



Electronic Long Form (ELF) Disclosure of Alison Bateman-House, PhD, MPH, MA  
This contains events from 2014-to July 6, 2020

My salary is paid by New York University Grossman School of Medicine and a gift from Parent Project Muscular Dystrophy, in support of the Pediatric Gene Therapy and Medical Ethics working group, which I co-chair.

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I tweet frequently about preapproval access and other issues. Tweets are my own; I do not tweet on behalf of my employer, nor do I tweet paid content. @ABatemanHouse

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I serve on a data safety monitoring committee for a clinical trial sponsored by the National Eye Institute (paid).

I serve on the NYU Langone Health COVID-19 Data Safety Monitoring Board (unpaid).

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I fill (or filled) the following roles for the Compassionate Use Advisory Committee (CompAC) project, a collaboration between NYU School of Medicine and Janssen Pharmaceuticals through which panels of physicians, patient representatives, and bioethicists provide guidance on the ethical allocation of a variety of investigational agents:

Non-voting, non-paid deputy chair, daratumumab (Darzalex) pilot – now closed

Non-voting, non-paid chair, CompAC Infectious Diseases

Non-voting, non-paid chair, CompAC Neurology/Psychiatry

Voting, non-paid member, Pre-Com (which handles requests not covered by another CompAC)

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I am an (unpaid) associate fellow of the foundation/public benefit corporation Governance, Ethics, Evidence, Policy, Practice (ge2p2), which sponsors a pro-vaccine policy project, <https://centerforvaccineethicsandpolicy.net/about/>, and publishes a weekly newsletter on vaccine ethics and policy, and advises industry, NGOs, and global health organizations on ethical access to medicines and vaccines. I am also a member of its Independent Bioethics Advisory Committee, which advises pharmaceutical companies and other organizations on the fair and transparent allocation of investigational drugs and provides ethics consultation in other areas. I do not get paid for my work in this capacity; however, GE2P2 has a financial relationship with the NYU Division of Medical Ethics.

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I am an unpaid member of Kids V. Cancer's compassionate use advisory board.

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I have received payment for ethical advice to the Sturge-Weber Foundation.

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I have advised the following entities on issues related to access to investigational medicines. I was not paid for this work.

Abeona Therapeutics  
Alexion  
ALS Association  
Biogen  
Coalition Against Childhood Cancer (CAC2)  
Cognition Therapeutics  
Cytokinetics  
Johnson & Johnson  
Kids V. Cancer  
MaxCure Foundation  
More Than Our Stories  
National Brain Tumor Society  
National Organization for Rare Diseases  
Neuralstem  
Pfizer  
Rare Advocacy Movement  
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In order to speak at/participate in events, I have accepted travel assistance from the following entities:

American Association for Cancer Research (AACR)  
American Society for Gene and Cell Therapy  
BIO  
CBI  
Children's Hospital of Philadelphia  
DIA  
Direct Relief  
European Organization for the Research and Treatment of Cancer (EORTC)  
EveryLife Foundation for Rare Diseases  
ExL Events  
Informa Connect  
Institute for Advanced Clinical Trials for Children (I-ACT)  
International Bar Association  
IQPC  
Johns Hopkins Carey Business School  
Johnson & Johnson  
Motor Neuron Disease Association  
Parent Project Muscular Dystrophy  
Polish Academy of Sciences  
Reagan-Udall Foundation for the Food and Drug Administration  
Society for Clinical Trials  
The Conference Forum



University of Cincinnati Center for Clinical & Translational Science & Training  
University of Pennsylvania Department of Medical Ethics and Health Policy  
University of Pennsylvania Orphan Disease Center Ethics Advisory Committee  
University of Rochester Technology and Rare Disease Symposium  
US Food and Drug Administration  
WCG  
World Orphan Drug Congress  
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I have received payment/honoraria for speaking about preapproval access from the following entities:

Biogen  
Amyloidosis Research Consortium  
University of Pennsylvania Department of Medical Ethics and Health Policy  
University of Pennsylvania Orphan Disease Center Ethics Advisory Committee  
Weill Cornell School of Medicine  
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The Division of Medical Ethics received payment for my speaking to the following entities:

ALS Association  
Bionical Emas/UCB  
GE2P2  
Roche/Genentech