PRIORITIES FOR INVESTMENT OVER THE NEXT FIVE YEARS

Priority Area One: Determine the Causes of Asthma and Develop Interventions to Prevent Its Onset

Research has not yet identified or demonstrated how to prevent the onset of asthma. Research to prevent asthma in individual patients or in high risk populations is known as "primary prevention" research. It includes both research to understand the causes of asthma and testing strategies to prevent its occurrence. This research is critical to discovering the reasons for the current epidemic of asthma.

Current DHHS Activities: Primary Prevention Research

NIH sponsors the majority of primary prevention research funded by DHHS. The Centers for Disease Control and Prevention (CDC) also undertakes work in this area. Relevant research focuses on the natural history of the disease, risk factors, genetics, and the basic mechanisms and pathogenesis of asthma. An example of the research on the natural history of asthma is exploring the hypothesis that infection with respiratory viruses in early life, such as respiratory syncytial virus, may predispose an individual to an increased risk of asthma. In contrast, certain other infections in early life may block the immune response to allergens and thereby decrease the risk of asthma (37, 38, 39). In addition, research on risk factors includes examining the potential role of environmental and occupational exposures in the onset of asthma.

A major portion of NIH asthma-related research is devoted to enhancing understanding of pathogenesis and basic mechanisms of asthma. This work covers a range of issues relating to cellular and molecular-level events in asthma that cause the lung to become injured and repaired. It will help explain why asthma persists for many years, as well as why asthma is severe in some patients and not in others. The National Heart, Lung, and Blood Institute (NHLBI), the National Institute for Allergy and Infectious Diseases (NIAID), and the National Institute of Environmental Health Sciences (NIEHS) support investigations of the immune system and asthma that may lead to prevention of the allergic inflammatory process. NIEHS is also studying other strategies for primary prevention of asthma, including how exposures to environmental agents modify the immune system, which may affect the early sensitization events preceding the onset of asthma.

Genetics Research
NIH is investing significantly in research on gene-environment interactions, including a genome-wide search to identify genes that confer susceptibility to asthma.

Family clustering of asthma and allergy suggests a genetic basis for asthma. However, since the genetic background of the population changes only slowly with the succession of generations, it is most likely that the rising trend in asthma in the last 15 years relates to environmental factors interacting with genetic susceptibility. Therefore, a major focus of research at several NIH institutes is on gene-environment interactions, and includes a genome-wide search as part of the Environmental Genome Project to identify genes that confer susceptibility to asthma. Early findings confirm that multiple genes may be involved. Defining how genetic and environmental factors interact to predispose certain individuals to asthma holds a key to prevention strategies for the disease.

Urgent Needs: Primary Prevention Research

DHHS will increase attention to three areas that show particular promise for uncovering clues to the onset of the disease, and will expand testing of innovative prevention strategies. (Many of these topics are also relevant to two other priority areas: reducing the burden of asthma and eliminating disparities in the impact of the disease on minority populations and the poor.)

Improve understanding of early life origins of asthma. While research on various aspects of the origins of asthma is already underway, further examination is needed of the potential for early life events to cause asthma, such as pre- and post-natal exposures to viral infections, allergens, tobacco smoke, and elements of the maternal and infant diet.

High levels of airborne allergen exposure in infancy have been shown to enhance the likelihood of sensitization and the development of asthma in childhood (34, 35, 37, 67). However, the immune mechanisms associated with the effects of allergens in infancy are not known and must be investigated. Another high priority need is the development of immunologic and clinical markers of asthma in infancy and early childhood among children of distinct genetic backgrounds.

Study gene-environment interactions and links to characteristics of asthma. As genes associated with asthma are defined, it will be important to establish their function, particularly how they regulate the disease process. Since genetic factors can also interact with environmental factors, understanding these links in the development of airway inflammation is another priority need. Recent data suggest that certain characteristics of asthma (e.g., whether it is exercise-induced, nocturnal, has persistent symptoms or episodic but severe attacks) are associated with specific genetic, immunologic and environmental factors (68). Examining these further could have significant implications for the prevention and treatment of asthma in individuals and in genetically distinct populations.

Investigate adult onset of asthma. Allergens may play an important role in some adults with asthma who did not exhibit the disease in childhood. In other adults with asthma, allergies are not detected; the mechanisms of "intrinsic" asthma are not well-understood. Additional research is needed on adult-onset asthma in areas such as: asthma during pregnancy, during menopause (especially in those on hormone replacement therapy), and in the elderly who have confounding medical complications. Another need is to characterize the conditions under which occupational asthma develops, including assessment of exposure-response relationships, so that prevention strategies can be developed.

Test strategies for prevention. Intervention trials are needed to test hypotheses of how to prevent asthma, even while work on understanding the basic mechanisms is proceeding. Tests of prevention strategies for those at high risk of developing asthma could include investigating whether eliminating various exposures during early life or providing pharmacologic treatments can delay or prevent the onset of the disease. Another promising strategy is to block the allergic immune response in susceptible individuals, for example by induction of immune tolerance[6], thus preventing asthma from ever developing. Identifying interventions to prevent asthma is the most promising approach to ending the epidemic of asthma.

[6]Tolerance is an immune state that can be induced, and that results in long term blocking of immune responses. Tolerance induction has recently been shown to be very promising for blocking immune responses leading to rejection of organs after transplantation.

Priority Area Two: Reduce the Burden of Asthma for People with the Disease

Widespread use of the *Guidelines* is essential for reducing fatalities, emergency room visits and hospital stays, and for improving day to day quality of life for people with asthma (58). Despite the existence of the *Guidelines*, a substantial gap remains between their recommendations and the actual practices of many clinicians, people with asthma, and their families. Expanded investment in two areas can help close this gap: 1) promoting widespread use of current scientific knowledge through public health activities, and 2) encouraging research to continually improve means of managing asthma.

Promote Wider Use of Current Knowledge to Diagnose and Manage Asthma: Public Health Actions

All segments of the health community have vital roles to play in improving the management of asthma. Medical professional societies can promote the use of best practices by their members and improve patient education. State and local health departments can sponsor education programs to promote improvements in managing asthma by health care providers, patients, families and the broader community. At the local level, coalitions among health care providers, public health planners, managed care organizations, school personnel, housing and environmental officials, and community outreach workers can promote improved asthma care in their community.

Current DHHS Activities: Promote Wider Use of Current Knowledge to Diagnose and Manage Asthma

DHHS supports an array of public health activities designed to promote broad dissemination and application of scientific knowledge to improve the diagnosis and management of asthma. These activities include clinician education and the promotion of improved quality in health care delivery, family and patient education, facilitation of community-based asthma programs and public education, and support for public health activities at the state level.

Research to Improve Quality of Care
The Agency for Healthcare Research and Quality is investigating whether several approaches to improve the quality of asthma care are effective in helping clinicians better manage the disease in accordance with the *Guidelines.*

NHBLI supports clinician education through the translation of research on asthma into clinical practice guidelines and practical health education materials and tools. The first set of the *Guidelines* was widely distributed to physicians, medical schools and other health professionals and organizations, as well as to asthma patients. To promote broad use by other key health care professionals, targeted companion documents were developed for nurses, emergency department personnel, pharmacists, and school personnel. NHLBI also produced specialized reports on asthma during pregnancy, asthma in the elderly and asthma in minority children.

Several programs are conducting research designed to understand which strategies are most effective in promoting the actual implementation of the *Guidelines* by health care providers. The Agency for Healthcare Research and Quality (AHRQ) has supported research on the factors that cause providers not to use the *Guidelines*. AHRQ is sponsoring several research projects to assess whether specific quality improvement approaches, being implemented in various clinical settings, are effective in helping clinicians better manage childhood and adult asthma in accordance with the *Guidelines*. Cost-effectiveness is being examined in several studies which are also testing health outcome measures such as symptom-free days to identify how treatments affect children's daily lives.

NHLBI sponsors a wide range of education and outreach activities through the National Asthma Education and Prevention Program (NAEPP), which is guided by a Coordinating Committee composed of diverse public and private sector organizations[7]. These groups have worked together and in partnerships with other organizations on outreach activities. Examples include: a national conference on "Managing Asthma in Managed Care;" a school-based asthma education program (implemented in partnership with EPA and the American Lung Association); and a bilingual asthma awareness program ("Sesame Street: A is for Asthma") with the Children's Television Workshop. The NAEPP has explored how best to convey strategies for asthma management not only to patients, but also to clinicians, family members, school personnel and caregivers.

Asthma Management Model System
The National Asthma Education and Prevention Program designed a model web-based system to improve the diagnosis and management of asthma. The site provides virtually all the scientific literature on chronic asthma that has ever been published, as well as practical information for clinicians, patients, and public health professionals. See www.nhlbi.nih.gov.

The National Institute of Nursing Research (NINR) evaluates the effectiveness of routine education in a clinic setting reinforced by nurse home visits which include a computer-based asthma instructional program on self-management. Another NINR program is instructing parents and caretakers to learn signs of pending asthma attacks in children living in rural areas. NIAID- and NHLBI-sponsored Demonstration and Education projects focus on improving management of asthma in under-served areas. The Inner-City Asthma study, (described more fully in the following section on research), has evaluated the impact of various types of outreach and education, including intervention with an asthma counselor tailored to the needs of each family.

Recently, DHHS has expanded efforts to address asthma in community settings, including collaboration with community-based coalitions that directly address asthma in a comprehensive manner at the local level. These coalitions are composed of community groups, health care providers, and other private and public sector organizations to foster better quality of care for asthma sufferers. For example, the NAEPP facilitates collaborative activities at the local level, has established a consortium of over 40 coalitions, and maintains an Asthma Coalition Exchange on the NHLBI website. CDC's National Center for Environmental Health has worked with DHHS Region IV and seventeen other organizations on a public health program known as "ZAP Asthma," a collaborative program to reduce the adverse impacts of asthma in the Atlanta Empowerment Zone neighborhoods.

[7] Coordinating Committee member organizations are listed in Appendix F.

NHLBI supports the development of model programs for improving asthma management in the school setting. NHLBI has also sponsored a number of media campaigns to promote asthma awareness among the general public and to encourage undiagnosed patients to seek care.

In communities where people might be exposed to hazardous substances in the environment, the Agency for Toxic Substances and Disease Registry (ATSDR) recommends actions for safeguarding people's health. The agency has made such recommendations at sites where exposures to substances known or suspected to exacerbate asthma have occurred. It has also supported general health education and promotion activities, including continuing medical education for physicians on the relationship between asthma and the environment.

To protect workers, the National Institute for Occupational Safety and Health (NIOSH) develops and recommends criteria for preventing disease (including asthma) and hazardous conditions in the workplace; the recommendations are transmitted to the U.S. Department of Labor for use in promulgating legal standards. Additionally, NIOSH issues alerts that urgently request assistance from workers, employers, and safety and health professionals in preventing, solving, and controlling newly identified occupational hazards. For example, alerts have been issued on asthma in animal handlers, and asthma from exposure to diisocyanate and natural rubber latex.

To support asthma programs at the state level, in late 1997, CDC established a network of asthma contacts that includes officials from every state, the District of Columbia, two city health departments and two territorial health departments. CDC supports the network through a series of activities, including sponsoring monthly teleconferences and annual meetings, working to identify and document scientifically proved intervention programs, identifying state laws that affect persons with asthma, and drafting model language for asthma to be used by state agencies in writing Medicaid contracts.

DHHS regions have also been involved in collaborative efforts on asthma. For example, in Region I (New England), DHHS, EPA, and the Department of Housing and Urban Development are convening a summit meeting of federal and state public health, environmental, and housing officials to develop a joint strategy to reduce the burden of asthma in New England. Region II (New York, New Jersey and Puerto Rico) awarded grants to the New York and New Jersey State Health Departments to develop community-based partnerships to focus on asthma. Region III (Philadelphia) co-sponsored a conference with EPA and Johns Hopkins University – involving health care providers, health educators, community health advocacy groups, managed care organizations, and others – to begin developing an asthma strategy for the mid-Atlantic region (See Appendix E for additional programs supported by DHHS regions).

Urgent Needs: Promote Wider Use of Current Knowledge to Diagnose and Manage Asthma

Help health care providers practice up-to-date asthma care. Recent evidence indicates that many health care providers do not follow the *Guidelines* for the diagnosis[8] and management of asthma (61, 62, 63, 69). Failure to follow clinical guidelines stems in part from factors related to knowledge, attitudes and behavior (70), so multiple approaches will be needed to see improvements. Proactive approaches appear to be the most promising, and include educational outreach visits, interactive educational meetings, and consistent reminders integrated into medical care routines (71, 72, 73). As an example, one asthma study reported that an interactive seminar for physicians resulted in improvements in the prescribing and communications behavior of physicians, more favorable patient responses to physician's actions, and reductions in health care utilization (74). DHHS must expand and sustain partnerships with state and local health agencies, medical professional societies, and other organizations to sponsor education and outreach programs to improve the quality of asthma care available to patients with asthma. Such programs need to be developed for particular settings, and those that have demonstrated effectiveness in both changing health care practices and improving health outcomes need to be expanded.

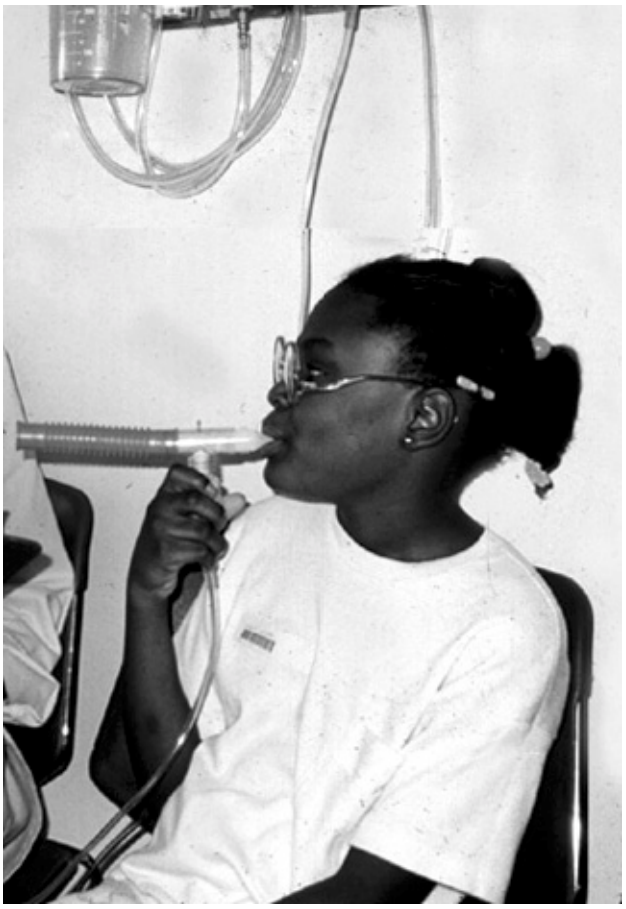


Photo courtesy of Centers for Disease Control and Prevention

Educate patients and their families. Asthma management often requires behavioral changes and vigilance on the part of people with asthma. This includes paying careful attention to respiratory symptoms and adhering to complex treatment regimens, which can be difficult for many asthma patients, including young children and the elderly, and for families and caregivers with multiple demands and stresses. To promote adherence to treatment recommendations, patients and their families need to be full participants in the development of the asthma management plan, and health care providers should seek to understand and address factors that can affect adherence. Additionally, some model programs promoting self-management of asthma have resulted in dramatic improvements in functional status and improved school performance for children. Moreover, they have achieved substantial cost reductions, in some cases up to 50 percent, by cutting hospitalizations and acute care visits (75,

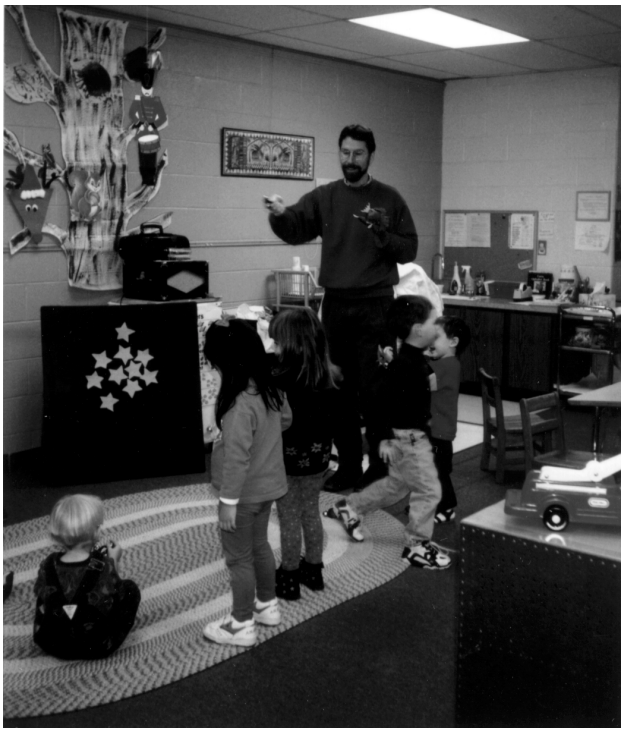
[8] Recurrent episodes of cough and wheezing are almost always due to asthma in both children and adults. However, children are often diagnosed with bronchitis, bronchiolitis, or pneumonia, even though the signs and symptoms are most compatible with asthma (58).

76, 77). DHHS, working with state and local health agencies and other organizations, must increase and sustain support for effective and culturally-competent approaches that teach patients and families to control asthma, enhance their ability to communicate with health care providers about asthma, and help sustain progress in managing this chronic disease.

Evaluate and address organizational barriers to quality care for asthma. Creating and evaluating cost-effective methods for ensuring implementation of the *Guidelines* by so many people in so many settings demands continued research. In addition to evaluating education and outreach programs (as indicated in the preceding paragraphs), research should address how other aspects of the health care system affect asthma care. For example, time constraints and payment policies can affect the amount of time a health care provider can spend educating patients. In addition, insurance plans may not reimburse families for equipment used in administering asthma medications (e.g., spacers).

A number of managed care organizations and other types of comprehensive health care organizations are implementing disease management programs for asthma. Disease management is "a systematic, population-based approach to identify persons at risk, intervene with specific programs of care, and measure clinical and other outcomes" (78). In one model of disease management, specialized teams work within a health care organization to assist primary care physicians in treating chronic illnesses (79). In another type of program, services are provided through contracts with disease management companies, which stratify patients according to their costs of care, and then target services accordingly (80). Such approaches warrant testing and evaluation to assess their impact on health outcomes, physician practices, and cost-effectiveness.

Expand asthma control activities in community settings. The environment outside the home is beyond the patient's control, and others in those settings may not be trained to recognize symptoms, help support asthma management, or handle an emergency. Apartment buildings and rental housing also create circumstances where the environment inside the home may be out of an individual's control. DHHS must work with state and local health agencies and others to intensify efforts to promote ongoing asthma education in schools, workplaces, public housing, child care and youth programs, job training programs, and other community institutions. This will include outreach to school personnel, workplace supervisors, housing officials, and others, to provide information and to help identify institutional policies that may hamper effective asthma management. For example, overly rigid policies resulting in inadequate access to and use of medication in school often unnecessarily disrupt classroom learning and make it difficult for children to achieve optimal management of their asthma. In addition to educating people with whom a patient comes into contact and generally expanding public awareness, public health programs should



highlight the need to reduce levels of irritants (e.g., environmental tobacco smoke and some air pollutants) and allergens outside of the home environment and otherwise make it easier for patients to follow their treatment plans. DHHS must also increase support for public education campaigns to enhance public awareness about asthma as a serious disease and appropriate asthma management techniques.

Sustain support for State and local public health action. DHHS will seek to equip state health departments, through a grant program, to promote asthma education, prevention, and public health outreach activities in local communities. Activities will target the urgent needs described above and the public health programs described in Priority Area III, including clinician education programs, patient and family education, and training for school personnel. By working with public health and environmental agencies at all levels, as well as organizations outside of the government, scientific advances can be made available to all patients.

Discover and Develop Improved Means of Managing Asthma: Research

While work proceeds to implement state-of-the-art science through public health programs, further research is required to answer remaining questions about asthma care and to explore new ways of improving quality of life for people with asthma. "Secondary prevention" research is designed to identify methods to reduce illness in those who have asthma, but is not directed at preventing the primary onset of the disease.

Current DHHS Activities: Secondary Prevention Research

Discovery of the role that inflammation and allergic sensitization play in asthma led to the development of several new approaches for treating asthma. For example, inhaled corticosteroids reverse the inflammatory process, prevent or reduce severity of symptoms, and reduce emergency room visits, hospitalizations, and deaths due to asthma. Also, two new classes of drugs aimed at reducing asthma severity by inhibiting the inflammatory process have recently been developed – antileukotrienes and anti-IgE therapy.

NHLBI devotes substantial resources to clinical trials evaluating and assessing treatment strategies. Multiple research investigations are underway to examine the impact and safety of medications at different stages of children's development (e.g., possible effects on bone growth and eye complications later in life) and to discover the best treatment options for children who have different genetic backgrounds or environmental exposures. NHLBI's Childhood Asthma Management Program supports a major multi-center trial to examine and compare the long-term effects of asthma medications on the course of the disease, lung growth and development, and overall physical and psychosocial development of 5-12 year old children. A new Pediatric Clinical Research Network has been established by NHLBI to evaluate clinical asthma

Managing Childhood Asthma
NHLBI's Childhood Asthma Management Program, a multi-center clinical trial with over 1,000 children enrolled, will provide critical information about the long-term effects and safety of three key therapies for childhood asthma.

treatments, especially in infants and young children. The Asthma and Pregnancy Trial, sponsored jointly by NHLBI and the National Institute of Child Health and Development (NICHD), examines the impact of asthma medication use and effective asthma control on perinatal outcome.

The National Cooperative Inner City Asthma Study, supported by NIAID since 1991, represents an effort to reduce asthma morbidity in inner-city, predominantly African-American and Hispanic children. The present study, funded by NIAID and NIEHS, tests the effectiveness of a comprehensive environmental intervention to reduce levels of indoor allergens such as cockroach, house dust mite and mold, and of environmental tobacco smoke, on asthma morbidity. Also, through a collaborative effort with the U.S. Environmental Protection Agency, a study will evaluate the impact of indoor and outdoor air pollutants on asthma among inner-city children.

The National Institute for Occupational Safety and Health (NIOSH) of the Centers for Disease Control and Prevention (CDC) examines environmental control issues in the workplace. NIOSH conducts studies evaluating the incidence, risk factors, and natural history of asthma in groups of workers employed in settings where substances recognized to exacerbate asthma are present. Exposures of current interest include: health care (natural rubber latex used in medical gloves), aluminum production, wood products manufacturing, and the indoor environmental quality of schools and offices. NIOSH has recently embarked on a multi-center trial to prevent latex sensitization in health care workers.

Photo courtesy of National Institute for Occupational Safety and Health

As the *Guidelines* assert, regular and effective monitoring of symptoms can help both health care professionals and patients gauge the severity of an asthma attack and react accordingly. NHLBI supports investigations examining the relative merits of different approaches to peak flow or symptom monitoring for guiding day-to-day therapeutic decisions. NINR is testing ways to promote children's use of home peak flow meters. In addition to approving safe and effective drugs for treating asthma, the Food and Drug Administration (FDA) approves medical devices such as peak flow meters and spirometers, as well as serologic tests used in allergy testing.

Urgent Needs: Secondary Prevention Research

Improve understanding of what makes asthma persistent and severe. Some patients, especially those with severe asthma, may have active inflammatory disease without apparent external triggers. Further, some patients may experience long-term, irreversible changes in the lungs. These permanent structural changes (known as airway remodeling) may contribute to the persistence of the disease, often lasting for many years or a lifetime. The mechanisms that induce these irreversible changes, and the methods to prevent them, are largely unknown. Identifying them will lead to effective therapies.

Develop improved means of controlling triggers of asthma and the allergic response to them. Recent research has shown that both the exposure and the allergic immune response to certain indoor allergens are responsible for many exacerbations of asthma. Present methods for modulation of the allergic immune response and for control of levels of certain allergens are of uncertain and possibly limited clinical benefit for asthma. Moreover, some allergens and other agents (in particular, cockroach and mold allergen, and respiratory viruses) are extremely difficult to control. There is a need to identify optimal and cost-effective methods for reducing levels of these asthma triggers in homes, schools and workplaces and for basic research to develop new approaches to modulate the human immune response to those allergens relevant to asthma. Another high priority is to identify as yet unknown triggers of asthma.

Magnified dust mite (photo courtesy of Environmental Protection Agency).

Investigate the relationship between outdoor air pollutants and asthma. Several ambient air pollutants are known to be respiratory irritants and can exacerbate asthma symptoms (e.g., ozone, sulfur dioxide) (51). DHHS must accelerate efforts to better understand the cellular and molecular mechanisms by which air pollutants perturb the normal functioning of cells, tissues, and organs. In addition to refining understanding of the role of air pollutants in exacerbating asthma, this research will help determine whether they are implicated in the initial onset of the disease. Moreover, some pollutants may act synergistically with other environmental factors to worsen asthma.

Investigate variations in patient response to asthma medications. Not all patients respond favorably or in the same way to the same medications, and some patients experience adverse side effects from asthma medications. Patients would benefit from the development of both new treatments and the means for tailoring therapeutic approaches to the specific genetic and clinical characteristics of the individual's asthma.

Establish causes and risk factors of asthma fatalities. Asthma fatalities should be investigated to identify specific risk factors and to enhance understanding of how events lead to fatal disease. This information can lead to ways to improve patient management and prevent fatalities.

Develop non-invasive methods for diagnosis and disease monitoring. Asthma can be especially difficult to diagnose, monitor, and study in infants, young children, and the elderly. Therefore, new technologies – such as imaging or biochemical markers of inflammation, and patterns of gene activation – are needed to detect disease and monitor disease progression, particularly in these vulnerable populations.

Expand research on asthma in pregnancy. Work has just begun on evaluating how infants are affected by asthma severity in the mother. Research is particularly needed on women whose asthma is difficult to control, and whose medication could have adverse side effects on the fetus.

Priority Area 3: Eliminate the Disproportionate Burden of Asthma in Minority Populations and Those Living in Poverty

Low income populations and minorities experience disproportionately higher morbidity and mortality due to asthma. The reasons for these disparities are not clearly understood, but where poverty is present they are probably due to an interaction of factors including: lack of access to quality medical care, high levels of exposure to environmental allergens and irritants, language barriers, and lack of financial resources and social support to manage the disease effectively on a long-term basis.

African American and Hispanic children appear to be at especially high risk of not receiving adequate preventive treatment for asthma attacks. Several studies have documented inappropriate treatment for asthma among inner-city children with asthma (64, 81, 82, 83). For example, an analysis of preschool children hospitalized for asthma found that only seven percent of African Americans and two percent of Hispanics, compared with 21 percent of white children, were prescribed routine medication to prevent future asthma exacerbations (82). A recent study of elementary school children in Baltimore, MD and Washington, DC, found that inner-city children with asthma frequently are undermedicated, using the wrong medication, or none at all despite daily symptoms, frequent school absences, and emergency room visits for asthma. More than 80 percent of those who did take regular medication did not use anti-inflammatory drugs (64).

Photo courtesy of *New York Daily News* - Photographer: Jon Naso

Inner-city children and their parents often live in highly challenging, difficult environments. Families often face economic uncertainty and live in homes or apartments with poor ventilation and high allergen levels. Children in these settings frequently have multiple caretakers for their asthma and little continuity of health care (84). A study of Hispanic families in San Diego found that parents who speak only Spanish have significantly more misconceptions about asthma than English-speaking Hispanic parents (85). Although not as well studied, children with asthma from rural America also face multiple barriers that adversely affect their health including extensive poverty, geographic barriers to health care, less health insurance and poor access to health care providers (86).

Current DHHS Activities: Eliminating Disparities

The asthma objectives for Healthy People 2010 emphasize the need to reduce the disproportionate impact of asthma on minorities, particularly with regard to asthma death rates and hospitalization rates. Several DHHS agencies support public health programs designed to meet the needs of individuals and families in poverty. The NAEPP supports several such programs, and CDC's ZAP Asthma and other Regional programs described earlier have a particular focus on improving the lives of inner-city children. The Administration for Children and Families' (ACF's) Head Start program offers comprehensive early childhood education, nutrition, and health and social services, along with strong parent involvement, to low-income children nationwide. Caring for children with asthma is addressed in two important training guides used by Head Start front line staff, management teams, and parents. The Office of Minority Health (OMH) supports the "Minority Health Asthma Attack Avoidance Education Program," which is designed to increase awareness of asthma triggers and ensure appropriate referral to medical care.

The majority of DHHS funds dedicated to asthma provide direct health services to underserved populations. The Medicaid program administered by HCFA reimbursed costs of asthma care for over one million low income patients in 1995 (65). The Health Resources and Services Administration (HRSA)-supported Health Centers and the National Health Service Corps programs aim to increase access to comprehensive primary and preventive health care and to improve the health status of underserved and vulnerable populations. Comprehensive primary care services in Health Centers include the treatment of asthma; in 1998, patient visits for asthma exceeded 600,000 (87). The Indian Health Service (IHS) delivers health care to American Indians and Alaska Natives. In addition to providing asthma treatment as part of standard care, IHS has helped to establish several specialty clinics focused on asthma.

HRSA is also working with non-governmental institutes (co-sponsored and endorsed by the NAEPP) to develop and apply an innovative model to accelerate improved asthma care. The care model uses five basic elements to improve care: 1) collaboration between the health system and community organizations and agencies, 2) patient/family self-management, 3) support to enable clinicians to use guidelines in their every day work, 4) practice re-design, and 5) information systems to track individual patients as well as assess the health of the asthma patient population in the medical practice. HRSA and other organizations are supporting a number of community health centers in adopting this model of care, which involves a 12-14 month training program for health center teams.

Various DHHS agencies and institutes conduct research to better understand the impact of asthma on vulnerable populations. NIEHS and NIAID sponsor research on community-based strategies to reduce exposures that trigger asthma in economically disadvantaged and/or

Inner-City Asthma Study
The NIAID-sponsored National Cooperative Inner-City Asthma Study found that empowering families to increase their asthma self-management skills and to improve their interactions with the primary care physician were important ways to improve quality of care and reduce asthma symptoms. An asthma counselor helped not only with asthma education, but with problem solving tailored to the families' needs. Improvement in health continued at the same level during the second year of the program when the asthma counselor was no longer involved (84).

underserved populations as in their National Cooperative Inner-City Asthma Study. Six of the eight NIEHS/EPA/CDC-sponsored Centers for Children's Environmental Health and Disease Prevention Research have projects focusing on asthma in under-served populations. NHLBI and NIAID support genetics research that is revealing that multiple genes may be involved in asthma, and early findings indicate that they may vary among ethnic/racial groups. The NIH Office of Research on Minority Health and NHLBI are also supporting a study of Genetics of Asthma in Hispanics. NHLBI and NINR sponsor research on the effectiveness of asthma education and self-management programs, targeting African Americans and Mexican Americans in both urban and rural areas.

Several DHHS agencies conduct research and evaluations to assess and improve both access to, and quality of asthma care. The Agency for Healthcare Research and Quality (AHRQ) supports research designed to measure and improve the quality of health care, reduce its cost, and broaden access to essential services. HRSA collaborates with AHRQ on the development of health center practice-based research networks. One of these projects is focused on asthma and involves epidemiologic investigations, clinical outcome studies, and intervention trials. HCFA conducts research on the use of services and expenditures for asthma care provided to its Medicare and Medicaid beneficiaries. Specific work includes examining the quality of asthma care – using the *Guidelines* – provided to Medicaid eligible children. NHLBI and NIAID support demonstration and education research to develop innovative, culturally-sensitive approaches to teaching asthma management strategies to African-American and Hispanic children and their families.

Urgent Needs: Eliminating Disparities

If we are to make progress in eliminating disparities, it is critical to investigate why these disparities exist. While the "Urgent Needs" described in the previous sections will help to address the disproportionately high impact of asthma on minority and low-income populations, more focused efforts are also needed. DHHS will seek a substantial expansion of public health programs to eliminate the disproportionate burden. The Department will accelerate research directed at the reasons for disparities and the means to reduce these impacts. Four key priorities include:

Promote wider use of current knowledge to diagnose and manage asthma, focusing on minority and low income populations. Programs that help health care providers practice up-to-date asthma care, educate patients and their families, and expand asthma control activities beyond the home – all need to be targeted toward special population groups hardest hit by asthma. In doing so, such programs need to address the unique circumstances of the particular community. A high priority is to implement education programs that take into account the complexities of poverty, language barriers, and cultural sensitivities.

Improve access to quality care. DHHS agencies must work in public/private partnerships to address the barriers to quality asthma care and provide ongoing, comprehensive, quality health services for asthma. Such services would be based in the community and would encourage active participation of families, while addressing their cultural needs. A policy of collaboration at the local level and coordination of services among community providers (including health, environmental, and housing services) are important ingredients for success.

Expand research on asthma in special population groups. While data indicate greater hospitalizations and deaths from asthma among population groups such as Hispanics and African Americans (4, 88), additional research is needed to understand the reasons for these higher rates. For example, research is needed to understand if these disparities are due to more severe disease in these populations or to differences in health care practices and access to care, or a combination of both. One research priority is distinguishing the roles of environmental, socio-economic, cultural and genetic factors in contributing to asthma severity. Genetics research will help explain different risks for severe asthma and differences in response to asthma treatments. This can help identify new therapeutic approaches. Exposures to environmental allergens and pollutants may be greater for some population groups, particularly in the inner city. Research is needed to design interventions that could reduce asthma severity by addressing these environmental factors. In addition, some Hispanic populations appear to have a markedly elevated risk for developing asthma. Environmental, genetic and cultural factors need to be examined to understand why these differences occur. Finally, as prevention strategies for asthma are developed and tested, their effectiveness in different population groups should be a special focus for evaluation.

Investigate access to care and evaluate quality. Another priority is to better understand the degree to which individuals in poverty, particularly children, have access to care and whether the quality of that care is sufficient. Recent studies reveal that traditional measures of access (e.g., insurance coverage and source of routine care) may not reflect the realities affecting poor health outcomes for asthma. The National Cooperative Inner-City Asthma Study reported that 92 percent of children in the study were covered by insurance, and nearly three quarters were covered by Medicaid. While most families reported a usual source of routine care (neighborhood or hospital clinic), more than 50% of respondents found it difficult to get follow-up care. Quality of care was deficient and participants were unlikely to have continuity between usual sources of routine (follow-up) and acute care (23). Further studies are needed to uncover the barriers to improved health, including: access to quality and continuous care and access to prescription medication and delivery devices. DHHS must also continue to evaluate the impact of managed care on delivery of health services and health outcomes.

Priority Area 4: Track the Disease and Assess the Effectiveness of Asthma Programs

Current DHHS Activities: Tracking the Disease

Surveillance – the systematic collection, evaluation, and dissemination of data used to track the occurrence and severity of particular diseases – is critical to research and public health practice. Combined with studies in large groups of people, surveillance results can identify populations with particularly high or low prevalence, and can shed light on factors influencing the development of asthma. Surveillance data can help identify high risk populations and risk factors to inform the design and implementation of interventions suitable for a particular community. Finally, state and local health agencies can use surveillance information to assess the impact of public health programs or environmental controls.

Surveillance for Asthma
National estimates for asthma are developed from ongoing general health surveys. CDC is collaborating with NIH and EPA to sponsor more localized surveillance activities in four states and two major cities.

Current surveillance for asthma provides national estimates, but cannot provide state or local level data on asthma. The national estimates are derived from ongoing health surveys[9] and data systems dealing with health events such as mortality, hospitalization, emergency room visits, and outpatient visits. This information does not reveal the detailed picture of how asthma varies from one location to another – information greatly needed for an effective public health response. Fewer than 10 states have conducted asthma prevalence surveys (89). Surveillance for occupational asthma is also limited. Since1987, NIOSH has provided funding to several state health departments to pilot case-based surveillance for selected occupational health conditions, including asthma. Currently, four states are conducting surveillance and preventive intervention programs for occupational asthma (90). In Fiscal Year 1999, NIH, CDC and EPA took an initial step toward addressing these limitations. They initiated a collaborative project to define ongoing surveillance activities and their utility in asthma control efforts. The activities were undertaken in four states and two city health departments.

Urgent Need: Tracking the Disease

Establish coordinated and systematic local, state and national systems for asthma surveillance. Timely data on asthma at the state and local level are needed to support the design of effective public health interventions. Such data are critical to finding answers to the troubling question, "Why is asthma prevalence rising?" Better data will also enable us to target populations in significant need of public health intervention, and to assess the geographic, ethnic, and

[9] Many of these surveys are carried out by CDC's National Center for Health Statistics (NCHS). State-based surveillance supported by the National Institute for Occupational Safety and Health has been used to identify high risk industries, occupations and substances.

gender differences in asthma morbidity and mortality. Furthermore, information about other aspects of the burden of asthma would be useful in designing interventions, including the quality of care or the severity of illness. Finally, surveillance data are needed to determine whether or not public health programs are succeeding in reducing the impacts of asthma.

Existing state-based surveys should be expanded to include questions related to asthma diagnosis, severity, management techniques, and suspected environmental and household risk factors. Also, DHHS could provide additional assistance to states to use existing data more effectively. In many cases, information is not analyzed or made accessible to those who plan asthma interventions. Finally, new systems of surveillance should be developed to gather additional information

Asthma, P.S. 48 Bronx. Class 512 in The Bronx where ten of the twenty-two students suffer from asthma. Here students were asked to raise their hands if they had asthma. (Photo courtesy of *New York Daily News* - Photographer: Jon Naso)

on locations with particularly elevated rates of asthma. One potential area for model surveillance in both urban and rural settings is in emergency rooms, where many children with asthma receive care for an acute episode, but fail to receive follow-up care. In addition, strategies to determine the incidence of asthma, at least in defined geographic areas, are needed.

Current DHHS Activities: Evaluations of Asthma Programs[10]

Evaluations of public health programs and health services addressing asthma can speed progress towards widespread establishment of programs that allow people with asthma to live fully active lives. Many of the major public health and health services programs sponsored by DHHS have

[10] A number of current activities and urgent needs related to the evaluation of asthma programs were described in Priority Area II and are not repeated here.

evaluation components to determine whether they are effective. The NAEPP and HRSA's Health Centers, for example, include evaluation elements to prompt shifts when programs are not meeting their goals, and to make possible replication of successful projects and components. AHRQ is developing new measures to help evaluate systematic improvements in quality of care. Valid, sensitive measures allow investigators to reliably identify those interventions that lead to real improvements. Recently AHRQ and NAEPP helped develop a new measure of quality care to track the use of anti-inflammatory medications. This measure will be used in the most recent version of the Health Plan Employer Data and Information Set (HEDIS 2000), a system widely used to evaluate the quality of health plans.

Research aimed at developing effective public health programs by definition provides evaluative information that helps determine what kinds of interventions work. For example, the Inner-City Asthma Study investigates not only the impact on asthma severity of reducing exposure to allergens and receiving proper medical care, but also the role of physician education and feedback in supporting the management of asthma.

Urgent Needs: Evaluation of Asthma Programs

Evaluate public health and health services interventions. Disseminate results. While some programs that educate patients and families about asthma management have been rigorously evaluated, most local and regional asthma coalition efforts that mobilize the broader community have not. To rapidly extend primary care and public health programs so that large numbers of asthma patients receive quality care, public health practitioners need to understand the characteristics of successful programs implemented in a variety of settings. ***Strengthening three aspects of evaluation*** could enhance the knowledge base about how to cost-effectively scale up public health programs and ensure that they significantly reduce rates of morbidity and mortality from asthma.

First, there is a need for *appropriate tools* to evaluate the effectiveness of asthma intervention strategies. Second, there is a need to build in an *evaluation component*, and sufficient funding to support it, to all public health programs that address asthma[11] . Third, there is a need to *disseminate evaluations of asthma programs* and encourage the use of such evaluations in designing and funding programs. Evaluation analyses combined with relevant research findings will help delineate determinants of success and failure in reducing the burden of asthma.

[11]Elements of such evaluations might include: whether an intervention program has an impact on reducing the health burden of asthma and to what degree; whether the activities themselves work as planned, such as whether the intended audience is reached, whether they understand what was taught, and whether they modify behavior as a result; whether the processes used to implement the activity are effective and sustainable over the long-term; and whether the intervention or activity is cost-effective.