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ADELPHI
GENETICS FORUM
*exploring heredity and society*

# Adelphi Review

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# EDITORIAL

Following a hiatus of two years, we finally returned to the Royal Society in October for our Annual Conference. It was organised by our Vice-President, **Professor Gregory Radick,** on the challenging theme of 'Living with the Eugenic Past'. It was so unfortunate that the date coincided with a rail strike so that many (including your Editor) were unable to attend. However, a full report can be found in this issue while videos and podcasts of the event are on our expansive new website. On page 32, there is also news of our 2023 Conference which will consider '**Population diversity, its biological consequences and impact on disease risk'**.

On page 26 there's a report on our latest Teachers' Conference by **Jane Masters**, a secondary teacher from Cheshire. The event was held as usual in Manchester and included lectures by our President, Vice-President and Treasurer. Jane is now a trustee of the Forum and has taken on the role of managing our Twitter account which I invite you to follow @AdelphiGenetics.

The latest reports from CHASE Africa are also in this issue, detailing the incredible work being done in Kenya with the help of a grant from the Adelphi Artemis Trust. This is a very worthwhile venture and shows that our organisation can make a difference in the 'real' world.

**Robert Johnston**
**Editor**

**The Adelphi Genetics Forum Annual Conference**
**Living with the Eugenic Past**
**5 October 2022 at the Royal Society**

This year's conference was held as usual in the Wellcome Trust Lecture Hall of the Royal Society. The full programme is available on our website along with a link to videos of the talks and podcasts of interviews with the speakers.

The President, **Professor Turi King** opened the conference by welcoming the attendees and explaining that this was the first conference since the change of name of the organisation from the Galton Institute to the Adelphi Genetics Forum. She directed attendees to her statement on the back of the programme.

The Conference organiser was one of our Vice-Presidents, **Professor Gregory Radick** from the University of Leeds, and he set the scene for the day. He reminded the audience that 2022 marks the bicentenary of the birth of two men whose work was foundational for the science of human heredity, indeed of heredity as such: Gregor Mendel and Sir Francis Galton. For this meeting it was decided to focus on the legacy of the eugenic past that was entangled with and motivated by studies of Mendelian Genetics and Biometry in the early 20th Century, and for which this organisation, as the Eugenics Education Society, was at that time a key player.

He emphasised that it was timely to show willingness not to turn away from this difficult topic, but instead to sponsor scholarship and public discussion on the eugenic past, and to highlight the dangers of using (and corrupting) science to justify prejudices and social policy.
To that end, three questions were considered:
(1) What are the demands of justice when it comes to the victims of eugenics?
(2) How should universities and other institutions involved in eugenics deal responsibly with that involvement?

(3) Can present-day biology education and research be improved to help safeguard the future from the mistakes of the past?
There would be speakers and discussion leaders from across the disciplines, from science and science education through to history, philosophy and law, and also from someone for whom "living with the eugenic past" is not just a conference theme but a decades-long daily challenge – one to which she has risen with great dignity and courage.

The opening session was chaired by **Professor Tom Shakespeare** and the first speaker was **Professor Joe Cain (University College London)** whose talk was entitled **'Why invest in Eugenics? The Case of University of London'**. Professor Cain considered how University College London became so closely connected with eugenics for so long. He listed the dates of importance in the early years of the 20th century when Francis Galton was looking for Karl Pearson to take up the banner of eugenics.

When Galton died in 1911, he bequeathed a legacy to endow Pearson as the Francis Galton Professor for National Eugenics. In 1912, the first International Eugenics Congress was hosted by UCL, which unfortunately suggested guilt by association. The core question is why did UCL grow so close to eugenics? Professor Cain believes it was not a desire to develop eugenics. Pearson was adamant that eugenics was a new scientific discipline but he was no flag waver. He had no time for the Eugenics Education Society calling them "ill-disciplined ideologues with simplistic understanding of the facts".

Professor Joe Cain

In 1933 Ronald Fisher took over on Pearson's retirement and eugenics became an actual department at a time when European eugenics was becoming "scary". Why? Professor Cain puts it all down to the need to use the endowed funds of an eminent scientist and the imperative of being seen to do it so that possible future benefactors would not lose confidence. When Lionel Penrose took over the chair in 1945, he hated the title but legally was unable to change it.

Professor Cain concluded by asking how do despicable practices gain a foothold at universities? How do we promote people with admirable skills without opening the door to those who may do bad? How do we call out the "dodgy" work without suffocating good innovation and discovery? And how do universities say "yes" when they should be saying "no"?

Following a break, the next talk was chaired by **Professor Angelique Richardson** and was given by **Ms Elaine Riddick (Rebecca Project for Justice)** and was titled '**Liberation from Eugenics: A Black Woman's Perspective**'. She spoke movingly about herself as a victim and survivor of eugenics. She told her story of how she was raped at 13 years of age by a perpetrator. At 14 years old she gave birth to her son (Tony Riddick, now 54 years old). Unknown to her, she was sterilised during the Caesarean birth of her son and only found out when she was 19 years old. When she asked why she was sterilised, she was told she was "feebleminded". This news was so upsetting that it steered her towards drugs and addiction. Ms Riddick mentioned how she found inner strength and picked herself up because she realised that this was not the person she was meant to be. She referred to "God's purpose" for her which is to tell her story and help others.

Ms Elaine Riddick

Ms Riddick became quite emotional when she spoke about children as young as 5 years old, whose sterilisation was authorised by the North Carolina Eugenics Board. What started as the sterilisation of poor "white" people escalated and became predominantly conducted among the "black" communities, with boys and men being castrated. Ms Riddick mentioned that only three states in the US have ended sterilisation associated with eugenics, with 29 states still practising eugenics. She stated that the authorities do not consider the environment when they examine people's circumstances. Instead, the authorities state that "three generations of imbeciles are enough". She gave the example of her situation at home which contributed to her circumstance – her mother was

an alcoholic, her father suffered from Post-Traumatic Stress Disorder (PTSD) on returning from World War II and was abusive. She added that children who end up in foster care, those on the streets, probably trafficked, and those institutionalised should be helped and their circumstances understood before conclusions are reached.

Ms Riddick questioned what gave anyone the right to do dreadful things to fellow human beings and to take their rights away by sterilisation and castration. She added that "eugenics is a crime against humanity" and asked for help for her projects. One such project is the **Elaine Riddick Sanctuary** which will care for abandoned babies and children at risk of human trafficking, and will provide shelter for homeless women living in cars with their children.

During the Q&A session, we learnt that Ms Riddick was successful in obtaining financial compensation from the state of North Carolina for its victims of forced sterilisation, estimated at over 7,600 people, with 299 being children under 18yrs old. Two other states (Virginia and California) followed and have also compensated victims. As Ms Riddick considers all life precious, we also learnt that she works against euthanasia, assisted suicide, and any form of coercion for abortion, giving talks on these topics all over America. Ms Riddick explained that her activities, including those of the Elaine Riddick Sanctuary, are under the Rebecca Project for Justice, which advocates for freedom and dignity for women.

The next speaker, **Professor Zofia Stemplowska** from the **Centre for the Study of Social Justice at the University of Oxford,** spoke on **'Commemorating and Mitigation of Injustice: The Special Difficulties of Commemorating Victims of Eugenics'**. Professor Stemplowska investigated the complexities around mitigating injustices. While mitigation is mostly acting for the sake of the living, it should also include acting on behalf of those who died with the caveat that referring to 'past victims' does not mean that eugenics is in the past. The victims of eugenics include those whose existence was cut short and persons whose reproductive rights were violated. There was also an injustice involved in who never came to exist. Mitigation of injustices focusses mostly on

reparations for the living but can include measures on behalf of those who died

These issues were explored in four questions. The first question addressed whether it is possible to mitigate injustice when the victims are not living. Do the dead have interests? Even if they cannot be made better off those who are no longer alive often had preferences about posthumous outcomes, such as Chopin's preference that his heart be buried in Warsaw. Drawing on Feinberg's work on 'surviving preferences', if the dead have expressed a reasonable preference, honouring these can mitigate injustice.


Professor Zofia Stemplowska

In the second question Professor Stemplowska investigated differences between mitigating injustices where the focus is on the dead and apologies that are addressed to the living. It is important to acknowledge that victims may not want to be confronted by their past in the form of a memorial that is meant to serve as an apology. Something permanent can take up victims' mental space so should not be offered without their permission.

If a suitable apology cannot be offered, might it be possible to mitigate injustice through remembrance? The example of Israel Lichtenstein's buried request in an archive before his deportation to Treblinka illustrated a way in which injustice can be mitigated by honouring his express wish to be remembered. If instructions are left, death does not always make it impossible to deliver remembrance, and remembering how people's lives had value. Sometimes only the names of victims are known, so can we commemorate with just a name? Names can help in remembrance. What happens when we do not know even the names? Graves of unnamed soldiers and monuments to child soldiers can provide a way of remembering the shared fates of lives when other details are missing.

Finally, Professor Stemplowska addressed the unknowns, or those for whom the bell cannot toll. These are individuals for

whom we lack names and any information about their lives. Without knowing details of nationality, adherence to a religious group or even a name, there is no way to remember them. We would only be hypothesising, but not truly remembering them. However, we can commemorate some of the dead. The victims of widescale injustices are owed remembrance when this is possible. Remembrance is owed not only to the living but to the dead, and this must be done for the dead.

The session after lunch was chaired by **Reverend Professor Keith Magee** and the first speaker was **Dr Brian Donovan (BSCS Science Learning, Colorado)** who spoke on **'Genomic Literacy Matters for Dismantling White Supremacist Culture'**. The main thrust of his talk was that in the United States, the classical approach to teaching genetics, starting with Mendelism, accelerates the spread of racial prejudice. He argued, however, that maybe we can 'vaccinate' the young against this before they encounter it online. White supremacists efficiently disseminate racist propaganda about the genetic inferiority of certain ethnicities online so we should take every opportunity to pre-empt them when teaching genetics in schools. The current school curriculum (in the US) is still firmly based in Mendelism which, while useful in many ways, oversimplifies what 'real' genetics is like and encourages belief in life being pre-determined by genes. Such teaching can be traced back to before WWII when the curriculum contributed to racist agendas in the age of eugenics. This was underpinned by a concept called 'Genetic Essentialism' in which each race was believed to have its own set of genes.


Dr Brian Donovan

Dr Donovan believes that right from the start, high school students should be taught that most genetic variation (95%) occurs within races and not between them (5%). They should also understand that people inherit their genes but also their environments showing them that claims that racial disparities are all gene-based cannot be proven. Indeed, no high-quality fair test has ever been done on this or is ever likely to be done.

Single gene characters are rare and most traits are complex and multifactorial so that most examples provided in high school textbooks are over-simplified. Many white supremacists' arguments fail if the students learn that correlation does not prove causation. A new improved high school curriculum is needed in the US if we are to stop the spread of misinformation.

The next speaker was **Professor Anneke Lucassen (University of Oxford)** whose talk was titled **'Genomic Medicine, Diverse Data and the Language of Race, Ancestry and Ethnicity'**. Professor Lucassen investigated genomic medicine and research, highlighting the Euro-centricity of genomic data and how this can impact research. While eugenics has links with historical discrimination, racism, ableism and colonialism, it is also connected to genetic determinism, where the phenotype is explained solely by the genotype. The NHS is mandated to collect and monitor ethnic data, but the reasons for asking questions around skin colour, ethnic identity and ancestry are not clear, and many of these questions are meaningless without also asking questions about socioeconomic background.

Professor Anneke Lucassen

Two examples were given to illustrate how ancestry and ethnic background present in medical practice. Professor Lucassen was asked by social care workers if she would genotype a potential adoptee to provide additional ethnic information as knowing the heritage of children can be 'helpful' in fostering and adoption. While the costs of this testing have reduced over time, test results may not be providing accurate or useful information. In breast cancer genetics, a patient will be screened if there is a family history or if they carry a causative variant, but patients who do not know their family history and/or carry variants of unknown significance (i.e., they carry variants which may not be causative in Europeans but may be significant in other populations), do not qualify for screening under NHS guidelines.

In genomic investigations, reference genomes are assembled mostly using white Europeans. For individuals from different ancestral populations outside Europe, it is more difficult to interpret genetic variation due to a significant Eurocentric bias in genomics. The UK BioBank is an excellent resource, but it is comprised of 94% white British and researchers often remove the 6% non-white British from analyses to reduce anomalies in the data.

In the reporting of race and ethnicity in medical and science journals, there is a need for clarity, consistency and equity. Race and ethnicity are dynamic social constructs, and these should be reported with other sociodemographic factors and social determinants. When race and ethnicity categories are collected in studies, the reasons for assessing these should be clearly described. While the *Journal of American Medicine* updated its racial reporting in 2021, it advised more on what not to do. Furthermore, the category of 'other' lacks clarity and needs better defining. While it is a deliberately broad term, there are tensions embedded in it.

While advances in technology offer the promise of personalised, stratified healthcare, there is a skew in research collections towards European ancestry. Diverse data are not ethical in and of themselves, but diversifying genomic data will improve the evidence base for genomic medicine for all ancestries. The European bias in resources needs to be recognised so that research practises consider the wider cultural contexts and structural issues. Ethics need to be at the forefront of genomic research, recognising the sensitivity required in quantitative approaches to ethnicity, race and ancestry while incorporating socioeconomic factors. More qualitative and interdisciplinary approaches are also needed to understand and respond to recent advances for all populations.

The final session was chaired by the President, **Professor Turi King,** who introduced **Dr Adam Rutherford (University College, London),** our inaugural Adelphi Lecturer. His talk was titled **'Eugenics and the Misuse of Mendel'**. He started his talk by highlighting that eugenic ideas are very much alive in the 21st century and are still influencing politicians as they were 100 years ago (eg Donald Trump; Dominic Cummings; Toby Young), before going back to the history of the 20th Century.

The term Eugenics “the study of the agencies under social control that improve or impair the racial qualities of future generations either physically or mentally” was first coined by Galton in 1883. The qualities alluded to include a variety of physical and mental disabilities and behavioural issues as well as the converse. Both Pearson and Fisher (both scientific geniuses in the area of statistics who were also at UCL) were taken up with the ideology of eugenics. The idea was latched on to by many eminent people of different political persuasions in the first half of the 20th century (including Bernard Shaw, Winston Churchill, William Beveridge, DH Lawrence and others) when those ideas were broadly supported across society.

Dr Adam Rutherford

Marie Stopes’ efforts in introducing birth control were motivated by the idea of selective breeding. There was general concern with the concept that the healthy superior (upper class white) ‘stock’ would be replaced by faster breeding poor ‘stock’. There were however a few notable campaigners against this idea including GK Chesterton and Josiah Wedgewood. The UK 1912 Mental Deficiencies Act narrowly escaped including a compulsory sterilisation clause, no thanks to Winston Churchill. Compulsory sterilisation was however widespread in other countries, and more than half of the States of the USA still have such laws on their books.

Rutherford went on to describe how flawed or misinterpreted science fuelled these ideas. This has continued over the years, and has ranged from bogus data, through mis-use of bone fide data, to inappropriate ‘Mendelisation’ of complex traits. A significant example given was that of the Kallikak family tree (H. Goddard, 1912) which showed dramatic bifurcation, of which one branch of healthy upstanding people descended from the ‘good’ Quaker wife and those descended from an affair with an unmarried barmaid, which was full of drunks and criminals, and those who were so-called feeble minded. It was claimed that these traits were inherited in a Mendelian fashion. This family was included in text-

books and also influenced the Nazis. But not only was it fictitious but the outcomes were likely to have largely arisen from poverty and the "feeble-mindedness" was perhaps foetal alcohol syndrome. The Nazis also benefitted from the enthusiasm of American benefactors (eg Rockefeller Foundation).

Charles Davenport (Eugenics Records Office, Cold Spring Harbour), inspired by Galton, stated that 'Social Problems have a proven basis in heredity', and he spread the word to the public, for example at fairs, encouraging perfect babies (as well as Friesian cattle) and used these events for harvesting data. He was also responsible for oversimplifying the heredity of traits such as eye colour, which is still widely used in text books. In the 21st century this over-Mendelisation comes out in the media and popular press, as 'discovery of the gene' for everything (including a gene for making risky decisions for example). Even Scientific American described a gene for Schizophrenia. In the discussion, however, Professor Dian Donnai raised the point that it is now known that most severe forms of mental deficiency are single gene de novo mutations with dominant effect (and would be impossible to breed out of the population).

The final talk on **'A Eugenic Philosophy that's Hard to Die'** was given by **Professor Michele Bratcher Goodwin (University of California, Irvine)**. She started with a fictional story about the lottery in a small US town where members of the community stone one of theirs to death, a cultural practice believed to improve their corn yield. No reason is given as to which member of the community meets this fate; it is simply by drawing a marked paper. In the story little Hutchinson unwittingly participates in the stoning of his mother to death, as the custom demanded. Professor Goodwin then reads out the names of several African Americans who have been killed in recent times in the US, including Ahmaud Arbery, Breonna Taylor, George Floyd and Jacob Blake. She mentions the increase in racism in the US in 2020, refers to attacks on African Americans, past events of slavery in the US, the racial caste system and "white supremacy" which has 36 different categories of "whiteness" - where supremacy is practised within the population to get rid of their poor and disabled people. Evidence of such eugenic philosophy can be found in many strands in society.

Professor Michele Bratcher-Goodwin

Professor Goodwin spoke about the American caste system and the existence of rank and order; the kidnapped and trafficked slaves, the poor "white" people used as tools to police slaves but then lose their role with the end of slavery. Laws put in place to establish and maintain the racial caste system. (1) Matrilineal laws which dictated that children inherit their mother's rights, basically no rights and continue as slaves. The offspring of a "white" slave owner and a "black" slave was legally "black" and took on status of the mother. (2) Hypodescent, the "one drop rule", relating to a single drop of "black" blood in a family, aided "black" second-class citizenship. Legally, one could not escape from the low status. There's Susie Guillory Phipps in Louisiana, whose lawyers filed a suit to change her status, but she lost her case for reclassification in 1984 as the state maintained its stance to avoid others filing cases. Professor Goodwin added that to understand eugenics is to understand how states passed laws. (3) Anti-miscegenation laws which prevented "interracial" marriages, eg in Virginia. In 1987, Mississippi voted to repeal the law by a slim margin of 52% for vs 48% against. (4) Compulsory sterilisation laws by the "white" elite even against fellow "white" people considered socially undesirable.

"White supremacy" and eugenics use skin colour, not only against "black" people but also against Asian and indigenous people. There were Asian men who sued to reclassify as "white", why? Simply because no one wanted to live under rules governing "non-white" people. Compulsory sterilisation of petty thieves operated in Oklahoma. In the case of Skinner v. Oklahoma, Justice Douglas argued that this was against the human right of the individual and he did not consent to sterilisation. Justice Douglas is known to have fought against the segregation of "black" people and for other matters that affected "black" people.

**Dallas Swallow**
**Rosemary Ekong**
**Catherine Walker**
**Robert Johnston**

# My Life in Genetics

## An Interview with Mr Robert Johnston, Librarian of the Adelphi Genetics Forum

**Tell us about your early years and what first appealed to you about genetics.**

I grew up in Liverpool and in my secondary school, Biology was not available at O-level so those of us who wanted to study it for A-level were thrown into the deep end. At the time, I really didn't know what career I wished to follow but as my father was a paediatric surgeon (of considerable renown) at Alder Hey Hospital, it was in a way assumed that I'd follow in his footsteps, so I did A-level Biology.

I soon realised that I would prefer spending time in a laboratory rather than treating sick patients so as I became increasingly interested in Biology, the potential medical career faded into the background. I don't think my father minded at all and besides, I could never have hoped to compete with someone so famous.

My interest in Genetics really took off when my biology teacher, Frank Swallow, lent me a book by Tony Bradshaw called 'Teaching Genetics in School and University'. At that moment, I decided to read Genetics at University.

**What about your experiences as a student?**

I decided to stay close to home so studied Genetics at the University of Liverpool. At the time, in the early 70's, Liverpool was a world leader in this field and I was fortunate enough to be taught by the likes of Philip Sheppard, Cyril Clarke (famous for their work on Rhesus disease), Arthur Cain, Tony Bradshaw and a very young Brian Charlesworth. It was something of a golden age for population genetics and I loved it.

**What were the reasons for becoming a teacher?**

Initially I had planned to stay on for a PhD but the reality was I needed to earn a living and I'd always thought that teaching would suit me well. I spent a further year at the University of Liverpool doing my Teaching Certificate and was lucky enough to have a couple of great teaching placements during that time. I was then very fortunate to get a teaching post at St. Mary's College in Liverpool, a Direct Grant Grammar School run at the time by the Christian Brothers. It was a very academic school and although the Brothers seemed scary at first, I found it to be a very friendly establishment which might explain why I stayed there for the next 39 years! My first Head of Department was Mike Duffy who, from the beginning treated me as an equal. He allowed me to teach A-level Biology from my very first year and I always enjoyed teaching the Genetics components of the syllabus best. I think the students enjoyed it too as, over the years, more than 20 went on to study it at university. I suppose the majority of them went on to study Medicine or Dentistry, indeed my own dentist and GP are both former students and still call me Sir! I developed

many close friendships over the years, none more so than with the Head of Physics, Roger Duxfield. Incredibly, we went to school together too and have been friends for nearly 60 years. We still meet up once a month.

**How did you become involved with the Galton Institute and now the Adelphi Genetics Forum?**

I had been a member of the Genetics Society for many years and in 2010 saw an advert for the Galton Institute Conference on Epigenetics, a topic I wanted to learn more about. I attended the conference and found that everyone was so pleased to see a secondary teacher at their event, I decided to join and the following year met Geoffrey Vevers, the editor of the Newsletter and he suggested that I should write an article for him. Before I knew it, he had persuaded me to take over as editor and so I joined Council in 2014.

**What role do you consider that the Adelphi Genetics Forum can play?**

I believe that public engagement is our key role. The Annual Conference is always a good showcase but so are our Teachers' Conferences which have been great opportunities for academics to interact with secondary teachers so that their knowledge can be kept up to date. We're hoping to expand our public engagement events in the near future.

**Tell us something about yourself that isn't widely known**

As a teenager I was greatly involved in amateur dramatics. My finest hour was playing the lead in Julius Caesar. We never did get the blood out of my toga – my mother's bedsheets. Et tu Brute!

**Previous contributors to the *My Life in Genetics* series:**

Published in the ***Adelphi Review:***

| | |
|---|---|
| **Dr Jess Buxton** | **Issue 1** |

Published in the ***Galton Review***:

| | |
|---|---|
| **Professor Nicholas Wood** | **Issue 15** |
| **Professor Dallas Swallow** | **Issue 14** |
| **Professor David Galton** | **Issue 13** |
| **Professor Andrew Read** | **Issue 12** |
| **Professor Veronica van Heyningen** | **Issue 11** |
| **Professor Dian Donnai** | **Issue 10** |
| **Professor Philippa Talmud** | **Issue 9** |

## CHASE Africa progress report to the Artemis Trust 1 January – 30 June 2022

Work has been continuing well this year in Eldama Ravine, with Community Health Workers (CHWs) and Youth Peer Providers (YPPs) sharing family planning information widely in the community so that people understand the range of options available to them. The long rains experienced between March and May this year meant that many people were out working at their farms, making it a challenge for the CHWs to reach out to people with information via door-to-door visits. However, in preparation for the recent general election in Kenya, the government had been organising meetings, at which the Community Health Workers were given the opportunity to speak about Sexual and Reproductive Health and Rights.

In addition, CHWs and YPPs have also held meetings with local tree nursery groups and have run information sessions in schools and colleges and interacted with youths in various social places. These gatherings have enabled us to reach larger numbers of

people with family planning information. 6,400 people were reached with information through Community Dialogue events, while 4,884 people were reached with information through door-to-door visits by the YPPs and CHWs. Now that information has been thoroughly disseminated throughout some of the communities in which we had been working, and women there have been enabled to access family planning services, the project has been able to move its focus to new locations. As such, 2 of the 4 'safe spaces' this year are new sites, around which the CHWs have begun reaching out to new communities with family planning information. It is encouraging to have been informed that data from school daily registers and transition records indicate that teenage pregnancies are beginning to reduce in the area, enabling girls to complete their education and improve their future prospects. The table below shows some of the numbers involved:

| **Total no. of people reached with SRHR and FP information from Jan – June 2022** | 11,284 |
|---|---|
| Of these | |
| - males | 3,537 |
| - 19 years old and under | 3,655 |
| - living with disabilities | 39 |
| **Total no. of women to receive FP:** | 2,263 |
| Of these | |
| - first time users | 1,415 |
| - 19 years old and under | 332 |
| - living with disabilities | 4 |
| **Total CYP** | 3,298 |

Due to increased opportunities for larger group meetings this year in comparison to the previous two years, the number of people reached with family planning information has grown considerably, from 6,327 in our last report, to 11,284. It is noteworthy, however,

that in contrast to this, the number of women to receive family planning during this reporting period has slightly reduced, from 2,646 in our last report, to 2,263. We attribute this to a combination of reasons.

For the sharing of family planning information there was an unavoidable shift in emphasis for part of this year, from the door-to-door visits to large group meetings and due to the rains making it difficult to speak with people in their homes. As we had noted when our service delivery methods changed in the early stages of the pandemic, the one-to-one conversations with people, made possible by the CHW home visits, are very effective compared to the 'light-touch' approach of sharing information with large groups. This meant that although the total number of people reached with family planning information increased during this period, the depth of information and private dialogue was more limited for many of those people, and a lower percentage of women subsequently chose to use family planning. In addition to the rains, making it difficult to speak to people at home, the weather also made it a challenge for any women who did intend to use family planning to travel to the health facility or safe space during that time, since the rains can make many roads in the area impassable.

As mentioned above, we moved our work to two new locations this year, in which the process of mobilising the communities, breaking through cultural barriers and dispelling commonly held myths about family planning is just beginning. In any new marginalised area, it takes time before trust is built, attitudes change and the use of family planning becomes more acceptable within the community. On review of the total number of women to have received family planning during this period, although the total number was lower, in light of the reasons described above, we

are satisfied that the result was reasonable. The number was still well above target (the projected number of women to receive family planning was 1,620), and the project is expanding its reach into more marginalised and under-served communities, bringing the benefits of family planning to those for whom it will have the greatest impact.

During this period, providing one couple year of protection (CYP) cost £5.29. Each year that a woman is empowered to prevent an unintended pregnancy can make an enormous difference to the health and economic prospects for herself and her family, and the fact that a year's protection costs so little, demonstrates remarkable value for money. **Philip** from Ol-Rongai is a father of 3, working as a motorbike taxi rider. He accompanied his wife to get routine immunisations for their daughter and to enquire about available family planning options at one of Dandelion's safe spaces. After counselling from the health provider, they took a 3-year implant to give them time to plan for their children's education. "I am so grateful that this clinic has come close to us, and we don't need to travel long distances even for reproductive health counselling. This is what we had missed for years, and it is of great assistance to the community. My wife told me about family planning, and I wanted to listen for myself to see how it works and if it can affect her fertility. I am glad I now understand and with the current state of economy it will ease our cost of upbringing our three babies."

Thank you for your support.

**CHASE Africa, August 2022**

## CHASE Africa progress report to the Artemis Trust

During 2021, CHASE Africa, with partner organisation Dandelion Africa, continued to successfully deliver family planning information and services to adults and youths in marginalised rural communities of Eldama Ravine, Baringo County, Kenya. Health-seeking behavior in the communities is beginning to change as a result of people's improved knowledge and understanding about family planning and its benefits. Women of reproductive age are now beginning to safely access family planning from health facilities, unlike previously when stigma around the use of family planning was high.

Face covering and social distancing protocols are still in place in Kenya, and large crowds are still prohibited. However, most other COVID-19 restrictions such as curfews and travel constraints have now been lifted, schools have re-opened and vaccinations are being rolled out. COVID-19 sensitization and vaccination has encouraged people to interact more (while still observing COVID-19 safety protocols) with less fear of contracting the virus, which has boosted the uptake of family planning services.

**Outputs**

The Community Health Workers (CHWs) and Youth Peer Providers (YPPs) have continued to engage well in dialogue with community members to provide people with family planning information and address any misconceptions held. Anyone then wishing to ac-


*Back-pack nurse consultation*

cess family planning services has been referred to the nearest linked health facility or back-pack nurse's 'safe space'.

During the 6 months from the beginning of July to the end of December 2021 family planning information was shared with 6,327 people (2,032 males and 4,295 females), including 34 people who were living with disabilities. 2,236 of those reached with family planning information were under 18s.

2,646 women and girls (including 4 living with disabilities) subsequently accessed family planning services via referrals to our

linked family planning providers. 635 of those were under 18s. The total Couple-Years of Protection (CYP) provided was 3,946, and the number of women choosing to use family planning for the first time was 1,556.

*Community Health Worker using an IEC aid to educate women on the various available family planning methods.*

**Challenges** There was a nationwide shortage of Depo-Provera injectable contraceptive, propelling more women to be counselled on long-term family planning methods. Towards the end of August, some health facilities in Eldama Ravine sub-county experienced a shortage of long-term family planning methods also.

**Finance report** The budget was adjusted slightly in light of rising fuel prices in Kenya, so the anticipated spend was consequently revised and the actual expenditure at the end of the period

was £16,970 – slightly over budget due to increases also in the prices pharmaceutical commodities.


*Youth peer provider conducting a sexual and reproductive health and rights (SRHR) session with primary school students*

In line with the kind pledge of the Artemis Trust, I hope the Adelphi Trustees will be encouraged, as we are, that attitudes towards family planning in marginalised rural areas of Eldama Ravine are beginning to change, and people are slowly becoming more accepting of modern contraceptive use. As a result, the number of people accessing family planning services continues to steadily increase. The contribution of the Artemis Trust is making a significant, lasting difference to thousands of families in Kenya and we thank you for your support.

CHASE Africa, January 2022

## Adelphi Genetics Forum: Teachers' Conference
## 1 July 2022, The NOWGEN Centre, Manchester

On Friday 1st July a small group of UK Biology teachers made their way into Manchester for the Adelphi Genetics Forum Teachers' Conference at the Nowgen Centre. Personally, I was very much looking forward to dedicating an entire day to refreshing my subject knowledge on Genetics; the downside to being an experienced teacher is that it's a long time since I graduated and the field of genetics is so rapidly evolving.

The format for the day was introduced by **Robert Johnston**; he explained the rationale behind the recent change in name of the forum from The Galton Institute which was historically rooted in the field of eugenics. The Adelphi Genetics website is a hive of useful information for A-level teaching, particularly their "occasional papers" section with booklets on epigenetics, stem cells and precision medicine which all link in beautifully to the A-level Biology specification.

The first session of the day was led by **Professor Andrew Read**, on "Genome-Wide Association Studies and Polygenic Scores" and looked at how small changes in DNA can lead to disease, how people can go about looking for these changes and completing statistical tests to show significance. He explained that SNPs (single nucleotide polymorphisms) are the place that researchers go to look for differences which might be related to disease; for example on Chromosome 8 around 19 million bases along, 90% of people have a cytosine base and only 10% of people have a guanine base. Genome-wide association studies can be used to look at SNPs that might cause disease by analysing the DNA of people with disease compared to a control group and looking for a correlation with SNPs. This has been done for a range of physical and mental disease including T1 and T2 diabetes and bipolar disorder.

After a coffee break we had a session led by Clinical Scientist **Dr Panos Sergouniotis** on stem cells and their applications. He started by speaking about the history of stem cell use and the creation of iPS cells using a cocktail of transcriptional factors by Yamanaka in 2006. As a consultant ophthalmologist, he spoke of his experience in using stem cells taken from the limbus of the eye in treating some eye disorders. He gave examples of treating trauma to the eye following a firework accident and age related macular degeneration using stem cells. This session really opened my eyes (no pun intended) to exactly where we are up to with the use of stem cells in treating disease; the fact that they are being used but many applications are still at the clinical trial stage.

We then has a superb talk from **Professor Turi King** who is president of the Adelphi Genetics Forum as well as being well-known for her role in the BBC's "DNA Family Secrets" documentary series and her work on the Richard III case. She told us about the role of mitochondrial DNA in tracing back female relatives and Y-chromosome DNA in tracing back male ancestors. Her talk was really interesting in highlighting that we are all so genetically related; her easy to grasp table of data showing that if you trace someone's family tree back over 600 years they would have more great grandparents (24 x great grandparents) than there are people in the UK at present, and the fact that it is actually incredibly unlikely that we are not, in fact, related to royalty!

After lunch **Professor Gregory Radick** gave a very thought-provoking talk about teaching order which really made me re-assess when I introduce the work of Mendel to avoid students' fixation on genetic determinism. His suggestion, after trials of both options, was to start with a case study like heart disease where both genetics and environment are involved and only then move on to study Mendel as there are very few accurate examples of human traits coded for by a single gene. When it comes to teaching Punnet squares he recommend pre-loading each example with the phrase "all else being equal", meaning we need to assume the offspring are all under exactly the same environmental influences.

Next up **Dr George Burghel** from Manchester Centre for Genomic Medicine gave a talk on Precision Medicine which is featured in Topic 8 of the AQA A-level course. He spoke about the Brca1 and Brca2 genes, mutations of which can lead to increased risk of breast and ovarian cancer. Something I found interesting was the fact that cells secrete DNA into the blood and so a blood test could be used to screen people for a variety of mutations to potentially increase the amount of preventative medicine or early interventions in cancer cases. He mentioned we need to be careful not to over test, as some genetic changes do not lead to issues further down the line. Dr Burghel was kind enough to bring along the print out of Chromosome 21 base sequence which comprises of two weighty tomes – as a prop it was quite the eye opener; it would be awesome to have a full genome print out in school but I suspect my colleague in reprographics would not thank me.

Finally, **Dr Rhona Macleod** spoke to us about careers in genetics; specifically the clinical scientist, genetic counsellor and bioinformatician. It was useful to hear about the differences in these careers in terms of entry pathway but also the fact they all work together in a multi-disciplinary team. I found this session interesting as the role of the genetic counsellor is specially mentioned in the AQA A-level course so to watch a video of a (role-played) consultation was really useful and gave me a much better idea of their job. Dr Macleod recommended a Future Learn course about genetic counselling and also the NHS careers website.

I found the day to be incredibly useful and it was so good to meet up with some of my Twitter colleagues in real life! I'd never heard of the conference before, but definitely hope to attend future ones. Thank you so much to everyone involved in organising and running the conference and to our seven speakers; I'm sure I speak for all attendees when I say we hugely appreciated the day.

**Jane Masters, The Grange School, Hartford**

## Gene People Leadership Symposium 2022

4-10 November 2022

The theme for the event was 'New: genetic conditions in a (hopefully) post-pandemic world.' In addition to speaker sessions, the nominees and winners of inaugural Gene People Awards were announced.

Gene People is grateful to the **Adelphi Genetics Forum** for their support of the Symposium. There were over 60 registrations for each afternoon session, with the majority of registrants coming from patient organisations (47%) and the NHS (24%). The event was chaired by **Professor William Newman**, University of Manchester, to whom we are extremely grateful. While there were nine breakout sessions, this summary will focus on the keynote and panel sessions.

The first keynote speaker was **Delores Cvitičanin** of Rare Diseases International talking about the implementation of the UN Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families" by using the #Act4Rare Toolkit. The Resolution has the potential to create global change for those with rare conditions and Cvitičanin called for all attendees to use the Toolkit to achieve progress.

There was more reason for optimism from **Nina Pinwill** of NHSE, **Thomas Strong** of NICE, and **Paul Catchpole** who introduced and discussed The Innovative Medicines Fund and what it might achieve for patients with genetic conditions. It is clearly early days for the Fund, and this will definitely be a topic that Gene People will return to in the future.

**Jackie Hunter** from Benevolent AI ended the first afternoon with an inspirational session entitled 'How AI is enabling drug

discovery and development.' The possibilities for using Artificial Intelligence to identify potential drugs that will have a higher chance of clinical success, which will, in turn, shorten discovery time. The opportunities for the genetic conditions' community are distinct.

The second afternoon opened with **Maria Chatzou Dunford** of Life-Bit giving delegates a comprehensive overview of how data is being used to help people with genetic conditions. The importance of partnerships in the UK and beyond was demonstrated as a vital way of accelerating discovery to improve the lives of those with genetic conditions. That keynote dovetailed with the session from **Rory Popert** and **Catherine Ludden** of Genomics England, who outlined how Genomics England is working with partners to turn science into healthcare.

The final keynote and last session of the Symposium was from **Patrick Short** of Sano Genetics. 'Accelerating precision medicine by putting patients and families at the centre of development' looked at what true 'patient centricity' means for patients, families and industry. The key theme that came out strongly in the presentations is that the speed of change is increasing in all parts of the system. This will bring huge possibilities for people with genetic conditions and their families and carers, although the changes are not without challenges. The overriding feeling delegates were left with was hope.

**Thinking and Networking Sessions**

Delegates were invited to connect during short Thinking and Networking Sessions on the intervening days between the two Symposium sessions. The aim was to reassess the Rare Disease Framework priorities following the pandemic. Delegates decided that the priorities were valid. Diagnosis and Co-ordination of Care were the priorities delegates focussed on, while recognising that for very small patient communities, co-ordination of care might be difficult to achieve. There were other matters raised during the sessions which will inform the Gene People work programme for the coming months.

**Gene People Awards**

The Gene People Awards were presented during the Symposium, with nominees announced on the first afternoon and winners and highly commended nominees on the second.

An open call for nominations was shared among the Gene People Partnership Network and with other partners resulting in 10 nominations across the four award categories. All nominations met the criteria, and all were of high quality.

The Judging Panel consisted of Alastair Kent (Chair, Gene People and Rare Disease Advisory Group), Joel Rose (Chief Executive, Cardiomyopathy UK), and Emily Clarke (Genetic Counsellor).

The full list of winners and nominees is as follows:

**Best Campaign**

**Winner:** Huntington's Disease Alliance UK & Ireland
**Highly Commended:** Pulse Infoframe & BHD Foundation/ Myrovlytis Trust

**Best Research Partnership**
**Winner:** Timothy Syndrome Alliance and The Neuroscience and Mental Health Research Institute, Cardiff University
**Nominee:** The AKU Society, National Alkaptonuria Centre, and the University of Liverpool

**Best Volunteer**
**Winner:** Lee Reavey, NCBRS Worldwide Foundation
**Highly Commended:** Clare Stacey, Annabelle's Challenge

**Lifetime Achievement**
**Winner:** Patricia Durao Lewi, The CATS Foundation
**Nominee:** Louise Fish, TSA/Genetic Alliance UK
**Nominee:** Dr Michael McGrath, Muscle Help Foundation
**Nominee:** Prof Lakshminarayan Ranganath, The AKU Society

**Samantha Barber**

# ADELPHI GENETICS FORUM

## Conference 2023

## *Population diversity, its biological consequences and impact on disease risk*

**The Royal Society**
**18 October, 2023**

It has long been known that people not only differ in DNA sequence from each other- (any two people plucked at random differ by the order of 0.1% of their DNA bases), but the frequencies of many of the nucleotide changes differ in different parts of the world. This means that people living within the same geographic areas or societal groups tend to cluster together as a result of their shared ancestry, while those living further apart may form distinguishable clusters. But migration of peoples leads to admixture, and also differing non-genetic factors in different parts of the world may lead to differential selection and thus also differences in gene frequency. So, our genetic history is complex. This conference attempts to address the extent and functional significance of this diversity. Talks will cover population history, single gene disorders and selection, disease susceptibility, pharmacogenetics and the challenges of precision medicine.

*Admission is free but strictly by ticket from:*
*The General Secretary at:* executiveoffice@adelphigenetics.org