Geneletter: An Internet-Based Newsletter on the Ethical, Legal, and Social Implications
of Genetics

Final Report to the Department of Energy

Background

Geneletter began as a project to help educate interested members of the public about ethical, legal, and social aspects of genetics. Between July, 1996, and February 1999, ten issues appeared, with a total of 252 articles, excluding lists of conferences or newspaper articles. A list of articles, by category, appears below.

Readership

Between September 18, 1996 and October 26, 1999, there were 2,106,415 hits, 777,934 page impressions, and 394,339 user sessions. The average number of hits per day over the entire period was 1857. Page impressions per day averaged 686, and user sessions per day averaged 347. The most active day was February 22, 1999 (shortly after we published the eugenics issue), with 6904 hits. The least active day was September 21, 1996, with 19 hits.

Starting with the March, 1997 issue which contained articles on the ethics of cloning, readership shot up to an average 5000 site visits per week and remained there until the site was transferred from the Shriver Center in October 1999. The average user session lasted 7 ½ minutes.

About 64% of users were from the US, 15% were international, and the rest were unknown. The largest numbers of known international site visits were from Canada (12,550), Australia (10,176), United Kingdom (7965), Singapore (2216), Germany

DOE Patent Clearance Granted

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(2145), Malaysia (1610), Sweden (1497), France (1378), Japan (1339), New Zealand (1221), the Netherlands (1150), Italy (845), Israel (843), and United Arab Emirates (793).

Within North America, the states/provinces with largest known numbers of site visits were Virginia (75,159), California (6210), Ohio (1658), Ontario (1064), Oregon (711), Washington (588), Massachusetts (534), Maryland (517), Florida (394), and North Carolina (355). Towns/cities providing the largest numbers of users (probably through network providers) were Vienna, VA; Falls Church, VA; San Jose, CA; Mountain View, CA; Columbus, OH; Springfield, VA; San Francisco, CA; Medford, OR; Tustin, CA; and Cambridge, MA. Users were divided among company (.com-38%), network (.net-31%), education (.edu.-26%), with fewer from organizations (.org-4%) and government (.gov-1%).

User visits were equally divided (50-50) between working hours and after-hours. The most active hour was 3-4 p.m.; the least active 4-5 a.m. Tuesday was the most active day, Saturday the least active.

The most requested articles were “Cloning Humans - Is It Ethical?” (March 1997 - 40,589 views); “Proposed Canadian Reproductive and Genetic Technologies Act” (- 35,769 views) [probably because it mentioned cloning before cloning became a real possibility]; “Update on Cloning; Dolly is Not the Same as Her Genetic Mother” (May 1997 - 22,368 views); “Table of Contents, February, 1999” [the Eugenics issue] (22,023 views); “Genetics and Homosexuality” (-10,798 views); “Adam, Eve, and Mitochondria (9372 views). Together, these articles accounted for 30% of views.

Awards

Geneletter received two awards:

The Links2Go Key Resource Award (Nov. 10, 1998)

(<http://www.links2go.com/award/Genetics>)

Featured Study web (<http://www.studyweb.com>) as one of the best educational resources on the web. (July 16, 1999). The Medinex Seal of Approval, June 14, 1999.

In addition portions of Geneletter were reproduced by Spinney Press, Australia, for use in high school debates (about 5000 copies of the 21 Arguments for and Against Human Cloning); by the Center for Biomedicine and Law, National University of Taiwan (for a text book); and by a patient organization in Brazil (on prenatal diagnosis).

Interaction

We received over 800 Letters of the Editor on a wide variety of topics ranging from paternity testing (a favorite topic) to US patenting of Basmati rice. Many of the letters asked unanswerable questions, such as “Tell me everything you know about the Human Genome Project,” or were from students asking for substantial help in writing papers, or in some cases, asking us to write the papers for them. Students ranged in age from sixth grade to Oxford post-graduates, (wondering whether genes were on chromosomes or vice versa) with the majority appearing to be in high school. Whenever possible, we tried to answer readers’ questions, but we refused to write students’ papers for them.

Contrary to our expectations, our chatbox - the interactive feature of Geneletter - never took off. With almost 778,000 page impressions over a 2 ½ year period, we had fewer than 200 visits to the chatbox, and few queries or comments produced responses

from other readers. It appears that although people were eager to seek information from the editors via email, comparatively few were eager to “chat” about issues related to genetics.

From comments received by the editors at genetics conferences, it appears that clinical geneticists are reading Geneletter. We also received numerous emails from people in law and policy. There was little evidence, however, that primary care physicians - one of the groups originally targeted - were reading Geneletter. Perhaps this was because there was little clinically useful content from a physician’s point of view. Articles tended to concentrate on law, ethics, and information useful to the interested public.

Dissemination of Results

An abstract describing the project appeared in American Journal of Human Genetics, Vol. 16, NO. 4 (suppl), A191. Posters were presented at The American Society of Human Genetics Annual Meeting in Baltimore, MD, October 28 - November 1, 1997; at the New England Regional Genetics Group meeting in Durham, NH, December 1997; at the National Dialogue on Genetics, College Park, MD, March 1998; and at the DOE Contractor-Grantee Meeting, Oakland, CA, January 1999. Principal Investigator Dorothy C. Wertz received three speaking invitations as a result of Geneletter: 1) Tulane University School of Public Health, Dept. of Epidemiology, April, 1997, on ethical issues in genetic counseling; 2) Dubai Police (United Arab Emirates) conference on cloning, April, 1998; 3) Illinois College Department of Humanities, on genetics and identity, August, 1998.

Plans for Continuation

At the onset of the project, DOE made it clear that while DOE would launch Geneletter, ultimately another sponsor would be required to keep it going. In early 1999, Dr. Philip Reilly, the Principal Investigator during the first year of the project initiated contact with an Internet start-up, Genesage, which is aimed at genetic professionals. In October 1999, the files were transferred. Geneletter remains free and open to the public as part of Gensage.com, which has a staff of over 17 persons. Geneletter now appears monthly.

The following articles appeared in Geneletter while still under the DOE grant:

[listing not received by OSTI]