

Faculty of Law



Invitation Uitnodiging Taletšo

Inauguration
22 May 2018

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Professor Annelize Nienaber
Head of the Department of Public Law

(BA (UP) H Dipl (Ed) (Wits) B Hons (English Literature & Literary Theory) (Wits) LLB (UP) LLM (*cum laude*) (UP) Diploma in Datametrics (Unisa) LL.D (UP), cordially invites you to her inaugural address

Entitled:
**Meaningful knowledge? Law and ethics
in post-genomic gene-therapy research**

Date:	Tuesday 22 May 2018
Time:	18:00 for 18:30
Venue:	Senate Hall, Hatfield Campus, University of Pretoria
GPS coordinates:	S25° 45' 21" E28° 13' 51"
Dress:	Business attire
RSVP:	By 15 May 2018 (click on the invitation to access an online RSVP form) Inquiries: Juanita Larkin, +27(0)12 420 2415 or juanita.larkin@up.ac.za

Refreshments will be served after the conclusion of the address.

* Please refer to page 2 for an abstract of the inaugural address.

Make today matter



Abstract

Meaningful knowledge? Law and ethics in post-genomic gene-therapy research

"... Illness might progressively vanish, but so might identity. Grief might be diminished, but so might tenderness. Traumas might be erased but so might history. Mutants might be eliminated but so would human variation. Infirmities might disappear, but so might vulnerability. Chance would become mitigated, but so, inevitably, would choice."

Siddhartha Mukherjee *The gene: An intimate history* (2016) 492

Towards the end of the second decade of the twenty-first century scientists are at the point of discoveries that source the knowledge flowing from our ability to 'map' the human genome and see it put to use. New 'gene-editing' techniques such as CRISPR have the potential to enable scientists to engineer precise changes in the human genome – a feat unimaginable in the previous century. Though there is theoretical knowledge we have little understanding of their fidelity or efficiency in practice or of the consequences for the human genome. The future for genetic manipulation and of gene-therapy research is full of promise – foreseeing an end to some of the most devastating of human disease.

Perhaps now is the time to recall the lessons learnt from the history of clinical research: lessons of scientific, philosophical and ethical import. History may not repeat itself, but as the human genome is repeated in each generation, the history of clinical research may be a repetition. The impulses, desires and weaknesses that drive human history and scientific discovery, too, are encoded in the human genome. The genome itself is weighted with history – containing peculiar fragments of DNA inserted millennia ago – fragments which are neither human nor animal, but remnants of viruses long lost in the history of evolution. The history of clinical research, similarly, has in its DNA lessons of past failure, the consequence of ignorance, overreach and arrogance. Lessons that should have been well-learned.

In order to derive meaningful knowledge and benefit from the ability to 'read' the human genome and to use gene-editing technologies such as CRISPR we need to reassess the meaning of concepts such as 'consent', 'risk' and 'justice' in relation to clinical research. Here at the tip of Africa, in assessing the meaning and value of knowledge gained from clinical research and its application in gene-therapy techniques, research ethics committees must take to heart the lessons to be learned from the past of clinical research and scientific discoveries.