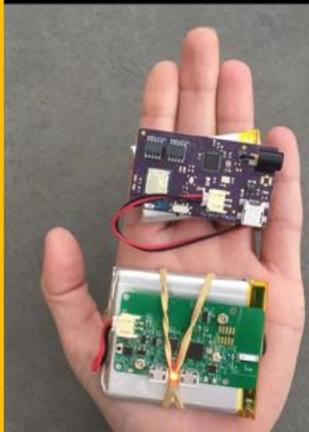
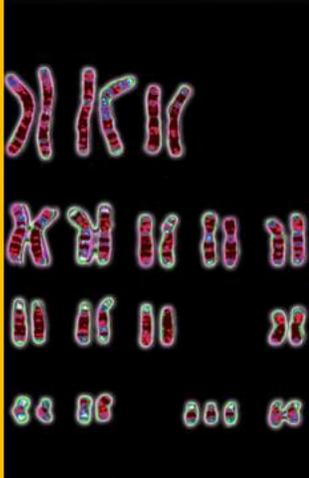


# Cure and Its Malcontents: The Promises and Problems of Biomedical Technology

Dr. Becca Monteleone

@BeccaMonteleone

Slides Available at [RebeccaMonteleone.Com](http://RebeccaMonteleone.Com)

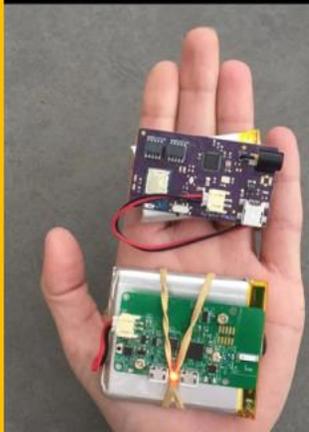
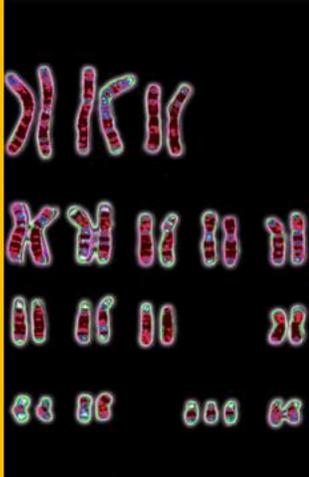


“If they had talked to the patient first, they would’ve pointed that out right away. You’re going in the **wrong direction** here. People with Parkinson’s should be the ones who are designing these things.”

Barry, Spouse of DBS User



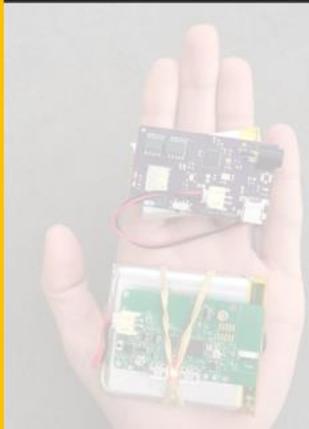
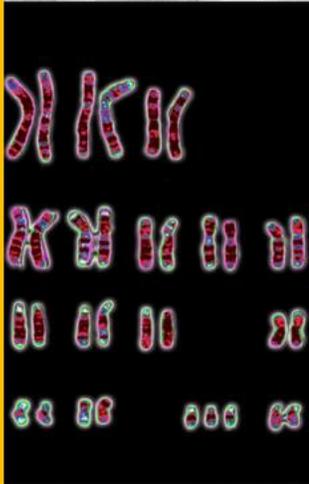
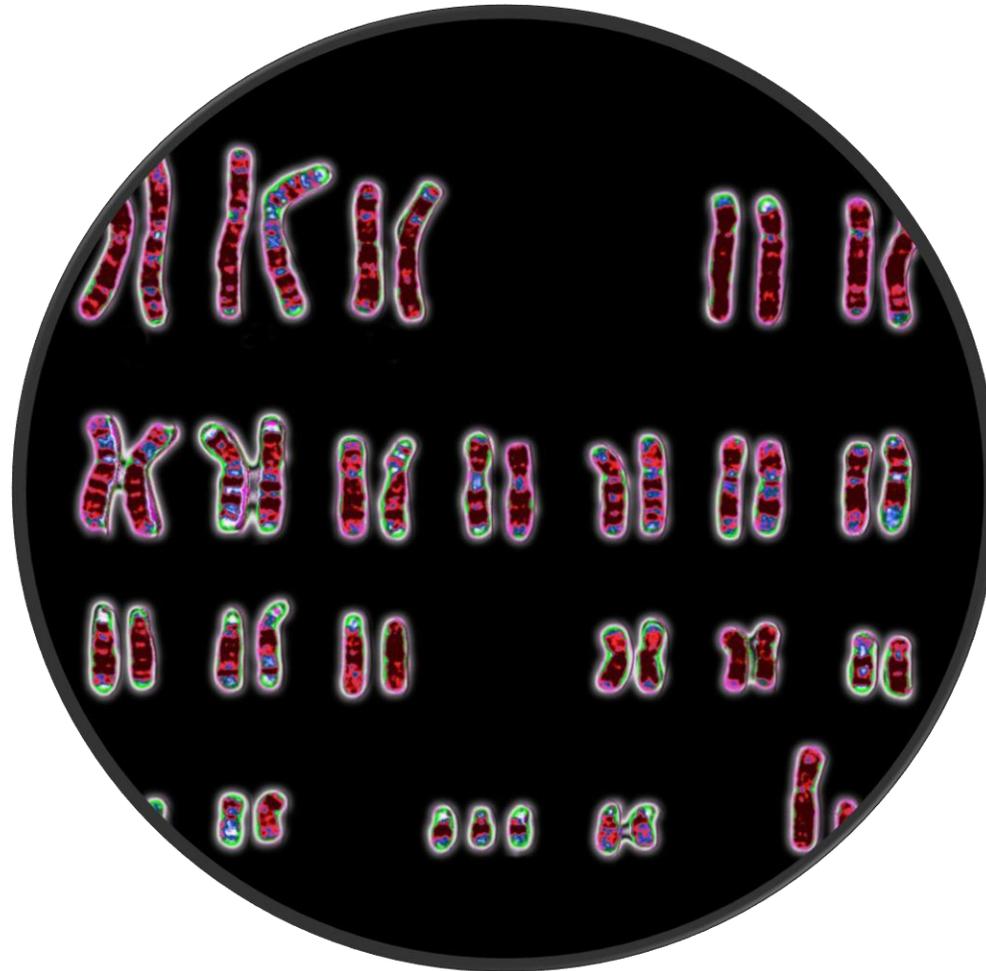
Biomedical technologies are designed to ostensibly provide new kinds of knowledge or autonomy.



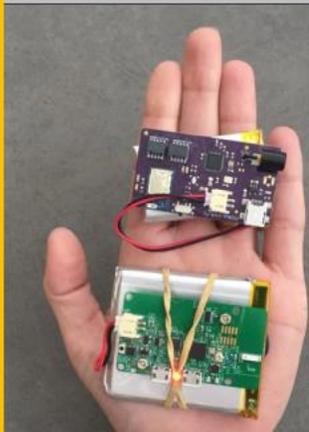
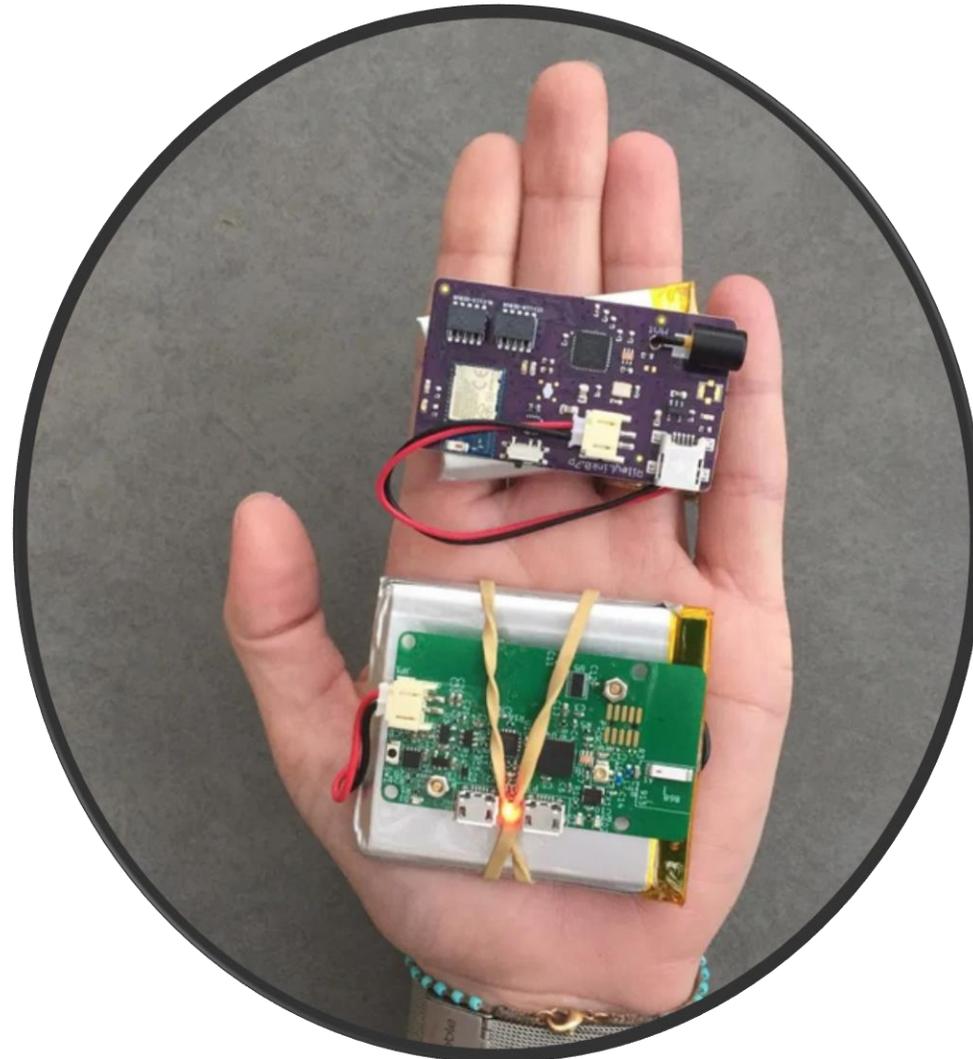
# Deep Brain Stimulation



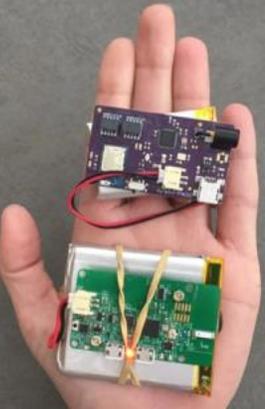
# Prenatal Genetic Testing and Screening



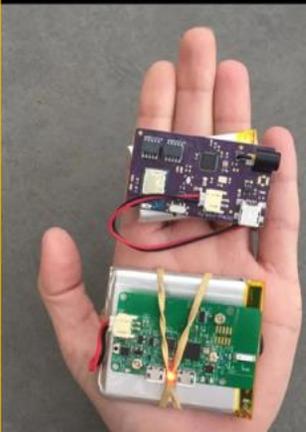
# DIY Artificial Pancreas Systems



Biomedicalization  
demystifies and pathologizes  
disability

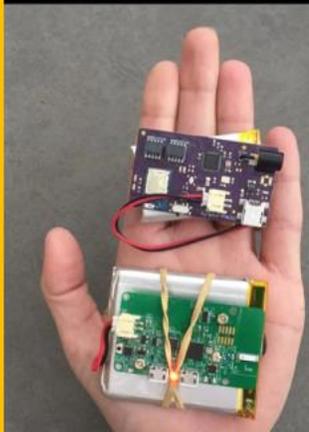
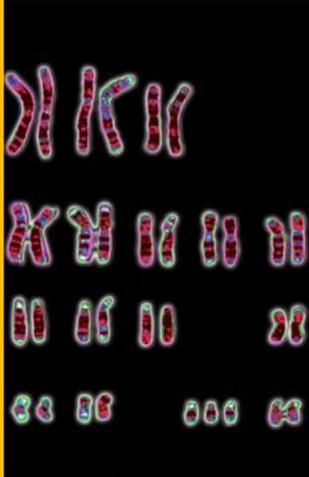


Technology is embedded with  
political and social assumptions



**Technoableism** is “a rhetoric of disability that at once talks about empowering disabled people through technology while at the same time reinforcing ableist tropes about what bodyminds are good to have and who counts as worthy.”

Shew, 2020

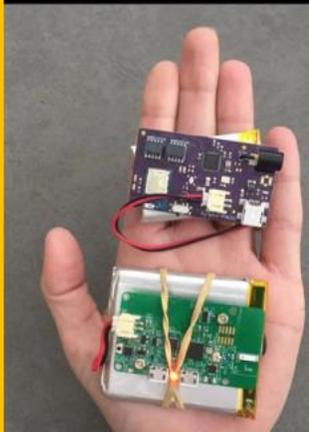
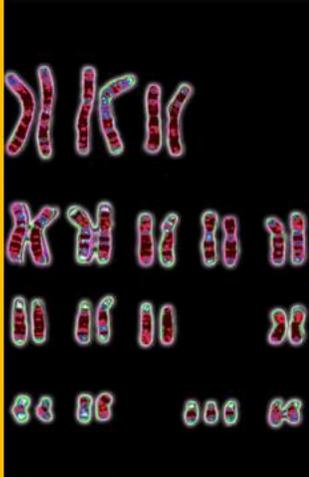


# The Promise of Self-Responsibility



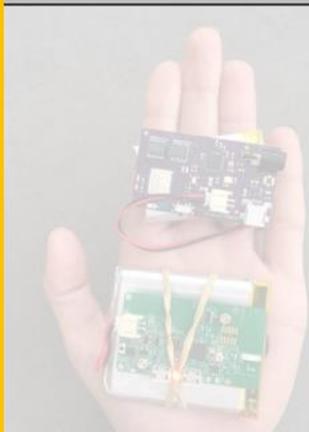
Neoliberal Ableism results in  
“increased expectations on the  
autonomy of self-responsible  
citizens to care, educate, and  
govern themselves.”

Goodley, 2014



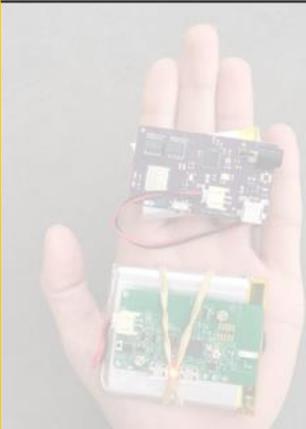
“I needed to lighten the load, which has not been terribly lightened, but I needed to lighten the load of my lovely caregiver wife, who I owe everything to...it’s one of those difficult things, where you know you’re a burden but you don’t know what to do about it.”

John, DBS User



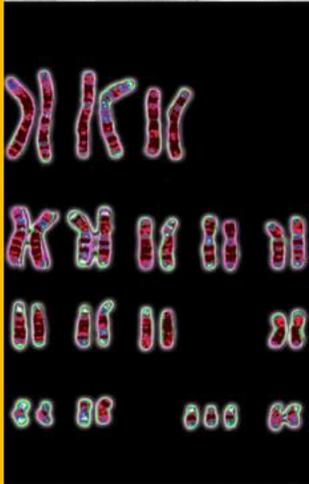
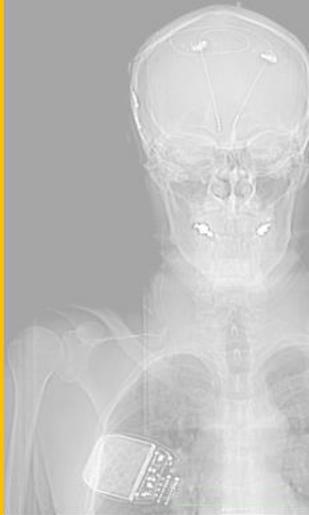
“It’s kind of like, you die and go to heaven and you’re all upset at God and you tell him and he’s like, ‘Well, what do you mean? I gave you DBS, why didn’t you try it?’”

John, DBS User

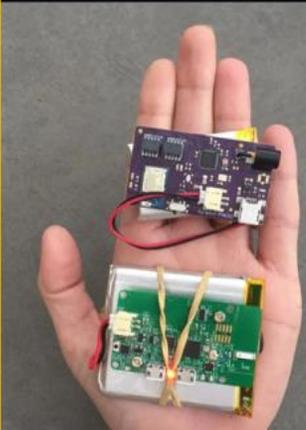
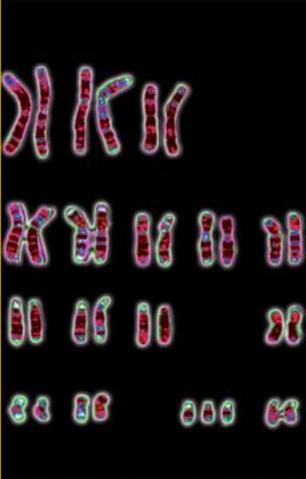


“I had to **prove** that I'm going to do everything I can if it's going to be something wrong or whatever.”

Abby, Prospective Parent, NIPT User

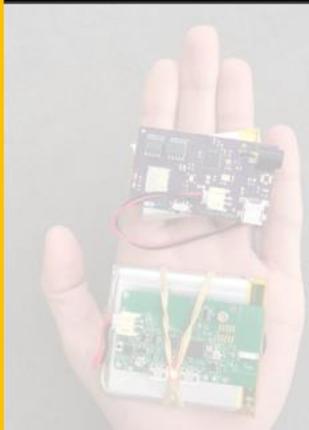
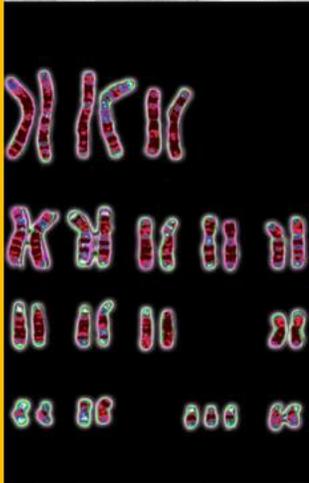
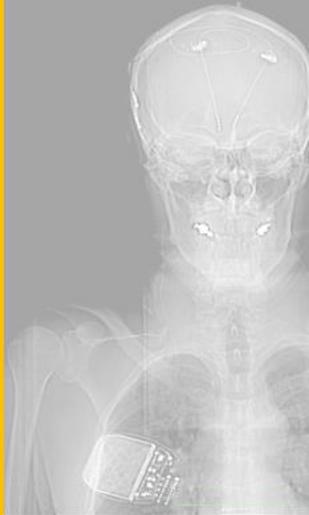


# The Promise of Knowledge



“I just figured **knowledge is power** and we might as well know what we’re dealing with.”

Patsy, Prospective Parent, Preconception Genetic Screening User



“Some stuff you want to take off the table. In terms of the ultimate goal of providing the start of a long, healthy, and happy life... [I don't] know much of the ins and outs... you could test for other, more common issues. Down syndrome and the like.”

Gene, Prospective Parent, PGS User

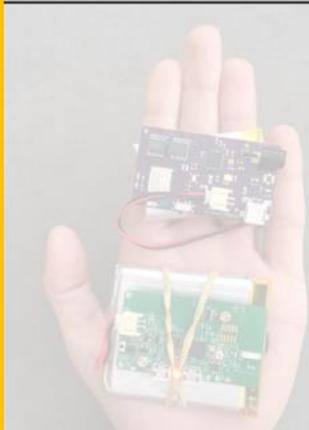


# The Promise of Control



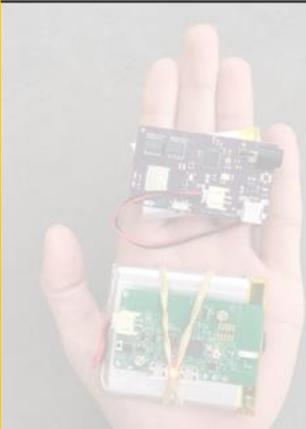
“Don’t let tremors  
control your life.”

Hospital Information Sheet for DBS



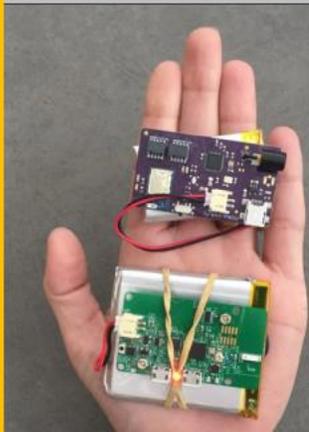
“His ego was in the way. It was like he had to somehow conquer my brain. And conquer these tremors and make them go away.”

Vickie, DBS User



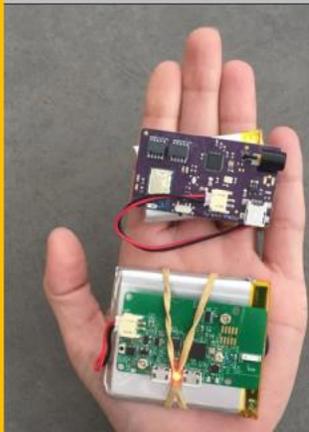
“...they're not evil people. They're just burned out. **They're tired.** They're overwhelmed by it. And how do you keep doing the same thing, and not getting good results, and keep caring to do it?”

Carolyn, APS User



“And also, there's a lot of blaming patients for not getting desirable results...And right now if you are sticking to the book, I don't think it's possible to get anywhere near the desirable temp 7% target that all the professional associations want.”

Gary, APS User

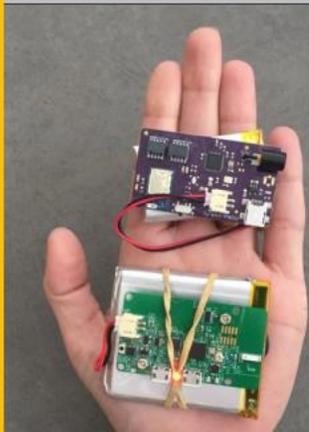


# The Promise of Cure



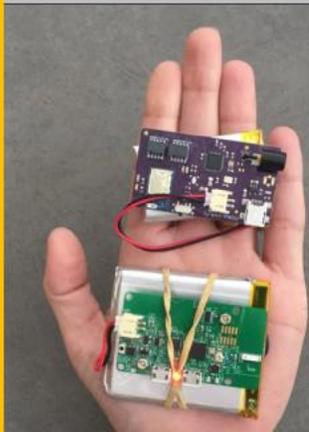
“These are human choices that humans made, and it's changeable...The disease state, maybe not, but everything that we build around it is. We made it this way and it doesn't have to be this way. It could be a different way.”

Gordon, Father of APS User



“I mean, even just this insight of like, the shift from quality of life to cure, I think is really critical. Because cure is so inaccessible, like it's the specialized guild and **priesthood of medicine** that has all these boundaries around it that you can't cross.”

Gordon, Father of APS User

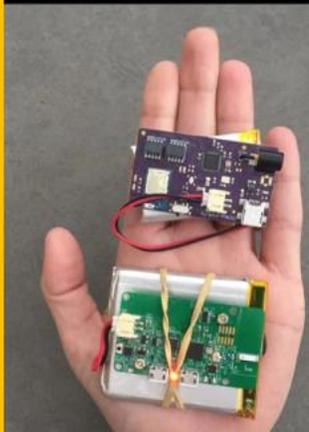
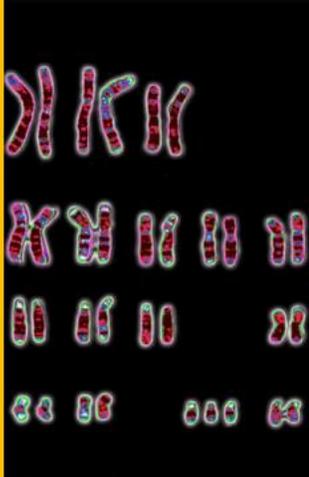


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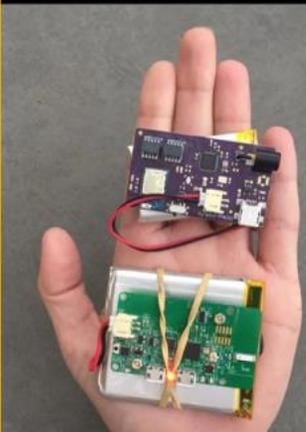
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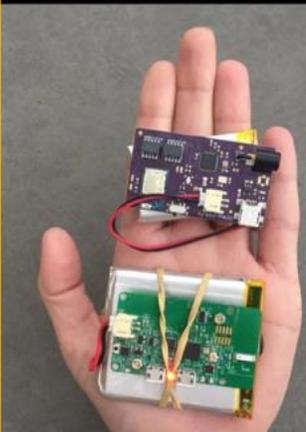
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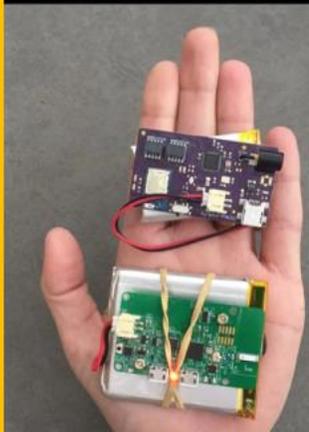
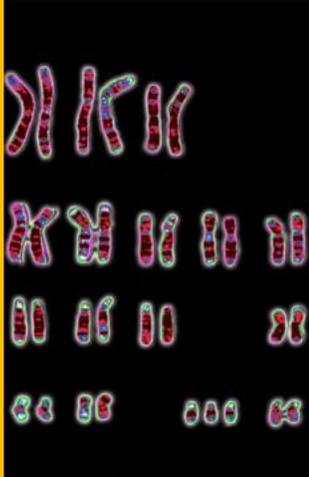
# Obligations of the Neoliberal Subject



# Boundaries and Transgressions

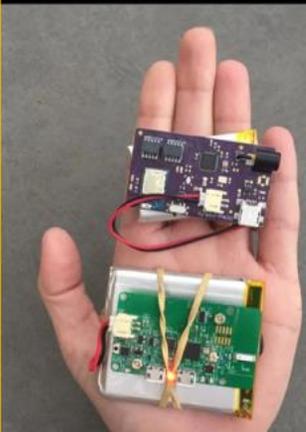


# The Mundanity of Technology



“It has changed the way I live my illness,  
but it has not changed me as a person.”

Abene, APS User



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