

Epidermolysis Bullosa Research Association

Voluntary health associations have made enormous contributions to the control of many major diseases. The National Tuberculosis Association (NTA), established in 1903, was one of the first to be organized, and others that followed patterned their organizational structure and activities after the NTA. The major strength of voluntary health groups is the cooperative effort and understanding they create between physicians and lay persons who together share responsibilities on governing boards and committees.

The main activities of voluntary health associations are support of research, public education service to patients, support of professional education, and advice to government on legislation and regulation. The control of tuberculosis and the conquest of poliomyelitis, advances in the prevention and treatment of heart disease, and the success of renal dialysis and transplantation are examples of what can be accomplished by voluntary health agencies. These successes have served to encourage the formation of other groups whose members have a special concern for a disease that has afflicted a family member or friend. Most of the voluntary health groups organized in recent years have been small in size and have directed their attention to relatively uncommon diseases. These organizations face an uphill battle for recognition, are unable to raise large sums of money to support their activities, and often are battling against diseases that will not yield to current research technology. Often, however, the greater the challenge, the greater the enthusiasm of those who are being challenged.

A recent addition to the voluntary health movement is the Epidermolysis Bullosa Research Association. Although the prevalence of epidermolysis bullosa in the United States is not precisely known, the new association has identified more than 1,500 cases and believes that through increased research this distressing disorder may either be prevented or more definitively treated. Epidermolysis bullosa is a group of inherited skin disorders, characterized by the formation of blisters that follow mild trauma. The genetic basis for these disorders make them a lifelong problem for those unfortunate enough to inherit the disorder. Like other chronic diseases, it arouses greater concern and interest in the establishment of a society than do acute self-limited diseases.

The Epidermolysis Bullosa Research Association is interested in receiving reports of research on epidermolysis bullosa, in recruiting both lay and medical professionals to its ranks, and, of course, in receiving donations to advance its cause. Interested persons should contact the executive director of the association at 2936 Avenue W, Brooklyn, NY 11229.

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Guidelines for the Determination of Death

The report on "Guidelines for the Determination of Death" in this issue (p 2184) is a landmark document with far-reaching medical, ethical, and legal implications. It is a summary of currently accepted medical practices for the determination of death, both cardiorespiratory and neurological, although the majority of the report is devoted to the diagnosis of neurological, or brain, death. Physicians from numerous specialties contributed to the drafting of this report, which was coordinated by the staff of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. These guidelines are included as an appendix to the more comprehensive report by the President's Commission on "Defining Death: A Report on the Medical, Legal and Ethical Issues in the Determination of Death" (this entire report was approved by the President's Commission and sent to the President on July 9, 1981).

Until now, the most widely accepted standards for brain death in the United States have been the criteria developed by the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, published in *JAMA* in 1968 (205:337-340). These new guidelines are an update of currently accepted standards in the light of a great body of clinical experience accumulated since the original report of the Harvard Committee, and the development and refinement of new technologies in the laboratory confirmation of the diagnosis.

This report is important primarily because so many physicians were able to reach a consensus on a common set of guidelines, even though there were (and still are) differences of opinion on specific aspects of the criteria, and the signatories were aware of the ethical and legal implications of developing a set of national standards. For this many physicians from the fields of neurology, neurosurgery, electroencephalography, critical care medicine, anesthesiology, and legal medicine to reach a consensus is truly a remarkable achievement, of which the medical profession can be proud. Efforts such as this suggest that physicians have recognized the need for cooperation in developing standards in areas of controversy. In the next few decades, it will become more apparent to the medical community that it will need to take positions on even more controversial issues. Future statements will cover such areas as organ donation, "do not resuscitate" orders, and guidelines for the termination of treatment of "hopelessly ill" patients.

This report is not the final word on standards for determining death, but it is an important step forward in society's attempts to deal with bioethical dilemmas brought about by advances in medical technology, and it further reinforces the view that the medical profession must and will continue to assume a leadership role in these endeavors.

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