Medicare beneficiaries seeking the same life-saving treatment as Randy may be out of luck.

Biden has long been a champion for patients in the fight against cancer. As we all know and understand, for him cancer is deeply personal. His administration is well-positioned to reverse the mistakes of his predecessor and protect proton therapy access by removing it from this harmful payment model. Cancer patients deserve the right to work directly with their medical teams to determine the best care plan for them.

Biden has [committed](#) to making cancer a priority in his administration, and to end this disease as we know it. One critical step on the path to ending cancer is ensuring that cutting-edge cancer treatments like proton therapy are available to all who need them.

*Daniel E. Smith is the executive director of the Alliance for Proton Therapy Access.*

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