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# 1 Genetics and Medicine Historical Network



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## Genetics, History and Public Understanding 3rd International Workshop Barcelona 30-31 May, 2008

All Network members and Newsletter readers will be pleased to see the following notice from Professor Toine Pieters, Amsterdam, who will organise this Workshop. Please note the dates in your diary and share this information with your colleagues.

Following the successful second workshop in Brno in 2005, this third Workshop will precede the **2008 European Society for Human Genetics** meeting, to be held in **Barcelona 1-3 June**.

Different from the previous ones this **history and public understanding of human genetics workshop** will be more narrowly focused thematically and includes both historical and contemporary studies on:

### Hope, trust and troubled dreams of genetics

Genetics increasingly dominates medical and public thought and practice. The transformation of genetic medicine from a marginal field in the 1950s to a core activity of biomedicine is one of the most interesting developments in modern science. The rise of the new genetics with its promises and perils does affect the medical and public perception and communication around health and disease. The past decade we witness an increase and more intense focus on the genetic and biological basis for disease by the media. How does this spill over to discussions in the public sphere and what implication might be visible with regard to the **public's expectations, trust and concerns** regarding genetics and medicine?

Accounting for genetic or hereditary factors in medicine is nothing new in itself. Since at least the eighteenth century scientists, doctors and patients have tried to establish links between heredity and disease.

But the meaning, visibility and legitimacy of these links have changed over time; from the brave new world of eugenics to medicine's 21st century holy grail. For instance, in the past the increased visibility of hereditary and other genetic factors has generated among other things problems of fatalism, stigmatization and discrimination. More recently, doctoring healthy people on the basis of their genetic susceptibility has raised concerns of misuses of genetic information. **This raises the question how the understandings of genetics as a technological and social project have changed over time?**

The Workshop seeks to address this relatively neglected topic. Scholars are invited to explore how beliefs, knowledge and practices regarding genetics are distributed, exchanged, and shared, and to what effect in different contexts. The Workshop will be organized around the following **three themes**:

1. **Organizing public communication and genetic literacy**
2. **Public challenges: Data sharing, risk and stigma**
3. **Understanding genetics as a technological and social project**

We invite scholars from the fields of genetics, medical history, social medicine, philosophy, medical ethics, anthropology and communication studies to submit contributions.

More details about the Workshop can be obtained from Prof. Toine Pieters at: [a.pieters@vumc.nl](mailto:a.pieters@vumc.nl) or Prof. Martina Cornel at: [mc.cornel@vumc.nl](mailto:mc.cornel@vumc.nl)

## 2 American Philosophical Society Genetics Collections

Most American readers of the GMHN Newsletter will be familiar with the activities of the **American Philosophical Society**, including the **Mendel Newsletter** <http://www.amphilsoc.org/library/mendel> and will know that it has the world's most extensive archival collection of the personal scientific records of American geneticists.

Many European readers may be less aware of this rich source, however, and also not realise how much information is available on the APS website about its genetic collections.

Much of the credit for ensuring that these collections were not lost goes to Bentley Glass, himself a distinguished geneticist at Johns Hopkins University, who over a prolonged period encouraged his geneticist colleagues to donate their records to the Society. Valuable record sets include those of Hermann Muller, Curt Stern and many others (a full list is given on the APS website).

Since Glass's efforts in the 1960s and 1970s there has been less of a coordinated effort to attract records in the genetics field, so that human and medical genetics are currently not extensively represented.

Fortunately this is now changing; a notable acquisition has been the records of Arno Motulsky (see **GMHN Newsletter No. 10**). Since many of the founders of American medical genetics have recently retired, there is a real opportunity and challenge to ensure that their records are preserved and archived, either as part of the APS collection or by their own universities. (The records of Victor McKusick are now held at the Johns Hopkins University Archive).

How do European efforts for archiving key records of human and medical geneticists compare with these systematic American approaches? I fear that the answer is 'not well', but there is a lack of accessible information across Europe as a whole, so a judgement cannot be made. It would be most helpful if Newsletter readers could send a note for their own countries so that this gap can begin to be filled.

Meanwhile, anyone visiting Philadelphia will find a visit (by prior arrangement) to the **American Philosophical Society's Library**, in the heart of the Philadelphia Historical District, enjoyable and worthwhile; even those not leaving home will gain a good picture of the resources it holds by visiting its website at <http://www.amphilsoc.org/library/>

## 3 Oral History of Human and Medical Genetics

### Interviews with the Founders of Human Cytogenetics

In 2006, to mark the 50th anniversary of the discovery of the correct human chromosome number, **Scion Press** published the book '**First Years of Human Chromosomes**' by Peter Harper. Based on a series of interviews with those involved, the book contained a CD with excerpts from 10 of these interviews.

The book is now going into paperback edition, which will be less convenient for including a disc, so the publishers are making these recordings available to all interested people. You can access them on the [genmedhist.org](http://genmedhist.org) website, or on the **Scion Press** website at <http://www.scionpublishing.com>

It is hoped that this will form the core of a more extensive series of recordings and transcripts based on interviews with human geneticists across Europe, now in progress.

A considerable amount of editing of transcripts (as well as the permission of those interviewed) will be required before web based versions of these interviews can be created, and funding is currently being sought for this.

### The Oral History of Human Genetics Project

[www.societyandgenetics.ucla.edu/hgp/index.htm](http://www.societyandgenetics.ucla.edu/hgp/index.htm)

Led by science historians **Nathaniel Comfort** (Johns Hopkins University), **Andrea Maestrejuan** and Marcia Meldrum (UCLA), in conjunction with medical geneticist **Edward McCabe**, this project is undertaking a series of in depth oral history interviews with American human geneticists.

Since the project started in 2001, almost 30 individuals have been interviewed and a full list is available on the UCLA website, along with details of the project.

Actual transcripts are not yet available, apart from two interviews (**Victor McKusick** and **David Rimoin**).

## 4 10th International Human Genetics Congress, Brisbane - Historical Session

The Newsletter has previously given the abstracts of all presentations at this session, but we have now placed the full text of two of these, from Professors **Patricia Jacobs** and **Grant Sutherland**, on the [genmedhist.org](http://genmedhist.org) website.

## 5 Links to other Websites

The [genmedhist.org](http://genmedhist.org) website gives a series of links to **other websites** containing historical information on genetics, especially human or medical genetics. Some **new links** are listed here and it will be very helpful to be informed about others that may well have been missed.

[www.aim25.ac.uk](http://www.aim25.ac.uk)

This is an electronic guide to all the **main archival collections** in the greater **London** area (i.e. that bounded by the M25 orbital motorway). The number and range of archives is very considerable and some are very valuable for genetics (e.g. **University College, London, UCL**).

<http://digital.library.adelaide.edu.au/coll/special/fisher/genetics.html>

This is the **R. A. Fisher Collection** website, archived and digitised at **University of Adelaide** by **J. H. Bennett**. It provides a very complete record of Fisher's work.

[www.genome.gov](http://www.genome.gov)

This site also gives details of the **American** programme of interviews with human geneticists, as described above. The parent website given above (the **US Department of Energy Genome Centre**) gives a range of general, non-historical information.

### Timelines

The 2006 issue of the **Mendel Newsletter** (not yet on the website itself) lists a series of '**timelines**' for the history of genetics. Although none is specific for human genetics, they contain much interesting material and include:

#### Dynamic timeline

<http://www.genome.gov/Pages/Education/Kit/main.cfm?pageid=1>

#### History of Genetics Timeline

<http://www.accessexcellence.org/AE/AEPC/WWC/1994/geneticstln.html>

#### Landmarks in the History of Genetics

<http://dorakmt.tripod.com/genetics/notes01.html>

#### Landmarks in the History of Genetics

[http://cogweb.ucla.edu/ep/DNA\\_history.html](http://cogweb.ucla.edu/ep/DNA_history.html)

## 6 Newsletter Format

Until now the GMHN Newsletter has used a very 'basic' format, but thanks to the work of **Joanne Bolton** and **Steve McAllister** (Media Resources Centre, Cardiff University), we have tried to make this issue rather more reader friendly.

**Now we need more content!** So please send any notes, comments and information, however brief or informal, on relevant future events, to the Editor: [HarperPS@Cardiff.ac.uk](mailto:HarperPS@Cardiff.ac.uk) to give it a broader perspective.