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.

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

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).

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)

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.

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

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