The Human Genome Organisation

June 21, 1989

Purnell W. Choppin, President
Howard Hughes Medical Institute
6701 Rockledge Drive
Bethesda, MD 20817

Dear Purnell:

As Founding President of the Human Genome Organization (HUGO), I am writing to you to request consideration by HHMI of foundation funding to help us initiate our program for international coordination of the human genome project. We are grateful to the support which the HHMI has provided for the initial steps in forming HUGO; that support has come, as I understand it, from your second program. The additional support which I am requesting hereby will initiate the programs which we have planned for HUGO and will place us in a better position of achieving multinational governmental funding for the long range.

You are probably familiar in general with HUGO because of the support which HHMI has already provided. I am including herewith a reprint of my paper "Mapping and sequencing the human genome" which appeared in the New England Journal of Medicine, April 6, 1989. This has a bit on HUGO and how it fits into the total picture. In addition, I am enclosing a preprint of a description of HUGO which will be published in GENOMICS in August.

The history of HUGO is a short one: the suggestion of an international coordinating organization was raised at a Cold Spring Harbor meeting on the genome in late April, 1988 -- by Sydney Brenner of Cambridge University, who also suggested the name Human Genome Organization and the acronym HUGO. At a rump session held in Cold Spring Harbor on April 30, 1988, I was asked to convene an international group to consider the proposal in more detail. A founding council of 42 members met in Montreux, Switzerland, in early September, 1988; 31 of the members were present. The broad outline for articles of incorporation and bylaws was laid out and the following officers were elected: President, Victor McKusick; Vice presidents, Walter Bodmer, Jean Dausett, and Kenichi Matsubara; Secretary, John Tooze; Treasurer, Walter Gilbert (resigned February, 1989; replaced by George Cahill, June 1989); others of executive committee, Charles Cantor, Malcolm Ferguson-Smith, Leroy Hood, Lenart Philipson, Frank Ruddle.

We are finally incorporated in Geneva and expect to have the necessary legal representation in this country under the laws of the State of New York.

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Our overall purposes are three: the first is to provide coordination of the human genome initiative -- among nations, among scientific disciplines and among scientists working on the human genome and those working on the genomes of model organisms.

A second objective is to enhance the progress and usefulness of the human genome effort by ensuring open access to the data generated by the project and the ready availability of biomaterials and technology to conduct the research.

A third objective is to provide a forum for the discussion of ethical, societal, legal, political, commercial and other implications of the human genome project, the information which it will generate, and the uses to which that information may be put.

To implement the above objectives we have taken steps to establish three HUGO offices: one in London, one in Bethesda, and one in Osaka. We are in the process of setting up five standing committees: 1) committee on physical mapping, 2) committee on data bases, 3) committee on the mouse genome, 4) committee for Human Gene Mapping Workshops, and 5) committee on ethical and societal issues.

At its meeting in Montreux, the HUGO Founding Council decided to follow an "academy model" in setting up HUGO. By this it is meant that we will have membership elected on merit. In the conduct of the work of HUGO, it is understood that some persons will be co-opted to the several committees who are themselves not members of HUGO. In this respect, we will follow the well-known practice of similar academies in setting up work parties.

We see the regional offices as filling, in time, an important role in the collection and distribution of data through networking. The offices will be expected to maintain information on the characteristics and availability of biomaterials and technology.

There have been a total of 10 Human Gene Mapping Workshops, the first in 1973 and the most recent in New Haven earlier this month. These have been very useful in collating the information on the genetic map, but the meetings themselves have reached the size and complexity and the body of information which they attempt to collate has become so large that a major change in the workshops is necessary. It is no longer possible for the upkeep and evaluation of the data to be done on an intermittent (every other year or even annual) basis, and it is not possible for a convener who is himself an active scientist to administer it on a rotating basis. At the New Haven meeting earlier this month, it was voted by the executive committee of the Human Gene Mapping Workshops to become a component of HUGO. HUGO in turn voted at its meeting to take on the Human Gene Mapping Workshops as part of its administrative and scientific responsibility.

Discussions of the human genome project in broad terms, in the Advisory committee to Jim Watson's Office on Human Genome Research, have led to the conclusion that the unit of scientific management for the project is the individual chromosome, or in the case of large chromosomes, the individual

chromosome arm. That advisory committee looks to HUGO for leadership in the establishment of work parties which will have responsibility for the organization of the information forthcoming on the mapping and sequencing of each chromosome, which will have oversight of the special biomaterials, e.g., cell lines and probes, relevant to the particular region of the genome, and which will have some responsibility for achieving "closure" in terms, for example, of achieving a complete set of overlapping cloned DNA segments. This scheme is based very much on that used by the Human Gene Mapping Workshops which at each of the meetings has had committees responsible for collecting information on a given chromosome. The only difference conceived here is that these will be standing committees that communicate among their members and with the overall organization by electronic means and that will have responsibility not only for the linkage mapping but also for the physical mapping related to the particular chromosome. There is clearly no intention to assign, in any monopolistic sense, a given chromosome to a given country or laboratory. Depending on competence and interest, however, particular laboratories and particular countries might be asked to take the lead in organizing the work party and assuming the responsibilities outlined above. HUGO is seen as the appropriate body to undertake this organization of chromsome-by-chromosome work parties. HUGO will need to assume the expenses of the networking of the members of individual groups, of any meetings they may wish to hold, etc.

We are also keen on mounting a substantial fellowship training program. We see this as a major way to increase the manpower necesssary for the human genome initiative as well as to provide increased expertise in the area of molecular biology and biotechnology in general. Training funds are limited these days. We have in mind the importance of providing such training on a worldwide basis.

In general, we do not see HUGO as a research grant-giving agency, except in the fellowship/training realm and the support of programs to coordinate data bases and to conduct the work of chromosome work parties.

So far, I have been able to raise $51,000 from Dupont, Markey, The Wesley Foundation, and other sources. Italy and Australia are considering a $200,000 award each, the latter possibly for each of three years. We have been in contact with several other potential donors most of whom have, unfortunately, declined for the present.

It is my hope that HUGO will be able to raise $500,000 from each of the Western European and Pacific rim areas, We would very much like the HHMI to initiate this effort with a sum of $1,500,000 as the first major donor for this world effort. This would, I feel, catalyze other donors as well as permitting HUGO to get on with the implementation of its programs.

In informal discussions with George Cahill, he mentioned that in view of the extensive involvement of HHMI in genetics research, support for HUGO might be considered eligible as part of direct participation. I have spelled out in some detail the nature of our programs in hopes that it will be helpful to you in arriving at that decision.

As I mentioned earlier, George Cahill has assumed the position of treasurer of HUGO in our election earlier this month. We have a total of 219 members and an election for additional members and for the 18-member council will be held during the next few months.

The enclosed materials will provide you with details concerning HUGO.

Thank you for your consideration of this proposal, and very best personal regards.

Sincerely

CC: Dr. W. Maxwell Cowan
Vice-president