European Society of Human Genetics

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April 2001
Newsletter no.4

What's in this issue

This issue contains the agenda and reports for the annual membership meeting on Thursday 17th May 2001, 18:30, Austria Center, Vienna.

Please bring it with you.

BOARD MEMBERS

New President Elect

Statement of Gert-Jan B. van Ommen President Elect 2001/2002

In my term as President, a principal goal will be to further the integration of basic genetics and genomics with the clinical specialties, to enhance the conversion of insights into applications. Two areas of attention associated with this aim are, on one hand, the interfacing between academia, industry and patient and caretaker groups. And, on the other hand, the extension of the dialogue between science and society, in the fields of ethics, political and legal issues including the patenting debate.

New Board Members

Nominations from the ESHG members

Nominations were requested from the ESHG membership for two members of the Board. Two nominations were received. They are Thierry Frebourg (France) and Karen Brondum-Nielson (Denmark). Their statements follow.

Thierry Frebourg nominated by Stanislas Lyonnet and Arnold Munnich

I am a Professor of Genetics at the University of Rouen. I head the Department of Medical Genetics at the Rouen University including the clinical unit and DNA laboratory. My research field includes genetic predisposition to cancer (HNPCC syndrome and Li-Fraumeni syndrome), molecular basis of chromosomal instability, and molecular basis of Alzheimer's disease. I have a special interest in the development of functional assays for human genes based on simple organisms such as yeast and drosophila and in the development of new methods for mutation detection.

Karen Brondum-Nielson nominated by Karen-Helen Orstavik and Niels Tommerup

I am a professor of Clinical Genetics, adjunct to University of Copenhagen, and I work as Head of Department (Department of Medical Genetics) and Director at the John F Kennedy Institute, Glostrup, Denmark. The focus for the Institute's research activities is genetics of mental retardation. My main research projects concentrate on molecular genetics of Fragile X syndrome, genotype-phenotype correlations in chromosomall disorders, and genetic aspects of autism. I am member of the International Molecular Genetic Study of Autism Consortium. My clinical activities include genetic counselling in relation to pre- and postnatal cytogenetic and molecular genetic analyses. I wish to participate in the ESHG board in order to promote research of high quality in Europe, as well as contributing to maintainance of high quality genetic service in Europe and last but not least to participate in and stimulate the never ending debate on ethical issues, which is essential in clinical and human genetics.

Nominations for the ESHG board

The Board of the Society, according to the Statutes, nominates two members of the Board, for approval by the Society. They are:

Helena Kaariainen (Finland)

I have worked all my life in the field of medical genetics as a clinician and also my research has mainly been clinically oriented. I feel that I have been privileged as I have had the opportunity to work on this field during these recent years when so many interesting new possibilities and problems have come up. Personally, I would find it interesting to be able to plan and discuss with top European geneticists the present and future activities of the Society. The topics I would like to promote are

1) the professionality and high quality of the provision of clinical applications of new genetics
2) the importance of supporting studies on rare diseases (as there will be enough resources for studying genetics of common diseases anyway) and also reporting these in the ESHG meetings
3) the community aspects like teaching, informing etc the public, the patient organisations etc

and

Eduardo Tizzano (Spain)

Eduardo Tizzano was born in La Plata (Argentina) in 1957. After taking his degree in Medicine and Surgery at the National University of La Plata (UNLP, 1980) he did his Pediatric Residency (1981-4) at the Children's Hospital of Buenos Aires and his Medical Genetics Residency (1984-1987) at the National Institute of Medical Genetics of Buenos Aires. He was internist in the Pediatric Hospital "J.P. Garrahan" of Buenos Aires (1987-8), fellow in the Molecular Genetics Unit of the Hospital of Sant Pau of Barcelona (1988-90) and postdoctoral fellow in the Department of Genetics of the Hospital for Sick Children of Toronto, Canada (1990-1993). He obtained his Ph.D. Degree in Medicine in 1992 (UNLP) and from 1994 is an Associate Researcher of the Institut de Recerca, Servei de Genética, Hospital Sant Pau of Barcelona. He is Vice-president of the AEDP (Spanish Association of Prenatal Diagnosis) and member of the AEGH (Spanish Association of Human Genetics), the AEP (Spanish Association of Pediatrics) and the Academy of Medical Sciences of Catalonia and Balear Islands. At present he is devoted to molecular diagnosis and research of haemophilias, spinal muscular atrophies and other hereditary disorders.

Annual Membership Meeting 2001: Agenda

Thursday 17th May 2001, 18:30, Austria Center, Vienna

Opening by the President of the Society, Professor Gerd Utermann

1. Activity report of the Society 2000-2001
2. Financial report of the Society 2000
3. Discharge of the board members for the year 2000-2001

Opening by the new President of the Society, Professor Stylianos Antonarakis

4. Results of election for president-elect
5. Results of election for board members
6. Membership fee 2002
7. Sites of future European Human Genetics Conferences
8. Budget proposal 2002
9. Major policy questions proposed by Board

EUROPEAN SOCIETY OF HUMAN GENETICS

MINUTES OF MEMBERSHIP MEETING HELD ON MONDAY 29TH MAY 2000, AMSTERDAM

The meeting was opened by Jean-Louis Mandel at 18h20. The members had received an agenda and reports from the committees as part of Newsletter no.2

I. ACTIVITY REPORT 1999-2000 *(Peter Farndon)*

- Membership administration is now handled by the ESHG office.
- Current total (paid) membership now 811 (735 in October 1999). It was noted that only 99 members eligible for an electronic membership have requested one.
- Summary of finances. An interim report was presented as the Board had agreed that the accounting year would now be a calendar year (January - December), the same as the membership subscription year. Consequently a complete breakdown will be provided at the end of the new accounting period.
  - The ESHG is not able to increase spending on fellowships or other new initiatives this financial year since ESHG has to make prepayments for the Vienna meeting
  - Geneva meeting made a small profit.
  - Web site is growing and being widely used (http://www.eshg.org)

II. REPORTS FROM COMMITTEES

Report from the PPPC *(Ségolène Aymé)*: explained the organization of workshops and their reports: A background paper is written, sent to about 100 experts; during a workshop with some 50 experts the paper is revised and recommendations drafted by the PPPC; the working document is then open for discussion on the ESHG website before endorsement is requested by the membership. The first document, "Population Screening", is now available on the web. "Genetics and Insurance" and "DNA banking" are being revised and will be available on-line as soon as possible. A workshop on the prevision of genetic services will be held in September. Some potential topics for the future were mentioned; the membership is urged to contribute ideas.

- PPPC membership will be increased by the "presidential team" (President, Vice-President and President-Elect) acting as associate members, as of this year. PPPC membership is otherwise on a rotating basis.
- PPPC/ESHG policy recommendations will be updated every 3 years.
- The recommendations paper will be published in EJHG and a book may be produced to cover the background papers

Report from the International Federation of Human Genetics Societies *(Marcus Pembrey)* Two new corresponding members, the Danish and Belgian Human Genetics Societies, have joined, bringing the total to 36. Two other groups are close to meeting the requirements for full membership: the Latin American organization and the Indonesian Society (which is forming an "Asian-Pacific" genetics network). The Japanese and Korean Societies may also apply for full membership

Scientific Program Committee: The successful Amsterdam meeting is their report. SPC members, and particularly their chairman, Andrew Read, were thanked by the membership.

III. Report from the EJHG *(Gert Jan van Ommen)*:

- Journal has gone to monthly issues, which are nearly on time now. For next year we will have a modest (10%) increase in volume.
- Acceptation rate 45-48%. Impact position between 2-3. EJHG is in the top 30% of all indexed journals, but we still need to improve.
- Quickest turn-around time from receipt to print was under one month for the first time—can thus send competitive papers and have them "fast-tracked." A new category of article is planned "genes in clinical practice" where the scientific, diagnostic and counselling aspects of a disorder will be discussed in a review.
- The Society has set up a Publications Committee to deal with issues between Editor, Publisher and Society.

IV. Vienna Meeting:

- JJ Cassiman is the chairman of the organising committee for the Vienna meeting; Jerome del Piccia is the representative from Vienna Medical Academy. About 3000 attendees are expected. A major effort is being made to reduce prices, particularly for students and non-EU countries. Are hoping to offer 250 fellowships for attendance at the meeting (EU request pending), particularly for those from less-developed countries.
- Charles Buys is chairman of the International SPC, which met for many hours during the European Human Genetics Conference in Amsterdam. From a list of over 60 suggested topics, 14 have been chosen for plenary sessions and 20 for workshops or symposia. It is planned to accommodate about 160 submitted abstracts. The completed program for invited speakers is expected by mid-July.

V. Changes In The Executive And Board

- Gerd Utermann of Austria, took up the office of President and thanked JL Mandel for his work over the past year, which is to continue with his active participation. Stylianos Antonarakis was welcomed as President-Elect.
- New Board members were welcomed: Lina Florentin (Greece) and Andreas Metspalu (Estonia) were nominated by the Board and Shirley Hodgson (UK) was proposed by the membership. Each of the new Board members made a short statement about their background and interests

VI. Proposals/Update by Secretary General *(Peter Farndon)*

- Membership fee and budget proposal for 2001: the secretary general proposed, and the meeting agreed, that the membership fee could be raised by 5 pounds to cover the costs of increasing the number of pages in our Journal.
- Partners: BioMerieux has resigned, leaving us with 4 partners. They contribute 5000 pounds per year, in exchange for having their names on our Website and letterhead; they can also benefit from our "advice" on genetic questions.
- Future meetings
- It was noted that the Annual Meetings Committee has the responsibility of requesting and assessing bids before they are presented to the Membership meeting
- Society members have expressed concern about the political situation in Austria and the holding of the 10th International Congress of Human Genetics in Vienna. The Board has discussed this at length, having previously asked the Society's Public and Professional Policy Committee to consider the issues and draft a statement. The PPPC statement, which had been agreed by the Board, was presented to the Membership meeting, who accepted it for publication on the ESHG Website.
- In 2002 the European Human Genetics Conference will be in Strasbourg
- The AMC is reconsidering the venue for 2003 because no one venue in London has adequate space for both trade exhibition and meeting rooms.
- For 2004, Munich and Hamburg have been proposed and will be assessed by an AMC visit.
- Eurocongres has organized our meeting for the past three years and were thanked for their efforts, particularly in making the Amsterdam meeting such a success.
- The contract of Rose International, responsible for the exhibitions, has been renewed for three more years.
- An ad hoc committee has been formed to contact the European Cytogenetics Association about the possibility of joint meetings (including perhaps in May 2003—Rimini, ITALY): SE Antonarakis, Anne Hagemeijer, Gerd Utermann.
- The AMC and the Executive will be considering models for future conference organisation, including the possibility that the Society hire its own conference organizer to coordinate the efforts of the local organisers, conference centre, abstract handling and professionals (such as our exhibition organiser).

VII. Major policy questions proposed by the Board:

- It was proposed that ESHG should increase links with other societies, such as the European Cytogenetics Association and the metabolic and population genetics societies in Europe. Board members have volunteered to contact the Presidents of these organisations.
- The Board has appointed an ad hoc committee to consider the society's organisation and procedures, and make recommendations, which may include changes to the Statutes: Celia DeLozier, Marcus Pembrey, Ulf Kristofferson. This committee will report back to the Board prior to their October meeting.
- The Board has approved a suggestion that, if possible, the membership directory be put on the Website, with safeguards preventing misuse of that information.

The meeting was adjourned by Gerd Utermann at 19h25.

Dr Celia De-Lozier Blanchet, June 2000

Future ESHG Conferences

European Human Genetics Conference
Strasbourg, France May 25th-28th 2002
Birmingham, England May 3rd-6th, 2003
Munich, Germany June 11th-15th, 2004

Activity Reports 2000-2001 (Pending approval by the board)

Secretary-General's report -

Peter Farndon

A thriving organisation

The Society is continuing to thrive, now having its own membership office communicating directly with our members, a strong European Journal of Human Genetics, a widely consulted website (over 16,000 hits) and reports from its Public and Professional Policy Committee which are widely accepted and reported.

Annual meeting 2000

The European Human Genetics Conference (the Society's 32nd annual conference) was held in Amsterdam from Saturday 27th to Tuesday 30th May 2000. This was a highly successful conference and our thanks go especially to the local host Professor Gert-Jan van Ommen and his colleagues. The scientific programme included interactive workshops, symposia, plenary sessions presenting latest research, a public awareness session, 59 spoken presentations from submitted abstracts and over 650 posters. There were over 1000 participants. The Young Investigator Awards were won by Alessandra Maugeri (The Netherlands) and Roman Chrast (Switzerland).

International Congress of Human Genetics

The 2001 conference is subsumed in the 10th International Congress of Human Genetics which the ESHG is organising on behalf of the International Federation of Human Genetics Societies. There has been much to do! I am sure that you will join me in thanking the chairman of the organising committee, Jean-Jacques Cassiman, and the chairman of the Scientific Programme Committee for all their hard work. We have had excellent support from Jerome del Picchia at the Vienna Medical Academy and Jantie de Roos at our exhibition organisers, Rose International. There is a more detailed report below.

Future European Human Genetics Conferences

The Executive Board was asked to consider future arrangements for the organisation of our own conferences, especially because everyone is concerned that the costs should be as low as possible, whilst maintaining the excellence of the scientific programme. The Society has a logistical problem: if the attendance at our conferences was below 800 we could take accommodation on campus universities, offering a very attractive package including overnight accommodation. Unfortunately there appear to be no facilities in Europe in academic institutions for conferences of about 1500: we therefore have to hire the large conference centres which command commercial rates. The higher costs then result in fewer people being able to attend! We have considered the possibility that the Society should set up its own conference organisation in order to reduce costs but this may place a burden on the existing officers and local host which is greater than they might reasonably be expected to bear on behalf of the Society. We are still considering the options. In the meantime, the Society is pleased to receive expressions of interest from National Societies for the 2005 conference.

Collaboration with European Genetics Foundation

We wish to broaden our educational collaboration with the European Genetics Foundation. We have been supporting two fellowships to the Medical Genetics Course held in March each year, with the intention of increasing these in number when the finances of the Society permit (much of the ESHG reserves were committed as prefinancing for the International Congress).

Publications Committee

The Publications Committee is continuing to look at ways to develop the European Journal of Human Genetics in accordance with the wishes of our editor and Society board.

Genetics as a recognised speciality

The Society's Board asked Dr Ulf Kristofferson to determine the mechanism for ensuring that medical genetics is accepted as a medical speciality in the European Union, and this is being progressed.

Review of the Society's statutes and organisation

The ESHG Board also set up a subcommittee, with Professor Marcus Pembrey as chairman, to consider the Society's statutes and determine if changes were advisable.

More detailed reports of many of the Society's activities now follow. I hope that you will encourage your colleagues and friends to become members of the Society (details on http://www.eshg.org/membership.htm).

The International Congress of Human Genetics, Vienna, May 15 - 19, 2001

ISPC chair: Charles Buys.
AMC-Vienna Chair: JJ Cassiman

The organizing committee and the International Science program committee had their work cut out during the past year. At the Amsterdam ESHG meeting, a second ISPC meeting was held. The final tasks for the ICHG were discussed and the ISPC finalized the outline of the scientific program and the abstract categories as well as the preliminary list of invited speakers. In the month following the ESHG meeting the ISPC members continued active exchanges by e-mail and further refined the topics of the different sessions and suggested names for the speakers to be invited.

As a result, many invited speakers could be contacted before September, resulting very rapidly in a first preliminary program, printed and mailed out to 15.000 persons in 170 countries by end of September/beginning of October 2000.

The deadline for the abstracts, December 15, will be known in the annals of the Vienna Medical Academy (VMA), our professional congress organizers, as the day the web turned red-hot from all the submissions arriving of course on the last day. When the temperature of the PCs came down, more than 1800 abstracts could be counted. In the following days Jerome Del Picchia and collaborators ordered and forwarded all the abstracts to the ISPC members on the different continents. On January 13, 2001, the ISPC met in Vienna to finalize the selection of the abstracts for oral presentation, and to order the different concurrent sessions into the program of the meeting. By that time the invited speakers for the plenary sessions and symposia had almost all confirmed their participation so that an impressive and near final program could be placed on the web. 108 abstracts were selected for oral presentation. In addition, two poster discussion sessions were planned allowing an additional 20 abstracts to be briefly presented orally. Four lunchtime workshops were approved. A series of satellite meetings will be organized at not competitive time slots. The ISPC also decided not to award any presentation prizes at the congress in view of the very heterogeneous quality of the submitted abstracts. The authors of the accepted, selected or the few rejected abstracts were notified by e-mail and by letter before February 2. All the information was placed on the web in the following days.

During the last few weeks preceding the Congress the ISPC will select and notify the persons selected to chair the different sessions. A last task for the ISPC will be to select the contributions for the late breaking session after the deadline of April 1.

The organizing committee met in Amsterdam to finalize the provisional budget of the meeting and to review all the practical aspects of the organization both at the local and at the international level. In the following months, the second announcement was finalized and placed on the web. At the ASHG meeting in Philadelphia the second announcement could be distributed to the participants and the ICHG booth, constantly manned by Jerome (VMA) and Marita (Rose Int.), received quite some attention from the delegates. The meeting of the committee in Philadelphia reviewed the progress in sponsoring activities, the further need for publicity of the meeting and the practical issues to be solved. A major e-mail and postal campaign already started in September was finalized.

The committee met, following the ISPC meeting, at the Austria Center in Vienna on January 15. The facilities were inspected as a function of the finalized scientific program and the room assignment for the different sessions, the posters and the exhibition was decided. The very positive progression in the sponsoring and exhibition activities was evaluated and an adapted budget was finalized. The activities and functions of the pressroom were discussed with John Hodgson, who will be in charge of this activity together with the local press contacts. It was decided to select up to 200 from the 343 candidates for fellowships based on the abstract acceptance, the age (<35y) and the presence of a letter of support of the scientific director of the candidate. In the following days, 189 recipients could be notified of the acceptance of their candidacy including support for their travel expenses, free registration and lodging. This takes care of the 200,000 Euro provided by the EU.

In the mean time the formal letters of invitation for the opening ceremony have been sent to the invited personalities and the first wave of early registrations, estimated at more than 2300 is being processed. All members of the ISPC and AMC are looking forward to an undoubtedly major success for the ESHG in May.

A public evening on human genetics is organised by the local host (Austrian Society of Human Genetics). At the IFHGS board meeting in Amsterdam Uta Francke accepted an invitation to give a public lecture (in German) at this occasion.

Professional and Public Policy Committee -

Ségolène Aymé

The PPPC activities have continued. The final recommendations of the last two reports, on "DNA Banking" and on "The Provision of Genetic Services" will be submitted for approval at the members meeting in Vienna.

European Journal of Human Genetics -

Editor in Chief - Gert-Jan van Ommen

With the first year of 12 issues completed in 2000 (vol. 8), 2001 is becoming a year of consolidation. While the number of published pages will increase by only 3%, further typographic changes allow us to achieve a net increase of published material by about 10%. This implies that we can maintain a 45-50% acceptation rate despite the gradual increase of submissions. To increase the immediate attention value of published material, a bulleted shortlist of topics has been introduced as of February 2001. The world coverage of the editorial board has been extended as far north as Tromso (Lisbeth Tranebjaerg) and as far south as South Africa (Ram Rameshar), while also new editors were added from the UK (Sue Kenwrick) and US (Eric Hoffman). The recently announced series of 'disease minireviews', describing basic features and diagnostic state of the art, has been a bit slower in crystallizing than anticipated, but the first manuscripts have been accepted. Once again we invite the readership to submit succinct descriptions (about 1500 words) of genetic diseases or syndromes of their expertise, ideally accompanied by two figures, a gene map with a few particular highlights (eg. mutation distribution relative to phenotypes) and a characteristic clinical or histochemical picture.

NOMINATIONS FOR THE MAURO BASCHIROTTO AWARD 2002

The Mauro Baschirotto Award, established in 1992 and funded through the philanthropy of the Mauro Baschirotto family, is presented by the ESHG during its annual European Human Genetics Conference in recognition of individual achievements in human genetics. The laureate is invited to give the Mauro Baschirotto lecture during the conference, and receives a gold ring, specially designed by the silversmiths of Vicenza in Italy and cast in a single copy each year, and a cheque for EUR 1,500 to cover the expenses of participating in the conference.

Previous Mauro Baschirotto Award Holders

1992	Lore Zech	1997	Leena Peltonen
1993	Pierre Maroteaux	1998	Jean-Louis Mandel
1994	Mary Lyon	1999	Pat Jacobs
1995	Jean Weissenbach	2000	Dirk Bootsma
1996	Malcolm Ferguson-Smith	2001	Robin Winter

Nominations are requested for 2002.

Candidates working in Europe may be nominated from any of the disciplines. Nomination letters describing the scientific accomplishments of the candidate should reach the chairman of the Scientific Program Committee (Prof Andrew Read, andrew.read@man.ac.uk) by May 30, 2001. The letters can be handed in during the International Congress of Human Genetics at the ESHG booth in the exhibition area.

European Human Genetics Conference 2002 - *Jean-Louis Mandel*

The 34th annual meeting of the European Society of Human Genetics will take place on May 25 to 28, 2002, in Strasbourg, France. This city houses the European Parliament and many other european institutions, such as the Council of Europe, the European Court of Human Rights, the European pharmacopoeia, and the European cultural TV channel Arte. It is also host for the headquarters of the Human Frontier Science Program Organisation, an important source of grants and postdoctoral fellowships for international research programs in Molecular Biology and Neurosciences, and of the European Science Foundation, that fosters cooperative networks in various areas of science. It is thus particularly fit that an ESHG meeting takes place in Strasbourg, and this may be an occasion to discuss with european authorities, how EEC can further support both research and service activities in human genetics. In fact, its impact is already very significant, as research on rare diseases and human genome and postgenome activities, are among the topics actively supported by EEC. One can note that both the European Molecular Genetics Quality Control Network (EMQN), and the Public and Professional Policy Committee (PPPC) of the ESHG developed their activities through EEC grants. Another recent action of interest for our community was the voting of an " Orphan diseases " legislation, that should favour the development of drugs for treatment of genetic diseases.

Strasbourg has a particularly rich history in medicine and in genetics. Medical teaching was established in 1540, and a first chair in medicine created in 1585. The university hospital has important architectural remains of this period (the old pharmacy and the wine cellar, both still in activity). Neurofibromatosis was first described there in 1882, by Friedrich von Recklinghausen, the professor of pathology, who also introduced the name hemochromatosis in 1889. The same year, Oskar Minkowski discovered in Strasbourg the central role of pancreas in diabetes. DNA, that was discovered in the nearby city of Basel, by Friedrich Miescher, was soon studied in Strasbourg by the young Albrecht Kossel, who later moved to Berlin and then to Heidelberg (130 km from Strasbourg), where he got in 1910 the Nobel Prize for his work on the chemical constitution of proteins and nucleic acids (notably the identification of the bases). Interest in nucleic acids was renewed in the late 40s, and has never stopped, leading to the creation of several major public research centers in molecular and cellular biology and genetics, where more than 1200 people are working and where key discoveries were made, such as the nucleosome structure of chromatin, the split structure of vertebrate genes, the role of transcription enhancers, the dual role in transcription and DNA repair of the transcription complex TFIIH etc. This concentration of expertise led to the creation of Transgene, one of the major biotech companies in Europe, that devotes its efforts to the development of gene therapies for cancer and genetic diseases. Pharmaceutical companies have established research labs (Synthelabo) or production plants (Lilly). Basel, Freiburg, and Heidelberg are three other major centers of research in biology and medicine located within 150 km from Strasbourg . This unique environment led to the Biovalley trinational cooperation for development of biotechnology over the Rhine valley, and the creation of a trinational school of Biotechnology engineers.

But Strasbourg has many other appeals. It is certainly one of the most beautiful european city, rich in architectural treasures (including its magnificent cathedral in pink sandstone), in picturesque sites with rivers and canals bordered by half-timbered houses or stone palaces, and in art museums. The gourmet will find an extensive choice of restaurants, from 3 stars Michelin most sophisticated cuisine to the busy and picturesque wynstubs around the cathedral , or to a score of tantalizing pastry shops (and end of May is the time of the succulent white asparagus, grown in the villages nearby). All these attractions are within 5 to 10 minutes reach of the Congress Center, using the high-tech and fast tram system that deserves the city. For pre or post congress leisure, one can enjoy the beautiful villages lining the Route du Vin (Road wine), overlooked by romantic medieval castles,(attractive sites for short hikes) and the picturesque town of Colmar (that hosts one of the most spectacular and impressive painting of all times, the Issenheimer altar by Grunewald). Strasbourg can easily be reached by plane (especially through the Paris or Brussels airport, or by shuttle bus from Frankfurt), and for closer cities, by train or car.

The Strasbourg meeting should thus provide very good science and profitable encounters with colleagues, in an enjoyable environment. I look forward to see you there in May 2002.

Genetics in Europe (4):

Human Genetics in Austria

Austria will be the host of the 10th ICHG in May 2001. It seems therefore appropriate to give a brief portrait of Human Genetics in Austria in this issue of our newsletter.

The detection of the ABO bloodgroup system, precisely a century ago (1901) by Karl Landsteiner, then assistant in the University Department of Pathological Anatomy in Vienna is an early major, and still unmatched contribution of an Austrian scientist to Human Genetics. Landsteiner left the country in 1919 due to lack of support and most of his pioneering work which was honoured by the Nobel Prize in 1930 was performed at Rockefeller in New York. His portrait is on the Austrian 1000 Shilling banknote but the science of Human Genetics to which he contributed so much is not regarded very highly in Austria.

Later, there were also some famous clinicians at the Vienna Medical Faculty and at Vienna community hospitals which were the first to describe some well known genetic syndromes which now carry their names e.g. Asperger Syndrome. Eminent among these is the late Andreas Rett, professor for childhood and adolescent psychiatric disease at the Hospital Rosenh¸gel its name is linked to the Rett-Syndrome.

Austria has only a small community of Human Geneticists. In 1996 the Austrian Society of Human Genetics was founded which presently has 70 members. In November 2000 this society had their first independent annual meeting hosted by Christa Fonatsch from the Vienna Institute of Medical Biology. However from the beginning the society had joint annual meetings with the German Society of Human Genetics. Together with the German and lately also Swiss Society of Medical Genetics, the Austrian Society of Human Genetics has "Medizinische Genetik" as its official organ. The society has recently established a curriculum for non-medical Human Geneticists (Fachhumangenetiker).

After a long period of negotiation Human Genetics became a subspecialty in Austria in 1994 i.e. specialists in several disciplines including Medical Biology, Internal Medicine, Gynaecology, and Pathology can subspecialize in Human Genetics in a three years curriculum. Though this sounds good news the bad news is that the training is also done by the respective specialty (i.e. a pathologist specializing in Human Genetics is trained by a pathologist, not by a Human Geneticist). In the absence of a full specialty for Medical Genetics this is likely to hinder the further establishment of Medical Genetic Centers in Austria which are viewed as the favoured model to deal with the challenges of genetics in medicine in the post genomic area by our society. The Austrian Society therefore is negotiating the introduction of Medical Genetics as a specialty in Austria.

The present underprivileged situation of Human Genetics in Austria is still a consequence of the disastrous involvement of the scientific forerunners of modern Human Genetics, Anthropology and related disciplines, in Nazi eugenic programs. At the end of world war II these institutions were closed, a history which Austria shared with Germany.

However whereas Institutes for Human Genetics were established at most German medical faculties beginning in the 1950s this formally never happened in Austria.

Instead, Human Genetics sprouted from Institutes for Medical Biology. The three Austrian medical faculties, Graz, Innsbruck and Vienna, each have an Institute for Medical Biology. They had been erected to supply teaching in biology to undergraduate medical students. The need to offer cytogenetic and prenatal diagnosis was first recognized by these institutions in Graz and Innsbruck and units for genetic diagnostics and genetic counselling were opened in Graz and Innsbruck by the Austrian Ministry of Health in the 70ies and early 80ies. These were the crystallization points for emerging Medical Genetic centers in these faculties and the institutes were renamed Institutes for Medical Biology and Human Genetics in the 1980s and 90s. These institutes are the only ones to provide a broad

training in all disciplines of Medical Genetics - though the specialty is still called Medical Biology.

Teaching in Human Genetics in the first two terms is also performed by the three Institutes for Medical Biology but unfortunately the medical curriculum does not yet contain Medical Genetics.

The historical development and outcome is different in the capital Vienna. Here cytogenetic research and diagnostics were established at the Institute for Histology and Embryology which was pioneering in the development of chromosome banding techniques. However the development was discontinued and molecular human genetics was not established. As a consequence there is no Medical Genetics center in Vienna. Instead there are numerous institutions and groups, each small, which work on special aspects of Human Genetics and also deliver services in restricted areas. Only recently has the chair at the Institute for Medical Biology in Vienna been occupied by a Human Geneticist which gives new hope.

Despite the fragmented situation in Medical Genetics in general there are several research groups in Vienna which are strong in cytogenetics and in particular in tumour cytogenetics, most notably at the St.Anna Childrens Hospital and at the Institute for Medical Biology.

Finally it should be mentioned that Austria is among the few countries which has a law related to Human Genetics - the Austrian Gene Technology Act. Amongst others this act regulates nucleic acid based genetic diagnosis in humans. It states, for example, that genetic counselling is mandatory before presymptomatic diagnosis and heterozygous testing and forbids insurance companies to ask for or accept results from DNA testing.

Human Genetics in Austria still is a fragile plant and needs support. Hopefully the 10th ICHG will demonstrate to some insightful individuals in health politics and academia the important role Human Genetics has to play as a bridging discipline in modern medicine.

Professor Gerd Utermann

EUROPEAN GENETICS: NATIONAL NEWS AND VIEWS

ESTONIA

The Estonian parliament has passed a new law on genetic research.

See www.genomics.ee

Andres Metsalpu

GERMANY

For details regarding the German Society of Human Genetics please turn to: http://www.gfhev.de. Here you will find a number of documents compiled by our Commission on Public Affairs and Ethical Problems: position paper, guidelines and declarations. The documents (approximately 80 pages) can also be purchased from Verlag Medizinische Genetik, Goethestr. 29, D-80336 Muncih: "Richtlinien und Stellungnahmen des Berufsverbandes Medizinische Genetik e.V. und der Deutschen Gesellschaft fuer Humangenetik e.V.". An English version is in preparation.

ITALY

The Italian Minister of Health, Professor Umberto Veronesi, has set up a committee, chaired by the Nobel Prize Winner Renato Dulbecco, consisting of 25 expert members from science and ethics. The committee is conducting a study on the use of stem cells for therapeutic aims. More details are available on: www.sanita.it (www.sanita.it/sanita/bacheca/cellstami/)

The Italian Ministry of University and Scientific Research has set up a National Post-genome Committee which has drawn up the IPERGEN project (the Italian Human Post-genome project) outlining the guidelines to be followed in order to manage the different aspects of Post-genomic Research in Italy. For more details see MURST website: www.murst.it (search-IPERGWEN-)

Dr Bruno Dallapiccola

SWITZERLAND

Switzerland creates clinical and laboratory medical genetics specialisations

In 1999, after many years of preparatory work by the Swiss Society of Medical Genetics, the Swiss Medical Association has recognized clinical genetics as a full medical specialty ("FMH have Medical Genetics"). One year later, in 2000, Swiss Association of Medical Laboratory Directors also recognized medical genetics as a clinical laboratory specialty ("FAMH in Medical Genetic Analysis"). Full details of the training programs and requirements are available from Dr Suzanne Braga, email: suzannebraga@datacomm.ch or Dr Martine Jotterand email: Martine.Jotterand@chuv.hospvd.ch

UNITED KINGDOM

The United Kingdom's Human Genetics Commission (an independent body advising the Government on policy issues) is conducting a public consultation on the storage, protection and use of personal genetic information. More details: www.hgc.gov.uk

This is a new feature for the Society's newsletter.

We would be pleased to receive news of national clinical/research/service developments, but especially of policy initiatives which may be of interest and value to other countries. Please email contributions to Celia DeLozier-Blanchet (delozier@cmu.unige.ch) or Mrs Ruth Cole (eshg@eshg.org)

Genetics and Insurance in the UK - The Continuing Public Debate

As often happens in the UK, questions of genetics and insurance are not governed by laws but by non-statutory agreements and advice. A government committee (Genetics and Insurance Committee; GAIC) considers the technical validity of particular DNA tests for particular types of insurance policy, but not wider social and ethical issues. Last year, in its first decision, GAIC ruled that a CAG repeat number above 38 in the Huntington gene was sufficiently predictive to be used in underwriting life insurance policies. This decision provoked considerable public anxiety about insurers having access to DNA test results. Curiously, few people seem troubled by the fact that insurers have always been free to ask about a family history of Huntington disease (or anything else) and decline a proposal on that basis.

The present climate of heightened public anxiety poses a threat to research. People may be unwilling to take part in genetic research for fear that they will then be denied insurance. In response to these concerns, and after long discussion with the (British Society of Human Genetics; BSHG), the insurance trade association (Association of British Insurers; ABI) has drawn up a statement confirming that research genetic tests will not be used in underwriting and do not need to be declared in any insurance application. At the time of writing, this statement has not yet been issued, but if the ABI do issue it, then the BSHG will publicly welcome it. Some of our members feel we should not be talking to insurance companies at all, but the majority view is that commercial insurance has a proper place in society and that constructive dialogue is better than blind opposition.

Your Views Please!

We would like to hear your views about the newsletter and the Society's activities. Please either contact a member of the Society's Board (see http://www.eshg.org/board.htm) or visit the ESHG booth in the exhibition area at the International Congress in Vienna and meet the Society's administrator, Ruth Cole, and her assistant, Linda Bates.

THE EUROPEAN GENETICS FOUNDATION

The European Genetics Foundation (E.G.F.) is the result of a collaboration among Faculty members of Italian and foreign Universities, who for the past 12 years have met in Sestri Levante to teach Genetics to more than 2000 post graduate students coming from 45 different countries. The success of these courses covering mainly Medical Genetics and Cancer Genetics has led to the constitution in 1995 of the European Genetics Foundation (EGF) whose aims are to establish a centre of excellence for genetics and preventive medicine in Sestri Levante. Starting fall 2000, the EGF will move into a new permanent venue, La Nunziata Centre, in Sestri Levante. This will become the centre of excellence for post graduate training in genetics and preventive medicine with the following functions:

a) to host training courses, meeting's in genetics and other events promoting the public understanding of genetics. The latter initiatives should lead to the development of a European forum for the discussion on the benefits and social problems related to genetic research.

b) to host an information and reference centre for genetic disorders (equivalent to that of the March of Dimes in the U.S.), run directly by the patients associations.

All the courses are organised according to the following traditional format: plenary lectures (4-5) in the morning, based on reviews of a research field and afternoon concurrent workshops consisting in group discussions of specific topics among one or more Faculty members and 15-20 students. A Questions from Students session is regularly held after the lunch break at the venue of the course.

The main features which usually make these courses successful are:

- the high scientific quality of lectures and workshops made possible by the presence of a large and highly motivated Faculty (e.g. 25 members for every ESGM course);
- the continuous presence of the Faculty throughout the course and their continuous interaction with students through organised or informal discussions;
- the availability of computers and dedicated lines for connections with Internet especially during the afternoon workshops;
- the atmosphere of great collaboration created by the staff of secretaries and technicians helping the Faculty and students.

EGF commitment to young researchers

Since its very first activities, the EGF has always done its best in order to ensure the maximum participation of young and motivated researchers to its high-level training courses. Due to the limited budget of the EGF, external sources of grants have always been extremely important in order to ensure this participation. Unfortunately the only support for the 13th Course in Medical Genetics came from the European Society of Human Genetics which gave 1,000 Euro for the course fees and living expenses of two students.

Visit our website for further information
www.eurogene.org

CALENDAR OF NATIONAL AND INTERNATIONAL MEETINGS *(see also http://www.eshg.org/Noticeboard.htm)*

MAY 2001

VI International Symposium on Mutations in the Human Genome
3-8 May, 2001; Bled, Slovenia
www.2001.bled.si/MAINWELCOM.HTML
4th Annual Meeting, American Society of Gene Therapy
May 30-June 3, 2001; Seattle, Washington, USA
www.asgt.org
10th International Congress of Human Genetics
15-19 May, 2001; Vienna, Austria
www.ichg2001.org

JUNE 2001

11th International Clinical Genetics Seminar
The Genetics of Diabetes Mellitus
9-14 June, 2001; Heraklio, Crete
Congress Secretariat: fax (30/1)7705752,
e-mail: congress@triaentotours.gr
Prader-Willi Syndrome World Conference
June 27-July 1, 2001, St. Paul, Minnesota, USA
e-mail: JLGMN@worldnet.att.net

JULY 2001

Behavioral Genetics Association 2001 Meeting
July 8-11,2001; Cambridge, UK
http://www.bga.org/meetings/
42nd Annual Short Course in Medical and Experimental Mammalian Genetics
(Jackson Laboratory and Johns Hopkins University)
16-27 July, 2001; Bar Harbor, Maine USA
Sandy Wilcomb, Course Coordinator, Jackson Laboratory,
e-mail: slw@jax.org www.jax.org/courses

AUGUST 2001

9th Biennial Southern African society of Human Genetics Congress
12-15 August, 2001; contact Philip Venter (philipve@mweb.co.za) or Lynn Luttig e-mail: luttig@unin.unorth.ac.za

SEPTEMBER 2001

British Human Genetics Conference
10-12 September, 2001; University of York, United Kingdom -
www.bshg.org.uk
Human Genome Epidemiology Workshop
23-25 September 2001, Cambridge United Kingdom -
www.medinfo.cam.ac.uk/phgu
7th International Meeting on Psychosocial Aspects of Genetic Testing for Hereditary Breast and/or Ovarian Cancer (HBOC) and Hereditary Non-Polyposis Colorectal Cancer (HNPCC)
27-28 September 2001, Franfurt/Main, Germany
contact: j.jordan@em.uni-frankfurt.de

OCTOBER 2001

51st Annual meeting of the American Society of Human Genetics
12-16 October, 2001; San Diego, California
www.faseb.org/genetics/ashg/meet-2001/2001meetmenu.htm

NOVEMBER 2001

Advanced European Bioethics Course - Life without Disease: 15-17 November 2001
Venue: University Nijmegan, the Netherlands
Contact: Fax: +31 24 354 0254 email: n.steinkamp@efg.kun.nl