European Society of Human Genetics

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The Society's Administrative Office
ESHG c/o Vienna Medical Academy
Alserstrasse 4, 1090 Vienna, Austria
Tel: +43 1 405 13 83 20
Fax: +43 1 405 13 83 23
Website: www.eshg.org
Email Inquiries: office@eshg.org
Membership Inquiries: membership@eshg.org
Online Access EJHG: http://members.eshg.org

ESGH welcomes the new President

Prof. Dr. Andres Metspalu

Andres Metspalu is Professor of Biotechnology at University of Tartu and Estonian Biocentre, Estonia. He is founder and scientific advisor of the Estonian Genome Project (www.geenivaramu.ee) and again since 2004 a member of the Management Board of Estonian Genome Project. Also, he is head of the Molecular Diagnostics Centre at Tartu University Hospital (www.dnatest.med.ee) and founder and Chairman of the Board of Asper Biotech Ltd. (www.asperbio.com), Tartu, Estonia and P3G consortium of biobanks in Canada (www.p3g-consortium.org). He is a council member of the Scientific Competence of the Ministry of Education and Research of Estonia. He is member of the American Society of Human Genetics (ASHG), member of The Human Genome Organization (HUGO), editorial board member of the journals "Clinical Genetics" and "Heredity Cancer in Clinical Practice", member of the European Society of Human Genetics (ESHG), since 2000 a board member, since 2005 President and Executive Board Member.

He has published more than 60 articles and chapters in peer review journals and has supervised 8 completed Ph.D. thesis (www.biotech.ebc.ee).
He has received his M.D. at the University of Tartu, Estonia, in 1976 and Ph.D. on Molecular Biology in 1979. 1981-1982 he was guest scientist at Columbia University and Yale University. He received fellowships from FEBS, EMBO, DAAD, HUGO and he worked at MPI of Molecular Genetics in Berlin, EMBL in Heidelberg, University of Tampere and University of Hamburg. 1993-1994 he was guest professor at Baylor College of Medicine, Houston, USA, working on micro arrays with Dr. Tom Caskey and he was granted a guest scientist position at WHO International Agency of Research on Cancer for the year 2000 in Lyon, France.
Andres Metspalu has received the Soviet Estonian Scientific Award (1980) and Estonian Scientific Award in Medicine (2002). He was nominated "Man of the Year 1999" by the journal "Loop" in Estonia. Also, he received the Order of The Red Cross (III) from the Estonian President in 2001. 2002 he received the Prix de la Garantie Medicale et Chirurgicale and 2003 L'Ordre des Palmes Académiques Chevalier from the Republic of France.

Tartu University
Institute of Molecular and Cell Biology
Department of Biotechnology
23 Riia Street, Tartu, 51010, Estonia
Tel: +(372) 7 375 029, Fax: +(372) 7 420 286
E-mail: Andres@ebc.ee, Web: www.biotech.ebc.ee

New Board Members were elected:

Françoise Clerget-Darpoux, MD

Françoise Clerget-Darpoux has a double background in mathematics and genetics. She is the head of an INSERM department (the French National Institute for Health and Medical Research). Her research group aims at developing methods for the study of multi-factorial diseases, taking into account specific population structures such as consanguineous or founder populations. It benefits from international recognition. Dr. Clerget-Darpoux is one of the pioneers of advocating and designing candidate gene strategy for multi-factorial diseases. She is past president of the International Genetic Epidemiology Society (1998) from which she received a Leadership Award. She focuses on neurological disorders and auto-immune diseases. Through 8 years, she has co-ordinated a French national network for the study of Alzheimer disease and a north-south international network on celiac disease. She has published over 200 reviewed scientific articles and has served on numerous advisory and editorial boards.

Dr. Clerget-Darpoux is responsible for the only Master in Statistical Genetics in France (University Paris XI) and she was external examiner for the Sheffield Master of Genetic Epidemiology in UK for four years. Her assignment in the Scientific Committee of ESHG just ended and she is Associate Editor for the section of Statistical Genetics of the EJHG.

Professor Vaidutis Kučinskas, PhD., Dr.Habil

Professor Vaidutis Kučinskas is professor for Human Genetics at Vilnius University, Lithuania, and chairperson of the Department of Human and Medical Genetics at the Faculty of Medicine of Vilnius University (http://www.genetica-humana.lt/VU/engl/personal/Kucinskas-en.htm). At the same time he holds the position as Director of the Center for Medical Genetics at Vilnius University Hospital.

Vaidutis Kučinskas completed his training in genetics (1970) and mathematics (1982) at Vilnius University and, later on, at the Centre of Medical Genetics of the Medical Academy of Sciences in Moscow (1974 – Ph.D., 1987- Doctor Habilitatus).

After Lithuania regained independence he entered a new era of Human Genetics and Genomics. Starting 1992, he worked as a guest scientist at the NCI NIH (USA), in 1993 at Umea University (Sweden) and later he was guest professor of the Royal Society at the University College London (UK, 1996), in 1996 of the National Research Council (Italy), in 2002 at National Yang Ming University (Taiwan, R.O.C.).

At a national level he is an active member in various scientific and health care institutions: he is consultant for medical genetics at the Ministry of Health (Lithuania), member of the National Committee on Bioethics, president of the Lithuanian Society of Human Genetics, member of the Lithuanian Academy of Sciences, member of the Lithuanian Science Council, also a member of various councils of the Faculty of Medicine (Vilnius University), Research Institute of Mathematics and Informatics, Institute of Oncology and Vilnius University Hospital.

At a European level, V.Kučinskas also works as a research expert and an expert on bio-ethics and actively participates in the EC research FP4, FP5 and FP6 programs.

Vaidutis Kučinskas has published over 400 scientific reviewed articles (in Lithuanian, Russian, German and English). He is author of three textbooks in Genetics and co-author of three textbooks dealing with Genetics. In 2004 he summarized his research on Lithuanian population in monography “Genome Diversity: Lithuanians in Europe” (287p.). The textbook “Genetics”, 2001, by V.Kučinskas was awarded as best textbook in biomedical sciences in Lithuania in 2003. 2002-2003 he was awarded the highest degree Fellowship of the Government of the Republic of Lithuania.

At present, an urgent need emerges for the leading Human Geneticists to face Central and East Europe and in this context Prof. V.Kučinska’s strives to harmonize medical genetics training (residency) in EU. His efforts for a more formal recognition of the non-medical laboratory experts in medical genetics and his active participation in the development of genetic education programs for non-genetic physicians will be beneficial for Europe.

Silke Sperling, MD, PhD

Dr. Silke Sperling MD / PhD in Cardiac Physiology studied medicine from 1991 up to her full medical license in 1997. During her education she moved from Berlin to New York, San Diego, Chicago and Rochester. Afterwards she worked as a MD at the German Heart Center of Berlin for one and a half years.

In 1999 Dr. Sperling began her postdoctoral research at the department of Prof. Dr. Lehrach at the Max Planck Institute for Molecular Genetics and there she became head of the research group " Cardiovascular Genetics" in 2001.

Currently she specializes in the research of Congenital Heart Diseases (CHD) which are the most common birth defects in humans.

She investigates a broader range of disease-associated genes on the genomic, transcriptional and protein level in humans and mice in order to study the function of these genes during cardiac development. One of her main interests focuses on the global molecular and bio-informatical analysis of transcriptomes, aiming to gain further insights on the transcriptional regulation process. In addition to these efforts, she has established a cardiovascular genetic database for storage and analysis of various cardiac malformation phenotypes and their genetic data, obtained throughout her studies. Motivated by this database, she developed a generic database front-end with embedded knowledge discovery and analysis features, named d-matrix.

In 2004 Dr. Sperling became member of the FANTOM Consortium and lecturer at the Free University of Berlin. As a work package co-ordinator she is one of the initial scientists of the EU FP6, Integrated Project "Heart Repair" (2005- 2009).

Prague 2005

Prague Conference

ESHG Membership Booth

Exhibition

Local Musicians

Presentation of the ESHG award to Professor Giovanni Romeo

ESHG Young Scientists Awardees

ESHG Membership Meeting in Prague

The ESHG Membership meeting was held during the ESHG Conference in Prague, Sunday, 8th May 2005, in the Prague Congress Center. ESHG has about 1000 members, however, not more than 100 were present in the meeting, as usual.

ESHG President Elect , Andres Metspalu, chaired the meeting.

The Society's activities were briefly reviewed. As always, the most important activity is the annual European Human Genetics Conference.

The Committees' activity reports were published in the Newsletter. In addition, Segolene Ayme, Chair of Public and Professional Policy Committee (PPPC), wanted to discuss future plans of PPPC with the membership. PPPC is to organize workshops on the following topics:

- 2006: Patenting of genetic invention: societal issues
- 2007: Transition from research to clinical practice
- 2008: Behavioral genetics

This plan was approved by the membership.

The Treasurer, Professor Andrew Read, gave a financial report for 2004. As financial results of some previous conferences had been positive, the Board suggested that, in addition to funding the activities of the Society, the money should be used for future fellowships. The financial report and the suggestion were accepted, and so was Professor Read's proposal for the budget 2006.

Members leaving the Board are Stylianos Antonarakis, Lina Florentin-Arar and Shirley Hodgson. They were thanked for their work for the Society. Also, Vice-President Veronica van Heyningen was thanked for her valuable contribution.

There were one proposal for President-Elect and three proposals for new Board members. Thus, no voting was necessary. John Burn was elected President-Elect and Francoise Clerget-Darpoux, Vaidutis Kucinskas and Silke Sperling as members of the Board for 2005-2010.

The revised Statutes of ESHG had been distributed to the members by electronic mail. Deputy Secretary General Thomas Meitinger presented the 3 items which had been rephrased by the Board. The membership accepted. However, the revised Statutes will still have to undergo electronic ballot voting by the membership. Old versions of the Statutes can be found on the ESHG web-site.

Second International Workshop on Genetics, Medicine and History May 11-12, 2005 Brno, Czech Republic

A total of 52 people from 20 countries took part in this workshop, held in the historic surroundings of Gregor Mendel's St Thomas Abbey in Brno. The meeting was made possible by the support of Wellcome Trust and it was also supported by the Wales Gene Park, with organisational help from the European Society for Human Genetics, whose annual congress had been held in Prague immediately before the workshop.

Photographs from the workshop will be placed on the Genetics and Medicine Historical Workshop web site, (genmedhist.net).

The theme of the meeting was 'preserving the history of human genetics' and the first day was devoted to this topic. Julia Sheppard (head of Special Collections, Wellcome Trust) opened the workshop with a highly informative talk on 'saving the archives of genetics', in which she outlined the key issues to be addressed and the steps to be taken if comprehensive and effective archives are to be achieved for human genetics. She was followed by Tim Powell, senior archivist at the Bath University National Cataloguing Unit for the Archives of Contemporary Scientists, who discussed the archives of human geneticists already involving this unit, notably the recently acquired and extensive records of Professor James Renwick. The papers were followed by discussion of other countries' experience and how international co-operation might help to ensure a more comprehensive archive.

A brief presentation by Alan Bittles (Perth, Australia) showed how human genetics research could utilise wider archives, in this case Swedish Lutheran church records for studies of intermarriages. Finally, Peter Harper (Cardiff) with Steve Pritchard, mentioned the recently established Human Genetics Historical Library, involving Cardiff University Library Special Collections, and based on donations and collections from genetics units that would otherwise been lost.

The second session moved to the field of oral history. In a discussion led by Soraya de Chadarevian (department of History and Philosophy of Science, Cambridge and Max Planck Institute for History of Science, Berlin) both the importance of oral history and its potential pitfalls were outlined, as well as the urgent need for undertaking this in the case of human genetics, where many of the founding workers are still living, though now very elderly.

Mila Pollock (Cold Spring Harbor Laboratory, USA) presented the extensive range of interviews based on workers visiting this laboratory, one of the key world centres for genetics research, where a systematic programme is underway for both an oral and written record of the field. From the UK, Marcus Pembrey gave his experience of chairing the witness seminar on genetic testing, organised by the Wellcome Trust History of 20th Century Medicine Group, while Peter Harper described a pilot series of interviews with early human cytogeneticists, hopefully to form part of a more extensive study.

At the end of this session Tayfun and Iclal Ozcelik (Ankara) presented a series of remarkable artistic creations where gene structures were translated into the forms of classical Turkish art.

Day Two opened with a session on early pioneers and early concepts in human genetics. Alan Rushton (New Jersey) showed how William Bateson, the founder of British genetics, interacted extensively with clinicians in developing his ideas, so that human genetics formed a key part of the new field from the beginning. Soren Norby (Copenhagen) gave an account of the life and links to human genetics of Wilhelm Johanssen, the founder of genetics in Denmark, while Bent-Olle Bengtsson (Lund) described a previously unrecognised Swedish book on heredity and medicine from 1879.

In presentations from the Netherlands, Toine Pieters (Amsterdam) showed how ideas on heredity and cancer had fluctuated over the past 200 years, with phases where first heredity, and then environment were regarded as predominant, while Stephen Snelders showed how comparable changes had occurred in the field of alcoholism.

Session 4, on human genetics, eugenics and Lysenkoism, with contributions from Finland (Jaakko Ignatius) Austria (Tomas Meyer) and the Czech Republic, produced, as expected, a lively discussion and could have filled considerably more time. The session was especially interesting in the local context with
presentations from the Czech Republic by Michal Simunek on eugenics and by Milan Macek Sr, Jiri Santavy and colleagues on the effects of the Lysenko period. It was clear that the legacy of these momentous episodes remains painfully real and that the history of Lysenkoism in relation to human and medical genetics has so far been largely undocumented. No Russian workers were able to attend the workshop but contacts with both historians and geneticists in Russia have been made which should allow this area to be explored further.

In the final session on historical aspects of medical genetics, Susan Lindee (Philadelphia) used the genetic research of Victor McKusick on the Pennsylvania Amish to explore how the beliefs and society of this unique population interacted with modern medical genetics, often in unexpected ways. Presentations by William Leeming (Toronto) and Patrick Macleod (Vancouver) illustrated the evolution and particular features of medical genetics services in Canada and the key role of some of its pioneers over the past 60 years.
The closing discussion looked ahead to possibilities for future workshops, their location and funding support, and also debated how wider historical activities in the field might best be encouraged and co-ordinated. There was general support and enthusiasm expressed for such developments to continue on both sides of the Atlantic, the most likely scenario being a further workshop in two years, with specific shorter sessions forming part of other meetings.

In conclusion this proved a most valuable and stimulating meeting, which brought together historians and interested geneticists from numerous countries, many of whom would not have had the chance to meet otherwise. There was notable enthusiasm for future collaboration and a recognition that both historians and geneticists have key roles to play in documenting the history of this important field. The interactive nature of the workshop was greatly helped by the unique setting of Mendel's beautifully restored abbey and by the informative tours of the Abbey, its library and the Mendel exhibition that were arranged by the expert staff of the Mendel Center. The Programme Committee would like to thank all those whose hard work made possible such a worthwhile and pleasurable workshop.

Peter S. Harper, on behalf of the Programme Committee
University Research Professor in Human Genetics
Institute of Medical Genetics
Cardiff University
Wales, UK

News Information 2005

Peter S. Harper receives the US March of Dimes Lifetime Achievement Award, March 2005

Founded in 1938, the March of Dimes is a USA national voluntary health agency whose mission it is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. The agency funds programs of research, community services, education, and advocacy to save babies. The March of Dimes/Colonel Harland Sanders Award (established in 1986) is given annually to an individual whose lifetime body of research and education had made a significant contribution to the genetic sciences. In March 18 of this year, Peter Harper, a long time Professor of Medical Genetics at Cardiff University in the United Kingdom, received the 2005 March of Dimes/Colonel Harland Sanders Award for lifetime achievement in the field of genetics. Professor Harper is the first European recipient of the prestigious award.
The award was presented to Professor Harper at the Annual Clinical Genetics Meeting of the American College of Medical Genetics in Grapevine (Dallas), Texas, by the President of the College, Dr. Charles Epstein. Michael Katz, M.D., Senior Vice President for Research and Global Programs of the March of Dimes, presided over the ceremony.

ESHG Newsletter is happy to publish below the speech Professor Harper gave on that occasion.

THE ATLANTIC - BRIDGE OR CHASM?

It is both a great honour and a great pleasure to receive this award today.

A great honour, when I look at the others who have received the award over the past 20 years, most of whom have for long been heroes of mine. It is especially an honour when I see that I am the first European to receive the award.
It is a great pleasure too, for several reasons. First the March of Dimes itself. My associations go back to 1969 and the Birth Defects Conferences in Baltimore. I have happy memories of preparing cases for these while a fellow with Victor McKusick, and I believe that I have a complete set of the ‚blue volumes', that are now part of medical genetics history.
It is a particular pleasure to receive the award at this meeting, where I have met many old friends, and especially to receive it from your President Charles Epstein, for whom I and others across Europe have the utmost respect, both for his achievements and for his personal example.
At this point I might well sit down, leaving you with the feeling that all is well between Europe and America, and that we, in the human and medical genetics community, need to do no more than we have done in the years up to now. But I think I would be wrong to do this, and perhaps those of you who know me well will not be surprised to hear me strike a questioning note. Some of you will also know that for nearly three years I have not visited the United States, in protest against your Government's international policies, though I have to say that in some ways those of my own government have been little better.

Peter S. Harper

That I am here today is in part on account of the immense respect I feel for the President of your College and for the American medical genetics community, but especially because I see this award as part of a bridge between America and Europe, a bridge that we must all work hard to strengthen, as I shall try to point out during the next few minutes.
So is the Atlantic a bridge or a chasm? For most of my life it has been a bridge; I was brought up during and after World War Two, then living with the threat of Soviet Russia, and later made strong links resulting from two very happy years living and working in Baltimore. The Atlantic was indeed a bridge for Europeans.

But now I and many other Europeans begin to see it differently and to fear that a widening divide between Europe and America might turn into a chasm, an unnatural separation, imposed largely from outside, yet still affecting our scientific and medical communities deeply.
So what can we do to bridge and to heal this divide, and to stop it widening further, as I fear it surely will if we do nothing? Here I give just a few personal suggestions, though I am well aware that I am today largely preaching to the converted. Perhaps some of you may say that our own individual efforts can have little effect when pitted against powerful external forces, political and other, but I firmly reject this. I have been involved in a series of battles over the years against what were said to be unstoppable political or commercial interests, and I am convinced that our own efforts as individual people can indeed have a powerful influence.

So here are just a few suggestions:

First, our Societies, Colleges and other institutions can have a major effect and I think that they are under used as bridges in both Europe and America. I see your award today to a European as sending a strong and positive message.

I know that many Americans value the considerable European attendance at the annual American Society for Human Genetics meeting and it would not surprise me if this American College meeting likewise will interest clinical geneticists from Europe. We come both because of the quality of the meetings and also so that we can benefit from the international links.

But why is this not reciprocated to a comparable extent? Language is rarely a barrier, nor do I think is quality, as those of you who do come can attest; is there perhaps an increasing tendency for Americans to be content to remain in America for meetings? If so, we are all losers for this. And if large meetings seem at times unproductive, what about the many smaller and more specialised conferences and workshops held across Europe?

On a smaller scale, international collaborations are a key way for strengthening the bridge across the Atlantic. Many exist, and those involved all recognise their value. But there could be many more, and I have listed some of their advantages here. The importance of well defined and stable populations is a great advantage in Europe, while for applied research and the development of clinical services, Europe's systems of universal health care are a major benefit. There are many such projects that would be difficult to achieve without a European link and many more where this would enhance the value of the work. This is especially so now that so much research is funded on a Europe-wide basis by the European Union.

Individual exchanges are a most powerful bond and, sadly, one which I feel has diminished considerably in recent years, partly because our training systems, at least in the UK, have become so much more rigid. I wonder how many of you here, whether clinical geneticists or laboratory scientists, have ever done a Fellowship or institutional exchange in Europe? Fewer, I suspect, than 30 years ago. Yet there is no substitute for the immensely powerful effect that living and working in an other country - any other country - has on one's understanding of how others live and think, especially if this is undertaken when one is young.

Finally, at a personal level, it is impossible to dehumanise or demonise a people or country, as politicians too often wish us to do, if we have lived there and made personal and family friends as a result. Again, this is especially powerful when one is young, and I and my own family find that many of these friendships are as strong now as when they were first forged 35 years ago.

So, in conclusion, will the Atlantic prove to be a strong bridge or become a chasm? If we do nothing, I fear the latter may be the case. But fortunately there is much that we can do, both as individuals and collectively.

We shall all gain by actively strengthening these links, though what we do will vary for each of us. I see your award today as a vital link in this bridge, and this is why I am both deeply honoured and very happy to be here today to accept it.

ESHG remembers a grand lady

Margareta Mikkelsen died in her home on June 28, 2004, at the age of 80, after several years of a severe malignant disease.
We honour her as a distinguished member of the ESHG. She was an ESHG Board member and President in 1993. She chaired the successful 24th meeting of the ESHG in 1992 in Elsinore
Margareta Mikkelsen became known as an outstanding Danish scientist, however, was born in Germany in 1923 and baptised Irmtraud Elvira Anna Margareta Wieser
At age 23 she was married to a Dane and moved to Denmark in 1947. From then on she used the Margareta as her first name.
Margareta grew up in Berlin and Hamburg in pre-war and war-time Germany. She began her medical studies during the war and graduated from Copenhagen University in 1955.
For many years she did not speak about her life in Germany, but in later years she gave interviews to the press revealing her experiences of the horrors of war, which included attending wounded soldiers from the east front in a military hospital.
In 1959 she got a position as a research assistant at the University Institute of Medical Genetics in Copenhagen. Here she received training in medical genetics and started to build a cytogenetic laboratory together with Anders Frøland. From then on, the focus of her research interests was Down syndrome and she submitted her thesis (DMSci) on Down syndrome in 1967. Her early work concentrated on familial forms of Down syndrome and soon she got contact with prominent European cytogeneticists.
In 1968 she moved to the newly founded John F Kennedy Institute, Glostrup, where she got a position as director of the department of medical genetics. Here she built an internationally renowned research and diagnostic cytogenetic laboratory. Her work on Down syndrome was internationally highly respected. Furthermore, patients and parents found in her a compassionate doctor with time and patience to listen and give advice.

She was a leading figure in Denmark, building up clinical genetics including prenatal diagnosis and was the mentor of a whole generation of medical geneticists. Also, she was always aware of the ethical and societal aspects of genetics and she had important public positions in councils, boards and committees.

Her international network brought her to Sri Lanka where she helped setting up a laboratory together with Prof. Soysa with whom she published a paper on a Sri Lanka family with the fragile X syndrome.

Margareta had extensive European collaboration e.g. on prenatal diagnosis and she was an editorial advisor for a number of scientific journals. She also encouraged young researchers from Eastern Europe and became an honorary member of the Hungarian and Yugoslavian Medical Genetics Societies.

She received many prizes, for instance the NOVO prize in 1978 and the Gold medal from the Danish Royal Academy of Sciences in 1994. Official Denmark honoured her with the Knight First Class of the Order of Dannebrog.
Even long after her retirement she was active in research in 1993 and kept a small office at the Kennedy institute until illness constrained her active life. Only a month before her death she became an honorary member of the German Society for Human Genetics with a ceremony held at the Kennedy institute.
By that time a review of the literature revealed a production of 176 international publications. One of her last papers appeared in the Lancet and described the risk of leukaemia and solid tumours in Down syndrome individuals.

She was a remarkable person with great generosity towards friends, colleagues and employees.
Many of us not only got professional advice but also benefited from her honest and real interest in people. She was the supervisor on a number of theses and PhD degrees, and she used to call us, the students, her “genetic children”. We will always keep the memory of a great scientist and a warm hearted human being.

Karen Brondum-Nielsen, MD, DMSci,
Director
Kennedy Institute- National Eye Clinic
Glostrup, Denmark

Science & Education

The GenEd Project: Improving non-genetics health professionals' understanding of genetic testing

June 2005 was the end of the GenEd project, co-ordinated by Rodney Harris and Caroline Benjamin in Manchester and involving partners from France (Claire Julian-Reynier), Germany (Irma Nippert and Jörg Schmidtke), Netherlands (Leo ten Kate), Sweden (Ulf Kristoffersson) and the UK (Hilary Harris). Observer countries were Greece (Lina Florentin-Arar), Hungary (György Kosztolányi), Italy (Giovanni Neri), Lithuania (Vaidutis Kucinskas), Poland (Jacek Zaremba) and Spain (Maria Ramos-Arroyo). It was funded as an Accompanying Measure under FP5 GA10 Public Health and Health Services Research activity from 2001-5.

Previous research has shown that Clinical/Medical Genetics Services exist in many, but not all, countries of the European Union. The accessibility of these services to individuals and families was found to be different due to geographical and financial constraints(1, 2). In contrast, the GenEd project focused on those health professionals who were the most likely to be approached first by an individual or family with a genetic concern.

The main objectives of the project were to:

- start a collaborative European genetics education initiative between genetics specialists, consumers and members of non-genetic health professions;
- assess priority needs for genetics education;
- increase primary care providers' and non-genetics specialists' understanding of genetic testing and to raise their awareness of consumer issues in the provision of genetic tests;
- found the empirical base for a human genetics educational model that can easily be adopted by EU member states and candidate countries where the provision of genetic services is still in its infancy.

The project had two phases:

Phase 1 –To ascertain the amount of genetic education in health professional curricula from the responsible organisations.

Phase 2 – To undertake a postal survey of four 'primary care' health professional groups (paediatricians, obstetricians & gynaecologists, general practitioners and midwives) where appropriate in each country. This survey contained a set of core questions relating to current practice, current use of genetic information in practice, perception of personal educational need and awareness of genetic issues in the respondent's own practice. Personal contacts have been made by the partners in each country with health professional organisations, consumer groups and clinical genetics specialists in the hope of fostering further genetic educational initiatives based on the results of phase 2.

Phase 1 found a plethora of organisations responsible for setting and assessing the level of genetic knowledge required by primary care health professionals. There was evidence that genetics in curricula is very limited at undergraduate level, and that what genetics is present is mainly scientific and molecular genetics rather than clinical genetics as applied to health and illness. It is sometimes difficult to identify genetic content in the curricula as often the curricula differs between institutions and also the terms clinical and medical genetics are not explicitly stated. Many countries also do not require genetic knowledge for specialist training. It is likely that those practitioners who are the first point of contact for patients with a genetic concern may have had very little training/education in genetic conditions or the contribution of genetic factors to health and disease. The genetics content explicit in curricula was more often found in post-graduate or specialist training than undergraduate or continuing professional development. As most practising medical doctors qualified before the new advances in genetic technology as applied to healthcare it is particularly relevant that continuing professional education resources in genetics were deficient in most countries. Due to the multiplicity of organisations involved in the provision of genetic education, changing professional education is likely to be challenging, although it was apparent in some countries (France, Germany and the UK) that the Clinical Genetics Professional National Societies had published core competencies in genetic knowledge and skills(3).

Information from the 4,707 respondents in Phase 2 (41% response rate) suggests that many health professionals have received limited training in genetics, with 13.3% receiving none (38% in France as against 4% in the Netherlands). The specialty group with the least training were General Practitioners with 19.3%. Many respondents stated they were not confident performing genetic tasks and only 26% felt confident or very confident in identifying the risk in a recessive pedigree. However 26% stated that genetics forms an element of a case more than once a week. Responses to clinical scenarios demonstrated wide variability between countries over offers of genetic testing and attitudes to the dissemination of information.

The Educational Priority topics differed between countries and between specialty groups. There was consistency in the ranking of priority educational topics for the Obstetricians & Gynaecologists and Paediatricians – the highest ranking being Basic Genetics/Congenital Malformations. However, the GPs preferences were found to be different – the highest ranking being Genetics of Common Diseases.

These results have shown that there is an urgent need to ensure that all Health Professionals are aware of

the impact that genetic technology has upon health and disease. The ability to react appropriately to the concerns of patients affected or at risk of genetic influences to health is important to ensure equality of care across Europe. In the UK this has been acknowledged by the Government with the introduction of the National Centre for Genetics Education acting as a focal point for new teaching initiatives and research.

In the USA the organisation NCHPEG (National Coalition of Health Professional Education in Genetics), again supported by Federal Grant aid provides many excellent teaching initiatives. The 6th Framework Network of Excellence EUROGENTEST which is primarily motivated to improve the use and understanding of genetic tests has a work programme which involves both patient and health professional education.

The GenEd group aims in the future:

- To gain acknowledgement that many of the Health Professionals surveyed have received no or limited genetic education and that this is a major concern for the EC if it wishes to benefit from the application of new technologies (by dissemination of the results of the Health Professionals' Survey).
- To undertake a concerted effort to increase the visibility and priority of genetic content in undergraduate and post-graduate medical and nursing training programmes (by dissemination of results/editorials in journals that will be read by Medical Educators, Leaders of Medical Specialties and Professors of Clinical Genetics).
- For individual members of the GenEd research group to continue collaboration with other research initiatives, such as EUROGENTEST (6th Framework Network of Excellence) in their work-packages professional education and patient education relating to genetic testing, the work of the European Society of Human Genetic Education Committee in their objectives for 2005-2006, and the use of the information to help inform the UK National Genetic Education Centre strategy for the development of educational tools.
- To consider collaboration both within and outside the EU to seek future funding to gather more empirical data from other specialties and countries not covered in this project.

1. Harris R, Reid M, Florentin L, (ed). Genetic services in Europe: a comparative study of 31 countries by the Concerted Action on Genetic Services in Europe. Eur J Hum Genet 1997;5(suppl 2):1-220.
2. Ayme S. European Society of Human Genetics Public and Professional Policy Committee Guidelines. European Journal of Human Genetics 2003;11(suppl2):1-141.
3. Challen K, Harris H, Julian-Reynier C, Ten Kate L, Kristoffersson U, Nippert I, et al. Genetic education and non-genetic health professionals: educational providers and curricula in Europe. Genetics in Medicine 2005;7:302-10.

Kirsty Challen
Research Fellow
Rodney Harris
Emeritus Professor (Medical Genetics)
GenEd Co-ordinating Centre
University Department of Medicine
Manchester Royal Infirmary

8th BALTIC Congress of Laboratory Medicine

Dear Colleagues,

On behalf of the Organizing Committee it is our great pleasure and privilege to invite you to attend the 8th Baltic Congress of Laboratory Medicine to be held in Vilnius, Lithuania, 18 – 20 May, 2006.

This congress is organized by the Lithuanian Society of Laboratory Medicine, Lithuanian Society of Human Genetics and Vilnius University together with the Latvian and Estonian Societies.

The 8th Baltic Congress of Laboratory Medicine will be devoted to a very challenging programme focusing on the recent advances in different areas of laboratory medicine and human genetics. To give the opportunity to discuss the latest research findings, submission of abstracts would be much appreciated. As usual, exhibition of laboratory equipment and supplies will be an integral part of the meeting.

We are confident that the 8th Baltic Congress of Laboratory Medicine will satisfy you scientifically, culturally and socially, and that you take home new ideas and new friendships.

We look forward to welcoming you to Vilnius for the 8th Baltic Congress of Laboratory Medicine.

Professor, Zita Aušrelė Kučinskienė,
President of the Congress
Assoc. Prof. Valerija Jablonskienė
Secretary General

Structure Organisation 2005

THE BOARD OF THE SOCIETY (May 2005-May 2006)

Term as board member ends at the general assembly in the year shown in brackets

EXECUTIVE BOARD

President	Dr. Andres Metspalu (2009)
Vice-President	Prof. Leena Peltonen (2008)
President-Elect	Prof. John Burn (2010)
Secretary General	Prof. Helena Kääriäinen (2007)
Deputy Secretary General	Prof. Thomas Meitinger (2007)
Treasurer	Prof. Andrew Read (2007)

BOARD MEMBERS

Dr. Nurten Akarsu	Ankara (2009)	Prof. Milan Macek	Prague (2007)
Prof. Jacques Beckmann	Lausanne (2009)	Prof. Gert Matthijs	Leuven (2008)
Dr. Alexis Brice	Paris (2008)	Prof. Pier Franco Pignatti	Verona (2008)
Prof. Karen Brondum-Nielsen	Copenhagen (2006)	Prof. Alessandra Renieri	Siena (2009)
Prof. Francoise Clerget-Darpoux)	Paris (2010	Dr. Silke Sperling	Berlin (2010)
Prof. Dian Donnai	Manchester (2009)	Dr. Eduardo Tizzano	Barcelona (2006)
Dr. Thoas Fioretos	Lund (2007)	Prof. Veronica van Heyningen)	Edinburgh (2007
Prof. Thierry Frebourg	Rouen (2006)	Prof. GertJan van Ommen	Leiden (2006)
Prof. Vaidutis Kucinskas	Vilnius (2010)	Dr. Christos Yapijakis	Athens (2007)
Prof. Nicolas Levy	Marseille (2008)		

LIAISON MEMBERS

Dr. Ségolène Aymé	Chair, PPPC	Prof. Jean-Jacques Cassiman	IFHGS
Prof. Han Brunner	Chair, SPC	Dr. Domenico Coviello	Chair, Education Com

Election of President-Elect & Board Members 2006

The Society Board intends that the President-Elect and four Board members will again be elected by postal ballot of all the members, rather than by voting in person at the Annual General Meeting, to increase participation of all members. Members of the society who wish to stand for election are requested to read the job descriptions of the duties of the President and Board Members detailed on the back of the enclosed nomination form. The Statutes of the Society state that the Board should be broadly representative of nationalities and specialties. A list of current Board members is on the Society's web site www.eshg.org (Term of office ends at the general assembly in the year shown in brackets)
The ballot form showing the names of members wishing to stand for election will be sent to eligible voting members in the next mailing and a date given by which it should be returned. The result will be announced at the Annual General Meeting.

Membership Renewal - Information for 2006

It is now time to ask you to renew your subscription for 2006. You will shortly be receiving a form to renew your membership, showing the different categories available. Please note, that if you take out a full (regular) membership you may have an electronic subscription to the Journal as well as a paper copy. The Journal will not be delivered to you from December 2005 until we receive your renewal form and payment, so please do not delay when you receive your renewal request.