UNIVERSITY OF UTAH
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CANCER INSTITUTE

Testimony of Heloisa Soares, MD, PhD
Before the U.S. House of Representatives Ways and Means Committee
Field Hearing on Access to Health Care in America:
Unleashing Medical Innovation and Economic Prosperity
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Salt Lake City, Utah

I am Dr. Heloisa Soares, a medical oncologist specializing in gastrointestinal and neuroendocrine cancers at Huntsman Cancer Institute, University of Utah. Neuroendocrine cancer is a rare cancer that can affect any part of the body, but mostly presents in the gastrointestinal tract and lungs. I take pride in our institution's Neuroendocrine Cancer Destination Care Program, designed to provide specialized care for patients who travel from afar. Our program is supported by a dedicated team of experts and offers state-of-the-art treatments that draw patients seeking advanced care.

For me, the journey into medical innovation is deeply personal. My father has courageously battled a rare, slow-growing cancer for the past 20 years. Regrettably, effective treatments for his type of cancer remain limited, leaving us uncertain about how much longer we will have him with us. In a twist of fate, my 35-year-old brother was diagnosed with neuroendocrine cancer, the very disease in which I specialize. He underwent a complex surgery to remove his tumors and is now enrolled in a research study. Witnessing his journey firsthand and the advancements made in the field, when he asked me about putting his affairs in order, I reassured him with heartfelt conviction: "*Always plan ahead, but not because of cancer. Live your life to the fullest, pursue your dreams, and if you desire, expand your family*." The remarkable progress and innovations in treating his type of cancer have given us hope and underscored the transformative impact of medical research and innovation.

However, I am not here to delve into my family history; rather, I wish to highlight the journey of patients like Charlene Edwards, who joins us today with her husband, Rick, from Lindon, Utah. Charlene was diagnosed with neuroendocrine cancer over 18 years ago, a time when her youngest child had not yet entered high school. Upon diagnosis, most of her physicians had never heard of the disease. She was given little hope as, at the time of her diagnosis, there was only **one medical treatment available** to care for her disease. Now, at least another 5 treatments can be offered to patients with her disease, and many more are expected given the progress made thanks to investments and innovations in the field. Charlene's story is a testament to the rapid advancements in medical innovation. Much of this progress is made possible by the robust infrastructure supporting cancer research in the U.S., including the vital contributions of the National Institutes of Health and other federal institutions supporting innovative research and clinical trials.

As the Medical Director of the Clinical Trials Office at Huntsman Cancer Institute, I have the privilege of overseeing over 250 active treatment intervention clinical trials at any given time. These trials are not merely “experiments”; they represent lifelines for patients, offering novel treatments and avenues for hope where conventional therapies have fallen short. One of the

important reasons we can offer these trials in Utah is because the Huntsman Cancer Institute is a National Cancer Institute (NCI) Designated Comprehensive Cancer that serves the entire Mountain West – an area that comprises 17% of the landmass of the continental U.S. We are the **only federally designated cancer center in our region**, **serving Utah, Idaho, Montana, Wyoming, and Nevada**. We work across state lines to serve patient needs in all domains of cancer – these include community partnerships, six affiliate hospitals in neighboring states, collaborative research grants, working with federally qualified health centers, working together to organize state cancer plans, and so much more.

A primary focus of our work at Huntsman Cancer Institute is elevating the standard of cancer care in local communities. Conducting clinical trials is resource-intensive, involving specialized teams and often requiring patients to travel long distances; approximately 30% of our trial participants travel over 150 miles each way. Despite these challenges, we continuously strive to extend research innovations closer to patients' homes, fostering stronger connections to family and community.

Because our mission includes serving rural and frontier communities, where access to specialized care poses significant challenges, we use innovation to improve the care of our patients. Through initiatives like our "short course" radiation therapy clinical trials, we are working to reduce the burden on patients who must travel long distances for treatment by developing effective radiation treatments given in a shorter period of time compared with the traditional 6 weeks of treatment. These trials not only aim to improve accessibility and compliance but also strive to enhance treatment outcomes and quality of life for our patients.

Our researchers have shown that rural residents face higher mortality rates and later-stage diagnoses than their urban counterparts (Cancer Med. 2018, PMID: 29533005). To address distance as a disparity, Huntsman Cancer Institute, for example, collaborates closely with Sweetwater Regional Cancer Center in Wyoming, advising and facilitating trials to enhance accessibility for patients in rural areas. This initiative addresses the unique disparities faced by patients living far from major medical centers.

Federal support is crucial to support these efforts. The federal government in the U.S. has been a major catalyst of medical innovation. There are many ways this can continue. Initiatives like our nationally praised *Huntsman at Home program*, delivering specialized cancer care directly to patients at their homes, exemplify innovative care models that require sustainable funding pathways. So, I advocate for the **Development of Innovative Payment Models** (models outside of traditional "inpatient" or "outpatient" modes of care*)*. Additionally, **coordinating care across state lines** remains challenging, particularly for patients receiving advanced and complex emerging therapies like cellular therapy or radioligand therapies, also known as Theranostics. **Extending telehealth services** and **refining care models for established patients** are critical steps to improve access and support innovation**. Implementation science** is essential for translating cutting-edge therapies and AI into sustainable clinical practice and addressing regulatory and payment challenges. In fact, Huntsman Cancer Institute researchers are leveraging AI and data science to advance cancer research, highlighting the need for federal support to enhance infrastructure for data management and sharing across healthcare systems.

In conclusion, medical innovation is the cornerstone of our progress in cancer care, bridging gaps and enhancing outcomes for individuals and families in our community affected by this disease. Through these innovations, I've been able to conduct telehealth visits with patients who reside

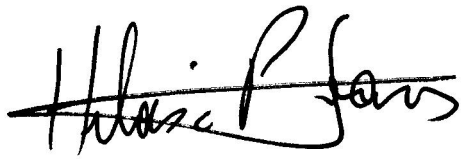
hundreds of miles away, facilitating local coordination of care and administering anti-cancer treatments remotely. This approach has improved treatment adherence and broadened access to virtual care, significantly enhancing symptom management and overall quality of life for cancer patients. Furthermore, I've had the privilege of offering cutting-edge treatments available only at a few select centers nationwide, witnessing firsthand their immediate impact in relieving pain and shrinking tumors....Charlene has received some of these treatments. Providing such new avenues of treatment instills hope where previously there was little, a deeply gratifying aspect of my work. As a poignant reminder, Charlene often reminds me that Huntsman Cancer Institute is located on Circle of Hope Drive, a testament to our commitment to advancing cancer care and inspiring optimism.

I am honored to be with you today and grateful for Congress' role in advancing innovations through federal programs, notably the National Institutes of Health and the National Cancer Institute Cancer Centers Program. This has fostered an outstanding infrastructure that translates research highlights into medical innovations daily through community collaborations, clinical trials, transformation of healthcare delivery, and so much more.

And, I am incredibly grateful to my patients, like Charlene, and their families. Patients are our critical partners in advancing innovation.

I'd be happy to answer any questions you may have.

Sincerely



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