

ASTHMA PROGRAMS OUTSIDE OF DHHS

U.S. Olympic gold-medalist Jackie Joyner-Kersey encourages fellow asthma sufferers, “I control my asthma every day. So can you.” Olympic gold medalist swimmers Amy Van Dyken and Tom Dolan, as well as NBA All-Star Dennis Rodman also devote time and resources to carrying the message that asthma should not prevent people from pursuing their dreams — even in top-level athletic competition.

Organizations involved in community outreach and education include corporations, professional societies, government agencies, and state and local coalitions. These same groups also conduct research. They often work in collaboration with each other and with federal agencies.

This appendix gives examples of activities undertaken by organizations in six broad categories. Its purpose is to highlight the depth and breadth of work on asthma beyond DHHS in order to stimulate thinking about how DHHS funded activities can best complement and support activities by other organizations. It is by no means exhaustive. More information on asthma activities in the U.S. and overseas can be found at the NHLBI web site: www.nhlbi.nih.gov

Professional Societies

Several professional societies sponsor asthma programs that support research, distribution of information to physicians and other health care professionals, and education of asthma patients. Research support includes both seed money and longer-term funding for clinical and epidemiological studies examining, for example, treatment options and implementation of the Asthma Management Guidelines in different health care settings.

Professional societies also distribute information on asthma to physicians and the public. Recent examples include a forum for physicians and scientists from around the world who work in pulmonary and critical care medicine, and a speaker’s bureau to assist in providing speakers and funding on topics related to asthma. Several organizations sponsor programs for continuing education to update health care providers on the diagnosis and treatment of asthma including an on-line resource for physicians and other health professionals. Several groups provide information resources for the public as well, via hotlines, internet sites, pamphlets, booklets, and newsletters on asthma.

Non-Governmental Organizations

Non-governmental organizations (NGOs) also play a vital role in educating the public about asthma. Some are well-established, well-funded groups; others are newer and work with modest budgets. At the national level, and often through local chapters, NGOs have raised awareness about asthma and supported effective education and outreach efforts. They have developed innovative, interactive teaching curricula that bring together children with asthma, their families, and community volunteers in school settings. To reach younger children with asthma, NGOs

have prepared educational kits and television programs geared toward pre-schoolers and their families. These materials are disseminated during presentations at health fairs, meetings of support groups, schools, industry, government, and community organizations. They are used at asthma camps — where children learn about managing their asthma while also building friendships through shared activities — and in direct delivery of care: NGO supported clinics on wheels regularly deliver state-of-the-art care to schools in the inner city. NGOs are also involved in research, and make available results of population-based studies and surveys to companies or others investing in the care of people with asthma.

Private Industry

Insurance and managed care companies are active in education and outreach through classes, workshops, and programs on asthma-related topics such as maintaining a healthy lifestyle, smoking cessation, and chronic disease management. One program designed for members and their physicians to better manage asthma integrates comprehensive education in asthma self-management and instruction in the use of asthma management equipment designed for home use.

The pharmaceutical industry is active in asthma outreach as well. Several companies provide educational materials directly to asthma patients. Others fund educational services carried out by other groups. Easy-to-read pamphlets developed by the industry provide helpful tips and updates on asthma control. Research by the pharmaceutical industry includes drug development as well as investigations — usually in conjunction with other groups — of the effectiveness of various methods of outreach or treatment.

Other Federal Agencies

A number of Federal agencies other than DHHS support research, public education and outreach programs related to asthma. The Environmental Protection Agency (EPA) conducts and supports research on the respiratory health effects of air pollutants and sets regulatory standards that control their emissions. In partnership with the National Institute of Environmental Health Sciences, EPA supports an innovative research centers program on children's environmental health and disease prevention, including asthma. EPA supports research and dissemination of information relating to the health effects associated with exposure to environmental tobacco smoke. It also supports education and outreach programs in schools and communities related to environmental aspects of asthma through such programs as Childhood Champions and Tools for Schools. In fiscal 2000, the EPA plans to expand school and community-based programs that teach parents and children how to identify and avoid allergens that trigger asthma attacks. NIEHS and the Department of Housing and Urban Development are developing a National Allergen Survey to provide estimates of allergen exposure in the U.S. population. The study will also facilitate evaluation of regional, ethnic, socioeconomic, and housing characteristics and their relationship to allergen types and levels.

State and Local Governments and Coalitions

State and local governments, often in cooperation with coalitions of various kinds of organizations, support a variety of programs to reverse increasing rates of asthma and reduce the burden of the disease. State health departments and Medicaid agencies educate the public about effective asthma care and support health services delivery. For example, Virginia substantially reduced hospitalizations and emergency room visits by providing Medicaid physicians with asthma

patients six hours of training in appropriate asthma treatment. State and local environmental agencies set and enforce air pollution standards established to reduce risk of exacerbation of asthma and other health effects. In addition, many state environmental agencies conduct education and outreach on reducing exposure to environmental factors that can aggravate asthma.

State and local coalitions working on asthma include groups of concerned patients or parents, representatives from community recreation centers, schools, hospitals and clinics, local NGO chapters, and members of the medical community, among others. They are a relatively new phenomenon—sixty three percent of the 43 coalitions identified by the NIH-coordinated National Asthma Education and Prevention Program (NAEPP) are less than two years old—but they are proving to be powerful and effective mechanisms for addressing asthma. Examples of activities include encouraging local primary care physicians and other health care professionals to adopt clinical practice guidelines, developing culturally competent and appropriate outreach programs to inner-city and other high risk communities, and establishing partnerships with local schools.

International Initiatives

In 1992, the National Heart, Lung, and Blood Institute and the World Health Organization initiated a collaborative project—the Global Health Initiative for Asthma (GINA)—to address asthma as a global health problem. It is now estimated that over 150 million people worldwide have been diagnosed with asthma, and there is evidence that prevalence is increasing in most countries, especially in children. GINA's objectives are to decrease asthma morbidity and mortality by developing and implementing optimal strategies for the management and prevention of asthma, to increase public awareness, and to stimulate research into the causes of the increasing prevalence of the disease.

Member Organizations of the National Asthma Education and Prevention Program Coordinating Committee

Many of the organizations outside DHHS active in asthma (as well as several DHHS agencies) are represented on NAEPP's Coordinating Committee, which provides input to strategies and materials developed by NAEPP.

- **Agency for Healthcare Research and Quality**
- **Allergy and Asthma Network/Mothers of Asthmatics, Inc.**
- **American Academy of Allergy, Asthma, and Immunology**
- **American Academy of Family Physicians**
- **American Academy of Pediatrics**
- **American Academy of Physician Assistants**
- **American Association of Respiratory Care**
- **American Association of Occupational Health Nurses**
- **American College of Allergy, Asthma, and Immunology**

- **American College of Chest Physicians**
- **American College of Emergency Physicians**
- **American Lung Association**
- **American Medical Association**
- **American Nurses Association, Inc.**
- **American Pharmaceutical Association**
- **American Public Health Association**
- **American School Health Association**
- **American Society of Health-System Pharmacists**
- **American Thoracic Society**
- **Association of State and Territorial Directors of Health**
- **Asthma and Allergy Foundation of America**
- **National Association of School Nurses**
- **National Black Nurses Association, Inc.**
- **National Center for Chronic Disease and Health Promotion**
- **National Center for Environmental Health**
- **National Center for Health Statistics**
- **National Institute for Occupational Safety and Health**
- **National Heart, Lung, and Blood Institute Ad Hoc Committee on Minority Populations**
- **National Heart, Lung, and Blood Institute**
- **National Institute of Allergy and Infectious Disease**
- **National Institute of Environmental Health Sciences**
- **National Medical Association**
- **Society for Academic Emergency Medicine**
- **Society for Public Health Education**
- **U.S. Department of Education**
- **U.S. Environmental Protection Agency**
- **U.S. Food and Drug Administration**
- **U.S. Public Health Service**