

European Society of Human Genetics

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Officers 1999-2000:

President: Professor Jean-Louis Mandel
Vice-President: Professor Andrea Ballabio
President-Elect: Professor Gerd Utermann
Secretary-General: Professor Peter Farndon
Deputy Secretary-General: Dr Célia DeLozier-Blanchet

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ELECTION OF PRESIDENT ELECT AND BOARD MEMBERS

President Elect

We received two nominations for President-Elect (to become President in 2001), Professor Gert-Jan van Ommen and Professor Stylianos Antonarakis. Professor Gert-Jan van Ommen subsequently asked that his nomination be withdrawn this year to enable him to concentrate on further developments to the Society's *European Journal of Human Genetics*.

Each nominee was invited to provide 200 words expanding the reasons for wishing to serve the ESHG as President.



Stylianos E Antonarakis Nominated by Roberto Ravazzolo and Isabella Ceccherini

Stylianos Antonarakis is professor of Medical Genetics and director of the Division of Medical Genetics in the University of Geneva Medical School since 1992. He was trained as a Pediatrician, Clinical and Molecular Geneticist.

Why president of ESHG ?

I would like to contribute to the further development of the ESHG and increase its visibility and impact in the European level. Important items in the agenda include

- i) the improvement of relations with the cytogenetics community, the gene therapy community, the genetics societies of the different European countries, and the providers of genetic counselling;
- ii) the presence of ESHG in the international bioethical debates;
- iii) the homogenization of genetic services in the different European countries;
- iv) the improvement of the Annual meetings in terms of content, diversity and participation;
- v) the transparency of the Society and more "grass roots" participation and decisions;
- vi) the improvement of the educational role of the Society.

I would be delighted to work closely with the secretary, the members of the board, the members of the various committees, and all the Society members towards the achievement of the various objectives.

BOARD MEMBERS

Nominations from the ESHG Members

Nominations were requested from the ESHG membership for two members of the Board. One nomination was received from Dr Shirley Hodgson. Her statement follows. She is duly elected to the Board in the absence of other nominations.



Shirley Hodgson Nominated by John Burn and Chris Mathew.

I wish to be a board member of the ESHG because I would value the opportunity to contribute to its unique and important role in the exchange of ideas and research interests across Europe. I feel it is important to promote multicultural collaboration, opening up opportunities for research and service development in countries of different socio-economic and cultural backgrounds. My interest in research and service development in cancer genetics, particularly in the European context (as a member of an EC BIOMED 2 Demonstration Project on Familial Breast Cancer) has given me insight into the value of collaborative efforts in developing genetic services based upon the results of broad-based research. Cancer genetics provides a paradigm for the understanding and management of other multifactorial disorders in which the contribution of inherited factors are increasingly becoming appreciated. I have experience in organising Royal Society exchanges between scientists in Russia and the U.K., and as a member of the European committee of the Royal College of Physicians, U.K. and an author of two books on Inherited Cancer Susceptibility, I feel that my experience will allow me to contribute enthusiastically to the work of the ESHG, and to promote awareness of how this can enhance health improvement in a multicultural European setting.

Nominations from 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 ***Lina Florentin*** (Greece) and ***Andres Metspalu*** (Estonia).

ANNUAL MEMBERSHIP MEETING AGENDA

Monday 29th May 2000, 18.15h, RAI Congress Centre, Amsterdam

Opening by the President of the Society, Professor J.L.Mandel

1. Activity report of the society 1999-2000
2. Financial report of the society 1999-2000
3. Discharge of the board members for the year 1999-2000

Opening by the new President of the Society, Professor Gerd Utermann

4. Results of election for president-elect
5. Results of election for board members
6. Membership fee 2001
7. Sites of future European Human Genetics Conferences
8. Budget proposal 2000-2001
9. Major policy questions proposed by the board



Secretary-General's report

Peter Farndon

The past year has seen some major changes in the organisation of the Society. Professor Jean-Jacques Cassiman ended his term of office as Secretary-General. During his tenure, he worked hard and tirelessly for the Society and I would like to add my personal thanks to those of the ESHG members for passing on the Society in such a healthy shape.

Membership administration

One major change is that the Society is now responsible for administration of its own membership records, as from 1st January 2000. Mrs Ruth Cole is our part-time administrator, sharing office accommodation with the British Society for Human Genetics in Birmingham, UK. Stockton Press, our publishers, had been maintaining our membership records, but their computer systems were designed to deal with magazine subscriptions, rather than the intricacies of a membership database. Consequently, many of our members were confused by the renewal forms sent out by Stockton, and so the Board decided to rectify this by maintaining our own records. The current Secretary-General personally checked all the Society's archive records and records from Stockton and Rose International, to ensure that we contacted everyone who had previously been a member. If you know of someone we have missed, please do encourage them to visit the website and download and complete the membership form there. It is intended that a printed directory will be produced as soon as we are confident that our membership records are in order.

New membership categories

In order to encourage younger members, a new category of on-line membership only was devised. The Board will be reviewing how this category has been received.

Financial Statement

Jean-Jacques Cassiman mentioned at the Annual Membership Meeting in Geneva that preparing the accounts is a challenge because the financial years of different organisations with whom we deal are different from our own. The final set of accounts for our current financial year are, in a break with previous tradition, not included in this newsletter. This is because we still are awaiting several outstanding invoices, including those from our publishers for payment for the copies of the Journal so far this year. The current situation will be presented during the Membership Meeting in Amsterdam.

Annual meeting, Geneva 1999

The meeting was a great success scientifically and socially, with many new collaborations being formed. The attendance was a little less than we had anticipated, but from comments we have received, this appears to be a reflection of the cost of attending the meeting. Consequently, the Society feared that the meeting would make a large deficit, but, thanks to the efforts of the local hosts (Celia DeLozier-Blanchet and Stylianos Antonarakis) and our professional organisers, Eurocongres and Rose International, by careful budgetary management the meeting in fact made a small surplus of about 5000 NLG.

Organisation of future European Human Genetic Conferences

At the end of the Amsterdam meeting our contract with Eurocongres expires, with our thanks for the very detailed work which they perform for us behind the scenes. The organisation of the 2001 conference in Vienna is being undertaken by the Vienna Medical Academy, the contract being won in competition. A further contract for three years has been agreed with Rose International to promote and manage the trade exhibition and sponsorship. The precise administrative organisation of the conference in Strasbourg has not been decided, and will be discussed by the Annual Meetings Committee and the Society Board. The aim is to have an excellent scientific conference at the lowest cost to participants, to continue to encourage younger scientists and clinicians to attend. We are reviewing the part that the local organiser plays, and trying to identify the best way of providing registration facilities, logistical organisation at the conference centre, hotel accommodation and abstract handling and abstract book production. If it is decided organisations outside the ESHG will be approached to provide these, an open call will be made.

ESHG website

During the year the Society adopted its own web domain, www.eshg.org. The Society has thanked Bruno Ubero for his work in maintaining the previous web site on the Infobiogen server. The Society is pleased that its website is being increasingly accessed, and we are committed to its future development. We are investigating the safeguards necessary to place the membership directory in searchable form on the site. We also wish to develop the section on policy statements, both of the ESHG and other organisations. Comments and suggestions for future content are gratefully received, but please remember there is no vast professional organisation configuring the website - just the

Publications Committee

During the year a new committee, the Publications Committee, was formed as an official forum to discuss organisational and financial matters. The remit of this committee will be formally discussed at the Board meeting in May. This new committee does not affect the development of editorial policy which is the remit of the Editor in Chief and the editorial board.

Collaboration with European Genetics Foundation

We have developed a collaboration with the European Genetics Foundation, which is dedicated to advanced training in Human Genetics and Preventive Medicine in Europe and to the public understanding of genetics. It is intended that this will be a practical collaboration, with the ESHG providing financial support for fellowships. Because of the uncertainty of our level of income during the change in membership administration, the Board agreed that we would offer only two fellowships this year. It was agreed that the EGF would be responsible for giving out these fellowships.

Newsletter

This year has also seen the birth of a newsletter as a means of direct communication with our members in a less formal style than appropriate for the Society's European Journal of Human Genetics. Your comments are encouraged - please send them to Dr Celia DeLozier-Blanchet.



The European Journal of Human Genetics

Editor in chief: Gert-Jan van Ommen

This year has seen the reaching of the goal set for the EJHG since its inception: To become a regular monthly journal. In the initial months, the typographic changes to accommodate a bit more material on a page and the increased frequency have caused a delay in the appearance of the first issues but this will be resolved in the rest of the year. At the editorial office the increased frequency is already becoming detectable. The monthly journal proofs seem to come fast and furious. This makes the decision on what to include the current month and what to leave, for lack of space, a bit less painful, since this now only involves one month. Compared with the status of the journal when the current Editor took over, the throughput has more than doubled: From ca 160 to 320 manuscripts received per year, being published in over 1000 pages against 420 only in 1997, spread over 12 issues rather than 6. The acceptance rate lies around 45-50% but this

continues to be under pressure. Notably we have had to become more demanding on series of mutations or single cases, which, however interesting and/or diagnostically relevant regionally, do not advance the general insights in the field sufficiently. Rather than placing extra burden on our reviewers and wasting precious time of the submitting authors, we tend to return these manuscripts after a short in-house assessment.

New category: Disease Profile

The journal will continue its current policy of publishing "all the news that fits", in molecular and clinical genetics, cytogenetics, genetic epidemiology, and on psychological and societal matters and well as methodological and technological items. In addition, in the coming period we hope to implement a series of short disease status descriptions, providing the basic and diagnostic state-of-the-art. The readership is welcomed to send in manuscripts in this category, of any type of genetic disease or syndrome for which they might contribute their expertise. The format is not yet fully crystallized so the first submissions will help shape the format. So take a chance and help write the rules on your favourite topic!



The Scientific Program Committee (SPC)

Chair: Andrew P Read

The committee met twice briefly during the Geneva ESHG meeting (29th May and 1st June 1999) to deal with urgent matters. Andrea Ballabio, Celia DeLozier-Blanchet, Michel Vekemans and the Lisbon hosts, Heloisa Goncalves Santos and Carolino Monteiro, rotated off the committee; we are very grateful for their many positive contributions to its work. Peter Farndon resigned as a full member, because of his new commitments as Secretary-General. New members welcomed onto the SPC are Han Brunner, Françoise Clerget-Darpoux and Orsetta Zuffardi. We met in Amsterdam on 25th-27th June 1999 to draw up the outline of the Amsterdam 2000 programme, and to nominate the recipient of the Mauro Baschirotto Award, Prof Dirk Bootsma.

Much work was done by email after that, and a small "unofficial" meeting was held in San Francisco on Oct 21st 1999 during the American Society of Human Genetics meeting, to review progress. We had a busy weekend in Amsterdam on 28th-30th January 2000 to review the abstracts submitted for the Amsterdam meeting, award East

and West Fellowships, and check the status of the programme. Over 700 abstracts were received. All were read by at least two, usually three or four, SPC members to draw up shortlists in each category, and the final selection was made by the whole committee. As always, it is difficult to select 55-60 abstracts from this number for oral presentation. The final selection depends primarily on scientific quality, but in addition some abstracts containing large amounts of data are more suitable for poster presentation, and our final choice was also influenced by our wish to keep some sort of balance between topics and to package presentations into coherent sessions. We can only sympathise with the many people who requested oral presentation but had to be offered posters instead. Of course, some people prefer a poster for their abstract.

Looking ahead, in 2001 the ESHG meeting is subsumed into the 10th International Human Genetics Congress. A special International SPC has been constituted, chaired by Charles Buys, for this. It includes most of the ESHG SPC, but to preserve continuity over the long planning horizon, it was decided to base the ESHG representation on the 1998-9 SPC. The only function of the ESHG SPC will be to award the Baschiroto Prize. The question then arises, what should the term of office of ESHG SPC members be? We decided on the principle that each SPC member would take part in organising four ESHG meetings. Thus somebody joining in 1998 would help organise the 99, 00, 02 and 03 meetings, and would also be a member of the ISPC; the people who joined the SPC in June 1999 would help organise the 00, 02, 03 and 04 meetings, but not be a member of the ISPC. After the Amsterdam meeting this summer, the ESHG SPC will not reconvene until June 2001, when planning of the 2002 Strasbourg meeting starts. As always, we are interested to hear suggestions for new SPC members, especially people with special knowledge of a scientific or geographical area that is not well represented at present.



The Professional and Public Policy Committee (PPPC)

Chair: Segolene Aymé

The PPPC was created at the ESHG 1997 annual meeting. Its present members are: S.Aymé (France, chair person), M.Bobrow (U.K.), JJ Cassiman (Belgium), D. Coviello (Italy), G.Evers-Kiebooms (Belgium), P. Farndon (U.K.), H. Kääriäinen (Finland), U.Kristoffersson (Sweden), M.Pembrey (U.K.), J.A.Raeburn (U.K.), J.Schmidtke (Germany), L. ten Kate (The Netherlands), L.Tranebjaerg (Norway, secretary). To start renewing the PPPC members, 2 of them offered to resign this year (S. Raeburn and P. Farndon). New nominations will be made at the annual meeting in Amsterdam. Suggestions are welcome.

The PPPC convened three times in November 1999, February and April 2000. The committee was mainly dedicated to the organization of workshops supported by a Biotech contract, from which three already took place:

- Genetic screening: technical and ethical issues, including commercialization of genetic tests (Amsterdam, November 18-20, 1999)

- Insurance and employment: Technical, Social and Ethical Issues (Manchester, February 25-27, 2000)
- Data storage and DNA banking: quality issues, confidentiality, informed consent (Paris, April 6-8, 2000)

The fourth workshop will be dedicated to Guidelines for the provision of genetic services in Europe (Helsinki, September 7-10, 2000)

The background document and the recommendations will be available for discussion one month on the web site of the society. The recommendations will be published in the EJHG and the background documents as a book or a supplement issue of the journal.

As the work of the committee requires resources to formally convene and to staffing to prepare the working document, it was decided to re-apply to the EC to get funded. The topics for further discussion and issues of recommendations which are proposed are: 1) Challenges of information availability on Internet in human genetics 2) research use of cells, embryonic cell lines, fixed samples, and embryos from IVF clinics. The application can be also about the implementation of the recommendations previously issued.



International Congress of Human Genetics : Vienna : May 15-19th 2001

Preparations for the ICHG

Chair of organising committee: Jean-Jacques Cassiman

The special Annual Meeting Committee (AMC-Vienna) for the preparation of the Vienna meeting has started the preparations for the International congress in close contact with the International SPC set up specifically for this meeting. Based on the evaluation of the competitive bid by three Viennese PCOs, the Vienna Medical Academy (VMA) was selected as professional congress organiser for the meeting. Andreas Muzik of the VMA is our official contact person. Rose International was asked to take care of the exhibition and sponsoring as in the past.

The facilities at the Austria centre were carefully checked by the committee in order to plan the different activities of the meeting. Our PCO opened a website at www.ichg2001.org with all the relevant information and a first announcement flyer was printed and distributed from a special ICHG booth at the ASHG meeting in San Francisco. The flyer is also distributed at every possible occasion.

The time table for the different preparatory activities, mailings, announcements, participation at national and international meetings was set up and mailing addresses of potential participants were obtained through the IFHGS and all other possible channels.

S. Ayme and JJ Cassiman met with David Bennett, the secretary general of the European Federation of Biotechnology, Task Group on Public Perception of Biotechnology. With their help the press coverage of the Vienna meeting will be realised. In addition the EFB will help us in organising activities for the local Viennese public and for university students. A meeting between A. Muzik and D. Bennett further filled in the steps to be taken.

Unesco, WHO, NATO, the EU and Europabio, the federation of European Biotech companies, were contacted to ask for financial and moral support for this unique event. Unesco already approved official (moral) sponsorship. Europabio is very interested and further contacts are planned to discuss their involvement. Applications for support from NATO and from the EU for fellowships for young investigators from developing countries are in progress, while an invitation to commissioner Busquin to attend the opening ceremony is in preparation. A statement of the board of the ESHG on the opportunity of meeting in Vienna will be available soon.

The committee hopes that all ESHG members will make this meeting known to all geneticists in the world. Flyers or other material can be obtained from the PCO or from the above mentioned website.



*Scientific Program
Committee ICHG 2001
(ISPC)*

Chair: Charles Buys

The committee - whose membership can be found on the ICHG website (www.ichg2001.org) - met for the first time during the annual meeting of the ESHG in Geneva, 29 May 1999, to discuss the philosophy of the Congress, the Congress format, suggestions of topics, submission categories for abstracts, and the abstract selection procedure.

The ISPC wants the Congress to have a truly international flavour, pay attention to the globalisation of genetic knowledge and its applications, be educational and at the same time emphasise active participation. This philosophy should be clear already in the initial brochures.

The great majority of presentations will be posters. Therefore, the ISPC will make considerable time available for poster viewing and wants to have the posters on display during the whole meeting. In order to avoid no-shows only those abstracts will be printed of which the first author has paid the registration fee. A few poster workshops will be organised, the subjects of which are to be decided after the ISPC has seen all abstracts.

Plenary sessions will be organised after the official opening in the afternoon of Tuesday 15 May and in the mornings of 16-19 May. Concurrent sessions of different types, including oral presentations from selected abstracts and educational symposia will take place in the afternoon. The Congress Centre has space to allow five sessions to be run in parallel. A plenary late-breaking research session and the Baschiroto

lecture will be held in the afternoon of Saturday 19 May. A plenary evening session on a "genetics and society" issue will be organised jointly by UNESCO and the PPPC.

The ISPC decided to work with 16 abstract submission categories that can be found on the website. Per category one or two ISPC members plus a few outside reviewers on whose names the ISPC has to agree will score the abstracts and produce a shortlist. The shortlists will then be discussed by the ISPC to arrive at the final selection.

Through the International Federation of Human Genetics Societies, the individual societies have been asked for suggestions of session topics. Several suggestions have been put forward in response to that request. Together with the input from the members of the ISPC, this has resulted in a long list of topics, which is under discussion at present to arrive at a preliminary programme. This discussion, including numbers of different types of sessions, topics, and sizes of session rooms to be assigned to the various topics, is being held electronically. At the next meeting of the ISPC during the European Human Genetics Conference in Amsterdam, decisions will be taken, so that possible speakers can be identified and invited. The programme should have its more or less definite form next July. The preliminary deadline for submission of abstracts is 15 December 2000.

ESHG liaison with the International Federation of Human Genetics Societies

President: Uta Francke

Presidency - The presidency rotated from S. Aymé (ESHG) to Uta Francke (ASHG) in January 2000.

Web site - The IFHGS web site was moved to the following address:

www.faseb.org/genetics/ifhgs. To enable all members to view policies and endorsements easily, a link will be established from the member society list on the Federation site directly to the members' web site policy page. The list of Federation members who approved the conclusions of the "workshop on the science and ethics of eugenics" developed at the 18th International Congress of Genetics in Beijing, August, 10-15, 1998, will be added to the published articles section of the Federation site. Also to be added to the web site are: an application for membership; an e-mail link to the Federation secretary's office; a link for updating membership data.

11th ICHG in Brisbane, Australia, 6-10 August, 2006 - John MacMillan of the Queensland Clinical Genetics Service at the Royal Children's Hospital will be chair of the organising committee for this congress. Planning is getting started and convention space has been reserved. The HGSA will report to all future Executive meetings the progress of the 2006 meeting planning.

12th ICHG to be held in 2011 - The 2011 Congress was discussed. It was preliminarily discussed that ASHG would subsume its meeting and host the Congress in Montreal. The Executive was in favour of this plan. The policy of allowing some of the profit from an international congress to go to the next congress in the form of a loan was discussed. This would mean that all monies collected from registration and exhibit fees would first go to repay the loan before being regarded as a profit. The Executive favoured this policy.

Bylaws Revision - Bylaws revision will allow for new categories of membership: affiliate and preliminary memberships. An Affiliate would be a national or international organization representing a specialty dedicated to human genetics. A Preliminary Member would be a newly formed organisation in a country that does not have a national society of human genetics.

New full members - The network of South American Societies is working hard to become soon a Full Member. The Japanese and Korean societies may join together to form a regional society. China has expressed interest in participating but it is not known if they are in the process of planning to join with another national society.

Corresponding members - The IFHGS has currently 34 corresponding members:

Argentina Society of Medical Genetics (*Susana B. Turyk*), Austrian Society for Human Genetics (*Gerd Utermann*), Brazilian Society of Clinical Genetics (*Juan Clinton Llerena, Jr.*), British Society for Human Genetics (*Andrew Read*), Canadian College of Medical Genetics (*Jane Evans*), Czech Society of Medical Genetics (*Jiri Santavy*), Finnish Society of Medical Genetics (*Minna Poyhonen*), French Society of Human Genetics (*Roland Berger*), German Society for Human Genetics (*Jörg Schmidtke*), Hellenic Society of Human Genetics (*Michael B. Petersen*), Hungarian Society of Human Genetics (*Gyorgy Kosztolanyi*), Indian Society of Human Genetics (*Kiran Kucheria*), Irish Society of Human Genetics (*Nollaig Parfrey*), Israeli Society of Medical Geneticists (*Zvi Borochowitz*), Italian Society of Human Genetics (*Bruno Dallapiccola*), Japanese Society of Human Genetics (*Yasuo Nakagome*), Korean Society of Human Genetics (*Ho-Suk Saw*), Latvian Medical Genetics Society (*Rita Lugovska*), Lithuanian Society of Human Genetics (*Vaidutis Kucinskas*), Mexican Association of Human Genetics (*Jose Maria Cantu*), Netherlands Society of Human Genetics (*Gert-Jan B. van Ommen*), Norwegian Society of Medical Genetics (*Trond P. Leren*), Polish Society of Human Genetics (*Jerzy Nowak*), Portuguese Society of Human Genetics (*Carolino Monteiro*), Romanian Society of Human Genetics (*Covic Mircea*), Russian Society of Human Genetics (*Evgeny Ginter*), Serbian Society for Human Genetics (*Miroslava Micic*), Southern African Society for Human Genetics (*Arnold L. Christanson*), Spanish Association of Human Genetics (*Alberto Valiente*), Swedish Society of Human Genetics (*Ulf Kristofferesson*), Swiss Society of Medical Genetics (*Daniel.F. Schorderet*), Turkish Association of Medical Genetics (*Memnune Apak*), Genetics Society of Vietnam (*L. Dinh Luong*).

FUTURE ESHG CONFERENCES

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

European Human Genetics Conference,
Strasbourg, May 25th-28th 2002

NEW RESOURCE ON ESHG WEBSITE

We are hoping to add resources and links to the website. The first is a pdf version of a 61 page booklet "Genetics: Basis for Medicine in the 21st Century. An Introduction to genes, diseases and genetic tests" written by Dr Achim Regenauer and Professor Dr Joerg Schmidtke. It is published by Munich Re. Visit www.eshg.org for details.

GENETICS IN EUROPE: MEDICAL GENETICS IN THE NETHERLANDS



Medical genetics in the Netherlands was dominated for many years by the impressive figure of Dr. Waardenburg. Waardenburg was an ophthalmologist working in Arnhem who was meticulous in his documenting and reporting of interesting patients. The famous Waardenburg syndrome now bears his name. Medical genetics as an independent speciality was given a solid basis in 1977 when the Dutch government decided to fund Clinical Genetic Centres in each of the eight university hospitals. This achievement was largely due to the efforts of Prof. Galjaard and Dr ter Haar. The system of the clinical genetic centres covering all activities in the field of clinical genetics, cytogenetics, DNA-diagnostics and metabolic diseases, has been upheld to the present day and has provided a solid foundation for genetic patient care in the Netherlands.

Clinical genetics was formally instituted as a medical speciality in 1987, with approximately 55 board-certified clinical geneticists now in active practice. Non-medical genetic counsellors have only recently been introduced, and their numbers are increasing rapidly. Their main focus as a group is on cancer genetics, cystic fibrosis, and inherited chromosome anomalies. Laboratory speciality training in clinical molecular diagnosis and clinical cytogenetics similar to that for clinical chemists is expected to be in place soon. The number of referrals for genetic counselling is around 700 per million population per year. For prenatal cytogenetics, postnatal cytogenetics and DNA-diagnostics the numbers are all around 1000 per million population per year.

The clinical genetic centres are integrated with university departments of medical genetics where teaching and research are the core business. In most cases there is a single University department with two chairs, one in clinical genetics and one in medical or human genetics.

Much of the research in medical genetics builds on the excellent infrastructure for medical genetics patient care.

Strong research groups outside the clinical genetic centres are those at the National Cancer Institute in Amsterdam, that radiation genetics group at the University of Leiden, and the Department of Cell Biology of the University of Rotterdam

There are few specifically Dutch syndromes. However it has been established that there are specific Dutch mutations in a number of genetic conditions, as for instance is the case for BRCA1. In fact some mutations are clearly much more frequent in certain parts of the country. Recently several groups in genetic epidemiology have started to exploit the fact that the population in Holland has been relatively stable and tends to stay in the same place. For this reason projects are ongoing that focus on genetic factors in multifactorial diseases, by examining specific populations in the west and in the north of Holland.

The Dutch Society of Human Genetics has a yearly two-day meeting that covers all aspects of clinical, medical and human genetics including genetic epidemiology. It will act as local host for the ESHG 2000 meeting and is looking forward to seeing many of you in Amsterdam in May!

Han Brunner

Swiss Genetics - Correction

In the first newsletter genetics in Switzerland was highlighted. I stated that Switzerland has five university centres and four private laboratories.

My apologies to a fifth commercial laboratory which I did not mention, in St. Gallen. CDB

HUMAN GENETICS NEWS

A weekly news digest on human genetics from the Austrian Society of Genetics and Gene Technology (OEGGGT) is available for everyone interested. The digest is a collection of interesting news items on the subject but not an exhaustive news summary. If interested, please send an email to Barbara Streicher at Streiche@bch.univie.ac.at.

PARTICIPATE IN THE INTERACTIVE WORKSHOPS AT THE EUROPEAN HUMAN GENETICS CONFERENCE!

Training of non-medical genetic counsellors in Europe

Sunday, 28 May 12:30-14:0

Organisers: Domenico Coviello (Modena, Italy) and Lauren Kerzin-Storrrar (Manchester, UK)

This workshop will review developments in Europe and in North America since the last ESHG workshop on training of non-medical genetic counsellors (genetic associates/ counsellors/nurses) was held in 1997. Contributions have been invited from the US, UK, Italy and the Netherlands, and the organisers also welcome informal contributions from colleagues from other countries who can report on training developments. Anyone interested in making contact with the organisers before the ESHG meeting, can contact one of us : LStorrrar@central.cmht.nwest.nhs.uk or coviello@unige.it

Dysmorphology Workshops

Sunday and Monday 28 and 29 May 2000, 12.30-14.00

Organisers: Dian Donnai, Robin Winter

We welcome your participation in these workshops which will be informal and hopefully interactive. On Sunday we will begin with a short presentation by Jeanne Amiel on a new Soto-like syndrome

After that the programme is up to you.....

So please bring along your slides of patients with RARE KNOWN SYNDROMES and UNKNOWNNS with DISTINCTIVE FEATURES

If you can let us know before that you have cases to present please email ddonnai@central.cmht.nwest.nhs.uk. to indicate how many cases you have (maximum 2-3 per person). You can however bring cases direct to the workshop room about 15 minutes before the start of the session and someone will put you on the presentation list and help organise the slides.

We will have the London Dysmorphology Database available. Please do contribute cases: the success of the workshops depends on YOUR participation.

Cytogenetics

Monday 29 May, 2000, 12h30-14h00

Organiser: Albert Schinzel (Zurich)

When information becomes available, it will be placed on the ESHG website (www.eshg.org)

Prenatal Diagnosis

Monday 29 May, 2000, 12h30-14h00

Organisers: Célia DeLozier-Blanchet (Switzerland) and Lars O. Vejerslev (Denmark)

We would like to organise a different kind of prenatal workshop at the ESHG this year. The goal will be to inform each other about national or international *collaborative prenatal studies* which are in various stages of realisation. We are looking for presentations (as oral presentations, posters, or information leaflets/protocols) of the following types:

- *presenting results from a multicentric study:* when these have not yet been published
- *introducing an ongoing study which is still open to collaborators:* you would like to present the protocol and preliminary results
- *suggesting a new study:* which you would like to (help) initiate and organise, but for which a forum for discussion about the feasibility and/or technical aspects of the study is needed.

Please contact Dr. Célia DeLozier-Blanchet (delozier@cmu.unige.ch, fax: (41/22) 702.57.06)) with potential subjects, no later than 28 April.

NOMINATIONS FOR THE MAURO BASCHIROTTO AWARD 2001

The Mauro Baschirotto Award, established in 1992 and funded through the philanthropy of the Baschirotto family, is presented by the European Society of Human Genetics 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 Society's European Human Genetics Conference.

Previous Mauro Baschirotto Award Holders

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

Nominations are requested for the 2001 award.

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 ESHG Scientific Program Committee (Prof Andrew Read, andrew.read@man.ac.uk) before Tuesday 30th May 2000, the last day of the European Human Genetics Conference in Amsterdam.

MINUTES OF THE ESHG MEMBERSHIP MEETING, 31 MAY 1999

Geneva, Switzerland

The meeting was opened at 18h40 by Andrea Ballabio, President.

- I. **Activity Report** Jean-Jacques Cassiman summarised the previous year's activities, most of which had been described in detail in previously circulated papers.
 - The Annual Meetings Committee is continuing to look at ways to improve and/or enlarge the annual meeting, such as combining or overlapping with large national societies or with the European Cytogenetics Association.
 - The International Congress will be held in 2001 in Vienna, under the auspices of the ESHG. Our Scientific Program Committee has been enlarged with members from other continents to form an International ISPC, under the chairmanship of Charles Buys. It met for the first time in Geneva.
 - The AMC is investigating bids for future meetings.
 - Our industrial partners were thanked for their support. Each donates £5000 per year in exchange for this status. To our partners from past years, Amersham Pharmacia Biotech, Beckman, Genzyme and Roche Diagnostics, we welcomed a new partner, bioMérieux.
 - Problems with the collection of membership fees by Stockton were being addressed.
- II. **European Journal of Human Genetics** (*GJ van Ommen*)
 - Journal is increasing from 480 to 720 pages (8 issues) in 1999 and will be published monthly in 2000.
 - 20-30 manuscripts are received each month, 45% of which are accepted. Offers to write review articles are particularly welcome.
 - Membership fees for next year will be £60. Alternative types of memberships are being considered, e.g. with on-line journal only, or collective from same department
- III. **Scientific Program Committee** (*Andrew Read*)
 - SPC were to meet in June 1999 and suggestions for topics for 2000 were welcomed, particularly those which would prove more attractive to clinicians and cytogeneticists
 - Nominations for the 2000 Baschirotto Award were also being accepted up until the SPC meeting

IV. Public and Professional Policy Committee (*Segolene Ayme*)

- Funding has been obtained from the EC for the organization of workshops, one goal of which is to issue guidelines which will be published by the Society.
- Forthcoming workshops:
 - Genetic Screening: Technical and ethical issues (Amsterdam, November 1999)
 - Insurance and employment: Technical, social and ethical issues (Manchester)
 - Data storage and DNA banking: quality issues, confidentiality, informed consent (Paris, April 2000)
 - Guidelines for the provision of genetic services in Europe (Helsinki)
- The PPPC also plans the Public Awareness Sessions at the annual meetings. The theme for 2000 is "Genetics and the media" and the suggested topic for 2001 is "Market forces and their effects on the provision of genetic services."

V. International Federation of Human Genetics Societies (*Marcus Pembrey*)

- The number of corresponding members has grown to 31
- A grouping of Latin American Societies may be ratified as a full member
- The Beijing conference and the human rights declaration, all eight points of which were endorsed by the IFHGS, was a good opportunity to test the function of the organization

VI. Financial Report (*Jean-Jacques Cassiman*)

- The finances of the Society's annual meetings are administered by two Foundations, established under Belgian law.
- The budget, received in advance by the members, was summarised. It was noted how difficult it was to present the budget at the annual meeting, since the financial year of most organisations (including our sponsors) is not the same as our own, which runs from one annual meeting to another.
- In response to a question by Giovanni Romeo, it was reported that the Lisbon meeting surplus of income over expenditure had been used to prefinance the Geneva meeting. The full financial accounts of the Lisbon meeting would be sent to the local organisers.

VII. Discharge of Board members (*Andrea Ballabio*)

- John Burn, Marcella Devoto and Karl Sperling were thanked for their service to the ESHG over the past five years.

VIII. Changing of ESHG officers (*Andrea Ballabio*)

- Jean-Jacques stepped down as Secretary General, after six years of service during which, it is unanimously agreed, the European Society grew immensely. He was thanked on behalf of all members of the Society and a gift and a "memory book" were presented to him.
- Jean-Louis Mandel took the floor as the new President, and thanked Andrea Ballabio for his work over the past year. Andrea became the Vice-President.
- Peter Farndon was welcomed by Jean-Louis Mandel as the incoming Secretary-General

IX. Election of President-Elect and Board members:

- Stylianos Antonarakis (Geneva) and Gerd Utermann (Vienna) had been nominated for President-Elect. After each presented his motivations, a vote was taken by secret ballot. Gerd Utermann was elected the new President-Elect of the ESHG.
- Up to four Board members are chosen each year. Up to two can be proposed by the Board; this year, since there are several ad hoc members (a total of 26 persons), the Board nominated only one person, Anne Hagemeyer from Belgium. She has accepted. She will also be the Belgian representative for the legal foundations of the Society, as required by law.
- Six individuals had been nominated by the membership for the Board. Each took the floor briefly to state his motivations, prior to a vote by secret ballot. Thomas Meitinger (Germany) and Rodney Harris (United Kingdom) were duly elected.

X. Varia

- Our new President, Jean-Louis Mandel, spoke about some of his views and plans concerning the Society for the future, including political links with the European Parliament and closer relations with National societies and other professional groups involved in human genetics.
- The meeting closed at 19h50

CDB, July 1999

CALENDAR OF NATIONAL AND INTERNATIONAL MEETINGS

(see also <http://www.eshg.org/Noticeboard> and Issue 1 of the ESHG newsletter)

APRIL 2000

1st Alps Adria Meeting on Human Genetics

Brijuni Islands, Croatia, 14-15 April, 2000

Contact: <http://www.alpsadriagenetics.crolink.net> (ana.stavljenic-rukavina@zg.tel.hr)

1st Workshop on Molecular Basis of Mental Handicap

27-30 April, 2000, Chamonix, FR

Contact: Italian Society of Medical Genetics : M. Fontes (fontes@medecine.univ-mrs.fr)

MAY 2000

VIIIth CEPH Annual Conference: "Genetic history of modern humans"

25-26 May, 2000, Paris, FR

Contact: Foundation Jean Dausset- CEPH see: <http://www.cephb.fr/> (conference@cephb.fr)

JULY 2000

Congresso Internazionale "La Genetics sulle Neuroscienze"

2-5 July, 2000, Terni IT

Contact: Fondazione Agarini, fax: (39/0744) 56.61.26 (sigu@dnaserver.med.uniroma2.it)

SEPTEMBER 2000

28th Conference of the European Teratology Society

11-14 September, 2000, Ferrara, IT

Contact: European Teratology Society (ets2000@sestantenet.it)

OCTOBER 2000

50th Annual Meeting of the American Society of Human Genetics

3-7 October, 2000, Philadelphia, Pa., USA

Contact: ASHG: <http://faseb.org/genetics/ashg/ashgmenu.htm>

NOVEMBER 2000

IIIrd National Meeting of the Italian Society of Human Genetics (SIGU)

29 Nov-1 December, 2000, Populo, Orvieto, IT

Contact: Secretariat: cscpg@tin.it

DECEMBER 2000

DNA Molecular Diagnostics

14 December 2000, Prague

Contact: Inst. Hematology & Blood Transfusion, Prague; Prof. R. Brdicka (tel: 004202/29.32.28)

*Appropriate announcements are published free of charge here and on the ESHG website.
Please contact Dr. Célia DeLozier-Blanchet (delozier@cmu.unige.ch) or Mrs. Ruth Cole (eshg@eshg.com)*



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CONTRIBUTIONS

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