An Advocacy Role for A.C.P.A.

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Professional associations are often asked to assume an advocacy role supporting political, economic or social positions which, at least to some members, seem pertinent to the mission of the organization. Issues dealing with the environment, civil rights and defense spending, among others, can become agenda items at national meetings and generate much discussion and even discord. An association which takes a position on any of these significant concerns runs the risk of polarizing its membership over issues which do not directly pertain to the professional objectives of the group.

However, when events have direct impact on an organization’s primary mission and the membership demonstrates concern, then the leadership must consider an appropriate response. At the recent American Cleft Palate Association meeting in Denver, the membership of the American Cleft Palate Association was asked by its president to consider a new, expanded role for the organization.

According to the preamble of our constitution, the Association was formed because of our interest in the welfare of individuals with cleft palate and associated deformities of the mouth and face, our desire to encourage the improvement of services by every appropriate means, and finally to stimulate public interest in rehabilitation.

Although the Association provides annual scientific sessions, special symposia, short courses and publishes an outstanding journal, there has been minimal activity directed toward stimulating public interest in facial deformities. The abrupt changes in government policies experienced at federal and state levels in recent years have made it essential for the American Cleft Palate Association to monitor the development of public laws, regulations and policies closely. The Omnibus Reconciliation Act of 1981 created a maternal and child health block grant consolidating a number of children’s health programs including Crippled Children's Act funding. As for all block grants, there are no standards mandating how much money a state must allocate to each service. In fact, funding for one or more programs within a block grant could be eliminated.

Changes in medicaid funding are of concern to those involved in providing treatment to children with cleft lip and palate. Certain basic medicaid services are “mandatory” (i.e. a state must pay the cost of these services to receive matching federal medicaid funds); other services such as dental care, speech therapy, and rehabilitation services are “optional.” The extent of optional services varies from state to state and, as states are increasingly pressed to trim medicaid costs, we can expect some optional services to be eliminated. There may also be initiatives at the national level to limit the range of mandatory services.

The American Cleft Palate Association must become concerned with state insurance regulations. Many health plans cover only part of the necessary treatment of children with cleft lip/palate. For example, dental care is frequently omitted from medical coverage in spite of the fact that treatment of this medical condition usually requires some dental intervention. We must better inform insurance companies, state insurance commissioners, legislators and officials of state agencies about the necessity for complete coverage of treatment for cleft lip and palate individuals.

Many critical decisions concerning the care of our patients will be made by state and federal governments in the coming year. At present, because of time constraints, most states simply continue to fund all programs in the same proportion as they had been funded before block grants. This year, however, with

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the potential of even less money forwarded to
the states there will be close scrutiny of every
program. The American Cleft Palate Associ-
ation must be prepared to defend programs
which sponsor treatment of individuals with
cleft lip and palate.

With this in mind, Dr. Mohammad Ma-
zaheri and I went before the American Cleft
Palate Association/Educational Foundation
and sought approval for developing an advo-
cacy role. The mechanism we believe to be
most appropriate is to combine our efforts
with a professional organization experienced
in public relations and lobbying. The mem-
bership approved this approach in principle
and negotiations with several firms are antic-
ipated. Our specific goal is to provide better
information to state and national leadership.
This information will include the numbers of
individuals born with cleft lip and palate and
associated anomalies, the physical and emo-
tional problems associated with these condi-
tions, the complex habilitative process in-
volved, and the need for public and private
assistance. If policy makers are better in-
formed, they are more likely to make decisions
that will be beneficial to our patients.

Thus our proposed advocacy efforts will
focus on education and the sharing of accu-
rate and timely information. This strategy
would eventually involve a network of profes-
sionals within the American Cleft Palate As-
sociation/Educational Foundation as well as
parents and patients with whom we work. If
forthcoming, this will be a new role for the
American Cleft Palate Association/Educa-
tional Foundation. It is both timely and ap-
propriate, however, because the abrupt shift
in government policies requires an informed
response.

This is a challenge we cannot afford to
ignore.