

GENETICS & MEDICINE HISTORICAL NETWORK

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1. NEWSLETTER No. 15

The Genetics and Medicine Historical Network Newsletter has come a long way since the first issue appeared in January 2003. In this, the 15th issue of the Newsletter, readers can see that a great deal of progress has been made towards meeting the Network's early goals.

One of the ongoing projects of the Genetics and Medicine Historical Network has been the creation and cataloguing of oral histories of important members of the field. We have news of the continuation of the GenMedHist Interview Series, previous interviews done by the Edinburgh University Science Studies Unit, and a new DVD with images of European human and medical geneticists donated by Hans Galijaard.

We are also happy to include a report on the archiving and cataloguing of the papers of the geneticists Sir Walter and Dame Julia Bodmer at Oxford University's Bodleian Library. Closer to home, the Human Genetics Historical Library housed at the University of Cardiff continues to add material to its collections. It has recently been the recipient of material from the Annals of Eugenics Archive at University College London.

The Fifth International Workshop on Genetics History and Medicine will take place 21-23 June 2012 as a satellite meeting to the 2012 European Society of Human Genetics Meeting in Nurnberg, Germany. Dr. Heike Petermann from the Institute for Ethics, History, and Theory of Medicine at the University of Münster is heading up the organizing committee for the workshop. I hope to see many members of the Network next summer at this historic meeting.

New to the Newsletter are conference reports detailing recent work in the history of human and medical genetics. I would like to thank Amy Samson, Andrew Hogan, Peter Collopy, and Stephen Mawdsley, the graduate students who contributed these reports which provide a view of cutting-edge research in the field. If Network members know of upcoming meetings in which similar subjects will be addressed, I would appreciate their help in soliciting reports of these meetings for future newsletters.

Judith Friedman



2. Living Archives on Eugenics in Western Canada

***Living Archives on Eugenics in Western Canada* Inaugural Public Conference, October 22-23, 2010, Edmonton, Alberta Amy Samson, PhD Candidate, University of Saskatchewan**

Throughout the late nineteenth- and early twentieth-century various parts of North America and Europe witnessed the rise of eugenic programs designed to improve the human race. Within Canada, eugenic ideology was particularly influential in the West, with Alberta (1928-1972) and British Columbia (1933-1973) being the only two provinces to successfully pass sexual sterilization legislation.

The CURA funded *Living Archives on Eugenics in Western Canada* project aims to bring awareness to this under-studied history through the identification and development of resources, and the engagement of various groups in "discussions about aspects of the past that can inform current practices and policies." The project is headed by University of Alberta professor Rob Wilson, and composed of scholars, sterilization survivors, and community partners.

The project's inaugural public conference started on the evening of October 22nd, 2010 with a keynote address given by Douglas Wahlsten, Psychology Professor Emeritus at the UofA, entitled "Eugenics in Alberta: Science and Politics." After establishing the state of genetic science in the 1950s, Wahlsten demonstrated that the provincial Eugenics Board, created under the *Sexual Sterilization Act*, did not apply the scientific knowledge available to it in its process of deciding which "mentally defective" individuals presented before it should be sterilized (the Board rarely said no). He argued that from the perspective of the science available at the time the sterilization program in Alberta was an "absurd and flagrant waste of resources."

The second day of the conference, held at Stanley A. Milner Library, began with Leliani Muir reading the Mayor's proclamation declaring October 23rd, 2010 as "Remembering History of Eugenics Day" in Edmonton. Muir was the first individual to successfully sue the Alberta government in court for wrongful sterilization; she is also a member of the *Living Archives* team.



Throughout the remainder of the day the attendees heard from a number of the project's team leaders including Nicola Fairbrother, Erika Dyck, Claudia Malacrida, Gregor Wolbring, and Dick Sobsey and Heidi Janz. Their presentations covered a broad range of topics thematically relevant to the project. Fairbrother, for instance, discussed the various forms of eugenics that have emerged since the repeal of Alberta and British Columbia's respective sterilization legislations.



For more information on the *Living Archives* project, its team members, and upcoming public events please see <http://eugenicsarchive.ca/>

Amy Samson (University of Saskatchewan)

Images of the Proclamation and Leliani Muir reading the Proclamation
courtesy of Erika Dyck (University of Saskatchewan)

3. Annals of Eugenics Archive, UCL

I joined Prof. Ruiz-Linares' team in 2009 and was soon involved in an exciting project to publish online the original *Annals of Eugenics* (AE), 1925-1954. This journal had originally been founded by Karl Pearson at UCL in 1925 and continued under this name until 1954 when the title was changed to the *Annals of Human Genetics* (AHG) in order to reflect more accurately the work being published in the journal. Mid-way through this work, we also began sorting through our papers in preparation for the GEE (Genetics, Evolution and Environment Department) move to the newly refurbished Darwin building. Safely stowed away in the bottom drawer of my filing cabinet, I came across Galton's passport that had travelled with him through Germany and various drawings by him. This was something of a surprise and led me to speak with Sue Povey who first introduced me to the Annals of Eugenics archive. For someone with a background in ancient history rather than the history of genetics, some of the material was rather eye-opening.

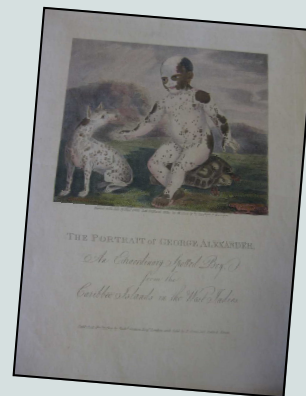


The archive room was filled with floor-to-ceiling rolling shelves which were stacked with many hundreds of volumes of UCL publications including, for example, Annals of Eugenics, Treasury of Human Inheritance, Drapers' Company Research Memoirs and Questions of the Day and Fray. There was also a considerable amount of original material, both documents and artefacts, associated with the eugenics and early genetics work that had been done in the Galton Lab. The documents

included photographs and hand-drawn pedigree charts associated with some of the AE articles.

Other extraordinary material ranged from an original photograph of Darwin's study that was taken by his son, Leonard, and which hung in Galton's study; a photograph of Galton lying on his deathbed; original portraits of Galton's family; to Julia Bell's consanguinity data cards and two of Karl Pearson's microscopes. One of the

most moving finds involved a young boy named George Alexander Gratton who had been born on the Caribbean island of St Vincent and who suffered from piebaldism – a rare genetic skin pigmentation condition. A large, rather innocuous, blue folder contained a print of George, two adverts describing him as the 'Spotted Negro Boy', an original legal document, dated 1810, leasing the two-year-old George for seven years to a group of individuals for £200. After being displayed to a fee-paying public for some years, he tragically died at the age of four.



Three groups of material were identified and it was agreed that the contents of the archive would be split up. The most historically important material would be sent to UCL's Special Collections, under the care of Gill Furlong, and UCL's Galton Collection, currently Jayne Dunn's responsibility. The multiple copies of the various journals would be offered *gratis*, firstly, to institutions with strong links to the history of genetics where individuals could access the material, and, secondly, to individuals with an academic research interest in this subject.

Sushma Jansari (UCL) s.jansari@ucl.ac.uk

4. History of Science Society 2010 Annual Meeting, Montréal (Quebec, Canada) 4 - 7 November 2010

The History of Science Society met this past November in Montreal for a conference that included a number of sessions touching on genetics and medicine.

An engaging panel on Cystic Fibrosis (CF) brought together scholars who offered historical, philosophical, and sociological perspectives. Susan Lindee discussed the complex etiology of the disease, focusing on the rise and fall of gene therapy as a highly anticipated magic bullet for curing it. Lindley Darden looked at the disease from a mechanistic perspective, revealing the challenges involved in focusing on the CFTR gene alone when attempting to better understand and treat CF. Rachel Grab focused on the impact of CF testing for affected families. She discussed the state-by-state variation among diagnostic testing thresholds used for identifying children likely to develop the disease, and how they influence the way parents come to understand CF and its long-term effects.

Vassiliki Betty Smocovitis gave the Forum for the History of Science in America Distinguished Lecture on Masuo Kodani, a Japanese-American geneticist whose research and biography were shaped by his internment during World War II.

In a session on "Rethinking Science and Race," panelists examined the role of race in the thought of Charles Darwin, German-American anthropologist Franz Boas, and Ukrainian-American geneticist Theodosius Dobzhansky. Roberta Milstein argued that Darwin's conclusion that sexual selection explains the existence of human races was anomalous in his work and not central to his ideas about selection, as Adrian Desmond and James Moore have recently contended. John P. Jackson, Jr. examined Boas' rhetoric concerning head shape and his 1911 argument that it was environmental, not hereditary, while Veronika Lipphardt, also a Boas scholar, evaluated his German-language publications and support for German biological anthropologists after his emigration to the United States. Finally, Lisa Gannett surveyed the use of the term "gene pool" in American biology, tracing it to discussions of eugenics, race purity, and agricultural breeding in the 1940s, and suggesting that Dobzhansky - previously credited with introducing the term in English by Mark B. Adams - was only one of many geneticists using it.

Andrew Hogan and Peter Collopy (University of Pennsylvania)

5. Conference Report – International Society for History, Philosophy, and Social Studies of Biology Meeting, Salt Lake City (Utah, USA) July 10-15 2011

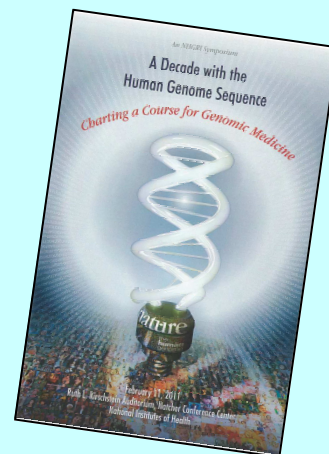
The University of Utah campus located at the foothills of the Wasatch Mountains in Salt Lake City provided a picturesque setting for the 2011 meeting of the International Society for History, Philosophy, and Social Studies of Biology. ISHPSSB meetings offer a place where scientists who study the biological sciences can meet and interact with scholars who study the history, philosophy and social studies of biology. Work on eugenics and human genetics was well represented at this year's meeting. The session 'How Eugenics Does Its Work' included a paper given by the noted historian of biology Garland Allen, who also gave the conference's plenary address. Several sessions addressed topics in human and medical genetics ranging from genetic counseling and personalized genomic medicine; the role of cytogenetics in medicine; and population studies. Others explored our understanding of the gene and of the genome in the light of current discoveries. The conference ended with members participating in a biohumanities public forum on 'Evolution, Gender & Sexuality' at the downtown branch of the Salt Lake City Library where the audience was educated and entertained by Lisa Diamond's talk on human sexual fluidity, John Dupré's discussion on 'normal' people, and Elisabeth Lloyd's account of the evolution of the human female orgasm.

Judith Friedman

6. A Decade with the Human Genome Sequence – Charting a Course for Genomic Medicine

NHGRI Symposium 11 February 2011 Bethesda (MD, USA)

February 2011 marked the 10th anniversary of the publication in *Nature* of the draft sequence of the human genome produced by the Human Genome Project. On 11 February 2011 the National Human Genome Research Institute (NHGRI) hosted a day-long symposium at the National Institutes of Health (NIH) celebrating this anniversary and examining how far the field of human genomics had come over the past decade and assessing the challenges that lay ahead. The symposium coincided with the release of the 10 February 2011 issue of *Nature* which contained several articles reflecting on the first decade of the genome.



The morning session began with Eric Green, the Director of the National Human Genome Research Institute who welcomed symposium attendees. Francis Collins, the Director of the NIH (and previous NHGRI director) spoke eloquently on how the human genome project has paved the way for new and important discoveries concerning rare human diseases and raised hopes for the development of future treatments. Eric Lander (Broad Institute) provided an overview of the human genome at 10. Sean Eddy (Howard Hughes Medical Institute) discussed the genome from a data analysis point of view and remarked on the importance of comparative genome sequence analysis. David Page (Whitehead Institute) related what genetic sequencing had revealed about the development of human sex chromosomes. Richard Lifton (Yale University) used the example of the role of salt in hypertension to discuss the importance of the study of genes and genomes to the future of medicine and health care. Dan Kastner (NHGRI) discussed how the development of new genetic technologies had allowed researchers to better understand genetic causes of fever and inflammation and to develop targeted treatments for patients with these rare illnesses. Many of the speakers reflected on how technological developments have decreased the cost and increased the speed of genetic sequencing.

6. A Decade with the Human Genome Sequence – Charting a Course for Genomic Medicine cont.

NHGRI Symposium 11 February 2011 Bethesda (MD, USA)

One of the highlights of the symposium was the panel “Exploring Your Genetic Blueprint: A Panel Discussion” where a group of individuals whose genomes had been sequenced (including James Watson, the head of the Human Genome Project at the NIH from 1990-1992) spoke about what insights the process had offered them – and what they had learned, and did not want to learn, about their genetic futures. Bradley Bernstein (Harvard Medical School) discussed the importance of examining not only the genome but the epigenome in order to better understand the expression of genes. Lynda Chin (Harvard Medical School) spoke about the promise that genomic research has for the development of targeted treatments for cancer. Amy McGuire (Baylor College of Medicine) discussed the Ethical, Legal, and Social Implications (ELSI) Program funded by NHGRI as part of the Human Genome project and its importance in developing ethical, legal, and policy responses to new genetic technologies. Amy Harmon, a reporter for the New York Times, reminded symposium participants to remember the public place of human genomics. She has reported on several individuals and communities affected by genetic research and encouraged scientists to reach out to the public in order to better explain their work and to make their research results available to the public through open access publishing. In the final session of the afternoon Maynard Olson (University of Washington) spoke about the need to integrate the biological science of genetics with basic medicine and to move genomics away from genetic exceptionalism and out into the real world.

The entire symposium was recorded and is available for viewing at:
<http://genome.gov/Symposium2011>

7. 2011 Annual Meeting of the Canadian Society for the History of Medicine, Fredericton (New Brunswick, Canada)

The 2011 Canadian Society for the History of Medicine Conference, held from 28 – 30 May at the University of New Brunswick, Canada, boasted a number of interesting academic papers concerning the nature, politics, and history of medical genetics. Indeed, graduate student Steve Malone (University of Western Ontario) offered an analysis of Tay-Sachs and Beta-Thalassemia screening launched in Montreal, Canada, in 1972. Malone’s paper stressed the complexities of “genetic communities” and the discourse of disease prevention. Moreover, sociologist Dr. Bill Leeming (Ontario College of Art and Design University) delivered a fascinating presentation that explored the role of genetic counselling in Canada and how its purpose has shifted over time. Moving from genetics to ethics, the annual AMS Paterson Lecture, delivered by medical historian Dr. Susan Lederer, was a conference highlight. Lederer’s paper examined the notion of “presumed consent” in respect to human tissue transplantation in post-1950s America. The politics of organ donation and the complex nature of state regulations were shown to be contested territory. The conference papers, when taken together, highlight the burgeoning scholarly interest in medical genetics and their importance to understanding both historical and contemporary issues.

Stephen E. Mawdsley (University of Cambridge)

8. American Association for the History of Medicine 84th Annual Meeting, Philadelphia (Pennsylvania, USA) 28 April – 1 May 2011

This year's AAHM meeting was held at the Sheraton Society Hill Hotel in the historic area of Philadelphia. The National Constitution Center hosted the Fielding H. Garrison Lecture, given this year by Martin Pernick (University of Michigan) on the subject of 'Disease and the Racial Division of Labor in America'. The plenary session 'Medical Science, Media Spectacle' had papers by two scholars. Bert Hansen (Baruch College) spoke on the role of the media in popularizing medical discoveries and Susan Reverby (Wellesley College) reflected on how her work on unethical US-sponsored research into syphilis in Guatemala in the late 1940's sparked a media firestorm which is still ongoing.

Several papers on the subject of eugenics were given at this year's conference. Arleen Tuchman (Vanderbilt University) examined the eugenic movement's oddly positive view of diabetics who were capable of controlling their disease. University of Saskatchewan graduate student Leslie Baker discussed the adoption of segregation rather than sterilization in eugenic legislation enacted in the Canadian province of Nova Scotia in the 1920s. Erica Dyck (University of Saskatchewan) spoke about the human costs of eugenic sterilization policies in her talk which examined the experiences of two female survivors of the eugenic legislation enacted in Alberta, Canada. Ben Harris (University of New Hampshire) looked at the relationship between eugenics and psychology in the early 20th century in his analysis of the early work of the child psychologist Arnold Gesell.

Judith Friedman

9. Interviews with staff of the Edinburgh University Institute of Animal Genetics , 1969-1971

A search for additional recorded interviews with human geneticists led me to the following series documented on the British Library Sound Archive website (<http://sounds.bl.uk/>).

Edinburgh has been a key centre for genetics since the 1930s and a number of those interviewed are important in the early development of human and medical genetics, including:

Frank AE Crew
John Fraser Roberts
JM Robson
Guido Pontecorvo
Pio Koller
Honor Fell
Charlotte Auerbach

These interviews were made by the Edinburgh University Science Studies Unit (catalogue no. C1271) and have been transferred to CD from the original files.

Peter Harper (Cardiff University)

10. Human Genetics Historical Archives

Readers of this newsletter may be familiar with the ongoing UK genetics archives project that has formed a strand of the concern to preserve the historical information documenting its origins and development that has run in parallel with the development of this Network. The background lies in Professor Peter Harper's oral history interviews and establishment of the *Human Genetics Historical Library* at Cardiff University. In the course of these activities he enquired as to the existence of surviving archival records and what, if any, provision had been made for their preservation. In 2003 Peter Harper approached the National Cataloguing Unit for the Archives of Contemporary Scientists (NCUACS) in Bath, for which I then was senior archivist, to discuss how the Network and the NCUACS could work together in ensuring the preservation of the archives of leading figures in human and medical genetics. These discussions were productive and the fourth Genetics and Medicine Historical Network newsletter announced the commencement of a project to try to ensure the documentation of British human genetics.

As an immediate result of Peter Harper's work the NCUACS catalogued archives of J.H. Renwick, C.A.B. Smith and M.A. Ferguson-Smith (the Renwick archive had been saved from immediate destruction through the action of John Edwards and Sue Povey, but was still under threat from redevelopment work at the Galton Laboratory). As the wealth of archive material of other leading figures in human and medical genetics became apparent, with funding from the Wellcome Trust I was able to make a series of visits, in the course of which I surveyed nine genetics archives and discussed my plans with archives colleagues and historians of science.

Arising from this, a plan was formulated to catalogue all these archives in one comprehensive project. although the NCUACS ceased to exist at the end of 2009; with continued and active support from the Wellcome Trust, I have been able to advance the project in instalments. Working in Cardiff with Simon Coleman, a colleague from the NCUACS at Bath, the archives of J.H. Edwards, G.R. Fraser, and the Medical Research Council's Human Biochemical Genetics Unit have been added to the list of geneticists' archives preserved. They have been placed in Birmingham University, the Wellcome Library and University College London respectively. More are under way, catalogued by Simon Coleman, including archives of Peter Harper himself, Rodney Harris and additional records of C.A.B. Smith.

Dr Tim Powell (Consultant Archivist, Bodmer Archives Project, Bodleian Library)

11. Video film: 'Images of Human Genetics' - Hans Galjaard

This important resource of historical material has very recently become available, so this is a preliminary note to alert readers of the Newsletter to its existence.

Hans Galjaard was until recently Professor and Head of Medical Genetics at Erasmus University, Rotterdam, making many important contributions to inherited metabolic disease, in particular the molecular basis and prenatal diagnosis of lysosomal storage disorders. Filming has always been a hobby of his and for many years he has taken a video camera to conferences to film colleagues, obtaining footage on more than 200 workers in the field of human and medical genetics. Now he has edited this material and produced a DVD that he is kindly making available to those interested, in particular the Genetics and Medicine Historical Network. Anyone wishing to receive a copy should contact Jo Richards (richardsJE2@cardiff.ac.uk).

The DVD contains images of many of the world's most significant human geneticists, some no longer living. I found it a vivid experience to see these people again, as well as others still living but several decades older. There is an accompanying written key to identify the particular individuals. Over the coming months we shall be working to see how best to link the disc to the genmedhist website, but meanwhile we should like to thank Professor Galjaard for creating this unique resource and for generously making it available.

12. Interviews with Human and Medical Geneticists

The series of recorded interviews mentioned in previous Network newsletters is at last fully available on the Genetics and Medicine Historical Network website (www.genmedhist.org/interviews), so now seems a suitable time to say a few words about it that may encourage readers to look at the transcripts in more detail. Currently 65 interview transcripts are viewable, representing most of the original series of 76 interviews. Others will be added as further interviews are completed and processed, but already the collection is a substantial one and should represent a useful resource for those interested or working in the field.

Background

The need for, and almost complete lack of recorded interviews with the founders of human and medical genetics was one of the main factors that made me start the Genetics and Medicine Historical Network nearly 10 years ago. It soon became clear that it would be fruitless to wait for funding, or for others to undertake such a project, so in late 2003, armed with a small mini disc recorder, some practical information from attending a short oral history course, but also with more than 30 years experience of genetic counselling interviews, I started to make the recordings.

Two practical aspects determined the initial plan: first, many of the key people to be seen were elderly and frail, so that most interviews would need to be done at home; second, lack of funding meant that I would have to confine most interviews to Europe, with an emphasis on the UK. Fortunately a comparable American initiative was beginning around the same time, so that the two series were likely to be largely complementary.

The interviews

My first interview was with Paul Polani, founder of one of the UK's earliest and most important medical genetics centres at Guy's Hospital, London. Almost 90 at the time, he soon made me realise that age is no barrier to enthusiasm and vigour, as can best be appreciated from the audio clip made from the interview.

It rapidly became clear that a high proportion of the people on my initial list had been involved in the early discoveries of human chromosome research, so with the 2006 50th anniversary of the discovery of the correct human chromosome number in 1956 approaching, I deviated from the original plan and tried to interview as many as possible of those in this field still living, who fortunately were mostly based in Europe rather than America. These interviews formed the basis for my 2006 book *First Years of Human Chromosomes* (1) (paperback edition 2008), and I was pleased that it proved possible to include a CD with 10 audio clips from the interviews in the hardback edition.

Once I had completed, as far as I could, the cytogenetics interviews, I returned to medical geneticists and human geneticists in general; during 2005 and 2006 in particular I seem to have spent much of my time making interviews. This was largely because after retiring from my previous post I now had the time, while I was still being invited to lecture across Europe on various non-historical topics, giving me the opportunity of using these visits for interviews while in the particular region or country.

UK Medical Genetics

For most European countries I have only attempted to interview the small number of founders in the field, some of whom were clinicians, others laboratory scientists. I felt, and still feel, that for other workers, perhaps less known internationally, such interviewing is best done by someone from the particular country, rather than by an outsider who is relatively ignorant about many local factors. (being a 'foreigner' can be an advantage though in being outside local rivalries or political issues).

12. Interviews with Human and Medical Geneticists

For the UK I have been keen to interview as wide a range as possible of those who founded and developed medical genetics in the country, along with scientists involved in the main research discoveries. By comparison with most other European countries, the UK has had a relatively 'flat' structure, with important developments and discoveries spread across a wide range of academic and medical centres, and a tradition of mutual help and support, rather than a hierarchical pattern. I hope that, taken as a whole, the interviews will give an overall picture of how the field has developed in Britain. They certainly show what a major contribution UK workers, both clinical and laboratory based, have made in such areas as cytogenetics, neural tube defects and thalassaemias, to name but a few. Many of the British interviewees later took part in a 'witness seminar' organised at Wellcome Trust by Professor Tilli Tansey and now published both in print and electronically (2).

Earlier generations

Although I have not used any fixed structure in the interviews, most took a broadly chronological or biographical approach, apart from a few that were undertaken for specific reasons. This has resulted in a remarkable amount of information on an earlier generation of geneticists, mostly long deceased, who had been teachers or mentors for interviewees. Taking as the UK as an example, people such as J B S Haldane, Ronald Fisher and Lancelot Hogben featured prominently, while Lionel Penrose of the Galton Laboratory, London, was cited by many, from outside as well as from within Britain, as the person who had most influenced their ideas and career. At a more clinical level there was information on Cyril Clarke, Cedric Carter and on Paul Polani (now himself deceased).

I gained a powerful impression of how important an influence these early teachers had had on subsequent careers and attitudes, and how much of a 'founder effect' there was; perhaps the most striking example comes from Russia, where the first three directors of the renewed Moscow Medical Genetics Institute have all been students of the outstanding geneticist Nikolai Timoffeef-Resovsky, one of the few survivors from the terrible destruction of Russian genetics.

Inevitably there have been workers that I missed being able to interview, who died relatively recently (eg: Charles Ford of Harwell), sometimes when young (eg: Robin Winter; Leena Peltonen). I was especially sad that Tony Murphy (Johns Hopkins, Baltimore), who I had arranged to interview in Barcelona, to where he had retired, suffered a major and subsequently fatal stroke the day before my visit.

On the more positive side, there have been 10 interviewees in the series who have since died, but where the interview itself remains as a permanent record, available to scholars and others.

The founders of human molecular genetics

A generation or more younger than their counterparts in human cytogenetics, only a few of the first workers in human molecular genetics have featured in the initial interview series now on the Web. There is an urgent need to cover this group of workers, especially since few historians seem aware so far of their importance, in contrast to the studies that have been made on the earlier origins of molecular biology and the recent publicity given to the Human Genome Project.

I have now begun a second interview series focusing on this area, though I am not the person best placed to do this, being more a clinical than a laboratory scientist. Hopefully the 2010 workshop in Gothenburg on the origins of human molecular genetics, organised last year by the Network, will encourage others to undertake such interviews.

12. Interviews with Human and Medical Geneticists cont.

Personal aspects

While undertaking the interviews I did not attempt to ask about personal aspects of an interviewee's life, apart from those arising naturally while describing childhood and early years. However many such aspects were brought up spontaneously, and added greatly to the overall picture given of the individual's character, in some cases being directly relevant to their decision to enter a career in science or medicine.

Especially striking were the experiences of the many people in the series who had been caught up in World War Two and its aftermath, mostly during early life. Britain in particular gained some of its most outstanding workers in human genetics as refugees from the disasters occurring in continental Europe.

Conclusions

How important and useful historians and others will find this interview series remains to be seen, but early indications are encouraging. One thing is certain - today's discoveries are becoming part of 'history' at an ever increasing rate and it needs younger people than me to take on the task of capturing this history before it is too late. I plan to complete a hundred interviews myself and then to hand the task on to others. I hope that some of the readers of this newsletter may be encouraged to take on what for me has been a pleasurable as well as a worthwhile project, and a rare privilege in making and renewing acquaintance with such a welcoming as well as talented series of people.

Acknowledgements

I thank all those who agreed to be interviewed and especially of those giving permission to place their edited interviews on the Web. I have been most fortunate in being able to call on the skilled services of June Williams and Joanne Richards for transcribing interviews; Joanne Richards has also done most of the organising and preparation of material for the Web. Although it has proved impossible to obtain specific funding for the work, I am most grateful to Cardiff University and the Wales Gene Park for providing facilities, and to Wellcome Trust for their support of other aspects of my work.

References

1. Harper PS. 2006. *First Years of Human Chromosomes: The Beginnings of Human Cytogenetics*. Oxford: Scion.
2. Clinical Genetics in Britain. Origins and Development. Harper PS, Reynolds LA, Tansey EM (eds) (2010) Wellcome Witnesses to Twentieth Century Medicine, vol. 39. London: The Wellcome Trust Centre for the History of Medicine at UCL

Peter Harper - Cardiff University

13. A Historian's Eye View of the Human Genetics Historical Library

The University of Cardiff's Special Collections and Archives (SCOLAR) houses the Human Genetics Historical Library. The Genetics and Medicine Historical Network has played an active role in soliciting donations for this unique collection which has grown significantly over the past few years. An overview of the history and development of the library was published in March 2010 (see Harper and Pierce *Clin Genet* 2010: 77: 214-220).

I was privileged to view this unparalleled collection of human and medical genetics textbooks, monographs, dissertations, journals, and other materials during a visit to Cardiff last year. At that time the collection was particularly strong in the fields of human and medical genetics spanning the second half of the twentieth century. Some significant works from the first half of the twentieth century, mainly English but also important texts written in other languages, were also part of the collection. In recent weeks, this portion of the collection has been strengthened by the donation of material from the Archive of the *Annals of Eugenics*, later the *Annals of Human Genetics* at University College London.

The Human Genetics Historical Library will be of inestimable use to historians, philosophers, and those engaged in the social studies of science and medicine. To my knowledge there is no similar collection covering the development of the field of human heredity from the nineteenth century through the twentieth century. For my own research I traveled to many university libraries in Canada, the United States, Great Britain, and elsewhere and while many of these libraries contained some of the volumes in the Human Genetics Historical Library, none of the holdings were as complete or as representative of the development of the field as that now housed in Cardiff. Indeed, as universities discard old works in order to make space for newer ones, fewer and fewer libraries will contain copies of these important seminal texts.

However, the historical importance of the collection is found in more than just its contents. The Human Genetics Historical Library contains the donated working libraries of several important human and medical geneticists including Malcolm Ferguson-Smith (Glasgow and Cambridge), Paul Polani (London), Professor JH Edwards (Oxford), Professor HJ Evans (Edinburgh), Doctor Stanley Walker (Liverpool Cytogenetics Unit), and books from Northwick Park Hospital which belonged to Professor Lionel Penrose. The cataloguing process has tracked the provenance of the books in the collection which will enable scholars to know which books were owned and used by which human and medical geneticists. Importantly the collection contains annotated works, theses, and lab manuals, which offer researchers invaluable insight into the development of the field over time.

It is my hope that over the next few years that the scientific and medical members of the Genetics and Medicine Historical Network will continue to donate material to the Human Genetics Historical Library and that the members of the Network who are engaged in the study of the history of the fields of human and medical genetics will travel to Cardiff to take advantage of this unique and important collection.

Judith Friedman

14. The Bodmer Archive Project

The ongoing work to preserve the archives of leading British geneticists outlined earlier in the newsletter (page 8) is also continuing in Oxford, under the auspices of the Bodleian Library, again with Wellcome Trust support. With my colleague Adrian Nardone, previously of the NCUACS and latterly of the Centre for Scientific Archives, I am working on a preliminary sorting and box-listing of the archive of Sir Walter Bodmer and Julia, Lady Bodmer. This huge archive is currently in a warehouse in Cowley, where it occupies the whole of the upper floor of one unit (at the beginning of the project it filled over 50 four-drawer filing cabinets, 10 metal cupboards and over 450 records boxes and boxfiles).



The archive offers comprehensive documentation of nearly all aspects of the career of Sir Walter, from his Cambridge postgraduate work to the present day. Material of Julia Bodmer is focussed on her later scientific work from her period as the head of the Imperial Cancer Research Fund Tissue Antigens Laboratory and co-headship of the Cancer and Immunogenetics Laboratory at the Institute of Molecular Medicine, and her contributions to the HLA Workshops. The account below can only touch on some of the facets of this magnificent archive.

Research material forms the heart of the archive and it encompasses studies of a wide range of topics in genetics over six decades. It goes back to Sir Walter's time as a postgraduate at Cambridge, working under R.A. Fisher, through his periods at Stanford and Oxford, to research in a number of areas related to cancer, by his team at the ICRF Director's Laboratory.

There is a voluminous scientific correspondence, which comprises Sir Walter's correspondence from the 1960s to the 2000s. It forms a virtual who's who of geneticists, as well as including students and researchers, opinion-formers and administrators with whom Sir Walter dealt in his many roles. There is also a shorter sequence of Julia's correspondence.

There is considerable material relating to Sir Walter's publications, (many co-authored by Julia). It features drafts, correspondence and other material for his books, principally *The Genetics of Human Populations* (with L.L. Cavalli-Sforza, 1971) and *The Book of Man* (with R. McKie, 1993). The archive has material relating to Sir Walter's public lectures, for example, the Royal Institution Christmas lectures for 1984-1985 on 'The Message of the Genes'.



14. The Bodmer Archive Project cont.



The Bodmers travelled extensively throughout their careers. This is reflected in a very large sequence of visits and conferences, with documentation running from 1959 to 2008. It includes travel to nearly all parts of the world in connection with a huge variety of occasions. In addition to scientific meetings, Sir Walter travelled in connection with his positions of authority in a number of organisations, including the ICRF, the British Association for the Advancement of Science, and others. The International HLA Workshops form a separate sequence. Beginning in 1964, these came to be highly important in the study of immunogenetics, for sharing information and transmitting new techniques and coordinating research worldwide. Julia was responsible for organising data collation and analysis

from the 5th and 6th workshops held in 1972 and 1975. The 7th workshop was held in Oxford in 1977 and the Bodmers played the major role in its organisation. Julia continued to play a key role in data collection and analysis from the workshops and the 11th and 12th workshops held in Japan and France respectively, are particularly well documented.

The Bodmer archive is of key importance for the history of genetics in the second half of the twentieth century. Sir Walter's research career covered major advances in genetics, from developments in linkage in the 1950s and 1960s to the mapping of the human chromosomes from the 1980s to the 2000s, as well as cancer research. He made many other contributions to the development of genetics in Britain, for example, his service on the Cell Board of the Medical Research Council in the 1970s and his chairmanship of the MRC Subcommittee on Clinical Genetics which examined the state of clinical genetics in the UK and the implications of developments for future planning. The development of formal international cooperation in genetics is reflected throughout the archive, for instance in the HLA workshops and HUGO.

The archive also reflects Sir Walter's contribution to biomedicine more generally. During his period at the ICRF, for instance, there was a great increase in the research effort of the charity. Sir Walter was highly influential in the direction of cancer research not only of the ICRF but, through the UK Coordinating Committee on Cancer Research, more widely. Sir Walter was closely involved in broadly-based campaigns to raise awareness of environmental causes of cancers and means of its prevention, most publicly the connection between smoking tobacco and lung cancer. At the time of his leadership the issue of animal testing aroused much opposition, some of it violent, and while remaining adamant as to the necessity of such testing, Sir Walter saw the need to explain better the scientific work of the ICRF to the general public. Internationally Sir Walter played important roles in the International Union Against Cancer and the Organisation of European Cancer Institutes.



The Bodmer archive has the potential to contribute significantly towards the ongoing documentation of human and medical genetics, as well as broader themes in biomedicine and science more generally. Furthermore, while the archive is of great potential interest in its own right, its interest is enhanced by the connections that can be made between it and with archives already and being processed. We are currently in the process of seeking the additional funding needed for full archival cataloguing that will complete the work begun on the archive and enable it to be made accessible to researchers.

Dr Tim Powell (Consultant Archivist, Bodmer Archives Project, Bodleian Library)

15. Fifth International Workshop on the History of Human Genetics

Fifth International Workshop on the History of Human Genetics. Nuremberg, Germany. June 21-23, 2012

"The Biological Future of Man: Continuities and Breaks in the History of Human Genetics, Before and After 1945."

Organizer Dr. phil. Heike Petermann, Institut für Ethik, Geschichte und Theorie der Medizin, University of Münster, Münster, Germany

In June 2010, the last international workshop on genetics, history, and medicine, "The Early History of Human Molecular Genetics" took place in Gothenburg, Sweden. This workshop brought together geneticists, historians, and archivists to examine key developments in human molecular genetics. The Fifth International Workshop on the History of Human Genetics will take place as a satellite symposium of the 2012 meeting of the European Society of Human Genetics in Nuremberg.



'Nuernberg' (Nuremberg) has a long and interesting history. The town was founded in the Middle Ages and held the first 'Reichstag' of the Holy Roman Empire. It was also home to a number of famous artists, including Albrecht Durer. (See: www.nuernberg.de, available in English). During the Third Reich, Nuremberg gained prominence as the location of the 'Reichsparteitage' (the Nuremberg Rallies of the Nazi party) and the place where the Nuremberg Laws were enacted in 1935. The workshop will begin with a visit to the Documentation Centre which illustrates not only the history of the Third Reich but also the Nuremberg Trials which took place in 1945-6. A visit to the site of the Nuremberg Trials is being arranged for those who are interested. Other options will be available on request. It will be a great pleasure to welcome you to Nuremberg to discuss the history of human genetics in the 20th century!

Heike Petermann (University of Münster)

Organizing Committee:

Dr. Heike Petermann M.A., Muenster (responsible)

Dr. Stephen Snelders, Utrecht

Scientific Committee:

Prof. Dr. Peter Harper, Cardiff

Prof. Dr. Toine Pieters, Amsterdam

Prof. Dr. Joerg Schmidtke, Hannover (requested)

Prof. Dr. H.-P. Kroener, Muenster

Thanks to H.W. Taeubrich, Documentation Centre Nazi Party Rally Grounds, Nuremberg for the image

15. Fifth International Workshop on the History of Human Genetics cont.

Fifth International Workshop on the History of Human Genetics. Nuremberg, Germany. June 21-23, 2012

Preliminary Program:

June 21, 2012 (Thursday):

6 to 9 p.m.: Visit to the Documentation Centre: The problematic role of genetics in the history of the Third Reich up to Nuremberg Trials.

June 22, 2012 (Friday):

9 a.m. to 6 p.m.: Workshop

7:30 p.m.: Dinner in the city of Nuremberg

June 23, 2012 (Saturday):

9 a.m. to 3 p.m.: Workshop

Abstracts

Please see the Call for Abstracts for information about the goals and themes of the workshop. The maximum length of abstracts is 250 words. Abstracts must be received by January 15, 2012.

Contact:

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More information at (coming soon): www.eshg.com

15. Fifth International Workshop on the History of Human Genetics. Nuremberg, Germany. June 21-23, 2012, cont.

Call for Abstracts – Due 15 January 2012

Human Genetics is a science with two sides: on one side concepts of human genetics have often influenced social and political events, on the other side the development of human genetics has been influenced by various political forces.

At the end of the 19th century, heredity was dominated by Mendel's gene concept and Galton's biometrical approach (according to A. Motulsky). These were followed by early achievements in human genetics like the identification of chromosomes as the carriers of genetic information (1888), the discovery of the ABO blood group system (Landsteiner 1900) and the inheritance of blood types (von Dungern and Hirschfeld 1911), and the fundamental theorem of population genetics (Hardy-Weinberg-Law 1908).

At the beginning of the 20th century, the eugenics movements in many countries (e.g. Germany, Great Britain and the USA) became stronger. Many scientists believed that genes strongly influenced biology. They were convinced that the human species should either encourage the breeding of those with desirable traits (positive eugenics) or discourage the breeding of the sick and 'mentally defective' (negative eugenics). These eugenic concepts led to the sterilization of 'unfit' persons in many countries. During the Third Reich, these efforts at 'Rassenhygiene' became part of Nazi philosophy. In Germany, the Second World War formed a break in the history of heredity and human genetics. This was not the case in Anglo-American countries.

Important landmarks in Human Genetics after 1945 include the discovery of DNA (1953 Watson and Crick) and biochemical methods for detecting molecular diseases (1949 Pauling, sickle cell anemia). This period saw great progress in DNA technology, genetic epidemiology, cytogenetics, somatic cell genetics, and prenatal diagnosis.

Goals

The Second World War and its consequences greatly influenced the development of human genetics. However, continuities and discontinuities, breaks and changes varied with national settings. This workshop aims to evaluate the state of research and discuss the history of human genetics from a comparative perspective.

Themes

The workshop will be organized around the following three themes:

- Eugenic ideas and human genetics before 1945: Concepts of heredity and research on genetic diseases
- Changing approaches after 1945: From molecular biology to molecular genetics.
- The shadow of eugenics on today's human genetics: Scientific, social, ethical, legal and political aspects

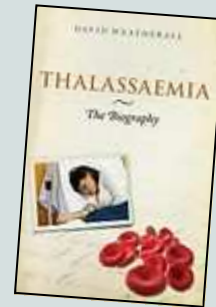
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16. Bookshelf

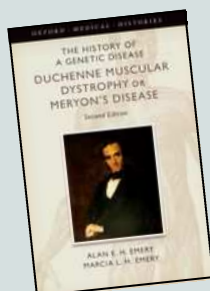
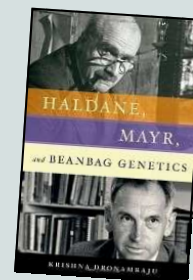
The following books of a historical nature have been published recently, which may be of interest to Newsletter readers:

Weatherall D. 2010. *Thalassaemia: The Biography* (Biographies of Disease). OUP



Skloot R (2010) *The immortal Life of Henrietta Lacks*. Crown

Dronamraju K (2010) *Haldane, Mayr, and Beanbag Genetics*. OUP USA



Emery Alan E.H & Emery Marcia L.H (2011) *The History of a Genetic Disease. Duchenne Muscular Dystrophy or Meryon's Disease*. OUP

17. GenMedHist-I

Coming soon: GenMedHist-I. With the goal of facilitating communication among members of the Genetics and Medicine Historical Network, I am pleased to announce that we will soon be launching a new mailing list – GenMedHist-I. Current members of the network will receive an email inviting them to join this new mailing list. I hope that you will join us in this new venture. The list will provide a forum for communication between the annual Newsletters.

If you would like to join the Genetics and Medicine Historical Network please contact Jo Richards on: richardsJE2@cardiff.ac.uk