



# ARESA

ADVANCING RESEARCH ETHICS  
TRAINING IN SOUTHERN AFRICA

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**Editors:** Prof. Stuart Rennie, Bioethics Center, University of North Carolina, Chapel Hill (USA) and Prof. Keymanthri Moodley, Centre for Medical Ethics & Law, Dept of Medicine, Faculty of Health Sciences, Stellenbosch University, South Africa

Dear REC Members,

As this Newsletter was going to press, a substantial contingent of ARESA Faculty, Alumni and trainees were headed to Mexico to participate in the 12<sup>th</sup> World Congress of Bioethics. It was only a short three years ago that the ARESA program was initiated, and we are enormously proud to see how our program is gaining exposure beyond the context of Southern Africa.

From September 8-17th, 2014, Module 3 of the ARESA program will take place. The module will concentrate on the general theme of vulnerable populations. As mentioned on page 7 of this newsletter, we will also be holding our third annual ARESA Research Ethics Seminar on September 18-19<sup>th</sup>, 2014. Last year, the ARESA Research Ethics Seminar attracted more than 120 delegates from around Southern Africa to discuss shared ethical concerns regarding health research involving human subjects, and we expect an equally stimulating and well-attended event this year. For more details, please visit the ARESA website ([www.sun.ac.za/aresa](http://www.sun.ac.za/aresa)) where you will also find ARESA faculty information, how to apply for the PGDip in Health Research Ethics, and much more.

Best wishes, Stuart Rennie and Keymanthri Moodley



**Viva Mexico!**

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## REPORT: RESEARCH ETHICS TALK AT THE MRC

On the 21<sup>st</sup> of February 2014, Professor Daniel Nelson of the University gave a talk at the Medical Research Council (MRC) of South Africa entitled "US Perspectives on Compensation for Research-Related Injury." Professor Nelson, until recently the Director of the Office of Human Research Ethics at the University of North Carolina at Chapel Hill, is a nationally recognized expert on regulatory and ethical aspects of research involving human subjects. The issue of compensation for research related injury is a hot topic in the Southern African context, particularly in clinical trials – often led by foreign research agencies -- where there may be significant risks of harm to participants.

In his talk, Professor Nelson was quick to point out that in many ways, the United States is behind other countries when it comes to compensating those who are injured in the course of research. While a number of countries already have policies requiring researchers to offer 'no-fault compensation' to injured research participants, the United States does not. If a subject suffers a research-related injury, then neither the investigator nor the sponsor has any legal obligation under US federal regulations to care for or compensate the subject. This is odd for at least two reasons. First, the ethical arguments in favour of providing compensation for research-related harm are diverse and generally considered strong. Second, as Professor Nelson noted, high-level advisory bodies have been made recommendations to this effect for the past 40 years, from the Tuskegee Syphilis Study Ad Hoc Advisory Panel (1974) to the recent Presidential Commission for the Study of Bioethical Issues (2011).

It is generally recognized that failure to compensate for research-related harm is out of step with the goal of minimizing harm to research participants. In addition, failure to provide compensation threatens to undermine US-sponsored global health research if local research ethics committees do not approve studies for this

reason. While some US institutions/agencies (NASA, Department of Veteran's Affairs, Medicare, NIH Clinical Center) do have their own compensation policies, in the majority of contexts the researcher's obligation consists largely in informing the participant that no compensation will be provided.



In regard to changes to policy in the future, Professor Nelson identified three key roadblocks: lack of political will, legal barriers to the government buying insurance, and a lack of data on the magnitude of the problem. He noted that there are signs that these roadblocks can be overcome, and cited the example of the University of Washington's Human Subjects Assistance Program, which is a no-fault program developed to provide medical and other assistance to subjects who experience a research-related medical problem that is likely caused by University-conducted research. While the University of Washington's program – already in place since 1979 -- does not cover all research or all forms of research-related harm, it does indicate that the possibility of policy change in the United States towards provision of compensation cannot be ruled out.

## NEW VISITING ARESA FACULTY FOR 2014

We were pleased to welcome and host Dan Nelson and Arlene Davis, two new visiting ARESA faculty during Module 1 of the ARESA program back in February, and look forward to their

participation in Module 3 and the ARESA Seminar in September!



**DANIEL NELSON** is Director of the Human Research Protocol Office for the U.S. Environmental Protection Agency (EPA), Adjunct Professor of Social Medicine and Pediatrics, and Faculty Associate in the Center for Bioethics at the University of North Carolina-Chapel Hill (UNC). Trained in medical physiology, Prof. Nelson previously held faculty appointments at the Mayo Clinic, the University of Rochester and UNC-Chapel Hill, where he directed the Institutional Review Boards for 16 years.

A national leader in the field of human research protections, Prof. Nelson has served as past-president of the Applied Research Ethics National Association (ARENA); charter member of the Council for Accreditation, Association for the Accreditation of Human Research Protection Programs (AAHRPP); founding member of the Council for Certification of IRB Professionals (CCIP); and consultant to the federal Office for Human Research Protections (OHRP). From 2004-2014, he chaired a subcommittee of the Secretary's Advisory Committee on Human Research Protections (SACHRP), which advises DHHS on the regulations that govern this area. Prof. Nelson is also a co-investigator on several NIH grants on issues surrounding research ethics, and frequently lectures on related topics. In November 2013, he was honored by Public Responsibility in Medicine and Research (PRIMR) with the ARENA Legacy Award, for leadership and contributions to the field of research ethics.



**ARLENE DAVIS** is an attorney, Associate Professor of Social Medicine, core faculty in the UNC Center for Bioethics, and adjunct Professor at the UNC School of Law. Arlene's work focuses on clinical and research ethics and draws upon her prior experience in private practice and in pediatric and public health nursing. She teaches on topics related to ethics and to health law and co-chairs the UNC Hospitals Ethics Committee. She is also a Fellow at the UNC Parr Center of Ethics, and she has also served as an REC member and consultant to the Research Triangle Institute (Durham, North Carolina) REC for over 15 years. Arlene is currently co-chair of the UNC Hospitals Ethics Committee and director of clinical ethics services, whose multidisciplinary team offer ethics consultations and education in a variety of settings.

Since 1996, Arlene has been co-investigator on a series of grants from the National Human Genome Research Institute's Ethical, Legal and Social Implications Program, including an historical, ethical, and legal analysis and reevaluation of policy. She focused on the federal regulatory framework of human subject protection and the case law of informed consent, and a six-year study examining understandings of benefit and of vulnerable adult and pediatric populations enrolled in early phase gene transfer research. As an investigator in the Center for Genomics and Society, she is currently conducting research regarding the creation, understanding, and dissemination of genetic information through genetic screening and biobanking.

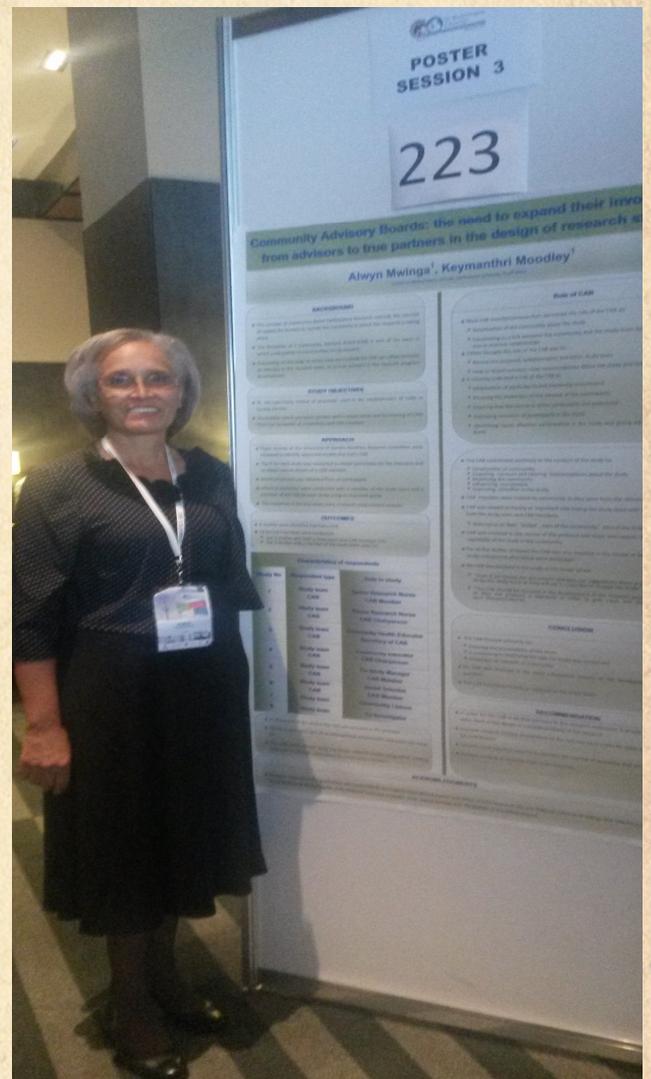
## **ARESA FACULTY AND TRAINEES AT WORLD CONGRESS OF BIOETHICS**

Mexico City is host to the 12th World Congress of Bioethics (June 25-28), and our ARESA program is very strongly represented there!

ARESA faculty conducted a symposium on Biobanking in Africa at the World Congress. Biobanking has become a controversial ethical topic in recent years. While biological samples have been exported from Africa for decades, there has been growing suspicion about this practice among researchers, participants and local communities. Is consent obtained? When consent is obtained, do the participants know what will happen with their samples? And to the extent that benefits derive from the use of samples, who are the beneficiaries, and how is this exchange not a form of exploitation?

The establishment of biorepositories in Africa as part of the Human Heredity and Health in Africa (H3Africa) project funded by the National Institutes of Health (NIH) and the Wellcome Trust is an opportunity to revisit these questions and promote responsible research within Africa and support international collaborations. As his contribution to the debate, ARESA Faculty Professor Eric Juengst analysed the notion of 'genomic sovereignty.' While the H3Africa initiative is focused on building a pan-African genomic research infrastructure, some African states are resisting the prospect of unrestricted use of 'their' specimens. These complications illuminate critical conceptual and ethical challenges to attempting to govern genetic information as national natural resources. Professor Keymathri Moodley connected biorepositories as business ventures to the principles of good governance: transparency, accountability, responsibility, fairness, discipline and social responsibility. These principles, she argued, are particularly important in resource-poor African settings, where there are significant tensions between economic interests and social responsibility in relation with local communities. Dr. Ciara Staunton examined the role of community engagement in African genetic

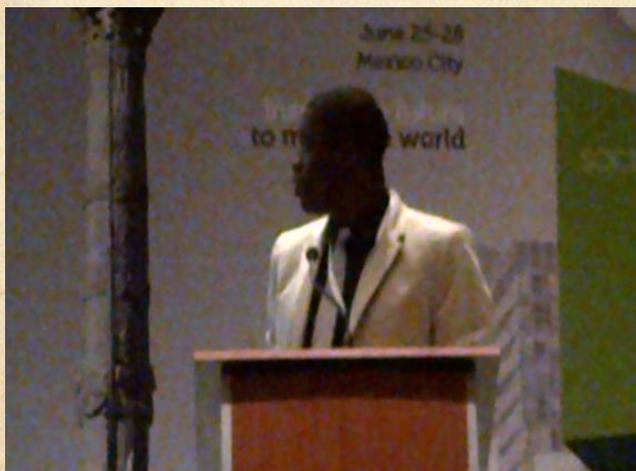
research initiatives. Unlike in western societies where autonomy, self-determination and individual informed consent are the focus, in African cultures, the community plays a much greater role in the lives of its members, and therefore individual informed consent may thus need to be accompanied by community consent. Dr. Staunton argued that little research has been conducted on community views on genetic research in Africa, and she identified some of the challenges involved in community engagement in this particular context and potential recommendations to guide researchers.



**Dr. Alwyn Mwinga, presenting her poster at the World Congress of Bioethics in Mexico City**

Professor Anton Van Niekerk gave a talk entitled 'Is biomedical enhancement a disenchantment of the world?' In his presentation, he explored whether ways of improving on (our) nature via biomedical technology necessarily leads (as sociologist Max Weber suggested) to a disenchantment of the world, i.e. a reduction of the world's mystery and our sense of wonder towards it. Prof. Van Niekerk controversially argued that biomedical enhancement could actually stimulate our sense of wonder rather than reduce it, at least in certain cases. We should distinguish between forms of enhancement that threaten important human values from others that do not, and may in fact reinforce them.

Our ARESA trainees made a number of oral or poster presentations at the World Congress. Dr. Blanche Pretorius (ARESA Alumnus, 2012), from Nelson Mandela Metropolitan University, presented a talk entitled 'A lens on current documentation of research ethics committees in South Africa which guide ethical review of research involving children.' Dr. Pretorius studied the documentation of 21 research ethics committees in South Africa regarding involvement of children in research. She found that there was much stronger and clearer understanding of parental permission than assert to research participation by children.



**Dr. Patrick Kamalo discussing compensation for research-related injury at the World Congress of Bioethics in Mexico**

Our Malawian alumnus from the College of Medicine in Blantyre, Dr. Patrick Kamalo (ARESA Alumnus, 2013) made an oral presentation with the title 'Compensation for research-related injuries: whither Africa? A collaborative responsibility approach.' Dr. Kamalo argued that while there is increasing consensus about the ethical obligation to provide compensation to participants for research related injuries, what models of compensation are appropriate to specific cultural contexts is partly an open question. He argued, in the case of Africa, for what he called a 'a collaborative responsibility' approach, which points to a no-fault insurance model financially supported by all potential research beneficiaries. Dr. Alwyn Mwinga (ARESA Alumnus, 2013) presented 'Community Advisory Boards: the need to expand their involvement as advisors to true partners in the design of research studies.' In this poster presentation, Dr. Mwinga did a retrospective survey of processes and procedures of research ethics committee by interviewing its members (n=14) in Lusaka, Zambia. Her main conclusion was that these research ethics committees typically do not explore the design aspects of the research studies they review, nor are local communities engaged in research design. She argued that, given the impact of study design on the ethics of research, communities and research ethics committees should be more engaged with design issues than they currently are.

## TIME TO RETHINK INFORMED CONSENT?



### Malcolm de Roubaix

*Disclaimer: The views expressed in this article are my own, and do not represent the views of the Centre for Medical Ethics and Law, or the Health Research Ethics Committee which I chair.*

Modernity – that phase of societal history spanning the discovery of science (let's say, the discovery of the telescope) to the detonation of the first atom bomb – was characterised by the overarching belief in one final and universal truth, be it about science, religion or human behaviour. In contrast, postmodernity defies this notion, and describes the current phase of human societal development as fundamentally complex, truth as something provisional and contextual, and ethics as something to be created in the quagmire of vibrant human interaction. The latter echoes a haunting bell some 2500 years old – the Socratic injunction that we should constantly re-examine societal truth claims in the light of newer developments.

As a student of both Socrates and postmodernity, I intend taking a fresh and hopefully somewhat provocative look at the accepted paradigm of informed consent.

It is self-evident that in the normal run of human affairs, and particularly in matters medical, whatever we do to others should be governed by their freely given and informed consent. This has both legal and ethical foundations. Legally, we may face criminal or civil litigation on grounds of assault or *crimen injuria* if we so much as touch a patient without her consent. In fact, in most

cases of litigation against doctors it is contended that information “provided” was inadequate; only rarely is frank negligence argued. The ethical foundation to informed consent is that this shows our respect for others as persons, and promotes their personal autonomy. The argument goes as follows: the information/knowledge asymmetry between the two parties implies an corresponding power differential, limiting free choice. The way to correct this is to “provide” information to the patient which (theoretically) eliminates the power differential, thereby empowering the patient to make free and informed decisions. This is the essence of the informed consent paradigm (ICP) as it has become known. A consequence not generally appreciated is that the doctor/researcher-patient/participant interaction assumes more of a contractual nature and its moral content diminishes.

But there are many problems inherent to this notion, and the demands made upon us in order to justify an authentic consent process are onerous. In this short reflection I aim to focus on one issue only: the nature of and the “transfer” of information. My arguments are loosely based on a provocative book by Manson & O'Neill entitled *Rethinking informed consent in Bioethics* (1), though many others have voiced similar thoughts.

Manson and O'Neill argue that the metaphors we generally use when talking about information and the process of informing describe our general – erroneous – conceptions. We conceive of information as content that passes from one person to another as if it were contents flowing passively via a conduit from one vessel to another (the container- conduit metaphor). Other metaphors we commonly use (some of which I've parenthesised above: provide, transfer) support this notion, and indicate that we conceive of information as something tangible, contained, packaged or like data on a memory stick or hard drive. But what then is the nature of information, and how do we make sense of the words we hear (i.e., turn it into knowledge)? For an explanation, I turn to the work of Willem Moore. The original meaning of the verb ‘to inform’ (to shape, like a

sculptor) illustrates the multi-faceted, complex and active process informing really is, starting with sense making (2). Disease changes the circumstantial environment of the patient, resulting in experiential discontinuity. Previous experience/knowledge provides the matrix in which any new information is laid down and sense is made through enactment as a sort of data-interpretation-action. There is selective retention of newly compounded experience for future use. The process is unique and contextual within each individual's own frame of reference and past experience, culture and understanding through language. Remaining gaps in existing knowledge are plugged with new knowledge that is created/transformed from implicit, explicit ('provided') and cultural knowledge. The eventual aim is rational deliberation in the face of existing choices. This process takes place within the mind of a person with a particular frame of reference and enculturation, and is influenced by existing emotions. It is a journey or process rather than an instantaneous act. Thus meaning is individually and actively created.

Now, not all medical information (used here as a verb) in the clinical sphere is so complex as to justify this description, but in medical, particularly clinical drug-related research, the process and nature of information can be very complex and the description above fully justifiable. It is for this reason that Moore has argued that there is space for a dedicated information therapist/ethics consultant to facilitate the process.

But let us return to Manson and O'Neill, whose argument then turns to the prerequisites in order for the ICP to succeed – and, by the way, their argument applies to both clinical and research informed consent. These are that "informing" must be both fully comprehensive and explicit, which I venture to say (expecting little dissent from my readers!) it can never be. If these two conditions are not met, it follows that the information requirement fails; thus the idea that we promote autonomy by empowering patients/participants through informing them and diminishing the information-based power

differential also fails (at least, partially) simply because we are not really informing them!

The dilemma is that informed consent, flawed as it might be, remains a moral and legal requirement. So if the ICP fails, what alternatives do we have? There are several possibilities:

Revert to paternalism: Respectfulness of human life and respect for humans are fundamental philosophical and legal tenets, as well as being non-negotiable practice guidelines (think for example of the Kantian dictum to treat others [and yourself!] always so that their own interests are also served (3); the South African Bill of Rights (4) and the National Health Act (5). If paternalism implies exerting control over autonomous individuals, it is therefore not an option.

Retain the illusion of autonomy: I suggest that we effectively and unwittingly practice some limited degree of autonomy combined with some degree of paternalism (flawed but 'good-enough' informed consent). This is unsatisfactory and poses several questions: how reflective should choices be? How do we define acceptable informed consent? Why should limited autonomy be honoured and override other important principles?

De-link the information and consent components of informed consent: this defensive mode of practising entails informing as well as possible, realising its limitations, and obtaining consent for legal purposes. There is no truly autonomous choice.

De-link the moral and legal aspects of informed consent: similar to the above, with more emphasis on moral obligations and a sincere attempt to treat the other as a moral agent whilst admitting that this is not fully autonomous informed consent.

Evaluate alternative models of informed morally acceptable doctor patient relationships: I would like to discuss only two:

1. *An ethics of responsibility*: This notion expresses, perhaps a bit more coherently, the

essence of the third and fourth options above, and may be developed from the work of Hans Jonas (6), the German environmental ethicist, and the postmodern ethicist Zygmunt Bauman (7). Jonas emphasises the responsibility humans have for others of our species, responsibility that spans time and space, and Bauman describes the moral nature of this responsibility. Recognition of need in others, an ability on my side to respond appropriately to that need, and my consequent action, legitimate me as a moral agent; it is the foundation of morality. This responsibility is awesome in scope and content. It is unlimited and not based on, and does not demand, reciprocity. Without assuming that such an onerous notion can or should be applied to medical practice, it nevertheless can be argued convincingly that any serious attempt at this form of practice would ensure prime care. Such responsibility would be incompatible with practices that do not take informing and consent seriously.

2. *Informed consent as a transaction* (8): A transaction may be defined as 'a communicative action or activity involving two parties or things that reciprocally affect or influence each other'. In essence, this notion recognizes that informing can never be comprehensively explicit and specific. Consequent consent would therefore not satisfy the demands of the paradigm model, or fundamentally promote autonomy. We *de facto* rely on a (limited and contextual) waiver of the legal and ethical claims attendant to treatment without so-called fully informed consent. The scope of the waiver is determined by the scope and nature of the legal/ethical norms that need to be waived in order to treat (i.e. the scope and nature of treatment). The notion emphasises the type of communicative action that the process of informing should be; reciprocal flow between two moral agents. It legitimises relative instead of absolute explicit/specific informing. But there are certain norms inherent to effective communication, e.g. comprehensibility, relevance and accuracy. In the final instance certain undertakings are made – here, about treatment/research. This notion also responds to several characteristics of communication obscured by the container-

conduit metaphor. Communication is context and norm-dependant, propositional, it is a rational action (and therefore rationally evaluable), allows agents to be aware of the bigger picture, and assists them in making a wide range of inferences, depending on personal circumstances and frames of reference.

#### Four practical suggestions

So what does this mean in our daily practice? I'll restrict myself to four conclusions/suggestions:

1. *Bauman's notion of responsibility is probably too onerous for general medical practice* (though, perhaps, due to its peculiar dynamics, not for the research environment). There have nevertheless been suggestions that an ethics of responsibility might be the only coherent approach to bioethics, given the unusual inherent moral demands. This ethic 'ruthlessly demands justification and responsibility for our moral actions even if not moulded in conventional moral argumentation' (9). It demands that we accept unconditional and non-reciprocal responsibility, and be empowered with the 'tools' of moral debate (10). This ethic is no lame excuse for paternalism which develops from a totally different mind-set. As Jonas puts it: the ultimate 'purpose' is the 'ever-transcendent possibility' of human dignity. There can be no better aim in medicine.

2. *Seeing the informed consent process as a communicative action emphasises our moral responsibilities and the continued importance of values such as the trust placed in medical caregivers*: that even if I can't know/understand everything, even if I am anaesthetised or on a ventilator, I can rely on the integrity of my doctor, and may be assured that my best interests will always predominate. This should apply to the research situation as well.

3. *A solid debate of the theory versus the practicalities of informed consent along the lines argued before seems appropriate*, even if we will only make progress if we admit the incoherence of the current paradigm, and convince others –

lawyers, lawmakers, theoretical ethicists – of our argument.

4. *We should take the suggestion of empowering ourselves with the tools of moral debate seriously.* Medical ethics has to do with daily patient-directed doctor-patient relational/therapeutic issues and decisions, including informed consent, and the practitioner should be confident in making these decisions. These often apply to clinical research as well. Appropriate ethics courses and CPD ethics events with more ethics and less medico-legal material are required to empower clinicians.

### **ARESA FACULTY AT BROCHER FOUNDATION CONFERENCE**

As mentioned in the previous newsletter, the Center for Medical Ethics and Law at the Stellenbosch University is collaborating with the University of North Carolina on a project on newly emerging research on cures for HIV. This project, sponsored by the US National Institutes of Health (NIH), focuses on the ethical and social implications of HIV cure research, and involves bioethicists, social scientists, policy experts and basic scientists at sites in South Africa (Cape Town), United States (North Carolina) and China (Guangzhou). Our project successfully applied to the Brocher Foundation in Switzerland to hold a 3 day conference which drew project investigators from all three sites, as well as interested participants from the WHO, UNAIDS, the Pasteur Institute, and Public Health England.

The international conference was entitled Unintended and Intended Implications of HIV Cure: A Social and Ethical Analysis, and ARESA faculty made presentations based on research that will soon be submitted for publication in peer-reviewed journals. Prof. Keymanthri Moodley gave a talk called 'Pluralistic Perspectives on Cures in Africa', in which she recounted the history of alleged cures for HIV that have been claimed in Africa over the past two decades. South Africa, given its high prevalence of HIV and its strong research

infrastructure, is likely to be a very important site for future HIV cure research, but attention should be paid to the connotations that 'HIV cure' may already have in local communities. Along similar lines, Dr. Malcolm de Roubaix explored the relationship between HIV cure research and traditional African conceptions of medicine, illness, personhood and community in his talk 'Reconciling the irreconcilable: Integrating traditional healers and biomedical science in HIV Cure Research'. To the extent will traditional African conceptions affect reactions to, understandings of, and participation in HIV cure research? Should traditional healers be integrated in future HIV cure research initiatives, and how can this be done responsibly? Should the ethics of HIV cure research in the African context reflect communitarian ('ubuntu') values, rather than the autonomy-emphasizing research ethics of the West? Dr. Ciara Staunton's presentation 'The legal implications of HIV cure – informed consent in South Africa' raised some serious challenges regarding the ethics of research on HIV cure in the South African context. South Africa has a history of HIV prevention and treatment research in which informed and voluntary consent on the part of participants was often far from ideal. Empirical studies on informed consent in South Africa reveal gaps between ethics guidelines and reality in the field, where comprehension may be patchy and voluntariness may be limited. The ethics of HIV cure participation in the South African context is also complicated by the partial access to antiretroviral treatment. For those unable to reliably access treatment, is participation in HIV cure research justified. For those able to access treatment, what would motivate them to join such a study, which might necessitate them stopping treatment? More generally, what sorts of reasons should we think are 'acceptable' or 'unacceptable' to motivate HIV-positive persons to join a HIV cure research study?



**Participants at the Brocher Foundation workshop on the social and ethical implication of HIV cure research, Hermance, Switzerland (May 6-9, 2014)**

Prof. Moodley also led a pilot qualitative study on HIV cure research whose preliminary results were presented at the Brocher conference. The study, conducted at Tygerberg Hospital in Cape Town, looked at stakeholder perceptions about HIV cure research. Results of the study will form the basis of a future journal article.

Professor Stuart Rennie, ARESA faculty from the University of North Carolina, gave a talk on a more philosophical level entitled 'The meaning of HIV cure and the ethics of HIV cure talk'. What is meant by the concept of cure, and how should this powerful and seductive concept be used by the various stakeholders involved in or affected by HIV cure research? Professor Rennie analysed cure concepts involving the eradication of underlying disease ('sterilizing cures') as well as those that controlled clinical symptoms without complete removal of disease ('functional cure', 'remission'). Conceptual confusions may impact processes of informed consent as well as community perceptions of HIV cure research. The media and HIV advocacy groups face the difficult (ethical) challenge of conveying the importance and excitement of HIV cure research advances without giving false hope or fuelling misconceptions.

ARESAs faculty will be channelling their research on the implications of HIV cure research into

manuscripts for peer-reviewed publications. The collaboration on this project may also have beneficial impact on the ARESA program in the future, as trainees may want to explore ethical aspects of this new and exciting field within HIV research.

## **ANNUAL ARESA SEMINAR**

The Annual ARESA Seminar will take place at the Southern Sun Hotel in Newlands, Cape Town, September 18-19th, 2014. This year the seminar will discuss four topics, namely: research with children, ethics and genetics, neuroethics and reviewing biobanking protocols. The seminar will include national and international speakers, and the registration fee is R300 per person. Closing date for registration is 22 August, 2014.

Please email registration forms to: [kelseyf@sun.ac.za](mailto:kelseyf@sun.ac.za) or fax to 021-9389731.

## **ARESAs SHORT COURSES**

### **ARESAs SHORT COURSE III: Research and vulnerability (8 to 17 September 2014)**

Module 3 will focus on the concept of vulnerability that has, for understandable reasons, become an important concept in regulations and ethical discussions in regard to the ethics of conducting research with human participants in developing countries. The goals of this module are to better understand what is meant by 'vulnerability' and how the various kinds of vulnerability should be taken into account in evaluating the ethics of research studies. Attention will be devoted to vulnerability connected to special populations, such as research with children, adolescents and mental health research, as well as vulnerability related to research on specific health conditions such as genetic diseases and cancer. A number of sessions will combine theoretical presentations with more hands-on case study work. Since the

concept of vulnerability is applicable at individual and community levels, attention will also be devoted to ethical issues regarding infectious disease control and associated principles of public health ethics.

The deadline for short course applications for this module is **13 August 2014**.

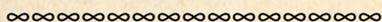
For more information, and If you are interested in applying for these short courses, please forward your curriculum vitae and a short motivation letter on why you would like to be considered to: [kelseyf@sun.ac.za](mailto:kelseyf@sun.ac.za) or [bioethics@sun.ac.za](mailto:bioethics@sun.ac.za).

### **ARESA 2015 Intake: Postgraduate Diploma in Health Research Ethics**

Ten scholarships for the ARESA Postgraduate Diploma in Health Research Ethics are available for 2015. The deadline for applications is **30<sup>th</sup> August 2014**.

For more details, please visit the ARESA website [www.sun.ac.za/aresa](http://www.sun.ac.za/aresa)

For queries please contact:  
**Dr Ciara Staunton** – [aresa@sun.ac.za](mailto:aresa@sun.ac.za)



### **TRAINEE NEWS**

The Stals Prize for Nursing has been awarded to ARESA trainee (2014) **Prof. Minrie Greeff**, affiliated to the Faculty of Health Sciences, North-West University, Potchefstroom Campus. The prize is awarded by the South African Academy for Science and Arts. Prof Greeff is hereby acknowledged as researcher nationally as well as internationally. Recognition is given for her extensive contribution to the field of Nursing as well as research in Nursing. This prize is only awarded bi-annually either to the field of Nursing, or to Social Work.

**Gonasagrie (“Lulu”) Nair**, ARESA trainee (2014) has been appointed to the ethics committee at CAPRISA.

**George Rugare Chingarande** (ARESA trainee, 2014) has received a Fulbright Science and Technology Fellowship to pursue a PhD in Bioengineering at the University of Missouri (USA), where he will be focusing the development, testing and use of small bio-molecules in the diagnosis and treatment of cancer using radiation.

**Ashley Ross** (ARESA alumnus, 2013) has been promoted to the position of Associate Professor in the Department of Homeopathy at the Durban Institute of Technology. He has also been selected to serve as a member of the University of KwaZulu-Natal Biomedical Research Ethics Committee.

### **Where are they now? ARESA Alumni Professor Ashley Ross**



As South Africa’s most senior homoeopathic academic, I have been engaged in academic and clinical teaching and supervision for 19 years. Over this period I have lectured in homoeopathic philosophy and materia medica, as well modules of medical diagnostics and research methodology.

My engagement in research activities of various types has been extensive, and over the period of my academic life I have participated in some form in all of the 27 homoeopathic pathogenetic trials (‘provings’) that have been conducted at the Durban University of Technology (DUT), supervised 15 Master’s students in proving research, and have presented a number of papers, most notably at international Liga Medicorum Homoeopathica Internationalis (LMHI) congresses, relating to various aspects of this specific field of research endeavour. In 2011 I

completed a PhD in which I investigated the relationship of proving data to the scientific and traditional African understandings of medicinal plants. In 2013 I was very fortunate to have completed a Postgraduate Diploma in Health research Ethics within the ARESA programme of the University of Stellenbosch-University of North Carolina, in which I conducted a conceptual analysis of the ethics of homoeopathic pathogenetic trials. I currently serve on the editorial boards of two international homoeopathic journals and as Chair of the LMHI Committee for Proving I am currently actively engaged in the LMHI-ECH (European Committee for Homeopathy) collaborative project towards the harmonisation of the LMHI and ECH Proving Guidelines.

I have served as Head of the Department of Homoeopathy at the DUT between January 2000 and March 2014. Within this role I have ensured the development of homoeopathic education and training in South Africa, facilitated the growth and exposure of homoeopathy within local communities, and raised the profile of homoeopathy within the University and the higher education sector in general. During this period I also served on departmental and faculty research ethics committees, and between January 2012-June 2013, served as Vice-Chair of the DUT Institutional Research Ethics Committee (IREC). In December 2013 I was awarded an Associate Professorship, in recognition of my academic achievements and my contribution to homoeopathy, education and research. This award is a 'first', and represents a significant step in the acknowledgement of the quality of homoeopathic education and research in South Africa. I trust my recent appointment will serve to further enhance the growth and development of the profession in South Africa and the world, as well as representing an opportunity for me to engage more fully within the broader field of biomedical research and, more specifically, in the development and appreciation of research ethics within higher education and South African society at large. My recent appointment as a member of the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (BREC) is a valued step in this direction.



We are very pleased to announce the graduation of **Prof. Joyce Tsoka-Gwegweni**, Associate Professor and Acting Head of Public Health Medicine at the Nelson R. Mandela School of Medicine, College of Health Sciences, University of KwaZulu-Natal. She is also a member of the University of KwaZulu-Natal Research Ethics Committee. Joyce's research assignment for ARESA was "Ethical Priorities Raised by a Research Ethics Committee in South Africa", and her mentor was Prof. Eric Juengst, Director of the Center for Bioethics at the University of North Carolina. We wish her all the best in the future, anticipate that her ARESA training will positively impact her home institution, and hope that she remain in close touch with us as new ARESA alumnus!



## **UPCOMING CONFERENCES AND EVENTS**

### **Public Responsibility in Medicine and Research (PRIMR), Advancing Ethical Research Conference, Baltimore, Maryland (November 4-7, 2014)**

This is the largest annual conference in the United States devoted to research ethics and regulatory issues for research involving human participants. The conference has a Global Research Scholarship Program open to REC members, administrators and researchers in low-

