

***Global Awakening in Genetic Counseling***

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The article by Ricki Lewis, *Nature*, Volume 449, October 18, 2007, correctly points out that the genetic counseling profession is on the "verge of being discovered by the rest of the world".

The rapid recognition of genes associated with single-gene disorders and complex conditions has deepened our understanding of the role of genetics in health and illness. The impact of genetic conditions on individuals and families, particularly in ethical, legal and psychosocial arenas, requires specially trained professionals to work in this unique and growing dimension of healthcare. The Transnational Alliance for Genetic Counseling (TAGC) represents fifteen countries currently providing genetic counselor education across five continents.

Global momentum in genetic counselor education is evident (<http://tagc.med.sc.edu>). The inception of Master's level education for genetic counselors in the United States dates from 1969; currently thirty-two U.S. programs graduate approximately 200 genetic counselors per year. Canada has been training genetic counselors since 1985, with four programs and another two under development. South Africa has been educating genetic counselors since 1987, their second program added in 2004.

The genetic counseling profession emerged in six additional countries during the 1990s. Europe's first program began in 1992 in Manchester, England; the United Kingdom's second program was initiated in Cardiff, Wales in 2000. Cuba has trained genetic counselors since 1995 in a unique model, providing a master's degree in genetic counseling to family physicians. The Dutch also have had a national training program since 1996. Four educational programs emerged in Australia between 1996 and 2000. Israel has trained over 40 genetic

counselors since 1997.

Since 2000 the pace has quickened as Japan created seven programs since 2002 and adds an eighth in 2008. Taiwan's first program emerged in 2003 and Norway soon thereafter. The French government decreed genetic counseling as a new health profession in 2004. Saudi Arabia formed a program in 2005 and has educated four Saudi nationals at home, and sent three abroad for education, bringing the trained cohort of counselors to seven in a very short time. Spain joins the ranks of established genetic counseling programs; their first students matriculated in January 2008. Other programs are envisioned for Finland, India, the Philippines and China as well as other countries who hope to develop the capacity to bring the genetic counseling profession into their genetic service delivery system.

The Transnational Alliance for Genetic Counselling (TAGC) serves to connect these educational programs and member societies for the purpose of transnational collaborations in education, research and the international development of the genetic counseling profession. The inaugural meeting of the TAGC in 2006 connected the worldwide community of genetic counselor educators who proposed this global definition, "*A genetic counsellor is a health professional who is specifically trained to work along with individuals, families and communities to develop a shared understanding of how genetics affects lives and health within the context of accepted cultural beliefs*".

Genetic counselors are educated to individualize each client, taking into account the impact of cultural, religious and socioeconomic issues for each family or population. (Begleiter 2002,

Weil 2003). The principle of beneficence with respect for confidentiality and individual autonomy guides their practice. Clients are facilitated in decision making as they are given accurate genetic information communicated with respect for individual beliefs. Genetic counselors in turn are acutely aware of their own personal values and do not impose advice on clients.

While philosophies among genetic counselors may be similar worldwide, health care systems vary from country to country and impact delivery of services. Within universal health care systems such as in Australia and the UK, for example, genetic counseling is offered free of charge to patients. Resources such as interpreters and access to screening and prenatal testing can be offered through the public health care system at no cost to the individual. Usually there will be eligibility criteria so that resources are managed; for example, women over a certain age are offered prenatal testing.

Difference as well as similarity is an important teaching tool in genetic counseling education. Recognizing this, the TAGC promotes student and faculty exchanges between genetic counseling programs. Graduate students have taken on international clinical rotations in several countries including Australia, Canada, France, the United Kingdom, South Africa and the United States. The student sees first hand the impact of health care system, culture and society on genetic counseling as it compares to their homeland. This broadens and expands perceptions, increasing awareness for the human aspect of genetic conditions shared among all people, superimposed by societal and cultural differences.

Despite the fact that genetic counselors are recognized health professionals with specialized graduate degrees and credentialing processes in many countries, there is still an urgent need to train enough genetic counselors for each and every country. According to the National Society of Genetic Counselors in the USA (<http://www.nsgc.org>) “ *To offer an optimum genetic service in a country it has been estimated that approximately 2 genetic counsellors per 1 million of the population would be the minimum number required.*” Yet, the number of trained genetic counselors is estimated at less than 3000 worldwide. In South Africa, for example, there is currently less than one Health Professionals Council of South Africa (HPCSA) registered genetic counselor per 5 million people which is inadequate to serve the population of ~ 50 million at the tip of Africa. To the best of our knowledge, there are no other genetic counselors on the African continent.

Establishing an effective, efficient and practical genetic service system, which includes registered genetic counselors in every country, is essential. A 2006 March of Dimes report on birth defects detailed the prevalence rates and the numbers of affected births in 193 countries. The data collected provides a basis for a broad comparison of specific birth defects across regions and among countries of different income levels. These comparisons interestingly showed that the highest birth defects prevalence was found among the world’s poorest countries, whereas many of the lowest rates are found among the world’s wealthier countries. If all genetic-related late onset disorders, such as hypertension, diabetes, certain cancers and psychoses in addition to the adult onset neurodegenerative inherited disorders are considered, it has been proposed that >60% of the population will be affected with one of these conditions during their lifetime. (see SA Policy Guidelines for the management and prevention of genetic

disorders, birth defects and disabilities. Department of Health, Pretoria, South Africa. (2001).

As global awakening in genetics continues, the Transnational Alliance for Genetic Counseling will promote transnational collaborations in genetic counselor education and research, stimulating international understanding of the role of genetics on human lives. As clinical practice informs clinical research, internationally published, peer-reviewed studies will continue to deepen our appreciation of genetic counseling and its contribution to the health and well-being of citizens of all countries. We invite interested readers to the electronic window for global genetic counselor education through the TAGC website, <http://tagc.med.sc.edu>.

#### REFERENCES :

Begleiter M (2002). Training for Genetic Counselors. *Nature Reviews/Genetics* 3 557.

Christianson AL, Howson C, Modell B. 2006. The March of Dimes Global, Report on Birth Defects. March of Dimes, White Plains, USA. [[www.marchofdimes.com](http://www.marchofdimes.com)]

National Society of Genetic Counselors: <http://www.nsgc.org>.

Policy Guidelines for the management and prevention of genetic disorders, birth defects and disabilities. Department of Health, Pretoria, South Africa. (2001)

<http://www.doh.gov.za/docs/policy/humangenetics.pdf>

Transnational Alliance for Genetic Counseling: <http://www.tagc.med.sc.edu>.

Weil J (2003). Psychosocial Genetic Counseling in the Post -Nondirective Era: A Point of View. *J Genet Couns*, 12(3), 199-211