MEDIA REPORTING IN THE GENETIC AGE:

POINTS TO CONSIDER

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The Alliance of Genetic Support Groups is a national, not-for-profit coalition that advocates for individuals and families with genetic differences from a cross disability perspective. The organization began in 1985.

Membership consists of over 200 organizations, including consumer and professional groups. The Alliance is recognized by the general public and the professional community as a voice of those affected by genetic conditions.

The Alliance of Genetic Support Groups

- Provides technical assistance to new and existing genetic support groups.
- Link families, whenever possible, to the appropriate group or needed services.
- Works with the press in an effort to encourage responsible reporting in the media age.
- Serves as a resource for consumers seeking genetic support, as well as for genetic counselors, nurses, social workers, physicians, researchers, educators, students, librarians, and the media, among others.

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III. RECOMMENDATIONS

This section seeks to provide points to consider when reporting about developments in genetics and about individuals who have genetic conditions. Fully cognizant of the First Amendment to the Bill of Rights, the Alliance of Genetic Support Groups issues emphatically that it is not our intention to dictate to the media how to report on a specific subject. Rather we offer suggestions about reporting in a way that is sensitive to the message being sent and to the individuals who may be the subject of reporting.

1. THE MEDIA AFFECTS PERCEPTIONS, POLICIES AND PEOPLE'S LIVES.

The attention paid to genetic issues by the electronic and print media has a major effect on the manner in which scientific discoveries and people with genetic conditions are viewed. The media play a crucial role in shaping public perception, defining the scientific and social issues on the public agenda, and interpreting issues of health policy. This role has significant consequences for consumers with genetic differences.

2. INCORPORATE CONSUMER PERSPECTIVES IN REPORTING ON GENETICS.

Many consumers with genetic conditions donate personal genetic and family information, time and specimens to genetic researchers and, in some instances, even take personal risks in order to contribute to science. Yet rarely are consumers with genetic conditions asked to share their views and experiences with the media. The inclusion of consumer perspectives in reports on genetic research, testing and treatment is critical for science news and public awareness. Consumers may view scientific developments or their own condition and can offer a broader understanding of what it means to live with a particular condition.

3. BE SENSITIVE TO SOCIAL BIAS.

It is important that the messages relayed to the public about the genetic research, discoveries, tests, treatments and the related genetic condition be sensitive to social biases. It is helpful to evaluate reports prior to their release and to ask the following questions: Are there judgments and predictions about quality of life and life span? If so, on what are these based? Are there unsupported comments or opinions that appear egocentric in origin or that may be harmful to consumers with genetic conditions? What biases exist?

4. PROVIDE A SOCIAL CONTEXT.

Developments in science and technology often occur within a social and cultural context involving human values. Decisions about what research is undertaken are shaped by organizational, professional, economic and political incentives. This context cannot be overlooked and ought to be brought to public attention.

5. AVOID GEE-WHIZMISM.

Many reports on genetics feature dramatic sound bites and headlines that have a "gee-whiz" flair, raising hopes and expectations that may be unrealistic. Sensationalism can generate false hope and can impact on people's lives long after the factual information in a story has been changed, qualified, or forgotten. With each report on genetics, consumers need to know what the information means in the present and how it might affect the future.

6. PROVIDE ACCURATE GENETIC INFORMATION.

Information about the scientific limitations of a study, known accuracy of the test, procedure, treatment or discovery, potential physical and emotional risks and associated ethical and social implications, as well as where people can get additional information about the scientific limitations of genetic research, discoveries, tests, treatments and the related genetic condition is also important. Use of value-laden terms such as "defective" or "disabled" should be avoided. Respect and dignity for human variation and diversity are important as is avoiding the objectification of people with genetic differences.

8. MAKE REASONABLE ACCOMMODATIONS.

The media can display sensitivity by making themselves and their products more accessible. This can be done by offering information on tape or in large print and Braille, utilizing relay services, and complying with the Americans with Disabilities Act (ADA) in spirit, as well as in law. In addition, when consumers discuss a personal story about a genetic condition or health problem, and the name of the condition may be awkward, many consumers believe it is acceptable to refer to a child with Down syndrome, rather than a Down syndrome child, is often preferable. Avoiding language that reflects or reinforces misperceptions about genetic conditions is also important. Value-laden terms that evoke pity, horror, and suffering can be harmful and hurtful. Use of words like "victims" and "genetic defect" reinforce negative stereotypes. Respect and dignity for human variation and diversity are important as is avoiding the objectification of people with genetic differences.

9. IDENTIFY CONFLICT OF INTEREST.

Media publicity about developments in genetic research serves to keep the public informed about new developments. At the same time, however, it can often be used to garner support and generate market interest. Media publicity materials are useful for the promotion of a research institution or company to secure continued support and generate market interest. Sources of genetic information for journalists often report on breakthroughs in research, commercialization, and development of products that may stand to profit from the publicity.

10. ACCEPT THE PRAISE WITH THE EXPECTATIONS.

Consumers have their own agenda and want access to the media in order to reach the public with their stories. The Alliance recognizes that it is impossible to meet everyone's hopes and expectations, especially in instances, come in conflict with media goals and objectives.

In its media outreach initiative, the Alliance will continue to foster better understanding of the process and implications of genetic discoveries and developments. At the same time, however, it can often be used to garner support and generate market interest. Such information helps to sell newspapers or increase television and radio ratings. For example, to determine which journalists are best able to blend journalistic accuracy with sensationalism, the media can display sensitivity by making themselves and their products more accessible. This can be done by offering information on tape or in large print and Braille, utilizing relay services, and complying with the Americans with Disabilities Act (ADA) in spirit, as well as in law.
"These days it seems like we are being inundated with the discovery of a gene a week... science, politics and business intersect with society and conflict... Reporters must be cognizant of this and continue to ask the question ‘why is this news?’

— Michael Waldholz, Wall Street Journal and Co-Editor, Genome

"Reports on genetics, both in the mass media and in scientific journals, often contain a mix of interesting facts, unsupported conjectures, and wild exaggerations of the importance of genes in our lives."

— Ruth Hubbard, Co-Editor, Exploding the Gene Myth

"The experienced reporter was hired by a leading popular magazine to write an article about me. Her investigative interviewing and commitment to accuracy made me think that it would be a really fine piece. She let me review every word. I approved. When it came out in the magazine there were absolute fabrications. The article portrayed me as a ‘victim.’ I was in tears. I am not a ‘victim.’ I am a survivor."

— Anonymous

IV. CURRENT ACTIVITIES
At the 1993 Annual Meeting of the Alliance of Genetic Support Groups, the Media Committee organized its first media workshop and roundtable discussion, “Media Reporting in the Genetic Age,” bringing together genetic writers and other media representatives, consumers with genetic conditions and genetic researchers. This initial meeting, designed to introduce the issues and to initiate discussion, was the first in a series of invitational programs to address the topic of reporting on genetics in the news, popular press, radio and TV.

At this meeting the Alliance released a number of its publications that can be useful to reporters and journalists preparing stories on genetics. These materials include:
1) Media Reporting in the Genetic Age: Points to Consider
2) Media Reporting in the Genetic Age: A Guide for Consumers
3) Directory of National Voluntary Organizations
4) Informed Consent Guidelines for Consumer Participation in Genetic Research
5) Consumer Health Insurance Resource Guide

The newly established Art of Reporting Award was also presented.

Recipient of the 1993 Art of Reporting Award
Mr. Brian Meehan, The Oregonian

V. FUTURE INITIATIVES
The Alliance anticipates that the information contained on the documents relating to media reporting on the genetic age will be made widely available to the media and consumers. Comments and criticisms on this website are welcome.

The Media Committee plans to organize an informal advisory group of journalists, consumers and researchers to better understand the needs and pressures on the press and to develop plans for promoting public awareness about reporting on genetic issues. Individuals interested in participating in this process are encouraged to contact the Alliance office.

The Alliance will continue to encourage collaboration and to provide information, referrals and resources to the media in an effort to encourage responsible media reporting on the genetic age.