Department of Health and Human Services

National Institutes of Health

National Heart, Lung, and Blood Institute

COORDINATION OF FEDERAL ASTHMA ACTIVITIES

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October 2001

Executive Summary

The Children's Health Act of 2000 (P.L. 106-310) requires the Director of the National Heart, Lung, and Blood Institute (NHLBI), through the National Asthma Education and Prevention Program (NAEPP) Coordinating Committee (CC), to identify all federal programs that carry out asthma-related activities, develop a federal plan for responding to asthma, and submit recommendations to the Congress on ways to strengthen and improve coordination of asthma-related activities of the federal government. The following report has been prepared by the Federal Liaison Group on Asthma (FLGA), a subcommittee of the NAEPP-CC, with coordination by the NHLBI. The report was submitted to the members of the full NAEPP-CC, and comments received from them have been incorporated.

An FY 2001 Inventory of Federal Asthma Activities has been prepared by the FLGA and is appended to this report.

A blueprint for planning federal asthma activities has already been established with the May 2000 publication of two important, interrelated documents: *Action Against Asthma: A Strategic Plan for the Department of Health and Human Services* and *Asthma and the Environment: A Strategy to Protect Children*. Specific national health objectives for asthma are also outlined in *Healthy People 2010*.

Recommendations for strengthening federal coordination of asthma activities in the future are addressed in this report and will focus on the following five goals:

- Discover ways to prevent asthma attacks and minimize uncontrolled asthma by improving understanding of the causes of asthma and its exacerbations;
- Gather, analyze, and disseminate data at the national, state, and local levels on a variety of asthma parameters, including morbidity, mortality, health-service utilization, federal expenditures, and quality of life;
- Identify and overcome barriers to full implementation of the NAEPP Guidelines;
- Enable optimal functioning of children with asthma in school and child-care settings;
- Develop and evaluate community-based interventions to address the asthma problem, particularly in high-risk communities.

The FLGA is committed to achieving and maintaining effective coordination that respects the unique contributions of individual agencies, facilitates exchange of information to avoid duplication, enables identification of opportunities for collaboration, and ensures that consistent messages about asthma are developed and disseminated. Much coordination of federal asthma activities already exists, and plans for expansion are under way. The FLGA will continue to explore current and planned asthma activities in greater depth in each of the five goal areas and seek new opportunities for interagency coordination and collaboration.

COORDINATION OF FEDERAL ASTHMA ACTIVITIES

Introduction

The Children's Health Act of 2000 (P.L. 106-310), Title V, Subtitle C – Coordination of Federal Activities, included the following language:

> "In general.– The Director of [the National Heart, Lung, and Blood] Institute shall, through the National Asthma Education and Prevention Program Coordinating Committee–
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> (1) identify all Federal programs that carry out asthma-related activities;
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> (2) develop, in consultation with appropriate Federal agencies and professional and voluntary health organizations, a Federal plan for responding to asthma; and
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> (3) not later than 12 months after the date of the enactment of the Children's Health Act of 2000, submit recommendations to the appropriate committees of the Congress on ways to strengthen and improve the coordination of asthma-related activities of the Federal Government."

In response to this directive, the following report was coordinated by the National Heart, Lung, and Blood Institute (NHLBI) for the Federal Liaison Group on Asthma (FLGA) of the National Asthma Education and Prevention Program (NAEPP). The FLGA includes representation from the Department of Education, the Department of Housing and Urban Development, the Environmental Protection Agency, and many components of the Department of Health and Human Services.

The FLGA was first formed as a subcommittee to the NAEPP in 1994. Its focus has been on information-sharing and looking for opportunities for collaboration on asthma activities among federal agencies. The approach has been for each agency to develop asthma activities relative to its own mission, and for the FLGA to serve as a sounding board for constructive input and ideas as well as a filter to look for and offset potential duplication and/or fragmentation of effort. The FLGA contributes to preparation of various reports and documents that provide a current inventory of federal asthma activities and that build consensus frameworks for strategic planning on asthma. The FLGA has been actively involved in the preparation of this report.

The report was submitted to the members of the NAEPP Coordinating Committee (NAEPP-CC) for review and concurrence; their comments have been incorporated. The NAEPP-CC consists of representatives from professional societies, patient advocacy groups, and other stakeholders who offer perspectives from outside the federal government.

Identification of All Federal Programs That Carry Out Asthma-Related Activities

The attached Inventory of Federal Asthma Activities was prepared by the FLGA with coordination by the NHLBI. The following agencies are members of the FLGA:

Department of Education (ED)
Department of Health and Human Services (DHHS)
- Administration for Children and Families (ACF)
- Agency for Healthcare Research and Quality (AHRQ)
- Agency for Toxic Substances and Disease Registry (ATSDR)
- Centers for Disease Control and Prevention (CDC)
  - National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
  - National Center for Environmental Health (NCEH)
  - National Center for Health Statistics (NCHS)
  - National Institute for Occupational Safety and Health (NIOSH)
- Centers for Medicare and Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- National Institutes of Health (NIH)
  - National Heart, Lung, and Blood Institute (NHLBI)
  - National Institute of Allergy and Infectious Diseases (NIAID)
  - National Institute of Environmental Health Sciences (NIEHS)
  - National Institute of Mental Health (NIMH)
  - National Institute of Nursing Research (NINR)
  - National Library of Medicine (NLM)
- Office of the Assistant Secretary for Planning and Evaluation (OASPE)
- Office of Public Health and Science (OPHS)
  - Office of Disease Prevention and Health Promotion (ODPHP)
  - Office of Minority Health (OMH)
  - Office on Women's Health (OWH)

Department of Housing and Urban Development (HUD)
Environmental Protection Agency (EPA)

Development of a Federal Plan for Responding to Asthma

The basic planning framework for responding to asthma was developed over the past several years through a collaborative effort among federal agencies that carry out asthma-related activities. Specifically, two important interrelated documents were developed to provide direction for federal programs addressing the asthma epidemic:

- *Action Against Asthma: A Strategic Plan for the Department of Health and Human Services*, a cornerstone of the DHHS Secretarial Initiative on Asthma

- *Asthma and the Environment: A Strategy to Protect Children,* a report of the President's Task Force on Environmental Health Risks and Safety Risks to Children, which was co-chaired by the EPA and the DHHS.

A collaborative effort of the agencies of the DHHS, with public input, *Action Against Asthma* outlines a four-pronged strategy to combat asthma. The report details actions in the broad areas of (1) research, (2) public health practice/interventions, (3) surveillance, and (4) health

disparities reduction. Specifically, the report calls for investment in research to determine the cause and prevent the onset of asthma. To reduce the burden of asthma, it proposes research on secondary prevention and an expansion of public health programs. A coordinated national, state, and local surveillance system is proposed to support better disease tracking and program evaluation. The report underscores the need to eliminate the disproportionate burden of asthma in minority populations and those living in poverty through focused research, improved access to care, and greater dissemination of current knowledge within those communities. Use of NAEPP Guidelines for Diagnosis and Management of Asthma is emphasized.

Developed simultaneously with the DHHS strategic plan, the President's Task Force report, *Asthma and the Environment*, focuses on the same four broad priority areas. It differs from the DHHS report by having a specific focus on environmental factors and childhood asthma. The plan emphasizes the need to expand research on the role of indoor and outdoor allergens in the development of childhood asthma and to identify cost-effective strategies to reduce exposure to them. Like the DHHS report, *Asthma and the Environment* underscores the need to promote greater use of the NAEPP Guidelines, expand existing public health activities, and develop a coordinated surveillance system for state, local, and national data collection.

It is important to understand the dynamic among the four broad priority areas that were selected for both reports. *Research* is the engine that drives scientific discoveries that shape health care programs and services which, in turn, influence quality of life for every person. Research findings must be translated quickly into effective strategies or practices that can be applied in clinical and public health settings. Single strategies/practices or a combination of several constitute an *intervention*. Ideally, interventions are pilot-tested to evaluate impact before they are widely implemented. Interventions that *reduce health disparities* among high-risk groups are a priority. *Surveillance* is essential to inform both program evaluation and program development, as well as to track the occurrence and severity of asthma over time. Information gleaned from program implementation and surveillance helps to formulate future research questions.

Both of the plans described above were developed with a view toward meeting the specific national health objectives outlined in *Healthy People 2010*, the DHHS national health agenda, which has two broad goals: (1) to increase quality and years of healthy life and (2) to eliminate health disparities. In the area of asthma, *Healthy People 2010* has the following specific objectives:

- Reduce asthma deaths;
- Reduce hospitalizations for asthma;
- Reduce hospital emergency department visits for asthma;
- Reduce activity limitations among persons with asthma;
- Reduce the number of school or work days missed by persons with asthma due to asthma;
- Increase the proportion of persons with asthma who receive formal patient education, including information about community and self-help resources, as an essential part of the management of their condition;

- Increase the proportion of persons with asthma who receive appropriate asthma care according to the NAEPP Guidelines;
- Establish in at least 15 states a surveillance system for tracking asthma death, illness, disability, impact of occupational and environmental factors on asthma, access to medical care, and asthma management.

The *Healthy People 2010* objectives facilitate the development of a nationwide surveillance system and promote the development of uniform measures for both monitoring asthma and evaluating asthma interventions.

Strengthening Coordination of Federal Asthma-Related Activities

The asthma objectives contained in *Healthy People 2010* are an important focal point for federal asthma activities. The DHHS Secretarial Initiative on Asthma and the President's Task Force on Environmental Health Risks and Safety Risks to Children share asthma priorities and are coordinated to promote a consistent and collaborative federal asthma effort. Together, the three initiatives form the basis of the federal approach to asthma. Federal agencies that are involved with asthma have incorporated the priorities identified in the three guiding documents into their asthma-related activities.

The agencies that constitute the FLGA are committed to achieving and maintaining effective coordination that respects the unique contributions of individual agencies, facilitates exchange of information to avoid duplication, enables identification of opportunities for collaboration, and ensures that consistent messages about asthma are developed and disseminated. They have expanded partnership collaborations with each other and with organizations in the private sector.

Over the years the FLGA activities have expanded well beyond information-sharing. The examples of collaborative activities that follow exemplify new ways in which federal agencies are coordinating their efforts, including the following:

- Collaborating on research, workshops, and community-based interventions;
- Serving on each other's advisory panels and grant/contract proposal review panels;
- Circulating documents and patient- and public-education materials for review and input;
- Establishing interagency agreements and links to each other's Web sites.

The increased interaction has been valuable, resulting in a stronger collective voice to address the growing asthma epidemic, consistent patient/public messages across agencies, improved coordination of resources at the local level, and integration of priority asthma strategies of multiple agencies to provide a comprehensive, seamless approach to delivering programs and services.

Recommendations

In preparing this report, the FLGA reviewed all federal activities related to asthma and identified five broad areas that are likely to benefit from strengthened interagency coordination. It is

recognized that overlap exists among the five areas, and that activities in one area will feed into others. For instance, new findings from surveillance activities are likely to generate hypotheses for research into the causes of asthma. Observations made in the course of implementing community-based programs are likely to influence Guidelines development and dissemination, and vice versa. Activities in all areas will provide critical new understanding of approaches to treating minority and economically disadvantaged populations and reducing health disparities.

It is recommended that efforts to strengthen and amplify federal coordination be focused on the following five goals, which correspond to priority areas identified in the two documents developed as the federal response to asthma. Examples of activities for which there is current collaboration, or for which there is movement toward future collaboration, are provided.

1. Discover ways to prevent asthma attacks and minimize uncontrolled asthma by improving understanding of the causes of asthma and its exacerbations.

Although asthma has reached near-epidemic proportions in the United States, the reasons for the increases in prevalence and death rates are uncertain. Research on development of the lung and the immune system, genetic susceptibility to allergy, and the role of environmental exposures promises to provide clues to prevention.

Much coordination of federal research activities already exists, and continued collaboration is recommended to share data and resources, enhance communication between investigators, and plan conferences, workshops, and initiatives in areas of emerging interest.

Examples of current activities and opportunities for collaboration in preventing asthma:
(Note: see Appendix for a complete inventory of federal asthma activities.)

The NHLBI and the NIAID co-fund a research initiative on the role of respiratory infections in the development of childhood asthma.

The NHLBI launched an initiative to examine the origins of asthma in early life by studying the interrelationships of genetic susceptibility to asthma, environmental exposures, and the developing immune system. This research will provide important clues for preventing asthma. The investigators share preliminary findings through joint meetings with NIAID researchers.

The NIAID supports 12 Asthma and Allergic Disease Research Centers on the pathobiology of asthma, 2 of which are co-funded by the NIEHS.

The NIEHS and HUD are collaborating on the National Allergen Survey, which is seeking to determine the health effects of exposure to indoor allergens.

The NCHS is working with the EPA to investigate the association between childhood asthma and outdoor air pollution.

The ATSDR, as part of its mandate to provide science-based assistance to Superfund communities, is investigating the health effects of citizens' exposure to hazardous substances.

NIOSH gathers data on risk factors, incidence, and pathobiology of work-related asthma to characterize and quantify exposures and determine the potential of workplaces to trigger existing exacerbations of asthma.

The NIAID and the NIEHS have just completed the second Inner-City Asthma Study, which tested the effectiveness of behavioral, educational, and environmental interventions to reduce cockroach and other indoor allergens. The NIAID is now initiating a new Inner-City Asthma Consortium to test the effectiveness of immune-based therapies.

2. Gather, analyze, and disseminate data at the national, state, and local levels on a variety of asthma parameters, including morbidity, mortality, health-service utilization, federal expenditures, and quality of life.

Activities in this area have increased markedly as a result of the DHHS Secretarial Initiative on Asthma, the President's Task Force on Environmental Health Risks and Safety Risks to Children, and the *Healthy People 2010* objectives, all of which place strong emphasis on asthma surveillance.

Coordination is needed to maximize the outcome of federal investments in this area, develop uniform measures and assessment tools, pool data, and ensure rapid data analysis and dissemination.

Examples of current activities and opportunities for collaboration in surveillance:
(Note: see Appendix for a complete inventory of federal asthma activities.)

The NCHS collects the following data on asthma: self-reported prevalence (National Health Interview Survey), office visits (National Ambulatory Medical Care Survey), emergency room visits (National Hospital Ambulatory Medical Care Survey), hospitalizations (National Hospital Discharge Survey), and deaths (National Vital Statistics System). Information on respiratory and allergic symptoms, previous diagnoses of asthma, and family history of asthma is collected via the National Health and Nutrition Examination Survey. These data systems are used to monitor progress toward the *Healthy People 2010* objectives.

The CDC Behavioral Risk Factor Surveillance System has expanded its asthma module to enable states to capture information on work loss, asthma severity, and asthma management for adults, as well as prevalence for children.

The NCEH is supporting development of state-based asthma surveillance through grants to 12 state health agencies. It supports asthma activities in state health agencies throughout the country through training, education and capacity building assistance.

NIOSH supplements national surveillance data with information from its state-based Sentinal Event Notification System for Occupational Risks (SENSOR).

The CMS has person-level data for fee-for-service Medicare and Medicaid beneficiaries on health-care costs associated with a diagnosis of asthma, including hospitalizations, provider visits, treatments, and prescription drugs.

In 1998 the CMS, HRSA, and the CDC signed a data-sharing agreement to allow states to link data sets from various sources. Its goal was to provide a basis for the three agencies to coordinate and direct various activities that support improvement in Medicaid and public health program design and outcomes.

The AHRQ Medical Expenditure Panel Survey collects information about utilization, quality, and costs of care for patients with asthma. The AHRQ Healthcare Cost and Utilization Project collects information about asthma hospitalizations from a nationally representative sample of community and other hospitals.

3. Identify and overcome barriers to full implementation of the NAEPP Guidelines.

The NAEPP Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma, published in July 1997 and currently being updated, incorporates the best available scientific information on the care of patients with asthma. It provides information on treating asthma at all severity levels and stresses both clinical and self-management strategies. It also provides a comprehensive discussion of current medications and their appropriate use. Despite widespread dissemination, the Guidelines are not being applied universally.

Ensuring that all Americans with asthma receive the best possible treatment requires a coordinated effort that involves developing, packaging, disseminating, and testing the Guidelines in real-world settings; identifying and overcoming systems barriers; educating health-care professionals; and addressing access and reimbursement issues.

Examples of current activities and opportunities for collaboration in promoting implementation of NAEPP Guidelines:
(Note: see Appendix for a complete inventory of federal asthma activities.)

The CMS has issued an agency letter strongly encouraging its state Medicaid administrators to use NAEPP Guidelines.

The National Committee on Quality Assurance Pediatric Health Plan Assessment Task Force (funded by the CMS and the AHRQ in the late 1990s), developed HEDIS (Health Plan Employer Data and Information Set) quality performance measures for asthma. The NAEPP provided review and input into these measures.

The NAEPP is working with the AHRQ to complete an evidence report on priority topics that will keep the Guidelines up to date by incorporating recent scientific evidence.

The NHLBI, the NAEPP, and the AHRQ are convening a meeting with professional societies to develop new approaches to expand implementation of the asthma Guidelines.

The NHLBI and the NINR are co-sponsoring an initiative, Overcoming Barriers to Treatment Adherence in Minorities and Persons Living in Poverty, to encourage evaluation of innovative yet practical methods to overcome patient, provider, and medical systems characteristics that impede or erode treatment adherence.

The AHRQ sponsors the Pediatric Asthma Patient Outcome Research Team (PORT II) co-funded by the NHLBI, a trial that tests the cost-effectiveness of the NAEPP Guidelines in reducing asthma morbidity among children.

HRSA, in collaboration with the EPA, supports the Asthma Collaborative, a quality-improvement initiative that identifies essential systems elements that encourage high-quality chronic-disease management.

The NAEPP is working in collaboration with the CDC to extract a list of key clinical activities from the four major components of care recommended in the NAEPP Guidelines. It will be used by public health planners and purchasers of health care to define key activities that are important to the provision of quality asthma care.

The AHRQ supports a number of cutting-edge research projects that are examining promising strategies to improve the quality of clinical care for asthma in community health centers, managed care organizations, hospital clinics, and a Head Start center. All are aiming to increase use of the NAEPP Guidelines.

Multiple federal components (HRSA, AHRQ, NIOSH, NHLBI, NINR, the National Institute of Child Health and Human Development, the National Institute on Drug Abuse) are collaborating on a program announcement to improve the quality of emergency room services for children, including those who suffer from asthma.

4. Enable optimal functioning of children with asthma in school and child-care settings.

Since its inception, the NAEPP has focused considerable attention on optimal management of asthma in the school setting. With the growing epidemic of asthma among children, many federal agencies have become involved in this effort.

Coordination through the NAEPP School Subcommittee strives to maximize the return on federal expenditures in this area, ensure that consistent messages are delivered, develop strategies that are appropriate for a range of school and child-care settings, and achieve widespread dissemination.

Examples of current activities and opportunities for collaboration in promoting asthma management in school and child-care settings:
(Note: see Appendix for a complete inventory of federal asthma activities.)

The NAEPP School Subcommittee continues to develop a wide range of educational materials for use in schools and child care settings.

The CDC Division of Adolescent and School Health (DASH) has partnered with the NCEH to plan strategies that enable the nation's schools to prevent asthma attacks and related absences. The DASH is also developing a comprehensive manual on asthma wellness in schools in collaboration with the NAEPP.

The NIAID Asthma and Allergic Disease Research Centers support research projects involving allergen avoidance and school-based asthma education.

The ACF has produced two training guides intended for use by Head Start front-line staff, management teams, and parents, that address asthma—*Sustaining a Healthy Environment* and *Caring for Children with Chronic Diseases*.

The EPA, in partnership with a variety of education and health organizations, is assisting school personnel in preventing, assessing, and resolving indoor air quality problems and in reducing exposure to asthma triggers.

The AHRQ is sponsoring a study of three models for expanding asthma primary care delivery to school-based health centers.

5. Develop and evaluate community-based interventions to address the asthma problem, particularly in high-risk communities.

Multiple federal agencies are using comprehensive community-based approaches to detect and manage asthma and developing innovative strategies to reach populations that are especially hard-hit by asthma. Nonfederal entities, such as the Robert Wood Johnson Foundation, are also active in this area.

Coordination of these efforts is under way to facilitate sharing of information, eliminate duplication, ensure that developers of community-based programs benefit from lessons learned in other settings, and enable communities to maximize use of available resources. These activities will be critical to achieving the goal of reducing disparities in the burden of asthma.

Examples of current activities and opportunities for collaboration in enhancing community programs on asthma:
(Note: see Appendix for a complete inventory of federal asthma activities.)

The NHLBI has awarded seven 3-year performance contracts to asthma coalitions with the goal of improving asthma care in communities that have exceptionally high asthma death rates.

The NIEHS Community-Based Prevention/Intervention Program supports a number of asthma projects in urban, socioeconomically disadvantaged populations.

The NCEH has made funds available via its Controlling Asthma in American Cities Project to implement interventions using asthma care concepts and innovative approaches shown to be effective in improving asthma control.

The EPA has launched a national asthma media campaign to raise public awareness about controlling environmental triggers as part of a comprehensive approach to address asthma in targeted high-risk communities.

The ODPHP established the Mid Atlantic Regional Asthma Initiative to promote regional government assistance and support to community partnerships for action against asthma.

The OMH supports a Community Coalition for Minority Children's Health that assists families affected with pediatric asthma in a variety of activities to increase quality of life for the children.

HUD's Healthy Homes Initiative is mobilizing public and private resources, involving cooperation among all levels of government, the private sector, and community-based organizations, to develop promising, cost-effective methods for identifying and mitigating housing-based hazards, including allergens, that may contribute to asthma.

In collaboration with the NIEHS, the EPA has funded eight Centers for Children's Environmental Health and Disease Prevention Research. Five of the centers focus on asthma and all emphasize community-based approaches to reduce the impact of asthma on children and their families.

In light of efforts to date, important areas identified as needing to be strengthened are the development of uniform measures and assessment tools, exploration of opportunities for sharing data and resources, and ensuring rapid data analysis and dissemination. These immediate issues are being considered by the FLGA.

Conclusion

Much coordination of federal asthma activities already exists, and plans for expansion are under way. As the FLGA continues to meet quarterly, it will explore current and planned asthma activities in greater depth in each of the five goal areas, and seek new opportunities for interagency coordination and collaboration.