



**James Allen Heywood**  
**Co-founder and Chairman**  
**PatientsLikeMe**

An MIT engineer, James Heywood entered the field of translational research and medicine when his brother Stephen was diagnosed with ALS in 1998 at the age of 29. With experience in design, information technology, systems modeling, neuroscience and industrial engineering, Heywood brings a unique perspective to drug discovery and medicine. The scientific and business innovations he has developed during his career are transforming the intersection of biotechnology and pharmaceutical development, personalized medicine and patient care.

In 1999, shortly after Stephen was diagnosed, Heywood founded the ALS Therapy Development Institute (ALS TDI), the world's first non-profit biotechnology company, where he served as CEO until 2007. Pioneering an open research model and an industrialized therapeutic validation process, Heywood led ALS TDI to become the world's largest and most comprehensive ALS research program. The comprehensive in-vivo validation program Heywood developed was unable to replicate any of the published preclinical studies of the field that led to human trials calling into question the standards that allowed many drugs to be tested on patients. ALS TDI continues to grow and runs large-scale discovery and informatics program focused on finding an effective pathway for treating ALS.

Today, Heywood is the chairman of PatientsLikeMe, where he provides the scientific vision and architecture for its patient-centered medical platform. He co-founded the company in 2004 with his youngest brother, Benjamin, and friend, Jeff Cole. Named one of "15 companies that will change the world" by CNN Money, PatientsLikeMe is a personalized research and peer care platform that allows patients to share in-depth information on treatments, symptoms and outcomes. This novel open model allows clinicians, providers and the pharmaceutical industry to better understand diseases and the patient experience. Patients improve their care while actively partnering with industry to accelerate and influence the development of new treatments and biomarkers.

In 2009, Heywood and a small group of thought leaders founded HealthDataRights.org, an organization that asserts a new patient right to access a copy of all of their medical data in a computable form. This has become a new voice for patient centrality in the healthcare debate.

A published author, frequent speaker, media pundit and active investment advisor, Heywood speaks at business, government and academic conferences around the world, including TEDMED, the Milken Global Conference, Health 2.0, Gov 2.0, Personal Democracy Forum, Institute of Medicine and the NIH. He is a member of the CDC's National Biosurveillance Advisory Subcommittee and has testified on privacy and social policy before the U.S. Department of Health and Human Services (HHS) and the U.S. Food and Drug Administration (FDA).

Heywood's work has been profiled in the *The New Yorker*, *The New York Times Magazine*, *Businessweek*, *60 Minutes*, *CBS Evening News*, *NPR*, *Science*, and *Nature*. In 2009, he was chosen for *WIRED* magazine's "Smart List" and *Fast Company*'s "10 Most Creative People in Healthcare." Heywood and his brother Stephen were the subjects of Pulitzer Prize winner Jonathan Wiener's biography, *His Brother's Keeper*, and the Sundance award-winning documentary, "So Much So Fast."