

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

*March 2000
Newsletter no.1*

PRESIDENT'S WELCOME

This is the first issue of the Newsletter that the ESHG intends to send two to three times per year to its members, in order to improve communication between the Society and you. We plan to publish here, in addition to a calendar of events, short descriptions of the status of human genetics in European states, and snapshots on information that you will find developed on our web site. This web site is the object of much work and attention from our new secretary general Peter Farndon, and we hope that you will become addicts of the information it contains. For instance, we plan to put on the site, position papers or national regulations on items linked to genetic testing, from various European states.

We will also inform you of the activities of the various subcommittees of the ESHG, notably the PPPC (Professional and Public Policy Committee) that is very active under the presidency of Ségolène Aymé, and that has convened 4 workshops, sponsored by a grant from the EEC.

This first newsletter is also the occasion to consider the progression and goals of our Society.

- ◆ It began with the organisation of the European Meeting of Human Genetics, the 32nd edition of which will take place soon (27-30th May 2000) in Amsterdam, with an exciting programme.
- ◆ A major step forward was the creation of the European Journal, in 1993. The journal has now grown to a monthly publication, allowing more papers to be published (but perhaps not as many as we would wish still), in a timely fashion. So, don't forget to send your best manuscripts to the journal.
- ◆ The third step we should promote, and that was in fact initiated by the activity of the PPPC, is to have the Society more and more involved as an interlocutor for the shaping of public policies on human genetic issues, especially at the EEC level. This is important as the EEC will have greater impact in not only setting regulations, but also in funding activities. One example is the recent ruling voted by the European Parliament that should push the development of orphan drugs for Orphan diseases, many of which of course are genetic diseases. And one could perhaps think about improved co-operation organised at the European level for DNA diagnosis of the many diseases for which clinical geneticists are at great pains now to find a laboratory that will test families.
- ◆ Finally, the ESHG has to take an active part in education issues, both for the training of human and medical geneticists, and also for information of the public. A recent step is the establishment of a collaboration with the European Genetics Foundation that organises, under the direction of Giovanni Romeo, the very successful Sestri Levante courses.

In order to promote these activities, we need energetic board members and presidents. You should thus participate in the postal vote for these positions. And we need of course, your collaboration for ideas, texts and information to put on the web or in the Newsletter.

Professor Jean-Louis Mandel, President

Visit the Website - <http://www.eshg.org>

MEMBERSHIP ADMINISTRATION AND THE SOCIETY'S OFFICE

The ESHG has set up its own administrative office in Birmingham, UK to offer a better service to our members. We have been keeping our own membership records from January 2000, and dealing directly with our members to request payment of the membership fee. We are sharing the facilities of the British Society for Human Genetics. Please contact Mrs Ruth Cole for membership queries and NOT Stockton Press at Nature Publishing Group. Ruth works part-time, so please do be understanding if you need to leave a message if she is not there. Ruth's administrative helper is Linda Bates.



Ruth Cole



Linda Bates

We have processed about 600 applications - if you receive this newsletter you are an ESHG member for the year 2000!

On line subscriptions may take up to one month to set up: this is because our publishers, Nature Publishing Group, use a third party to set up their electronic subscriptions. You will receive an email when your account is active.

ELECTIONS FOR PRESIDENT-ELECT AND TWO BOARD MEMBERS

This year the President-Elect and two Board members will be elected by postal ballot of regular members, rather than by voting in person at the Annual General Meeting, to increase participation of all members. Nominations are therefore requested on the enclosed form. The nominee must be a member of the Society. A job description of the duties of the President-Elect and a Board member are detailed on the enclosed 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).

The ballot form will be included in the next mailing and a date given by which it should be returned. The result will be announced at the Annual General Meeting.

SO WHAT ARE THE PPPC, SPC AND AMC OF THE ESHG?

(An explanation of the Society's acronyms!)

The Society has an **Executive Board** (comprising the officers of the Society) who report to the **Board of the Society** which usually consists of about 20 members. Each year up to 2 Board members (according to the Statutes) are elected by the Society membership, and up to 2 Board members are nominated by the Board itself. This is to try to achieve a wide spread of representation, in line with the special interests of the Society members.

The Board of the Society has set up several committees to oversee certain aspects of Society organisation.

There is an **Annual Meetings Committee** (AMC) which is responsible for all the practical and legal arrangements for the Society's European Human Genetics Conference. The Scientific Programme of this conference is arranged by the **Scientific Programme Committee** (SPC).

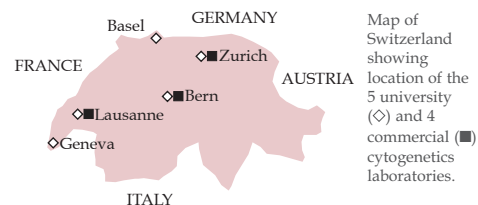
The Board appoints the chairmen of all these committees as well as the Editor of the European Journal of Human Genetics. There is an **Editorial Board** working closely with the Editor to develop editorial policy. There is a new **Publications Committee** which will be the Society's means of developing its relationship with our publishers over organisational and financial matters.

The PPPC is the **Public and Professional Policy Committee**. The PPPC builds up the programme of the Public Awareness Session at the European Human Genetics Conference in collaboration with the Scientific Programme Committee. The PPPC is organising four workshops on topics impacting on professional practice and on the relationship between human geneticists and the public - Insurance and Employment, Genetic Services in Europe, Genetic Screening, DNA Storage and DNA Banking.

The chair people and members of all these committees can be found on our website.

Professor Peter Farndon, Secretary-General

GENETICS IN EUROPE: HIGHLIGHT ON SWITZERLAND



Switzerland is a small country, with a population of only about 7 million. The standard of living, however, is high, and medicine as well as medical genetics well-developed. Most clinical genetics services are offered through University medical centres, of which there are five: Basel, Bern, Geneva, Lausanne, and Zurich. All offer clinical consultations and cytogenetic and molecular testing, and teach genetics in the medical school curricula. In addition, four private laboratories offer cytogenetic testing (some also offer a limited number of molecular analyses). Several groups outside of the university departments specialise in molecular investigation of specific types of disorders (e.g. hemoglobinopathies, familial cancer genes). Switzerland also hosts a large number of well-known research laboratories, within both the private and the public sectors.

Recognised training in medical genetics has however lagged behind until recently. Genetics as a medical sub-specialty has been offered only since 1999. The Swiss Society of Medical Genetics has developed recommendations for laboratory certification and the training of laboratory geneticists, but these are not yet requirements on a federal level. There is as yet no specific programme for para-medical training (genetics nurses, genetic counsellors) in our field, although a growing number of courses and seminars for nurses, biologists and primary care physicians attest to the

need for both initial training and continuing education programmes.

Switzerland has three major official languages: French, German and Italian, and a small proportion of the population speaks Romansch. Although the Swiss are talented linguists, it is hoped that similar genetics services can be offered in each linguistic region. This proposal in practice is sometimes difficult and reinforces a certain tendency for linguistic regions to collaborate with the neighbouring European country speaking the same language (e.g. Swiss Romand with France) rather than between themselves. Some regions, such as Geneva, have a high proportion of foreigners (30% in the city of Geneva), speaking a multitude of languages.

Switzerland is a popular democracy, in which initiatives and referendums come to the people for votation. Through this process some developments in medical genetics have been forbidden by law; a 1992 vote, for example, outlawed such practices as surrogate maternity, oocyte donation, and pre-implantation diagnosis. Controls on research involving animals are strict, as are federal regulations concerning the use and dissemination of genetically-modified organisms. Nonetheless, medical genetics is able to offer state-of-the-art clinical and research services to the population and the international community.

Dr Célia DeLozier-Blanchet

COURSES IN COLLABORATION WITH THE EUROPEAN GENETICS FOUNDATION

The ESHG has developed a collaboration with the European Genetics Foundation (EGF), a non-profit organisation dedicated to advanced training in human genetics and preventive medicine in Europe and to the public understanding of genetics. The EGF, with its headquarters in Genoa, Italy, has a permanent venue (La Nunziata Center) in the lovely seaside resort town of Sestri Levante, Italy.

The EGF is offering 10 courses:

Medical Genetics,

Cancer Genetics,

Genetic Counselling in Practice,

Developmental Biology and Dysmorphology,

Molecular Cytogenetics,

Thalassemias and Sickle Cell Anemia in the Mediterranean,

DNA fingerprinting (September 21-23),

Genetics of renal disorders (December 2000),

Bioinformatics (late October 2000),

Comparative functional genomics (October 27-29).

Please see the ESHG website (under "Courses") for more details.

CALENDAR OF NATIONAL AND INTERNATIONAL MEETINGS

MARCH 2000

22nd-25th March - Annual congress of German and Austrian Societies of Medical Genetics, co-jointly with the Swiss Society

Venue: Lubeck, Germany - Contact: Prof. E. Schwinger, tel. (49/451) 500.26.20
website <http://www.humangenetik.mu-luebeck.de>

APRIL 2000

10-14th April - Society for General Microbiology, Millennium Meeting

Venue: Warwick, UK - Contact: Josiane Dunn (j.dunn@sgm.ac.uk) see: <http://www.socgenmicrobio.org.uk>

19th April - 3rd Workshop on Molecular Genetics and Cytogenetics

Venue: Hraec, Kralove - Contact: Drs P. Balicek and Z Fiedler (0042/049)583.2553

MAY 2000

17th May - Prenatal diagnosis and fetal medicine

Venue: Olomouc, Tsh. - Contact: Dr. J. Santavy (santavj@risc.upol.cz)

25-26th May - 8th CEPH annual conference: Genetic history of modern humans

Venue: Paris, FR - Contact: Jean Dausset-CEPH (conference@cephb.fr) <http://www.cephb.fr>

27-30th May - European Human Genetics Conference

Venue: Amsterdam, NL
Contact: <http://www.eurocongres.com/eshg>

JUNE 2000

Issues in Human GenEthics

Venue: Portugal - Contact: F. Dias (fatima.dias@britcounspt.org) and Prof. Carolino Monteiro

14th June - Oncogenetics (with international participation)

Venue: Medical House, Prague - Contact: Prof. P. Goetz (petr.goetz@lfmotol.cuni.cz)

16-17th June - Issues in Human GenEthics

Venue: Portugal - Contact: The British Council, Portugal (Fatima.Dias@britcounpt.org)

26-30th June - Annual Conference of Cytogenetic Section, Biological Society & 14th European colloquium on cytogenetics of domestic animals

Venue: Brno - Contact: Prof. J. Rubes (rubes@vri.cz) and Prof. K. Michalova

SEPTEMBER 2000

2-5th September - 2nd HUGO Mutation Detection Training Course

Venue: Leeds, UK - Contact: Dr. Graham Taylor (gtaylor@hgmp.mrc.ac.uk) see: <http://www.leeds.ac.uk/cmgs/leedsdna/science/hugo/index.html>

11-13th September - British Human Genetics Conference

Venue: University of York - Contact: Mrs Ruth Cole (york2000@bshg.org.uk)

OCTOBER 2000

3-7th October - 50th meeting of the American Society of Human Genetics

Venue: Philadelphia, Penn. USA - Contact: ASHG (<http://www.faseb.org/genetics/ashg/ashgmenu.htm>)

9-10th October - Workshop on Prenatal Diagnosis

Venue: Brno - Contact: Dr. A. Altova (tel. 42/054)122.571

13-14th October - 3rd Luso-Prasilien Medical Genetics Symposium and 9th Brasilien Clinical Genetics Congress

Venue: Rio de Janeiro, Brazil - Contact: Dr. Jorge Saraiva (hpcgen@hotmail.com)

13-14th October - 4th meeting of the Portuguese Society of Human Genetics

Venue: Oporto, Portugal - Contact: Dr. Jorge Saraiva (hpcgen@hotmail.com)

NOVEMBER 2000

29th November - Clinics and Genetics of Hyperlipoproteinaemias, 20th symposium (in memoriam: Prof. Josef Sobra)

Venue: Karlov, Prague - Contact: Dr. R. Ceska (tel. 004202/249.19.780)

DECEMBER 2000

14th December - DNA Molecular Diagnostics

Venue: Prague - Contact: Prof. R. Brdicka (tel: 004202/29.32.28)

EUROPEAN HUMAN GENETICS CONFERENCE
an international forum for all workers in human and medical genetics
Saturday 27th - Tuesday 30th May 2000, Amsterdam, The Netherlands

THE SCIENTIFIC PROGRAMME WILL INCLUDE:

- Invited lectures from:
D Bootsma, A Brice, K Bushby, H Cooke, K Devriendt, R Fodde, A Fainberg, D Fitzpatrick, A Gouts van Kessel, A Goldberg, N Gregerson, P Guicheney, I Hanson, P Harper, U Hertl, A Holenias, A Karmikoff Smith, B Knoppers, I Liebaers, R McInnes, C Mecucci, M Pirastu, R Plasterk, M Richards, A Rosenthal, J Satsangi, D Shore, J Terwilliger, M UH, C Van Broeckhoven, G Vriend, B Weber, J Weissenbach, B Wieringa, C Wijmenga, E Wolf, M Zeviani, O Zuffardi
- Workshops on current topics
- Late breaking research session
- Posters

FURTHER DETAILS:
Please visit the conference website: www.eurocongres.com/eshg

CONTRIBUTIONS

for the ESHG newsletter should be sent to Dr. Célia DeLozier-Blanchet (delozier@cmu.unige.ch) or Mrs. Ruth Cole (eshg@eshg.org)