Remarks of Professor Gerard Quinn

Launch of Book

Genetic Discrimination – Transatlantic Perspectives on building the case of for a European –level response

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Thank you Aisling and I’d like to thank the European Commission representation in Ireland for allowing us the use of its premises here in Dublin. And special thanks to Barbara Nolan and all her colleagues including Jonathon Claridge here at the representation. They do a tremendous job here at the representation at bringing Europe home to its citizens. Europe is nothing if not a force for good for our citizens and it is right that this report, which has Europe-wide significance, is launched here today.

I want to say a few words about new trends in European research, research that gets the best from different disciplines.

And I want to put this book - and the research that underlies - it in context. It is a context that promises an explosion of scientific insights into what it means to be human and indeed how we might go beyond being human. It is a context that taxes our existing frames of reference to accommodate such changes whether they lie in ethics, public policy or law.
And I want to say a few words about what next. We are very fortunate to have with us today Marian Harkin MEP who is one of our most active MEPs and has taken a very personal interest in this topic in the Parliament. Research like this is worth nothing unless it helps Marian and others like her to reflect and come to their own judgments about what policy or legislative action, if any, is warranted at European level.

1. **First research and the future of university-based research.** I’m sure you have noticed it but a new turn is taking place in research right across Europe – it’s the turn toward pressing social and other challenges that confront us as we hunker down in the 21st century. To her immense credit ex-Commissioner Geoghean-Quinn has insisted that any future research supported by the EU must speak to these challenges – research that gives us not just inert explanations but which also makes a stab at providing answers and puts forward blueprints for change.

Almost by definition this cannot be done by discipline-specific research. It requires a new effort to reach beyond disciplines – and to turn disciplines toward practical problems in the real world. This is as it should be whether the research emanates from traditional silos either within the hard sciences or law or public policy. And almost by definition this cannot happen alone within ivory towers but requires an active dialogue with cross-sectoral actors – the people actually affected by change.

So, one reason we are proud of this book is that it brings several disciplines together including the hard sciences, public policy, ethics and law in a common discussion about how to enable genetic and other scientific research to evolve and grow, how to enhance public confidence in the research and how to tame it so that it underpins and not undermines our values.

This ‘reaching beyond’ our selves and our own disciplines is exemplified by the sterling contribution of Professor Noel Lowndes – a superb scientist with a real
gift for communicating science to both the public at large and indeed to policy makers who face the very hard task of balancing competing interests and rights.

Europe needs – and demands – more of this kind of joint inter-disciplinary effort and we in Ireland with our colleagues in Europe and North America feel we have made a good start. My own view is that our Universities need to embed a process of dialogue between the hard sciences and other disciplines such as the humanities. We have the intellectual assets – its time to build new and different kinds of bridges. Humanity in the 21st century needs this.

2. And what of the context behind this book. This book speaks to a larger story that is unfolding before our very eyes. Yuval Harari’s latest bestselling book on ‘Sapiens’ charts our evolution from the cognitive revolution through to the point where we, as species, can delve ever more deeply into what makes us human. The understandings that have evolved help re-define what we mean as human, the ingredients of humanity are being laid bare. The striking insights from neuroscience yield striking and new theories of the mind. So much so that the emerging possibilities of human augmentation – both cognitive as well as physical mean that for the first time in history we may be able to transcend our biological selves. Indeed, Harari reports on the impending possibility of merging human minds.

The next 10 years will be truly amazing in terms of the insights generated about our inner selves. This is not inherently bad or wrong or evil. Mankind has always been on a quest of discovery about the world and about ourselves. But we do need to harness these truly amazing breakthroughs – which are only likely to accelerate in the years to come – to our core human values.

So this work on genetic discrimination that we launch today is but a small slice of this larger picture – but an important one. Genetics is getting close to laying bare our makeup as individuals. It points to traits, exposure to risks and predispositions. Of course there is no one to one correlation. There probably never will be. But, note despite the best intentions of the scientists, a form of
social determinism usually attaches to scientific developments magnifying their import beyond what the science will bear. This is not a fault of science or the scientists.

Regulators have struggled to come to terms with this. Do we own our genetic makeup? Not according to the US Supreme Court. If we did we could sell it and market forces would commodify it. Do we have a right of privacy with respect to our genetic makeup? Note, I can surrender my privacy – and indeed that of my family. And in any event, you will have noticed how expectations about privacy have radically shifted in the last decade. Can we retain some vestige of control over the use of misuse of the information? In as much as there is a regulatory regime emerging this seems to be where it lies. If that be the correct frame then we, in Europe, are naked. We have no mechanism to balance the competing rights and interests. The Data Protection package is not yet enacted and even if it were it probably leaves to many loopholes.

3. Lastly, where to now? Research, good research, does not dictate answers – especially where delicate balances need to be struck. It should reach out to an informed citizenry and give our legislators new frames for understanding reality, for judging it and for intervening in the public interest if felt warranted.

Many will not know that the EU Charter of Fundamental rights protects people's 'genetic features.' But that's emphatically not the same as saying there is a case for European level-protection. This book is a first step – but only a first step in building the case. All sides need to be heard. The science will not be held back – and shouldn't be held back. But the debate about how to protect our citizens against mis-use of the genetic information as only just begun. Its now over to people like Marian Harkin MEP to reflect on it further.

Lastly I want to pay tribute to professor Peter Blanck at Syracuse University who has been a stalwart through this process. The US already has its Genetic Information Non-Discrimination Act and indeed celebrates the 25th anniversary
of the Americans with Disabilities Act next year which has been 25 year changing America and 25 years inspiring the world. Peter has been a key player in realizing the potential of the ADA in the US.

Peter and I had many ideas – but it was Aisling who put flesh on the concepts. Her passion, energy and drive mark her out as one of Ireland’s best researchers and policy entrepreneurs. She deserves the lion’s share of the credit today.