A European Parliament Seminar:

‘Genetic Discrimination – Transatlantic Perspectives on the Case for a European Level Legal Response’

organised by:

Centre for Disability Law and Policy, National University of Ireland, Galway, Ireland

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European Disability Forum

Date: 6th March 2012

Venue: European Parliament (Room P5B001), Brussels

*Co-funded by the Irish Research Council for the Humanities and Social Sciences
**Purpose and aim of the event:**
The purpose of this seminar is to highlight the case for a European level legal and policy response to protect the privacy of genetic information and to prevent genetic discrimination, particularly in the employment and insurance contexts.

On 19th November, 2011 the Centre for Disability Law and Policy (in conjunction with the Burton Blatt Institute, Syracuse University, USA) hosted a conference entitled ‘Genetic Discrimination – Transatlantic Perspectives on the Case for a European Level Legal Response’. This international conference, which was chaired by Justice John Mac Menamin of the High Court, was the first of its kind in Europe and brought together a diverse range of leading experts in the area, with the objective of exploring the case for a European level response to protect the privacy of genetic information and to prevent genetic discrimination.

The conference highlighted the interdisciplinary nature of this area and focused on the interaction between genetic science, technology, ethics and the law, and in particular, how best to regulate this complex area. On foot of the scientific and legal expertise offered, and on consideration of the potential for abuse and the fundamental human rights at stake, the conference strongly indicated a need for an appropriate regulatory response at European level to protect the privacy of genetic information and to prevent genetic discrimination.

This event aims to build upon the discussion generated from the conference on 19th November 2011, and further highlight the issue of genetic discrimination and protection of genetic privacy as one which merits attention and regulation at European level. It is necessary to present this case on a European level and raise awareness of the need to appropriately regulate this area. The seminar will focus on the legal and policy vacuum, and will propose a case for comprehensive and uniform legislation at European level. If left inadequately regulated, there is a real possibility that discrimination will become more widespread and that employers, insurance companies (and other interested third parties) will take advantage of individuals and misuse sensitive genetic information.

**Outcome of the event:**
The event will highlight the issues of genetic discrimination and genetic privacy on a European forum. It will also raise awareness of the issues to the key European Institutions in Brussels. This is an important and necessary step towards introducing reform in the area and taking the opportunity to make recommendations for legal intervention. The outcome of the seminar will further the discussion on what an appropriate European level response might be – involving stakeholders who will be contributing towards drafting, producing and implementing such a legislative response. The potential practical impact of this seminar is that it will make a meaningful contribution towards framing the necessary legal reform in this area.

**Who is the event aimed at:**
The event is aimed at legal practitioners and medical practitioners, academics and researchers, NGOs and those involved in disability issues, bioethics and practice. It is aimed at Members of the European Parliament, the European Commission and other European institutions. It is also aimed at those interested in medical testing generally as well as genetic testing specifically.

*Contact aisling.depaor@nuigalway.ie for further details.*
# PROGRAMME

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<td>Registration</td>
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<td>2.00-2.05</td>
<td><strong>Welcome:</strong> Marian Harkin (Member of the European Parliament)</td>
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<td><strong>Chair:</strong> Andre Gubbels (Director General, Federal Public Service at Social Security, Belgian Ministry)</td>
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<td>2.05-2.25</td>
<td><strong>The Evolution of Genetic Science &amp; Technology</strong></td>
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<td>Professor Ciaran Morrison (Centre for Chromosome Biology, School of Natural Sciences, NUI Galway)</td>
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<td>2.25-2.45</td>
<td><strong>Ethical and Legal Implications arising from the use of Genetic Information by Third Parties</strong></td>
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<td>Professor Yann Joly (Centre of Genomics and Policy, McGill University, Montreal, Canada)</td>
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<td>2.45-3.00</td>
<td>Q &amp; A</td>
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<td>3.00-3.20</td>
<td><strong>The US Legislative and Policy Response</strong></td>
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<td>Genetic Information Non-Discrimination Act (GINA), 2008</td>
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<td>Professor Peter Blanck (Chairman, Burton Blatt Institute, Syracuse University, USA)</td>
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<td>3.20-3.30</td>
<td>Q &amp; A</td>
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<td>Tea &amp; Coffee</td>
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<td>3.45-4.10</td>
<td><strong>Legislating at the EU Level: Possibilities and Challenges</strong></td>
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<td>Avv. Dr. Delia Ferri, (Honorary Research Fellow, Faculty of Law, University of Verona)</td>
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<td>4.10-4.20</td>
<td>Q &amp; A</td>
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Roundtable on the Case for a European Level Legal Response

European Disability Forum
J Patrick Clarke (Member of European Disability Forum Executive Committee/ President, Down Syndrome Ireland)

European Parliament – Disability Intergroup
Marian Harkin (Member of the European Parliament)

The EU Data Protection Perspective
Peter Hustinx, European Data Protection Supervisor

Office of the High Commissioner for Human Rights
Dima Yared, Human Rights Officer (Office of the High Commissioner for Human Rights)

Q & A

Rapporteur’s Report

Dr Elise Muir (Assistant Professor, Faculty of Law, Maastricht University)

Close of the Conference (Phil Prendergast, Member of the European Parliament)

Cocktail Reception
About the Centre for Disability Law and Policy

The Centre for Disability Law and Policy (CDLP) was formally established in 2008 and is dedicated to producing research that informs debate on national and international disability law reform. The establishment of the CDLP coincides with one of the most intensive periods of disability law reform in Ireland, as well as internationally. The adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006 also contributes towards accelerating this worldwide trend and provide further direction.

The purpose of the CDLP is to broaden debate about disability law reform in Ireland by placing it in an international and comparative context and by highlighting international best practice. The Centre has undertaken a number of major research projects (including projects on how to best configure national disability strategies and how to achieve the personalisation of disability supports). It contributes detailed legislative submissions to Government on emerging and topical disability issues. The CDLP has a vibrant Ph.D. programme, and hosts public lectures and seminars for interested stakeholders on a variety of diverse and topical areas throughout the year. The CDLP runs an LL.M. on International and Comparative Disability Law, which offers students an innovative and internationally focused programme dealing with the process of law reform and policy in the field of disability.

Lifecourse Institute

The CDLP is also part of the Lifecourse Institute in NUI, Galway: an alliance between the CDLP, the Irish Centre for Social Gerontology and the Child and Family Research Centre. This alliance aims to advance an integrated approach to research into policy and services for older people, children and families, and people with disabilities. Conceptually, the Lifecourse Institute marks an innovative approach in the social sciences by establishing the lifecycle as a key framework of reference for understanding existing vulnerabilities in society.

Marian Harkin, MEP

Marian Harkin is an Independent MEP for the North and West Constituency of Ireland. Marian was elected as an Independent Member of the Irish Parliament and has been elected twice as a Member of the European Parliament.

As a Member of the the Alliance of Liberals and Democrats for Europe (ALDE) in the European Parliament, Marian is a full member and ALDE co-ordinator of the Employment and Social Affairs Committee, substitute member on the Agriculture and Rural Development Committee and substitute member on the Petitions Committee. Marian is also President and founding member of the European Parliament Volunteering Interest Group and she successfully led the campaign in the Parliament to have 2011 designated as the European Year on Volunteering. Throughout this campaign Marian worked constantly with “The Alliance” – a network of NGOs and Voluntary Organisations, National and Transnational. She always insisted that the Voluntary Sector would play a central role during the year and her objective is that there will be added value at European level. Marian is also co-President and founding member of the European Parliament Carers Interest Group. She works closely with Credit Unions (not
for profit financial institutions) both in Ireland and globally and works to represent their interests at European and National Level.

More recently Marian has been appointed as co-chair of the Politicians for Cervical Cancer Prevention and is also co-chair of the Mental Health Interest Group and Member of the Disability Intergroup in the European Parliament.

**Phil Prendergast, MEP**

Phil Prendergast originally trained as a nurse and later a midwife and worked in hospitals in Ireland and the UK. She worked as a midwife for over 20 years. She was a trade union representative for student nurses, and went on to become a full representative with the Irish Nurses and Midwives Organisation thereafter. She sat on the executive board of the INMO in 1994. She first got involved in politics in 1985, being elected first as a town councillor, then as a county councillor and then as a senator from 2007 until 2011. She was twice Mayor of Clonmel.

She sits on three committees in the European Parliament. These are the Committee on Agriculture and Rural Development (AGRI), the Committee on the Internal Market and Consumer Rights (IMCO) and the Petitions Committee. She is also active on the European Economic Area (EEA) Joint Parliamentary Committee; the EU/US Interparliamentary delegation; the EU-Iceland Joint Parliamentary Committee and delegations for relations with Switzerland and Norway.

**European Disability Forum (EDF)**

The European Disability Forum is an independent NGO that represents the interests of 80 million Europeans with disabilities. EDF is the only European platform run by persons with disabilities and their families. It is the front runner for disability rights and the voice of persons with disabilities in Europe. EDF was created in 1996 by its member organisations to make sure decisions concerning disabled people are taken with and by disabled people.

**André Gubbels**

André Gubbels is the Director General of the Service for People with Disabilities which is an integral part of the Belgian Federal Public Service for Social Security.

The Service pays the following benefits:
- Disability income replacement and integration allowances (under 65 years of age) - paid at different rates depending on the extent of the disability
- Elderly support allowances (over 65 years of age) paid at different rates depending on the extent of the disability

Formerly, he has been Inspector General in the Walloon Agency for the Integration of People with Disabilities (AWIPH) in Belgium.
He also worked previously in the Disability Unit of the Directorate General for Employment and Social Affairs of the European Commission.
He has also been Deputy Chief Cabinet Officer to the Belgian Minister for Health and Disability Policy and Administrator in the Belgian Department of Labour.
He graduated in law at the University of Liège and edits a law review which focuses on Belgian disability legislation.
Ciaran Morrison

Professor Ciaran Morrison obtained a B.Sc. in Biochemistry and then an M.Sc in Microbiology/Genetics at the National University of Ireland Galway (NUI Galway). He then undertook his doctoral research on genetic recombination at the Institute of Molecular Pathology in Vienna, Austria, graduating from the University of Vienna ‘mit Auszeichnung’ in 1997. He then performed postdoctoral work on how cells repair their DNA at Kyoto University, Japan, returning to Europe in 1999 to study cell division at the University of Edinburgh. In 2002, he returned to NUI Galway with funding from Science Foundation Ireland and he has been there since, with the research theme of how dividing cells keep their genetic material intact.

Yann Joly

Yann Joly, Ph.D. (DCL), is a Lawyer and an Assistant Professor at the Faculty of Medicine, Department of Human Genetics at McGill University, Montreal, where he lectures ‘Genetics, Ethics and the Law’, and ‘Topics on the Human Genome’. He is also a research fellow from the Fonds de la recherche en santé du Québec (FRSQ) and a researcher at the Centre de recherche en droit public (Université de Montréal). He also works as an ethics and legal consultant in the private sector. Prof. Joly is the North American coordinator of the Association de recherche et de formation en droit medical (ARFDM) and the Data Access Officer of the International Cancer Genome Consortium (ICGC). His research activities lie at the interface of the fields of intellectual property, health law (biotechnology and other emerging health technologies) and bioethics. He has served as a legal advisor on several ethics committees in the public and private sectors. Professor Joly is a member of the Advisory Board of the Current Pharmacogenomics and Personalized Medicine Journal.

Peter Blanck

Dr. Blanck is University Professor at Syracuse University, which is the highest faculty rank granted to only eight prior individuals in the history of the University. He is Chairman of the Burton Blatt Institute (BBI) at Syracuse University. Blanck holds appointments at the Syracuse University Colleges of Law, and Arts and Sciences, David B. Falk College of Sport and Human Dynamics, School of Education, and the Maxwell School of Citizenship and Public Affairs. Prior to his appointment at Syracuse, Blanck was Kierscht Professor of Law and director of the Law, Health Policy, and Disability Center at the University of Iowa.

Blanck is Honorary Professor, Centre for Disability Law & Policy, at the National University of Ireland, Galway. Blanck received a Bachelor of Arts from the University of Rochester, a Juris Doctorate from Stanford University, where he was President of the Stanford Law Review, and a Ph.D. from Harvard University. Blanck has written articles and books on the Americans with Disabilities Act (ADA) and related laws, and received grants to study disability law and policy. He is a trustee of YAI/National Institute for People with Disabilities Network and is Chairman of the Global Universal Design Commission (GUDC). He is a former board member of the National Organization on Disability (N.O.D.), the Disability Rights Law Center (DRLC), and Disability Rights Advocates (DRA). He also is a former member of the President’s
Committee on Employment of People with Disabilities, and was a Senior Fellow of the Annenberg Washington Program, a Fellow at Princeton University's Woodrow Wilson School, and a Mary Switzer Scholar. Prior to teaching, Blanck practiced law at the Washington D.C. firm Covington & Burling, and served as law clerk to the late Honorable Carl McGowan of the United States Court of Appeals for the D.C. Circuit.

Blanck’s recent books in the area include: The Americans with Disabilities Act and the Emerging Workforce (AAMR, 1998); Employment, Disability, and the Americans with Disabilities Act (Northwestern U. Press 2000); Disability Civil Rights Law and Policy (with Hill, Siegal & Waterstone) (West, 2005, 2009); and Race, Ethnicity, and Disability: Veterans and Benefits in Post-Civil War America (with Logue) (Cambridge University Press, 2010). Blanck and Robin Malloy are editors of the Cambridge University Press series Disability Law and Policy.

Delia Ferri

Delia Ferri graduated in Law magna cum laude in 2003 at the University of Verona, Faculty of Law. Her LLB thesis on freedom of art was awarded "Premio Dugoni 2003". In 2004 she had the opportunity of being a stagiere with the Italian Representation at the EU, within the COREPER (Committee of Permanent Representatives of the European Union) and the Council.

In 2005/2006 she attended UNESCO as a legal observer during the negotiations of the Convention on the protection and promotion of the diversity of cultural expressions. In 2007, she gained a Doctorate in European and Italian Constitutional Law at the University of Verona Faculty of Law. Her doctoral thesis on EU cultural law and policies was awarded the national prize "Premio Ettore Gallo 2008". A refined version of her doctoral thesis has been published at the end of 2008 with the title "La costituzione culturale dell'Unione europea." In 2006, Delia Ferri also earned a Diploma in EU Legal Practice at the Central European University of Budapest.

In 2007, she was lecturer of European Union Law at the MA course “Informatore Europeo per i servizi locali” organized by the University of Trento-Jean Monnet Centre. From April 2008 to June 2008, she was Visiting Fellow in the Department of Law at European University Institute (San Domenico di Fiesole-Florence). Currently, Delia Ferri is Cultore della materia in European and Comparative Law at the University of Verona, Faculty of Law and Cultore della materia in Public Law at the University of Verona Faculty of Languages and Foreign Literature. She has written extensively on the areas of European Law, Disability Law, and in particular the United Nations Convention on the Rights of Persons with Disabilities.

Delia Ferri is also registered Attorney at Law (Verona Bar). In 2009/2010 she was EU law Consultant for the European Foundation Center (Brussels) She works as counsel for a law firm in Verona and as counsel for Germann Avocats (Geneve). With German Avocats, she collaborated to the "EU CINEMA STUDY" - “Study on the economic and cultural impact, notably on co-productions, of territorialisation clauses of state aid schemes for films and audio-visual productions". She collaborated to Study for the Azerbaijan I IFASC “Study on the French and Italian Public Film Funding Models”. In 2010 she collaborated the study "The Implementation of the UNESCO Convention on Cultural Diversity" (IP/B/CULT/IC/2009-057) for the European Parliament. She has extensive experience as legal adviser providing consultancy for relevant applied
research projects in Italy and abroad. From April 2009 she also member of the Human Rights Committee of the Verona Bar Council (Commissione Diritti Umani dell'Ordine degli Avvocati di Verona).

J Patrick Clarke

Pat Clarke is Chief Executive of Down Syndrome Ireland and President of Down Syndrome International. His son aged 30 has Down syndrome.

Pat serves on the board of the Children Rights Alliance and on the governing body of the International Disability Alliance. At a European level he is a member of the Executive Board of the European Disability Forum where he chairs its Youth Committee and its Committee on Stereotypes and Access to Health. He also serves on the advisory board of the European Coalition on Community Living.

Peter J. Hustinx

Mr. Hustinx (1945) has been European Data Protection Supervisor since January 2004 and was re-appointed by the European Parliament and the Council in January 2009 for a second term of five years. He has been closely involved in the development of data protection law from the start, both at national and at international level. Before entering his office, Mr. Hustinx was President of the Dutch Data Protection Authority since 1991. From 1996 until 2000 he was Chairman of the Article 29 Working Party.

He received law degrees in Nijmegen, the Netherlands, and in Ann Arbor, USA. Since 1986 he has been deputy judge in the Court of Appeal in Amsterdam.

Dima Yared

Dima Yared is a human rights officer at the OHCHR Regional office for Europe (ROE) in Brussels, Belgium. Prior to joining ROE, she worked in OHCHR headquarters in Geneva where she was most recently assisting the mandate of the Special Rapporteur on the sale of children, child prostitution and child pornography. Previously, she worked on the Universal Periodica Review as well as within the Rule of Law section at OHCHR, and at an NGO engaging armed non-state actors on the involvement of children in armed conflict.

Elise Muir

Elise is a Marie Curie Fellow (IEF) and Assistant Professor in European Union Law at Maastricht Faculty of Law. She also currently is a visiting lecturer at Sciences Po. Lille. Her fields of interest are EU social law and judicial remedies in EU law. Her Marie Curie research project is devoted to the effects of EU equality law in litigation between private parties. Before starting in Maastricht, Elise worked as a senior academic assistant in the LLM programme of the College of Europe for several years, teaching and researching on EU institutional law, social law and judicial remedies. She has been a visiting doctoral researcher at Columbia Law School (Fulbright grantee) and the European University Institute. Elise has also been a researcher at the Fondation pour l'innovation politique. She completed her PhD ("The Community at work: Community constraints on Member State competence to regulate access to labour markets") at the University of London in 2010. Elise studied law in both France and the UK (Maîtrise, LLB & LLM) before starting postgraduate European legal studies (LLM) at the College of Europe in Belgium where she graduated as the top law student in 2002-2003.