

**STATEMENT OF THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY**

**ON THE**

**FISCAL YEAR 2006 APPROPRIATIONS FOR THE**

**NATIONAL INSTITUTES OF HEALTH**

**AND**

**THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN  
DISEASES**

**SUBMITTED TO THE**

**HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH & HUMAN  
SERVICES, EDUCATION AND RELATED AGENCIES**

**PRESENTED BY**

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**SUMMARY OF FY 2006 RECOMMENDATIONS**

- 1) A 6% INCREASE FOR ALL OF THE NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS).
- 2) ENCOURAGE NIAMS TO CREATE AND ENHANCE ACADEMIC AND EDUCATIONAL OPPORTUNITIES FOR THE ADVANCEMENT OF SCIENTIFIC INVESTIGATION OF SKIN HEALTH AND DERMATOLOGIC DISEASES.
- 3) ENCOURAGE NIAMS TO SPONSOR FURTHER BURDEN OF SKIN DISEASE RESEARCH AND EPIDEMIOLOGY ACTIVITIES TO INVESTIGATE GENERAL AND SKIN-DISEASE SPECIFIC MEASURES IN ORDER TO GENERATE DATA SURROUNDING THE INCIDENCE, PREVALENCE, ECONOMIC BURDEN, QUALITY OF LIFE, DISABILITY AND HANDICAPS ATTRIBUTABLE TO THESE DISEASES.
- 4) PROMOTE THE DEVELOPMENT OF NIH-SUPPORTED TRAINING RESOURCES DEDICATED TO ATTRACT MORE INDIVIDUALS TO CAREERS IN SKIN DISEASE RESEARCH.

Mr. Chairman, and members of the subcommittee—I am very grateful for this opportunity to testify on behalf of the Society for Investigative Dermatology. I am Dr. Kevin Cooper, Professor of Dermatology, Chairman and Director of the Skin Diseases Research Center at the Department of Dermatology at Case Western Reserve University. I also serve as President of the Society for Investigative Dermatology.

### Background

The Society for Investigative Dermatology has over 2000 members worldwide dedicated to the advancement and promotion of the sciences relevant to skin health and disease through education, advocacy, and the scholarly exchange of scientific information. Members include scientists and physician researchers from universities, hospitals, and industries committed to the science of dermatology. Each member firmly believes that further research is critical to improved prevention, diagnosis, and treatment for the 3,000 different diseases of the skin, hair, and nails, which affect about 80 million Americans each year.

My purpose in being here today is to emphasize the need for increased funding for the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Last year, Congress provided the National Institutes of Health (NIH) with a modest 1.9% funding increase. This year, we recommend a 6% increase for the NIH budget, and a similar increase for NIAMS, which would lead to a funding level of \$542 million for NIAMS. I am also here to encourage follow-up to the “Burden of Skin Disease” workshop that took place in 2002. The workshop was held with the intention to investigate general and skin-disease specific measures in order to generate data surrounding the incidence, prevalence, economic burden, quality of life, disability and handicaps attributable to these diseases.

Good health depends on healthy skin. Much of what we see on the outside of the body is a reflection of a person’s health inside. From the yellow of hepatitis, to the deep purple lesions of Kaposi’s sarcoma- a common side effect of AIDS, from the sizeable skin lesions of lupus erythematosus, to the painful deformed nails which may occur in patients with severe arthritis and psoriasis- health disorders often show up first as problems on the skin’s surface. Skin samples are often used to make genetic diagnoses of internal disorders and in the future, the skin may be a target for gene replacement.

Advances in cell biology allow us to understand the life cycle of skin and hair-producing cells and to explain how a malfunctioning immune system undermines the health of the body overall and the skin, in particular. Furthermore, the ongoing revolution in molecular and cell biology, genetics, immunology, information and laser technology provides unprecedented opportunities for achieving advances in basic research and medical treatment. We are becoming rapidly more adept at growing skin cells in the laboratory and at producing artificial skin. Increasingly, laser surgery is commonly replacing more invasive and traditional surgical methods.

As the population ages and we live longer, dermatologists will be asked increasingly to treat cancers and other skin disorders that appear more often in aged individuals. Dermatologists will need to find new and better ways to help prevent and heal common conditions of the elderly, such as bed sores. Ulcers of the skin alone cost \$12 billion per year to diagnose and treat.

I would like to thank the subcommittee for the inclusion of the conference report language in your FY05 bill, calling for further attention to the numerous research opportunities and developments identified during the September 2002 Burden of Skin Disease workshop.

### The Burden of Skin Diseases

The Society for Investigative Dermatology along with The American Academy of Dermatology Association commissioned a study to quantify the burden of skin disease. On April 6, 2005, the Burden of Skin Diseases report was released. The September 2002 Burden of Skin Diseases workshop provided a solid foundation for collaboration and to set an agenda for skin disease research. The Burden of Skin Diseases Report builds upon initiatives developed at the workshop.

This study shows that skin disease is more prevalent than anyone ever imagined – and carries serious medical and financial consequences. The costs to society for medical care and lost wages due to conditions of the skin, hair and nails are estimated to be \$37 billion annually. However, the costs to those suffering from these debilitating conditions are immeasurable: they encounter discomfort and pain, physical disfigurement, disability, dependency and death. Skin conditions affect an individual's ability to interact with others and compromise the self-confidence of those inflicted. At any given time, one in every three people in the United States suffers from a skin disease. The prevalence of skin disease exceeds that of obesity, hypertension, or cancer.

### Research Advances

Skin cancer is the most frequent cancer diagnosis, this year more than 1.3 million new cases of skin cancer will be diagnosed in the United States. Melanoma is the most deadly form of skin cancer, and advanced melanoma is almost always fatal. Researchers at NIH are investigating a cell-based form of immunotherapy for stage IV melanoma that produced tumor shrinkage or disappearance in more than 50 percent of patients enrolled in a clinical trial. Additionally, researchers are investigating the possible genetic component of the disease and are also engaged in the search for a safe and effective melanoma vaccine

Acne is the most common and well-known skin disorder. As you know, acne strikes people at a time when their peers are especially judgmental and their egos are particularly fragile – during adolescence. The social penalty for the more severe and disfiguring form of cystic acne, in which many large cysts are formed, can be ostracism, exclusion and depression. Acne was traditionally treated with antibiotics, soaps and drying agents,

which are only partially effective. Recently, researchers have developed promising new treatments, such as the vitamin A derivatives called retinoids. These new treatments have the potential to dramatically improve one's ability to prevent and manage their acne, and may help ease the inevitable awkwardness that surrounds adolescence.

Psoriasis affects between six and seven million people in the United States each year. The inflamed, flaking and scaly skin of psoriasis is believed to be caused by inappropriate immunological activity that causes skin cells called keratinocytes to respond as they would during wound-healing. These cells multiply and grow excessively, failing to form the normal protective barrier. There is a strong genetic component to this disease, as with most autoimmune diseases, and researchers are hard at work to identify the genes responsible.

The past two decades have seen explosive growth in technology and in increased sophistication in our understanding of the genetic and cellular mechanisms underlying many skin, hair and nail disorders. One consequence of these findings is a radical new paradigm shift in which the skin is now viewed as a complex organ that is intimately responsive to the immune system of the body. Several distinct cell types in the skin actively generate, regulate and perpetuate immune responses. Other important new research findings include the following:

- A gene responsible for the inherited form of basal cell carcinoma has been identified and may lead to new information as to the origins of skin cancer.
- A gene for an inherited form of hair loss has been discovered.
- A new protein that links collagen and vascular defects in scleroderma has been identified.
- Advances in the design of drug-delivery systems allow for sustained release of drugs through the skin, which will most likely lead to treatments that are more effective.
- Methods to grow real and artificial skin in laboratories are used to prepare skin grafts for burn victims.

The past two decades have focused on developing evaluation techniques such as clinical epidemiology, biostatistics, economics, and the quantitative social sciences used to determine the effectiveness of certain procedures and whether they contribute to the quality of life and health of both patients and society.

As you know, medical research organizations such as the Society for Investigative Dermatology work closely with patient support and advocacy groups. We are pleased to say for many years we have worked with the Coalition of Skin Diseases for Skin Disease Research. The many organizations that participate in the Coalition have been the best possible advocates for increased funding, as they understand that unless major research efforts are undertaken, advances in understanding and improvements in the health of

patients will not occur. Every year, we participate with these organizations in advocating increased funding for the NIH and NIAMS. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.