The Importance of the Coalition of Skin Diseases to Dermatologic Research

Successful clinical investigation requires financial resources, patients with one or more identified diseases, personnel to conduct the research, and good hypotheses. Those who choose to conduct clinical studies soon learn that investigation is largely a business, even when it occurs in academic medical centers and research institutes. For example, access to money is often the “rate-limiting” step. This is true for all varieties of clinical research, ranging from case reports written by physicians in practice to complex multidisciplinary projects that cost millions of dollars (or Euros). Appropriate amounts of money buy time for investigators to develop good ideas, qualified personnel to conduct the laboratory work, space in which to conduct the work, essential materials, and, finally, time to prepare manuscripts and reports for publication and distribution.

Given this requirement for financial resources, productive investigators have necessarily devised various strategies for their generation. For example, physicians who write papers about patients seen in clinical practice have less time to provide medical care, thereby lowering cash flow and personal income, while at the same time hopefully increasing satisfaction. Thus, they support their work with their own funds. At the other end of the spectrum, investigators in departments of dermatology and basic science departments attempt to divert scarce institutional resources toward their own interests. At the same time, a large investigative effort in skin disease is conducted by for-profit companies, with the goal of developing drugs and equipment that ultimately will offset their costs. And finally—the object of this editorial—in North America and Europe, investigators apply for resources from national governments and from private funding agencies to support their work. In the United States, the National Institutes of Health (NIH) provides through grants and contracts major amounts of money. The same is true in Europe, albeit through national and EU sources.

In recent decades, several “not-for-profit” advocacy organizations have become critical players in the generation of national resources, as well as in providing necessary information to patients with specific diseases. These organizations, having mandates to address the needs of patients with specific diseases, now assist in the recruitment of money to support research and advocate the advancement of research in these disease categories. We first became acquainted with patient advocacy many years ago through activities of the National Psoriasis Foundation and then the Alopecia Areata Foundation, both chartered in the United States. Importantly, in more recent years, these organizations and many others have consolidated some of their efforts and resources in a collective organization now known as the Coalition of Skin Diseases (http://www.coalitionofskindiseases.org). We invite readers to consult this website to become more familiar with the member organizations.

The Coalition of Skin Diseases currently encompasses 16 organizations that pool their efforts, while at the same time providing resources for their own specific interests. Their activities include patient information resources, direct funding for research, and lobbying at the national level. In addition, other organizations with more general interests support the coalition, including five that are well known in the United States: the American Academy of Dermatology (AAD); the American Skin Association, Inc.; the Dermatology Nurses Association; the Society for Investigative Dermatology (SID); and the Society for Pediatric Dermatology. We highly recommend that readers study the great variety of resources and efforts provided by the coalition.

A simple personal experience illustrates the power of the Coalition of Skin Diseases. For many years, members of the coalition, along with representatives from the SID and the AAD, and supported by representatives of the National Institute for Arthritis and Musculoskeletal and...
Skin Diseases, have held an annual education event for members of Congress in Washington, DC. The point of this exercise, which continues today, is to keep research opportunities and activities on the agenda for members of Congress, who ultimately are responsible for funding by the NIH. For more than 10 years, I participated in this event. It was organized to enable small groups to visit congressional offices and to promote medical research in general, using evidence about patients with skin diseases. Each group includes at least one individual from a congressional district (or from a state when visiting a Senate office), one individual from an advocacy group, and one scientist. These groups then visit congressional “staffers,” or, if lucky, the member of Congress. The reception is invariably cordial.

Perhaps the most telling observation from these visits is that staffers and congressional representatives embrace the coalition members, but are not especially interested in speaking to the scientists, at least initially. I surmise that my presence (as a scientist) might be seen as self-serving because investigator salaries are included in grant requests to the NIH. On the other hand, members of the coalition have no apparent conflict of interest. They are strictly advocates for research funding, seeking benefits only for patients. They know the diseases, and they describe them well. The visual materials they present are outstanding and overwhelming, as images of skin diseases usually are. In these meetings, it is a relief to hear the coalition members state authoritatively their advocacy for funding by federal agencies, including the NIH and the National Science Foundation. We scientists can then affirm our interest in studying the disease for the benefit of others.

The Coalition of Skin Diseases is an effective proponent of skin research, through both funding and advocacy, and their efforts should be supported by members of the scientific community. Their interests are the same as ours: the alleviation of disease. Scientists who care for patients should recommend membership to their patients and, as members of the SID, we should encourage membership by our colleagues on their advisory boards. At the next Annual Meeting of the SID, seek out members of the coalition to learn more about their agenda.

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