

Jacquie Greenberg PhD

Professor of Human Genetics at the University of Cape Town

Professor Jacquie Greenberg is an HPCSA registered medical scientist and genetic counsellor who has been involved with molecular genetic diagnostic testing in the Division of Human Genetics at UCT and GSH for over 40 years. She is one of only 16 registered genetic counsellors in SA; is a NRF rated scientist and served on UCT Research Ethics Committee/s for a number of years. She is the course convenor of one of only two Masters in Genetic Counselling courses in SA and is an advisory board member of the Transnational Alliance of Genetic Counsellors (TAGC).

Prof Greenberg has been involved with the Department of National Health in South Africa with the drafting of regulations and guidelines relating to the new National Health Bill for the section on human cloning, stem cell research, the use of DNA, genetic testing and the import and export of biological material. She was a member of the Faculty of Health Sciences Research Ethics Committee (2002-2007) having previously served on the Animal Research Ethics committee (2000-2001).

Prof Greenberg's current research focus is on translational genetics and in particular, is concerned about the practice of safe science and providing an ethically sound genetic healthcare service.

Selected publications related to ethics.

Stem cells on South African shores: Proposed guidelines for comprehensive informed consent. **Greenberg J**, Smith D, Pope A. Correspondence S Afr Med J 2013;103(1):6

Genetic testing and related ethical issues. **J Greenberg**. 2005 CME January 23 (1) 18-21

A rare homozygous rhodopsin splice site mutation : The issue of when and whether to offer presymptomatic testing. **J. Greenberg**, L. Roberts, R. Ramesar. Ophthalmic Genet. 2003 ; 24(4): 225-32.

Analysis of RPGR in a South African Family with X-linked Retinitis Pigmentosa; research and diagnostic implications. George Rebello, Alvera Vorster, **Jacquie Greenberg**, Natalie Coutts, Lisa Roberts, Liezle Ehrenreich, Dumisani Gama, Rajkumar Ramesar. 2003 : Clin Genet 2003 Aug, 64(2):137-41

Huntington Disease: Prenatal Screening for late onset disease. **J Greenberg** : 1993 J Med Ethics. Letter to the Editor 19: 121-122.

Chapter in SA Ethics Book : *Medical Ethics, Law and Human Rights: A South African Perspective*. Co-authored chapter entitled : *Genetic and ethical complexity*. **Jacquie Greenberg**. Editor: Keymanthri Moodley ISBN Number: 978 0 627 02809 0 : Associate Professor & Head, Bioethics Unit - Tygerberg Division, Faculty of Health Sciences & Centre for Applied Ethics, University of Stellenbosch. Van Schaik Publishers 2011: This book is recommended by all medical schools for undergraduate teaching. Published January 2011 P291-316

- Invited Speaker/Chair at the 3rd Annual ARESA Research Ethics Seminar Southern Sun Newlands, Cape Town 18-19 September 2014 **Prof J Greenberg (UCT)**, Prof H Soodyall (Wits), Prof S Rennie (Chapel Hill, North Carolina) Prof W Jaoko (University of Nairobi, Prof A Davis (Chapel Hill, North Carolina).
- Invited speaker at the Stem Cell Flagship Project collaborators workshop, University of Pretoria, 01 September 2014: “*New Technologies, new challenges: Implications for the ethical oversight of the informed consent process.* »
- The fifteenth congress of the SA Society of Human Genetics (SASHG) together with the African Society of Human Genetics (AfSHG) Joint Congress: 2013, Maslow Hotel, Johannesburg. Oral Presentation: **Some proposed guidelines for an ethical approach to comprehensive informed consent for patient-derived stem cell use.* **Jacquie Greenberg & Danielle Smith** in the special closing Stem Cells session.
- Invited speaker at the 2010 IRENSA MODULE 2 : (17th May — 28th May 2010) at GSH Bioethics center: SESSION 5 (May 21) ETHICAL ISSUES IN GENETICS RESEARCH
- Ran a one hour workshop on “*Ethics and public engagement* “ at a Wellcome Trust-funded International Engagement initiative organised by Professor V Corfield at the MTN Science center on 17 March 2010 entitled : *Catalysing partnerships: the role of science centres as intermediaries between the public and scientists in engagement with biomedical sciences in South Africa* : phase 2 which was attended by 25 participants involved in science education from the Western Cape.
- Invited speaker at the PathTech 2009 Congress September 6-9 in Durban ICC. 2 Talks : Plenary (1 hour) on “*Ethics and Genetic Testing*” > 100 attendees. Breakaway session : 20 Min talk on “*Are Umbilical Cord Blood Banks the Ultimate Investment?* ”
- Chaired a colloquium on Genetic Counselling at the 6th International Communication, Medicine & Ethics Conference (COMET) meeting at the ICTCC in July 2008
- In May, 2008, was a plenary speaker at the South African Paediatrics Association (SAPA) in Sun City. Talk was in the session on Ethics and was entitled “ *Ethics of stem cell research: The potential use and abuse of stem cells in medical research* “ .
- Invited to give an Ethics and Genetics lecture talk at the National Neurology meeting at Spier, Stellenbosch in March, 2008. Lecture entitled “ *To test or not to test. Is there a question?* ”
- Invited to give an Ethics and Genetics lecture talk at the Physicians Conference in February, 2008. Lecture was entitled “ *Issues in Genetic Counselling* “
- Participated in a session at the PAEDIATRIC REFRESHER COURSE in NEONATAL MEDICINE in February 2007 which comprised case presentations and a panel discussion of ethical and psychosocial issues.
- Was an invited speaker at the MRC research day 2008 and talked on ““*Ethics of stem cell research.*”
- Optometry congress of Southern Africa : November 2005 at Spier, Cape Town and then at Caesars palace in Gauteng : “*Genetic testing & Genethics*” .
- Attended 3 “*Ethics in Research*” two day courses over the past few years offered by . IRENSA in Cape Town : 2002, 2004,2006, 2007. Invited to present a case study for the 2006 IRENSA course.
- Participated in and chaired a number of 2-3 hour session on ethics and genetic research as part of the International Research Ethics Network for Southern Africa Diploma course at the UCT Bioethics Centre every year in July from 2003 to 2007.