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Editorial: Organized Medical Genetics at a Crossroad

I am using my position as editor of *The American Journal of Human Genetics* to comment on the current situation of organized medical genetics. I use the word "organized" to refer to the institutions that have been developed, by persons working in the many fields that fall within the purview of medical genetics, to govern and guide the practice of their profession.

In considering the remarks that follow, it is important that the reader know the vantage point from which I write and the biases that may be operative. I have been a participant in the medical genetics establishment for quite a long time. I am a member of the Board of Directors of the American Board of Medical Genetics (ABMG), of which I was recently president. In the latter capacity, I was directly involved in the negotiations that led to the recognition of ABMG by the American Board of Medical Specialties (ABMS). I have twice been a member of the Board of Directors of the American Society of Human Genetics (ASHG), presently by virtue of my position as editor of the *Journal*. Outside of these organizational roles, I have been the director of a genetics clinic for 25 years. This clinic has been and continues to be heavily involved in the training of many types of genetic professionals, including counselors, laboratory directors, and physicians. The opinions expressed are my own and do not represent the official policy of any of the organizations listed above or of the *Journal* itself.

During the time that I have been involved in medical genetics I have seen the profession grow from one that consisted of a relatively small number of physicians and Ph.D.'s, along with some laboratory technicians and a handful of assistants who were usually nurses or social workers, to one in which many highly trained individuals are organized in various ways to deliver a large number of specialized and often complex genetic services. During much of this period of growth, the only formal organizational structure available to represent the interests of medical geneticists was ASHG—"the Society." Although initially and still primarily a research society, ASHG gradually assumed responsibility for many of the clinical aspects of human genetics—those encompassed within the rubric of medical (or clinical) genetics. To do this and to deal with the issues that arose, a large number of committees, both regular and ad hoc, were established. These committees, some of which have their own subcommittees, now number over 10 and are concerned with a variety of issues ranging from the human genome, public policy, and social issues to genetic testing and insurance, cystic fibrosis, and genetic services.

The gradual expansion of medical genetics as a clinical specialty and of the responsibility of ASHG for clinical matters, coupled with the rapidly accelerating progress in the science of human genetics, created significant stresses within the Society. These stresses eventually culminated in the "spinning off" of two new entities to address issues that either the Society could not legitimately deal with by itself or to which its structure and purposes did not permit it to devote the required attention. The first of these new entities was ABMG—"the Board"—which was established to certify persons delivering genetic services and to accredit programs for training them. This was an area that was clearly outside the purview of ASHG. ABMG is formally equivalent to the several boards responsible for certifying practitioners in other areas of medicine but, unlike them, certifies both physicians and nonphysicians, as well as professionals with either doctoral or master's degrees. The second and more recent spinoff, which is still in an early stage, is the American College of Medical Genetics (ACMG)—"the College." The College, to be composed of ABMG-certified clinical and laboratory geneticists, is designed to be formally equivalent to the several colleges and academies associated with other recognized medical specialties. Its principal function will be to deal with a large variety of issues that are critical to the practice of medical genetics, many of which are, once again, not optimally handled by ASHG.

As a result of the creation of the Board and the College, organized medical genetics now has a tripartite structure that is the same as that found throughout clinical medicine—a College, to deal primarily with issues of clinical practice; a Board, to be responsible

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for certification of practitioners and accreditation of training programs; and a Society, to provide a forum for the exchange of scientific information. In our own case, the scope of the Society, in so far as its science is concerned, goes well beyond that of medical genetics per se, since that latter is but one component of human genetics.

In parallel with the formal development of medical genetics along the lines of organized medicine has been the establishment of a variety of other organizations representing special needs and constituencies within the medical genetics community. These have included, among others, the National Society of Genetic Counselors (NSGC), the International Society of Nurse Geneticists (ISONG), the Council of Regional Genetics Networks (CORN), and the Association of Cytogenetic Technologists (ACT). These organizations have, to a significant extent, overlapped in various ways with the Society, the Board, and the College, as have the latter three with one another. Nevertheless, despite these overlaps, each of these organizations has a different mission and a special constituency for which it is responsible. And, despite the sometimes competitive nature of these missions and constituencies, there has been a remarkable degree of harmony within the overall community. It is with the maintenance of this harmony that this editorial is concerned.

Why am I concerned? With its emphasis on organizational structures, the bare-bones history of medical genetics that I have sketched out does not do justice to the people who have been involved in the formulation of these structure and who are affected by them. In this regard, what has truly distinguished medical genetics during its evolution as a medical specialty separate from all other medical specialties have been the central roles played by persons who were not physicians. These roles were recognized and codified when ABMG was established. Genetic counselors and Ph.D. medical geneticists, clinical cytogeneticists, and biochemical geneticists were, in addition to the physicians, each regarded as having a valid specialty deserving of formal recognition, and ABMG was structured accordingly. This was a remarkably successful plan that led to a coherent approach to the training of medical geneticists of various types and to a degree of cooperation and mutual respect that extended well beyond the formal functions of the Board itself. In a sense, the Board represented a microcosm of the larger universe of medical genetics and set the tone for how the different professionals working in this universe could and should interact. And now, the structure of this microcosm—the Board—must be radically altered. Why must this be, and what consequences will this have for the medical genetics universe?

The admission of ABMG to ABMS—as a primary specialty board—represents a tremendous victory for medical genetics. By virtue of the Board's admission, medical genetics is recognized as a valid specialty of medicine. This comes at a time when there is a great resistance to subdividing the practice of medicine further than it already is. By being admitted as a *primary* board, as are the boards that certify pediatricians, internists, and obstetricians, medical genetics is recognized as being able to stand alone as a medical specialty that is independent of all of the others. And, by being permitted to continue to certify nonphysicians with doctoral degrees—in particular, Ph.D. medical geneticists, molecular geneticists, cytogeneticists, and biochemical geneticists—it has been recognized that several types of specialists are involved in the provision of genetic services and that physicians cannot fill all of the required roles. This is no small accomplishment—actually, it is a great accomplishment—since only one other ABMS-recognized board is able to certify nonphysicians.

The direct result of all of this is that medical genetics can now speak with a new voice—as a member of the organized establishment of medicine. The ramifications of this are many and hit at every level of clinical and academic medical practice. These include, but are certainly not restricted to, the listing of medical geneticists in the standard directories of medical specialists, improvement in the position of medical geneticists on hospital staffs and in their relationships to other specialists, participation in decision making with regard to matters such as reimbursement codes and laboratory standards, and the granting of independent departmental status to medical genetics groups within medical schools. Furthermore, the recognition of the Board by ABMS is crucial for the ultimate recognition of the College by organized medicine. It is this recognition that gives the College real credibility in the eyes of the other organizations with which it will have to interact or in which it will participate.

All of this is, of course, good for medical genetics in general and for those medical geneticists who will be able to participate in the future activities of the Board and the College. But the cost to one segment of the medical genetics community—the genetic counselors—has been very high indeed. The price for recognition of ABMG by ABMS was that the Board cease from further certification of genetic counselors. The

price for having the College accepted by organized medicine was similar—counselors can not be full-fledged members. Thus, while the recognition of the Board and the formation of the College have served to place the Ph.D. geneticists firmly within the camp of the medical establishment, the same has certainly not been the case for the counselors. Their previous central role in the workings of the Board is about to become undone, and a central role in the College has never existed. Will this not drive a wedge into the medical genetics community, a wedge that will, in essence, have the effect of separating the genetic counselors from everyone else? At first appearances this would appear to be the case. One hopes that, in reality, it will not.

Well before the time that this editorial appears, all diplomates of ABMG will have received information about the steps that are being taken by leaders of the genetic counseling community and ABMG acting in concert to constitute a new board to carry out the certification of genetic counselors and to modify the existing Board to transfer this certification function to the new counseling board. These steps will involve the writing of bylaws and articles of incorporation for the new counseling board; the negotiation of agreements between this new board and the National Board of Medical Examiners, for the administration of the general and counseling examinations; and the appropriate division of the assets of the existing board, between the new counseling board and the modified residual ABMG (ABMS requires that the name remain with the existing board). The new genetic counseling board will probably parallel ABMG in its overall structure, but the details had not been worked out as of the time that this editorial was sent for publication.

Just about the time that this editorial will be published, the diplomates of ABMG will be asked in a mail ballot to approve the measures just outlined. Why must they do so, and why must they do so now? The short answer to the question *why* is that *not* to do so would be disastrous for medical genetics as a medical specialty and for all members of the medical genetics profession, not just to the physicians and Ph.D.'s. We have been given a rare opportunity—to become a recognized and legitimate medical specialty—and this opportunity is not likely to come again. If the amended bylaws of ABMG are not approved and business continues as usual, then recognition by ABMS will be withdrawn. Once such recognition is withdrawn, the probability of obtaining it at any time in the foreseeable future is vanishingly small. Once withdrawn, the chances of being able to create a meaningful and recognized college are, likewise, very low. The answer to the question *why now* is that everything must be completely in place before the 1993 examinations are given, and that is just ten months away. Time is truly of the essence in this situation. These are, of course, negative reasons—reasons based on the loss of something that has finally come within our grasp. The positive reasons have already been outlined above and will not be repeated.

But where does this leave the counselors? They will have their own certification board. They already have their own organizations—NSGC and ISONG—which are, in many ways, functionally equivalent to the College. They will continue to be members of the Society. Nevertheless, the concern is that, even given all of this, they will still be excluded from the major decision-making processes, that they will not remain equal members of the team. In my view, the answer to this is the creation of a powerful channel for communication—open, effective, and meaningful communication—not only between the counselors and the other medical geneticists but also among all of the boards, societies, colleges, and other entities that now constitute the structure of organized medical genetics. I do not believe that the formation of new groups within the overall sphere of clinical medical genetics is itself intrinsically dangerous. What will be dangerous, however, is if these groups lose the sense of common purpose that has prevailed until this point in time. As I have already discussed, the mere fact that we have reached the point at which ABMG could be accepted into ABMS and at which the formation of a College could have been initiated derives directly from the phenomenal development of medical genetics in all of its aspects. These developments have been driven by two things—the change in the science of genetics and, more important, a change in the way genetic services are delivered. The latter, in turn, is the direct result of the major contributions that have been made by the nonphysician members of the genetics community—in particular the genetic counselors—operating in concert with the physicians. It is critical that this sense of cooperation continue.

To facilitate the continuation and strengthening of this cooperation, the Board of Directors of ASHG, at their spring meeting, has taken the lead to establish a Council of Medical Genetics Societies (COMGEN or COMGENS might be acronyms that a computer person would think up), or an organization with a similar-type name, to serve as a body for the coordina-

tion of the activities of all of the organized groups within human and medical genetics. The purpose of this council will not be to dictate to any of its constituent groups. Rather, it will be to provide a forum for communication. Each genetics group will be equally represented, and each will be able to speak with its own voice. For the first time, in addition to the input that genetic counselors have had and will continue to have individually, the counselors' organizations will really be able to have their say.

As the title of this editorial states, organized medical genetics is now at a crossroad. We can either continue on the road that we have been taking to full recognition as a medical specialty and to equality with all of the other specialties of medicine, or we can turn aside and retreat to the previous status quo.

For the good of the entire profession, we must go ahead now!

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Editor