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The Value of Innovation Policy Forum in Five Quotes

Michelle Winokur, DrPH, Executive Director of the Institute for Patient Access

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.

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If you missed it, here's a summary of the meeting in five quotes.

1. "My patients deserve to define value on their terms – to appreciate innovation for not only what it does for their health, but also for the meaning it brings to their daily lives."

In his opening remarks, David Charles, MD, reminded attendees that patients' definitions of medications' value have nothing to do with money. For example, they more often frame value as quality of life – feeling good enough to enjoy time with family and be productive at work.

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2. "We're going to need more innovation in drug development for Alzheimer's."

Geriatrician Howard Fillit, MD, of the Alzheimer's Drug Discovery Foundation, emphasized that while beta-amyloid drugs might affect disease progression, there's also a need to look at the effects of aging – the leading risk factor for Alzheimer's. Transferring what is known about aging into the therapeutics for Alzheimer's will be essential.

3. "The reason we can debate whether the pandemic is over is because of the vaccines."

It took just 338 days from when Chinese scientists revealed the sequence for a new coronavirus to the day an ICU nurse on Long Island became the first person in America to roll up her sleeve and get the shot. In his keynote address, author David Health provided the backstory to this feat and explained how vaccine science has changed forever.

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4. "It's hard for innovation to continue if it's not paid for."

Pam Traxel of the American Cancer Society Cancer Action Network implored policymakers to provide adequate payment for innovative diagnostics and treatments. For example, Medicare reimburses for only five types of cancer screening. It's impossible to beat cancer if it's not diagnosed – and doing that requires meaningful insurance coverage.

5. "My name is Emily Bonnell. I have CF, and I'm going to die."

In the event's closing video, parent and advocate Laura Bonnell described her daughter Emily as a kindergartner grappling with cystic fibrosis. Laura explained that the breakthrough drug that corrects the underlying condition that causes cystic fibrosis worked for only one of her daughters – Molly, not Emily. Laura advocates for continued innovation in hopes that both of her daughters will get to live.

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Even though the event didn't focus on innovation in neonatology, the need for it – and the policy that supports it – are undeniable. Watch the recording of the event on IfPA's website.

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This content article was also published at InstituteforPatientAccess.org

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