

Editorial

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I am pleased to have this opportunity to comment about the burden of skin diseases from a congressional and public policy perspective. Two years ago Dr Luis A. Diaz, then President of The Society for Investigative Dermatology (SID), testified before the appropriations subcommittee of the US House of Representatives, which funds the National Institutes of Health (NIH), and indicated the concerns of the SID regarding the matter of insufficient data about the burden of skin diseases upon the people of this country. The SID has testified before the House Appropriations Committee every year for the past 15 years for research funding to improve the lives of patients. From the 2001 testimony, I quote:

There are more than 3000 different diseases of the skin, hair and nails, which in an average year affect about 60 million Americans. The combined annual cost to society of medical care and lost wages from these conditions is estimated to be in the billions. The potential cost to individuals suffering from these conditions include: discomfort and pain, disfigurement, disability, dependency, and death.

You will be surprised to know, I expect, that information regarding the total costs to society of dermatologic diseases has not been updated since 1979. That includes incidence, prevalence, mortality and disability, along with economic costs, including direct costs of in-patient and out-patient care for physicians and other health professionals, drugs, administrative costs, hospital and nursing home care, as well as loss of economic productivity and activities that are foregone as a result of disease. Upon learning of these problems from the SID, I requested that the appropriations subcommittee formally call for a workshop at the National Institution of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to assess the burden of skin diseases, in collaboration with other federal agencies and voluntary health and professional organizations.

The workshop was held in September 2002, and a preliminary report is available at the NIAMS Web site: http://www.niams.nih.gov/ne/reports/sci_wrk/2002/burden_skin_disease.htm. These recommendations were made:

- Workshop participants recommended that core measures of the burden of skin disease be developed (general, skin-specific, and skin-disease-specific) to generate data on incidence, prevalence, economic burden, quality of life, disability, and handicap.
- These outcomes should be arrayed in a matrix against personal, family, and societal impacts.
- The available metrics then should be organized within this matrix so that gaps can be identified and metric development prioritized.

It was particularly pleasing to see that the workshop included input from leaders of many patient organizations.

In May 2003, Dr David Bickers testified about the workshop and made some specific recommendations. Again, I requested and obtained language from the appropriations committee in its bill to carry out those recommendations. I have been pleased to see that the Senate Appropriations Committee also included language. To reinforce our intentions, the Senate–House Conference Committee on the bill also called for action, including requesting a “detailed action plan of Institute activities to effectively implement the recommendations of workshop participants.” It is a real tribute to the SID that it has shown so much persistence in this effort and that it enthusiastically has included the patients’ organizations every step of the way. The issue now has the attention of key congressional policy makers, whom I hope will realize that nearly a quarter-century (1979) has passed without a thorough inventory of all databases and an updating of the quality of sources of information about all impacts of the burden of skin disease. It seems to me that a real opportunity exists now, because of the work that has already begun, for the field of skin disease research to create an information system to provide updated data to policy makers, including congressional appropriators, so they may make sound judgments about expenditures of taxpayers’ dollars.

As is widely known, Congress has doubled the budget of the NIH over the past 5 years, and many members are asking what research advances are being translated to patient care—which, after all, is what taxpayers’ dollars are being spent for. Therefore, any systematic action plan for the development of data that indicates the size and nature of the problem involved, and a program of research translation to patient care, should be welcomed by all policy makers.

With these new data, skin diseases may be an important model and new paradigms can be established on how societal needs may be addressed by the best of medical science founded on fundamental research.

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