

# Advocating for genetics at the local level: The Medicare Part B Carrier Advisory Committee

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With the dawning of the new millennium, genetics is beginning to assume an increasingly important role in clinical medicine. One of the enduring frustrations of practice relates to issues of billing and reimbursement. While some important strides are being made locally and nationally with some carriers, there has been limited understanding and incorporation of genetic practices into programs administered by the Health Care Financing Administration (HCFA). While the American College of Medical Genetics (ACMG) is actively working to develop relationships with HCFA, the purpose of this invited article is to describe an opportunity for ACMG members to have input into the Medicare system at the local level through involvement in Carrier Advisory Committees (CACs).

## A MERCIFULLY BRIEF INTRODUCTION TO MEDICARE

Before discussing CACs, a brief discussion of Medicare and HCFA is in order. The Medicare program was signed into law in 1965. Its intent was to provide a safety net for costs related to catastrophic illness in the elderly (defined as over age 65), some disabled individuals, and people with end-stage renal disease. A library could be filled with the changes to Medicare since its inception, but we'll hit a couple of the highlights.

HCFA is the federal agency charged with administering the budget of the Medicare and Medicaid programs. Medicaid dollars are distributed to states, which have the final say over utilization of those dollars within the mandates of the federal program. That is the subject of another article. The Medicare program is broken into three parts: A, B and C.

Medicare Part A (hospitalization insurance) represents the catastrophic illness coverage from the enabling legislation. It covers care in hospitals, skilled nursing facilities, hospice, and some home health services. Most Medicare eligible patients receive this part at no charge.

Medicare Part B (medical insurance) covers physician services, outpatient hospital care, physical and occupational therapy, lab, x-ray, and durable medical equipment. Preventative medicine exams and services are excluded from coverage, with certain legislated exceptions. Eligible members pay a monthly premium for Part B coverage.

Medicare Part C includes options for coverage such as Medicare managed care plans, private fee for service plans and many

other programs. If a member opts to join a Medicare Part C plan, this replaces Parts A and B. Members pay a premium to the individual Part C plan and that plan manages the provider network and payment. The plan also receives a monthly premium from HCFA. Part C plans are required by law to provide at least the same benefits as those provided under Parts A and B, although most provide additional benefits as well (such as preventive medicine services). We will concern ourselves with Medicare Part B for the rest of this article.

Until recently, each state had a carrier (i.e., an insurance company) for Medicare Part B. HCFA is now developing a series of regional carriers. Each regional carrier has a medical director for Medicare Part B. In addition, each state has a medical director, that is under the regional carrier medical director. For example, Wisconsin Physician's Service (WPS) is the Part B regional carrier for Wisconsin, Minnesota, Illinois, and Michigan. In addition to the WPS Medicare Part B medical director, there is a medical director for each of the four states. This is necessary, as individual state laws regarding coverage can lead to differences in benefits between states covered by the same carrier. National coverage decisions do supersede state mandates if there are differences.

## WHAT IS A CAC?

One of the mandates of Medicare Part B is that each state medical director develop a Carrier Advisory Committee (CAC). The composition of the CAC is not specified and varies greatly from state to state. It is also fair to say that the effectiveness of the CAC is highly variable. I have served on the Wisconsin CAC since 1993 and will use it as an example, as it is looked upon as one of the most effective CACs in the country. In Wisconsin, all recognized medical specialties are able to appoint a representative to the CAC. I was appointed by the Wisconsin chapter of the American Academy of Pediatrics (AAP) to serve as the pediatric representative. Following my "conversion" to geneticist, I have unofficially served as the ACMG's representative to the CAC (don't tell my Wisconsin colleagues!!). Additionally, there is representation from recognized medical paraprofessionals (nurses, physical therapists, speech therapists, to name a few) and other administrative entities (such as Medicare Part A, Medicare Peer Review Organization, American Group Practice Association, etc.). Policies are developed by representatives of the relevant specialties and are distributed to all CAC members for review and comment. The key in this process is that the policies are care oriented as opposed to provider oriented. To put it another way, the ques-

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tion asked is, is this in the best interest of the patient, not, how can we put more money in the pocket of the provider? The latter question has significantly limited the impact of CACs in other states. Involvement of a wide range of practitioners is critical to ensure a policy that accurately reflects clinical practice.

The purpose of the CAC is to provide the local medical director with a range of expertise that will assist in the development and revision of local coverage policies. While the local carriers must provide all benefits that are mandated by HCFA, they also have the discretion to add additional benefits on a local level over and above the national benefit. The ability to implement local policies is important, as medical care and technology progresses at a much faster rate than a large bureaucracy such as HCFA can reasonably respond to. The local carriers can, thus, implement “best practice” in lieu of a directive from HCFA. The CAC serves as an expert review panel for the medical director. Local policies can be generated by the medical director and reviewed by the CAC, or, in some cases, the CAC specialty member will propose a new policy that will be endorsed by the medical director. All of these policies are then reviewed by the entire CAC membership. Following discussion by the CAC, the draft policy is available for public comment for 45 days before the final policy is drafted and implemented. An example from the Wisconsin CAC may help to illustrate this process.

Ocular photodynamic therapy (OPT) is a novel treatment to prevent vision loss due to wet macular degeneration. There are no effective alternative treatments for this condition. Based on information provided by the CAC representatives from Ophthalmology, a local policy was developed to provide coverage for this procedure for Medicare Part B recipients in Wisconsin. This is allowed, as it provides more generous coverage than the national mandate and it does not conflict with any national policy that would restrict coverage. Ultimately, this policy will have much broader impact. Once approved and published, all Medicare Part C carriers in Wisconsin are obligated to provide this same coverage. This policy will be used as a draft to develop similar policies in the other WPS states (Michigan, Illinois, and Minnesota). It may also be used as a model policy that other carriers will adopt, which could provide for coverage of this procedure across the country.

Another function of the CAC is to allow discussion of issues relating to focused medical review. These relate to concerns about over- and underutilization issues within the local area. Carriers are required by HCFA to perform these reviews and respond to the results. Again, using Wisconsin as an example, there were questions raised about utilization of tests and medications relating to malignant hyperthermia susceptibility (MHS), which were seen at a much higher frequency than the national benchmarks. I was able to point out that this is not unexpected in Wisconsin, as families from northern Europe that are known to harbor “founder mutations” for MHS emigrated to Wisconsin and still reside here. Consequently, the prevalence of MHS in Wisconsin is much higher than that seen nationally and utilization was, therefore, not excessive. This

prevented unnecessary scrutiny of physicians caring for these patients. In another instance, the Medical Director from Illinois brought a draft policy on heavy metals to the Wisconsin CAC as part of the process of implementing this policy in all the WPS states. The genesis of the policy was overutilization of heavy metal tests being performed by a freestanding lab that would run a large battery of tests for insufficient clinical indications. The policy did not address all diagnoses where testing is appropriate. In particular, Wilson’s disease was not referenced under copper testing. This could have resulted in inappropriate exclusion of coverage for this test.

CACs provide a forum for distribution of new policies and procedures both from the local carrier and HCFA that can sometimes affect certain specialties. Also, the state medical director can communicate local physician and provider concerns to HCFA, either directly, or as part of meetings of the state medical directors. These examples illustrate the way local CAC involvement can have very far-reaching effects. Ideally, this provides the ability to communicate both upstream and downstream, although with any bureaucracy as large as HCFA, communication is tenuous under the best of circumstances.

## WHAT THE CARRIER AND CAC CANNOT DO

It is dealing with these issues that creates much frustration. Before proceeding, let me teach you the Wisconsin CAC’s mantra for dealing with these frustrations—**Yes, it’s stupid, but it’s HCFA and it’s consistent.** Recite as necessary until pulse and blood pressure normalize. I will indicate appropriate use of this mantra below.

Local carriers must provide or exclude coverage that is specifically mandated or excluded by HCFA. It is not an option to deny or modify coverage in a way that would be determined to lessen the benefit as defined by HCFA. As noted above, a local carrier would have the option to provide benefits over and above those defined by HCFA, unless this is specifically prohibited in the coverage language. An example of this is screening mammography. HCFA implemented a national coverage policy that allows coverage for a mammogram annually for all women over the age of 40. A local carrier cannot decide that this is too frequent and implement a policy that covers mammograms only every 2 years, as this would be viewed as decreasing the benefit as defined in the national policy. If, however, the local carrier decided that it would cover a mammogram every 6 months, this would be allowed, as it increases the benefit and is not specifically prohibited by the national policy.

One of the most frustrating and confusing issues relates to coverage of preventative examinations and tests. The enabling legislation for Medicare specifically excludes coverage for preventative tests. (At this point recite mantra.) Seriously, the Medicare program was initiated as a catastrophic coverage program at a time when medicine’s orientation was management of disease rather than prevention of disease. This is why physical examinations, routine vision and hearing exams, and many recommended blood tests are excluded from coverage.

(Any of you covered under Medicare know that, whenever you get a laboratory test, you must sign a waiver that states you are responsible for payment if this is a noncovered test.) Ah, you say, but mammography is a covered benefit and it's preventative. That is true, however, the Medicare act was amended by an act of Congress to specifically extend coverage for mammography. Any preventative measure that is covered has been added in this fashion (recite mantra). Here is a genetic example. A local carrier could decide to allow molecular testing for Huntington disease in a symptomatic patient. This would be a diagnostic test. The same carrier could not decide to cover presymptomatic testing for Huntington disease in at-risk individuals who are not symptomatic, as this would be considered preventative (or at least nondiagnostic) and is excluded from coverage (recite mantra). Until Congress passes legislation that specifically allows coverage of this test, this will remain as an uncovered item. It is obvious that the majority of the genetic tests on the horizon will fall into this presymptomatic or predispositional category, and will not be covered, no matter how high the clinical utility. The same proscription relates to relevant state statutes that define coverage and are not superseded by HCFA regulations. ACMG will need to continue to advocate both at the state and federal level to address these coverage issues.

The A in CAC stands for Advisory. The role of the CAC is strictly as an advisor to the carrier. CACs can provide input to the decisions regarding carrier policies but do not have the final say. Ultimately, the carrier will publish the final form of the policy, which will define the coverage. As mentioned, the degree to which this reflects the CAC recommendations varies widely from state to state. In some states, the CAC meetings are perfunctory and the input is rarely incorporated into the development of medical policies. In states such as Wisconsin, the CAC provides vital input and, with very few exceptions, the final policy incorporates the recommendations of the CAC.

### **WHY SHOULD I SERVE ON A CAC?**

The simple answer is that it is the only way to provide information about genetic disease in a local forum that can affect policy decisions. We tend to think of Medicare as a program for

the geriatric population, but Medicare Part B provides coverage for a variety of other medical conditions, including coverage for the disabled population, many of whom have genetic diseases. Involvement of geneticists would hopefully lead to better patient care, increased understanding of the role of geneticists in the care of patients, improved reimbursement for services, and ultimately may play an important role in the integration of the "new" genetics into clinical practice. Also, many other third party payers look to Medicare and its fiscal intermediaries in development of their own coverage policies, which could result in more rapid dissemination of coverage without dealing with every payer on an individual basis.

### **HOW DO I JOIN A CAC?**

The answer will vary depending on the state. A list of the fiscal intermediaries is available on the HCFA Web site (<http://www.hcfa.gov/medicare/incardir.htm>). This site lists the fiscal intermediaries and carriers for both Parts A and B, as well as durable medical equipment (DMERC) and rural health (RHHI). This list is current as of publication of this article, but changes frequently. To use the list, find your state and look for the Medicare Part B Carrier. Clicking on this hyperlink will give you information about this carrier including phone, fax, and E-mail. Unfortunately, there is no information about who the state medical director is and how to contact them. (Hey, this is the government. No one said it was going to be easy!!) The next step is to contact the carrier and find out the name and number of the Medicare Part B medical director for your state. You can then contact the medical director for information about CAC membership. Membership is on a volunteer basis. The carrier will not provide reimbursement for travel or accommodations (although you may get lunch). If you come from a state that has an organized genetics network, it would be appropriate to "elect" a representative from that organization for CAC membership, unless the state's CAC policy suggests an alternative arrangement. Most important is to be persistent. You will be dealing with a large bureaucracy that will do whatever it can to impair your ability to talk to the right person. As Stanislaw Jerzy Lec said, "No snowflake in an avalanche ever feels responsible." Here is your chance to be a "snowflake" that hopefully will start an avalanche.