The Ninth Anglo-Islael Colloquium, 8 – 10 September 2011

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On my first night in Jerusalem, I knew that accepting the invitation from the AIA to attend its ninth colloquium, on genetics and society, had been a smart move. For, within hours of stepping on Israeli soil, at our group's first meal, the most extraordinary untold story began to unfold. Our after-dinner speaker, the eminent paediatric neurologist and ethicist Rabbi Avraham Steinberg, spelt out for the assorted gathering of scientists, philosophers, social scientists and lawyers, the social implications of widespread genetic testing. How prospective parents, determined to have a healthy child, push for it. How the Government pays for it, and how doctors collude in it. How lawyers were now exploiting it, by encouraging disabled children to sue medics for not detecting their deformities and diseases.

Most breath-taking of all, how lawyers were quietly trawling inbred villages, scouting for disabled children who would sue doctors for ever allowing them to be born. As the sole working journalist on the trip, the revelation was a gift. And the rest of the three-day September colloquium was no less enthralling: a mix of renowned specialists from both the UK and Israel, delivering thoughtful, enlightening presentations in an atmosphere that encouraged robust but respectful discussions.

The colloquium wisely recognised that genetics is about more than science: it touches on sensitive issues such as the creation of families, identity, privacy, rights and responsibilities, and – as illustrated by Rabbi Steinberg's talk – philosophy and morality. We were also addressed by the British ambassador to Israel Matthew Gould, who talked frankly about the politics of the Middle East. But then again, how could the ambassador turn the AIA down when his old Cambridge tutor, the philosopher Michael Banner, was among our number (and jokingly gave him an A for effort)?

The association's considerable clout was in evidence in the opening session: Baroness Ruth Deech introducing Sir Walter Bodmer, the Oxford scientist who has been at the international forefront of genetics research for decades. He gave a sweeping overview of the genetics field: the use of family studies to pinpoint genes for diseases, his explanation that many common conditions such as heart disease are caused not by one or two well-defined gene variants but a complex interplay of many genes plus environment; the use of genetics to trace ancestry and the growth of consumer genetic testing. Two other eminent UK professors, Dian Donnai from Manchester University and Alison

Murdoch from Newcastle University, took up the scientific baton but, crucially, spoke about what it was like to apply it in the real world, with real patients.

For example, Dian frequently deals with the Pakistani Muslim community in Britain, which has high rates of consanguinity (cousin marriage). Marriage between relatives roughly doubles the risks of genetic disease, and some couples seek her advice about testing either before or during after pregnancy. Consanguinity is a taboo subject in the UK, and communities that practise it are often subjected to hostile media coverage. Alison spoke about couples who undergo IVF in order to have babies free of debilitating diseases that run in the family, such as Huntingdon's disease.

The cultural contrast between the UK and our host country was striking: Professor Ruth Landau revealed that Israel has the highest rates of IVF in the world, mostly state-funded. The geneticist Joel Zlotogora, from Israel's Ministry of Health, told us of his extensive work with various isolated communities, including Bedouin, which also show high rates of cousin marriage. Some villages have as many as 40 distinct diseases and conditions as a result of intermarriage. But, crucially, Joel opened our eyes to the positive aspects of consanguinity that we in the West never hear about: that it lowers rates of marital breakdown and domestic violence.

If the purpose of testing is to avoid or abort diseased babies, is the new era of genetic testing a new form of eugenics? Carmel Shalev, an ethicist and human rights lawyer from Haifa University, believes so, and relayed her fears about "neo-eugenics" and the quest among Jewish couples for a perfect baby. This was a theme echoed by the Israeli philosopher David Heyd. He spoke about the so-called non-identity problem raised by disabled children suing doctors. In essence, these children are arguing for the right not to exist, when in reality those children must necessarily exist with their disease or disability. Gil Siegal, a doctor and lawyer with both American and Israeli academic affiliations, revealed some fascinating legal dilemmas: can genetic information be regarded as truly private when you share half your genes with your estranged sister?

Fuelled by delicious banquets and not a little Israeli wine, conversation sailed effortlessly on through lunch, dinner and long into the night. Over green tea on a sofa, the prize-winning geneticist Ephrat Levy-Lahad revealed, to British gasps, that non-orthodox couples often wished to abort babies found to have bilateral club foot or cleft palate. The prospect of such late-night enlightenment meant my head rarely hit the pillow before midnight.

Besides producing a fabulous news story and allowing me a first glimpse of the Holy City, my memories of the trip are these: acquaintances formed, opinions re-evaluated and prejudices neutered (we were not bombed!). On Shabbat, as I was regularly queue-jumped by non-AIA hotel guests in a rush for the chicken soup, an Israeli colleague whispered to me through gritted teeth: "It drives me mad that Israelis don't know how to queue." In the spirit of international cooperation, I think we Brits can help with that one.

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Her article about the colloquium, *Children Who Sue For Being Born*, appeared in the 29 October issue of New Scientist.