

Irish Council for Bioethics
Comhairle Bitheitice na hÉireann

Minutes of Council Meeting
Thursday 5th February 2009

- In the Chair:** Dr Dolores Dooley
- Present:** Dr Alan Donnelly; Professor Cliona O'Farrelly; Professor David Smith; Mr Stephen McMahon; Mr Asim Sheikh; Professor John Vincent McLoughlin; Professor Richard O'Kennedy; Dr Mary Henry; Dr Sheila Willis; Mr Turlough O'Donnell
- Apologies for absence:** Dr Peter McKenna; Professor Andrew Green; Dr Richard Hull;
- Also present:** Dr Siobhán O'Sullivan; Ms Emily de Grae; Mr Paul Ivory; Ms Emma Clancy

1. Minutes

The minutes of the previous meeting were adopted and signed.

2. Report from the Chair:

The chair welcomed the three new Council Members - Dr Sheila Willis, Director of the Forensic Science Laboratory, Mr Turlough O'Donnell SC and Dr Mary Henry, and said she looked forward to working with them during the Council's current term-of-office.

3. Report from the Managing Scientific Director:

Dr O' Sullivan informed Council that progress was being made on the charitable status application and that she hoped the Council would obtain charitable status in the near future.

4. "Begotten Not Made" – Farmleigh House

Dr O'Sullivan thanked Council Members for their attendance at the staged reading of *Begotten Not Made* in Farmleigh. Dr O'Sullivan explained that the reading was the culmination of a three-year project, in which a national playwriting competition was run. Dr O'Sullivan reported that 100 invited guests attended the reading that they had provided overwhelmingly positive feedback.

The Council expressed satisfaction that the project proved such a worthwhile initiative, which brought 'the particular to the general'. Council also expressed their gratitude to Fishamble: The New Play Company who produced and directed the reading.

Dr O'Sullivan informed Council that the secretariat was currently examining ways of developing the play further with a view to future staging.

It was suggested that a staged reading be held in the Four Courts for members of the Judiciary, because due to the dearth of regulation in Ireland, many complex bioethical questions are left for the courts to answer. It was also suggested that hosting a staged reading in Leinster House might be beneficial to politicians and policy makers who are tasked with introducing legislation.

It was agreed that the secretariat would follow up on both of these suggestions and investigate potential funding opportunities for future staging.

5. Biometrics Report:

Dr O' Sullivan informed Council that the comments received from Members regarding the draft report had proved very helpful in restructuring the document.

Mr Ivory informed Council that a cover for the report had been designed and an editor procured and once the wording was finalised and signed off on by Council the report would be ready for the final stages of production.

Dr O' Sullivan informed the Council that she hoped to present the report to the European Forum of National Ethics Councils (NEC) in Prague in June.

6. Submissions on the New Council Work Programme:

Following a discussion on the merits of various topics suggested for the council's next work programme a number of subjects were decided on:

1. **Research Governance:** Ireland has no national guidelines or legislation in this area. Drafting collaborative guidelines on research governance designed to provide a quality assurance mechanism for all research on humans, their tissue or their data would serve to promote Ireland's participation in R&D.
2. **Biobanking:** given the complex ethical issues, including consent, confidentiality, ownership and commercialisation of biobank material, it was deemed timely to follow up the 2005 report with an opinion document dealing specifically with the issue of biobanks.
3. **Academic - Industry Collaboration:** it was agreed that there is a pressing need to seek innovative ways to encourage industry-academic links, which will maintain openness and integrity in the research endeavour.
4. **Organ Donation:** by producing a report on the topic of organ donation the ICB could have an input into the development of a sustainable, ethical and acceptable framework for cadaveric and living organ donation in Ireland and which could tie in with similar developments at a European level. Legislation

on Organ Donation is pending and the ICB could make a valuable contribution to the drafting process.

5. **Ethical Youth Forum**(to be run in tandem with other topics and dependant on external funding): as the national body for considering the ethical issues raised by developments in science and medicine it was agreed that the ICB is best placed to host an ethical forum for young people to allow second-level students to voice their opinions/concerns regarding certain aspects of biomedicine.

It was decided that Council would vote on the order the topics via e-mail in the coming weeks.

7. **Dates Of Next Meeting**

Thursday 2nd of April 2009, in the Radisson SAS Hotel. Rearranged to Thursday 30th of April 2009.