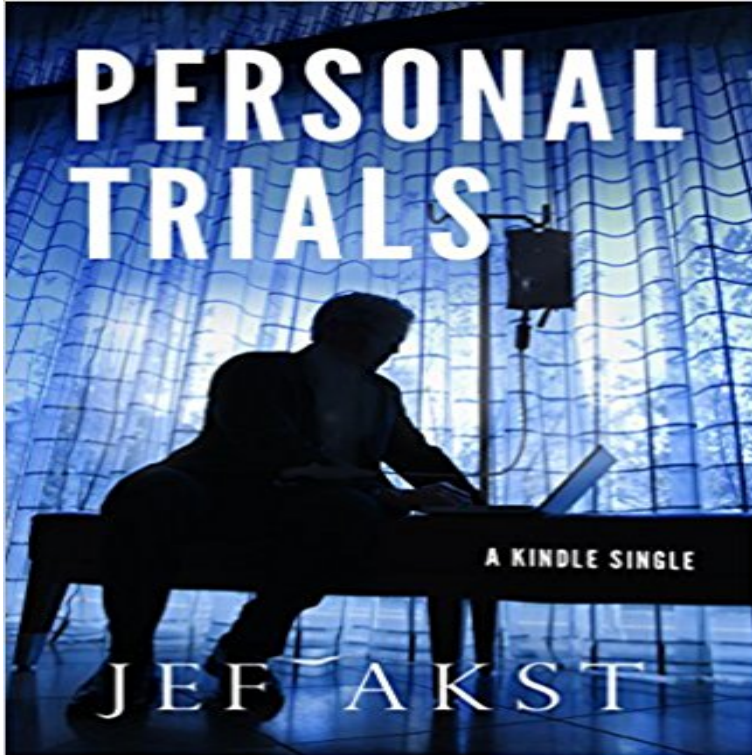


Personal Trials: How Terminally Ill ALS Patients Took Medical Treatment Into Their Own Hands (Kindle Single)



ALS is fatal. There is no cure. There is only one approved treatment, which extends the life span of ALS patients by an average of only three months. But one group of patients took their treatments into their own hands fighting not just for their own lives, but for a disease community that for years has struggled to be heard. Personal Trials is the story of Ben Harris, Rob Tison, and Eric Valor, who joined dozens of other patients in meticulously researching experimental treatments and in dosing themselves with chemical substitutes. All the while, the patients tracked their results openly online charting thrilling improvements and devastating physical decline hoping their experiences would enlighten others and advance ALS research. Facing a frustratingly slow and opaque biomedical research system, they believed their most important work was to share their data with the world. As Ben always said, If it is done in secret, it is done in vain. Jennifer Jef Akst is an editor at The Scientist magazine, where she has worked since she finished her masters degree in biology at Indiana University in 2009. She writes about all things life science but has a special interest in patients who self-experiment with unproven treatments and track their results online. She refers to this phenomenon as do-it-yourself (DIY) medicine and has reported on how such DIY efforts could either hinder or accelerate traditional clinical research. Cover design by Kerry Ellis

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