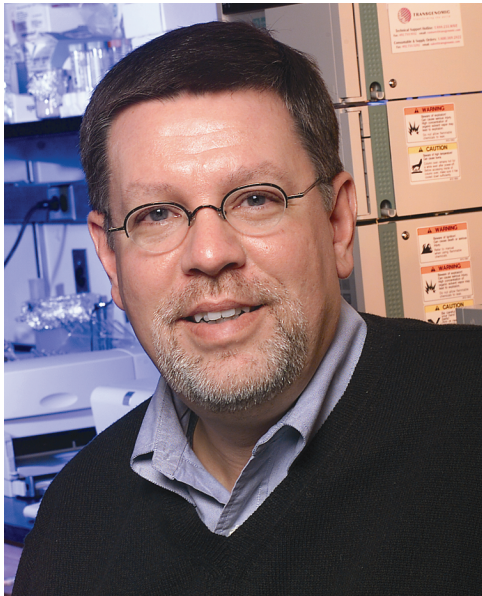


Our Society and the Scientist-Citizen*

Stephen T. Warren



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Good afternoon. My name is Steve Warren, and I am honored, as the 58th president of the American Society of Human Genetics, to address you today. At least two of my predecessors, Arno Motulsky and Ron Worton, began their address by stating that a presidential address to the Society is a difficult task. I am sure this feeling was shared by most other past presidents and, most certainly, by the current one. As this date approached, I found myself doing what many of my predecessors had done, namely reviewing the prior presidential addresses. I was heartened to learn that almost half of the prior presidents discussed their research, including the delivery, over 50 years ago, of a 65-page treatise by our first president, H. J. Muller, on "Our Load of Mutations." Do not worry, I have only prepared 50 pages on fragile X syndrome.... No, all our recent presidents have discussed the field of human genetics, the state of our Society, and its past accomplishments and future goals. While presenting the detailed data on the health of our Society is appealing, as it lends itself easily to PowerPoint slides, I choose instead to discuss the role of our members in society and in our professional society. The first topic I would like to discuss is our inter-

action, as ASHG members, with society in general, specifically involving legislation and education. I would then like to discuss a few aspects of our society and end with a few personal comments about this annual meeting. But first, I would like to say a few words about this great city we find ourselves in this afternoon.

New Orleans

I am delighted that we, as a Society, maintained our plan to hold our annual meeting here in New Orleans, despite the devastation of Hurricane Katrina, and to stand with the people of this great American city. I am grateful also to each of you for attending. Our most recent estimate of attendance approaches 3,500 attendees, which compares favorably with our projections. I am very grateful to the ASHG staff, who worked hard to accommodate the revised dates and to ensure, during the past several months, that the meeting would flow smoothly. The board of directors have been resolute in their view that this meeting should be held here in New Orleans and that our presence would be one small but important act to help rebuild this city. This is something we as a Society should be very proud of.

We have a number of activities and programs planned during our meeting to benefit the citizens of New Orleans. We again held a high-school workshop, with over 200 students and teachers in attendance. This included hands-on experiences in extracting DNA, but from a source I doubt many of us have experience in—strawberries. Actually, there are good genetic reasons to choose strawberries. For example, they are octaploid, provide more bang for the buck, so to speak, relative to DNA isolations. Moreover, DNA is easily isolated from strawberries, as they make terrific smoothies, or, as we refer to them, "lysates."

The Society has also coordinated a visit by the Discovery Genomics Mobile Laboratory from the Venter Institute to provide laboratory courses for middle- and high-school students yesterday and today. The mobile lab is parked outside the entrance to hall F, and I encourage you to visit.

We also held the first-ever workshop for undergraduate educators. This was attended by over 50 undergraduate faculty, many from local universities and colleges, but a few from elsewhere, including Europe. Using an interactive format relating genetics to such social issues as race, popular media, and genetic testing, this workshop pro-

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vided these educators with the resources to now include human genetics into their individual curriculum.

Finally, as many of you know, we have established a fund-raising effort on behalf of the New Orleans school system. This will help their professional-development center with training and materials/equipment for genetics and biotechnology, so that our visit to New Orleans will have a lasting impact. So far, we have raised almost \$9,000 from members, those with the "donor" tag on their name badges. The ASHG is matching this donation dollar for dollar, up to \$20,000. If you have not done so, it is not too late to donate to this worthy cause at booth #1018 or at the cybercafé.

Thanks to the ASHG staff, particularly Kenna Shaw and the Information and Education Committee, for providing the leadership on these important efforts. Now on to the remainder of the address.

The Member in Society

As investigators and practitioners of human genetics, it is easy to become so engrossed in our daily work that we occasionally risk losing sight of all the external influences that affect our professional lives. Social, governmental, and educational policies are evolving, and the dynamics are often driven by the most influential but not necessarily the most well informed. Governmental actions can affect how we practice our craft, how we fund our research, indeed can legislatively and criminally ban aspects of our work, and, in general, limit the scope of our efforts. Often, the actions taken mirror social opinions that influence what should or should not be taught in our schools. As human geneticists, I believe we have a special responsibility to be aware of and participate in the dialogue surrounding these issues. It is critical that we help our public and elected officials understand the impact of our work on human health. We do good work, and they need to know this.

This past spring, the ASHG Board of Directors met in Washington, D. C., for our spring board meeting. We set aside a day to go to the Hill and meet with members of Congress and their staff regarding genetic nondiscrimination legislation, as well as NIH funding. Although Otto von Bismarck commented many years ago that "Laws are like sausages. It is better not to see either being made," the visit was fascinating and, more importantly, successful, as I think our message was heard and appreciated by the legislative offices. I encourage you all to get involved in these advocacy efforts. Meet with your local representative, either at the home office or when you visit the D. C. area. Invite your elected officials to your laboratory to learn about the important work you do and to see first hand that NIH funding goes well beyond Bethesda. A common misconception on the Hill is that the NIH appropriation is largely for the Bethesda campus. Point out how many people are employed in your group, your university, or hospital and how important NIH funding is to maintain

an active effort. Explain to them how rapid the advances are in human genetics and how important the genome effort was for our field and most other disciplines. But also explain that the translation of basic science breakthroughs to the clinic and population takes time. However, great strides have been made against a large number of disorders since the doubling of the NIH budget, and we are poised on the cusp of truly revolutionary advances made possible by genetic studies. We must not slow this effort, and we need to let our representatives know this. Many universities have legislative offices; find out if your institution does and ask them to help. But really, simply picking up the phone or writing a letter to your local representative, inviting him or her to visit, can begin a dialogue.

Such efforts are particularly important today, as human genetics is certainly on the radar screen in the legislative offices. There are important issues currently under debate that could substantially impact your work. The Genetic Nondiscrimination Act has passed unanimously in the Senate and now has 246 sponsors in the House and hopefully will pass soon or, probably more likely, in the new Congress. This act ensures that an individual's private, personal genetic information cannot be used against him or her. For example, employers cannot fire someone because he or she is more likely to develop a genetic disorder. Nor can they require employees to undergo genetic testing. Under this bill, health insurance companies cannot deny coverage or charge a higher premium to a healthy individual solely on the basis of genetic disposition to a disease or a disorder. Another issue to pay attention to is the NIH Reauthorization Reform Act. While this appears to be a good thing at first glance, it includes language to establish what is called an "NIH Common Fund," where a substantial amount of the NIH budget, half of all new funding up to 5% or more, would not flow through the institutes but rather would remain under the control of the director. While it remains to be seen how well this will work, it is a significant departure from the way NIH funds are normally disbursed. This could potentially be a good change for our field, with, for example, these funds being used for multi-institute, multidisciplinary efforts that are particularly large scale and expensive. It is important, however, that these funds be used for the best science possible. At a time of diminished NIH funding, it is important that every dollar is used wisely.

Senator Barack Obama recently introduced the Genomics and Personalized Medicine Act in the Senate, which would substantially increase congressional awareness of the promise and power of human genetics. It is still the early days for this bill, but I think you can appreciate that, at the federal level, all these bills, and others I do not have time to mention, impact one way or another what we do. It is not just the legislature that is interested in human genetics; various regulatory agencies also are considering aspects of human genetics. Indeed, in recent months, the FDA has shown increasing interest in the regulation of genetic testing that could have a major impact on clinical

genetics and the translation of research discoveries into the diagnostic laboratory.

It is therefore imperative that we pay attention to the legislative process and voice our opinions. When you receive an e-mail from ASHG (or any other professional societies you may belong to) regarding an upcoming congressional vote, please be make your opinion known to your Representative or Senator. It really is not hard. If you go to the ASHG public-policy Web page, you can find detailed legislative information and access to the e-mail addresses of your representatives in the House and Senate. A simple e-mail does the trick. Remember, we are the experts, and it is incumbent upon us to educate our political leaders and help guide them, the best we can, into making the best decisions possible. Bad decisions are sometimes like toothpaste—very difficult to get back into the tube once squeezed.

We should also be good role models in this regard to our fellows and students. Part of their training should include the importance of public policy on their future livelihood, and participation in policy forums and public education is an important task. I realize, after writing this, that these comments are very U.S.-centric, and I did not mean to not include our Canadian colleagues and those from elsewhere in North America and, indeed, the world. I believe the general message of participation in the public discourse regarding human genetics is important in any country, and I encourage everyone to play a role in heightening public awareness of our field.

Indeed, public education is the other cornerstone to enhance biomedical research. People fear the unknown, and I believe some of the mistrust of “genetics research” by the public is due to both a lack of understanding and journalistic sensationalism. This mistrust is also not uncommon, even among university and medical-school faculty. How many of us have had to “jump through hoops” or otherwise excessively justify our research plans to our IRBs simply because we will collect DNA? Somehow, drawing a few ccs of blood or, worse yet, a buccal wash, places our research into a category evoking high anxiety among IRB members, right along with highly invasive and risky surgical protocols, simply because we wish to genotype. While there most certainly are special circumstances involved with genetic studies that I do not wish to minimize, often the concern is beyond the reality. The problem, I am convinced, is a pervasive lack of understanding of genetics and the actual risks associated with genetic information, as opposed to the perceived risks often garnered from the popular media, as opposed to competent scientific evaluation of risk. Education is the key. We need to educate members of the IRB and provide a voice at the table. We must make IRB service, an often time-consuming, little-rewarded effort, an important service contribution for human geneticists. We have also found placing genetic counselors on IRBs to be particularly effective, since they are skilled at explaining genetics to the naive, which, unfortunately, is sometimes the situation on such boards. When we teach medical students and residents,

we should include a balanced and realistic discussion of genetic risks. These are the future IRB members, and it is our obligation to educate them on ethical issues related to genetics research on humans.

While we are fortunate that human genetics enjoys a certain level of popular interest, with television programs like CSI and such, however, again, I am surprised how little the general population knows about what we do. Despite the Genome Project’s massive press coverage making most folks aware of DNA and even genomics, the depth of understanding is rather shallow. This has led to a general suspicion, at times, regarding what we do. Indeed, one of the underlying reasons for the Genetic Non-discrimination Act was simply to alleviate largely unsubstantiated fears of genetic testing. It is a real concern that, if people are fearful of the consequences of genetic testing, they will avoid it and therefore not realize the full potential, over the coming years, of advances in testing for genetic predisposition to disease. The popular press, in many cases, has emphasized the sometimes real and often imagined dangers of genetic research. What can we do? Write op-ed pieces for your local newspaper, call in to local talk-radio shows, and be available for the local printed and electronic press. If we shrink away from such issues, it is our fault and our fault alone. There is no reason to be defensive or apprehensive about this. First, we are not, in the words of another president, evil doers. We do good work for which we should be justifiably proud. Second, biomedical research has long been regarded by the public as a highly respected profession. Indeed, the recent, annual Harris poll showed the profession of scientist as the most respected occupation in the country, edging out firemen by 5 points. Every 5 year old should be told this.

We should be a clear and frequent voice in support of science in general and, in particular, human genetics. The Society is enhancing its efforts in public education. I am very pleased to report that ASHG’s expanded educational efforts, begun by my predecessors, is paying off in a big way. Kenna Shaw recently received word that her NSF proposal to establish the Genetics Educator Network of Alliances (GENA) will be funded. This award, in excess of \$1 million, will fund a partnership among ASHG, the Genetics Society of America, the National Science Resources Center, and the National Association of Biology Teachers, to develop a network of geneticist mentors partnered with high-school biology teachers. With the nationwide cadre of 92 such high-school teachers, a minimum of 15,000 students are expected to be reached. Moreover, this program will vastly improve science-education outreach by genetics faculty at all levels of career development. Among many other aims, GENA will also make it much easier for us to do community outreach, by providing content-specific support. So, in this coming year, I ask each and every one of you to do something for the betterment of our field at a societal level. We can make a difference if everyone put in even a small effort.

Finally, not all efforts should be external to the ASHG. We need more involvement in our Society by its members.

Participation is essential to the growth, vibrancy, and success of this organization. Please play a role in the direction that ASHG takes and let your voice be heard regarding how our Society can better serve its members. For example, seek nomination to one of the ASHG committees. Send your name to the Society office or any of the board members, indicating your willingness to serve. Nominations, particularly of early career scientists, are needed also. We need to broaden our reach and need fresh viewpoints to make this happen.

Please attend this year's business meeting on Thursday at 2:30 P.M., here in hall F. Only through engagement of the membership can we really be a strong and positive force influencing the many aspects of the future of human genetics.

I began this address by saying I was proud to stand before you as president of the American Society of Human Genetics. I am more proud simply to be a human geneticist. It is, without a doubt in my mind, the best job in the world. Being a scientist is great, being a human geneticist is better. We are part of a most remarkable field. Human genetics research is one of the broadest areas of science I can imagine. Everything from anthropology, evolution, and human history to mathematics to clinical genetics to public health is included. If we simply look at our membership applications under the interest query, we see a myriad of topics. Cancer genetics, cytogenetics, DNA forensics, ethics, biochemical genetics, molecular genetics, epidemiology, genomics, model systems; the list goes on and on. We are the ultimate translational field that, throughout its history, has bridged between the basic sciences and the clinical sciences. We collectively move from populations to molecules to mathematic theory with ease. The American Society of Human Genetics brings us all together. It is the a remarkable collection of people from all over the world who come together annually at our meeting that is special. It makes this Society our home. This I want to emphasize to all the trainees and students in the audience. In my estimation, one ingredient of having a successful scientific career is to have a solid long-term scientific home. I came to this meeting the first time in 1975. I was still an undergraduate, relegating me to ride behind the back seat in Tom Glover's Pinto, all the way from East Lansing to Baltimore. At that meeting, I saw all the giants of the field, many of whom are still with us at this meeting. I knew I had found a home. When I now look at colleagues in different disciplines, I know how lucky I am that I found this scientific home. Of course, the Society was a lot smaller back then and the meetings more easily navigated. With our success as a field, some mixed blessings have occurred. The annual meeting is quite a bit larger, for example. This makes it somewhat more difficult for the younger members to network and meet each other. I want them to meet their peers and begin viewing this annual meeting as a means to reconnect with old friends and meet new ones. Accordingly, this year, we

established an ad hoc postdoctoral committee to develop meeting content specifically for those in training. Tonight, nearly 300 students and postdoctoral fellows will gather for a program designed to illustrate the many career paths available to them. Besides the traditional academic and corporate PI route, other options, such as laboratory diagnostics, scientific publishing, science policy, and intellectual and patent law, will be discussed. The attendees will be able to make contact with and network with the speakers, who have all agreed to be a contact point for further investigation of careers. Finally and equally important, they will gather informally over refreshments to meet each other and make new and hopefully lifelong friends in this field. This will keep them coming back, as I have year after year. We shouldn't forget, however, other long-standing aspects of our meeting that are particularly good for trainees. This meeting is one of the only meetings of a large professional scientific society where trainees often deliver platform presentations. This has been a unique aspect of our meeting. In many other areas, the annual meeting largely, if not exclusively, comprises invited talks by leading authorities. Senior members, let alone trainees, are happy for their abstract to be chosen for a poster presentation. Here, trainees often compose a large fraction of our platform presentations as well as our poster sessions. We should make this very positive aspect of our meeting known to trainees at our institutions who might be doing work that would fit well within our meeting.

Few societies have the social fabric of this meeting. If I am honest with myself, it really isn't the science alone that draws me every year to this meeting. To be sure, there is plenty of terrific science here, and the program committee works very hard to put together a vibrant and intellectually stimulating meeting. That is the draw. But there are also quite a few other meetings with outstanding science. It is not, however, the same. I enjoy those meetings, but I come every year to this meeting to see all those friends I have made in the human genetics community since 1975. To me, it is that interaction that is priceless. Yes, this meeting involves science—but not necessarily limited to the talks or posters. It is a meeting that virtually everybody in the human genetics community attends. Collaborations are established, data and insight are informally shared, potential postdocs or faculty are met, and, yes, a good time is had by all. This year, we have limited some of the evening sessions, not only to take advantage of New Orleans, but also to allow time to reconnect with your friends. The social interactions are absolutely a key piece of doing outstanding science, and going out to dinner with colleagues or meeting them over a drink is as important a part of this meeting as are the talks and poster.

Victor McKusick began his presidential address 14 years ago with the words "Science is a social enterprise." I will end mine with the same sentiment. This meeting, this Society, is the fabric of our field. So enjoy each other, enjoy the city, and *laissez les bons temps rouler*!! Thank you.