INITIATING INTERNATIONAL COLLABORATION:
A STUDY OF THE HUMAN GENOME ORGANIZATION

by

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(ABSTRACT)

The formation of the Human Genome Organization, nicknamed HUGO, in 1988 was a response by scientists to the increasing number of programs designed to examine in detail human genetic material that were developing worldwide in the mid 1980s and the perceived need for initiating international collaboration among the genomic researchers. Despite the expectations of its founders, the Human Genome Organization has not attained immediate acceptance either inside or outside the scientific community, struggling since its inception to gain credibility. Although the organization has been successful as well as unsuccessful in its efforts to initiate international collaboration, there has been little or no analysis of the underlying reasons for these outcomes. This study examines the collaborative activities of the organization, which are new to the biological community in terms of kind and scale, and finds two conditions to be influential in the outcome of the organization’s efforts: 1) the prior existence of a model for the type of collaboration attempted; and 2) the existence or creation of a financial or political incentive to accept a new collaborative activity.
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This thesis is dedicated to Doodle, gone but not forgotten.
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INTRODUCTION

The creation of the Human Genome Organization (HUGO) in April 1988 is often associated with the development of the international Human Genome Project, a quest to map and sequence the entire human genome in a 15-year period. In reality, genomic research programs involving mapping and sequencing small parts of the human genome had already been established in many countries, and the need for an organization that could foster international collaboration of the research had been discussed in the scientific community for several years before the Human Genome Project was formalized. The official backing of an international Human Genome Project by the U.S. government did, however, provide an incentive to translate talk into action.

In February and April of 1988, respectively, the National Research Council, of the National Academy of Sciences, and the Office of Technology Assessment, of the U.S. Congress, released reports on the subject of a federally funded human genome project. Members of the committee commissioned by the National Research Council endorsed a recommendation to initiate a project for completely mapping and sequencing the human genome in 15 years. The report from the Office of Technology Assessment proposed various

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1 The term Human Genome Project refers simultaneously to the U.S. human genome project and to the international effort, since the U.S. project was designed to be an international project.

2 The human genome is made up of one set of chromosomes and all the genes they contain.

3 Mapping the genome involves locating the genes to a particular chromosome and then determining the position of the genes relative to one another on each chromosome.

4 Sequencing is the act of determining the specific order of the nucleotides or bases (guanine, cytosine, adenine, thymine) that make up the DNA of a chromosome.
potential administrative frameworks for carrying out a federally funded genome initiative, including the structure eventually adopted: multi-agency oversight, coordinated by an inter-agency committee. On April 29, 1988, days after the release of the Office of Technology Assessment report, HUGO was formed at an informal session that was announced at the opening of the Cold Spring Harbor summer symposium on genome mapping and sequencing.

HUGO is not the first organization to be formed with the intent of initiating international scientific collaboration. In fact, it is modeled after another international organization, the European Molecular Biology Organization (EMBO), which, in turn, is modeled after the European Nuclear Research Organization (CERN). HUGO is unique, however, because of its original combination of structure, function, and activities, and because it is coordinating collaboration for the biological sciences’ first large-scale, international research project, a size and type of collaboration not previously attempted by this community.

Despite the confidence of HUGO’s founders that HUGO would attain immediate success and acceptance both inside and outside the scientific community, the organization has been struggling since its inception to gain credibility in either. Although successful as well as unsuccessful HUGO efforts have been publicized by the scientific media, there has been little or no analysis of the underlying reasons for those outcomes. This study examines the collaborative efforts promoted by HUGO, which are new to the biological sciences in terms of kind and scale, and finds two conditions to be influential in the outcome of these efforts: 1) the existence of a model for the type of collaboration attempted; or 2) the existence or creation of an incentive to accept a new collaborative effort.
Chapter 1 begins with a brief historical overview of international collaboration in science. First, it describes traditional ways scientific collaborative efforts have been structured and the incentives for such collaboration. Second, it compares organizations preceding HUGO that have initiated international scientific collaboration. Third, it introduces a new type of collaboration in biology: the Human Genome Project and HUGO.

Chapter 2 provides a descriptive account of the formation and early years of HUGO, from April 1988 to December 1992. The account is divided into two time periods: April 1988 to December 1989, and January 1990 to December 1992. Each time period corresponds to a term of office served by a HUGO President, since the path of HUGO's development has been strongly influenced by the individuals occupying that office.

Chapter 3 analyzes the successful and unsuccessful collaborative efforts of HUGO and finds two conditions to be influential in establishing new forms of international scientific collaboration: 1) the pre-existence of a model, on which a new effort can be based, and 2) the existence or creation of a financial or political incentive, which can facilitate the acceptance of an effort for which there is no model. The significance of this second condition lies in the realization that need for a novel type of collaboration is not always enough incentive to garner acceptance of it. This section also considers the areas of scientific research in which the lessons of HUGO might be useful for future research activities.

This study of the Human Genome Organization has two purposes. First, it is a modest attempt to piece together the history of this organization, which has been documented only intermittently until now. HUGO is a unique organization not only within the biological
community but within the scientific community in general. In addition, it is an interesting organization because it has received a significant amount of criticism from the community that initially supported it, even though it has achieved some important accomplishments. Unfortunately, much of HUGO's history is undocumented, and details are increasingly being lost as HUGO grows older.

Second, this study is intended to add to the limited but growing body of literature on international scientific collaboration and the conditions required for successful collaborative activity in international scientific projects. For the policy community, the usefulness of studying HUGO is linked to the trend in science whereby international collaboration is becoming increasingly important. HUGO's unique collaborations, and HUGO itself, may serve as useful models on which to base future collaborative efforts in science. An analysis of the factors influencing the success or failure of HUGO's activities can provide a foundation for the successful establishment of novel international collaborations and of the organizations designed to coordinate them.
Chapter 1  Science and International Collaboration

Overview of International Scientific Collaboration

Advances in many communication techniques along with recent social and economic changes have made access across national borders easier and are making it possible for scientists widely separated from each other to undertake international projects. Within the scientific community international collaboration provides an expansion of resources, particularly in terms of funding and personnel, two limiting factors in the pursuit of large scientific projects.

While technological, political, and economic developments of the last several decades have been essential in the development of a global scientific research, international scientific projects are not a new idea. They have an extensive history, traceable as far back as the International Polar Year, August 1882 to August 1883 (see Table 1). This international enterprise organized expeditions to different areas of the Arctic to observe weather, since it was believed that the weather in that region could seriously influence weather changes in the surrounding countries. The project was organized by the Conference of Meteorological Directors, whose goal it was to have thousands of scientists from eleven nations observe the weather from fifty observation stations using a common plan of study.¹

<table>
<thead>
<tr>
<th>Organization</th>
<th>Year Founded</th>
<th>Inter-governmental Structure?</th>
<th>Membership*</th>
<th>Structure</th>
<th>Function</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>IPY</td>
<td>1882/1883</td>
<td>No</td>
<td>Open</td>
<td>N/A</td>
<td>Common study of the weather in the Arctic region</td>
<td>Intensive observations of the weather, the aurora borialis, and magnetic disturbances in the Arctic region</td>
</tr>
<tr>
<td>UNESCO</td>
<td>1946</td>
<td>Yes</td>
<td>Open</td>
<td>General Conference of UNESCO; Executive Board</td>
<td>Contribute to world peace and security through education, science, culture, and communication</td>
<td>Establish scientific foundations and programs. Correct the centralization of scientific activity and manpower</td>
</tr>
<tr>
<td>CERN</td>
<td>1952</td>
<td>Yes</td>
<td>Open</td>
<td>Council; Scientific Policy Committee</td>
<td>Pursuit of fundamental research in particle physics</td>
<td>Design, build, and operate particle accelerators for use in basic particle physics research</td>
</tr>
<tr>
<td>IGY</td>
<td>1957/1958</td>
<td>No</td>
<td>Open</td>
<td>International Council of Scientific Unions Special Committee; Executive Committee</td>
<td>Common study of our planet by all nations for the benefit of all</td>
<td>Intensive observation of the weather, the aurora, the earth's magnetic changes, the ionosphere, and the sun</td>
</tr>
<tr>
<td>EMBO</td>
<td>1963</td>
<td>Yes</td>
<td>Academy Model</td>
<td>General Assembly</td>
<td>Unite molecular biologists of Europe and stop their emigration to the U.S.</td>
<td>Distribute fellowships, finance workshops and practical courses, and publish professional journals</td>
</tr>
</tbody>
</table>

Abbreviations: IPY, International Polar Year; UNESCO, United Nations Educational, Scientific and Cultural Organization; CERN, European Nuclear Research Organization; IGY, International Geophysical Year; EMBO, European Molecular Biology Organization; N/A, not available.

*The open model of membership is characterized by unlimited membership; the academy model is characterized by limited and elected membership.
Since that initial effort there have been other types of international cooperative efforts. The structure of such ventures has taken various forms. At the large-scale end the structure may be a large, international project, such as the International Polar Year. At the small-scale end, the structure often takes the shape of informal exchanges or visits. The specific framework chosen depends on several considerations, some of which were outlined in a study conducted by the National Research Council and adapted in part from the National Science Foundation's Advisory Council's final report on expanded scientific cooperation with Western Europe. According to that study, the factors listed below appear to be determinants of the structure eventually chosen for an international collaborative activity.\(^2\)

(1) the nature and frequency of the information to be exchanged,

(2) the length of time for which cooperating scientific personnel must interact,

(3) the extent to which the problem lends itself to a division of labor and the relative scientific strength of the cooperating partners,

(4) the relative economic strength of the cooperating partners,

(5) the type and cost of the facilities involved,

(6) the degrees to which global coordination is required (e.g., the model of the International Geophysical Year), and

(7) the extent to which national security or proprietary concerns or other sovereign prerogatives are involved.

In addition to these factors, a collaborative effort is often structured according to its intended function. Generally, for collaboration focusing mainly on the exchange of

information multilateral agreements are favored, as exemplified by the international conferences on AIDS. For collaboration involving more than the exchange of data and personnel, however, a bilateral agreement is frequently used, particularly if the countries involved are technologically advanced. The development of the Hubble Space Telescope, for example, is the product of an international bilateral collaboration between the U.S. National Aeronautics Space Administration and the European Space Agency.

The incentives for initiating international scientific collaboration are varied, but often they can be motivated by political and financial considerations. One incentive arises from the pressure generated within the scientific community due to scientists’ access to high levels of government decision making and their reliance on government funding. By organizing under the structure of international collaboration, scientists can often function as formal or informal pressure groups for particular projects. In some cases, groups of scientists within a discipline are also capable of exerting pressure on intergovernmental or nongovernmental organizations to support a specific collaborative effort for which they may be considered to be beneficiaries.

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3Ibid., p. 7.


Another incentive for collaboration at the international level is the attainment of "critical mass," with respect to funding, human expertise, and facilities. The benefits of attaining that size include access to multiple sources of funding, the ability to produce research results not otherwise achievable by an individual country, and the avoidance of unnecessary duplication of effort. In cases where collaboration is a generalized effort within a discipline, the collaborative effort can promote the coordination of various projects into a significant global program, such as has happened in geophysics with the first International Polar Year.⁶

Well-coordinated collaboration can have a significant financial impact on research, as well, in that it can bring a higher level of visibility to certain areas of research, leading to an improvement in overall funding possibilities.⁷ The organizations listed in Table 1 were established in part to promote international collaboration in scientific areas such as geophysics, molecular biology, and nuclear research when research in those areas looked promising but before the fields were well established or well funded. The improvement of funding, in turn, can increase research activity within a field and strengthen the chances that "spin off" research initiatives will produce unforeseen breakthroughs.


⁷Ibid., p. 21.
Scientific Organizations Initiating International Collaboration

The initiation of international collaboration is frequently accomplished through the establishment of scientific organizations, which are often formed by the scientists themselves for that purpose, as with the European Molecular Biology Organization and the European Nuclear Research Organization (Table 1). An important element of scientific organizations that impacts their function is the relationship between the governments of the countries participating in the organization and the organization itself. Most scientific organizations can be classified as either nongovernmental (also known as international) or inter-governmental.

Nongovernmental organizations can be defined in several ways. Financially, they are usually organizations that do not receive any funding, or only a small portion, of their funding directly from individual governments or through a United Nations type system (assessment system). They may, however, receive funding through governmental endowments for scientific purposes. Functionally, nongovernmental scientific organizations can be classified as organizations that advocate science policy and that assist in the education of scientists through activities like training programs. General characteristics of nongovernmental organizations include a non-profit status, legal independence from governments, a voluntary decision-making structure, and activities that are not controlled by governments that have donated funds. 8

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Inter-governmental organizations differ from nongovernmental organizations mainly with respect to function. In nongovernmental organizations, individual countries or agencies unite and form an agreement to pursue a certain agenda, as with the International Geophysical Year (Table 1). Any decisions regarding appointments or the allocation of resources are made by an international bureaucracy (the International Council of Scientific Unions Special Committee, in the case of the International Geophysical Year) with weak links to individual governments. Thus, while individual governments have little influence over the organization, they do have considerable autonomy in how much money, if any, they allocate to it.  

In contrast, the method of operation of an inter-government organization requires that member governments sign a treaty, thereby committing themselves to contribute a specific amount of money over a definite time period toward a certain set of goals, as exemplified by the European Molecular Biology Organization (Table 1). The general result is that the governments accept responsibility for providing the financial resources and also give up a significant amount of autonomy in terms of how the resources are administered, since that responsibility falls to the organization created by the treaty.  

Nongovernmental organizations are often more appealing in theory to scientists than

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10 Ibid., p. 60.
inter-governmental organizations, since there is less governmental interference and the traditional values associated with science - objectivity, neutrality, production of new knowledge - are shared transnationally by scientists, who do not want their research entangled with political objectives. In reality, however, scientific organizations are frequently inter-governmental due to the financial stability provided by an international treaty.

**Traditional Types of Collaboration in Biology**

The form that an international collaborative effort will take is decided not only by discussion among and consultation with the parties involved; equally influential is the existing historical model of collaboration among the interested parties or within the scientific discipline. In biology, the simple but useful exchange of data and information between two scientists studying similar problems, and the cooperative activities between researcher and assistant are perhaps the oldest forms of collaboration. Although these forms may be the cornerstones of collaboration in biology, they may not have the same significance in other disciplines. At least one study has shown that the most frequently used types of international collaboration for one discipline may be the least used types in another. A survey of National Science Foundation program managers found that certain forms of cooperation were cited with greater frequency in some disciplines than others.\(^{11}\) According to the survey, the biological and behavioral sciences utilize international conferences and focused seminars with

\(^{11}\)Wallerstein, *Scientific and Technological Cooperation Among Industrialized Countries*, p. 7.
almost twice the frequency that they relied on a temporary, multinational mode of cooperation with Western European nations. For research categorized as applied science or research applications, focused seminars and international conferences are used 6 and 10 times more frequently, respectively, than the temporary multinational mode for science and technology cooperation with Western European nations. Astronomical, atmospheric, earth, and ocean sciences, on the other hand, rely on international conferences with only slightly greater frequency than they rely on temporary multinational forms of collaboration.\textsuperscript{12}

There are examples in genomic research where the more unusual multinational mode of collaboration has been used and quite successfully so. The hunt for the cystic fibrosis gene was conducted by a group of research teams from the U.S. and Canada and culminated in the pinpointing of the disease in 1989. Similarly, the search for the gene that causes Huntington’s disease was successfully conducted by “a rare collaboration in the unusually fiercely competitive world of gene-hunting.”\textsuperscript{13} The international research group, formally known as The Huntington's Disease Collaborative Research Group, was comprised of six different research teams from the U.S., England, and Wales. The international collaborative effort began in 1984 and was initiated by the Hereditary Disease Foundation, a nonprofit organization, after the general location of the gene had been determined.\textsuperscript{14} A smaller

\textsuperscript{12}Ibid., p. 8.


collaborative effort is currently underway to identify the gene responsible for a hereditary hearing loss affecting many descendants of a man born in Costa Rica in 1754. A team led by Pedro Leon (University of Costa Rica, San Jose) is working with a team led by Mary-Claire King (University of California, Berkeley) to identify the gene, which Leon’s team mapped to chromosome 5.\footnote{Victor McKusick, "First South-North Human Genome Conference," \textit{Genomics} 14, (1992): pp. 1121-1122.}

\textbf{A New Type of Collaboration in Biology: HUGO and the Human Genome Project}

In the mid 1980s various suggestions were put forth from within the scientific community for the development of a special project to map the entire human genome. However, even before this genome initiative began to take shape, genomic researchers in the United States and several other countries were discussing the need for a coordinating organization to assist scientists in the collaboration of genomic research already being conducted. Only a few days after it became obvious the U.S. would support and help fund an international Human Genome Project, an organization to promote international collaboration in genomic research was created. It was named the Human Genome Organization (HUGO).

The scientific collaboration developed in response to the Human Genome Project is exemplified by the uniqueness of HUGO, whose goal is to promote the international
collaboration that will be necessary in order for the project to be completed. Although HUGO is not the first organization to be formed with the intent of initiating international scientific collaboration in the biological community, it is original because of its combination of structure, function, and activities and because it is coordinating collaboration for biology's first large-scale international research project.

Formed and run by the scientists themselves, HUGO initially received enthusiastic endorsement from the scientific community and the scientific media. It has not, however, attained the success or credibility envisioned by its founders and supporters either inside or outside the scientific community. While the successes and failures of HUGO have been frequently publicized, there has been little or no analysis of the underlying causes of these outcomes. Since the collaborative activities promoted by HUGO are new to the biological community in terms of type and scale, this study examines the early development of the organization and finds that the success of new collaborative efforts is related to the following conditions: 1) the existence of a model for the type of collaboration attempted; and 2) the existence or creation of a financial or political incentive to accept the new collaborative effort.

To examine the activities of HUGO within the framework outlined above, however, the activities promoted by HUGO must be understood within the context of HUGO’s development structurally and functionally over the last 5 years. The details of this development are presented in Chapter 2.
Chapter 2  The Formation and First Years of HUGO: 1988 - 1992

In 1988, HUGO was founded as an organization that would foster new types of international collaboration in conjunction with the international Human Genome Project. HUGO envisioned itself setting policies for collaboration and data-trading practices using a bottom-up type approach through its membership. By the end of 1992, however, HUGO had become mainly a facilitator and coordinator, bringing genomic researchers together but letting them set their own policies. This chapter examines the collaborative efforts initiated by HUGO in an attempt to characterize conditions influential in successfully establishing new forms of cooperation.

Although the U.S.-backed, international effort known as the Human Genome Project\(^1\) was not officially launched until October 1, 1990,\(^2\) by April 1988 numerous research laboratories around the world were engaged in sophisticated research focusing on the human

\(^1\)The term Human Genome Project is often used interchangeably with human genome project, human genome program, and human genome initiative. To date there has been no clear standardization of the terminology in the literature. For the purposes of this paper, Human Genome Project refers simultaneously to the U.S. human genome project and to the international effort, since the U.S. project was designed to be an international effort. Otherwise, the term human genome program is used when referring to a nationally coordinated, government-funded genomics project. The term human genome initiative originally referred to the Department of Energy’s vision of a human genome project before the National Institutes of Health proposed one, but now it is used interchangeably with the term Human Genome Project.

\(^2\)There is not really an exact date for the beginning of the Human Genome Project, but this date is often cited as the official start date because it marks the implementation of the joint DOE-NIH five-year plan. See T. Lee, The Human Genome Project: Cracking the Code of Life (New York, Plenum, 1991), p. 228.
genome, and several countries were developing national genome programs. Italy had initiated its national genome program in 1987, and the United Kingdom and the former Soviet Union were each close to implementing their own nationally coordinated programs by 1988.3 In the U.S., the debate over the merits of a national genome project to completely map and sequence the human genome began in 1985 at a scientific meeting held in Santa Cruz, CA, organized by molecular biologist Robert Sinsheimer, then chancellor of the University of California, Santa Cruz.4 In September 1986, subsequent to the 1986 Cold Spring Harbor symposium on Molecular Biology of Homo sapiens, at which considerable time was devoted to discussing the Department of Energy’s proposed plan to sequence the human genome, the National Research Council of the National Academy of Sciences initiated a study on the feasibility of a U.S. human genome project. At about the same time, a complementary study was undertaken by the Office of Technology Assessment in response to a request by John Dingell, chairman of the Congressional House Committee on Energy and Commerce, for an assessment of a project to sequence the human genome.5 Unlike the National Research Council study, the OTA study focused less on whether there should be a national genome


5From a copy of "Proposal for an Office of Technology Assessment of Mapping the Human Genome" in Robert Cook-Deegan’s archival materials. See also, Watson and Cook-Deegan, "Origins of the Human Genome Project," p. 10.
project and more on Congressional concerns regarding the type of management and coordination a genome project would require.

On February 11, 1988, the National Research Council released the report of its study, which endorsed the implementation of a 15-year project to completely map and sequence the human genome. Eleven weeks later, on April 27, 1988, the OTA report was released. The report proposed various potential administrative frameworks for carrying out a federally funded genome initiative, including the structure eventually adopted: multi-agency oversight, coordinated by an interagency committee. It also approached the issue of international collaboration and cooperation, noting that the size and noble mission of human genome projects made them ideal prospects for international collaboration, and that a willingness by researchers to cooperate on gene efforts was evidenced by the existence of international genomic databases.

The report was formally released during hearings held on the genome project by the House Committee on Energy and Commerce. According to Robert Cook-Deegan, Project Director of the OTA study, the scientific witnesses appearing before the committee formed an impressive list and were largely the same individuals who at the end of the week went straight from the hearings to the Cold Spring Harbor symposium on genome mapping and

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sequencing. It was clear at that point that there was going to be a genome project of some scale, and that it would likely involve more than the U.S. program.  

The Founding of HUGO (April 1988 - December 1989)

Due to the initial excitement generated by founding the Human Genome Organization, expectations were high that the organization would be an immediate success. With a highly respected membership, founders did not anticipate the difficulty they would encounter in funding the organization or in getting it to function well. During its first year and a half HUGO struggled to garner funding and spent little time pursuing its initial goals.

The formation of the Human Genome Organization (HUGO) is rooted in the Genome Mapping and Sequencing symposium held April 27 to May 1, 1988, at the Cold Spring Harbor Laboratory on Long Island. The laboratory, now over 100 years old and directed for the 25th year by molecular biologist and Nobel Laureate James Watson, is a venerable institution where promising scientists pursue scientific work in molecular biology without the burdens of teaching and administrating. The topic of the 1988 conference and the highly regarded reputation of Cold Spring Harbor symposiums ensured that an impromptu meeting held during the conference would include an international array of senior genomic researchers. At the 1988 conference, the announcement of an informal session regarding the

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8Robert Cook-Deegan, interview at the Institute of Medicine, Washington, D.C., January 26, 1993.
formation of an international genome organization was made at the introductory meeting of the symposium by Victor McKusick, physician and Professor of Medical Genetics at the Johns Hopkins University.\(^9\) The informal session was set for 5:00 p.m. on April 29,\(^10\) and was attended by 30 or 40 individuals. Excitement ran high, and an animated discussion ensued.\(^11\)

Scientists involved in genomic research had informally discussed the necessity of forming this type of organization for more than a year prior to the 1988 symposium.\(^12\) There was strong sentiment in the scientific community that the management of international aspects of a human genome initiative should rest in the hands of scientists, not government, to avoid governmental control and the inevitable bureaucracy associated with government organizations.\(^13\) The release of the National Research Council report in February 1988 and the disclosure of the Office of Technology Assessment report in April 1988, both of which

\(^9\)Victor McKusick, interview at Johns Hopkins Hospital, Baltimore, MD, February 18, 1993.

\(^10\)A discrepancy exists concerning the date of this meeting. In a memo drafted May 3, 1988, McKusick cites the date of the meeting as April 29. Likewise, notes taken during the meeting by Robert Cook-Deegan and the article "Origins of the Human Genome Project," by Watson and Cook-Deegan also indicate the date of April 29. However, at least one publication cites the meeting date as April 30. See Victor McKusick, "The Human Genome Organization: History, Purposes, and Membership," *Genomics* 5, (1989): 385-387.

\(^11\)Thomas Caskey, telephone interview, Houston, TX, March 11, 1993. See also, draft memo from Victor McKusick to proposed HUGO Founding Council members, May 3, 1988.


advocated a formal U.S.-supported, government-funded human genome project, seemed to heighten the sense that governmental control of international collaboration was an imminent possibility.

If the reports provided the incentive for the scientific community to implement the formation of an international organization, the symposium at Cold Spring Harbor, coming just days after the release of the second report and attended by many of the same scientists involved in the NRC and OTA studies, provided a timely opportunity. At the informal meeting on April 29, McKusick spoke first, noting the need to consolidate the biennial Human Genome Mapping Workshops\textsuperscript{14} and to plan future symposia similar to the Cold Spring Harbor one. Discussion also focused on the specifics of structuring an international organization. Watson referred to the initial structure of the European Molecular Biology Organization (EMBO), which itself was based on the European Center for Nuclear Research (CERN). Views on requirements for membership ranged from open membership, advocated by Leroy Hood, a prominent researcher in immunology and an innovator of technologies in the analysis of the human genome at California Institute of Technology, to the elected and limited membership of an academy model, proposed by Sydney Brenner, a leading molecular biologist working on gene mapping at Cambridge University, U.K.; however, a final decision

\textsuperscript{14}The first Human Gene Mapping Workshop was organized by Frank Ruddle and held at Yale University in 1973. The purpose of the workshop was to collate information on the human gene map. Subsequent workshops have been organized by various individuals in the genomic community and have been held in The Netherlands, Baltimore, Winnipeg, Edinburgh, Oslo, Los Angeles, Helsinki, Paris, New Haven, and Oxford. For more detail about the workshops, see Victor McKusick, "Current Trends in Mapping Human Genes," FASEB J. 5, (1991): 12-20.
was not made that night. In the end, the formation of an international organization to further
collaboration and communication in what was becoming a worldwide effort to map and
sequence the human genome was endorsed. Brenner suggested the organization be named
the Human Genome Organization and abbreviated HUGO, although he personally advocated
the acronym THUG\textsuperscript{15}. Brenner also nominated McKusick as the first president, who was
duly elected and given the task of setting up the organization.\textsuperscript{16}

Five days, later, on May 3, McKusick directed a memo to eleven senior scientists\textsuperscript{17}
that briefly summarized the discussion of the April 29 meeting in a tone foreshadowing the
elitist attitude HUGO would eventually embody. McKusick proposed that he and the eleven
scientists constitute the Founding Council of HUGO, and that members of the proposed
Founding Council and up to thirty-eight others constitute a group of fifty Founding Members.
He also requested suggestions for individuals to add to the council list, cautioning that they
did not want the group to become too large. His memo further indicated that he would
accept additions or deletions to the list of founding members but he requested only additions
to the founding council list.\textsuperscript{18}

\textsuperscript{15}It is believed that THUG would have been an acronym for The Human Genome, although this
hypothesis could not be confirmed.

\textsuperscript{16}From notes recorded by Robert Cook-Deegan during the session, April 29, 1988. A brief summary
of the meeting is also found in Victor McKusick’s draft memo to potential HUGO Founding Council

\textsuperscript{17}Those receiving the memo were Walter Bodmer, Sydney Brenner, Thomas Caskey, Jean Dausset,
Renato Dulbecco, Leroy Hood, Kenichi Matsubara, Frank Ruddle, John Tooze, James Watson, Harald zur-
Hausen, Robert Cook-Deegan, and George Cahill.

\textsuperscript{18}McKusick memo, May 3, 1988.
By early July the structure of HUGO was beginning to take shape. The publication *Science* reported that HUGO would in fact be loosely modeled after EMBO\(^{19}\) and that HUGO planned to organize offices in North America, Europe, and Asia, subsequently named HUGO Americas, HUGO Europe, and HUGO Pacific, respectively. HUGO’s initial sources of funding had also been established. Financial support from the United Kingdom was pledged by Walter Bodmer, HUGO Founding Council member and Director of Research at the Imperial Cancer Research Fund in London, which offered the organization $40,000 a year. Kenichi Matsubara of the Human Frontier Science Program in Japan and another HUGO Founding Council member also pledged financial support from his country, although no specific commitment was made. In the U.S., the Howard Hughes Medical Institute\(^{20}\) offered to fund HUGO’s first Council meeting, which had been scheduled for September 6-8, 1988, in Montreux, Switzerland.\(^{21}\)

By the time the Montreux meeting commenced, the Founding Council members

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\(^{19}\)For specifics on the structure of EMBO, see Table 1.

\(^{20}\)The Howard Hughes Medical Institute is a nongovernment, medical research organization created in 1953 by Howard Hughes. By 1988 its involvement in genetics research was already considerable. It conducted basic genetic research and supported investigators in areas of genetic and physical mapping. It also operated a genome resources project through which it supported non-sequence databases related to human genetics, assisted in maintaining a mouse genetics database, and collaborated with the Center for the Study of Human Polymorphism (CEPH) in Paris. It had also participated in and sponsored numerous meetings on the human genome. For additional detail, see the U.S. Congress, Office of Technology Assessment, *Mapping Our Genes-The Genome Projects: How Big, How Fast?*, pp. 105-106.

numbered forty-two and represented thirteen countries. Thirty-one of the forty-two members attended the Montreux meeting, the purpose of which was to formulate the Articles of Association and By-Laws for HUGO and to plan its future activities. According to the Articles of Association drafted at the meeting, HUGO’s legal headquarters would be in Geneva, Switzerland, although its administrative offices could be located anywhere in the world. The Articles also established HUGO as a nonprofit, nongovernmental organization that could be funded by gifts and legacies, by governments and foundations, and by the interest on invested sums.

The decision to headquarter HUGO in Switzerland seemed to be influenced by three factors. First, HUGO’s structural model, EMBO, was successfully headquartered there, as was EMBO’s model, CERN. Second, it was believed that HUGO’s legal incorporation in Switzerland would serve as a tax advantage for the nonprofit organization. Third, using Switzerland as the headquarters would give HUGO the desired reputation of impartiality with respect to international issues. Unfortunately, each of these reasons was flawed. Unlike EMBO and CERN, HUGO was an international organization whose boundaries encompassed more than European nations. This scale of internationality complicated the tax scenario considerably and forced HUGO to devise a funding structure different from EMBO’s, while also making Switzerland an unwise choice for the location of its legal headquarters.

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22 These countries were The Netherlands, U.S., U.K., Canada, France, West Germany, Switzerland, Japan, Greece, Sweden, Australia, Italy, and the USSR.

23 Articles of Association of the Human Genome Organization.
Headquartering HUGO in Switzerland could have been useful in supporting an organizational image of neutrality, but almost from the beginning HUGO placed itself in the contradictory position of being an nongovernmental organization that intended to rely primarily on governments for its funds.\textsuperscript{24}

The Articles of Association developed at the Montreux meeting also described the governing structure of HUGO, which is comprised of three main bodies: the General Assembly, the Council, and the Executive Committee. The General Assembly is the supreme body of HUGO and consists of all HUGO members. Its main authority is to approve or reject any reports presented to it, and to annually nominate and elect new members to HUGO and to the Council. According to the Articles of Association, anyone concerned with the human genome, or scientific areas relating to it, is eligible to apply for HUGO membership with the sponsorship of five HUGO members.\textsuperscript{25} Initially members were not required to pay dues; their main obligation was to make their expertise accessible for the benefit of the organization.\textsuperscript{26} At the Montreux meeting the membership issue was decided in favor of an academy model, meaning membership would be limited, applications would have to be sponsored by other HUGO members, and final decisions about membership would be

\textsuperscript{24}For details on nongovernmental organizations, see Chapter 1.

\textsuperscript{25}Articles of Association. That policy changed in 1992 when the number of sponsors needed to support a candidate was reduced to two.

determined by election\textsuperscript{27}.

The management of HUGO is the responsibility of the Council, which consists of eighteen members, twelve elected by the General Assembly and six chosen, or co-opted, by the twelve elected members. Membership of the Council is restricted to members of HUGO. Each elected or co-opted member of the Council serves a 3-year term, but members of the Council are permitted to be re-elected or co-opted at the end of their term for one additional term of office. Every year six Council members retire and are replaced by four members elected by the General Assembly and two members co-opted by the Council\textsuperscript{28}.

The third body of HUGO, the Executive Committee, is formed mainly from the Council members and includes the following officers, each of whom serves a 3-year term: one President, three Vice-Presidents, a Secretary and a Treasurer (who may be chosen from outside the Council members), and five Elected Members. In addition to the Executive Committee, HUGO has six standing Advisory Committees\textsuperscript{29}, which are comprised of

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\textsuperscript{28}Articles of Association.

\textsuperscript{29}There are six advisory committees, as listed in a March 1990 grant proposal to the Howard Hughes Medical Institute: Human Gene Mapping Workshop Committee, Physical Mapping Committee, Informatics Committee, Mouse Mapping Committee, Committee on Ethical, Social and Legal Issues, and Intellectual Property and Ownership. For more detail on the purpose of each committee, see W. Bodmer, "HUGO: The Human Genome Organization: History, Purposes, and Membership," pp. 73-74.
HUGO members appointed by the Council for a 3-year period.\textsuperscript{30}

At the Montreux meeting HUGO elected its first Executive Committee\textsuperscript{31} and reaffirmed its purpose to be the promotion of "international collaboration on the mapping and sequencing of the human genome"\textsuperscript{32}, specifying the following goals\textsuperscript{33}:

1. To plan regional centers for large scale mapping and sequencing which will also coordinate major resources including databases, collections of DNA clones, cell lines, and other biological reagents.

2. Until such regional centers are established, to oversee the networking and distribution of data and biological samples.

3. To assist in organizing and funding the human gene mapping workshops and other international meetings.

4. To assist international exchange of knowledge and research techniques through training fellowships, instructional courses, and workshops.

5. To offer expert advice to governmental and nongovernmental agencies on the support of genome research.

6. To produce and distribute a periodic summary of genome activities.

\textsuperscript{30}Articles of Association.

\textsuperscript{31}The Executive Council members elected at that meeting were: President, V. McKusick (U.S.); Vice Presidents, W. Bodmer (U.K.), K. Matsubara (Japan), and Jean Dausset (France); Secretary, J. Tooze (West Germany); Treasurer, W. Gilbert (U.S.); Elected Members, C. Cantor (U.S.), M. Ferguson-Smith (U.K.), L. Hood (U.S.), L. Philipson (West Germany), and F. Ruddle (U.S.).

\textsuperscript{32}Notes of HUGO meeting, September 7, 1988, Montreux, Switzerland, from Robert Cook-Deegan's archival materials.

\textsuperscript{33}Ibid.
The image HUGO promoted of itself as a result of this meeting was of "an independent international body of self-appointed people whose interest is to encourage the genome project, to monitor progress and to anticipate problems". More specifically, HUGO envisioned itself coordinating the work being done in small laboratories around the world, thereby preventing the Human Genome Project from becoming an international competition. It planned to exist as a nongovernmental organization but be dependent on governmental financial contributions. The founders of HUGO never intended it to be a grant-giving organization for the funding of basic research: they felt that its role as an international coordinator of on-going genome research was a unique role that could not be fulfilled by any existing national agency.

The reception HUGO received from the scientific media was warm and encouraging. The goals of HUGO seemed noble but also practical. The response by the British scientific journal Nature was fairly typical: "If nothing else, HUGO w[ill] command attention based on the stature of its membership. Five of the 42 individuals on the HUGO Council are Nobel laureates...and the rest represent a Who's Who of molecular genetics." It was also believed by some that those characteristics would make fund-raising for HUGO relatively

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35 Ibid.


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easy. Walter Gilbert, a Nobel Laureate molecular biologist at Harvard serving as HUGO's first treasurer, was not as optimistic, perhaps due to his recent failure to raise enough money to launch the Genome Corporation, a private gene mapping company.\(^{38}\)

Despite its inspirational membership and goals, HUGO struggled to garner financial support, and without money the organization found it nearly impossible to accomplish any of the goals outlined at the Montreux meeting in September. There are various theories as to why funds were not successfully raised. According to Diane Hinton, Administrator for HUGO Americas and current Secretary of its Executive Committee, HUGO's legal incorporation in Switzerland but its establishment of administrative offices in the U.S., Europe, and Japan resulted in a complex tax law scenario with many constraints.\(^{39}\) Many private organizations could donate money only to organizations legally incorporated in their respective country or region. Furthermore, some funds could be expended only in the country or region to which they were donated.\(^{40}\) For example, money given to HUGO by a U.S. contributor usually cannot be used to pay for meetings held in Europe. Within the U.S. there was an additional complication, as the federal government has no model to follow for the funding of a private, nonprofit organization through contracts and grants, leaving HUGO Americas heavily dependent on nongovernment funding.\(^{41}\) As a result, HUGO

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\(^{38}\)Ibid.

\(^{39}\)Interview with Diane Hinton, Bethesda, MD, January 25, 1993.

\(^{40}\)Human Genome Organization proposal to Howard Hughes Medical Institute, March 1990, p. 7.

\(^{41}\)Interview with Diane Hinton, Bethesda, MD, January 25, 1993.
sought to incorporate in each country hosting a regional office as well as in Switzerland while maintaining the operation of each office under almost uniform Articles of Association and By-Laws.\textsuperscript{42} HUGO's incorporation in Geneva, Switzerland on July 24, 1989, was closely followed by its incorporation in Delaware on November 3, 1989 and its subsequent incorporation in the United Kingdom.\textsuperscript{43} While this strategy simplified fundraising for HUGO by giving each regional office the flexibility to seek funding, each office also acquired the burden of financially supporting itself.

An alternative theory regarding HUGO's fundraising difficulties is proposed by Bob Cook-Deegan, Director of the OTA study who briefly filled the position of Director of HUGO Americas in 1990. He believes that HUGO actually spent little effort trying to raise funds and instead spent its time and money deciding who should be allowed HUGO membership and who should not.\textsuperscript{44} Norton Zinder, a molecular geneticist at Rockefeller University who was considered for the position of Executive Director of HUGO in 1991, says it was a silly mistake to incorporate in Switzerland and agrees that no one tried very hard to raise money, in part because HUGO was a part-time job for almost everyone involved. He also notes that it is difficult to attract funding from foundations because they do not like to support administration, they like to support studies, which HUGO did not

\textsuperscript{42}Human Genome Organization proposal to Howard Hughes Medical Institute, March 1990, p. 1.

\textsuperscript{43}Ibid.

\textsuperscript{44}Interview with Robert Cook-Deegan, Institute of Medicine, Washington, D.C., January 26, 1993.
conduct. Businesses, on the other hand, are tempted into investment by products. Unfortunately for HUGO, its only "products" were scientific meetings.46

For the most part, the period between October 1988 and December 1989 marked a time of struggle for HUGO, but the organization did manage to initiate one international collaborative effort. On October 2, 1989, in San Diego, HUGO and the American Association for the Advancement of Science co-sponsored "Human Genome I," the first international conference held to evaluate the status of the Human Genome Project and to work on improving international cooperation. Among the mix of over 1300 attendees were scientists, science writers, and commercial sector representatives47. Charles Cantor, a prominent geneticist at the DOE and a HUGO Council member, gave the keynote address and indicated that the annual Human Genome Meeting would provide an account of progress of the genome project not only to scientists, but also to the public and to funding agencies. HUGO President Victor McKusick and Founding Council Member James Watson were also among the speakers, and each used the opportunity to press the case for HUGO. McKusick described the role of HUGO in the genome project and discussed the speed with which genetic map data were accumulating, whereas Watson stressed the necessity of international support if the mapping and sequencing of the human genome was to be accomplished.48

45Telephone interview with Norton Zinder, March 9, 1993.
48Ibid.
At the end of 1989, the United Kingdom and the Soviet Union had joined Italy in establishing national genome programs. The U.S., Japan, and France, three leaders in genomic research, were working toward implementing their own national programs. Japan and France in particular had complementary genomic projects within their countries even without formal national coordination. HUGO, however, was not faring as well. By December, the organization had only $25,000 in its bank account and many within the organization felt a change in leadership was necessary for survival. There was frustration due to the lack of money but also because HUGO was not functioning. In the absence of a Director position, the responsibility for getting HUGO off the ground fell to the Council President. McKusick, however, had not been an aggressive initiator, and he himself admits the approximately $50,000 he was able to raise for HUGO was "peanuts."

As a result, a "politically delicate" meeting was held in Bethesda, MD, on December 3 at which new officers and twenty new members were elected. McKusick was made Founding President and was succeeded by Walter Bodmer (United Kingdom) as President of the HUGO. The support for Bodmer was linked to the realization that HUGO needed administrative as well as scientific expertise. As Director of the Imperial Cancer Research Fund, Bodmer was a science administrator in addition to being a scientist well

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49 Interview with Robert Cook-Deegan, Institute of Medicine, Washington, D.C., January 26, 1993.

50 Interview with Victor McKusick, Johns Hopkins Hospital, Baltimore, MD, February 18, 1993.

51 Robert Cook-Deegan, Gene Wars: Science, Politics, and the Human Genome, work in progress.
connected with the British government.\textsuperscript{52} The Vice Presidential positions were filled by Kenichi Matsubara (Japan; Founding Council member and a current Vice President), Charles Cantor (U.S.; Founding Council member and current Council member), and Aadrei Mirzabekov (Eastern Europe; Founding Council member and Director of the Engelhardt Institute of Molecular Biology of the U.S.S.R. Academy of Sciences).\textsuperscript{53} Bronwen Loder, a non-scientist working at the Imperial Cancer Research Fund in London, became Secretary, and George Cahill, Director of Basic Research at Howard Hughes Medical Institute, was slotted as Treasurer.\textsuperscript{54} At this time, Loder, who also worked in the HUGO Europe office in London, and another non-scientist, Diane Hinton, officially an administrator at Howard Hughes Medical Institute but working as the Administrator for the HUGO Americas office in Bethesda, became instrumental in coping with the staff work associated with HUGO. Both administrators began preparing a series of proposals in an effort to acquire private funding so HUGO could begin to function.\textsuperscript{55}

**Turbulent Times (January 1990 - December 1992)**

During the period from 1990 to 1992 HUGO began initiating cooperative ventures

\textsuperscript{52} Interview with Robert Cook-Deegan, Institute of Medicine, Washington, D.C., January 26, 1993.


in earnest, but it also struggled to overcome two major problems: its reputation as an elitist organization and the perception that it lacked a mission. As a result, the three-year time period proved to be a series of ups and downs for the organization as it tried to establish new collaborative initiatives in the genomic community and to gain credibility, particularly within the scientific community.

A Promising Start

HUGO’s financial status began improving early in 1990. On February 26, HUGO President Bodmer sent Council members a copy of a grant application submitted to the Wellcome Trust, the United Kingdom’s largest philanthropic organization for medical research, with an accompanying note stating that the Trust had agreed to partially fund the grant. P.O. Williams, then-director of the Trust, saw HUGO as an important development in ensuring that all nations could share in the Human Genome Project. Specifically, the Trust awarded HUGO a three-year grant to assist in funding HUGO’s London office and its European activities. It allocated $296,000 for the first year and set aside an additional $84,000 for activities such as single chromosome workshops. The Trust expected to give smaller financial awards in the two subsequent years as HUGO succeeded in securing long-term support from governments and it expected HUGO’s London office would be located in the headquarters of The Wellcome Trust.

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56From a copy of the note and grant application sent to Victor McKusick.

HUGO was also off to better start organizationally in 1990 than it had been in 1989. By March, HUGO had selectively agreed to sponsor or cosponsor three genomic activities and had scheduled four Council meetings for 1990. At its first meeting, on March 19 in London, the Council voted to restructure the organization slightly by creating a permanent Chief Executive position for which a candidate had been selected and an offer extended. That same month HUGO also submitted a grant proposal prepared by HUGO Americas Administrator Diane Hinton to the Howard Hughes Medical Institute, which ultimately led to the receipt in early May 1990 of a $1 million grant, designated to support HUGO over a 4-year period. It was expected that the money would be put toward establishing permanent offices in Bethesda, London, and Osaka as well as help organize the 15-year human genome initiative. The grant was also expected to help fund several meetings of the HUGO Council and its committees and to make a contribution toward a scientist-exchange program.

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58The three activities were the Wellcome Summer School "DNA-related methods in human genetics: YAC cloning in genome analysis" in London (August 31 to September 8, 1990), the "Human Genome II" meeting in San Diego (October 22-24, 1990), and the "First European Genome Conference" in Frankfurt (December 1990 or Spring 1991). Information from Human Genome Proposal to Howard Hughes Medical Institute, March 1990.

59The meetings were scheduled for March (London), May (Cold Spring Harbor), and September (Oxford, HGM 10.5), with the fourth to be decided, as given in the Human Genome Organization Proposal to the Howard Hughes Medical Institute, March 1990.

60Human Genome Organization Grant Proposal to Howard Hughes Medical Institute, March 1990.


At this point Japan had yet to contribute financially to HUGO despite the pledge made by Matsubara after the initial formation of HUGO in 1988. Part of the explanation for this seemed to be related to stringent laws governing the establishment of foundations in Japan. To establish a foundation, $1.5-$2.2 million must be raised first, which means twice that amount must actually be raised since donations are not tax free initially. Additionally, the foundation must then operate for several years before it can acquire status as a tax-free organization.63

Although HUGO’s financial status had improved, many in the scientific community believed HUGO was still struggling to establish its role in the Human Genome Project. In an attempt to counter such criticism, Cantor, a HUGO Vice President and Chair of its advisory Physical Mapping Committee, wrote a letter to Nature in May detailing HUGO’s plan to begin coordinating the physical mapping efforts on individual chromosomes.

It is our [HUGO’s] desire to sponsor, on a chromosome-by-chromosome basis, committees, workshops and scientific meetings aimed at facilitating exchanges of data, samples and materials and optimizing the integration of individual laboratory efforts. HUGO will also help to coordinate these evolving physical mapping efforts with the existing chromosome committees of the Human Gene Mapping Workshops.64

HUGO had expressed a general interest in coordinating single chromosome workshops in

1989, and in its 1990 grant proposals to the Wellcome Trust and the Howard Hughes Medical Institute it had identified a need to coordinate efforts directed at developing a physical map, saying it was "important that a concerted, collaborative effort replace the present fragmented or parallel approaches." Ultimately, according to Cantor, HUGO hoped to go beyond the biennial Human Gene Mapping meetings and establish a series of meetings on individual chromosomes.

Cantor also spoke about HUGO’s activities a month later in Bethesda at a June 19 meeting of the NIH-DOE Joint Subcommittee, the inter-agency committee created to oversee the U.S. genome program. He announced that HUGO had recently received private funding and that financial support from foreign governments was expected to materialize. In terms of immediate activities, HUGO would concentrate on forming committees to coordinate the formation of genetic and physical maps of individual chromosomes. These committees would evolve from existing ones when possible or be created when necessary. There already existed a 7-member committee that generally advised on the issues of physical and genetic mapping. He also mentioned that the organization expected to gain an additional 100 members over the course of the year, increasing the geographic and subject areas represented, and he announced that James Wyngaarden, former Director of NIH and current


66From a copy of "Application to the Wellcome Trust," February 26, 1990.

Foreign Secretary of the National Academy of Sciences, would be serving as HUGO's corporate executive officer as of July 1, 1990. Wyngaarden's election to the position was likely favored by his job as Foreign Secretary, a position that had already placed him in the international arena and would be helpful in developing international treaties.

HUGO made another key appearance a few weeks later at the "Latin American Symposium on Molecular Genetics and the Human Genome Project," held June 28-30, 1990, at the University of Chile in Santiago. Meeting organizer Jorge Allende had structured the symposium to include countries without strong research projects, such as Bolivia and Honduras, and HUGO's appearance at the symposium served to affirm its commitment to include all countries in the international collaboration known as the Human Genome Project. HUGO Council member Edwin Southern of the University of Oxford addressed the South American scientists by outlining the European Community's newly approved genome program, the Human Genome Analysis Program, and by describing HUGO. Discussion at the meeting indicated that many scientists were reaching out to Western countries such as Germany and France for assistance with their research. It was believed that HUGO could facilitate the international cooperation, and Southern asked for suggestions from the meeting participants as to ways HUGO could be useful to them.


69Interview with Robert Cook-Deegan, Institute of Medicine, Washington, D.C., January 26, 1993; and interview with Victor McKusick, Johns Hopkins Hospital, Baltimore, MD, February 18, 1993.

HUGO's goals were publicly reiterated again in the July 1990 issue of the *Human Genome News*, a bimonthly newsletter co-published by the Department of Energy's Human Genome Program and the NIH National Center for Human Genome Research. Major objectives listed for HUGO included the encouragement of international collaboration among researchers, acting as a coordinating body in the international Human Genome Project, and assisting with the coordination of the physical maps of individual chromosomes. To achieve these goals, the article stated,

HUGO will establish international training programs on relevant methodologies and will facilitate the exchange of appropriate data, samples, and technology. HUGO also plans to foster parallel studies of model organisms, such as the mouse, and to coordinate research with the U.S. Human Genome Project.⁷¹

Although the article went on to say that HUGO was committed to encouraging discussion among the public of the social impacts the genome data might have, it did not indicate how HUGO planned to accomplish that goal.⁷²

By July 1990, when James Wyngaarden began his term as the Executive Director of HUGO, the organization had an elected membership of 239 primarily prominent scientists representing 23 nations. Wyngaarden's main responsibility was the elusive task of helping HUGO clearly define its role in the Human Genome Project. It was reported that in tackling

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⁷²Ibid.
this goal, Wyngaarden would handle responsibilities such as the supervision of HUGO’s international activities, coordination of its offices internationally, direction in fundraising, and assistance in defining scientific areas of interest to HUGO, such as informatics and ethics.\textsuperscript{73}

Although the HUGO Council intended to hire Wyngaarden to work half-time, Wyngaarden was only able to commit to working one-third time.\textsuperscript{74} Acknowledging his time shortage and the amount of work to be done, Wyngaarden offered Robert Cook-Deegan the position of Director of HUGO’s Americas office. Following lobbying efforts by Wyngaarden and James Watson, Cook-Deegan initially accepted the position, but in making calls to determine who would be paying his salary he learned from Americas office Administrator Diane Hinton that she was unaware of the decision to hire him, and a power struggle immediately ensued. Seeing no compromise on the horizon, Cook-Deegan resigned from the position a short time later and instead accepted a position with the National Academy of Science’s Institute of Medicine.\textsuperscript{75}

HUGO helped itself toward the goal of defining its role in the Human Genome Project by generating activity in one of its advisory committees. On July 27, 1990, the ad hoc Physical Mapping Advisory Committee of HUGO Americas met in San Francisco to plan the approach HUGO Americas should make to the National Institutes of Health and the


\textsuperscript{74} Telephone interview with James Wyngaarden, April 2, 1993.

\textsuperscript{75} Interview with Robert Cook-Deegan, January 26, 1993.
Department of Energy for potential funding. The resulting memorandum outlined physical mapping roles desirable to HUGO, including 1) the minimization of cost and maximization of sharing through coordination of efforts on a chromosome-by-chromosome basis, 2) coordination of HUGO efforts and Human Genome Mapping Workshop endeavors, and 3) participation in the selection process of individuals to organize the workshops and provision of incentives to encourage them to work through HUGO. HUGO would "select or approve workshop chairs and assist in fund-raising and in organizing and running the meetings."  

The following policies about the workshops were also established:

All three regional components of HUGO...will probably organize workshops under HUGO sponsorship. To help HUGO Americas get started, the committee developed a proposal of policies and procedures for organizing workshops. The committee also drew up a tentative list of high-priority chromosome meetings likely to be held in the United States in the next 18 months.  

In August the Executive Council of HUGO agreed to Cantor’s proposal to direct HUGO’s attention to chromosome-specific workshops. HUGO’s goals relative to these workshops would be to "apply for funding from government agencies and private sources to hold the meetings, standardize the reporting format, and ensure speedy publication of individual workshop reports." In addition, HUGO would try to find a single facility that

77 Ibid.
could be used consistently to permit the use of computer links to databases and perhaps an accumulation of resources, possibly even a library.\textsuperscript{79}

Two months later HUGO co-sponsored with \textit{Science} magazine "Human Genome II," the second international conference on the status and future of research on the human genome. The meeting was again held in San Diego, October 22-24, 1990, and was chaired by James Watson and Charles Cantor. The purpose of the conference was to analogous to "Human Genome I": to determine how much progress had been made since the 1989 conference in the planning and implementing of the Human Genome Project, and to provide an opportunity for the project’s administration and scientists, the larger scientific community, and the public to communicate. With more than 700 scientists attending, and major advances being reported in international genome efforts, HUGO considered the conference successful.\textsuperscript{80}

Toward the end of 1990 Wyngaarden reported on HUGO’s status at a DOE-NIH Joint Subcommittee meeting. He noted HUGO’s membership had reached 333, with 25 countries represented, and reported that the subcommittees HUGO had established were similar to the joint DOE-NIH working groups: ethical, legal, and social issues, informatics, intellectual property, mouse gene mapping, physical mapping, and genetic mapping of the human

\textsuperscript{79}Ibid.

genome. Moreover, HUGO was involved in activities related to its original goal of coordinating chromosome-specific workshops. Wyngaarden also touched on HUGO activities planned for the upcoming year. The Council was planning to meet in Oxford on January 7, 1991, at which time the idea of finding a conference center with appropriate computer facilities for exchanging information from the chromosome-specific workshops would be discussed. HUGO's major meeting commitment for 1991 appeared to be the 11th International Workshop on Human Gene Mapping, scheduled for August 1991 in London, which HUGO would be responsible for organizing and running. 81

HUGO's last activity for the year was the sponsorship of the "First European Genome Conference," held December 10-12, 1990, in Frankfurt, Germany. The purpose of the conference was to bring together scientists in medicine, molecular biology, and informatics to discuss European genome research and to encourage interaction with national and European policymakers. The meeting succeeded in assembling 200 scientists from 16 countries, and it highlighted a variety of innovations in methodological developments and applications. For HUGO, though, the conference had significance beyond its visible success; not only was it the first HUGO-sponsored meeting held in Europe, it was also the first time a federal or private German institution had contributed to a HUGO activity. 82


At the end of 1990, HUGO's goals were still generally focused on strengthening its infrastructure, financially and organizationally, and on delineating its role in international genomic research. The Human Genome Project had officially begun in October 1990, and HUGO had made progress throughout the year toward establishing a financial base as well as an identity. By the beginning of 1991, the Human Genome Program was a solid international effort. While seven countries\textsuperscript{83} were seriously considering starting human genome programs, seven other countries\textsuperscript{84} and the European Community had each established at least one such program. HUGO, the international agency charged with initiating international collaboration among the programs, had accumulated over $1 million by early 1991. The ideology underlying HUGO seemed well founded as the numerous human genome programs threatened to generate an overwhelming amount of information. It became obvious that the flow of this information, and the usefulness of ensuring consistent interpretation of the information, required significant international collaboration, especially with respect to the various genome databases.\textsuperscript{85}

One indication that HUGO was struggling to maintain international support for its mission was evident from an article published in Human Genome News, detailing the U.K. human genome program and co-written by Diane McLaren, of the U.K. Human Gene Mapping Project Secretariat. In closing the article read, "Success of the U.K. genome

\textsuperscript{83}These countries were The Netherlands, Australia, Canada, Chile, Sweden, Korea, and New Zealand.

\textsuperscript{84}These countries were the U.S., the U.K., the USSR, France, Japan, Germany, and Italy.

project depends on the consolidation of resources, emphasis on collaboration, and central coordination of the national effort in order to compete (underlining mine) with major international teams."\textsuperscript{86} Interestingly, the Secretariat, which was headed by McLaren, is responsible for establishing international links and for coordinating with HUGO, whose goal is to prevent a worldwide competition in mapping and sequencing the human genome.\textsuperscript{87} Another indication of HUGO’s weak impact on the international genome scene was evident in early March 1991, when Europe was wrestling with the coordination of its various genomic programs. Although some members of the scientific community believed HUGO should have been the organization to assist in the coordination, the European Science Foundation objected, claiming that HUGO’s objective was too broad for the organization to effectively deal with specific European problems.\textsuperscript{88}

HUGO had, however, observed the increasingly important role the single-chromosome workshops played in the international Human Genome Project and had made the organizing and running of them one of its central activities. Its offices kept updated records of the workshops’ times and locations, and the office staff had access to information concerning funding sources. By the middle of 1991, HUGO was working on a common


\textsuperscript{87}Ibid., p. 3.

\textsuperscript{88}Robert Cook-Deegan, \textit{The Gene Wars: Science, Politics, and the Human Genome}, work in progress.
format for application to funding agencies to ease the process of getting financial support.\textsuperscript{89}

HUGO was also expanding its administrative structure. At a DOE-NIH Joint Subcommittee on the Human Genome meeting in Bethesda on June 25, 1991, HUGO Vice President Cantor announced plans to open an office in Moscow on July 1, 1991. The establishment of the Soviet office resulted from meetings held in June with representatives of HUGO and three Soviet scientific organizations: the Academy of Sciences, State Committee for Science and Technology, and Council of the Human Genome Program.\textsuperscript{90} Although the office was described as a satellite to HUGO Europe in London, its objectives reflected Eastern European scientific concerns, and its stated goal was

to encourage Soviet genome scientists to become integrated more fully into the global Human Genome Project. As the project’s international coordinating body, HUGO will both facilitate and be implemented by the development of communication links, the exchange of scientists, the improved flow of genome-related information, and the spread of new technologies between the Soviet Union and other countries.\textsuperscript{91}

One significant distinction between the Moscow office and the London, Bethesda, and Osaka HUGO offices was that the establishment and operation of the Moscow office was completely


\textsuperscript{91}Ibid.
funded by the Russian government, despite that country's fragile economy.

HUGO continued its organizational restructuring, and within weeks of announcing its plans for a Moscow office it publicized a plan to affiliate its Americas office with Johns Hopkins University in Baltimore, MD. The benefit of such a move was the ability of the office to begin receiving grants from the federal government, not just charitable foundations. Although any large university could have served as the umbrella organization to HUGO, Johns Hopkins was favored because of its proximity to Bethesda, MD, and because the main repository for human gene mapping data, the Genome Database, was located there.92

In August, HUGO sponsored and organized its most prominent activity to date: the 11th International Workshop on Human Gene Mapping, held August 18-22, 1991, in London. The workshop was a crucial event for HUGO, the meeting organizer. Until the establishment of the Human Genome Project, the Human Gene Mapping Workshops were the only true international scientific activity in this area of research, and they had been very successful, meeting biennially since 1973. A successful workshop in London would substantially promote HUGO's credibility in the genomic community and help establish its validity as an organization.

Although the workshop was perhaps the largest ever, controversy soon dominated the

international gathering. Its unwieldy size prompted HUGO to announce at the meeting a plan to restructure future gene mapping conventions. HUGO envisioned replacing the single, biennial meeting with a three-meeting system comprised of annual Single Chromosome Workshops, an annual Chromosome Coordinating Meeting, and a biennial Human Gene Mapping Workshop with limited attendance. Many researchers immediately opposed the plan, feeling that by restricting attendance at future mapping workshops, the workshop would be comprised almost exclusively of HUGO representatives with no room left for the scientists actually doing the mapping work. Even though HUGO’s plan included an opportunity for the larger, traditional meetings, scientists feared that the real decisions of genome mapping would be made at the smaller, HUGO-oriented meetings.93

A second controversy ignited at the London mapping workshop with the revelation that an American research team from NIH had filed a patent for 337 unidentified DNA segments from the human genome. The surprise caused by the announcement indicated that HUGO was not functioning as intended. It had obviously failed in its role as a communication channel for issues of international importance in the Human Genome Project, despite the existence of a HUGO advisory committee on Intellectual Property and Ownership.94 Nevertheless, Europeans opposed to the application urgently requested discussions through HUGO to avoid "a transatlantic split in the programme"95, and after the


workshop HUGO set up a committee to examine the problem of international data access.\textsuperscript{96}

HUGO did receive a vote of confidence during the workshop at a meeting organized to consider a possible role for HUGO in the coordination of complementary DNA (cDNA)\textsuperscript{97} studies. The meeting was chaired by HUGO Vice President Charles Cantor and attended by approximately twenty-five people. The general consensus was that the entire cDNA community would benefit if HUGO collated and provided information about the nature and scope of cDNA work conducted globally. Specific ways HUGO could help the cDNA community avoid duplication of research efforts were suggested: 1) arranging for researchers to screen existing cDNA sequence databases to determine which sequences were already present; and 2) establishing procedures for the exchange of characterized cDNAs so research groups could remove corresponding sequences from existing libraries. It also came to the attention of the group that the proprietary value of partial or complete cDNA sequences was viewed quite differently between the U.S. and European research groups, and some suspected further differences could be found in Japan and other countries.\textsuperscript{98}

Even as it began creating a niche for itself in the Human Genome Project by promoting and assisting in international collaboration with regard to chromosomal sequencing


\textsuperscript{97}cDNA is produced from messenger RNA and can itself be used to produce a type of physical map that provides information on the location of expressed genes.

and mapping efforts, HUGO was criticized for being too limited in scope. The September 17, 1991, issue of New Scientist specifically stated, "If HUGO is to maintain its key role in determining how the overall project of mapping and sequencing the genome proceeds, it is only reasonable that it should help ensure that the research in the social and ethical implications is carried out in an equally coordinated and responsible way."99

HUGO was also undergoing internal turmoil. By the beginning of October 1991 Wyngaarden was resigning after one year as Director, claiming he had "insufficient time to devote to fundraising for the perpetually cash-strapped organization"100, although other HUGO members indicate that the difficulty of working with President Walter Bodmer was also a factor.101 Reports circulated that Norton Zinder, a microbiologist at Rockefeller University and a Founding Council member, was the most likely candidate to fill the position and that he was leaning toward taking the job. The Council, however, had redefined the position as a full-time job and Zinder was not willing to give up his tenured position at Rockefeller University.102

Zinder confirms he was interested in the position and says his interest stemmed from


101Interview with Robert Cook-Deegan, Institute of Medicine, Washington, D.C., January 26, 1993; and telephone interview with Norton Zinder, March 9, 1993.

102Anon., "HUGO to Get a New Director--and a Mission?" p. 19.
the belief that HUGO should exist, but he was never actually offered the job because there were several problems that could not be worked out. He was in fact not willing to give up his job at Rockefeller University and did not want to move to Washington, D.C., making his acceptance of the job contingent on opening a HUGO office in New York. Although this would have been an additional expenditure for HUGO, Zinder felt Rockefeller University would have generously picked up overhead costs, leaving HUGO to pay for a secretary and for himself. He also notes HUGO would only have had to pay him about $30,000, much less than what they were paying Wyngaarden. Adding to the logistical and financial difficulties was a power struggle that surfaced between HUGO’s Bethesda office Administrator Diane Hinton and Zinder when Zinder stipulated that as Director he would want all papers concerning HUGO activities to go through his office rather than the Bethesda office, as the existing system worked.\textsuperscript{103} Although a report in \textit{Nature} claimed HUGO left the position unfilled after it realized it could not afford to pay Zinder\textsuperscript{104}, it seems the financial problems were solvable but the conflict of power issue was not.

Later that month HUGO and \textit{Science} jointly sponsored the "Human Genome III" meeting in San Diego, October 21-23, 1991.\textsuperscript{105} HUGO used the meeting, the first international gathering since the tumultuous 11th Human Gene Mapping Workshop, to

\textsuperscript{103}Telephone interview with Norton Zinder, March 9, 1993.

\textsuperscript{104}C. Anderson and P. Aldhous, "Still Room for HUGO?" p. 4.

\textsuperscript{105}A report of the meeting by C. Cantor and C. Fields was published in \textit{Genomics} 12, (1992): pp. 419-420.
resolve the controversy generated at the London workshop about HUGO’s role in the Human Genome Project. President Walter Bodmer specified HUGO’s role to be that of mediator between the traditional gene mappers and the more technologically sophisticated physical chromosome mappers, the two waring factions constituting the Human Genome Project. As mediator between the two communities, HUGO would help ensure that a map of each chromosome was completed. HUGO’s announcement reflected an important philosophical change in the organization, originally developed as an elite scientific group. According to Vice President Cantor, HUGO would no longer try to manage and dictate; instead, it would try to assist and help by changing its focus from power to cooperation.\footnote{L. Roberts, "HUGO Takes on Role as Marriage Broker," \textit{Science} 254, (1991): p. 932.}

As 1991 drew to an end, HUGO held the workshop "Sequencing by Hybridization"\footnote{A report of the workshop by C. Cantor, A. Mirzabekov, and E. Southern was published in \textit{Genomics} 13, (1992): pp. 1378-1383.} in Moscow, November 19-20, at the Englehardt Institute of Molecular Biology. Although organized by HUGO, the workshop was sponsored by the Department of Energy, the Wellcome Trust, and the Human Genome Project of the former Soviet Union. The forty-four participants, representing government and university research laboratories as well as companies of various sizes, came from the U.S., the former Soviet Union, Sweden, and the U.K. to discuss the development and feasibility of the new sequencing technique. HUGO undertook the organization of the workshop in recognition of the high priority placed on the development of faster and more efficient mapping and sequencing techniques by the
scientists involved in the Human Genome Project.\textsuperscript{108}

For HUGO, 1991 began as a year with promise but ended as a year of pain. The organization still suffered from a lack of funding, receiving almost no new monies throughout the year. Exceptions to this were a grant of $A 50,000 from the Australian government, which was earmarked for HUGO program activities held in Australia\textsuperscript{109} and a contract award from the European Community of 20,000 ECU for the support of conferences and workshops sponsored by HUGO.\textsuperscript{110} It lost its first Director after one year and was unsuccessful in hiring a new one. It was unable to steer the international Human Genome Program clear of various warfare clashes, which HUGO supposedly had been created to help avoid. Finally, there was significant confusion about just what HUGO was supposed to do. In 1988 it hoped to set policies for collaboration and data-trading practices, but that goal soon grew distant as it became obvious that, without money, HUGO would not be a significant player in genome research. By the end of 1991 HUGO had become mainly a facilitator and a coordinator, bringing researchers together but letting them set their own policies.\textsuperscript{111}


\textsuperscript{111}C. Anderson and P. Aldhous, "Still Room for HUGO?" pp. 4-5.
A Change in Focus

As part of the transition to its new role as a facilitator, HUGO refocused its goals for 1992. Of primary interest was coordinating the input of data into the main gene-mapping database, the Genome Database (GDB), at Johns Hopkins University. Formerly, the consensus mapping data in the GDB were agreed upon and entered into the database during the frenetic biennial Human Gene Mapping Workshops. But the volume of data had become too overwhelming to be handled at a single meeting, so HUGO decided that consensus maps for each chromosome would be updated at HUGO-sponsored Single Chromosome Workshops, eighteen of which were planned for 1992. HUGO also planned to organize annual Chromosome Coordinating Meetings at which representatives of the teams working on each chromosome would get together to discuss common problems.\(^{112}\)

HUGO’s first actual activity of 1992 was to release a position statement drawn up by the Council at the end of 1991 on the filing of patent applications by NIH for sequences of arbitrary fragments of cDNAs. The statement formally opposed the action and gave reasons for taking that position. HUGO issued the statement on January 6, circulating it to government officials and patent offices worldwide, as well as to the scientific and lay press.\(^{113}\) By January HUGO’s small task force on yeast artificial chromosomes

\(^{112}\)ibid.


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(YACs)\textsuperscript{114}, chaired by Gert-Jan van Ommen of the Netherlands, was making progress. The task force was formed as a result of the 11th Human Gene Mapping Workshop held in London, at which a group met to discuss the availability and use of human YAC libraries in the genomic community and discovered that practices for handling YACs in the U.S. and Europe were very different. In addition to compiling inventories on chromosome-specific and genomic YAC libraries, the HUGO group worked on making the information on those libraries available through the HUGO offices.\textsuperscript{115} The importance of compiling the information was apparent by the progress being made in France toward completing a crude but complete physical map of the human genome through the use of this technique.

By May 1992, HUGO had grown to 427 members from 32 countries and had become more of an international scientific society than a scientific academy. New members now needed sponsorship from only two HUGO members instead of five, and a subscription charge was implemented to help cover the cost of communicating among members.\textsuperscript{116} HUGO also continued to expand its activities. The Mouse Genome Committee was compiling mouse mapping resource and project information not generally available from regular sources, and HUGO planned to sponsor a database of such material, believing that the mouse resources would be useful to both mouse and human genome communities and would foster many new

\textsuperscript{114}YACs are cloned DNA fragments that can be up to 500,000 nucleotides in size, approximately ten times larger than fragments cloned with the more commonly used bacterial-host systems.


contacts between the two groups.\textsuperscript{117} At the First South-North Human Genome Conference\textsuperscript{118} held in Caxambu, Brazil, May 12-15, 1992, HUGO's international activities were summarized by HUGO President Walter Bodmer, before he announced plans for establishing a Latin American office of HUGO.\textsuperscript{119}

HUGO also assisted in supporting the First International Human Chromosome 12 Workshop held September 18-20, 1992, at Oxford University. Earlier in the year the European Community had awarded a contract of 225,000 ECU to HUGO Europe for the support of one person, as well as operating and travel expenses, to develop a coordinated program for Single Chromosome Workshops and for direct financial support of the workshops themselves.\textsuperscript{120} In addition to HUGO, Chromosome 12 meeting sponsors included the Medical Research Council (U.K.), the Department of Energy, and the National Institutes of Health. The conference was attended by 50 people. Since it was the first workshop on human chromosome 12, the major activity was the exchange of information about mapping research strategies.\textsuperscript{121}


\textsuperscript{120}"Background Information to: Application for a Wellcome Grant," (1992): p. 33.

HUGO continued its co-sponsorship with *Science* of the annual conference on the Human Genome Project. The fourth annual meeting was similar to the first three, undergoing modifications only to its title, changed from the predicated "Human Genome IV" to "Human Genome '92," and its location, moving from San Diego, CA, to Nice, France. The Chromosome Coordinating Meeting 1992, attended by 150 people, was held November 15-17 in Baltimore, MD. It represented an important change in international collaboration of human genome mapping and sequencing because it was a trial transition between the traditional Human Gene Mapping meetings, whose main function was data entry and editing, and future workshops, to be conducted in the context of continual database updating. Many participants at the Chromosome Coordinating Meeting represented individual chromosome communities which were organizers of established or soon-to-be established single-chromosome workshops, or as Genome Database editors, responsible for data entry, validation of information, and maintenance. Other participants included HUGO staff, current and former members of HUGO’s Human Genome Mapping Committee, and funding observers.\(^{122}\) Discussion topics at the meeting included the role of single-chromosome workshops, the need to keep workshops from overlapping, and the importance of reporting meeting data efficiently through the Genome Database. Many participants were interested in returning to the large-style meetings so more researchers could attend. One possible scheme would be to hold Single-Chromosome Workshops every year or two depending on the amount of additional information collected between the meetings. It was felt that

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scientific needs could be met through periodic Chromosome Mapping Meetings without the costly overhead associated with editorial database access and also through alternating the Single-Chromosome Workshops with larger conferences fashioned after the Human Genome Mapping Meetings. Although the Baltimore meeting focused on policy issues of the genome program, it is expected that future Chromosome Coordinating Meetings will concentrate more heavily on technical and scientific issues.\textsuperscript{123}

At the end of 1992 Walter Bodmer’s term as President of HUGO ended, and he reluctantly relinquished his position. In early December, Thomas Caskey, a geneticist at the Baylor College of Medicine and a HUGO Founding Council Member, was elected as the new President with the hope that his strong administrative skills would enable him to solidly root HUGO within the scientific community and the international Human Genome Project. According to the scientific press, the two most obvious problems facing HUGO were still its reputation as an elitist organization and its lack of a mission.\textsuperscript{124}

Like most new organizations, HUGO has gone through a turbulent period of development, with encouraging progress accompanied by significant setbacks. The excitement initially expressed by the scientific community over the founding of HUGO soon fizzled as fundraising and membership concerns remained unresolved through December

\textsuperscript{123}Ibid.

1989. A change in presidential leadership in January 1990 from Victor McKusick to Walter Bodmer temporarily relieved some of the stress within the organization when large grants from The Wellcome Trust and the Howard Hughes Medical Institute were secured.

Finances, however, did not change HUGO into a well-functioning organization. HUGO, which early on had proclaimed a bottom-up management approach, was hampered by a poorly defined mission, an elitist membership, and directives issued from the top down. Despite these obstacles, HUGO has been successful in establishing several new types of international collaboration, the most significant of which appears to be collaboration between the physical and genetic mapping communities. It has also tried to address some of the criticism it has received. Membership requirements were relaxed and HUGO redefined its role in the Human Genome Project as a coordinator and facilitator rather than a manager. Still, by the end of 1992, HUGO remained characterized as an elitist and foundering organization facing an uncertain future.
Chapter 3  Implications for Successful International Collaboration

HUGO's development as an international scientific organization with a self-imposed mandate to coordinate international collaborations in the Human Genome Project approach has been slow and subject to considerable criticism from the scientific community. This observation is surprising since HUGO was created by scientists, for scientists. To date, little or no analysis of HUGO has focused on why some HUGO efforts to initiate new collaborations in the biological community have been successful while others have not. Successful efforts are characterized by their acceptance within the genomic community and by their ability to meet pre-determined goals. In the case of new collaborations in the form of international meetings, for instance, success would depend not only on drawing the intended audience, but also on accomplishing the goals of the specific meeting, such as exchanging data and information, resolving targeted issues, or making progress toward long-term goals. This chapter shows that HUGO's efforts which meet these criteria for success can be mapped to pre-existing models of collaborative activities. HUGO's unsuccessful efforts, on the other hand, lack not only a collaborative model but also any political or financial incentive that could override the inertia preceding the acceptance of novel collaborations by the scientific community.
International Collaborative Efforts Accomplished by HUGO

Although HUGO has been characterized by the scientific community and the scientific media as a floundering organization,\(^1\) over the past five years it has been successful in initiating several international collaborative activities. HUGO has been particularly successful with collaborative efforts structured as international conferences, meetings, and workshops that focus on scientific issues of the Human Genome Project. Its first success of this kind was "Human Genome I" in 1989, the first international conference held to evaluate the status of the Human Genome Project and to promote international cooperation. HUGO’s co-sponsorship of the conference with the American Association for the Advancement of Science in 1989, 1990, and 1991 helped establish the conference as an annual event in the international genomic community.

HUGO has organized a similar series of annual meetings in Europe known as the "European HUGO Meetings," the first of which was held in Frankfurt in December 1990. This series was developed to provide an open genome meeting in Europe for scientists unable to attend the Human Genome meeting in the U.S. and to give younger scientists an opportunity to present their work. The second European HUGO meeting was scheduled for

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April 1992 in Alghero, Sardinia, and a third was tentatively slated for Spain in 1993. HUGO also supported an attempt to establish serial genome meetings in Latin America by sponsoring the first "South-North Human Genome Conference" in Brazil in May 1992. The focus of the conference was to determine a role in the Human Genome Project for researchers in Latin America. These scientists expressed interest in collaboration but stressed that a balanced collaboration between competent scientists from the developing countries as well as the developed ones was needed. The success of the first conference has led to the scheduling of a second conference to be held in Bangkok in October 1993.

More recently, HUGO has turned its attention to developing workshops and seminars on more narrowly defined topics. Toward the end of 1991, for instance, HUGO organized a workshop in Moscow on "Sequencing by Hybridization." The purpose of the international meeting was to bring together researchers working on the technique to discuss problems, evaluate progress, coordinate efforts, and catch the attention of the scientific community, funding organizations, and biotechnology industries. In September 1993, HUGO is planning to co-sponsor an international lecture course in Moscow on data banks and computer support in an attempt to facilitate the integration of East European scientists and those from developing countries into international information networks.

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These HUGO activities exemplify novel international collaborations that are based on a general and historical pre-existing model: international conferences and focused seminars. As described in Chapter 1, biology has traditionally favored this structure for international collaboration, utilizing it twice as often as it does a temporary multinational mode of collaboration. This kind of structure is also generally favored by most scientific disciplines when the purpose of the collaboration is mainly to exchange information among more than two interested parties. Given HUGO’s all-inclusive geographic boundary and its intent to assist in the international exchange of knowledge, it is not surprising that HUGO activities patterned after this structural model would be successful.

The significance of having a pre-existing model on which to base a new kind of collaboration is especially clear where, in addition to a general, historical model such as international conferences, a specific version of the general model is used, as in the cloning of a particular style conference or meeting. An example of this type of modeling is the collaborative effort of the Human Gene Mapping Workshops, established since 1973, which HUGO began organizing as of 1989. The first Human Gene Mapping Workshop organized by HUGO was held in London in 1991 and patterned exactly after the previous ten workshops, due in part to the merger of the Human Gene Mapping Workshop’s Executive Committee with HUGO soon after HUGO was created.5

5Ibid., p. 8.
While the HUGO-organized Human Gene Mapping Workshops are a clone of the existing mapping workshop model, HUGO’s establishment of Single Chromosome Workshops are an adaptation of the mapping workshop model. The Single Chromosome Workshops in fact grew out of the Human Gene Mapping Workshops, where the scientific research was organized on a chromosome-by-chromosome basis. HUGO has made the development of these collaborative workshops a main focus, not only by organizing a coordinated program of Single Chromosome Workshops, but also by initiating collaboration on chromosomes that do not have an active or coordinated mapping community. In 1992, for example, HUGO supported the "First International Human Chromosome 12 Workshop" in Oxford. Since it was the first collaborative event for this chromosome, the majority of the workshop was devoted to exchanging mapping strategies rather than gaining a consensus on mapping data.

HUGO has also used the mapping workshop model to initiate a series of annual "Chromosome Coordinating Meetings," which are designed to gather representatives of all the Single Chromosome Workshops together with individuals who are interested in policies related to the entire genome, such as researchers interested in databases and nomenclature. An annual report on the progress of the genome map, described chromosome-by-chromosome, is expected to be produced from each meeting. While these meetings are a natural extension of the Single Chromosome Meetings, they also serve as a link between the individual chromosome meetings and the large, biennial Human Gene Workshop Meetings. HUGO held its first Chromosome Coordinating Meeting in November 1992, which focused
mostly on policy issues of the genome program.

While most of HUGO's successful activities appear to be patterned to some degree after what can be called the international meeting model, other effective efforts are associated with HUGO's establishment of advisory committees. As noted by HUGO Director James Wyngaarden in an address to the DOE-NIH Joint Subcommittee in 1991, the HUGO committees are modeled after the joint DOE-NIH working groups, most notably with respect to issues: Informatics; Intellectual Property and Ownership; Ethical, Legal, and Social Issues; Mouse Gene Mapping; Human Gene Mapping Workshop Committee; and Physical Mapping.⁶

Perhaps the most important collaboration achieved by HUGO has been through its Physical Mapping Committee, which in 1990 initiated an effort not only to coordinate the international physical mapping efforts being made on individual chromosomes, but also to establish collaboration between international physical mapping efforts, which were soon to be chromosome coordinated, and the parallel international gene mapping efforts, which had become chromosome coordinated through the Human Gene Mapping Workshops prior to the creation of HUGO. Essentially the Physical Mapping committee was attempting to establish collaboration between the two contentious and independent communities of the Human

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⁶As described in the Introduction, gene mapping involves locating the genes to a particular chromosome and then determining the position of the genes relative to one another on each chromosome. Physical mapping refers to sequencing, or determining the specific order of the nucleotides that constitute the DNA of a chromosome.
Genome Project, the physical mappers and the gene mappers, to coordinate the formation of genetic and physical maps of each chromosome. This goal was essentially realized when the two communities agreed to the collaborative effort in 1991 at the controversial Human Gene Mapping Workshop in London, where the HUGO committees representing the communities were disbanded and a new committee representing both interests, the Human Genome Mapping Committee, was formed. Further success of the collaboration is evident from the steadily increasing number of single chromosome workshops each year.

The success of HUGO in initiating these collaborative activities is clearly related to the pre-existence of a structural model on which new collaborative activities can be based. However, a collaborative relationship established between scientists prior to the initiation of a new kind of collaborative effort is another type of model that can foster acceptance. Scientists who have collaborated on previous cooperative ventures may be more willing to accept new forms of collaboration with old collaborative partners.

In a study of the Rockefeller Foundation and spectroscopy research, Zallen\(^7\) compares the implementation of a Rockefeller program to foster the use of spectroscopy in the biological sciences at the University of Chicago and at the University of Utrecht. When the program was initiated at Utrecht, it was very successful in meeting the goals set forth by the Rockefeller Foundation. The Chicago program, however, never achieved the same

productivity. Zallen cites the establishment of a genuine cooperation between the two lead scientists, who had different disciplinary backgrounds but who also had extensive experience with other collaborative work prior to their cooperation on the Rockefeller program, as one of the factors influential in the success of the program at Utrecht. The program at Chicago, on the other hand, was established very quickly and was directed by researchers with no previous collaborations among themselves.\(^8\)

The establishment of the single chromosome workshops reflects this important collaborative model. For instance, the first Single Chromosome Workshop for chromosome 4 was an international collaborative activity and was attended by, among others, geneticist James Gusella’s research group from Harvard Medical School and Hans Lehrach’s group from the Imperial Cancer Research Fund in the United Kingdom. These were two of the six groups that in 1984 formed the international collaborative group responsible for the discovery of the Huntington’s disease gene in April 1993. The influence of collaboration of individuals is also reflected by the relative order in which the Single Chromosomal workshops appeared. As noted in Chapter 2, chromosomes with fairly well developed mapping communities, such as chromosome 4, were among the first to hold the collaborative workshops in the early 1990s.

\(^8\)Ibid.
Unsuccessful Efforts by HUGO

There are, of course, areas in which HUGO has not been successful in its collaborative efforts. One of these is HUGO's efforts to gain international government funding as a nonprofit, nongovernment organization. To date, HUGO has had to rely primarily on contributions from philanthropic foundations, but those monies usually represent a one-time donation or start-up contribution, and cannot be counted on to continue. Essentially there appear to be two factors underlying this failure. First, many national governments have no provision for allocating grants to a nonprofit, international organization that is not incorporated in their country or region. This was initially an obstacle for the United States government, according to HUGO Americas administrator Diane Hinton, because no model existed for funding an organization structured as HUGO was through a contracts-and-grants system. Realizing this problem, HUGO has tried to make amends by incorporating in several countries as a charitable organization. While it has since received money from some governments, it has yet to receive much more than a trickle. According to the HUGO Americas' office, government funding HUGO has received to date has come from Russia, for which there is no actual figure but is basically the amount given to support the HUGO Moscow office,⁹ and from Australia in the amount of $A 50,000, designated for the support of HUGO program activities in Australia, such as the Chromosome 16 workshop held in Adelaide at the end of February in 1992.¹⁰ The U.S. government has not yet

⁹Letter from Fran Yates, HUGO Americas, Bethesda, MD, June 1, 1993.

contributed money to HUGO despite its incorporation in this country.

Since adopting a financial structure modeled after earlier structures has not made HUGO’s fund-raising efforts successful, then clearly some type of financial or political incentive is needed in order to do so. HUGO obviously provides that incentive to Russia, a country that, despite its fragile economy, has allocated government money not only to a substantial genomic program but for an administrative HUGO office as well. For Russia, HUGO seems to represent a strongly Western organization in which Russian scientists not only have a status equivalent to Western scientists, but they can benefit from the scientific advances of richer nations at very little cost.

Unfortunately, HUGO provides neither type of incentive to the U.S. government. The U.S. genome project is well supported politically and therefore financially, having overcome the controversial debates of the mid 1980s long ago. In fact, the 1993 budget for the National Center for Human Genome Research is $106 million for fiscal year 1993 and is one of the few National Institutes of Health programs scheduled to receive an increase for fiscal year 1994, according to the Clinton Administration’s new budget.\textsuperscript{11} Current HUGO President Thomas Caskey referred to the absence of an incentive when he commented that the U.S., among other countries, could get along quite well in their genome programs.

\textsuperscript{11}Christopher Anderson, "Genome Project Plans Described," \textit{Science} 260, p. 152.
without HUGO.\(^{12}\)

The lack of a political or financial incentive also seems to be a factor in the absence of government contributions from France, which has become the leader of sorts in the Human Genome Program by developing the first crude, but more or less complete, physical map of the human genome. Michele Durand, French Attache for Science and Technology at the French Embassy in Washington, D.C., confirms that the French government has yet to sponsor any HUGO activities or designate any funding to the organization.\(^{13}\) Financially, France has no incentive since its national genomic program is well funded and firmly established, with even the U.S. adopting its strategy and techniques for physically mapping the human genome.\(^{14}\) Politically, France may have many more reasons not to contribute to HUGO than to do so. First, the British have exercised considerable control over HUGO for most of its existence through former HUGO President Walter Bodmer. Given the traditional French emphasis on its own research programs and research initiatives, in addition to the admitted difficulty of working with Bodmer, it is not surprising that the French would be unmotivated to contribute funds to the organization.

Furthermore, when the British have not been running HUGO the Americans have,


\(^{13}\) Telephone interview with Michele Durand, June 10, 1993.

and it is possible that the collaborative fiasco between the French research team led by Luc Montagnier (Pasteur Institute, Paris) and the American research team led by Robert Gallo (National Cancer Institute, Bethesda, MD) searching for the AIDS virus is still a raw wound, making France wary of supporting international cooperation when the Americans are clearly in charge. The controversy goes back a decade to the middle of 1983 when Montagnier was first isolating the AIDS virus, which he called LAV. Although Montagnier published his discovery in *Science* in May 1983, he did not claim that LAV caused AIDS.

Two months after the publication, Montagnier sent a sample of LAV to Gallo’s lab, and then sent a second sample to Gallo in September 1983. In May 1984 Gallo’s group published four papers in *Science* describing virus isolates from Gallo’s lab, collectively named HTLV-III. Within a year it was discovered that the French LAV virus and the American HTLV-III were genetic twins, indicating that either accidental contamination or theft had occurred. Additional controversy erupted when it was revealed that one of the four 1984 Gallo papers claimed the LAV virus had never been permanently grown in a cell line, even though Gallo’s lab had in fact accomplished that feat before the papers were published. Additionally, the Gallo papers made very little mention of the French LAV virus, even though the Gallo team had worked with it extensively and gotten it to grow permanently in a cell line.\(^{15}\)

The result of the event has been two investigations by the National Institutes of Health, the most recent one concluding earlier this year that Gallo is guilty of research misconduct. Although some of Gallo’s supporters acknowledge he did something wrong, many feel that denying the French researchers credit is not a "major thing."\(^\text{16}\) Given this attitude of American researchers, it does not seem unreasonable that the French government would be reluctant to support an organization fostering international collaboration in which the Americans are clearly in charge.

A related issue is HUGO’s relative lack of success in lining up financial support from foundations and businesses, aside from the Howard Hughes Medical Institute and the Wellcome Foundation, both of which were only willing to commit start-up funds. Now that HUGO is 5 years old, requests from HUGO for large donations may not be viewed as requests for start up money but as requests to keep the organization from sinking. HUGO offers no political incentive for these potential funding sources since after 5 years in existence it still has a lackluster reputation. Financially, HUGO does not tempt money from many foundations because historically they have favored the support of studies, not the administrative costs of running an organization.

Businesses, on the other hand, look for a product to support if they decide to invest in an organization, and HUGO’s only "products" to date are meetings, conferences, and

\(^{16}\text{Ibid.}\)
workshops. Even so, on September 30, 1990, a satellite meeting to the "Human Genome II" conference was sponsored by the Parke-Davis Pharmaceutical Research Division of Werner Lambert. It was organized by molecular biologist and sequencer Craig Venter and Jack B. McConnell (retired director of Johnson & Johnson) and was attended by nearly 70 pharmaceutical and genome representatives. The goal of the meeting was to inform the pharmaceutical industry about the Human Genome Project and to encourage them to transform project data into pharmaceuticals and diagnostics for improving health care.\textsuperscript{17} While the attendance at the meeting indicated some interest in the Human Genome Project on the part of business, the funding possibilities for HUGO through the pharmaceutical industry were never really followed, according to Norton Zinder.\textsuperscript{18}

A second effort that has not yet proven successful is HUGO's bottom-up approach to initiating international research efforts. Although HUGO itself is comprised of working scientists and was established with the idea that those were the individuals who should have control over international collaboration, it is the Executive Committee, not the General Assembly, that makes the decisions and issues the directives governing international collaboration. The General Assembly, according to the Articles of Association drawn up at the Montreux meeting in September 1988, may approve or reject any reports presented to it and may nominate and elect new members, but the management of the organization rests


\textsuperscript{18}Telephone interview with Norton Zinder, March 9, 1993.
with the Council. The difficulty of initiating bottom-up type cooperation is due partly to the fact that HUGO had no model to follow for that type of coordination since other international scientific organizations have accepted the traditional top-down approach for running their group. The international scientific organizations shown in Table 1 all use some form of Executive Committee and all have signed treaties, foregoing the possibility of bottom-up approach to coordinating collaboration.

Neither has HUGO been successful in maintaining international free access to genomic information, as exemplified by the patent application of an NIH research team of Craig Venter. The effort by Venter’s research team to patent thousands of fragments of human DNA, the utility of which is unknown at this time, is threatening HUGO’s ideology of sharing all data from the Human Genome Project with everyone. This is another effort where no previous model exists for maintaining data from international collaborations of the scale of the Human Genome Project and where there are few incentives to remain a part of the effort. The incentives, in fact, are much stronger to leave the effort, as in this case the financial rewards could be tremendous.

Resolving the Difficult Issues

From the discussion above, it is clear that the existence of a previous model is influential in the successful launching of a new kind of collaboration. Often the model is a structural one, although previous collaborations among the same people is also an important
consideration. However, if new collaborative efforts could only be successful when a model pre-existed, dramatically different types of collaboration could never be established. This study supports the indication that for new collaborations not based on a pre-existing model, a political or financial incentive must be present for them to be accepted.

The use of incentives to initiate successful international collaborations, however, is not without problems. Inherent in the tactic is the fact that what may be considered an incentive by one party is often a dis-incentive to another party, a conflict that is seldom reconcilable. Furthermore, while HUGO is the organization coordinating new efforts, it has limited control over what incentives it can offer. This is due, in part, to its structure as a non-government organization rather than an inter-government organization, in which governments commit their interest in the organization by signing a treaty.

Demonstration of the association between these two conditions (a pre-existing model and financial or political incentives) and successful collaborations supports the indications in the literature on international scientific cooperation and provides one interpretation as to why only some of HUGO’s attempts at initiating collaborations in genomic research have been successful. Although the findings are therefore not surprising, they are significant in the context of HUGO’s success as an organization. Despite the indications in the literature and, in fact, the somewhat obvious nature of the two conditions, HUGO overlooked or ignored their importance when planning its goals for new collaborative ventures and as a result contributed to its own difficulties in establishing a successful organization.
As outlined in Chapter 2, HUGO articulated six goals at its first Council meeting in September 1988. Of its six goals, HUGO has currently accomplished half of them to some extent. It has, for instance, coordinated the networking and distribution of data, primarily through its organization of the Single Chromosome Workshops where gene data are entered into the GDB. HUGO has also been quite successful in assisting in the organizing and funding of the Human Gene Mapping Workshops and other international meetings, another of its initial goals. And finally, the organization has assisted with the international exchange of knowledge and research techniques through instructional courses and workshops, although not through the use of fellowships.

As for the three remaining goals, HUGO has yet to reach them. The planning of regional centers for large-scale mapping and sequencing likely requires an amount of funding so far unavailable to the organization. In terms of offering expert advice to governmental and nongovernmental agencies on the support of genome research, there is no record that HUGO has acted in this manner or that it has had any requests to act in this manner, perhaps due to its lackluster reputation. HUGO's final goal, to produce and distribute a periodic summary of genome activities, may actually be outdated, since the National Institutes of Health and the Department of Energy co-publish Human Genome News, a newsletter that not only reports genomic activities worldwide but also reports the activities of HUGO.

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19For a review of the goals, see p. 27.
Although HUGO, now a five-year-old organization, has not been successful with every collaborative effort and has not reached all of its initial goals, it has accomplished much of what it set out to achieve. Why, then, has it been tagged with a poor reputation? One answer may be that the criteria for a successful organization focus more on continuity in accomplishments and less on the number of accomplishments. Sporadic successes, however many of them there are, may be less inspiring than the continual growth and development of a formal activities program sponsored by the organization.

When current HUGO President Thomas Caskey took office in January 1993, HUGO had 538 members from 35 countries.\textsuperscript{20} Despite the less stringent requirements for gaining HUGO membership and its endorsement of a democratic, bottom-up approach to coordinating international collaboration, the image of HUGO has remained one in which decisions are made by the Executive Committee, not the General Assembly, as would be the case with a bottom-up approach. Caskey has come into office with specific ideas for dispelling the image. For a start, he announced a membership meeting to be held in Kobe, Japan, the first membership meeting ever called\textsuperscript{21}. Since HUGO's charter allows membership business to be conducted by mail or by meeting, mail had become the normal procedure due to HUGO's farflung membership and limited budget.


\textsuperscript{21}Anon., "Caskey Promises a Democratic HUGO," p. 1575.
In response to criticism about HUGO's lack of activities and lack of a HUGO program, Caskey has announced plans to improve the exchange of information and research tools, such as genetic probes, among researchers worldwide by forming member committees, a type of system that already exists in U.S. genome centers. Caskey also plans to revive the idea of fellowships, which would support travel costs between labs for the purpose of scientific collaboration and technology transfer. In a recent telephone interview he confirmed that this year HUGO will be starting international travel awards for scientists. While the awards need not be only for HUGO members, the individual receiving the award must be member-sponsored. Later this year HUGO, in conjunction with UNESCO, will be sponsoring an international lecture course on Data Banks and Computer Support of the Human Genome Project, scheduled for September 13-17, 1993 in Moscow. The intention of the course is to disseminate information about data banks in molecular biology and genome research. A special focus of the course will be on integrating scientists from Eastern Europe and developing countries into international information networks.

At this time, Caskey says he is not worrying about filling the position of Executive Director, choosing to focus instead on getting HUGO functioning using its current structure. Some of the areas in which he plans to direct HUGO's attention include intellectual property

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22 Ibid.


rights, cDNA-based diagnostics, white papers in controversy, and the summit meeting of the
genome. And as a long-time acquaintance of HUGO Americas Administrator Diane
Hinton, Caskey will hopefully be able to avoid the type of personality clashes that have
hindered HUGO in the past.

For Caskey, the importance of HUGO lies in the speed with which genomic research
is advancing. He claims that countries with strong genomic programs do not need HUGO;
however, scientists in other countries who would like to participate in the genomic effort
would have no chance to do so without HUGO. According to Caskey, the benefit HUGO
confers on countries without substantial genome programs is that if a scientist joins HUGO,
she has an equal voice regardless of where she is from. Although HUGO is not working
directly with third-world countries, Caskey claims it is working indirectly with them through
the World Health Organization and UNESCO.

For the policy community, the usefulness of studying HUGO is linked to the novel
collaborations it has tried to initiate, which are directly related to the international Human
Genome Project, a project unlike any other ever attempted by the biological community in
terms of kind and size. The Human Genome Project is an unusual type of research effort
for biologists in that it is mission oriented; it has a specific endpoint in terms of time and


goals. Although the Human Genome Project is the first biological project of its kind, there are indications that it will not be the last.

In the future more biological research may take the form of large, international projects. One area in which this approach is being considered is AIDS research, where AIDS activists are endorsing President Clinton's campaign idea of a "Manhattan Project," an intense, government-directed effort to find an AIDS vaccine or cure. According to a report by Science, "[b]oth scientists and activists are frustrated by the failure of science to come up with a vaccine or an effective therapy in the decade since HIV was first isolated."\textsuperscript{28} Specifically, many critics of the present system feel a centrally directed scientific effort would eliminate redundancy, foster cooperation, and provide answers more quickly.\textsuperscript{29}

While proponents of this approach for AIDS research have not specifically described the proposed project as an international effort, the large number of countries currently involved in AIDS research may cause them to consider, as the U.S. supporters of the Human Genome Project did, whether numerous centrally directed, national projects might be more effective and efficient if international collaborations were encouraged. If the project did become an international effort, it is likely an organization would need to be formed to foster


\textsuperscript{29}Ibid.
and coordinate international collaboration, an organization for which HUGO itself could serve as a model.

Based on this study of HUGO, the following recommendations are offered as guidelines for establishing a well functioning organization designed to initiate new collaborative activities in the international scientific community. First, the structure of the organization needs to be inter-governmental as opposed to nongovernmental, given current funding practices of nations around the world. Without a long-term commitment of funds and interest, governments are unlikely to voluntarily support a new organization until it has established a solid reputation and is able to offer useful services or other enticements. The catch is that without government funding, an international organization can seldom reach that point.

Specifically, a lack of funds impacts the depth, and in turn the function, of the organization, as HUGO has experienced. For instance, the number of staff working at HUGO is so small that the organization finds it difficult or impossible to function without them. As a result, a person may indirectly acquire enough power to control the direction of the organization without explicitly being given that power. A shortage of funds also hinders the number and type of activities the organization can initiate. Activities that are sporadically held, even if successful, make it difficult for an organization to establish a solid reputation. The ability to demonstrate continuity of events and implementing a program for the organization appear to be implicit criteria for consideration as a successful organization.
Finally, use of an intergovernmental structure increases the likelihood of a successful organization because it forces the group to address key issues, such as clearly defining its mission, before it gets off the ground. If key issues have not been addressed or are unfocused, governments are unlikely to become involved.

A second recommendation is that the organization endorse and coordinate the exchange of information and data gathered during the project. An important consideration of this policy is that not all countries benefiting from such access are able to contribute to it by means of funding or expertise. One way to address this inequality is to acknowledge that, in general, most nations accept that all countries are not equal economically or technically, and that to some degree developed countries must support the less developed ones. But another consideration is that less developed countries can often make contributions to international projects in other ways. For instance, in a study of genetic diversity, the economic status of a country may be less important than the fact that the country’s population may have unique genetic characteristics in its native population, a different but valuable resource for the scientific community at large.

A third and final recommendation for establishing a functional organization is to recognize that there are conditions which are influential in, if not necessary for, initiating successful collaborative activities. Efforts are likely to be successful if they are modeled on similar activities or if a financial or political incentive exists to encourage the acceptance of a very different form of collaboration. While these observations seem obvious and intuitive,
forgetting them, as HUGO has learned, can significantly impede the development of an organization and jeopardize its future.

In consideration of the current trend in biology, and other scientific disciplines, toward larger, international research projects, there is likely to be a corresponding increase in the number of new organizations formed to coordinate such collaborative efforts. While HUGO is certainly not a perfect model to use as a basis for future organizations, it does provide useful insights into the successful establishment of collaborative activities and of the organizations initiating them.
APPENDIX A  Implementation of National Genome Programs.

1989  Italian Genome Project
1989  USSR Human Genome Project
April 1989  United Kingdom Human Genome Mapping Project
January 1990  UNESCO Program for the Human Genome Project
June 1990  Latin Human Genome Program
June 1990  European Community Human Genome Analysis Program
October 1990  United States Human Genome Project
October 1990  French Human Genome Research Program
Fall 1990  Japan’s Committee on Human Genome Research
APPENDIX B  From International Academy to Scientific Society.

4/29/88  HUGO is formed during informal meeting at Cold Spring Harbor symposium on mapping and sequencing. Victor McKusick elected President.

9/6/88  HUGO's first Council meeting is held in Montreux, Switzerland. Articles of Association and By-Laws are drawn up. Executive Committee is chosen. Decision made for membership to limited and by election.

3/1/89  HUGO membership numbers 220, represents 23 nations.

10/2/89  HUGO co-sponsors "Human Genome I," the first international meeting to evaluate status of the Human Genome Project and HUGO's first international collaborative effort.

12/3/89  A "politically delicate" meeting is held at which McKusick becomes Founding President. Walter Bodmer is elected as HUGO's new President, and new Executive Committee members are also elected.

2/26/90  Wellcome Trust awards HUGO a 3-year grant totaling $380,000.

3/19/90  HUGO Council creates Chief Executive position and selects a candidate.

5/12/90  Letter from HUGO Vice President Charles Cantor published in Nature detailing HUGO's plan to begin coordinating physical mapping efforts.

5/15/90  Howard Hughes Medical Institute awards a 4-year, $1 million grant to HUGO.

6/19/90  Cantor announces James Wyngaarden's election as HUGO's Executive Officer to DOE-NIH Joint Subcommittee.

6/28/90  HUGO represented by member Edwin Southern at "Latin American Symposium on Molecular Genetics and the Human Genome Project." Meeting participants suggest ways HUGO could assist them.
7/1/90 Wyngaarden begins term as Executive Director. His main goal is to define HUGO's role in the Human Genome Project.

**HUGO membership numbers 239, represents 23 nations.**

10/22/90 HUGO co-sponsors "Human Genome II" with Science.

12/10/90 HUGO sponsors "First European Genome Conference" in Frankfurt, Germany. Conference is first HUGO-sponsored meeting in held in Europe and first time federal or private German institution contributes to HUGO activity.

12/31/91 **HUGO membership numbers 333, represents 25 nations.**

6/25/91 Cantor announces plans to establish HUGO office in Moscow to DOE-NIH Joint Subcommittee.

7/30/91 Plans publicized by HUGO to affiliate HUGO with Johns Hopkins University to enable solicitation of federal grants.

8/18/91 Eleventh International Workshop on Human Gene Mapping sponsored and organized by HUGO. Controversy results over announcement of restructuring workshop format and over decision by American research team to file patents on fragments of DNA. HUGO asked to coordinate information on cDNA studies and YACs.

10/15/91 HUGO Executive Director Wyngaarden resigns. HUGO member Norton Zinder considered leading candidate for position, but power struggle between Zinder and HUGO Americas Administrator Diane Hinton results in position being left unfilled.

10/21/91 HUGO and Science co-sponsor "Human Genome III." HUGO announces change in philosophy. Focus now on assisting and helping, not managing and dictating.

11/19/91 HUGO holds workshop "Sequencing by Hybridization" in Moscow.

1/6/92 HUGO circulates position statement on American attempt to patent sequences of arbitrary fragments of cDNAs.
5/1/92  Number of sponsors needed for HUGO membership changed from five to two.

**HUGO membership numbers 427, representing 32 nations.**

5/12/92  HUGO President Bodmer summarizes HUGO activities at "First South-North Human Genome Conference," and announces plans for establishing a Latin American office of HUGO.

11/15/92  First Chromosome Coordinating Meeting is held by HUGO in Baltimore. It represents a trial transition between traditional Human Gene Mapping Workshops and Single Chromosome Workshop; most researchers favor a return to the larger-style meetings.

12/31/92  Bodmer is been succeeded by HUGO Founding Council member Thomas Caskey. Bodmer reluctantly relinquishes position. Caskey announces plans to focus on more bottom-up coordination within HUGO.

**HUGO membership numbers 538, represents 35 nations.**
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