Second International Workshop on

Genetics, Medicine and History

11th – 12th May 2005

Mendel Center, Abbey St. Thomas, Brno, Czech Republic

Programme and Abstract Book

Supported by the Wellcome Trust

Organised by the Genetics and Medicine Historical Network

Held in conjunction with the European Society for Human Genetics 2005 annual congress, Prague

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Programme and Organising Committee

Soraya de Chadarevian (Berlin/Cambridge)
Peter Harper (Cardiff; Organiser)
Jaakko Ignatius (Oulu)
Helena Kääriäinen (Turku)
William Leeming (London/Ontario)
Milan Macek Jr (Prague; Co-organiser)

Acknowledgements

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We are also most grateful to Irena Triskova of the Mendel Center, Brno, Dr Jerome del Picchia, of the ESHG Office, Vienna, and Audrey Budding and Flo Ticehurst, of the Institute of Medical Genetics and the Wales Gene Park, Cardiff for their help and support in the organisation of the workshop.

Contents

Wednesday 11th May

9:00am Coach leaves Prague Congress Centre for Brno (for those attending ESHG Congress)

11:30am Arrive Brno (approx) Hotel Voronez (near

12:30am Buffet lunch in Abbey

1:15-1:45pm Tour of Abbey

2:00pm **SESSION 1: Preserving the Records of Human Genetics**

Julia Sheppard Archivist Wellcome Trust, London
The Future of the History of Human Genetics; the role of Archives

Short contributions, posters and discussion:
Tim Powell, Bath
Human Geneticists and the UK National Cataloguing Unit for the Archives of Contemporary Scientists

Alan Bittles Perth
Historical Patterns of Consanguineous Marriage in Northern Sweden

Peter Harper and Steve Pritchard Cardiff
The Human Genetics Historical Library

General discussion on archiving and records

3:30pm Tea/coffee break.

4:00pm **SESSION 2: Oral History and Human Genetics — a discussion session**

Chair and lead discussant: Soraya de Chadarevian Berlin/Cambridge
The Value of Oral History

Short contributions, posters and discussion:
Marcus Pembrey London/Bristol
Witness seminars and Human Genetics

Mila Pollock Cold Spring Harbor
Talking Genomics

Peter Harper Cardiff
Interviews with early Human Cytogeneticists

Tayfun Özçelik Ankara
DNArt: A contemporary Sci-Art movement inspired by genetics - poster

5:30pm Informal reception in Mendel Museum (in Abbey) with introduction to exhibition by one of Mendel Center staff

8:00pm Workshop Dinner at 'Mendel Cellar' (close to Abbey and hotel)

Thursday 12th May

9:00am **SESSION 3: Early Pioneers and Concepts of Human Genetics Chair Peter Harper**

Alan Rushton USA
William Bateson and Human Genetics

Søren Nørby Copenhagen
Wilhelm Johannsen and the development of Danish Human Genetics

Toine Pieters Amsterdam
Two Centuries of Medical Thought About Heredity and Cancer

Short contributons, posters and discussion
Bengt-Olle Bengtsson Lund
Clinical Genetics Before Mendel.
Stephen Snelders Amsterdam
Heredity, Genetics and Alcoholism in the Netherlands
Miguel DeArce Dublin
Brno Revisited

10:30am Coffee

11:00am **SESSION 4: Human Genetics, Eugenics and Lysenkoism**
Chair William Leeming

Michal Simunek Prague
Eugenics in the Czech Lands

Tomas Mayer Vienna
Brief comments

Jaakko Ignatius Oulu
How Eugenics Reached Finland

Discussion: Lysenkoism and Eastern Europe
Milan Macek Sr Prague, **Peter Harper** Cardiff, and others

12:30pm Lunch

1:30pm **SESSION 5: Historical Aspects of Medical Genetics**
Chair Jaakko Ignatius

Susan Lindee USA
Provenance and the Pedigree: Victor McKusick's Work with the Amish

Patrick Macleod Canada
F. Clarke Fraser and the Birth of Medical Genetics in Canada

William Leeming Canada
Development of Medical Genetic Services in Canada and Britain

Posters and discussion
Hubert Soltan and Patrick MacLeod The Early History of Medical Genetics in Canada
Jiri Santavy and Colleagues History of Medical Genetics in the Czech Republic

3:15pm Tea/coffee

3:45pm Discussion on future workshops

4:15pm Close of Workshop

4:30pm Coach leaves for Prague

Author(s): **Bengt O. Bengtsson**
Lead author's contact details:
Cell and Organism Biology
Lund University
Sölvegatan 29
Lund
223 62
Sweden
Email: Bengt_Olle.Bengtsson@cob.lu.se

Title: **Clinical Genetics before Mendelism**

Abstract

The explosion of Mendelism in the first years of the twentieth century had many causes and many effects. One of the effects was a belittlement of the knowledge about heritable processes that existed prior to the rediscovery of Mendel's rules. Some of this knowledge was lost, while other parts became incorporated into the new thinking in re-steeped form. One finds, for example, much about "race" and "degeneration" in the early literature on human genetics, despite the fact that these notions in many ways belonged to pre-mendelian times.

To learn more about how Mendelism restructured and reorganized earlier knowledge, I have studied an excellent little book on "clinical genetics" published in 1879, more than twenty years before the advent of Mendelism. The book, *Några ord om sjukdomars ärftlighet* [Some words on the inheritance of diseases], was written by Dr Gustaf Trägårdh, lecturer and later professor in practical medicine at Lund University. It seems to have fallen into oblivion almost immediately and I will not claim it as an unknown masterpiece. However, a careful reading of Trägårdh gives us reasons to reconsider, among other things, the way early medical genetics was influenced not only by clinical knowledge but also by anthropological thinking.

Author(s): **Alan Bittles and Inez Egerbladh**
Lead author's contact details:
Centre for Human Genetics
Edith Cowan University
100 Joondalup Drive
Perth
WA 6027
Australia
Email: a.bittles@ecu.edu.au

Title: **Historical patterns of consanguineous marriage in Northern Sweden and their influence on the present-day gene pool**

Abstract

Historical data indicate a longstanding suspicion of consanguineous unions in most European populations. Within the Roman Catholic Church this resulted in a general ban on close kin unions that remained in force until 1917, although couples related as first, second, or third cousins could apply for a fee-based Diocesan dispensation to allow consecration of their marriage. Information on cousin marriage was seldom systematically collected in the predominantly Protestant countries, since no comparable consanguinity proscription existed. The Lutheran State Church of Sweden is an important exception to this rule, with detailed information on all marriages routinely collected from the late 17th century onwards. The Demographic DataBase in Umeå University has created digitized copies of the parish record books of the State Lutheran Church dating back to the late 17th century. To determine the historical prevalence of consanguineous marriage in northern Sweden, information on all marriages in the Skellefteå region were abstracted for the period 1720-1899 and extended family pedigrees constructed. Of the 14,639 marriages recorded, 3,043 (20.8%) were between couples related as sixth cousins or closer ($F \geq 0.00006$), with a mean coefficient of inbreeding (α) for the population of 0.00204. Assessed in terms of the cumulative coefficient of inbreeding (*F*), first cousin marriages accounted for 62.7% of total inbreeding in the population. Following changes in Swedish civil law in 1844 which removed the requirement of royal dispensation for first cousin unions, there was a significant increase in their prevalence that was independent of population size. There also was strong evidence that consanguineous marriages were favoured within particular families and sub-populations. The findings of the study are consistent with the patterns of single gene disorders reported for specific communities in the region, and suggest that founder effect, drift and consanguinity all influenced population genetic structure in previous generations. Further detailed investigations of the multiple consanguinity loops that developed through time are in progress.

Author(s): **Soraya De Chadarevian**
Lead author's contact details:
Department of History and Philosophy of Science
University of Cambridge
Current mailing address:
Max Planck Institute for the History of Science
10117 Berlin
Germany
Email: Sd10016@cam.ac.uk

Title: **The Value of Oral History**

Abstract

In my brief introductory remarks to the session on oral history I will point to debates among historians regarding the value of oral history interviews. I will reflect on the status of interviews in respect to other historical sources, on possible pitfalls when working with interviews and on their usefulness for historical work.

Author(s): **Miguel DeArce**
Lead author's contact details:
Department of Genetics
Trinity College
Dublin 2
Ireland
Email: mdearce@tcd.ie

Title: **Brno Revisited**

Abstract

This is a website that enables the user a detailed study of Mendel's Pisum paper (1866), in relation to subsequent criticisms made by Fisher (1936), Edwards (1986), and Novitsky (1995)concerning the excessively good fit of Mendel's data with expectations. 'Excel' spreadsheets produce Montecarlo simulations of all the crossings summarised by Mendel, and display chi-squared calculations for each experiment and its iterations under different expectations. For each of the seven traits studied by Mendel, the simulations assume a binomial distribution of the genotypes with equal probabilities (=0.5) for each allele. Also assumed is the reliability of 'Excel's' random number generating function. A summary page shows global comparisons including all experiments. The suggestion by F. Weiling (1989) that the hypergeometric distribution (as opposed to the binomial) explains the results better is also investigated. Original Flash ™ movies introduce and conclude the presentation. Please visit a preliminary version of the work at the address below.

http://www.tcd.ie/Genetics/staff/Miguel/Brno_Revisited/Index.htm

Author(s): **Peter S. Harper**
Lead author's contact details: Institute of Medical Genetics
Cardiff University
Heath Park
Cardiff
CF144XN
Email: HarperPS@cf.ac.uk

Title: **Interviews with early human cytogeneticists**

Abstract

The founding generation of scientists and clinicians in human and medical genetics, whose work began in the 1950s and 1960s, are now mostly retired and increasingly elderly; some are no longer living. Capturing the memories of these workers, who laid the foundations for modern medical genetics, will form an important part of the history of the field, but the opportunity needs to be taken soon.

As an initial endeavour in this area, a series of audio recordings is being made of key people, principally in Europe, but linking with a comparable initiative underway in America. So far 32 people have been interviewed, of whom 20 were particularly involved in the beginnings of human cytogenetics.

Since the series is currently biased towards the UK, there is a need for the initiative to be extended more widely across Europe and to ensure that more recent areas, such as human molecular genetics, are also documented.

Author(s): **Peter S. Harper**
Lead author's contact details: Institute of Medical Genetics
Cardiff University
Heath Park
Cardiff
CF144XN
Email: HarperPS@cf.ac.uk

Title: **Human Genetics and Lysenkoism in Russia. An Untold Story.**

Abstract

The tragic story of the destruction of genetics in Russia during the years 1936 to 1964 has been fully told from the perspective of basic genetics and agriculture, largely through the books of Russian geneticists who painstakingly documented and published the events, to their own risk and harm.

The history of human genetics in Russia, by contrast, has received relatively little attention, despite its important role in the overall catastrophe. The remarkable work done by Russian workers in human cytogenetics in the late 1930s is largely unrecognised, while the achievements and fate of the Moscow Medical Genetics Institute under Solomon Levit are likewise little known in the West. Also underestimated is the wider role played by human genetics through its conflict with the Lysenkoist and Marxist philosophy of change through social rather than genetic factors, and through the false association of human geneticists with Nazi eugenics by those attempting to destroy them.

Although the length of time since the initial events and the liquidation of many prominent workers will hinder the full documentation of early Russian human genetics, it is of the greatest importance that efforts are made, especially by Russian geneticists, to locate records and to record memories of those involved in this period.

Author(s): **Peter S. Harper and Steve Pritchard**
Lead author's contact details: Institute of Medical Genetics
Cardiff University
Heath Park
Cardiff
CF144XN
Email: HarperPS@cf.ac.uk

Title: **The Human Genetics Historical Library**

Abstract

Monographs and related books form an important part of the historical record for the development of human and medical genetics. Dating mostly from after World War Two, they are of minimal commercial value and are still regarded largely as 'outdated' rather than of historical importance. Many university departmental, as well as personal collections are being dispersed or even destroyed.

This situation gives both the need and the opportunity for creating a specific collection of early human genetics books that can form a resource for workers, whether historians or scientists, studying the field. The Human Genetics Historical Library, founded on the basis of donation of several key individual collections and already exceeding 500 volumes, is curated by Cardiff University Library Service. It forms part of the Special Collections Research Initiative and is monitored by a steering group with external members.

Further donations are welcome and the library is available for consultation. Detailed cataloguing is in progress and it is planned to link this index electronically with those of other libraries (e.g. John Innes Centre, Wellcome Trust) containing large collections relating to genetics, as well as to those in countries whose collections are mainly in languages other than English, to give an extended 'virtual' library, in addition to the specific collection.

Author(s): **William Leeming**
Lead author's contact details:
Faculty of Liberal Studies
Ontario College of Art & Design
100 McCaul Street,
Toronto
Ontario
Canada
M6G 2W3
Email: bleeming@faculty.ocad.ca

Title: ***Inter*national Aspirations and National Differences in Medical Genetics: A Comparative Analysis of Britain and Canada, 1945-1989**

Abstract

As Jonathan Harwood has observed, we 'commonly think of science as quintessentially cosmopolitan, the very model of a classless and *inter*national community bound by shared norms of evidence and argument'. There is nonetheless, he argues, something to be gained in distinguishing those developments which are genuinely international from those which are local and distinctive. This argument is both elaborated and tested using a work-in-progress summary of research on the formation of medical genetics as a service specialism in Britain and Canada. Similarities between British and Canadian medicine in conditions arising from a shared British heritage have given rise to comparable educational programmes, licensing standards, professional bodies, and scientific periodicals – the so-called 'hallmarks of professionalisation'. Yet, in spite of this, the international aspirations surrounding the circulation and institutionalisation of new medical knowledge and practices have evolved in Britain and Canada in noticeably different ways. Whereas, for example, associative strategies among Canadian medical geneticists are most properly characterised as part of a system set up for expansion under the auspices of local professional groupings, service providers and scientists in Britain, with its National Health Service, owe much of their influence and status to a history of strong centralised bureaucracy.

Author(s): **Susan Lindee**
Lead author's contact details:
Department of History and Sociology of Science
University of Pennsylvania
249 S 36th Street
Philadelphia
19104
United States
Email: mlindee@sas.upenn.edu

Title: **Provenance and the pedigree: Victor McKusick's field studies with the Pennsylvania Amish**

Abstract

Provenance, the record of the "ultimate derivation and passage of an item through its various owners," is commonly used to describe the history or pedigree of a painting. It also has a meaning in silviculture, in which it refers explicitly to genetic stock. Provenance, for forestry professionals, is the record of where a seed was taken and of the character of the "mother trees." In this paper, I explore provenance in both senses, as a record of ownership and as a record of genetic stock. The ownership to which I refer is both biological and intellectual. Someone's body yielded every blood sample collected in the vast post-1945 project of human genetic population research in the United States. Every sample belonged to a certain person, and that person's identity was specified in some form in the textual record built around the blood sample. And just as blood came from specific persons, so too did data, evidence, and interpretation. My primary focus is on Victor McKusick's field work with the Pennsylvania Amish in the early 1960s, and especially his studies of a rare form of dwarfism, Ellis-van Creveld Syndrome. The social practices in Amish populations around Lancaster and Mifflin counties in Pennsylvania produced genetic disease, bringing it out into the open, both biologically and culturally. The acceptability of cousin-marriage combined with a closed breeding population to make recessive genetic diseases more common in the offspring of these marriages. Meticulous Amish genealogical records facilitated the research. And the Amish practice of chronicling illnesses of all kinds in newspapers made disease socially visible and easier to track. The cultural specifics of this population seemed to be almost tailored to field research in human genetics. In this paper, I consider how Amish identity and human population genetics converged in the tranquil Pennsylvania countryside, as medical and religious beliefs intersected with the rise of scientifically grounded human genetics at a critical crossroads in the 1960s.

Author(s): **Milan Macek Sr.**
Lead author's contact details: Institute of Biology and Medical Genetics of 2nd Medical Faculty
Laboratory of assisted reproduction and reproductive genetics
Charles University Prague
V Uvalu 84
Prague
15006
Czech Republic
Email: pavel.roubic@lfmotol.cuni.cz

Title: **Medical Genetics in the Czech Republic (1961 — 1980): a model of its development in Eastern Europe**

Abstract

The development of medical genetics in this period was significantly influenced by the political system. The ideological conflict between defenders of Mendelian genetics (B. Sekla) and of the Lysenko/Mitchurin "genetics" (M. Hašek) ended in 1962 by an excuse of M. Hašek to B. Sekla at the public session of Czech Academy of Sciences and by organization of an international congress (1965; Brno) that commemorated Mendel's contribution to modern genetics. This congress refused criminal persecution of famous Mendelian scientists in the former USSR. These important changes, preceding the Prague Spring (1968), enabled foundation of the Cytogenetic Section of Biological Society of the Czechoslovak Academy of Sciences (CSAS; 1962) and Society of Medical Genetics of Czech Medical Society J. E. Purkyně (SMG JEP). Subsequently, state support for the scientific and clinical development in cell genetics, cytogenetics, population genetics, immunogenetics, mutagenesis research, oncogenetics and different fields of clinical genetics has been initiated. Genetic research started to be supported by the Ministry of Health (MH). Its public health impact was expressed by first attempts to organize national network of genetic services and by the first scientific price of the MH (1967) in genetic research plans in cooperation with the Genetic Scientific Committee. This development was supported by the representatives of Czech Academy of Sciences in biological research (M. Hašek), including genetic research in plant and animal genetics, in clinical medicine and pediatrics (J. Houštěk) and by prominent clinicians in Medical Schools and by research workers in Faculties of Natural Sciences and institutes of Ministry of Health. First departments of medical genetics were established in 1961 in Prague and Brno. International cooperation has been conducted not only within former COMECON countries, but also with Western European scientists in annual international cytogenetic symposia, that also provided meeting ground for West- and East German scientists. The abrupt end of Prague Spring (1968) negatively, though temporarily, influenced further promising development. Some of the best scientists emigrated and career promotion of former Communist Party members was politically obstructed. Board members of SMG JEP, who survived political party purges, fulfilled the duty to preserve further clinical and scientific development during the critical post-invasion "normalization" period, both for non-party and/or ex-party members. The board supported actively contacts with Western geneticists in cooperation with the MH to overcome political and bureaucratic obstacles. The most important success during this period was integration of medical genetics into the state system for "Mother and Child Care" as a top priority for the MH. MH created with SMG JEP the "Conception of Medical Genetics" (1980). Regional network of medical genetic services in all regions of our country was based on local departments of

medical genetics, comprising genetic counseling, clinical, cytogenetic and prenatal genetic laboratories, including genetic registries. State financial support, personal, space and laboratory equipment was guaranteed by the state plan. These departments were linked to sub-regional genetic counseling units that provided local access to genetic care and referred patients to specialized genetic laboratories with national services (e.g. in the field of inborn errors of metabolism screening). This strategy, growing interest of clinicians, further international and national cooperation with the Institutes of Czech Academy of Sciences, research institutes of the MH, laboratories of Faculty of Natural Sciences enabled further progressive development of genetics in our country. The main lessons from this period are that despite the negative political/ideological influences, the solidarity of the genetic community, that respected freedom of scientific research, ethical and legal rules of basic human rights, effectively blocked their negative impact. Furthermore, it enabled implementation of medical genetics in the improvement of the health care, prevention and treatment of severe disorders of prenatal and postnatal development and also because of universal positive value of human/medical genetics for the benefit of affected families for present and further generations in any political system.
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Author(s): **Patrick MacLeod**
Lead author's contact details:
Division of Medical Genetics
Department of Pathology
Victoria General Hospital Vancouver Island Health Authority
1 Hospital Way
Victoria B.C.
V8Z 6R5
Canada
Email: pmacleod@caphealth.org

Title: **F. Clarke Fraser and The Birth of Medical Genetics in Canada**

Abstract

The emergence of Medical Genetics as a formal discipline in Canada owes many things to many people. From its inception in the Montreal Children's Hospital in 1950 through to the recognition by the Royal College of Physicians & Surgeons in 1991, Doctor Fraser has been at the forefront in guiding the process.

Doctor Fraser is also credited with the development of the discipline of teratogenetics and a founding member of the Teratology Society. His early post-doctoral research in the Department of Genetics at McGill University continued while he developed the first clinical service in North America. This brought him into contact with families and by default, counselling. By his own admission, nothing learned in medical school prepared him for this. Over the next decade, he explored the emotional, psychological and ethical pressures associated with what we now call the discipline of genetic counselling. He has imparted a vision for this undertaking, which was formally recognized by the American Society of Human Genetics in 1974. For his efforts, he has received many awards, including election to the office of the President of the American Society of Human Genetics at 42, the William Allan Award at 59, and the Order of Canada at 65, and the Prix de Quebec at 79.

Doctor Fraser celebrated his 85th birthday in March 2005 and this presentation is meant to acknowledge his many thoughtful contributions to genetics, medicine, and history.

Author(s): **Thomas Mayer**
Lead author's contact details:
Dept. of History of Medicine
Medical University of Vienna
Währingerstr. 25
A-1090
Vienna
Email: thomas.mayer@meduniwien.ac.at

Title: **The Austrian Ophthalmologist Herwigh Rieger (1898-1986) between Eugenics and Genetics**

Abstract

In my contribution I want to discuss the relation between Genetics and Eugenics in Interwar Austria on the basis of the career of the Austrian ophthamologist Herwigh Rieger (1898-1986) from 1925 until 1955. In 1925 Rieger began to examine genetical issues as a student and assistant of the Austrian Hygienist and Racial Hygienist Heinrich Reichel (1876-1943). Rieger combined his early interest in eugenical issues and his dedication to the german-national wing of the Austrian youth movement (Wandervögel) with the popularization of eugenics as well as his own scientific progress. He held a speech in 1925 in one of Austria's leading Racial Hygiene societies, the Wiener Gesellschaft für Rassenpflege (Rassenhygiene) and published scientific papers in eugenic periodicals. He encouraged Reichel to found a university lecture on Social Hygiene, which became the main academical meeting place for medical scientists interested in Eugenics in Vienna. After Rieger's training at the second opthalmic clinic at the university of Vienna under Karl Lindner he became head of the opthalmic clinic at the German university in Prague in 1940. There he not only published one of his most known papers of a genetically determined syndrome of malformation of eye and teeth (Rieger's syndrome), but also furnished opinions of descent (Abstammungsgutachten) together with the head of the institute of Racial Hygiene in Prague Karl Thums, whom Rieger already knew from Reichel's Vienna lectures. The results of those examinations were published after 1945. The scientific use of this paper and Riegers genetical concepts will be discussed in my contribution.

Author(s): **Søren Nørby**
Lead author's contact details: University of Copenhagen
Rolighedsvej 6
Frederiksberg C
Denmark
DK-1958
Email: SIRN@dadlnet.dk

Title: **Wilhelm Johannsen – father of the genotype/phenotype concepts, founder of genetics in Denmark.**

Abstract

W. Johannsen (1857-1927) was a remarkable scientist with an extraordinary career. Finished school at age 15, graduated in pharmacy, took interest in plant physiology, became research assistant at the Carlsberg Laboratory – incl. studies abroad – and after more or less idle years in a waiting position became associate professor in plant physiology at the Royal Veterinary and Agricultural College in Copenhagen in 1892, full professor in 1903. In 1905 Copenhagen University nominated him to his final assignment as full professor of plant physiology and genetics, without advertising the position. He held his first lectures in genetics in 1903; in 1920 he took charge of the introduction of genetics in the medical curriculum.

Johannsen was internationally known before the end of the 19th century due to his studies on the stimulating effect of ether and chloroform on budding in plants. It was, however, his groundbreaking studies in heredity and variation in barley and beans (1898-1903) that made him widely known as a scientist and earned him a lasting place as one of the main contributors – next to Mendel – to the founding of this new discipline, which William Bateson later named genetics.

Through his demonstration that variation in seed size can be due to environmental influence alone, namely in purebreeding varieties which he termed *pure lines* - in which case attempts to select for offspring with larger or smaller seeds were in vain - Johannsen pointed to the need for distinction between the hereditary constitution of an organism on one side and its appearance/properties on the other. For these he later, in his textbook "Elemente der exakten Erblichkeitslehre" (1909) introduced the terms *genotype* and *phenotype*; distinctions and terms which have since been fundamental in the handling of problems in all fields of genetics. He also coined the catchy term *gene* and – in the 3rd edition (1926) - proposed *allele* as a substitute for the cumbersome term allelomorph.

Johannsen received many honours, was very productive, and a spiritual, humourous and aimiable person as well. The latter phenotypic traits can be observed in a short movie from 1923, which I hope to show.

Author(s): **Tayfun Özçelik and İclal Özçelik**
Lead author's contact details:
Molecular Biology and Genetics
Bilkent University
Science Faculty
Bilkent 06800
Ankara
Turkey
Email: tozcelik@fen.bilkent.edu.tr

Title: **DNArt: A contemporary Sci-Art movement inspired by genetics**

Abstract

Discovery of the structure of the DNA molecule was one of the most significant achievements of the 20th century science. It influenced almost all-basic science fields including medicine and biology, paved the way for the emergence of the biotechnology industry, and most interestingly it became the "Mona Lisa of contemporary arts". Often referred to as gene art, genome art or DNA art this contemporary art movement has become increasingly more prominent during the past decade (Nelkin D, Anker S. The influence of genetics on contemporary art. Nature Reviews Genetics 3:967-970, 2002). We initiated a project that aims to disseminate scientific knowledge to the society through the production of artistic images of selected genetic discoveries by employing traditional Byzantine and Ottoman arts such as ceramic mosaics and quartz İznik chini tiles. For example, "half-chromatid mutation" (Figure 1) symbolically relay emergence of new mutations on the DNA molecule (Özçelik T. Cover art, Nature Genetics, 34: August 2003). It was inspired by the identification of a disease causing MECP2 mutation in a boy with classic Rett syndrome. This mutation was not inherited but instead it occurred postzygotically and therefore is represented in a subset of the cells in the affected individual. Other examples include "transcription" (Figure 2) and "chromatin" (Figure 3). More examples, such as "microchimerism", "naked DNA", and "pedigree" are in the production phase. Our ultimate goal is to complete the production of a novel series of quartz Iznik Chini tiles and mosaics called "The Science Connection – Heritage Line".

Author(s): **Marcus Pembrey**
Lead author's contact details:
Picketts South
Picketts Lane
Redhill
Surrey
RH1 5RG
United Kingdom
Email: M.Pembrey@bristol.ac.uk

Title: **Wellcome Trust History of Twentieth Century Medicine Group Witness Seminars**

Abstract

The Wellcome Trust's History of Twentieth Century Medicine Group (HTCMG) was formed in 1990 and became part of the Academic Unit of the Wellcome Institute for the History of Medicine, University College London in 2000. The Witness Seminar is a specialised form of oral history, where several people associated with a particular set of circumstances or events are invited to come together to discuss, debate, and agree or disagree about their memories, the whole proceedings being recorded. To date the HTCMG has held over 30 such meetings, most of which have been published. I was asked to chair the Witness Seminar on Genetic Testing held on 13 July 2001 and published in 2003. Several other Witness Seminars touch on specific areas of medical genetics and all are downloadable from the website - http://www.ucl.ac.uk/histmed/witnesses.html

I will use my experience of the Genetic Testing Witness Seminar to describe, and comment upon, the process of planning, conducting and editing this particular form of oral history.

Author(s): **Toine Pieters, Stephen Snelders and Frans J. Meijman**

Lead author's contact details:
Department of Metamedica
VU Medical Center
van der Boechorstr str 7
Postbox 7057
1007 MB Amsterdam
Netherlands

Email: a.pieters@bio.vu.nl

Title: **Two centuries of medical thought about heredity and cancer: From morbid constitution and pre-marital advice to cancer genes and genetic counselling**

Abstract

Historians have over the last 10 years been working on revisions of the history of human and medical genetics and of the evolution of ideas about hereditary transmission. Following these revisions it appears that the transition of knowledge regarding heredity and other genetic aspects, within and between scientific, medical, and public spheres, have been astonishingly complex and multi-layered. In medicine a diversity of approaches to heredity were pervasive and influential, not only Mendelism but for example also neo-Lamarckian beliefs in the inheritance of acquired characteristics. Throughout history medical practitioners have been rather pragmatic and eclectic in their ways of looking at inheritance and other genetic aspects of disease.

A research focus on the diversity and fluidity of medical and public debates around heredity opens up new questions about the dynamics of their roles in health care and public health. As yet, we know very little about these dynamics.

In this paper presentation the roles of heredity in coping with cancer, breast cancer in particular, is examined in the period 1805-2005. By disregarding traditional essentialist and reductionist, linear accounts of progression of genetic knowledge I will show how the meaning of the 'potential cancer patient', in the context of the development of a modern disease has undergone several transformations.

Author(s): **Mila Pollock**
Lead author's contact details:
Director of Libraries and Archives
Cold Spring Harbor Laboratory
1 Bungtown Road
Cold Spring Harbor
NY 11724
United States
Email: pollock@cshl.edu

Title: **Talking Genomics**

Abstract

Cold Spring Harbor Laboratory, located in New York, is a non-profit academic research institution whose scientists conduct groundbreaking research in cancer, neurobiology, plant genetics, and bio-informatics. This institution is a crossroads for biological scientists worldwide. The renowned meetings and courses program at Cold Spring Harbor Laboratory attracts more than 8,000 scientists to the laboratory each year.

One of the first meetings to discuss the large-scale sequencing of the human genome, convened at Cold Spring Harbor Laboratory in 1986. Since 1988, genome meetings have taken place at the Laboratory, annually. In April 2003, when the human genome had been completely sequenced, CSHL themed its annual symposium on theMolecular Biology of Homo Sapiens. The CSHL Oral History Group—which includes scientists, an historian, and an archivist—chose to interview twenty-three scientists for the CSHL Oral History Project who attended the symposium. An archivist and an historian working in tandem conducted the majority of these interviews.

Since 2003, bioinformatics scientists, molecular biologists and sequencers have been interviewed during the annual Genome Meetings at CSHL and some scientists who do not attend these meetings have been interviewed off-site about their work in genomics. The interviews involve casual discussions about advances in genome research, the mechanics and politics of the HGP, the ethical considerations of genome research, genome applications and the future of genome research. To date, 47 scientists have been interviewed for our Genome Research Oral History Project.

Each full-length video interview is burned onto a DVD and together with its full text transcript is placed in the CSHL Library's Oral History DVD Collection; all materials can be requested by users. After carefully reviewing the oral history interview transcripts, eleven major themes in genome research were chosen and placed on the CSHL Oral History Collection Website http://library.cshl.edu/OH/mainMovie.html. Selected clips from each narrator's interviews, no longer than three minutes, are placed on the website within these thematic topics. The clips are linked together by an extensive hypertext system and each clip can be cross-referenced and full-text searched.

The poster presents the first stage of our CSHL Oral History Project. It will also explain the second stage of development for the Oral History Project, which is currently underway and includes four major goals:

a) Expand the website's hypertext system and incorporate links from video clips to related documents, photos, articles and catalogue records. This will enable the viewer to gain a comprehensive understanding of the past, present and future of genome research. The Archives is currently undertaking a major digitization initiative to allow a variety of original documents to be accessed via the Genome Research Oral History Project Website.
b) Make abstracts of each narrator's full-text interview accessible online.
c) Interview, in addition to leading scientists, technicians, bench scientists, and post-doctorates involved in genome research.
d) Focus interviews on how eugenics has framed our attitudes and policies concerning the use of social and biological information.

Author(s): **Timothy Powell**
Lead author's contact details:
Senior Archivist
National Cataloguing Unit for the Archives of Contemporary Scientists
University of Bath
Convocation Avenue
Bath
BA2 7AY
United Kingdom
Email: listep@bath.ac.uk

Title: **Human Geneticists and the UK National Cataloguing Unit for the Archives of Contemporary Scientists**

Abstract

This short paper will introduce the work of the UK's National Cataloguing Unit for the Archives of Contemporary Scientists <www.bath.ac.uk/ncuacs>. This Unit was established in 1973 to locate, catalogue and find permanent places of deposit for the archives of distinguished contemporary (that is, post 1945) British scientists, and thus make accessible for research the original source materials for the history of science. It will make reference to the archives of geneticists that the Unit has listed, give a brief overview of the archives of Professor J.H. Renwick, recently received for cataloguing in the Unit's offices, and conclude with an outline of our anticipated continuing collaboration with the Genetics and Medicine Historical Network.

Author(s): **Alan Rushton**
Lead author's contact details:
Department of Pediatrics
Hunterdon Medical Center
2100 Wescott Drive
Flemington
New Jersey 08822
USA
Email: arrdoc@aol.com

Title: **Bateson and the British Doctors 1900-1910**

Abstract

By 1900 British physicians recognized the hereditary nature of many human variations and diseases. They used pedigrees to document family histories, and defined direct, indirect and sex-limited patterns of human heredity. The biologist William Bateson of Cambridge University communicated to many physicians the applicability of Mendel's theory of genetics to their daily concerns about heredity and disease. Physicians from academic centers and rural practices sent him family histories for his analysis: "Was the trait Mendelian?" Bateson learned about the difficulties in working with human family data, while the doctors learned about modern genetics.

Bateson's medical colleagues presented the new ideas on human heredity before diverse medical society meetings and published their genetic findings in both general and specialized medical journals. The usefulness of Mendelian theory to explain the inheritance patterns of many different human disorders became evident by the end of the first decade of the new century.

Author(s): **Jiri Santavy, Vit Orel, Petr Goetz, Frantisek Losan, Vladimir Gregor and Alexandra Oltová**

Lead author's contact details: Department of Medical Genetics and Fetal Medicine
University Hospital
I.P. Pavlova 6
Olomouc
775 20
Czech Republic

Email: santavy@aix.upol.cz

Title: **History of Medical Genetics in the Czech Republic**

Abstract

History of medical genetics in our country has the roots already in teaching scientific animal, plant and breeding and heredity by Professor J. K. Nestler (1783-1841) at the Olomouc University. On his suggestion formulated Abbot F. C. Napp (1792-1867) in 1837 in Brno the physiological research question "what and how is inherited". In 1851 Abbot sent Mendel to study exact science at the Vienna University. Returning to Brno he provided experiments to explain the research question that arose from the communication between breeders and naturalists in Brno thirty years ago.

In Prague professor V. Růžička (1870-1934) introduced teaching of geneticsin the context of man. His pupil B. Sekla (1903- 1987) paid main attention to human genetics. Růžička´s contemporary in Prague, B. Němec (1873-1966), professor of plant physiology, acknowledged in plant cytology, supported his pupil A. Brožek (1882-1934) in his study genetics. On his proposal he could study genetics in USA and was named first professor of genetics in our country. His successor was Professor K. Hrubý (1910-1962) involved in biometrical and cytological research.

The epoch for the enthusiast teaching of genetics with the experimental research in our country was interrupted after the communist's putsch in 1948, when genetics was stigmatised as the reactionary science and substituted with Lysenkoism. Professors Hrubý and Sekla in Prague were not allowed to teach genetics and Křížený in Brno was dismissed from university teaching and later even arrested. The renovation of genetics in the country was connected with rehabilitation of Gregor Mendel.

Author(s): **Julia Sheppard**
Lead author's contact details:
Head of Special Collections
Wellcome Library for the History and Understanding of Medicine
210 Euston Road
London
NW1 2BE
United Kingdom
Email: j.sheppard@wellcome.ac.uk

Title: **Saving the archives of genetics**

Abstract

Historians of genetics are aware of the need to locate, select and preserve relevant materials for future research, but need to consider the implications of their involvement in the activities around this. Before saving and preserving the papers of individual scientists or the records of organisations, it is essential to have clear aims and to appreciate what can realistically be achieved. By failing to address these crucial questions at the beginning of the process much time and effort can be wasted.

There are some key issues that need to be remembered when contemplating undertaking survey work to locate material and when considering the selection and transfer of archives and papers from their point of creation and private ownership to a repository and public access. These include: ownership, authenticity, how pro-active the acquisition process should be, terms of acquisition or purchase, deposit and formal agreements, tax concessions, access arrangements, ethical issues. the physical cost of storing and making material available for research, staffing and stewardship, appraisal, cataloguing and promotion. Recent records of Science Medicine and Technology, especially electronic and born-digital materials, pose special problems when it comes to their transfer and maintenance in a permanent archive. Professional standards need to be adopted from the beginning and an awareness of the costs and time involved.

I will discuss some of these issues and suggest that the business of transferring records should involve the creators of these records as well as archivists and historians.

Author(s): **Michal Simunek**
Lead author's contact details:
Institute of Philosophy and History of Science
Faculty of Science
Charles University Prague
Vinicna 7
Prague
12844
Czech Republic
Email: michal.simunek@post.cz

Title: "*Fortes creantur fortibus et bonis*": Early Reception of Eugenics in the Czech Lands (Bohemia, Moravia, Silesia) 1900-1920

Abstract

Eugenics, as defined by its founder Sir Francis Galton (1822-1911) in the second half of the 19th century, was a program designed to influence the inborn characteristics (or qualities) of the human kind ("race") through planned control. After 1883 it was based on the idea of "*… the science which deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost advantage*"[1].At its core, there was the fundamental belief that nature had not smiled equally on all men and that social reformers could guarantee social progress only by "biological" means. In the neo-Darwinian paradigm it meant eliminating the "weak" and encouraging the birth of the "strong". At its beginning, it was an utopian plan that at the beginning of the 20th century spread worldwide parallel to the development of biology and the amplification of the study of heredity (genetics).

In the Czech case the idea and ideals of eugenics started to gradually penetrate the intellectual circles at the very beginning of the 20th century from different sources. Eugenics was closely linked to issues of many scientific fields and mostly academically active scholars played a major role in that process. "Getting to know" eugenics then usually took the form of both deliberations and clarifications about its theoretical bases and about eugenics as "social genetics" [sociální genetika] or "applied genetics" [aplikovaná genetika] in the form of specific "practical" measures as for example the proposals to revise marriage law. The common and prevailing motive for that can be found in the effort to avoid negative effects of what was seen - parallel to the situation in other industrialised countries of Europe and North America - as "degeneration" and "deterioration", or rather in the efforts to protect the Czech national community from such effects.

The Great War (1914-1918) fundamentally altered and changed the starting points of contemporary Czech eugenics. During this huge military conflict, the need to protect both the quantity and the quality of Czech population, newly defined in more and more hereditarian sense, seemed more pressing than ever. The creation of the Czech Eugenics Society [Česká eugenická společnost; abbreviation ČES] in the second year of the war (1915), which was to remain the most important Czech eugenic forum in the following years, was the first step in the process of institutionalization of eugenics and of improvement in the efficiency of its activities. It was within the framework of the ČES and other allied organizations that all the theoretical debates concerning the form of Czech eugenics in the close future after the end of the war were to take place.

In the very short period of five years between 1915 and 1920 a rough concept of Czech (Czechoslovak) "national" eugenics was developed. Czech eugenics was - after the concept of Galton, Pearson and Davenport - declared to be "national", and thus clearly distinguished

from the German movement of "racial hygiene" [Rassenhygiene] or "generative hygiene" [Fortpflanzungshygiene]. In this concept, two features are typically emphasized: basic research in the field of human heredity, and the constructive role in building of the new Czechoslovak state and the scientific infrastructure after 1918. Both these features are reflected in the demands to undertake an ambitious research (hybridization, vital statistics, family pedigrees etc.) focusing both on hereditary/biological constitution of the population living in Czechoslovakia after 1918, and on all relevant external social factors that could in the eyes of contemporary eugenicists influence this constitution.

[1]Francis GALTON, *Essays in Eugenics*, New York: Garland 1985 (reprint), p. 35.

Author(s): **Stephen Snelders, Frans J. Meijman and Toine Pieters**

Lead author's contact details:
Metamedica
VU Medical Center
van der Boechorststraat 7
1007 MB Amsterdam
Netherlands

Email: s.snelders@vumc.nl

Title: **Heredity, Genetics and Alcoholism in the Netherlands**

Abstract

The proposed paper reports findings of the on-going research project at the Vrije University Medical Centre, Department of Medical Humanities, Amsterdam, on "Heredity, Genetics, and Concepts of Illness and Health in the Netherlands in Modern History". The paper will focus on the period between c. 1860 and the First World War. It will investigate the roles played by notions of heredity and genetics in health care debates and policies, by analysing the case-study of prevention and treatment of alcoholism and alcohol abuse.

The field of alcoholism is a promising subject for the investigation of the evolution of the complex and changing roles of heredity and genetics in Dutch debates and policies. In the framing of a pathological heredity based on different degeneration theories, in an increasing shift of focus from the sick to his/her family as a basis of aetiology at the end of the 19th century, and in the application of scientific theories on genetic transmission in medicine and health care, alcohol abuse and dependence performed a central role. Alcoholism was seen as both cause and consequence of pathological forms of heredity. In the emerging Dutch public health perspective around 1900 alcoholism was considered one of the three major enemies, a position shared with tuberculosis and syphilis. The construction of alcoholism as a major enemy to public health in the Netherlands was given impetus by the rise of the organized temperance movements and the involvement of the medical profession in a variety of new forms of treatment and prevention. An emphasis on the hereditary dimensions of alcoholism could lead to therapeutic pessimism, advocacy of total abstinence as opposed to moderation, and to support for programmes of negative eugenics (such as marriage restriction and other measures against reproduction of hereditary "degenerates"). On the other hand there was a significant optimism among physicians and temperance activists about the possibilities of developing treatment options for alcoholics that historians still have to relate to notions of heredity and genetics. These notions could play a central role in supporting flexible and pragmatic treatment strategies that did not exhibit therapeutic pessimism.

Author(s): **Hubert Soltan and Patrick MacLeod**
Lead author's contact details: Department of Pediatrics (Medical Genetics)
University of Western Ontario
London Ontario
Canada
Email: s.snelders@vumc.nl

Title: **The Early History of Medical Genetics in Canada**

Abstract

A commemorative symposium to mark the 100th anniversary of Mendel's key paper was held in Brno in 1965. At that time, medical genetics in Canada was beginning to grow. This growth was largely stimulated by new techniques which made possible discoveries about the variability of the human karyotype and the clinical significance of this variability. The development of medical genetics in Canada was also possible because of the work of just a very few practitioners who, working in relative isolation in our far-flung country and often on the fringes of mainstream medicine, laid the groundwork for the discipline. One of these was Dr. Clarke Fraser whose remarkable contributions will be discussed in a separate presentation at this Workshop.

In 1965, Dr. Norma Ford Walker was retiring from a 30 year career as a self-taught human geneticist in Toronto whose fascination into the degree of variability displayed by the Dionne quintuplets converted this entomologist into a human geneticist in the 1930's. Her educational legacy was a number of former students who, like Dr. Clarke Fraser's former students in Montreal, were now dispersing across the country's medical faculties to establish the discipline across Canada. One eminent example of this genetic lineage was Dr. James Miller of Vancouver; a product of postgraduate genetic training at both Toronto and Montreal. This small group of Canadian trained geneticists was augmented by several young immigrant paediatrician geneticists and cytogeneticists trained abroad, mainly in the United Kingdom. However, our country's genetic history also goes back to the second quarter of the twentieth century when the indomitable Madge Macklin, while teaching medical students at the University of Western Ontario (1922-1945) attempted to influence the medical establishment to look at disease from a genetic perspective. Through her numerous presentations and publications in American and British medical journals on this topic, as well as on the necessity of genetics education for medical students, she deserved to be numbered among the worldwide pioneers of medical genetics.

The early history of the discipline of medical genetics in the various provinces of Canada and its professional organization has been documented by a group of late 20th century medical geneticists (1). This book elaborates on the contribution of the pioneers mentioned above as well as those of many others. The more recent and more complex history since the molecular era began remains to be written by Canadian geneticists of the 21st century. They would bring a different perspective to the recent history of the discipline and to the Canadian contribution to international co-operative research projects such as the Human Genome Project and participation in specific efforts to localize and characterize several genes of major clinical significance.

1 Medical Genetics in Canada: Essays on the Early History (H.C. Soltan (Ed.))
Graphic Services, The University of Western Ontario, 1992

LIST OF PARTICIPANTS

Gerhard Baader
Institute for the History of Medicine, Charité - Universitätsmedizin Berlin, Klingsorstr. 119, Berlin, 12209, Germany
gerhard.baader@charite.de

Bengt O. Bengtsson
Cell and Organism Biology, Lund University, Sölvegatan 29, Lund, 223 62, Sweden
bengt_olle.bengtsson@cob.lu.se

Alan Bittles
Centre for Human Genetics, Edith Cowan University, 100 Joondalup Drive, Perth, WA 6027, Australia
a.bittles@ecu.edu.au

Jean-Jacques Cassiman
Human Genetics, Center for Human Genetics, Campus Gasthuisberg, Leuven, 3000, Belgium
jean-jacques.cassiman@med.kuleuven.ac.be

Tara Clancy
Department of Medical Genetics, St. Mary's Hospital, Hathersage Road, Manchester, M13 0JH, United Kingdom
tara.clancy@cmmc.nhs.uk

Angus Clarke
Institute of Medical Genetics, University Hospital of Wales, Heath Park, Cardiff, CF14 4XN, United Kingdom
ClarkeAJ@cardiff.ac.uk

Soraya De Chadarevian
Department of History and Philosophy of Science, University of Cambridge, Free School Lane, Cambridge, CB2 3RH, United Kingdom
sd10016@cam.ac.uk

Miguel DeArce
Department of Genetics, Trinity College, Dublin 2, Ireland
mdearce@tcd.ie

John Edwards
Department of Anatomy and Genetics, Oxford University, South Parks Road, Oxford, OX1 3QU, United Kingdom
jheox@ntlworld.com

Peter Farndon
Clinical Genetics Unit, Birmingham Womens Hospital, Metchley Park Road, Birmingham, B91 1JX, United Kingdom
p.a.farndon@bham.ac.uk

Claude Férec
Génétique Moléculaire et épidémiologique, INSERM U613, 46 rue Félix Le Dantec, Brest, 29220, France
claude.ferec@efs.sante.fr

LIST OF PARTICIPANTS

Peter Harper
Institute of Medical Genetics, Cardiff University, Heath Park, Cardiff, CF14 5LU, United Kingdom
HarperPS@cf.ac.uk

Arvid Heiberg
Medical genetics, Rikshospitalet, Forskningsveien 2 B, Oslo, 0027, Norway
arvid.heiberg@rikshospitalet.no

Helen Hughes
Tyn Lon, Rowen, Conwy, LL32 8YT, United Kingdom
helen.hughes@ukonline.co.uk

Maj Hulten
Biological Sciences, University of Warwick, Gibbet Hill, Coventry, CV4 7AL, United Kingdom
M.Hulten@warwick.ac.uk

Jaakko Ignatius
Dept of Clinical Genetics, Oulu University Hospital, P.O. BOX 24, Oulu, 90029, Finland
jaakko.ignatius@duodecim.fi

Johann Heidar Johannsson
Clinical genetics & Cytogenetics, University Hospital LSH, Hringbraut, Reykjavik, 101, Iceland
johannhj@landspitali.is

Julie Korenberg
Pediatrics/Genetics, Cedars-Sinai Medical Center, 8700 Beverly Blvd. (Davis 2069), Los Angeles, CA, 90048, United States
julie.korenberg@cshs.org

Ulf Kristoffersson
Department of Clinical Genetics, University Hospital, Lund, 221 85, Sweden
Ulf.Kristoffersson@klingen.lu.se

William Leeming
Faculty of Liberal Studies, Ontario College of Art & Design, 709 Manning Avenue, Toronto, Ontario, M6G 2W3, Canada
bleeming@faculty.ocad.ca

Susan Lindee
Department of History and Sociology of Science, University of Pennsylvania, 249 S 36th Street, Philadelphia, 19104, United States
mlindee@sas.upenn.edu

Milan Macek Jr.
Institute of Biology and Medical Genetics, Charles University Prague, V Uvalu 84, Prague, 15006, Czech Republic
milan.macek.jr@lfmotol.cuni.cz

LIST OF PARTICIPANTS

Milan Macek Sr.
Institute of Biology and Medical Genetics of 2nd Medical Faculty and of University Hospital Motol, Laboratory of assisted reproduction and reproductive genetics, Charles University Prague, V Uvalu 84, Prague, 15006, Czech Republic
pavel.roubic@lfmotol.cuni.cz

Patrick Macleod
Division of Medical Genetics, Department of Pathology, Victoria General Hospital Vancouver Island Health Authority, 1 Hospital Way, Victoria B.C., V8Z 6R5, Canada
pmacleod@caphealth.org

Thomas Mayer
Dep. of History of Medicine, Medical University of Vienna, Währingerstr. 25, A-1090 Vienna
thomas.mayer@meduniwien.ac.at

Søren Nørby
Rolighedsvej 6, Frederiksberg C, DK-1958, Denmark
SIRN@dadlnet.dk

Tayfun Özçelik
Molecular Biology and Genetics, Bilkent University, Science Faculty, Bilkent 06800, Ankara, Turkey
tozcelik@fen.bilkent.edu.tr

Vitezslav Orel
Brno, Czech Republic

Marcus Pembrey
Institute of Child Health, UCL, London, United Kingdom
M.Pembrey@bristol.ac.uk

Toine Pieters
Department of Metamedica, VU Medical Center, van der Boechorstr. 7, Postbox 7057
1007 MB Amsterdam, Netherlands
a.pieters@bio.vu.nl

Ludmila Pollock
Cold Spring Harbor Laboratory, 1 Bungtown Road, Cold Spring Harbor, NY 11724, United States
pollock@cshl.edu

Timothy Powell
National Cataloguing Unit for the Archives of Contemporary Scientists, University of Bath, Convocation Avenue, Bath, BA2 7AY, United Kingdom
listep@bath.ac.uk

Minna Pöyhönen
Medical Genetics, Family Federation of Finland, P.O.Box 849, Helsinki, FIN-00101, Finland
minna.poyhonen@vaestoliitto.fi

Stefan Pulst
Pediatrics/Genetics, Cedars-Sinai Medical Center, 8700 Beverly Blvd. (Davis 2069), Los Angeles, CA, 90048, United States
pulst@cshs.org

Alan Rushton
Department of Pediatrics, Hunterdon Medical Center, 2100 Wescott Drive, Flemington, New Jersey 08822, United States
arrdoc@aol.com

Riitta Salonen
Dept. of Medical Genetics, Vaestoliitto, Kalevankatu 16, POB 849, Helsinki, 00101, Finland
riitta.salonen@vaestoliitto.fi

Jiri Santavy
Department of Medical Genetics and Fetal Medicine, University Hospital, I.P. Pavlova 6, Olomouc, 775 20, Czech Republic
santavy@aix.upol.cz

Helga Satzinger
Wellcome Trust Centre for the History of Medicine at UCL, 210 Euston Rd., London, NW1 2BE, United Kingdom
h.satzinger@ucl.ac.uk

Marianne Schwartz
Clinical genetics, Rigshospitalet, Blegdamsvej 9, Copenhagen, 2100, Denmark
schwartz@rh.hosp.dk

Jorge Sequeiros
UnIGENe, IBMC, Rua do Campo Alegre, 823, Porto, 4150-180, Portugal
jsequeir@ibmc.up.pt

Julia Sheppard
Head of Special Collections, Wellcome Library for the History and Understanding of Medicine, 210 Euston Road, London, NW1 2BE, United Kingdom
j.sheppard@wellcome.ac.uk

Michal Simunek
Institute of Philosophy and History of Science, Faculty of Science, Charles University Prague, Vinicna 7, Prague, 12844, Czech Republic
michal.simunek@post.cz

Arabella Smith
Department of Cytogenetics, Children's Hospital at Westmead, Hawkesbury Road, Sydney, 2145, Australia
ellies@chw.edu.au

LIST OF PARTICIPANTS

Stephen Snelders
Metamedica, VU Medical Center, van der Boechorststraat 7, 1007 MB Amsterdam, Netherlands
s.snelders@vumc.nl

Alda Sousa
UnIGENe, IBMC, Rua do Campo Alegre, 823, Porto, 4150-180, Portugal
absousa@icbas.up.pt

Stefan Srsen
Medical Genetics, Jessenius University School of Medicine, Zaborskeho 2, Martin, 03645, Slovakia
hedviga.krausova@aero.cz

Klara Srsnova
Medical Genetics, Jessenius University School of Medicine, Zaborskeho 2, Martin, 03645, Slovakia
hedviga.krausova@aero.cz

Flo Ticehurst
Wales Gene Park, Cardiff University, Medicentre, Heath Park, Cardiff, CF14 4UJ, United Kingdom
ticehurstf@cf.ac.uk

Carina Wallgren-Pettersson
Department of Medical Genetics, Folkhälsan and University of Helsinki, P.O.Box 211, Helsinki, 00251, Finland
carina.wallgren@helsinki.fi

Christos Yapijakis
Department of Neurology, University of Athens Medical School, Vas Sophias 74, Athens, 11528, Greece
cyapijakis_ua_gr@yahoo.com

Gilardo Zafra
Department of Genetics, Hospital Espanol, Ejercito Nacional 613-19, Mexico, 11520, Mexico
gilzafra@redinternet.com.mx

Adriana Zatterale
Servizio di Genetica, ASL NA 1, v. Jannelli 190, Naples, 80131, Italy
genetna@tin.it

Genetics and Medicine Historical Network

This international network was established in 2002 to encourage historical activities relating to genetics and medicine, to promote the presentation of records and other material and to link those interested, whether geneticists, historians or others. Current activities include:

- A website www.genmedhist.net
- An electronic newsletter to keep members in touch
- Regular workshops and historical sessions at broader meetings
- The Human Genetics historical library of books in the field
- Archiving of scientific records of key workers in human and medical genetics
- An oral history programme of interviews with retired and older human geneticists
- A series of peer reviewed historical articles in the journal Human Genetics
- Further details can be obtained from Audrey Budding, budding@cf.ac.uk