kn·own·able

Ownership of Knowledge: Beyond Intellectual Property,
MIT Press, 2023.

Chapter 9
by Myles W. Jackson

WHO OWNS THE GENETIC INFORMATION *given to* PERSONAL GENETICS COMPANIES?

And what can be done with it?

BIOCAPITALISM

INFLUENCES THE RELATIONSHIP BETWEEN
OWNERSHIP & KNOWLEDGE:

GENE PATENTING
VS.
GENETIC INFORMATION

HISTORIANS HAVE A ROLE TO PLAY

in understanding and addressing the unequal power relations:
→ THERE ALWAYS HAVE BEEN ALTERNATIVES AND NOTHING IS INEVITABLE ←

Patent requirement:
KNOWLEDGE OF A
GENE'S FUNCTION

Patent requirement:
KNOWLEDGE OF
WHAT THE GENE CODED FOR

Patent requirement:
SEQUENCES OF GENES WITH **UNKNOWN FUNCTIONS**

1970 — 1980 — 1980

OWNERSHIP OF GENETIC KNOWLEDGE HAS SHIFTED FROM **MOLECULAR BIOLOGY** TO **BIOINFORMATICS**

PERSONAL GENOMICS COMPANIES

- BIG PHARMA COMPANIES
- INSURERS
- EMPLOYERS

LAW ENFORCEMENT

PRECISION MEDICINE
TAILORS TREATMENTS BASED ON GENETIC MAKEUP

MINE! vs. MINE!

GENETIC MATERIAL (BIOMATERIALITY) VS. **INFORMATION** THE GENETIC CODE PROVIDES

LEGAL PRECEDENTS

HIGHLIGHT TENSION BETWEEN **INDIVIDUAL RIGHTS** AND THE ADVANCEMENT OF **MEDICAL RESEARCH**

MOORE V. REGENTS OF THE UNIVERSITY OF CALIFORNIA (1990)

MINE!

BUT: THE PATENTED CELL LINE CELLS WERE LEGALLY DISTINCT

COURT DECISION: EXTENDING "CONVERSION LAW" TO BIOMEDICAL RESEARCH COULD HINDER SCIENTIFIC PROGRESS

GREENBERG V. MIAMI CHILDREN'S HOSPITAL RESEARCH INSTITUTE (1980S)

DONORS

WE ARE EXPECTING THE RESULTS TO REMAIN PUBLIC AND AFFORDABLE!

COURT DECISION: RECOGNIZING A PROPERTY RIGHT IN DONATED BIOLOGICAL MATERIALS WOULD HINDER MEDICAL RESEARCH

DR. WILLIAM CATALONA V. UNIVERSITY OF WASHINGTON (2006)

UPON RESIGNING, I WILL TAKE THESE SAMPLES WITH ME, BASED ON CONSENT FORMS

CONSENT FORM

INVALID

COURT DECISION: ALLOWING INDIVIDUAL CONTROL OVER RESEARCH SAMPLES COULD HINDER SCIENTIFIC PROGRESS

BIO-GENETIC INFORMATION *becomes a* SIGNIFICANT FINANCIAL ASSET

MORAL IMPLICATIONS

WE NEED: CLEARER PRIVACY POLICIES & CONSUMER PROTECTIONS

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doi.org/10.7551/mitpress/14648.003.0014