



# THE NATIONAL BIOETHICS COMMITTEE OF JAMAICA In collaboration with THE UNIVERSITY OF THE WEST INDIES & THE JAMAICA NATIONAL COMMISSION FOR UNESCO

## PRESENTS

"Beyond the Common law protection of Confidences in Health Care": A Seminar

# PROGRAMME

Mona Visitors Lodge 18 February 2013 4:30 p.m.

## 4:30pm – 5.45pm Registration and Refreshments

Welcome/Opening Remarks Mrs. Donna McKoy, Member, NBCJ (Moderator)

**Greetings** Prof. Nigel Harris, Vice Chancellor, University of the West Indies

"Consent & Confidentiality in Health Care in the Caribbean: Challenges & Solutions" Dr. Derrick Aarons

> "Confidentiality Issues in Research" Dr. Mark Taylor

#### Q & A

The National Bioethics Committee of Jamaica (NBCJ) Dr. Anthony Mullings, NBCJ Chairman

"Medical Informatics and Confidentiality" Dr. Kenneth W. Goodman

"Electronic Health Records – Solution or Problem" Carol Appathurai

Q & A

Vote of Thanks/Closing Remarks

(CME certificates are to be collected at the end of the Seminar)

in Applied Ethics, Centre for Applied Ethics, LinköpingUniversity, Linköping, Sweden; and Utrecht University, Utrecht, Netherlands.

In 2010 he served on the HHS Special Emphasis Panel, FOA-OC-HIT-10-001: Health Information Technology, Special Emphasis Panel, Office of the National Coordinator for Health Information Technology, Curriculum Development Centers, 2010. Also, he was Associate Editor, *Acta Bioethica* (journal of the Pan American Health Organization)



<u>Carol Appathurai</u> is currently a Senior Health Privacy Consultant. Previously while working for several organisations including Ministry of Health, Ontario, Canada she was responsible for developing and implementing a privacy compliance strategy for the Ministry of Health and Long-Term Care, including policies and procedures, breach protocols, fee schedules for access to personal health information, and training materials.

She was responsible for leading the development of

Ontario's Personal Health Information Protection Act, 2004 which has been cited as the "Gold Standard" for health privacy legislation by the Institute of Medicine in the USA. This involved:

- Identifying policy issues relating to the privacy of personal health information and developing solutions that balanced individual privacy with need for personal health information to flow for effective healthcare and planning and management of the system.
- Working collaboratively with a broad range of stakeholders including non-governmental organizations, health stakeholders, professional organizations, regulatory colleges, and consumer groups to ensure their needs were addressed.
- Preparation of legislative and regulatory submissions, and carriage of these submissions through government processes.

She was also involved in the Preliminary Privacy Impact Assessment to determine compliance with the federal Privacy Act and Treasury Board of Canada Directives and Guidelines, evaluate risk and provide recommendations for change as required.



<u>Dr. Mark Taylor</u> is a lecturer at the School of Law since 2002 and is the Programme Director for the LLM in Biotechnology, Law and Ethics, Sheffield University. He is also actively involved in Research and Teaching Development and is responsible for the student-tutor programme in the School.

He studied law at the University of Hull, graduating with an LLB (Hons) in 1994. From Sheffield he has MA in Biotechnological Law and Ethics and also completed a PhD on the morality of regulating genetic discrimination.

He is a member of the Ethics and Confidentiality Committee of the National Information Governance Board (NIGB ECC) and is Deputy Director, Sheffield Institute of Biotechnology, Law and Ethics. He is the Establishing Chair, Confidentiality Advisory Group, Health Research Authority (2013-14) and Chair, National Information Governance Board's Ethics and Confidentiality Committee (2013). He is a member of the Health and Social Care Information Centre 'Code of Practice' Working party (2012-13)

He has significant experience in International Research leadership and publications in the areas of privacy in medical research especially genetic research.



<u>Kenneth W. Goodman</u> is Professor of Medicine and Philosophy; Director, Bioethics Program, University of Miami. He directs a WHO Collaborating Center in Ethics and Global Health Policy, one of six in the world and the first in the United States, and work on ethical issues on international health informatics. A Fellow of the American College of Medical Informatics, he chairs the Ethics Committee for AMIA, and 10 years ago founded its Working Group on Ethical, Social and Legal Issues.

He was elected (2008) Fellow, American College of

Medical Informatics and was a visiting Scholar, Erasmus Mundus Programme

## THE NATIONAL BIOETHICS COMMITTEE OF JAMAICA

The National Bioethics Committee of Jamaica (NBCJ) was established through the UNESCO's Assisting Bioethics Committees (ABC) initiative. The initiative focused on the establishment and capacity-building of national bioethics committees across the world. The process of establishing a national bioethics committee in Jamaica commenced in June of 2007 under the auspices of the Jamaica National Commission for UNESCO (JNATCOM). JNAT-COM is a governmental agency of UNESCO. The appointment of members was confirmed on September 27, 2008 and a formal launch ceremony was held on October 1, 2009. Jamaica is the first English-speaking Caribbean country to establish such a committee.

A National Bioethics Committee is defined as "an independent platform for public debate and policy advice in bioethics" (Ten Have, 2009). According to Article 19 of the *Universal Declaration on Bioethics and Human Rights*: , "Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:

- Assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings;
- Provide advice on ethical problems in clinical settings;
- Assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration;
- Foster debate, education and public awareness of, and engagement in, bioethics." (UNESCO, 2005).

The National Bioethics Committee of Jamaica (NBCJ) defines bioethics as "a field of critical reflection on, and examination of, ethical issues of life and human existence".

The committee has identified fields of importance to the Jamaican society which would be of relevance to a bioethics committee. The twenty-two fields identified included science and technology and health care, but also covered the humanities, information technology, education, the environment, law, and human rights. Having identified the fields to be covered, the challenge was the identification of the best process for selecting Committee members in order to ensure the broadest social representation possible. It was agreed that a committee of not less than 15 persons would be recommended and that persons would be selected not to represent an organization or an interest group. Although such entities would be asked to nominate persons for ratification by the relevant government authority, it was stipulated that once appointed, the member would be expected to act independently.

The Constitution and the rules of procedure of the NBCJ are designed to create the space for an independently functioning committee. They grant the Committee the rights to determine its own work agenda, to have its own work agenda, to have its own secretariat, and to recall members for cause. They also set term limits on chairmanship and membership of the committee, and identify the process for electing members for the executive officers, as well as an evaluation process.

The JNC-UNESCO nominated members of the preparatory committee based on their expertise and demonstrated interest, without considerations of political or ideological allegiance

| Names                       | Positions        | Profession  |
|-----------------------------|------------------|---|
| Dr. Anthony Mullings        | Chairman         | Obstetrician and Gynecolo-<br>gist, Senior Lecturer |
| Prof. Ayotunde Bewaji       | Deputy Chair     | Professor of Philosophy                             |
| Ms. Nancy Anderson          | Secretary        | Attorney at Law                                     |
| Ms. Cheryl Brown            | Inaugural member | Attorney at Law                                     |
| Dr. Simon Clarke            | member           | Former UNESCO Director for the Caribbean            |
| Dr. Michael Coombs          | member           | Medical Doctor, CMO,<br>Ministry of Health          |
| Mr. Cezar Cunningham        | member           | Architect and Musician                              |
| Mrs. Shereen Dawkins- Cox   | Inaugural member | Bioethicist, Pharmacist                             |
| Rev. Oliver Daley           | Member           | Minister of Religion                                |
| Ms. Godiva Golding          | member           | Student   |
| Rt. Rev. Dr. Howard Gregory | Inaugural member | Anglican Bishop                                     |
| Mr. Everton Hannam          | Inaugural member | Secretary General, JNAT-<br>COM, UNESCO             |
| Lt. Col. Errol Johnson      | member           | Principal   |
| Ms. Leisha Lyn-Cook         | member           | Teacher   |
| Mrs. Donna McKoy            | member           | Nurse, Pharmacist, Admin-<br>istrator               |
| Miss Gillian Mignott        | member           | Bioethicist, Medical Tech-<br>nologist, Lecturer    |
| Mr. Simeon Mohansingh       | member           | Bioethicist, Lecturer                               |
| Prof. Ralph Robinson        | Inaugural member | Scientist   |
| Dr. Maria Smith             | Inaugural member | Cultural Specialist<br>&Administrator               |

### PRESENTERS



<u>Dr. Derrick E. Aarons MD</u>, PhD, is a Consultant Bioethicist, Palliative Care and Family Physician working in Jamaica. A medical graduate of the University of the West Indies, he did his Masters in Bioethics at the McGill Centre for Medicine, Ethics and Law (with subspecialization training in palliative care), and his PhD in Experimental Medicine and Bioethics, McGill University, Canada.

In his bioethics career, Dr. Aarons served as the Bioethicist on the Ethics Committee of the Faculty of Medi-

cal Sciences, University of the West Indies, Chairman of the Advisory Panel on Ethics & Medico-Legal Affairs in the Ministry of Health, Jamaica, and Associate Lecturer at the Faculty of Medical Sciences, University of the West Indies, Jamaica. He was also a member of the International Advisory Board for Bioethics for the Pan American Health Organization (PAHO/WHO), and Convenor and founding President of the Bioethics Society of the Englishspeaking Caribbean (BSEC). His publications include *Medicine and Its Alternatives: Health Care Priorities in the Caribbean* in the Hastings Center Report, *Overcoming Barriers to Pain Relief in the Caribbean* in the Developing World Bioethics Journal, and *Issues in Bioethics* in the West Indian Medical Journal.

Dr. Aarons is currently a member of the Editorial Board for the Developing World Bioethics Journal, and a member of the Executive Council of RedBioetica UNESCO.

#### Contact details:

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