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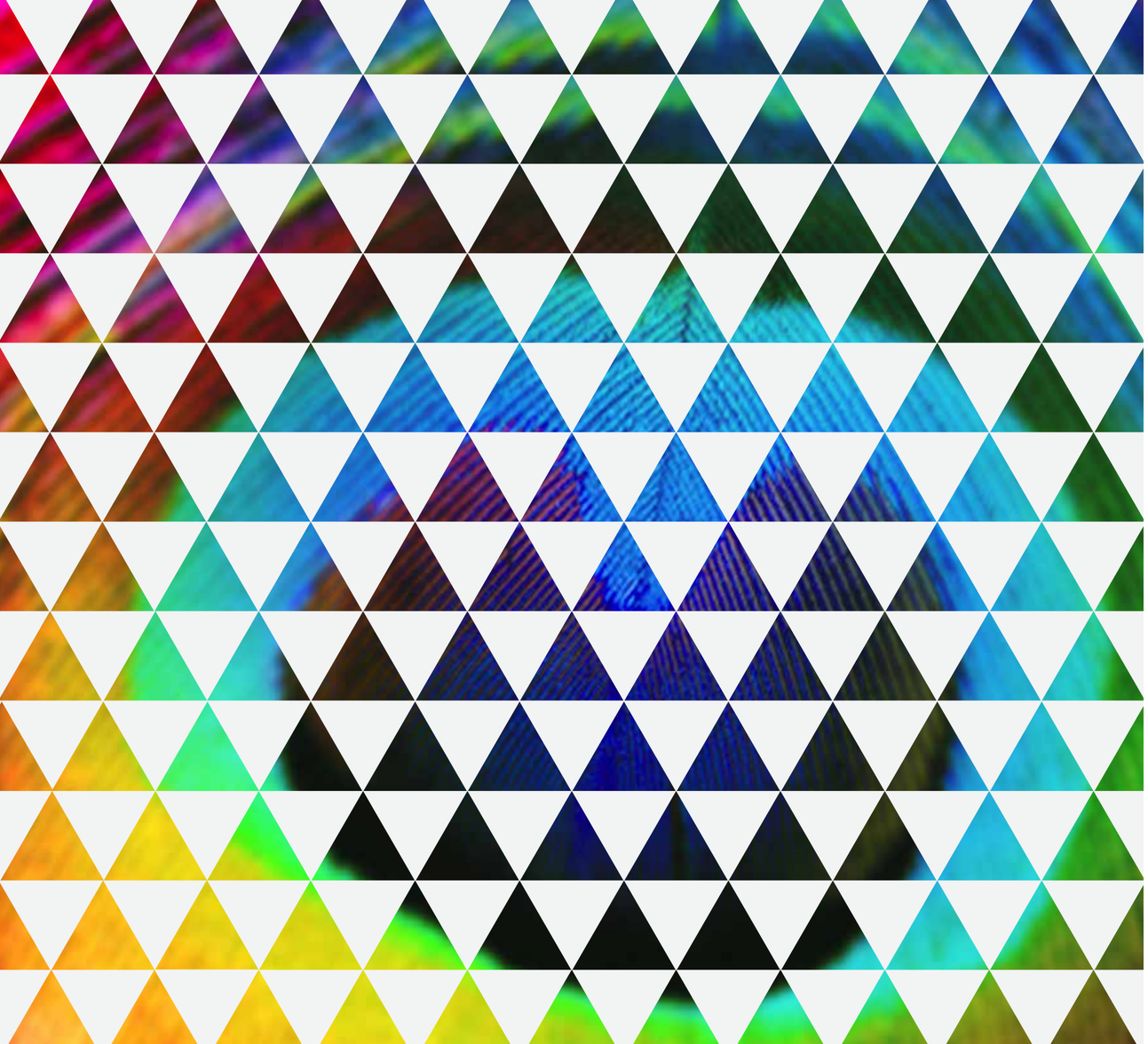
REPORT OF THE NINTH ANGLO-ISRAEL COLLOQUIUM 2011

GENETICS & SOCIETY

THE ANGLO-ISRAEL ASSOCIATION



THE NINTH ANGLO-ISRAEL COLLOQUIUM

GENETICS & SOCIETY

NEVEH ILAN

Judean Hills, Israel - 11-13 September, 2011

The Anglo-Israel Colloquium was launched in 1997 at the initiative of the Anglo-Israel Association in London, with the aim of bringing together prominent people from a variety of disciplines from the UK and Israel, to discuss a particular topic. The hope is that the participants, some experts in the field under discussion, others having a wide general interest and breadth of experience, will be able to share ideas, thoughts and practical knowledge. Our discussions at past Colloquia have frequently led to continued contacts and joint activities.

The Colloquia are organized by two steering committees, one in London and one in Jerusalem, under the auspices of the Anglo-Israel Association, in keeping with its objective of helping to develop wider understanding between British and Israeli people. I would like to take this opportunity of expressing my thanks to David Elliott, my opposite number in London as coordinator of the Colloquia and to Ms Ruth Saunders of the Anglo-Israel Association, for their ever-efficient help and cooperation throughout the planning period, and finally to Ms. Anjana Ahuja who was the Rapporteur for this Colloquium.

The following are the past Colloquia. A full list of all the participants in the nine Colloquia appears in a separate booklet which is available on request from the AIA in London or Jerusalem:

1. **1997** Wiston House, Sussex: "The Politics of Heritage"

2. **1998** Beit Gabriel, Sea of Galilee: "The Arts and Culture: whose Responsibility?"

3. **2000** Kibbutz Ma'aleh Hahamisha, Judean Hills: "Power and Responsibility – the Role of the Media in the Information Age"

4. **2001** Balliol College, Oxford: "The Universities: What are they for and can we Afford Them?"

5. **2004** Mitzpe Ramon, Negev Desert: "Ensuring a Healthy Environment for Future Generations: is Development Sustainable?"

6. **2005** Kibbutz Ginosar, Sea of Galilee: "Multiculturalism – A Comparative Perspective"

7. **2007** Kibbutz Kfar Blum, Northern Galilee: "Wealth and Happiness: Quality of Life in Israel and the United Kingdom"

8. **2009** Kfar Maccabiah, Ramat Gan: "In Loco Parentis: Who Should Raise our Children?"

At this year's Colloquium we concentrated on the many aspects of genetics in society, especially with reference to the ethical dilemmas involved. Touching upon human (and children's) rights, pre-natal testing, collecting genetic information, medical intervention, theological and cultural issues in multi-ethnic societies, and the extent to which government should or should not be involved.

It is my pleasant duty to acknowledge the financial support provided by the Alan and Babette Sainsbury Charitable Fund, The Sidney & Elizabeth Corob Charitable Trust, Mr R. Bolchover and Mrs J. Rosenfelder, Mr P. Brett and other anonymous donors, without whom the Colloquium could not have taken place.

Asher Weill

Convenor

Jerusalem, November 2011

From the Chair of the Anglo-Israel Colloquium

Professor the Viscount David Samuel

The Ninth AIA Colloquium was, in many ways, one of, if not *the* most interesting and successful out of the nine we have held over the past 14 years. Although not a geneticist myself, I have at various times participated in conferences on ethics and the combination of the two topics always generated very lively discussions. At our Colloquium, this was in no small measure, due to the skill of the two chairpersons, and in their choice of participants. I would, therefore, like, to congratulate Baroness Ruth Deech (from the UK) and Professor Ephrat Levy-Lahad (from Israel) for their choice of teams. It was also a pleasure to meet so many of the participants informally including two whom I had met before, many years ago. One was Professor Chaim Cedar who ran a one-day conference on genetics at Tel Aviv University. The other was Sir Walter Bodmer, who had participated in the fourth AIA Colloquium in 2001, held in Balliol College, Oxford, on the financing of universities, in his role as Principal of Hertford College. I was also delighted that we received so many letters and e-mails of approval from participants (from both the UK and Israel). It seems that we have, indeed, learned by experience that the subject chosen for debate should, besides being of current interest, with interesting participants, be confined to a single large "round" table.

It has become almost a tradition that serving British ambassadors address the participants at some stage of the proceedings. We were indeed very fortunate to have H.E. Matthew Gould tell us of his plans for improving British-Israel cooperation in two major spheres of research. In an unexpected turn of events, it also transpired that one of the British participants, Dr. Michael Banner of Trinity College, Cambridge, had been one of the ambassador's tutors at Cambridge when he read philosophy and divinity there in the early 1990s, before embarking on his career in the British Foreign Office.

The Colloquium was held this time in Neveh Ilan, a small resort in the Hills of Judea just west of Jerusalem. The choice of venue and all the arrangements for the Colloquium were made by our remarkable convener, Asher Weill and his assistant, Joy Bromley, who deserve our gratitude and thanks.

From the Israeli Chair of the Ninth Colloquium

Professor Ephrat Levy-Lahad

The year 2011 marked the tenth anniversary of the human genome sequence, so the choice of *Genetics and Society* as the Colloquium's topic was certainly timely. However, we were concerned that it would be a challenge to bring new ideas and stimulate original discourse on this well-worn theme. This concern was quickly laid to rest once the Colloquium began; presentations and discussions were consistently lively and thought-provoking, encompassing a wide range of topics - from the view of different faiths on genetics to the latest scientific discoveries in epigenetics.

As in every year, the Colloquium brought together two groups of nationals, British and Israeli, from a variety of disciplines. We increasingly refer to the world as a "global village," and the rapid rapport between participants from the Mediterranean and beyond, attested to this adage. But the Colloquium also highlighted how globally available information, in this case genetic information, is processed differently in different societies, each striving to apply new knowledge in ways that reflect its own, particular views on primal issues such as identity and reproduction. Discussions on the differing approaches were particularly revealing and enriching, and I believe forced each of us to re-examine our assumptions. For example, Israel has followed the US model of focusing on individual consent and confidentiality in genetic research, without examining Israeli public opinion on this issue, whereas the experience of the UK Biobank is that a less individual-centred approach is also possible. Use and availability of novel reproductive techniques is lower in the UK than it is in Israel. This was discussed as an exaggerated situation in Israel, but also raises the possibility that barriers in the UK are too high. The Colloquium offered all of us an opportunity to take a new look at our own, sometimes entrenched, practices.

We are living in an era of rapid technological, scientific, political and social change. Advances in genetics play a role in all of these arenas, and as a result, reflect the tensions in all of them, both locally and world-wide. In our discussion of "New Families" it was clear that new social definitions of what constitutes a family, while based in part on notions of greater autonomy (e.g. in sexual preference), are also dependent on scientific advances that enable such "new" families (e.g. gamete donation and surrogacy). Societies and countries must adapt to these rapid changes, on both regulatory and cultural levels, and one could argue that there has generally been more cultural adaptation in Israel, and more regulatory adaptation in the UK.

Ultimately, meetings are about the participants. Many of us felt that we had the good fortune to meet fellow travellers on the road of contemplation and curiosity about the role of Genetics in Society. We hope that the British guests enjoyed Israel in general and Jerusalem in particular, and that the wonderful opportunity for personal discussion will lead to enduring connections.

From the British Chair of the Ninth Colloquium

Baroness Ruth Deech

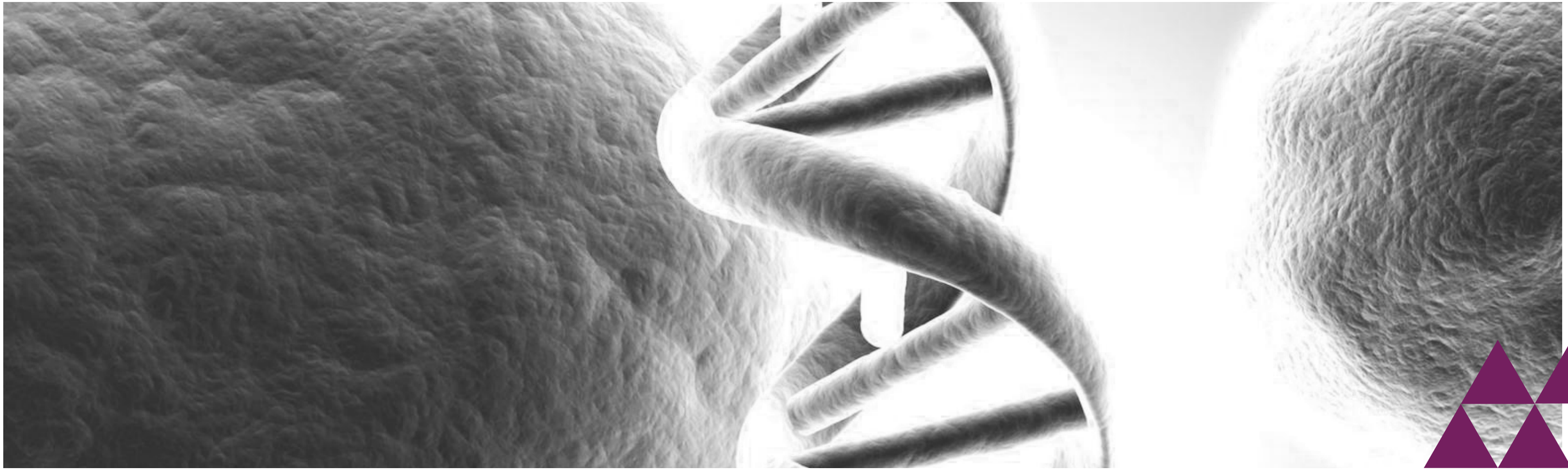
This year's choice of topic, *Genetics and Society,* proved a perfect meeting ground for our Israeli and British participants. It was a showcase for the complementary experiences and expertise of the very distinguished participants, and tapped into the passionate concerns on both sides for the health of society and of the family. From the moment that Sir Walter Bodmer (Britain's leading professor of the genetic makeup of peoples, an originator of the study of the public understanding of science, and of the Human Genome Project) started to speak, a few hours after our arrival at Neveh Ilan, we all knew we were in the presence of something special. So it proved: a weekend of enriching and contrasting insights, and the two sides of the Colloquium bonding with ease.

On the Israeli side we noted the national emphasis on the family. Israel was described as a pronatalist country, whereas some of the UK participants pointed out that a large family is occasionally seen as a parasite on the planet! There is more per capita use of preimplantation genetic diagnosis, IVF and other forms of reproductive testing in Israel than in most countries. Genetic screening is widespread and there is an emphasis on the nurturing of the perfectly healthy child. Religious objections to abortion and to new techniques have been overcome or sidestepped. There is in Israel a lack of regulation and transparency in this area, and important decisions are made by expert committees on an individual basis. Nevertheless, there is within Israeli society another group, the Arab population, who also want large families but, for cultural reasons, is very unwilling to abandon traditional practices such as cousin marriage, and is more wary of screening and counselling.

In Britain by way of contrast, we take a more collectivist approach, with the gathering of Biobank data, the application of widespread national regulation through the HFEA and medical research organisations, and an emphasis on making available information and choice in treatment.

Towards the end of the Colloquium we reminded ourselves of the societal context in which our expanding scientific knowledge plays out. We were aware of the sensitivity surrounding genetic information and social mobility, and of the growing respect for our own health and responsibility for that of the next generation. We concluded that we all needed more time to look at the conflict between public health issues and cultural norms, patient choice, education of the young about the new genetics, access to it and its connection to society at large.

We ended our stay with a tour of Jerusalem and a *Son et Lumière* spectacle in David's Citadel in Jerusalem's Old City. Many of us felt that we had never enjoyed a Colloquium so much both on an intellectual and social level. As with all the best events, it left us wanting more, not only of each other's company but that of past participants, whom we hope we can involve on an ongoing basis.



SESSIONSSIONSSIONS

FIRST SESSION

Next Generation Genetics

Chair: *Yossi Shiloh*

Introductory presentations: *Walter Bodmer; Chaim Cedar*

Walter Bodmer

The rediscovery of Mendelian genetics, and Crick and Watson's discovery of the structure of DNA, led to the human genome project, which has brought about the topics we are talking about today. Variability (in propensity for disease) can be divided into genetic and environmental influences. For example, up to 70 percent of variation in blood pressure can be heritable. But how does science go about finding genes that matter? Huntington's disease was an early success, and we can predict who is a carrier, but that brings an obvious problem – the conundrum of providing a prognosis that one can't do anything about. Should you tell people? Do people want to know? What are the implications for relatives? These are very difficult issues – contained in the new field of "genethics." On the other hand, in familial adenomatous polyposis (associated with cancers of the colon and rectum), family members who are virtually certain to get it can have a colonoscopy to remove growths and remove the risk.

But if genes account for only ten percent of disease variation, there's not much you can do prophylactically. For the majority of common gene variants, their association with common diseases is low. It is worth remembering that rare variations, that occur, for example, in one in a thousand people, won't be picked up by most studies, nor by family studies. For these reasons, the talk about personalised medicine, with people having their genome sequenced for $1,000, is exaggerated. Personalised medicine won't tell people that much about their risk for different diseases, although it is proving more helpful in targeting specific cancers (for example, breast cancer with Herceptin) and might in the future help to avoid severe responses to medication.

In the early days, people worried that insurance companies would penalise them for bad genes. We now know the number of people affected in this way is actually quite small. So, just as the large pool of insured drivers helps to meet the cost of uninsured drivers, the large pool of healthy people paying normal premiums means the costs incurred for less fortunate individuals can be met centrally.

As well as telling us about diseases, genetics can also tell us about our origins. Starting with blood types, Luca Cavalli-Sforza constructed evolutionary trees showing the relationship between populations. But what is the definition of a "population"? Can you find elements within Jewish populations around the world that suggest a common origin? There are similarities on the y chromosome, and among the Jewish priestly sect (who are said to be descended from the Cohanim). If, however, you look at the genes of Ashkenazi Jews, their composition is very similar to the population in which they are embedded, perhaps because of Jewish men marrying women who then convert. If this happens over successive generations, genetic assimilation happens quickly. There is no such thing as a Jewish gene (although there are over-representations of gene variations like Tay Sachs). This may explain the popularity of genetic screening in Israel.

By grouping people according to the similarity of their genetic profiles, one can get a genetic map of the British Isles. It is extraordinary how much you can discover – one can see the residues of Roman invasions and Viking incursions.

Bioinformatics – the ability to handle large amounts of biological information – has been very important. These technological developments might help us to pinpoint "low penetrance" gene variants that raise the risk of getting a disease by, say, 20 percent, but which don't get picked up in family studies . One area to watch will be induced pluripotent cells: a combination of cellular and genetic studies will show us how different tissues are switched on in different parts of genome. We may eventually be able to deduce what someone looks like from their DNA, which has forensic implications, and where the genetic basis of extreme ability (Mozart for example) lies. Scientists have obtained the DNA of Neanderthals, which could help us to pinpoint the genetic source of cognitive differences. Synthetic biology – the construction of organisms from scratch, as practised by Craig Venter, who hopes to create biofuels – is also important. It is crucial that there is social acceptance of these new technologies.

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Chaim Cedar

To construct an organism you need cells and proteins. This is the Lego of life. Genetics is a study of the instructions that make proteins; the instructions are written in DNA. But there is another aspect of this language: as part of the booklet there are annotations on how this language is read. This is what is known as epigenetics. For example, the colour of the iris is produced in iris cells but no other cells, and haemoglobin is only made in blood cells. How do cells know which instructions to read? The key is DNA methylation. DNA can be modified by adding methyl groups. In the iris, the gene for eye colour is not methylated but everywhere else it is methylated, so methylation is the equivalent of instructing a gene not to do something.

The growth of cancer cells, which start life as normal cells, might well be triggered by a change in the instructions or a change in the annotation, which means the instructions read differently. Whether you can turn stem cells into specific tissue cells depends on annotation.

Remarkable experiments have shown that pregnant mice can be fed a diet that will change the methylation in the embryo, and this in turn affects the fur colour of the baby mice. It could be that the environment affects how our genes are being used. The suggestion is that the environment does not change the text of our genes but how they are read (in other words, environment alters the annotation). This is a very exciting idea and we don't yet know if it is true or not.

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DISCUSSION

Studies in mice have shown that carriers of certain combinations of gene variants suffer the early onset of ageing diseases. This may have huge implications for public health. There are concerns about exaggeration and misinformation, particularly when it comes to epigenetics. However, should epigenetics hold true, it places responsibilities on those involved in assisted conception to control appropriately the early environment for embryos.

SECOND SESSION

Genetic Information – What Is It?

Chair: *Clare Thompson*

Introductory presentations: *Julian Hitchcock, Gil Siegal*

Clare Thompson

We leave a genetic footprint everywhere – in blood, semen, sputum and hair. Genetic information has widespread uses, such as in embryo selection and forensics, in consumer testing and ancestry studies. Genetic knowledge is a form of power. While the concept of DNA databases is widely accepted, concerns remain: how long should genetic information be stored? Who should have access? Culture matters: genetic rights are different in US and Europe.

Julian Hitchcock

What is information? On the one hand, DNA is a glorified bar code but it is also our story, our identity. As genomes become clinically and commercially available, people will want to access this information. While we now identify ourselves through our history, perhaps we will soon identify ourselves through genetics.

It may be a disruptive change. Information is power, and it can be used for good or ill. As the public gains knowledge, this brings about a kind of genetic democratisation. People can form social networks with other people on the basis of their genomes; what kind of society will Facebook genomics bring about? There is also an issue of property, such as in the patenting of the BRCA genes (associated with breast cancer). The other aspect is consent. For example, do you own your own genes? There is also the issue of equality, which is highlighted in the well-known case of Stephen Mobley (a convicted murderer whose lawyers used a "genetic defence" to argue that their client should receive clemency).

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Gil Siegal

Is our genetic information like bank account information, i.e. personal? Or is it unique, as the science world seems to regard it? If so, should we have special laws to deal with that uniqueness? Where do these laws fit alongside existing legislation covering human rights and patient rights?

In fact, what would a law protecting genetic information look like? It would need to define genetic information and who should have access to it. But definitions are not easy - in the US, there are 20 definitions of genetic information within 50 states. The US also has the GINA act: the Genetic Information Non-Discrimination Act, which forbids, for example, health insurers charging higher premiums to people who carry "poor" genes. Israeli law also recognises the uniqueness of genetic information.

What about the right to privacy? Ultra-orthodox Jewish communities, in which marriages are generally arranged, use a database for Tay-Sachs which allows potential partners to see if they are compatible. People can be tested to see if they are carriers but they just get a code, not their carrier status. The codes for the couple are checked and they receive a result – the union is advisable or non-advisable. They only get "couplehood" status, not individual status. In this case, people forgo their right to personal information for the greater good. Could it work with societies that don't practise arranged marriages, for example, for Western societies with HIV?

Privacy became an issue in the case of a tribe in the Colorado Grand Canyon which donated DNA for diabetes research. Later, scientists used that DNA to suggest they originated from a Mongolian tribe. The Native American tribe was offended, because this conflicted with their belief that they were born from the walls of the canyon – the court agreed that their privacy was invaded. Now, what if tribe members want to donate DNA but the chief refuses permission? This pitches group rights against individual autonomy. The new genetics puts us in the situation where genetics belongs to the group, not just to the individual.

Sex selection for social reasons also has implications for the protection of genetic information: an infertile priest (Cohen) was allowed to have a daughter because any son conceived through donor sperm could not become a priest (because there is no bloodline), and this would have raised questions in the community about the son's origins and legitimacy. A daughter conceived through donor sperm would not raise such questions; therefore sex selection allowed the child's genetic information to be protected.

Privacy may be compromised if a patient is found to be at high risk of a genetic disease, because of the clinician's duty, as far as possible, to inform relatives who may be at similar risk (for example, if a woman is found to carry a BRCA mutation, should the clinician try to contact the woman's female relatives, even if the relatives are estranged?)

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DISCUSSION

Genetic information is not something people on the street wrestle over; contributors to the UK Biobank, for example, were worried less about bioethics and more about who was going to pay their transport costs to donor clinics. The much-hyped debate over insurance and genetics turned out to be a storm in a teacup – with the exception of some well-defined genetic illnesses, some clinicians believe that family history is a more reliable guide to future illness than genome testing.

Would genetic tests change how people think of themselves? For example, will people found to be at a higher risk of some diseases believe they are not healthy even when they are not ill? Will anyone identify themselves as healthy, once we all have our genomes sequenced? The importance of social scientists to both clinicians and policymakers was also stressed – with particular emphasis on medical anthropologists and medical sociologists, who can research how people cope with genetic information.

Sometimes the public is labelled unfairly as being confused about genetics, when the reality is that many do not believe that their identity lies solely in their genome. In terms of clinical practice, what should doctors do if a patient discovers a family history of disease for which there is no treatment? Should first-degree relatives be informed?

THIRD SESSION

Prenatal Testing – Why?

Chair: *Michael Banner*

Introductory Presentations: *Alison Murdoch, Carmel Shalev*

Alison Murdoch

Prenatal testing exercises many people, including philosophers, social scientists and theologians. But clinicians take a more practical approach; we offer screening for such conditions as spina bifida and achondroplasia because it seems that society does not want a high burden of disability.

As well as screening, there are invasive tests that apply to people deemed to be at increased risk of having a disabled baby. These include amniocentesis, which can be done from 14 weeks, and chorionic villus sampling (CVS). Pre-implantation genetic screening has taken off in IVF because many IVF embryos are unviable. But PGS (pregestational screening, i.e. testing embryos for numerical chromosomal aberrations,) does not improve the chances of pregnancy; in fact, it might even decrease a woman's chances.

But genetic screening is still rare. Of 800,000 babies born in the United Kingdom, about two percent have genetic abnormalities. Only a few hundred babies are ever tested, and this is to prepare parents and make sure they get the correct clinical help. But who makes the choices?

Case studies show the dilemmas. What if a fetus carries the gene for Huntington disease, and the mother decides to keep it? The baby's choice to know or not know has been taken away. Or what about a woman who decides to have CVS, even though the risk of genetic problems is low, and the baby, which turns out to be healthy, is miscarried? Should society have restricted patient choice in this case? In conclusion, parents have to live with the decisions they make, and, while we should try to bring society along with whatever decisions are made, we should also be wary of minority pressure groups.

Carmel Shalev

Ninety-four per cent of Jewish pregnant women over 35 in Israel have amniocentesis, compared to about four percent in the US. In Jewish culture, the quest for a perfect child is associated with good motherhood. It buys into the idea of genetic consumerism and the emerging norm of "genetic responsibility", that is the responsibility of parents to have as healthy a child as possible. This leads to a low tolerance of disability, and to the appearance of "genetic anxiety" as a new phenomenon. We could call it "neo-eugenics," because babies deemed genetically unfit are less likely to be born. This attitude is fed by legal, social and cultural attitudes to the early embryo.

In Israel, prenatal testing is governed by administrative directives rather than legislation, with no reporting to parliament or the public. This leads to a type of sub-governance that ignores social and ethical aspects of policy.

We now have wrongful life lawsuits, for example, Zaitzoff vs. Katz (1986) which raised the question of whether a child has a right to a non-disabled life, or the right not to be born. One Israeli MP is trying to introduce a private members' bill to establish no-fault liability in such cases.

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DISCUSSION

Does the rise of testing by parents compromise a child's sense of autonomy and control?

Discomfort was expressed with the use of the term "neo-eugenics," since nobody is forcing Jewish women to abort babies after prenatal testing. What is an acceptable level of disability to abort? Should it be permissible for Down's Syndrome, club foot and cleft palate? In the United Kingdom, club foot and cleft palate are not normally associated with termination. What is driving the demand for prenatal testing: is it parents themselves, or society's wish to reduce the burden of disability?

FOURTH SESSION

Consanguinity: What are its Implications?

Chair: *Moein Kana'an*

Introductory Presentations: *Dian Donnai, Joel Zlotogora*

Dian Donnai

Consanguinity means related by blood. Each of us carry around five deleterious genes. If cousins marry, the risk of genetic birth defects and mental retardation is doubled. First-cousin marriages are banned in some states in the US and in China, but consanguinity is accepted by a fifth of world population and 8.4 percent of the world's children have related parents. It is especially common in the Middle East and South Asia, where between ten and 50 percent of marriages are consanguineous unions. The practice is rarer in Europe and the New World. In the UK, it is common among travellers, and the Pakistani and Somali communities, with 55 percent of UK Pakistanis married to first-cousins.

The well-designed Bundey study of 5,000 children in Birmingham, which followed babies from birth up until school age, showed that children of consanguineous unions ran a doubled risk of heart defects, learning disability, deafness and visual impairment. But discouragement of this practice was not effective. The alternative is education and perhaps screening. The World Health Organisation recommends cascade testing: start with a known affected person and then find other carriers in the family, focusing on young members. There are difficulties, including language barriers and the fact that many relatives live in Pakistan and can not be tested. The genetic knowledge obtained can be used to plan more distant marriages and, later on, for screening and prenatal diagnosis. We are now looking at how genetics is taught in the school curriculum.

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Joel Zlotogora

In Israel consanguinity rates vary between different communities. Among Ashkenazi Jews it is one percent, compared to three percent for those from Iraq and nine percent for those from Iran. Among the Bedouins in the Negev, 67 percent of marriages are consanguineous, mostly between first cousins. In the Muslim and Druze communities, the rate is about 20 percent. Among major congenital problems the rate of those due to consanguinity among Jews is 33 percent, over 60 percent among Muslims and higher among Druze (although this is often because very religious couples choose not to terminate affected babies).

The trend for first-cousin marriages is declining but other forms of consanguineous unions are on the increase, which still carries a risk because most people in villages are related (because they are descended from a handful of founders going back several generations). Some villages suffer from more than 30 diseases known to be associated with consanguinity. The options for those couples affected are: not to marry; to screen and possibly have an abortion; to have an affected baby but get early intervention and treatment. Thalassaemia and cystic fibrosis screening are offered free to all. Cases of cystic fibrosis are declining and the incidence of thalassaemia is declining somewhat but many couples choose to have an affected baby and then seek medical help. Free genetic counselling and screening is offered to isolated Bedouin tribes who are at risk of severe genetic diseases (this community undergoes 5,000 tests a year).

Our aim is not to reduce first-cousin marriages because there are cultural and social advantages to the practice. Our message is not "Do not marry your cousin," but "Marry your cousin but be aware of the risk."

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DISCUSSION

Is it possible that in-breeding also raises the risk of complex traits like schizophrenia and autism? Should carrier screening be carried out at a young age, for example, at school, or does this have ethical implications and risk stigmatising carriers? A high level of education appears to lead to lower rates of consanguineous unions. Are there, in fact, positive aspects to the longstanding cultural practice of cousin intermarriage, such as increased intelligence?

Data suggests that prior to genetic counselling, at-risk couples think they have a 40 percent risk of having an affected baby. So, does genetic counselling actually encourage them because the real risk of six percent seems small? Is there a conflict between public health and genetic counselling?

FIFTH SESSION

New Families – How Far Should Genetics Determine?

Chair: *Tony Gilland*

Introductory Presentations: *Ruth Bancewicz, Ruth Landau*

Ruth Bancewicz

Science is only one finger on the hand of humanity, according to the Dalai Lama. Monotheistic theology has informed the process of science and suggests that the universe is open to inquiry. What is the relationship between science and religion? If I am whole and unconflicted, I have values and a worldview that I take into the laboratory with me.

But I do not pray for the outcome of experiments. We need all faiths and none in the laboratory, because diversity leads to new insights. Our ideas about medical care, with a focus on care for the individual, are based on a faith tradition. How important is faith when people make family planning decisions? Genetic testing brings up questions regarding a person's genetic future and a child's genetic future. There is a huge capacity for medicine to prevent suffering, for example, cystic fibrosis, but how do we define disease and at what point is an embryo seen worthy of destruction? Does the existence of saviour siblings turn human beings into commodities?

Ruth Landau

The right to a family is enshrined in Israeli law, and this country now has the highest rates of IVF births in the world, currently about 4.2 percent of all live births. Women using their own eggs can have state-funded IVF up until the age of 45; and up to 54 with donor eggs. An Israeli woman is entitled to six cycles per year until she has two children. It is possible for a woman to start IVF at the age of 19 and finish at 54. In Israel, creating families does not mean one child; many single mothers go on for two or three children in their forties. Surrogacy is also permitted. It is common for soldiers to bank sperm in case they are killed but what if the parents of a dead child want to bank their dead child's sperm or ova in order to create a grandchild, as happened with a 17-year-old girl who died in a car crash?

What should IVF children be told about their origins? In the West, there is a growing move to openness but in Israel there is full anonymity for sperm donation. In lesbian couples, the mother who carries the baby uses the other partner's egg, so each woman has a biological stake in the resulting children. But what happens if they break up – who gets custody?

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DISCUSSION

Pronatalism (the encouragement of childbearing) is the embodiment of the biblical exhortation to be "fruitful and multiply." Some people have suggested that the drive to create large families stems from a national wish for Israel to be able to defend itself against hostile neighbours, and a societal wish to repopulate after the Holocaust, but there is little evidence for this. There is evidence that some couples have additional children as an insurance policy against terrorism.

If women start IVF, it can be hard to stop due to the social pressure to have children. Psychological help to these women is outside the remit of The Ministry of Health and is dependent on the clinic. Rather than knowledge about genetic origins, perhaps it is good parenting that really matters. There is no point in being a genetic father if you're a bad father. Does current technology and the law downgrade men to the status of sperm banks?

Donor siblings often seek each other out, suggesting genetic origins do matter to some. Bereaved parents of soldiers often ask to retrieve sperm so they can use IVF and a surrogate mother to continue the family line. But if the law does not enshrine the right to grandchildren from living children, why should it guarantee grandchildren from dead children?

SIXTH (SUMMARY) SESSION

The Issues Raised – or Ignored

Chair: *Ruth Deech*

Introductory Presentations: *David Heyd, Anjana Ahuja, Gillian Crawford, Ephrat Levy-Lahad*

David Heyd

When it comes to children bringing lawsuits for "wrongful life," there needs to be a distinction between actual and potential people. There is no way we can relate to unborn people, or virtual persons. We call it the non-identity problem (if the negligent act had not taken place, the complainant would not be here to complain).

These are logical problems for any rational legal or philosophical discussion about reproductive science when we talk about the rights of those who have not yet been born. How can we compare the value of our existence today with not being born or not existing? But by contrast, to compare the lives of healthy people to unhealthy people is helpful and rational.

While society may say it is undesirable for children to be born to single mothers, or to be chosen through sex selection, these arguments do not apply to the child. The child will not complain if it is born but might ask why haven't you employed the best technology to make me taller or cleverer? This requires philosophical work about what constitutes human identity. For example, I could contemplate ways in which having a few more IQ points or being a bit taller would make my life better, while still allowing me to be me.

On the other hand, if I wanted more IQ points I could ask my parent: "Why didn't you marry a smarter person?' This would clearly be a nonsensical question to ask. So, in some ways, the interests of a potential child cannot be taken into account because of the non-identity problem. In this case, what rights are left? They are those of parents and society. On this point, it is very hard to pinpoint why parents should not have the right to sex selection, especially if equal numbers of parents want boys and girls and therefore it would not skew the gender balance.

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http://plato.stanford.edu/entries/nonidentity-problem

DISCUSSION

Anjana Ahuja

What do we define as identity-fixing attributes, e.g. gender?_If a scientist performed an experiment on mice showing that fur colour could be genetically manipulated, what kind of questions might the public ask? They might include asking for what purpose the scientists had done the work in the first place; whether the technology could be used to change the skin colour of human foetuses; who funded the research; and what ethical supervision was there. But scientists might respond that they feel unqualified to talk about societal implications. This risks leaving the impression that scientists either do not care or do not know about the moral or social aspects of their research.

Science is generally welcomed when it has tangible benefits, even if people are initially hostile (as in the case of IVF). Genetic testing affects only a few percent of the population – most people's direct experience will come from direct-to-consumer genetic testing. This produces a great deal of information but limited knowledge as people do not yet know how to interpret the numbers. Other public concerns over the genetic revolution include privacy, corporatisation and power, the emerging field of synthetic biology and the difficulty of finding unbiased information in an age of social media. The United Kingdom has a history of wide consultation in reproductive medicine, leading to a widely-admired legislative framework. This framework, for example, bans sex selection for social reasons, to which the public remains opposed. The retention of the ban provides reassurance that genetics research is not about creating designer babies.

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Gillian Crawford

People come for genetic testing expecting answers but generally go away with more questions than answers. There are many choices and decisions to make; it is an extremely complex issue. There is testing available in pregnancy but this does not always result in termination. Newborn screening identifies carriers of certain genetic diseases. There is increasing genetic testing of children going through the adoption process for those children known to be at risk. Should this testing be deferred for adult onset conditions, as happens for other children? But this would hinder placing children because prospective families do not want the uncertainty about their adopted child's medical future. In this case, the child's right to autonomy – to determine his or her own genetic future - conflicts with the chances of getting placed with an adoptive family.

What are the motives for biological parents who want to carry out genetic tests on their children? Is it about preparing the child or preparing the parents? Is it right to perform carrier testing for children to assess their future reproductive risk, as opposed to assessing their health risk? Once we do test, follow-up care is very important to help people make reproductive choices. Another issue that we could consider is whether we are obliged to re-contact people in the light of new information. If we do so, should the responsibility fall to genetic counsellors, or to primary care providers, such as the family doctor?

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Ruth Deech

Differences have emerged between Israel and the United Kingdom – in Israel, there is more use of IVF and associated technologies. But unlike in the UK, there seems to be a lack of oversight and regulation. There seems to be a quest in some sections of the Israeli community for perfect babies, but not in others. Another difference is that very large families in Britain, if not frowned upon, are generally not approved of. There are access issues in the UK for IVF and genetic testing. Nobody has yet talked about genes and intelligence, and what we do with genetic knowledge.

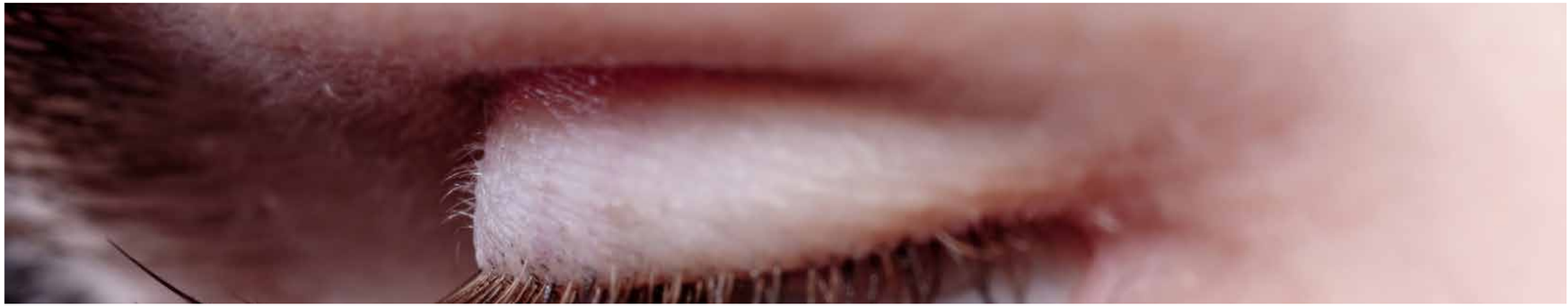
Ephrat Levy-Lahad

The topic we have been speaking about for the past two days defies wrapping-up. This conference has highlighted a number of important gaps. We still have a big gap between sequencing the genome and knowing what it means. So we have information but not much knowledge. And there is a social gap, by which I mean a gap between society and itself. We are undergoing great social change, partly driven by medical change. Science is not getting ahead of society - society is getting ahead of itself. The fact that the public does not perceive an ethical problem with the new genetics – for example if Biobank contributors worry more about parking than ethics – does not mean that the problem does not exist.

There are public health issues to be considered. For example, in both the UK and Israel, GP consultations last for about seven minutes each, so how will the delivery of genetic information work?

Colloquium Rapporteur:

Anjana Ahuja - (anjanaahuja@hotmail.com)



PARTICIPANTS

BRITISH PARTICIPANTS

Baroness Ruth Deech; (UK Chair), Bioethicist, former Chair Human Fertilization and Embryology Authority

Anjana Ahuja; Science writer, formerly of The Times. Colloquium Rapporteur

Dr. Ruth Bancewicz; Project Leader, Faraday Institute for Science and Religion, Cambridge

Dr. Michael Banner; Dean of Trinity College, Cambridge

Sir Walter Bodmer; Cancer and Immunogenetics Laboratory, John Radcliffe Hospital, Oxford

Gillian Crawford; Registered Genetic Counsellor/Clinical Doctoral Fellow, University of Southampton

Prof. Dian Donnai; Professor of Medical Genetics, University of Manchester

Tony Gilland; Science and Society Director, Institute of Ideas

Julian Hitchcock; Consultant Solicitor, Field Fisher Waterhouse LLP and Associate, PHG Foundation

Dr. Simon Kay; Director, British Council, Israel

Dr. Adee Matan; Science and Innovation Attaché, the British Embassy, Israel

Prof. Alison Murdoch; Professor of Reproductive Medicine, Newcastle Fertility Centre

Ruth Saunders; Executive Director, Anglo-Israel Association

Caron Sethill; Assistant Director, British Council, Israel

Clare Thompson; Immunologist; medical journalist and editor

NINTH ANGLO-ISRAEL COLLOQUIUM

ISRAELI PARTICIPANTS

Prof. David Samuel; Chair, Anglo-Israel Colloquium. Professor Emeritus of Chemistry and Neurobiology, Weizmann Institute of Science

Prof. Ephrat Levy-Lahad; (Israeli Chairperson) Director, Medical Genetics Institute, Sha'are Zedek Medical Centre, Jerusalem

Prof. Chaim (Howard) Cedar; (Biochemistry and Human Genetics) Department of Developmental Biology and Cancer Research, Faculty of Medicine, the Hebrew University, Jerusalem

Ella Gera; Lawyer, active in political and cultural affairs

Prof. David Heyd; Chaim Perelman Professor of Philosophy, Hebrew University, Jerusalem

Prof. Moein Kana'an; Professor of Molecular Genetics, Dean of Bethlehem University

Prof. Ruth Landau; Associate Professor Paul Baerwald School of Social Work and Social Welfare, Chair, Ethics Committee for Research with Human Subjects, the Hebrew University, Jerusalem

Ed Mlavsky; Chairman and founding partner, Gemini Israel Funds. Scientist and businessman specializing in high-tech venture capital projects

Moshe Raviv; Past ambassador of Israel to Great Britain

Prof. Aviad Raz; Director, Behavioural Sciences Programme, Professor of Organizational and Medical Sociology, Department of Sociology and Anthropology, Ben-Gurion University of the Negev, Beersheba

Dr. Carmel Shalev; Department of Reproduction and Society, the International Centre for Health, Law and Ethics, Haifa University

Prof. Eliezer Shalev; Gynecologist. Dean, Rappaport Faculty of Medicine, Technion, Haifa

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Prof. Shoshana Shiloh; Psychologist. Department of Psychology, Tel Aviv University

Prof. Yossi Shiloh; Department of Human Molecular Genetics and Biochemistry, Sackler School of Medicine, Tel Aviv University

Dr. Gil Siegal; Lawyer, bioethicist. Director, Centre for Health Law and Bioethics, Faculty of Law, Ono Academic College, Kiryat Ono

Asher Weill; Publisher and Editor. Past editor of "Ariel: The Israel Review of Arts and Letters." Convenor, Anglo-Israel Colloquium

Prof. Joel Zlotogora; Department of Community Genetics, Ministry of Health Sheba Medical Centre, Tel Hashomer, Ramat Gan

Guest Speakers:

H.E. Matthew Gould; British Ambassador to Israel

Rabbi Prof. Avraham Steinberg; Chair of Ethics, the Hebrew University Medical School and Sha'arei Zedek Hospital Neurological Diagnosis Institute, Jerusalem

Colloquium Secretary: **Joy Bromley**

COMMENTS

COMMENTS BY PARTICIPANTS

I have rarely enjoyed a conference so much. There was just something special about our two teams of speakers and organisers, and it all came together magically.

Ruth Deech

It was a good event all round. It was great to be at a meeting with such a high academic standard – definitely something to keep aiming for in future meetings - and such an interesting group of people. The informal and friendly atmosphere really helped in getting to know the other participants. Having a chance to explore Jerusalem was also fantastic. Thank you for the opportunity to be part of the Colloquium.

Ruth Bancewicz

I wanted to send a quick note to say how much I enjoyed the Anglo-Israel Colloquium. The programme was very coherent and thought provoking. It was a great opportunity to reflect on some familiar, and less familiar, issues in a very different context – I thought the mix of professional backgrounds of the participants, coupled with the opportunity for international comparison between Israel and the UK, worked extremely well. I certainly look forward to keeping in contact with a number of fellow participants. Many thanks for putting such a stimulating programme together which I know will help me in the programming of future debates and discussions I hope to run in the UK. I also appreciated the opportunity to spend a little time in Israel and to gain a wider appreciation of the country.

Tony Gilland

Thanks again for the invitation and for organizing such a wonderful and pleasant conference. [The participants] are exactly the kind of people who would not have reached Israel and whose visit seems to have changed their image of the country in exactly the way the Anglo-Israel Colloquium wishes to do. In these hard times for Israel it is I believe a hugely important investment in goodwill and favourable attitude to Israel on the part of British academics. In any case, beyond these more political aims, you succeeded in bringing together a group of excellent scholars from prestigious institutions. I found the comparative study of the two systems of regulations of genetic technology fascinating and fruitful.

David Heyd

The subject matter was perfect for an Anglo-Israel Colloquium, with both the UK and Israel at the cutting edge of research and clinical medicine. The UK is a beacon of regulation for the rest of the world, and the opportunity to be with leading scientists from there was unique. It was a pleasure and an honour to be part of the company. Last but not least, the setting and hospitality made for a convivial, relaxed and enjoyable meeting. Thank you for a memorable weekend.

Carmel Shalev

Thank you so much for all your hard work... I certainly appreciated the conference, the dinners, the sound and light show and the end-of -conference tour of Jerusalem... On the way home many people commented on how smoothly everything had worked and what a lovely atmosphere permeated, even though the topics sparked deep debate!

Clare Thompson

It was a great pleasure to take part in the symposium and to visit Israel again. In particular it was really valuable to be taken outside the comfort zone of one's usual academic discipline and to have the chance to discuss matters of importance to society in general. It is too easy for those of us in medicine to neglect the impact on society of our new knowledge and technologies whilst those in the humanities can too often concentrate on the theoretical and ignore the immediate needs of those disadvantaged for example by genetic disease or the pressures on those professionals in the front line. I think we all learned much from each other. I also very much appreciated the chance to understand in more depth the similarities and differences between the UK and Israel in many aspects of life. I am convinced that getting to know colleagues is surely the most powerful way to get rid of prejudice on both sides. Since my first visit to Israel about five years ago my department in Manchester has benefitted enormously from productive scientific collaborations and exchange visits by younger colleagues – the initial caution has long since disappeared and real friendships have developed.

Dian Donnai

It was a wonderful Colloquium, in terms of the intellectual stimulation, the camaraderie and the smoothness of the organisation. We were extremely well taken care of, the conference schedule seemed well planned (including those all-important slices of free time), and it was a privilege to meet the participants – as well as the ambassador!

Anjana Ahuja

I thought that the meeting was a great success. It was very interesting to see both the contrasts and similarities between the Israeli and UK situations and attitudes. I was glad to have the experience of Jerusalem on the Saturday evening. The informal contacts between the sessions are also very valuable.

Walter Bodmer

I echo the congratulations already made and warmly endorse all that has been said about the excellent Anglo-Israel Colloquium on Genetics and Society. The test of any conference is the extent to which delegates re-evaluate their initial views, report what they have heard to others and forge links. Equating such a standard, I need not persuade anyone present that this attainment was very much exceeded by the Colloquium.

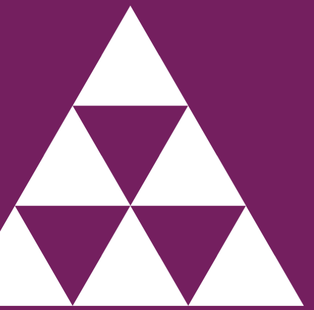
What a marvellous programme, and so well delivered! My head is plainly not the only one still abuzz with the information and ideas presented with such authority and eloquence in Neveh Ilan. Of course, I could not agree with everything that was said, but I am extremely grateful that it was. The insights gained about genetics and its position in the state of Israel were considerable.

Julian Hitchcock

I appreciated the warm hospitality, the chance to meet colleagues in different disciplines and in different places, and to form links which will lead to further collaborations. I hope future events are as successful!

Michael Banner

THE ANGLO-ISRAEL ASSOCIATION IS AN INDEPENDENT CHARITY WHICH ENJOYS THE ACTIVE SUPPORT OF PEOPLE OF DIFFERENT FAITHS AND FROM ACROSS THE POLITICAL SPECTRUM. FOUNDED IN 1949, IT IS THE OLDEST ORGANISATION FOR ANGLO-ISRAEL FRIENDSHIP IN THE UK. THE PURPOSE OF THE AIA IS TO PROMOTE WIDER AND BETTER UNDERSTANDING OF ISRAEL AMONG BRITISH PEOPLE, TO ENCOURAGE EXCHANGES IN BOTH DIRECTIONS AND GENERALLY TO SUPPORT ACTIVITIES WHICH FOSTER GOODWILL BETWEEN THE TWO COUNTRIES.



WITH THANKS TO...

SPECIAL THANKS TO LILIAN HOCHHAUSER FOR CONTINUING TO CHAMPION THE WORK OF THE COLLOQUIA IN SO MANY DIFFERENT WAYS, LILIAN'S UNSTINTING SUPPORT IN DEVELOPING AND GROWING THE SERIES OF ENCOUNTERS HAS BEEN INVALUABLE.

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