

# VALUE & OUTCOMES SPOTLIGHT

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## LETTER FROM THE EDITOR



This issue of *Value & Outcomes Spotlight* comes in the wake of the passing of Muhammad Ali, the self-proclaimed and widely acknowledged “greatest of all time” in the pantheon of boxing greats. Anyone alive during the second half of the 20th century would know Muhammad Ali, as for a long time he was the most recognizable human being on the planet. His influence went well beyond the boxing ring, as he was a pivotal figure in 1960s US politics based on his involvement in the civil rights movement, religious conversion to Islam, and refusal to be inducted into military service in protest of the war in Vietnam—an act that cost him his championship title and instigated a three-year ban from the sport.



But Ali spent nearly half his life in a very different kind of fight—against the debilitating effects of Parkinson’s Disease. He was diagnosed in 1984 at the relatively young age of 42 and it is widely believed that brain

trauma from repeated blows to the head played a causative role. It is possible that the disease had come on even earlier, as evidenced by his slurred speech in televised interviews even before his retirement from boxing in 1981. In any case, his disease progressed rapidly so that, by 1996, when he so courageously re-appeared on the global stage to light the Olympic flame at the Summer Games in Atlanta, his limbs shook uncontrollably as he held the torch.

In this era of patient advocacy, patient centrality, patient-reported outcomes, and the Patient-Centered Outcomes Research Institute (PCORI), we should acknowledge the example Ali set in this regard. He was a pioneer of sorts in regard to all matters related to the voice of the patient. Afflicted with a disease the symptoms of which could not be more overt as they progress, he chose not to hide away from public scrutiny but to continue on in the public eye, leveraging his celebrity and influence to increase Parkinson’s awareness and raise hundreds of millions of dollars to support research and treatment.



In his final years Ali resided in Phoenix, Arizona and contributed to the eponymously named Muhammad Ali Parkinson Center at the Barrow Neurological Institute ([www.barrowneuro.org](http://www.barrowneuro.org)). The website currently contains video tributes to Ali from other Parkinson’s patients who were positively impacted, directly or indirectly, by the example he set as he fought the disease. It’s pretty moving so highly recommended if you have an interest.

Muhammad Ali was definitely the greatest of all time — the greatest example of the power of the patient the world has ever seen.

David Thompson, PhD  
Editor-in-Chief, *Value & Outcomes Spotlight*

*Photos courtesy of David Thompson*

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