

MINUTES
Second Meeting of the Executive Committee of HUGO
27 April 1989, 13:30-15:30
Cold Spring Harbor Laboratory, CSH, New York, USA

In attendance:

Executive Committee:

Walter Bodmer - vice president
Charles Cantor - member
Malcolm Ferguson-Smith - member
Leroy Hood - member
Kenichi Matsubara - vice president
Victor McKusick - president
Frank Ruddle - member
John Tooze - secretary

Founding Council:

George Cahill
John Collins
Nancy Jenkins
Peter Pearson
Nobuyoshi Shimizu
Tom Shows
Ed Southern
Norton Zinder

Staff:

Diane Hinton
Joanna Strayer

Absent: Jean Dausset (vice-president), Lennart Philipson (elected member)

I. Articles and By-laws

Victor McKusick opened this second Executive Committee meeting by reviewing the Articles and By-Laws of Association. Special attention was given to the structure of the organization emphasizing that the General Assembly is the supreme body. The operating body will be a Council of 18 members. One-third of the Council will stand for election each year. Officers will be elected from within the Council by the Council. The Secretary and Treasurer are elected (appointed) by the Council and do not have to be members of the Council. The Council in 1990 will consist of the current 9 member Executive Committee, the Secretary and Treasurer (to be appointed) and 6 more members to be elected in the upcoming election.

A list of the 178 members elected at the beginning of this year was distributed.

The system for nomination for membership and Council was reviewed. A nomination is valid if signed by 5 HUGO members, 3 of whom are from a country other than that of the nominee. Each person at this meeting was urged to think of nominees. Nomination forms will be circulated later.

II. Program

Victor McKusick brought up the James Watson's suggestion that particular groups should be designated to take the lead in coordinating physical mapping and sequencing of each chromosome and in particular to see that the job is finished. The NIH and DOE are now talking about such a division of labor on the national level and will have a proposal in December 1990 that HUGO will be invited to review. This suggestion stimulated considerable discussion. The appropriateness of HUGO in this connection is clear because of the necessarily and desirably international nature of the undertaking.

Tom Shows pointed out that such a group had met to review the status of research on chromosome 11. This group was encouraged by its first meeting and would like to meet again and perhaps circulate a newsletter. It was cautioned, however, that HUGO's role is that of facilitation, and that these groups should be encouraged to evolve naturally. Also, the dangers of too early identification of a particular chromosome or of particular national interest was emphasized. Perhaps these groups could be logical extensions of the chromosome committees at the Human Gene Mapping Workshops.

Charles Cantor briefly reviewed the progress of the Physical Mapping Committee which will be meeting 28 April 1989. It is a general feeling that here, as in other areas, HUGO can serve a coordinating function between the physical mapping committees of various national groups and various groups within nations (e.g., DOE and NIH in the United States).

Lennart Philipson has been working on setting up a database committee. He would like to have input from the NIH and DOE database committees. It was evident that HUGO should take the initiative in this area to maintain international balance. Philipson will have the constitution of this committee by HGM10. Philipson does not want to be the committee chairman.

At the requests of Mary Lyon, Nancy Jenkins, and other mouse geneticists a Mouse Genome Committee formed. It was voted to ask Mary Lyon to chair this committee which is to have not more than 12 members who do not necessarily have to be members of HUGO.

An international fellowship program is very desirable and should be constituted as soon as funds are available. The Australian government is interested in supporting some sort of international training grants. UNESCO is interested in sponsoring training grants for underdeveloped countries. Kenichi Matsubara reported that one or more industrial firms in Japan would be willing to support a fellowship program or individual fellowships providing their name is associated with the fellowship. Matsubara indicated these companies contributions could be considerable. He will work with McKusick to follow up on these companies.

Germany and the EEC are deeply concerned about ethical issues surrounding research in genetics. It was said that HUGO should establish a committee on the scientific, ethical, social, legal and commercial implications of the human genome projects to help fulfill article 3.1 of the Articles of Incorporation.

III. Administration and Funding

It was voted to place the 3 regional offices as follows: In London, UK at the ICRF, in Bethesda, USA at the Cloisters, and in Osaka, Japan. Oversight at these locations will be provided by Bodmer, McKusick, and Matsubara, respectively.

John Collins reported that funding from West Germany will be difficult due to the popular opposition to genetic research. He thought that a letter from the president of HUGO would be helpful and will draft such a letter.

Peter Pearson indicated that support for the genome effort may be obtainable from the EEC. He will draft a letter for McKusick to send to Mr. Pandolfi, the Commissioner for Science.

Matsubara reported that the Human Frontier Science program in Japan is considering a budget of 20 billion yen per year. The money is marked for scientific research. The director, however, is interested in international collaboration, and Matsubara will urge him to consider giving money for such collaboration.

IV. Miscellaneous

Bodmer reported conversations with Federico Mayor, the Director General of UNESCO. He is under the impression that the role of UNESCO would be best served in connection with an international fellowship program and with the program of HUGO associated with ethical and societal issues.

It was announced that an informal planning meeting will be held in Moscow on Sunday, June 25 for the purpose of planning an official meeting in 1990. UNESCO plans a meeting on June 26 and 27 which will be attended by the HUGO members present in Moscow.

V. Other Old Business

A new rendering of the logo prepared by a London designer was displayed and discussed. Cantor mentioned that the DNA helix as represented was reversed from what it should be; this will be

corrected. Several others mentioned they preferred other designs. This matter was not resolved.

It is to be noted that organization in The Human Genome Organisation is to be spelled with an "s". This was viewed by McKusick as appropriate for an organization incorporated in Switzerland and with world-wide scope.

VI. Other New Business

It was voted to send Charles Cantor as the official representative of HUGO to the meeting of ICSU (International Council of Scientific Unions) in Lisbon on October 13, 1989. The invitation comes from Dr. Allende of Chile.

The business set out in the circulated agenda having been completed, the Executive Committee adjourned at 3:40PM.

MINUTES
Third Meeting of the Executive Committee of HUGO
13 June 1989, 10:15-12:30
Davies Auditorium, Yale University, New Haven, CT, USA

In attendance:

Executive Committee:

Walter Bodmer - vice president
Malcolm Ferguson-Smith - member
Lennart Philipson - member
Victor McKusick - president
Frank Ruddle - member

Members:

Arthur Beaudet
Kåre Berg
George Cahill
P. Michael Conneally
Charles Coutelle
David Cox
Muriel Davisson
Larry Deaven
Helen Donis-Keller
H. John Evans
Marc Fellous
Anna-Marie Frischauf
Karl-Heinz Grzeschik
Nancy Jenkins
Bronya Keats
Peter Lalley
Mary Lyon
Phyllis McAlpine
P. Meera Kahn
O.J. Miller
Felix Mitelman
Jan Mohr
Stephen O'Brien
Jürg Ott
Elizabeth Robson
Nobuyoshi Shimizu
Thomas Shows
Mark Skolnick
Ellen Soloman
Robert Sparkes
Grant Sutherland
Gert Jan van Ommen
Herman van den Berghe
Nguyen Van Cong
Raymond White

Observers:

Scott Diehl
Paul McDonough
Pierre Sinet
Hermona Soreq
Haim Zakut

Staff:

Diane Hinton
Bronwen Loder
Joanna Strayer

Absent: Charles Cantor (elected member), Jean Dausset (vice-president), Leroy Hood (elected member), Kenichi Matsubara (vice president), John Tooze (secretary)

I. Articles of Incorporation, Membership, Elections

Victor McKusick opened the meeting announcing that HUGO was nearly incorporated; the process having taken much longer than expected. He reviewed the organizational structure of HUGO as explained in the Articles and By-laws stressing that HUGO was following the academy model as decided upon at the Montreux meeting. He announced that 220 nominees received a majority of the Executive Committee votes in February. Membership now numbers 219 as Frederick Sanger declined the invitation.

Helen Donis-Keller requested that the discussion regarding open membership in HUGO be re-opened, and others requested a clarification of the nomination process. The nomination process was reviewed, and it was stated that open membership would require a change to the Articles and this discussion was put off to a later date. In addition, it was stated that members of HUGO committees do not have to be members of HUGO. This practice has precedence in other scientific organizations.

II. Election of Treasurer

There was a call for nominations for treasurer. Malcolm Ferguson-Smith nominated George Cahill. Lennart Philipson seconded the nomination. No other nominations were given. A general vote was taken; George Cahill was elected treasurer of HUGO.

III. Report on finances and Fundraising

Victor McKusick reported that HUGO has about \$90,000 in hand or promised over the next 3 years. He mentioned funding possibilities from the private sector in Japan and the Italian and Australian governments. He also reported that the Howard Hughes Medical Institute (USA) and the Imperial Cancer Research Fund (UK) have supported meetings of HUGO. The ICRF has promised funding to HUGO, and there is a good possibility of additional funding from HHMI. Eventually, HUGO would like to have multi-national funding to \$1-1.5 million per year.

Several members pointed out that for HUGO to obtain governmental funds it will be necessary to have clearly stated plans and budgets to carry out HUGO's objectives.

From here on, all financial matters concerning HUGO should be channelled through George Cahill.

IV. Mouse Genome Committee

The Mouse Genome Committee was established in May 1989 and is chaired by Mary Lyon.

Mary Lyon reported that the Mouse Mapping Workshop will be held in Oxford, UK from 24-26 August, 1989. The Mouse Genome Committee will be constituted at this meeting. The Mouse News Letter will be the primary organ of this committee.

V. Formation of Committee for Human Gene Mapping Workshops (HGMW)

Victor McKusick reported that there was a discussion with the Executive Committee of the HGMW and several members of HUGO's Executive Committee regarding the establishment of the HGMW as a committee under HUGO. This relationship was accepted and realized to be mutually beneficial. It was agreed that due to previous commitments, the workshops will continue in the same format for the next 4 years. During this period, the HGMW will retain virtual autonomy. A letter of understanding was circulated to the HGMW committee chairs (see attachment A).

HUGO is not seen as the major funding agency for the Workshops, but rather as source of funding to provide stability and management in the interim between workshops.

V. Database Committee

Lennart Philipson has constituted a tentative database committee; 3 from the US (hopefully with a link to existing NIH and DOE bioinformatics projects), 3 from Europe, and 1-2 from Japan. This committee is initially small, but will expand as needed. It is important that this committee have members with considerable computer expertise. As previously agreed, this committee will not have database managers or operators as members of the advisory or decision making body, but the database managers/operators will be invited to many of the meetings and consulted regularly. Considerable discussion ensued regarding this point, but in the end, it was felt that given what has happened with

databases in the past and the service oriented nature of databases, the only way the committee will be effective and neutral is to be constituted from outside the community of database operators and managers.

Philipson would like to have a meeting of the Database Committee this fall and invite the operators of the various genetics databases to come and make presentations about their databases. The chairman of the Database Committee will be selected then.

VI. Ethics, etc. Committee

As the genome projects progress, many ethical, societal, political, legal and commercial issues will arise. Some of the current issues have already threatened funding for biotechnology in several countries.

Victor McKusick called for names that would be appropriate for membership in this committee. They are as follows: Barton Childs, Charles Coutelle, Neil Holtzman, George Klein, Arno Motulsky, Benno Muller-Hill, Martinus Niermeijer, Charles Sriver, Marjory Shaw, Maxine Singer, Nancy Wexler, Haim Zakut. It was felt that the chairman of this committee should be someone that is not connected with the "Genetics Establishment." There will be further discussions regarding the nature of this committee at a meeting to be held 15 June 1989, time and place to be announced.

VII. Physical Mapping Committee

Walter Bodmer reported on the Physical Mapping Committee meeting held in Cold Spring Harbor on 28 April 1989. The major points from this meeting included the desirability of having sets of cell lines, chromosome and genomic libraries commonly available. Rules governing obligation and responsibilities of users, fees, networking, quality control and a plan for establishing ordered arrays of these libraries will need to be established. Physical mapping efforts should be encouraged to parallel the efforts in the gene mapping community. Three subcommittees were established to address these issues: Sample Accession (Hans Lehrach - chair); User Obligations (Anthony Carrano - chair); Distribution Network (Daniel Cohen - chair). HUGO will help with organizational matters. The overall cost should be shared internationally. The next meeting will be held later this year.

VIII. Planning Meeting in USSR

Several HUGO members will be attending a planning meeting in the USSR 23-30 July 1989. This meeting will be to initiate plans for a full meeting of HUGO there at a later date, perhaps October 1990. HUGO would also like to find out the extent of the Soviet commitment to a genome project. UNESCO has also planned a meeting there on 26-27 July to discuss similar issues. It is important that HUGO assume the dominant role.

IX. New Business

The next Executive Committee meeting will be held during the Human Genome I conference in San Diego, California 2-4 October 1989.

X. Old Business

As one of the co-editors of GENOMICS, Victor McKusick will provide space in the Special Features section of the journal for HUGO news. In the future, however, it may be useful to have a HUGO newsletter.

The polished version of the logo done at the ICRF was unveiled. Several previous logos were reviewed, since obtaining a consensus from the members was difficult, it was decided to leave the decision to the president.

The business set out in the agenda having been completed, the Executive Committee adjourned at 12:30 PM.

June 16, 1989

Dr. Robert S. Sparkes
President, Executive Committee
Human Gene Mapping Workshops

Dear Bob:

This is a letter of understanding which I am writing in my role as president of HUGO. It was the action of the meeting of the Executive Committee of HUGO on Tuesday, June 13, 1989, that the Human Gene Mapping Workshops be accepted as a component organization within HUGO with certain particular understandings.

It is the intention of HUGO to establish a committee for Human Gene Mapping Workshops: the committee will be chaired by members of HUGO and will have as a substantial portion of its membership those who are members of HUGO, but as in the case of other committees which have been constituted to date (Database Committee; Physical Mapping Committee; Mouse Gene Mapping Committee; Committee on Societal, Ethical, Legal, Commercial etc. Issues), other members will be drawn widely as necessary and appropriate to the conduct of the business of the committee.

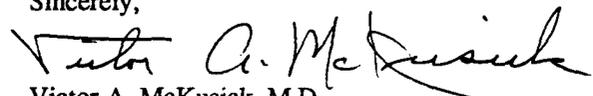
It is our understanding that autonomy will be extended to the Executive Committee of the Human Gene Mapping Workshops for the period covered by HGM 10.5 (to be held in Oxford in September, 1990), HGM 11 (to be held in London in August, 1991), and HGM 12 (to be held in Japan in 1993). This special concession is necessary because of commitments already made, particularly in relation to HGM 10.5 and HGM 11.

It is clear from the present constitution of the Executive Committee of HUGO that inevitably several members of the Executive Committee of the Human Gene Mapping Workshops will be on the 18-member Council of HUGO. However, for the next 4 years of special arrangements, it will be the intent of HUGO to coopt to the Council the Chairman of the HGMW Committee if that person is not already on the Council. It is by these mechanisms, I believe, that the interests of the human gene mapping community should be adequately represented in HUGO.

The by-laws of HUGO specify that the Council has the prerogative to appoint all committees. It would be my understanding that HUGO would assign to the executive group of the Human Gene Mapping Committee the prerogative to nominate the full committee, which would be formally approved by the Council. It is my further understanding that, in the spirit of the earlier understanding, autonomy will be extended to the HGMW group for the period of the next two workshops; the Council would reject the nominations only under extreme and unusual circumstances and with good and sufficient reasons.

Because of my interest in both HUGO and the Human Gene Mapping Workshops, I am delighted to see the prospect of the arrangements outlined in this letter.

Sincerely,


Victor A. McKusick, M.D.
President, HUGO

On behalf of the HGMW Executive Committee, I am signing this letter as an indication of acceptance of the above stated agreement.

 June 16, 1989

Robert S. Sparkes, M.D. Date
President, HGMW Executive Committee