

# It Was Worse Than Open-Heart Surgery

Ashley Yeary

The Alliance for Patient Access ([allianceforpatientaccess.org](http://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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Five weeks after Sawyer’s operations, things took a turn for the worse. He got very congested. His breathing was slow, then rapid. Thankfully, his pediatrician saw him right away.

## **RSV Positive**

The doctor diagnosed him with the respiratory syncytial virus. I didn’t know a lot about RSV then, but I was still scared. I knew any respiratory illness was going to be bad for him. His heart condition had allowed fluid to build up in his lungs, causing irreversible damage, and he was still recovering from heart surgery. Sawyer was admitted to the hospital close to our home but was soon transferred to Arkansas Children’s Hospital because he needed higher-level care.

I will never forget the terror of those few days. I was helpless as he struggled to breathe. Alarms were constantly going off, and all I could do was step aside for nurses to rush to his aid. More than a week later, Sawyer finally turned the corner.

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## **Fighting For Protection**

As fall rolled around, his pediatrician insisted we protect him with a medication called palivizumab. His lungs were weak and scarred, she told us. After fighting for coverage with our insurer, we got Sawyer his first injection.

Just a few weeks later, he caught RSV again. We started him on inhalers and antibiotics and watched him closely. He was sick, but this time his illness wasn’t as severe. I credit palivizumab. I’m certain his second RSV experience would have been worse without it.

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## **Sharing Our Story**

Now, Sawyer is a rambunctious four-year-old. He still uses an inhaler every morning and night, but he fills the hours in between playing soccer, swimming, and roughhousing with his little sister and their dog.

It’s refreshing for me to see Sawyer, who was once so delicate,



be so full of energy. It's what motivates me to share our story and to advocate for RSV awareness and access to treatments and interventions that will help protect all infants. Every parent deserves to see their child experience the same joy that Sawyer now has.

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*Ashley Yeary is a mom of two children and a member of the RSV Parent and Caregiver Advisory Council for the National Coalition of Infant Health, a coalition partner of the Alliance for Patient Access.*

*Guest blog posts like this one give life to policy, often discussed in technical jargon and sweeping generalizations. In reality, health care policy affects real people’s access to life-saving medications. As noted, Sawyer’s mother, Ashley, shares their family’s story to help policymakers and others in power understand the serious implications of cost-cutting utilization management approaches.*

*This content article was also published at [InstituteforPatientAccess.org](https://www.allianceforpatientaccess.org)*

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