GenMedHist

Newsletter No.17, November 2013

Bulletin of the Genetics and Medicine Historical Network

Contents

Introduction

2013 marks the 10th anniversary of the Genetics and Medicine Historical Network Newsletter. Now in its 17th issue, the newsletter takes on the title – *GenMedHist: Bulletin of the Genetics and Medicine Historical Network*. This issue celebrates past work in the field of human genetics in Peter Harper's (Cardiff University) article on the Oxford Monographs on Human Genetics series; reports on current work on the history of genetics and medicine being carried out by the Human Genome Archive Project at the Wellcome Library/Wellcome Trust Sanger Institute and at the National Human Genome Research Institute; and invites readers to participate in an upcoming publication and future historical workshops. Also in the newsletter, librarian Karen Pierce reports that the Human Genetics Historical Library housed in Special Collections and Archives at Cardiff University continues to add to its collections. Updates on the most recent research in the field are provided in the conference reports section, and I would like to thank PhD candidate Adam Turner (University of Oregon) for his review.

The 6th International Historical Workshop on Genetics, Medicine and History will be held in Glasgow (5-6 June, 2015). The date for this meeting has been altered by a year to bring it into alignment with the planned 7th International Workshop which will be held in association with the 50th anniversary meeting of the European Society of Human Genetics in 2017. The preliminary call for papers for the 2015 workshop and a 'save the date' notice for the 2017 workshop appear in this issue.

I am also pleased to announce that plans are underway to publish papers given at previous International Historical Workshops on Genetics, Medicine and History in a collection of essays. The volume will be edited by Heike Petermann and Judith Friedman. Details of the project appear below.

News of ongoing projects or upcoming events that Network members would like to see included in our next newsletter may be sent to me at jfriedma@uvic.ca.

Judith Friedman

Preliminary Announcement

6th International Workshop on Genetics, Medicine and History - June 5-6, 2015.

The 6th workshop on the history of human genetics will be held as a historical satellite meeting to the European Human Genetics Conference of the European Society of Human Genetics (ESHG) in Glasgow, 6-9 June, 2015. The International Workshop on Genetics, Medicine and History will be held before the main meeting, on 5-6 June, 2015.

The topic for the workshop will be: The Evolution of the Human Gene Map

Please note the following dates and deadlines:

Spring 2014	**First Announcement**
Summer 2014	**Call for Papers** **Deadline for Submission:** October 31, 2014
December 2014	**Decision** about accepted Abstracts

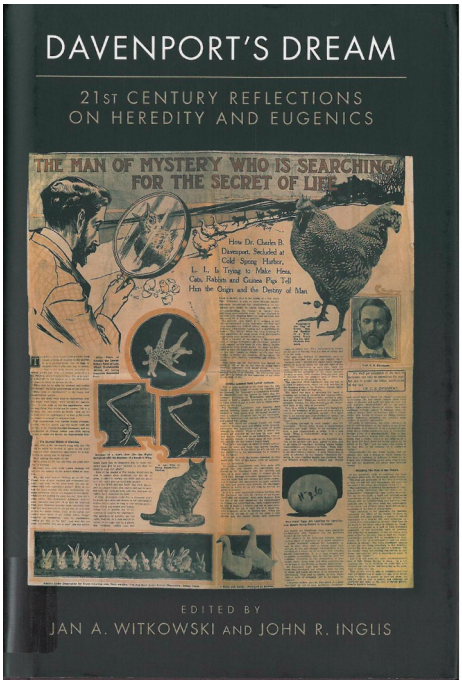
The Announcement and the Call for Papers will be sent out via email to all Newsletter subscribers. Notices will also be posted on the ESHG homepage (https://www.eshg.org/home.0.html)

Human Genetics Historical Library Update

The Human Genetics Historical Library at Cardiff University is continuing to grow. Material added this year includes the DVD *Past and Future of Chromosome Research: The Helsinki Chromosome Conference, 1977* which is a one hour presentation taken from the final panel discussion at the conference. The panel chair was Albert de la Chapelle and the panelists were C.D. Darlington, Arne Müntzing, Torbjörn Caspersson, Albert Levan, and Jacob Wahrman. The DVD includes both the panel discussion and a lively question and answer period with the audience members that followed.

A recent addition donated by Ernest B. Hook is relatively rare because it was never actually published. In 1977 a conference was held on the topic of 'Quality assurance in diagnostic cytogenetics' in Albany, New York under the auspices of the New York State Department of Health and sponsored by the March of Dimes-National Foundation. The proceedings were originally planned to be published, but due to a variety of reasons this didn't come to fruition in time, and although the material was gathered together it was eventually seen as irrelevant and dated. In 1987 a document containing the conference proceedings and explanatory notes about the lack of publication, edited by Ernest B. Hook, were deposited by him with the New York State Department of Health Library. It is a copy of this document which he had in his personal library that has now been donated to the HGHL in Cardiff.

This year we also added the English translation of V.V. Babkov's *The dawn of human genetics* which discusses the Russian eugenic movement and looks at the beginnings of medical genetics in Russia. Published in 2013 this is the most 'contemporary' book in the collection which predominantly covers the 20th century; we do however have several items from the 19th century, the earliest of which dates from 1871, and is St. George Mivart's *On the genesis of species.*



Items received and waiting to be catalogued include 73 Finnish theses from the Library of the Department of Medical Genetics of the Family Federation of Finland and 19 books from Sue Schmerler in New York.

Donations of books not already in the collection and other materials including documents and audiovisual materials are always welcome. Please contact: Peter Harper (HarperPS@cf.ac.uk) or Karen Pierce (PierceKF@cardiff.ac.uk).

Conference Reports

American Association for the History of Medicine 86th Annual Meeting Atlanta (Georgia, USA) 16-19 May, 2013.

Between May 16 and 19, historians, physicians, and other scholars gathered at Emory University in Atlanta, Georgia, USA, for the 2013 annual American Association for the History of Medicine meeting. Fittingly located just across the street from the Centers for Disease Control and Prevention, the two and a half day meeting included paper presentations by historians and other scholars from academic institutions in the United States, Canada, the United Kingdom and other countries in Europe and Asia. Many of these presentations, including entire panels, explored topics of interest to physicians, historians, and others interested in the history of medical genetics.

A session on "Eugenics and the Health Professions" featured three excellent papers that explored the diverse ways eugenic ideas developed around the world in the first half of the twentieth century. Nikolai Krementsov (University of Toronto, Canada) discussed how eugenics began to appear in the discourse of Russian professionals during the first two decades of the twentieth century. He focused on the professional concerns that led Russian psychiatrists/neurologists and public health doctors to embrace eugenics. Even though they shared a common eugenic discourse, psychiatrists/neurologists focused on the new methodologies and interpretive frameworks eugenics presented (family histories and the principles of heredity), whereas hygienists looked to eugenics as a public health tool and a means to bolster their authority. Martin Kuhar (Croatian Academy of Sciences and Arts, Zagreb, Croatia) traced the multiple financial, political, scientific, and moral factors that led Andrija Štampar, Yugoslavia's public health czar in the 1920s and a negative eugenics advocate in the 1910s and 1920s, to significantly tone down his enthusiasm for eugenics by the 1940s. Kuhar's talk highlighted how interconnected science, politics, and the realities of public health were in shaping social medicine in pre-World War II Yugoslavia. Tina M. Kibbe (University at Buffalo, New York, USA), looked at the history of eugenics field workers and public health nurses in the United States between 1910 and 1925. These workers helped construct a discourse about "fitness" that eugenicists and public health authorities later used to craft policies and practices to manage the eugenic "fitness" of the American people. Many of these workers were women, and Kibbe argued that their gender and status as professionals gave them access to homes and information inaccessible to others and that their subjective observations helped form the knowledge base for later definitions of "fit" and "unfit."

In his talk, "Eugenics and Crime: The Hillbilly Homicide of 1936," Paul Lombardo (Georgia State University, USA) told the story of a 1936 murder trial that implicated a locally well-known "degenerate" family and resulted in both guilty verdicts and the sterilization of some of the accused's family members. Lombardo's analysis showed the resilience of eugenic mythologies about "problem families" that were used to frame popular understandings of crime, poverty, and social disorder well into the 1930s. Adam Turner (University of Oregon, USA), in the "Children are the Future" session, discussed how genetic counselors and their clients both played a role in determining the focus and practice of genetic counseling in the mid-twentieth century United States. He described how early genetic counselors, primarily geneticists and medical doctors, wanted to use genetic science to help ensure "normal" babies, but that they avoided giving direct advice to clients in the interest of avoiding the coercive elements of eugenics. The evolution of this profession, Turner argued, helps to illuminate how geneticists and their clients conceived of the role of science in reproductive decision-making, and where they drew and redrew lines between difference, disability, and disease.

Other panelists at the 2013 AAHM meeting presented on a wide range of topics, including alternative insemination, reproductive technology, the role of physicians in early adoption, and prenatal diagnosis. The conference also include a fascinating panel on reproductive choice, "Forty Years After Roe v. Wade," and another on "Schooling, Play, and Disabilities." Randall Packard (Johns Hopkins University, Maryland, USA) generated much discussion with the annual Fielding H. Garrison Lecture on "Break-bone Fever in Philadelphia, 1780: Reflections on the History of Disease."

The annual meeting fostered lively discussions, both in-person and digitally on the Twitter back-channel, about current research and the multiple directions of scholarship in the future.

For an online archive of the conference Tweets compiled by the author see: AAHM 2013: The Twitter Version.

Adam Turner, University of Oregon

Canadian Society for the History of Medicine Annual Meeting, Victoria (British Columbia, Canada) 1-3 June, 2013.

The annual meeting of the Canadian Society for the History of Medicine and the Canadian Association of the History of Nursing was held this year on a gloriously sunny University of Victoria campus as part of the national Congress of the Humanities and Social Sciences. The Patterson Lecture was given by Nayan Shah (University of Southern California, USA) on the timely topic "Prison Hunger Strikes, Medical Ethics, and Globalizing the Anti-Apartheid Struggle." Papers presented at the meeting covered from the medieval to the modern period and examined a wide range of topics in the history of medicine and nursing. One session of particular interest to readers of the newsletter was on the topic "Genetics." Judith Friedman (National Institutes of Health, USA) examined the short-lived interest in the question of genetic anticipation in the inheritance of schizophrenia in the 1990s following the discovery of expanding DNA repeats as the molecular cause of anticipation in Fragile X, myotonic dystrophy, and Huntington's disease. A flurry of papers based on clinical observations suggested that there might be a decreasing age of onset of schizophrenia over succeeding generations. However, when no molecular cause for these findings was found, the community quickly returned to the idea that findings of anticipation in schizophrenia were artefacts rather than 'real' observations. The second paper in the panel was by Adam Turner (University of Oregon, USA). Turner explored the development of genetic counseling in North America from its origins in the 1940s through the 1970s. Early genetic counselors sought to distance themselves from the coercive practices associated with eugenics and presented their clients with information rather than direct suggestions for action, while the clients wished for medical advice that would lead to the birth of a healthy baby. He argued that the reciprocal relationship between clients and counselors and the expectations of both parties played an important role in the development of the field of genetic counseling.

Judith Friedman

24th International Congress of History of Science, Technology and Medicine, Manchester (England) 21-28 June, 2013.

In the largest such gathering in the field, 1758 scholars from around the world met in Manchester for the 24th International Congress of History of Science, Technology and Medicine. This mammoth event saw multiple concurrent sessions on a wide variety of subjects and time periods spread over the course of the week as well as a number of public events, receptions, and historical walks, tours, and excursions. The plenary address was given by Hasok Chang; the president of the British Society for the History of Science raised the provocative challenge to historians of "Putting the Science Back in History of Science." Two symposia at the conference concentrated directly on the history of eugenics, genetics, and medicine.

The symposium "The science of man? Bounds of knowledge in the twentieth century" was organized by Graham Baker (University of Oxford) and Erika Dyck (University of Saskatchewan) and examined several facets of the field of eugenics. In a talk titled "Biometrika and the statistical reinvention of British racial science, 1901-1930" Elise Smith (University of Oxford, UK) examined the way in which Karl Pearson used his journal Biometrika to promote his statistically-driven methodology of the study of human populations and their similarities and differences. Smith pointed out that while this approach was intended to be a more 'objective' way to study the human race, many of the underlying Victorian attitudes towards race remained unchanged, despite the adoption of this new methodology. Amy Samson (University of Saskatchewan, Canada) examined the often overlooked role of nurses and social workers in enacting eugenic policy in her talk "Complicating eugenics: gendered occupations and eugenic sterilization in Alberta, Canada." These women were the front line workers whose role it

was to assess children and submit their cases to the provincial Eugenic Board for assessment. Samson argued that through their participation in Alberta's eugenic programme public health nurses and social workers sought to maintain and expand their professional authority. The uses to which eugenic field work was put were examined by Molly Ladd-Taylor (York University, Canada) in her talk "Data of degeneracy: eugenics field research and institutional power in the US Midwest." She argued that eugenic field work played an important role in extending the power of state institutions to monitor and discipline even remote populations and laid the groundwork for the legalization of eugenic sterilization in Minnesota. Bradley Hart (California State University Fresno, USA) examined the role that philanthropic institutions (like the Rockefeller and Carnegie foundations) and individuals (like Charles Goethe and Henry Twitchin) played in providing significant funding for eugenic research in his talk "The marketplace of eugenic ideas, transnational organizations and the role of philanthropy." In her talk "Send in the clones? Naomi Mitchison, feminism, socialism, eugenics, and science fiction," Lesley Hall (Wellcome Library, UK) examined the way in which Naomi Mitchison explored the topics of eugenics, feminism, and social order in her science fiction novels following the Second World War. The last paper of the session was given by Graham Baker (University of Oxford, UK). In "Public-spirited co-operation': Julian Huxley, eugenics and popular education" he examined the British biologists role in the production of propaganda films for the British Eugenics Society in the 1930s and questioned his identity as a 'reform' eugenicist.

Later in the conference a second symposium organized by Toine Pieters and Pim Huijnen (University of Utrecht, Netherlands) addressed the subject "Genetics, Eugenics and Culture: Transatlantic Perspectives 1900-2000." In his talk, "Digital approaches to eugenic thinking in the Netherlands, 1860-1945," Pim Huijnen examined how the development of a new text-mining tool to study the contents of digitized newspapers might offer a new tool to historians engaged in the study of eugenics in the Netherlands. Heike Petermann (Westfälische Wilhelms-Universität Münster, Germany) examined the role that popular literature played in the spread of eugenic ideas in her talk "The case of perfection: eugenic ideas in literature in the Anglo-American countries and Germany." In "Gender, eugenics, and the population explosion: a case study of transatlantic demographic narratives of the nation," Carole McCann (University of Maryland, Baltimore County, USA) argues that the field of demography was strongly influenced by eugenics and there was significant continuity of thought in the field before and after the Second World War and are evident in the notion that progressive nations restrict their fertility while high fertility rates are the hallmark of 'lesser' or economically backwards nations. Dirk Thomaschke (Carl von Ossietzky Universität Oldenburg, Germany) examined the creation and development of the Danish national genetic register in his talk "'A stable and easily traced group of subjects has become more difficult than ever': human genetics and space in Denmark and the USA around 1945-1960." This register provided an important means to control and study individuals and families with genetic diseases but also encouraged the researchers to envision populations relatively closed "genetic containers." In her talk on "The cultural, scientific and political applications of eugenics in the United States, 1890-1940" Hannah MacGregor (University of Ottawa, Canada) argued that the American eugenics movement should be viewed as developing within the framework of the larger progressive reform movement and that the eugenics movement was, in fact, one of its most successful manifestations. Patrick Merricks (Oxford Brookes University, UK) examined the creation of the category "problem families" as a small sector of society disadvantaged by heredity and economics which is notable because it causes a disproportionate number of problems in his talk "Problem families and eugenics in British society, 1900s-1950s." He noted that the term still has resonance to this day in referring to certain groups characterized by social and economic inequalities who are disproportionately involved in acts of violence. In his paper "Aldred Scott Warthin's family 'G': the American plot against cancer and heredity (1895-1950)" Toine Pieters examined how findings concerning a family with a hereditary predisposition towards cancer came to be written out of a larger narrative on cancer by the American Society for the Control of Cancer which depended on the disease being detectable and treatable rather than something which was inherited and inevitable. Susanne Doetz (Charité-Universitätsmedizin Berlin, Germany) examined the intersection of science and politics that lay at the centre of genetic counselling in East Germany in her talk "Establishing genetic counselling in the GDR."

Judith Friedman

Human Genome Archive Project at the Wellcome Library

In last year's newsletter I introduced the UK strand of the Human Genome Archive Project (HGAP). The survey phase of this project is due to finish at the end of December 2013 so this feels like a good opportunity to provide an update on what has been achieved and our plans for the future.

Using the concept of documentation strategy, the project has seen the development, implementation and refinement of an imaginative collecting methodology for modern scientific records. A large number of scientists, bioinformaticians, scientific administrators and bioethicists have been contacted about their records. There has been a high level of support for this project from those involved in the Human Genome Project (HGP), even when they no longer have any material to contribute. The response rate to the scientific stage of the survey is currently around 70%.

In the process of surveying a number of individuals expressed a willingness to deposit their material in archive repositories so that it can be properly preserved and made available to researchers. The Wellcome Library has received some of these collections and outline descriptions have been added to our online catalogue (known as collection level descriptions). Although this material is not available to researchers at the moment, the descriptions allow people to know the full extent of our holdings and allow us to gauge the amount of potential research interest. Two notable collections that have been acquired and described in this way are those of Richard Durbin (catalogue reference GRL/DUR) and Michael Ashburner (catalogue reference PP/MIA).

One collection that we have acquired, catalogued and made available to researchers already is that of Carol Churcher (catalogue reference GRL/CHU). This collection neatly represents the documentation strategy approach that we have been applying for this project. Rather than simply focusing on the big names and the headline news, we have also been trying to preserve records of the processes, equipment and techniques that contributed to the sequencing of the human genome. The Churcher collection contains material from early work using automated sequencing machines and the evolving protocols. This is a far cry from the media headlines generated by the Human Genome Project, but is important for our understanding of the HGP.

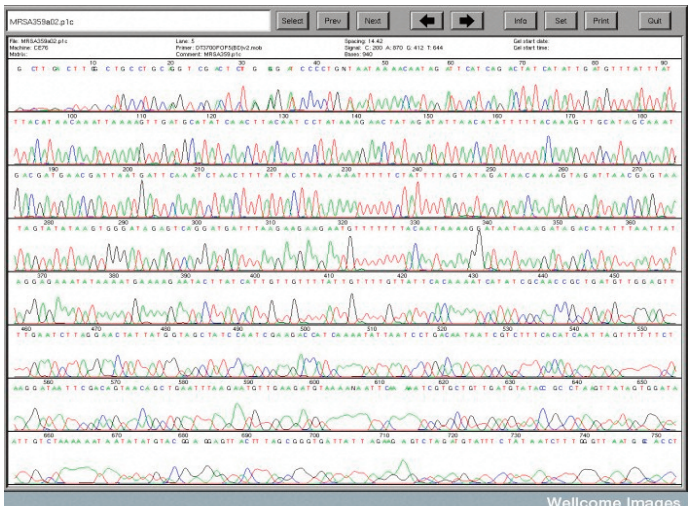
In the course of the HGAP we have developed relationships with other UK archive repositories and negotiated the transfer of collections to them where this would be appropriate. This has been particularly successful in the case of the Bodleian Library in Oxford, which is in the process of acquiring a number of collections of scientists with a strong connection to the University of Oxford.

The survey has also included some of the broader aspects of the HGP, such as the planning and construction of the Sanger Institute. This part of the survey aimed to identify the main individuals and institutions involved in a particular area of the HGP and to determine the location of their records.


Wellcome Images

Part of the purpose of the HGAP survey phase was to assess surviving material and determine whether any further work might be required. In the course of the project so far it has been observed that there is currently a large gulf between the archival community and the scientific community. Many archives shy away from scientific collecting while many scientific institutions lack basic record-keeping structures with individual scientists often unaware of the importance of the material in their keeping. The survival rate for material varies greatly and with the lack of institutional record-keeping structures is entirely dependent upon the attitude and interests of individual scientists. Many of these scientists require considerable support in order to appraise and sort significant legacy material which is otherwise at risk. This is particularly the case for born-digital material which is more vulnerable to loss that its hard-copy equivalent.

Many of the people involved in the HGP were also concerned that not all aspects of it were recorded as written documents. The importance of oral testimony



and the difficulty of capturing tacit knowledge were frequently mentioned.

The Wellcome Library has recently been given approval for a second phase of the project to address some of the issues discovered during the survey phase. It will also allow us to process some of the collections already deposited so that they can be made available to researchers soon. The next phase of the project will start in January 2014 and will run for three years.

Jenny Shaw (Project archivist for the Human Genome Archive Project, Wellcome Library and Wellcome Trust Sanger Institute)

Capturing the Historical Legacy of the National Human Genome Research Institute

In August 2012, the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH) launched a major effort to enhance the historical value of its print and digital resources. Christopher Donohue, who specializes in history of science and who will receive his PhD in the fall of 2013 from the University of Maryland, College Park, was hired to lead this effort. The initial focus of work was on the paper files of Dr. Francis Collins, who succeeded Dr. James Watson as director of the National Center for Human Genome Research in 1993, which became the NHGRI in 1997.

Shortly thereafter, NHGRI expanded these efforts to include digitizing a broader collection of easily assembled paper files archived at the Institute, from the earliest days of the Human Genome Project to Dr. Collins' departure from NHGRI in 2008. The latter collection totals nearly four hundred thousand pages and in aggregate provides a detailed picture of the inner workings of the Institute for nearly twenty years. A meticulous written survey of the digitized paper files is being developed; the aim is then to make these materials available publically to scholars and the interested public through the NHGRI's website, genome.gov, in 2014. The survey will describe key documents relating to NHGRI's rich history. It will also denote confidential or otherwise sensitive documents that will not immediately become available.

With the support of NHGRI staff and leadership, a series of initiatives have been undertaken to identify, preserve, protect, and most importantly, to communicate to a wider audience the role of NHGRI in the Human Genome Project and in subsequent and ongoing genomics research initiatives. To these ends, standard operating procedures are being developed for organizing and preserving the digital files of the Institute as well as the paper files of senior staff; surveys are being conducted to chronicle active genomics programs at NHGRI; oral history questionnaires are being collected for senior staff; and departing staff are downloading appropriate information prior to leaving the Institute.

Over the next few years, key scientists as well as NHGRI staff will be interviewed about their role in the Human Genome Project and other major genomics initiatives. These oral histories will be made public. These projects, as well as others in development, will ensure that a detailed record of the single most important scientific undertaking in the biological sciences (i.e., the Human Genome Project) will be available for future generations to learn from and to discover. Additionally, we plan to publish scholarly accounts of this rich history based on our own review of these materials. This work will attempt to answer important questions— such as, what is the proper role of government in promoting science and innovation, and, with the decline in government support for science in recent years, how can the United States maintain its competitive edge in a rapidly changing global environment.

Eric D. Green and Christopher Donohue, National Human Genome Research Institute, National Institutes of Health

The Oxford Monographs On Medical Genetics

A Piece Of Genetic History

Books form an essential strand of the history of any area of science, and the field of human and medical genetics is no exception. The richness of this strand has been captured, at least in part, by the formation of the Human Genetics Historical Library, founded 10 years ago in 2003, and now containing well over 3,000 volumes, most of which have been fully catalogued and are accessible via the web (www.genmedhist.org) .

Among these books are several long-running series that are valuable not only for the books that they contain, but also by reflecting the main evolving themes and developments over a period of decades. These series include several 'annual review' type collections (e.g.: *Progress in Medical Genetics; Annual Review of Human Genetics*), but also series of free-standing books, of which the *Oxford Monographs on Medical Genetics* series, published by Oxford University Press (OUP), is perhaps the most notable. The year 2013 marks the Oxford Monographs' 50th anniversary, so a note on some of its highlights seems appropriate.

The series began in 1963 in the UK, under the general editorship of John Fraser Roberts, director of the Medical Research Council's Clinical Genetics Research Unit, at the Institute of Child Health, London, and one of the few workers at the time (alongside Lionel Penrose) linking human and more general genetics, and also spanning the pre-and post World War II eras.

Roberts stated the aims of the series clearly:

'An important function of the Oxford monographs will be to provide handbooks covering the genetics relevant to particular specialisms, for example, neurology, mental disorders, gastro-intestinal disorders, and dermatology. These will be addressed primarily to the clinician and to those studying for post-graduate disciplines. Roberts' *An Introduction to Medical Genetics* will serve as an introduction to these handbooks, so that basic principles will not have to be stated afresh. There will also be monographs dealing with particular subjects and research projects. In addition there will be republication of some classical texts of the past with addenda to bring their subjects up-to-date.'

By and large the series has been remarkably faithful to these aims, as can be seen from the list in the table.

The Oxford Monographs On Medical Genetics Series

H. HARRIS: GARROD'S INBORN ERRORS OF METABOLISM (1963, UN-NUMBERED)
R. T. C. PRATT: THE GENETICS OF NEUROLOGICAL DISORDERS (1967, UN-NUMBERED)
C.A. CLARKE: SELECTED TOPICS IN MEDICAL GENETICS (1969, UN-NUMBERED)

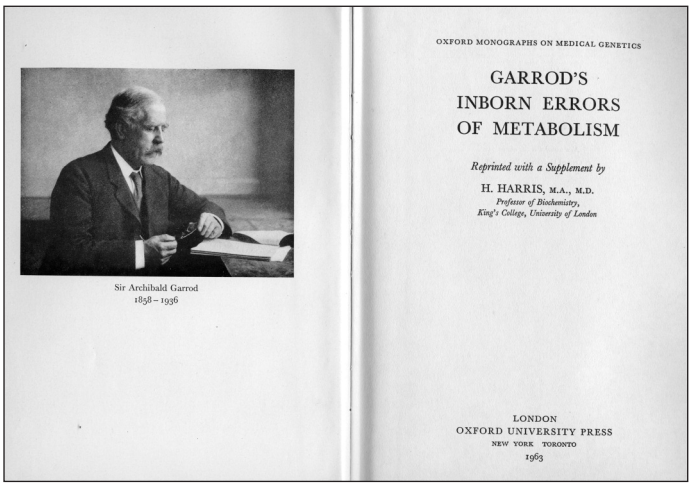
1. R. B. MCCONNELL: THE GENETICS OF GASTRO-INTESTINAL DISORDERS (1966)
2. A. C. KOPEC: THE DISTRIBUTION OF THE BLOOD GROUPS IN THE UNITED KINGDOM
3. E. SLATER AND V. A. COWIE: THE GENETICS OF MENTAL DISORDERS
4. C. O. CARTER AND V. A. FAIRBANK: THE GENETICS OF LOCOMOTOR DISORDERS
5. A. E. MOURANT, A. C. KOPEC, AND K. DOMANIEWSKA-SOBCZAK: THE DISTRIBUTION OF THE HUMAN BLOOD GROUPS AND OTHER POLYMORPHISMS
6. A. E. MOURANT, A. C. KOPEC, AND K. DOMANIEWSKA-SOBCZAK: BLOOD GROUPS AND DISEASES
7. A. G. STEINBERG AND C. E. COOK: THE DISTRIBUTION OF THE HUMAN IMMUNOGLOBULIN ALLOTYPES
8. D. TILLS, A. C. KOPEC, AND R. E. TILLS: THE DISTRIBUTION OF THE HUMAN BLOOD GROUPS AND OTHER POLYMORPHISMS: SUPPLEMENT 1
9. M. BARAITSER: THE GENETICS OF NEUROLOGICAL DISORDERS
10. D. Z. LOESCH: QUANTITATIVE DERMATOGLYPHICS
11. D. J. BOND AND A. C. CHANDLEY: ANEUPLOIDY
12. P. F. BENSON AND A. H. FENSOM: GENETIC BIOCHEMICAL DISORDERS
13. G. R. SUTHERLAND AND F. HECHT: FRAGILE SITES ON HUMAN CHROMOSOMES
14. M. D'A. CRAWFORD: THE GENETICS OF RENAL TRACT DISORDERS
15. A. E. H. EMERY: DUCHENNE MUSCULAR DYSTROPHY
16. C. R. SCRIVER AND B. CHILDS: GARROD'S INBORN FACTORS IN DISEASE
17. R. J. M. GARDNER AND G. R. SUTHERLAND: CHROMOSOME ABNORMALITIES AND GENETIC COUNSELING
18. M. BARAITSER: THE GENETICS OF NEUROLOGICAL DISORDERS (SECOND EDITION)
19. R. J. GORLIN, M. MICHAEL COHEN AND L. STEFAN LEVIN: SYNDROMES OF THE HEAD AND NECK, THIRD EDITION
20. R. A. KING, J. I. ROTTER, AND A. G. MOTULSKY: THE GENETIC BASIS OF COMMON DISEASES
21. D. WARBURTON, J. BYRNE, AND N. CANKI: CHROMOSOME ANOMALIES AND PRENATAL DEVELOPMENT: AN ATLAS
22. J. J. NORA, K. BERG, AND A. H. NORA: CARDIOVASCULAR DISEASE: GENETICS, EPIDEMIOLOGY, AND PREVENTION
24. A. E. H. EMERY: DUCHENNE MUSCULAR DYSTROPHY, SECOND EDITION
25. E. G. D. TUDDENHAM AND D. N. COOPER: THE MOLECULAR GENETICS OF HAEMOSTASIS AND ITS INHERITED DISORDERS
26. A. BOUÉ: FETAL MEDICINE
27. R. E. STEVENSON, J. G. HALL, AND R. M. GOODMAN: HUMAN MALFORMATIONS
28. R. J. GORLIN, H. V. TORIELLO, AND M. M. COHEN, JR: HEREDITARY HEARING LOSS AND ITS SYNDROMES
29. R. J. M. GARDNER AND G. R. SUTHERLAND: CHROMOSOME ABNORMALITIES AND GENETIC COUNSELING, SECOND EDITION

30. A. S. TEEBI AND T. I. FARAG: GENETIC DISORDERS AMONG ARAB POPULATIONS
31. M. M. COHEN, JR.: THE CHILD WITH MULTIPLE BIRTH DEFECTS
32. W. W. WEBER: PHARMACOGENETICS
33. V. P. SYBERT: GENETIC SKIN DISORDERS
34. M. BARAITSER: GENETICS OF NEUROLOGICAL DISORDERS, THIRD EDITION
35. H. OSTRER: NON-MENDELIAN GENETICS IN HUMANS
36. E. TRABOULSI: GENETIC DISEASES OF THE EYE
37. G. L. SEMENZA: TRANSCRIPTION FACTORS AND HUMAN DISEASE
38. L. PINSKY, R. P. ERICKSON, AND R. N. SCHIMKE: GENETIC DISORDERS OF HUMAN SEXUAL DEVELOPMENT
39. R. E. STEVENSON, C. E. SCHWARTZ, AND R. J. SCHROER: X-LINKED MENTAL RETARDATION
40. M. J. KHOURY, W. BURKE, AND E. THOMSON: GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY
41. J. WEIL: PSYCHOSOCIAL GENETIC COUNSELING
42. R. J. GORLIN, M. M. COHEN, JR., AND R. C. M. HENNEKAM: SYNDROMES OF THE HEAD AND NECK, FOURTH EDITION
43. M. M. COHEN, JR., G. NERI, AND R. WEKSBERG: OVERGROWTH SYNDROMES
44. R. A. KING, J. I. ROTTER, AND A. G. MOTULSKY: THE GENETIC BASIS OF COMMON DISEASES, SECOND EDITION
45. G. P. BATES, P. S. HARPER, AND A. L. JONES: HUNTINGTON'S DISEASE, THIRD EDITION
46. R. J. M. GARDNER AND G. R. SUTHERLAND: CHROMOSOME ABNORMALITIES AND GENETIC COUNSELING, THIRD EDITION
47. I. J. HOLT: GENETICS OF MITOCHONDRIAL DISEASE
48. F. FLINTER, E. MAHER, AND A. SAGGAR-MALIK: THE GENETICS OF RENAL DISEASE
49. C. J. EPSTEIN, R. P. ERICKSON, AND A. WYNSHAW-BORIS: INBORN ERRORS OF DEVELOPMENT: THE MOLECULAR BASIS OF CLINICAL DISORDERS OF MORPHOGENESIS
50. H. V. TORIELLO, W. REARDON, AND R. J. GORLIN: HEREDITARY HEARING LOSS AND ITS SYNDROMES, SECOND EDITION
51. P. S. HARPER: LANDMARKS IN MEDICAL GENETICS
52. R. E. STEVENSON AND J. G. HALL: HUMAN MALFORMATIONS AND RELATED ANOMALIES, SECOND EDITION
53. D. KUMAR AND D. J. WEATHERALL: GENOMICS AND CLINICAL MEDICINE
54. C. J. EPSTEIN, R. P. ERICKSON, AND A. WYNSHAW-BORIS: INBORN ERRORS OF DEVELOPMENT: THE MOLECULAR BASIS OF CLINICAL DISORDERS OF MORPHOGENESIS, SECOND EDITION
55. W. WEBER: PHARMACOGENETICS, SECOND EDITION
56. P. L. BEALES, I. S. FAROOQI, AND S. O'RAHILLY: THE GENETICS OF OBESITY SYNDROMES
57. P. S. HARPER: A SHORT HISTORY OF MEDICAL GENETICS
58. R. C. M. HENNEKAM, I. D. KRANTZ, AND J. E. ALLANSON: GORLIN'S SYNDROMES OF THE HEAD AND NECK, FIFTH EDITION
59. D. KUMAR AND P. ELIOT: PRINCIPLES AND PRACTICE OF CARDIOVASCULAR GENETICS
60. V. P. SYBERT: GENETIC SKIN DISORDERS, SECOND EDITION
61. E. I. TRABOULSI: GENETIC DISEASES OF THE EYE, SECOND EDITION
62. D. KUMAR: GENOMICS AND HEALTH IN THE DEVELOPING WORLD

NB: There are a number of errors and inconsistencies in the list as given in the front material of some of the individual monographs; a definitive corrected list of the numbered volumes appears in the 'ebook' second edition (2014) of the author's A Short History of Medical Genetics.

The initial volume in the series (1963) was Harry Harris's re-issue of Archibald Garrod's classic 1909 book *Inborn Errors of Metabolism*, framed by an introduction and extensive postscript. Sadly now out of print, this book (Fig 1) has itself become a classic. Garrod's second book (1931), *The Inborn Factors in Disease*, was also subsequently re-issued in the series as number 16 (1989) with a 'prologue' by Charles Scriver and Barton Childs.

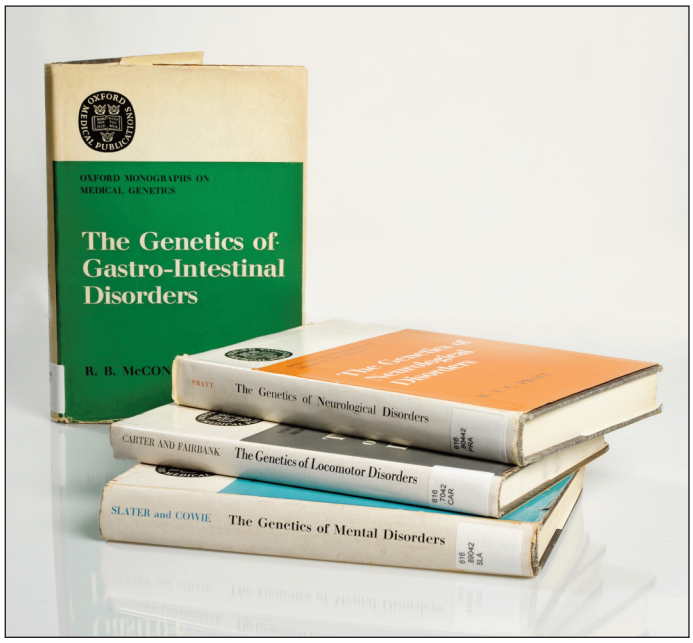
Figure 1. The initial (1963) volume of the Oxford Monographs on Medical Genetics series.



This initial volume of the series did not receive a number, so that the second volume (referred to as such on its dust cover), RB McConnell's *The Genetics of Gastro-Intestinal Disorders*, became 'number one' in subsequent listings of the series. McConnell was a Liverpool gastroenterologist, working closely with Cyril Clarke, and his book forms an exception to the mainly London-based authorship of the early volumes. (Another Liverpool book, *Selected Topics in Medical Genetics*, 1969, edited by Clarke, seems never to have received a series number).

A succession of clinical volumes (Fig 2) established the practical character of the series, and its value for clinicians and for the increasing number of full time medical geneticists, but these volumes were accompanied by several more basic studies on blood groups, (a particular interest of Roberts). Cytogenetics did not make an appearance until volume 12, in 1983, with Bond and Chandley's *Aneuploidy*, followed by Sutherland and Hecht's *Fragile Sites on Human Chromosomes*, which was also the first volume to come from outside Britain.

Figure 2. Some early volumes in the Oxford Monographs on Medical Genetics series.



The progressive shift from Britain to America at the end of the 1980s was reinforced by a more general decision by OUP to consolidate the publication of any particular subject on one or the other side of the Atlantic, resulting in the Medical Genetics Monographs series ending up being edited by OUP New York rather than OUP Oxford. This arrangement seems to have worked well, though with occasional confusion – one Oxford based author, unaware of the new process, apparently delivered the manuscript by hand 'down the road' to the Press, only to find that it remained unlooked at until it had finally reached New York!

Over the years, the series has produced several books that have become indispensable to those working in medical genetics and which can be regarded as true landmarks in the field. Gorlin's *Syndromes of the Head and Neck* and Epstein and colleagues' *Molecular Basis of Development* certainly rank in this category. Inevitably there has been a trend towards multi-author works, though the original concept of true single author monographs is by no means extinct.

The editorship has likewise evolved over the years; succeeding John Fraser Roberts (and Cedric Carter who died relatively young), Arno Motulsky and Charles Scriver joined the editorial panel from North America, as did the author and Martin Bobrow from the UK. Recent years have seen a further enlargement of the panel. Mention too should be made of the OUP staff who played the major role in commissioning the books and chasing often tardy authors. Deadlines in those years were a notional concept, though to my knowledge no OUP editor had to wait as long as did University of Chicago Press, who pursued Sewall Wright for over 40 years before his definitive work on evolutionary genetics was finally delivered. Julia Maidment (Oxford) and Jeffrey House (New York) were two of the long serving early OUP editors whose efforts were largely responsible for establishing the quality and success of the series.

Looking at the extensive, but not quite complete, series on my shelf (which will form part of the Human Genetics Historical Library), I can see that the format as well as the topics of the series have changed, from the uniform character of the early volumes, to a much more varied pattern. In 2013, after 50 successful years, the series has reached number 63 – but how much longer will print remain its medium? In 2014 the second edition of my own *Short History of Medical Genetics* will be published in the series – but only as an e-book. Already most of the larger textbooks in the field, such as McKusick's *Online Mendelian Inheritance in Man (OMIM)* and Scriver's *Metabolic and Molecular Bases of Inherited Disease*, are only published electronically. It will be interesting to see how the *Oxford Monographs on Medical Genetics* series evolves as it enters its second half-century.

Peter S. Harper
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Announcement

Publication of Papers from The International Workshops on Genetics, Medicine, and History - Call for Authors

Since 2003, there have been five International Workshops on Genetics, Medicine, and History held as satellite meetings of the European Human Genetics Conference of the European Society of Human Genetics (ESHG).

1st Workshop	2003, Birmingham	*History of Human Genetics*
2nd Workshop	2005, Brno	*Preserving the History of Human Genetics*
3rd Workshop	2008, Barcelona	*Genetics, History and Public Understanding*
4th Workshop	2010, Gothenburg	*The Early History of Human Molecular Genetics*
5th Workshop	2012, Nuremberg	*The Biological Future of Man: Continuities and Breaks in the History of Human Genetics, Before and After 1945.*

A publication of a collection of essays from past Workshops is now being planned.

Call for Authors

Speakers from past workshops who would like to publish their talks are invited to submit proposals for chapters. Those who did not have a chance to participate but would like to publish on similar topics are also invited to submit proposals.

Proposals should include the year of the workshop and the topic of your talk.

Please mail your submissions to: Dr. Heike Petermann (heike.petermann@uni-muenster.de)

Deadline for submissions: January 31, 2014

Once the submissions have been received authors will be contacted with detailed information about the length and format of their chapter.

The volume will be edited by Heike Petermann and Judith Friedman.

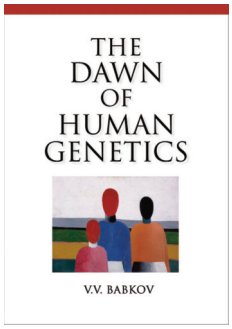
Save the Date

7th International Workshop on Genetics, Medicine and History

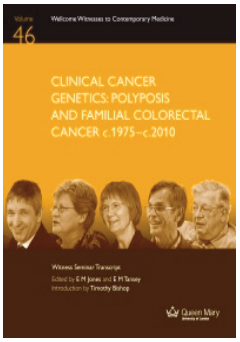
The European Society of Human Genetics (ESHG) will celebrate its 50th anniversary in 2017. A historical satellite meeting is planned for this conference. The 7th International Workshop on Genetics, Medicine and History will take place in 2017. Date and place to be announced.

On the bookshelf

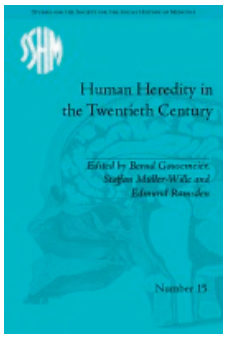
The following recently published books may be of interest to newsletter readers:



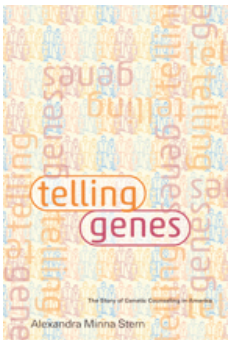
Babkov V.V. (2013). The Dawn of Human Genetics. Cold Spring Harbor Laboratory Press.



Jones E.M. and Tansey E.M. Eds. (2013). Clinical Cancer Genetics: Polyposis and Familial Colorectal Cancer c.1975-c.2010. Wellcome Witnesses to Contemporary Medicine, vol. 46. Queen Mary, University of London.



Gausemeier B, Müller-Wille S, and Ramsden E. Eds. (2013). Human Heredity in the Twentieth Century. Pickering & Chatto.



Stern A. (2012). Telling Genes: The Story of Genetic Counseling in America. Johns Hopkins.