

**Transnational Alliance for Genetic Counseling (TAGC)
Fourth International Meeting
Agenda**

Auditorium Josep Marull
Universitat Pompeu Fabra
Barcelona, Spain
May 19 -20th, 2016

Thursday 19 May - The Global state of Genetic Counseling

09:30am Breakfast with coffee and pastries will be available (included)

10:00 Welcomes and Introductions

Meeting chairs: Kelly Ormond (USA)
Clara Serra-Juhé (Spain)
Tina Marie Wessels (South Africa)

10:00-12:00 Current international state of the profession, workforce and training status

The session's focus in training of genetic counsellors and each presenter will give a 10 minute presentation with 3-4 minutes of discussion time.

Chairs : Tina-Marié Wessels (South Africa)
Lian-Hua Huang (Taiwan)

Panel:

Australia - Kristine Barlow-Stewart, Sydney Medical School
Canada – Jennifer Fitzpatrick McGill University (*slides presented by Tina Wessels*)
France - Emeline Davoine, Oscar Lambret
Phillipines – Mercy Laurino, University of Manila
South Africa – Shelley Macaulay, University of the Witwatersrand
Spain - Clara Serra-Juhé of University Pompeu Fabra
Taiwan – Lian-Hua Huang, School of Nursing, National Taiwan University
UK - Diana Scotcher, Manchester Centre for Genomic Medicine
USA - Cathy Wicklund, Northwestern University

12:00-13:00 Lunch (included)

13:00-15:00 The state of credentialing and plans for reciprocity across the globe

Each speaker will give an overview of how genetic counselors obtain registration/certification in their country, plus what recognition they have to accept the training and certification of genetic counselors from outside their country.

Chairs: Anna Middleton (UK)
Milena Paneque (Portugal)

Panel:

Australasia: Ivan Macciocca, representing the Board of Censors for Genetic Counselling

Canada: Kate Gardiner, representing the Canadian Association of Genetic Counsellors

Europe: Debby Lambert, representing the European Board of Medical Genetics (Genetic Counselling)

S.Africa: Tina Wessels, representing the Health Professions Council of South Africa

UK: Diana Scotcher, representing the Genetic Counsellor Registration Board

USA: **Karen Potter Powell**, representing either or both ABGC and ACGC

15:00-15:30 Coffee break with coffee, pastries and light sandwiches (included)

15:30-17:00 -- Open discussion about global workforce issues

Moderator: Barbara Biesecker (USA)

17:00 - Poster session

Optional group dinner (time/location TBA)

Friday 20 May -- Global trends in genetic counselor education

09:00-10:30 Workshops (see below) Rooms 61.101, 61.107, 61.109 and 61.301

10:30-10:45 Coffee break with coffee, pastries and mini sandwiches (included)

10:45-12:15pm Workshops (see below)

(1) Teaching technology and genomics in a rapidly changing environment (Room 61.101)

Presenters:

Kelly Ormond (USA)
Kristine Barlow-Stewart (Australia)
Anna Middleton (UK)

(2) Online teaching methods (Room 61.107)

During this session we will be discussing how online teaching can be utilized in genetic counselling training. The format will be formal presentations followed by group discussions:

Presenters: Kunal Sanghavi (Skype) (US/India)
Tina-Marié Wessels (South Africa)
Alexandra Obregon Tito (USA)
Sonia Margarit (Chile)

(3) Supervision in Genetic Counseling Training (Room 61.109)

This discussion-based, interactive workshop will focus on various aspects of clinical supervision. Topics for both novice and experienced supervisors will be addressed, including nuts and bolts of establishing a clinical rotation, styles of supervision, strategies for working with students at different developmental stages, and handling challenging situations.

Presenters:

Jennifer Fitzpatrick (Canada)
Andrea Hanson-Kahn (USA)

(4) Family communication and cross cultural issues that arise (Room 61.301)

Review the current state of interventions in promoting family communication. Small group exercises will assist participants develop techniques to support family communication. The session will conclude with facilitated discussion of the benefits and the challenges of introducing family communication techniques into genetic counseling curricula, with reference to cultural implications.

Presenters:

Louisa Di Pietro (Australia)
Allison Metcalfe (UK)
Margaret Sahhar (Australia)
Diana Scotcher (UK)

12:15-13:15pm Lunch (included)

13:15-14:00 Open discussion regarding international trends in genetic counseling education

14:00 – Conclusion of conference

Presenter Bios (Presented Alphabetically)

Kristine Barlow-Stewart, PhD, FHGSA (Gen Couns)

Director, Master of Genetic Counselling Program (Sydney Medical School – Northern)

Associate Professor Kristine Barlow-Stewart, BSc (U.Syd), PhD (U.NSW), Genetic Counsellor (FHGSA), Foundation Director of NSW Health's Centre for Genetics Education (1989-2012) has been the Director of the Master of Genetic Counselling program for the University of Sydney since 2011. Her career has focussed on addressing the information and support needs of the community, education and training needs of professionals and the impact of the rapidly developing field of genetic and genomics technologies. Kristine has contributed widely to development of policies in this area and was one of the first in Australia to be certified as a genetic counsellor in 1991.

Barbara Biesecker, PhD, MS

Associate Professor - Adjunct, Johns Hopkins University

Director, JHU/NHRGI Genetic Counseling Training Program

Barbara Bowles Biesecker completed her M.S. in human genetics at The University of Michigan in 1981. In 2011, she earned a Ph.D. in health psychology from Kings College London. Dr. Biesecker has been instrumental in fostering social and behavioral research in collaboration with the NHGRI ClinSeq® cohort. She teaches several courses within The Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program and serves as thesis advisor to genetic counseling graduate students, more than 20 of whom have published their thesis research in peer-reviewed journals. Among the awards Dr. Biesecker has received are the inaugural Diane Baker Alumnae Lecture Award from the University of Michigan, and NIH Director's awards for mentoring and for the Katrina Missing Persons Effort. She served as president of the National Society of Genetic Counselors in 1989.

Emeline Davoine, MSc GC, MSc

Genetic counsellor, Oscar Lambret Cancer Center, Lille

TAGC representative, French Association of Genetic Counsellors (AFCG)

Emeline received her MSc in biological and chemical engineering in 2012 from the Engineering School of Physics, Chemistry and Electronics of Lyon and her MSc in Genetic Counselling in 2015 from the Aix-Marseille University of Medicine. She worked from 2010 to 2011 as a research assistant in medicinal chemistry at the Broad Institute in Boston, USA and in 2012 as a research associate in cancer drug development at Pierre Fabre Pharmaceuticals, Toulouse. She currently works as a genetic counsellor at Oscar Lambret Cancer Center in Lille since 2015. She represents the French Association of Genetic Counsellors at the TAGC 2016 conference.

Louisa Di Pietro, MS

Group Leader, Genetic Support Network of Victoria (Victorian Clinical Genetic Services)

Louisa is the current Group Leader of the Genetic Support Network of Victoria (GSNV) at the Victorian Clinical Genetic Services (VCGS). She is an experienced researcher and educator with a particular interest in genetic counseling and reflective practice, ethical screening, testing and the diagnosis of genetic and rare conditions, the psychosocial impact of diagnosis on families and individuals and the delivery of ethical medical services in a genomics era. Louisa is an ongoing teacher and trainer in the University of Melbourne, Masters In Genetic Counseling and is an appointed research supervisor and peer reviewer in the course. She is actively involved in professional and community engagement and sits on numerous professional boards and advisory groups within the genetics and rare disease sectors.

Jennifer Fitzpatrick, MS, CGC

Assistant Professor, Department of Human Genetics (McGill University)

Director, MSc in Genetic Counselling Program (McGill University)

Jennifer Fitzpatrick, MS, is a genetic counsellor and Assistant Professor in the Department of Human Genetics, McGill University, Montréal, Canada. She obtained her BSc in Biology from McGill University in 1988 and her MS in Human Genetics/Genetic Counseling from the University of Michigan in 1989. She worked in Pediatrics at the Hospital for Sick Children, Toronto and at the University of Maryland Medical Center, Baltimore, and spent 2 years in Paris as a research assistant, prior to returning to McGill in 1999. At McGill she has worked in Pediatrics at the Montreal Children's Hospital and in Prenatal Diagnosis at the Jewish General Hospital. She became the Director of the MSc in

Genetic Counseling Program in 2005. After completing the Faculty of Medicine's Teaching Scholars Program in 2010, she became the coordinator of clinical teaching for her department. Her current research focus is on clinical supervision in genetic counselling.

Kate Gardiner, MSc, CGC, CCGC

Laboratory Genetic Counselor, LifeLabs

Chair, Canadian Association of Genetic Counsellors Certification Committee

Kate Gardiner completed her Master of Science in Human Genetics from Sarah Lawrence College in 2011. She is currently board certified with the Canadian Association of Genetic Counsellors (CAGC) and the American Board of Genetic Counseling (ABGC). Kate is current Chair of the CAGC certification committee (2014-present) and also served as a member of the CAGC education committee in 2013. She is a laboratory genetic counselor at LifeLabs – Genetics Department and has over five years of genetic counseling experience in clinical, laboratory, and academic settings.

Andrea Hanson-Kahn, MS, CGC, LGC

Clinical Assistant Professor, Department of Genetics (Stanford University)

Associate Director, MS in Human Genetics and Genetic Counseling (Stanford University)

Andrea Hanson-Kahn graduated from the Genetic Counseling Program at UC Irvine in 2000 and was certified by the ABGC in 2002. She has been at Stanford since 2000 and has worked in the Medical Genetics clinic, the Genetic/Dermatology Clinic, the Craniofacial Anomalies Clinic and in the outreach clinics. She is also the facilitator for the Palo Alto Huntington's Disease Association Support Group. In her role as associate program director, Andrea is directly involved in all aspects of training, including teaching courses, assisting with clinical rotation oversight and providing direct supervision, research project advisement and serving as an academic advisor for approximately half the students yearly.

Lian-Hua Huang, RN, EMBA, PhD, MS, FAAN

Professor, Genetic Counseling Program and School of Nursing (National Taiwan University)

Standing Supervisor, Taiwan Association of Genetic Counseling

Dr. Huang earned the following degrees from the University of Colorado: MS in Genetic Counseling, her MS in Community Health Nursing, and her PhD in Psychosocial Nursing. She also completed her EMBA in Business Administration from National Taiwan University. She is currently a professor for the Genetic Counseling Program and the School of Nursing at National Taiwan University, and is currently serving as the Standing Supervisor for the Taiwan Association of Genetic Counseling.

Debby Lambert, MSc, CGC, CCGC

Information Scientist, National Rare Disease Office (Mater Misericordiae Hospital)

Debby completed two MSc degrees from McGill University (MSc in Epidemiology in 1994 and MSc in Genetic Counselling in 1996). She is certified by the American Board of Genetic Counselors (1996, 2006) and the Canadian Association of Genetic Counsellors (2002, 2012), and is also a Registered European Genetic Counsellor (European Board of Medical Genetics, 2014). Debby is currently an Information Scientist and Orphanet Ireland Project Manager at the National Rare Diseases Office, MMUH. She spent the previous 11 years as a genetic counsellor at Children's University Hospital in Dublin, seeing patients in adult, paediatric, and prenatal outpatient clinics. Debby also serves on several committees, including the European Board of Medical Genetics (Genetic counselor and nurse division), the Board of Irish Society for Human Genetics, and the Temple Street Children's Hospital Ethics Committee. In addition, she is the nominated Irish representative to the Advisory Technical Group for the European Platform on Rare Diseases Registration

Mercy Laurino, MS, PhD

Mercy Laurino is a certified and licensed genetic counselor. She recently completed her doctorate degree in Public Health Genetics at the University of Washington, and she is founding president of the Professional Society of Genetic Counselors in Asia. For several years, she collaborated with the medical geneticists in the Philippines and successfully launched the master's degree program in genetic counseling at the University of the Philippines Manila in 2011. She currently resides in Seattle and manages the cancer prevention program at the Seattle Cancer Care Alliance. She periodically travels to the Philippines to forward initiatives regarding the genetic counseling program as well as provide student oversight and online lectures throughout the year.

Shelley Macaulay, MSc

Lecturer, MSc in Medicine in Genetic Counselling (University of the Witwatersrand, Johannesburg)

Shelley Macaulay is the Genetic Counselling Manager at the National Health Laboratory Service (NHLS) and the University of the Witwatersrand in Johannesburg, South Africa. She has 10 years of experience in the genetic counselling profession. Her degree qualifications include a BSc (Honours), an MSc (Med) in Human Genetics and an MSc (Med) in Genetic counselling. She is also currently completing her PhD entitled “Glucose metabolism and pregnancy in South African women,” in the field of Maternal and Child Health, at the MRC/Wits Developmental Pathways for Health Research Unit (DPHRU), University of the Witwatersrand. Shelley is also a lecturer at the University and runs the Masters in Genetic Counselling course. In addition to curriculum development for the MSc (Med) Genetic Counselling degree, her academic responsibilities include teaching, training, supervising and examining at both the undergraduate and postgraduate level, and being a member of several University Committees. She counsels a variety of cases including prenatal, paediatric and adult-onset cases but has a particular interest in cystic fibrosis, Huntington disease and the inherited cancer syndromes. Shelley is a published researcher with publications in peer reviewed journals and she has attended and presented at several conferences. She also enjoys engaging in community and publicity awareness and has written articles aimed at educating the general public about genetic conditions and genetic counselling.

Ivan Macciocca,

Clinical Project Manager, Melbourne Genomics Health Alliance

Ivan Macciocca is the Clinical Project Manager for the Melbourne Genomics Health Alliance, where he is responsible for facilitating clinical aspects of the translation of genomic sequencing into clinical care. Prior to this role, he worked for the Victorian Clinical Genetics Services (VCGS) as a genetic counsellor for 15 years and played an integral role in the establishment of new clinical genetics services, including throughout rural Victoria. He worked in London at the Heart Hospital managing the translation of individual genetic research findings into clinical care. After returning to Australia, his clinical work focused on inherited cardiac disease, where he was involved in establishing new cardiac genetics clinics at the Royal Children’s Hospital, Royal Melbourne Hospital, Monash Medical Centre and The Alfred, together with colleagues at each of these sites. He also contributed to the establishment of a new next-generation sequencing test for genes associated with inherited heart conditions offered by the VCGS and completed a Masters thesis on the impact of genetic testing for these conditions.

Sonia Margarit, MS

Professor of Natural Sciences, Escuela Superior Nacional del Profesorado Sarmiento (Argentina)

Sonia earned her MS in Human Genetics from Sarah Lawrence College and her MS in Health Psychology from P. U. Católica de Chile. She has been a member of the National Society for Genetic Counselors since 1997. Sonia is currently a faculty member at Escuela Superior Nacional del Profesorado Sarmiento. She is primarily focused on providing genetic counselling to affected patients and relatives, facilitating the understanding of disease, medical management and implications of the results of genetic studies to better adapt to the particular situation of each family.

Alison Metcalfe, PhD, BSc, RN, MBPsS

Professor, Health Care Research, Florence Nightingale Faculty of Nursing & Midwifery (King’s College London); Vice Dean for Research, Florence Nightingale Faculty of Nursing & Midwifery (King’s College London)

Alison became a registered general nurse in 1987, earned her PhD from Keele University in 1997, and completed some postdoctoral work in immunology and biomolecular science. She has worked on national and international committees advising on genetics education for nurses and midwives, and worked with charities and patient groups aiming to improve patient care for families affected by genetic conditions. Alison is currently a Professor of Health Care Research and the Associate Dean for Research at King’s College London. Her research interests include genetic science, risk communication and family psychology.

Anna Middleton, PhD, MSc, RGC

Principal Social Scientist, Lead: Social Science and Ethics (Wellcome Genome Campus)

Vice-Chair, Association of Genetic Nurses and Counsellors, UK

Anna received her MSc in Genetic Counselling in 1995 from the University of Manchester and her PhD in Genetics and Psychology from the University of Leeds in 2000. She is currently the Principal Staff Scientist for the Wellcome Trust Sanger Institute and an Honorary Researcher for The Ethox Centre in the Department of Public Health at the

University of Oxford. She specializes in research into the social impact of genetic technology and services on people. Dr. Middleton is also a registered genetic counselor working within various regional clinical departments in the National Health Service in the UK. She is currently serving as the vice-chair for the Association of Genetic Nurses and Counsellors (AGNC).

Alexandra Obregon Tito

Kelly Ormond, MS, CGC, LGC

Professor, Department of Genetics (Stanford University)

Director, MS in Human Genetics and Genetic Counseling (Stanford University)

Kelly Ormond received her Master of Science degree in genetic counseling from Northwestern University in 1994 and completed a post-doctoral fellowship certificate in Clinical Medical Ethics at the MacLean Center of the University of Chicago in 2001. She is certified by the American Board of Genetic Counseling (ABGC; 1996). Kelly is currently the Program Director for the MS in Human Genetics and Genetic Counseling and she oversees all aspects of the program's development. Kelly works closely with the CIRGE program on genetics/ethics research they are conducting and is especially interested in issues around informed consent and the translation of new technologies including NIPT and the clinical integration of whole-genome/exome sequencing. She has recently worked to start up a genetic counseling clinic in conjunction with the Executive Health and Concierge Medicine programs, meant to be a model for incorporation of genetic services into primary care. Kelly is active in the National Society of Genetic Counselors (and served as president in 2004-5), the American Society of Human Genetics (recently chairing the Social Issues committee), the American College of Medical Genetics, and the American Society of Bioethics and Humanities.

Milena Paneque Herrera, PhD, MSc

Psychologist and Genetic Counsellor, Center for Predictive and Preventative Genetics (CGPP) -

Institute for Molecular and Cell Biology (IBMC)

Chair, Genetic Nurses and Genetic Counsellors Division, European Board of Medical Genetics (EBMG)

Dr. Paneque Herrera earned her PhD in Biomedical Sciences from the Instituto de Ciências Biomédicas Abel Salazar, University of Porto in 2008 and her MSc in Genetic Counselling from Instituto Superior de Ciências Médicas, Cuba in 2002. She is currently a psychologist and genetic counsellor at the Center for Predictive and Preventative Genetics-Institute for Molecular and Cell Biology. Milena is the current Chair of the Genetic Nurses and Genetic Counsellors Branch Board of the European Board of Medical Genetics (EBMG) and the President of the Portuguese Association of Genetic Counsellors. She serves as the Co-Director of the Master's program of Genetic Counselling at ICBAS – Universidade do Porto.

Margaret Sahhar, BA, Dip. Soc. Studs.

Senior Social Worker, Victorian Clinical Genetics Services

Director, MSc in Genetic Counselling (University of Melbourne)

Margaret is the founding Director of the Graduate Diploma in Genetic Counselling, which was established in 1996. She was a member of the inaugural committee of the Human Genetics Society of Australasia, which established the guidelines for the training of genetic counsellors in Australia. Her clinical work is with families and people with MPS and bone dysplasia. Margaret served as a member of the first certification Board for genetic counsellors in Australia. She has encouraged the formation of international links with other programs and fosters student exchange. The Masters hosts many international student exchanges and Margaret was a founding member of the Transnational Alliance of Genetic Counselling Educators (TAGC) and is the Australian representative of this group.

Kunal Sanghavi, MS

Genetic Counselor, McKusick-Nathans Institute of Genetic Medicine (Johns Hopkins University School of Medicine)

Kunal Sanghavi is a genetics research program specialist at the McKusick Nathans Institute of Genetics Medicine at the Johns Hopkins University School of Medicine, Baltimore, USA. He leads primary care linkages and public health workgroups at the New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC), USA. He completed his medical education in Mumbai, India and pursued a program in genetic counseling at the Boston University School of Medicine, USA. Kunal developed and conducted different genetic education workshops within the US and at international locations. His research interests include improving genetics service delivery using

innovative approaches and distance strategies. Kunal conducts and manages online fellowship program for genetic counseling trainees and clinical genetics residents/fellows. Kunal is also involved in developing cross-border collaborations for genetics education, counseling, and service aimed at helping families with special health care needs to access appropriate genetic information, resources, and services.

Diana Scotcher, RN

**Registered Genetic Counsellor, Department of Clinical Genetics (St. Mary's Hospital, Manchester)
Honorary Lecturer, MSc in Genetic Counselling (University of Manchester)**

Diana is a member of the Genetic Counsellor Registration Board, and was Chair 2014-16. She is a Principal Genetic Counsellor in Manchester Centre for Genomic Medicine, where she is a member of the genetic counsellor management team, with a particular interest in neuromuscular conditions, cystic fibrosis, and prenatal diagnosis. Diana has been an Honorary Lecturer on the MSc in Genetic Counselling at the University of Manchester since 1995 and a member of the Programme Committee. She has been a supervisor of research dissertations and has coordinated several modules.

Clara Serra-Juhé, PhD

**Associate Professor, Genetics Unit, Department of Experimental and Health Sciences (Universitat Pompeu Fabra)
Academic Coordinator, MS in Genetic Counselling (Universitat Pompeu Fabra)
President, Spanish Association of Genetic Counselling
Member of the Genetic counsellors and Nurses Branch Board at the European Board of Medical Genetics(EBMG)**

Clara got her degree in Human Biology at Pompeu Fabra University. She studied a Master in Clinical Laboratory and the Master in Genetic Counselling (idEC-UPF) at the first promotion. She did her PhD, entitled "Genetic, genomic and epigenetic alterations in congenital malformations: implications in genetic counseling" at the Genetics Unit, Department of Experimental and Health Sciences (UPF). During her thesis, she did an internship in exome sequencing at Genomic Disorders Group, Department of Human Genetics, Radboud University, Nijmegen, The Netherlands. Clara was one of the founders of the Spanish Society of Genetic Counselling and she is the current President of the Society. At present she is a CIBERER Postdoctoral Researcher in Human Genetics at UPF and a lecturer at the same university. She is in charge of the coordination of the Master in Genetic Counselling (idEC-UPF) and a member of the European Board of Medical Genetics, Genetic Nurses and Genetics Counsellors Division.

Tina-Marié Wessels, PhD, MSc

**Senior Lecturer, Division of Human Genetics (University of Cape Town)
(representing the Health Professions Council of South Africa)**

Tina-Marié obtained her MSc(Med) in Genetic Counselling in 1997 and worked as a genetic counsellor in the department of Human Genetics at Wits. She then briefly joined the National department of Health (1998 to 2000) but missed the clinical contact with patients and returned to Wits. In 2001, she was appointed Manager Clinical Genetics in the Division Human Genetics at the National Health Laboratory Service and the University of the Witwatersrand. She obtained her PhD in 2013 from the University of the Witwatersrand, in association with the Health Communications Project and examined the communication aspects of the Genetic Counselling process in our antenatal multicultural context. She joined the Division of Human Genetics at UCT in April 2014 as senior lecturer in Genetic Counselling. Together with Prof Jacquie Greenberg, they run the Masters programme in Genetic Counselling and Tina-Marié is involved in other undergrad and postgraduate teaching.

Cathy Wicklund, MS

**Associate Professor, Obstetrics and Gynecology-Clinical Genetics (Northwestern University)
Director, Graduate Program in Genetic Counseling (Northwestern University)**

Ms. Wicklund is the Director of the Graduate Program in Genetic Counseling at Northwestern University and an Associate Professor in the Department of Obstetrics and Gynecology. She received her Master of Science degree in Genetic Counseling from the University of Texas-Graduate School of Biomedical Sciences and is a diplomat of the American Board of Genetic Counseling. She has over 20 years of experience in clinical genetic counseling and has

provided prenatal and pediatric genetic services. She served on the Board of Directors of the National Society of Genetic Counselors first as Region V Representative, then as Secretary and was President in 2008. Currently she is a member of the the Advisory Committee on Hereditary Disorders in Newborns and Children, the American Society of Human Genetics representative on the Scientific Program Committee of the 2016 International Congress of Human Genetics and the NSGC representative on the Institute of Medicine Roundtable on Translating Genomic Based Research for Health. Ms. Wicklund's research interests include issues regarding whole genome/exome sequencing and personalized medicine, psychosocial and counseling issues, and professional issues including workforce and access to and delivery of genetic services. She is a co-investigator on the Electronic Medical Records and Genomics (eMERGE) Network, which aims to bring personalized medicine into broader clinical use.