EXECUTIVE SUMMARY

Asthma: Epidemic of a Chronic Disease

Asthma is a chronic inflammatory disease of the airways. From 1980 to 1996, the number of Americans afflicted with asthma more than doubled to almost 15 million, with children under five years old experiencing the highest rate of increase. The steady rise in the prevalence of asthma constitutes an epidemic, which by all indications is continuing. Even if rates were to stabilize, asthma would continue to be a profound public health problem, responsible for nine million visits to health care providers per year, over 1.8 million emergency room visits per year, and over 460 thousand hospitalizations per year. The burden of this chronic disease is felt everyday at the individual level, whether it's a frightening asthma attack or the constant vigilance and adherence to treatment plans required to keep it under control. In addition, there are disparities in the burden of asthma. Although asthma affects Americans of all ages, races, and ethnic groups, low-income and minority[1] populations experience substantially higher rates of fatalities, hospital admissions and emergency room visits due to asthma.

Asthma is a common chronic disease of childhood, affecting an estimated 4.4 million children. Asthma is one of the leading causes of school absenteeism, accounting for over 10 million missed school days annually. Symptoms not severe enough to require a visit to the emergency room or to a physician can still substantially impair quality of life. Asthma results in many lost nights of sleep, disruption of family and caregiver routines, and restricted activities. It is the leading work-related lung disease; and recent evidence suggests that, in some regions, as much as 20 percent of adult onset asthma may be work related. Taking care of asthma is expensive and imposes financial burdens on patients and their families, including lost work days and income, as well as lost job opportunity. In 1990, the annual cost of asthma to the U.S. economy was estimated to be $6.2 billion, with the majority of the expense attributed to medical care. A 1998 analysis using different methods estimated the cost of asthma in 1996 to be over $11 billion per year.

Critical breakthroughs in science in the last decade have generated a body of information that, when effectively used to guide care of patients, enables most people with asthma to live fully active lives. The National Asthma Education and Prevention Program (NAEPP), sponsored by the National Heart, Lung, and Blood Institute (NHLBI), developed *Guidelines for the Diagnosis and Management of Asthma* ("*Guidelines*"), which translate the scientific findings into recommendations for patient care (see Appendix C). When the *Guidelines* are followed, health care providers, caregivers, and patients with asthma work together to control the disease. Appropriate medical care, monitoring of symptoms and objective measures of lung function, along with environmental control measures to reduce exposures to allergens and other asthma triggers (all described in the *Guidelines*), can substantially reduce the frequency and severity of asthma attacks.

[1] The term "minority" as used in the rest of this paper refers to "racial and ethnic minority."

Yet, many patients remain ill because of a complex interplay of factors. One impediment is that many patients are still not being treated or educated according to the *Guidelines*; another is patients' lack of access to quality medical care or resources to obtain sufficient medications or equipment. For example, a recent study found that one out of five children in Baltimore, MD and Washington, DC were receiving the wrong or no treatment for asthma. Even with high quality care, some cases of asthma are particularly difficult to control; and medications cause adverse side effects in some people. Moreover, lack of timely surveillance data[2] at the State and local levels impedes planning of intervention efforts. Finally, research results have not yet identified or demonstrated how to prevent asthma from occurring in the first place. The genetic basis of susceptibility to asthma and the biologic mechanisms that explain the interaction of susceptibility and environmental exposures are not well understood.

An array of activities — promoting effective implementation of the *Guidelines,* ensuring access to quality medical care, enhancing surveillance and intensifying research across the spectrum from molecular biology to health services delivery — implemented at an accelerated pace— holds great promise for reducing the burden of asthma and reversing the steady increase in rates.

DHHS Capacity to Address Asthma

The Department of Health and Human Services (DHHS) conducts and supports research, public health practice[3], and health services delivery to address the growing problem of asthma. In fiscal year (FY) 1999, DHHS invested $145 million in asthma research. DHHS-supported grantees have been responsible for many of the scientific breakthroughs that helped shape the *Guidelines*. In fiscal year 1999, relatively few dollars (less than $10 million) were spent on public health practice for asthma. With those funds, the Department supported partnerships that are discovering new ways to increase dissemination and use of information by communities, health care providers, patients and their families. DHHS spends much more on direct delivery of medical care; for example, estimates of Medicaid and Medicare expenditures for treatment of asthma exceed one billion dollars per year. DHHS also funds research to improve the quality of health care received by individuals with asthma and could expand its evaluation of asthma care.

[2]Surveillance is the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation and evaluation of public health practice (1). A surveillance system includes the functional capacity for data collection and analysis as well as the timely dissemination of these data to persons who can undertake effective prevention and control activities (2). Public health officials use surveillance to understand changes in rates of disease in different locations or populations, to help evaluate medical care and public health programs, and to identify clues about risk factors.

[3]Public health practice activities are those that facilitate the work of the medical community and others to prevent illness, reduce the severity of symptoms, and improve the quality of medical care. The role of government in public health includes: 1) the systematic collection and analysis of health information; 2) the development of goals and priorities based on scientific knowledge and measures to achieve them; 3) taking action through public education, advocacy, negotiation, and mobilization of resources; and 4) evaluation to determine whether policy goals are achieved (3).

Secretary's Initiative on Asthma

In the fall of l997, DHHS convened a high-level workgroup to assess the most urgent needs and opportunities for tackling the growing problem of asthma (Appendices A and B). Shortly thereafter, the President's Task Force on Environmental Health Risks and Safety Risks to Children, co-chaired by Secretary Shalala and Environmental Protection Agency Administrator Browner, decided to take immediate action across the government to address the environmental aspects of childhood asthma (Appendix D). At the Secretary's request, the DHHS workgroup developed a Department-wide strategy encompassing all age groups affected by asthma and the many factors, in addition to environment, influencing this disease. The DHHS initiative is closely coordinated with the activities of the President's Task Force. From FY 1999 to FY 2000, DHHS discretionary spending on asthma increased from $157 million to $183 million.

Four Priorities for Investment

This DHHS strategy includes four priority areas for investment over the next five years. The priorities are:

- **Determine the causes of asthma and develop interventions to prevent its onset.**
- **Reduce the burden for people living with asthma.**
- **Eliminate the disproportionate burden of asthma in minority populations and those living in poverty.**
- **Track the disease and assess the effectiveness of asthma intervention programs.**

This strategy is designed to help achieve the national Healthy People goals for asthma (See Table 1). The strategy envisions close coordination between DHHS initiatives and activities led by professional societies, universities, non-governmental and community-based organizations, providers of medical care, businesses, and other federal, state, local, and tribal government agencies in pursuit of progress in these areas over the next five years.

"My asthma attacks are very different depending on whether they are exercise-induced or triggered by an allergen or irritant. When I'm running, I get hints of an asthma attack when the rhythm of my breathing starts to change. After that, the real struggle to breathe starts. I feel like I'm fighting with some unknown force for each breath. Sometimes, I feel like the air comes into my mouth but will not go down into my lungs, and all the breathing is in vain. Other times, it feels like all the air is coming into my lungs, but nothing is coming out. My lungs feel as if they're going to explode. I'm lightheaded and weak. My whole upper body gets tense and I feel frightened and panicked which makes things worse. Attacks not caused by athletics seem to come on more gradually but also feel like I'm not getting enough air with each breath. It's a full body workout to take each breath. My chest tightens up a lot and it either feels like I have 1,000 pounds of bricks on my chest or that someone has their hands on my lungs and is squeezing with all their might."

-An eighteen year old asthma sufferer

"My son has had chronic asthma since he was 18 months old. That means we ask the same questions again and again: Did you do your second puff [i.e., medication]? Did you rinse your mouth? Have we packed the nebulizer? Do we have the prescription for the medication on hand? It means his dad and I stay watchful because every season brings its own danger: pollen in the spring, heat and air pollution in the summer, leaf mold in the fall, and infection in the winter. It means that everyday events like soccer practice, visits with friends who have cats, and even hay rides require vigilance. Most of all, it means a cough is not just a cough. It can be the first cough in a long day and night punctuated every 10 seconds with another sharp little cough.

One of the hardest things about being a parent of a child with chronic asthma has been to acknowledge to myself that asthma, for my son, is chronic. It is not a temporary thing. Another difficult thing has been to deal with the symptoms and treatment of his asthma without making him feel different. And finally, the emotions are hard too. Not just the niggling fear but also, the surprising anger — Why do some doctors seem to know so little about prevention and asthma management?"

-A young mother