

Summary Report

*THE
NATIONAL
ASTHMA
EDUCATION
AND
PREVENTION
PROGRAM
COORDINATING
COMMITTEE
MEETING*

*December 8, 2003
Hyatt Regency
Bethesda, MD*

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COORDINATING COMMITTEE (CC)

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM (NAEPP) NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI)

Meeting Summary December 8, 2003

The NAEPP CC met on December 8, 2003, at the Hyatt Regency in Bethesda, MD.

WELCOME AND OPENING REMARKS (Ms. Diana Schmidt)

Ms. Schmidt welcomed the participants to the meeting of the NAEPP CC. She reported a new member organization, the American College of Physicians, represented by Dr. Scott Wolf, as well as the following new representatives: Ms. Christy Olson, representing the Allergy and Asthma Network/Mothers of Asthmatics, Inc. (substituting for Ms. Nancy Sander); Mr. Mo Mayrides, representing the Asthma and Allergy Foundation of America (substituting for Mr. Bill McLin); Ms. Sarah Merkle, representing the Centers for Disease Control and Prevention (CDC); Dr. Bob Axelrad, representing the Environmental Protection Agency (EPA); Ms. Janice Nolan, representing the American Lung Association (ALA); and Ms. Judith Taylor-Fishwick, representing the Society for Public Health Education.

INVOLVEMENT OF THE ASTHMA TEAM IN PATIENT EDUCATION (Drs. Leslie Hendeles and Dennis Williams)

Institutional Settings

Dr. Hendeles discussed nondispensing roles of pharmacists and presented three models that show what pharmacists are doing to improve asthma care in institutional settings.

- In a multidisciplinary clinic, such as his at the University of Florida, patients are seen by the pharmacist as part of a team including physicians, nurses, and respiratory therapists. The pharmacist teaches the physician trainees and nurse practitioners about the clinical pharmacology of drugs for asthma. Pharmacists take patient medication histories, teach patients about their medications, and test patients' inhaler technique. Pharmacists suggest medication changes to physicians and intervene with patients with poor adherence rates. Dr. Hendeles gave an example of an incorrect prescription written by a physician, illustrating why pharmacists' input is needed. For example, pediatric residents might not check with the attending physician.
- At the University of Tennessee, pharmacists and pharmacy students who were under the supervision of a faculty member provided asthma education to patients in the emergency department (ED). A nonrandomized study, by Tim Kelso in 1995, looked at indigent adult African American asthmatics who were frequent users of the ED in the previous 2 years. While in the ED, patients were given 1 hour of education about asthma, asthma triggers, metered-dose inhaler (MDI) technique, and peak flow measurement; they were given a written asthma plan and a supply of oral prednisone.

The mean number of ED visits in the intervention group decreased from 4.4 to 2.6 within 1 year.

- In pharmacist-managed clinics, pharmacists with special asthma training see patients who have been referred by the ED staff as being frequent users of the ED. A nonrandomized study (CJHP 1993; 5:5–6) at Kaiser-Bellflower used interventions based on the National Heart, Lung, and Blood Institute (NHLBI) asthma guidelines; results were a significant reduction in the number of ED visits and increases in asthma control. Later, Dr. Dennis Williams mentioned a study of a pharmacist-managed asthma program in Florida (Pauley, 1995) that had good results. This study identified 25 frequent users of the ED. Interventions included patient education in the ED and an open-access clinic (run by a physician and a pharmacist) where patients could go if they had changes in their symptoms.

COMMUNITY SETTINGS (Dr. Dennis Williams)

Dr. Williams noted that the NHLBI document, *Role of the Pharmacist in Improving Asthma Care* (1995), lists the following roles of the pharmacist: educate the patient about asthma medications, instruct the patient in proper techniques for inhalation devices, monitor medication use and refill intervals, encourage patients purchasing over-the-counter (OTC) asthma therapies to seek medical care, help the patient use monitoring devices appropriately, and counsel the patient discharged from the hospital about the asthma management plan.

Dr. Williams also listed key areas of education programs as the following:

- Identify patients who might self-treat and are undiagnosed, untreated, or undertreated for asthma;
- Identify patients with poorly controlled asthma and refer them to appropriate care;
- Educate patients about asthma and its treatment;
- Assess and intervene with patients and health professionals in asthma therapy;
- Collaborate with other professionals in management;
- Consider medication- and situation-specific needs; and
- Consider referral to specialist care.

Dr. Williams then described challenges in the community pharmacy practice setting. These challenges include a manpower shortage, public trust, drug shortages, affordability of medications, and reimbursement and compensation strategies.

Studies cited in the community setting include the following:

- The Asheville Project, conducted in Asheville, North Carolina, has received much attention. This was a study, without a control group, of an effort to improve asthma

and diabetes control. Community physicians trained pharmacists in the management of asthma. Pharmacist care was offered for 6 months at no cost to the payer, and payment for services after this time was negotiated. Results published in *Pharmacy Times* indicate that 45 percent of patients showed overall clinical improvement in asthma control; average forced expiratory volume in 1 second (FEV₁) improved 38 percent; days of activity limitation were reduced from 5 to 2 days per month; and use of asthma action plans increased from 11 to 100 percent.

- The PEAK project, funded by the Agency for Health Care Policy and Research (AHCPR), was a randomized controlled trial (RCT) in Washington State. Community and health maintenance organization (HMO) pharmacists were trained to manage pediatric asthma patients who were followed for 1 year. The results (Stergachis et al., *J Am Pharm Assoc*, 2002) showed no significant effect on health or health services use. Compared with the control group, the intervention group showed (1) no evidence of improved lung function and other outcome measures and (2) no differences in the use of anti-inflammatory therapies or school days missed. The investigators gave several reasons for these results, including obstacles in community pharmacies (pharmacists who are too busy) and the number of patients with mild asthma in the study.
- Another RCT (*JAMA*, 2002; 28:1594–1602) examined the effectiveness of pharmacist care in asthma and chronic obstructive pulmonary disease (COPD) among 36 community pharmacies (all CVS stores). This study showed no significant difference in important asthma outcomes, in adherence, or in quality of life. The investigators suggested that making people more aware of their asthma goals makes them more likely to seek medical care, but an obstacle is getting pharmacists to take the time to provide care. Incentives were added part way through the study.
- An RCT published in the *Canadian Respiratory Journal* (2003) showed that paying pharmacists to provide care to asthma patients resulted in improved health-related outcomes.

Dr. Williams concluded that, although pharmacists clearly have the training to help patients improve their asthma control, the literature shows mixed results. Two challenges are finding the practice model that works best and receiving compensation for services. Pharmacists have applied to the Centers for Medicare and Medicaid Services (CMS) for provider status, and this status might resolve some of these issues.

Discussion

In response to questions, the speakers noted:

- Studies so far have not looked at the value of repetitive interventions or the optimal length of sessions.
- The failure of some studies to show improvement may be due to pharmacists who did not intervene. Pharmacists might hesitate to call a physician to suggest a treatment.

Younger pharmacists have a different attitude, so they may not hesitate. In the PEAK study (defined on p. 3), 58 percent of patients in the intervention group received one or fewer documented interventions. Because the Asheville study had physician buy-in, the pharmacists may have felt more comfortable contacting physicians.

- Better communication is needed to overcome the sometimes adversarial relationship between physicians and pharmacists (e.g., when pharmacists change a prescription). Both pharmacists and community practitioners must be educated. A clarification was noted: pharmacists do not change prescriptions; they dispense an FDA-approved bioequivalent formulation, and many third-party payers require generic medications.

CURRENT PATIENT ISSUES

Transition to Non-CFC Inhalers (Dr. Robert Meyer)

Dr. Meyer of the Food and Drug Administration (FDA) provided an update on chlorofluorocarbon (CFC) inhalers. As of December 2003, CFC essential-use nominations are approved through 2005, as decided at the 15th Meeting of the Parties of the Montreal Protocol, which was held in Nairobi in July. An issue of concern is the source of CFCs beyond 2005. Currently, they come from the Netherlands, but that plant will be shut down. The FDA has been told that CFC production will occur in Louisiana. The production of non-CFC technologies is well under way.

Products no longer considered essential include nasal corticosteroid MDIs (as of July 2003) and older adrenergic agents (e.g., isoproterenol). Other products that may soon be delisted include beclomethasone dipropionate (BDP), dexamethasone, aerosolized talc, and aerosolized ergotamine.

Transition is occurring in the case of BDP, which is available only as a hydrofluoroalkane (HFA). Dry powder inhalers (DPIs) are successful products. Salmeterol CFC was recently withdrawn by the manufacturer (not directly in response to the Montreal Protocol). Two albuterol HFAs are available (Proventil HFA and Ventolin HFA). Dr. Meyer also compared the CFC essential-use list 2 years ago and at present for various classes of drugs; he noted which products are no longer used and which are no longer considered essential.

Dr. Meyer made the following points concerning the CFC transition:

- The key asthma drug albuterol is the biggest single use of CFCs. Under 21 Code of Federal Regulation (CFR) 2.125, albuterol may be considered no longer essential when, following rulemaking, two or more non-CFC MDIs are available, supplies and manufacturing capabilities are adequate, and patients are adequately served by the supply (including consideration of cost and other factors). The main issue for the FDA is that branded albuterol (either HFA or CFC) costs more than generic CFC MDI.
- About a year ago, the FDA received a Citizens Petition from the ALA and other stakeholders asking the FDA to initiate rulemaking declaring albuterol to be

nonessential (because two alternatives are available). Comments to the petition have been received, primarily from industry and professional organizations. There has been little public notice of this issue.

- Albuterol is considered no longer essential in Canada, Australia, Japan, and much of the European Union (EU). Other HFA and DPI products are also making inroads or are well established in much of the developed world. The EU introduced a decision to make all countries adhere to timelines: albuterol is to be nonessential after 2005; all other MDIs are to be nonessential after 2007. The U.S. Government did not agree with the EU draft decision for several reasons; the FDA had promised that delisting occurs through public rule-making. It is unclear whether patients would be hurt by phasing out albuterol on this schedule. More public attention and discussion is needed to ensure satisfactory transition. The “end-game” for all CFCs being “nonessential” is not close enough to be certain in regard to the 2008 timeframe for final phaseout.
- The decision adopted by the Parties of Montreal calls for the United States and other countries to have a plan for phaseout of albuterol by mid-2005. These countries must inform the parties “as soon as predictable” when they will stop requesting CFCs for all other uses. Emergency requests are not affected, and all actions must take developing nations into account.
- Early in 2004, the United States will publish a proposed rule to designate albuterol as no longer essential by a certain date. A public meeting then will be held on the proposed rule, and written comments will be accepted. On a separate track, the FDA proposes a separate rule for delisting other nonessential products.

ALA Petition (Ms. Fran DuMelle)

Ms. DuMelle said that, at the request of the EPA, the ALA convened the stakeholders’ group for the MDI transition in 1996. The treaty obligations for the legislation are detailed in the Clean Air Act of 1990. The overarching goal is to use the transition as an opportunity to focus attention on the proper diagnosis and management of asthma.

The parties agreed to require submission of national transition strategies by January 1, 2002. They then focused on the essential use nomination—whether there should be certain limitations for CFC/MDI albuterol. Albuterol was singled out because it accounts for the single largest amount of CFC used and it was the product that was reformulated most quickly.

The FDA promulgated its final rule on the transition strategy on July 24, 2002. Using the rule as a guideline, the stakeholders filed a Citizens Petition to the FDA, requesting that it initiate rulemaking to remove CFC albuterol. The petition considered rulemaking the proper form for beginning the transition, allowing all persons to come to a public forum to discuss their views. The initial issues of concern were the continued long-term availability and uninterrupted supply after September 2005 as more countries transition away from CFC technology. Mounting pressure on the United States to demonstrate progress was another issue.

Ms. DuMelle said that the FDA is committed to publishing a proposed rule. All parties interested in the care of patients with asthma should participate in the process. We must ensure a seamless transition for patients and focus attention on the proper diagnosis and management of asthma. We need to identify the best ways to improve on progress to date and to develop and disseminate information to all providers as the FDA rulemaking proceeds and implements the transition in the United States.

Discussion

Dr. Leslie Hendeles facilitated the discussion, during which the following points were made:

- When asked if there is a future for an HFA or non-CFC albuterol, Dr. Meyer said that patent protection for the HFA extends through 2009. IVAX Pharmaceuticals has submitted an application to the FDA for an albuterol that is another option (though not truly a generic). It may be several years before a true generic albuterol is available.
- An obstacle to the use of inhaled corticosteroids is cost, especially for low-income uninsured patients. With the transition, the cost of albuterol will be comparable to the less expensive inhaled products. However, the cost differential on an annual basis is small if the patient's asthma is under control.
- In other countries, the health care systems absorb the cost of drugs or regulate products out of existence by reimbursement policies. The budget problems of the States in this country might prevent them from covering the cost of drug coverage for children.
- The ALA started the petition process to get the issue discussed in a public forum that is broader than the stakeholder organizations.
- The role of the FDA in this instance is beyond its usual approval process. Under the auspices of the Clean Air Act, rulemaking allows for delisting of products, and people want cost to be taken into consideration. The FDA will move toward rulemaking in the near future. Dr. Meyer will let the Coordinating Committee know when a rule is published, because the member organizations need to be involved in the public dialogue.
- The FDA is not aware of any interest in reformulating the OTC medication Primatene Mist.
- In 2005, a public forum may be held to discuss products that are not being reformulated. After 2005, a public meeting should be convened to determine whether there should be an OTC beta-agonist and whether it should be epinephrine. The possibility of making albuterol an OTC medication has been discussed at previous meetings, and the opinion of the advisory groups and public has been against it.

- The list of drugs in the NAEPP's asthma guidelines (the *National Asthma Education and Prevention Program Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma*) needs to be revised to delete those drugs that are delisted.
- Currently, no DPI devices deliver short-acting, quick-release beta-agonists.

PATIENT-PROVIDER PARTNERSHIPS

Can Better Communication Affect Patient Outcomes? (Dr. Michael Cabana)

Dr. Cabana, codirector of the Physician Asthma Care Education (PACE) program, said that PACE believes that physicians can use specific strategies to achieve more effective communication and improved outcomes. Barriers to effective communication include limited physician time with patients; the multiple tasks that physicians must perform; patients' different beliefs, concerns, and goals about the treatment plan; and the need for effective communication during the visit.

The program, initially developed by Dr. Noreen Clark with NHLBI funding, evolved into the PACE program with funding from the Robert Wood Johnson Foundation (RWJF). The educational intervention targets primary care providers (PCPs) to improve provider counseling and communication for asthma patients and to improve patient self-management and outcomes. The format includes brief lectures, case studies, a video modeling effective practices, and tools for self-evaluation. Two 2.5-hour sessions are given 1 week apart. The program reviews the NAEPP guidelines; includes a section on coding, documentation, and reimbursement; and focuses on the following three communication strategies:

1. **Teach physicians to use a framework to develop an approach to physician-patient education.** The Health Belief Model states that the patient must believe that he or she is susceptible to the health problem, that the threat is serious, and that the benefits outweigh the cost. Patients or parents must feel confident that they can carry out the recommended actions successfully.
2. **Ask physicians to apply 10 specific communication techniques during acute care visits or preventive visits with patients with asthma.** These communication techniques, used consistently over a number of visits, have been demonstrated to enhance both physician communication and asthma outcomes for patients. A videotape shows a physician demonstrating these techniques during a simulated patient visit. A trained facilitator discusses the techniques and leads a discussion. Strategies to relax and reassure the patient include nonverbal attentiveness, addressing immediate concerns, and the use of reassuring messages. Other strategies include interactive conversation to improve the exchange of ideas and feelings, to elicit fears, and to gather information needed for diagnosis and treatment decisions. Tailoring messages, planning for decision-making, and setting goals all prepare patients to carry out a treatment plan at home. Nonverbal encouragement and verbal praise build patients' self-confidence to carry out the treatment plan and to improve self-efficacy.

- 3. Convince physicians to deliver 12 key asthma education messages over a series of visits.** Physicians are encouraged to provide groups of three or four key messages over each of several visits. Physicians are given tools that allow them to track which messages have been delivered. One set of messages includes what happens during an asthma attack, how medicines work, how to take the medicine, and how to respond to changes in asthma severity. Another set includes information on the safety of medicines, specific goals of therapy, and criteria for successful treatment. A third set includes managing asthma in school, identifying and avoiding triggers, and providing resources for additional asthma education.

Evaluation

Dr. Cabana reviewed the results of the PACE program thus far. The controlled trial included 83 pediatricians and 637 patients with 2-year followup in Ann Arbor, Michigan, and in New York City. Twenty percent of the patients were covered by Medicaid, and 19 percent were Hispanic/African American. The 1-year followup was published in 1998 in *Pediatrics*, and the 2-year followup was published in 2000 in the *European Respiratory Journal*. The first paper reported that the intervention pediatricians were more reassuring, asked more about asthma management at home, and were more likely to set a goal for the child to be active. Parents reported an increased use of written plans. Pediatricians who received the intervention showed increased use of written action plans and anti-inflammatory therapy, and they paid more attention to patient fears. Physicians in the intervention group reported no additional time for patient visits compared with physicians in the control group.

A subanalysis separated the effects of drug therapy from the effects of good communication and patient education. Patients whose physicians provided both education and inhaled corticosteroids did better than those who received the drug alone. Outcomes included reduced numbers of ED visits, hospitalizations, and days with symptoms. These initial results indicate that improved physician communication can improve patient outcomes.

Additional questions are being examined in a controlled trial at 10 sites nationwide, including 99 PCPs and 896 children followed since 2001. This evaluation will determine the modifications needed to disseminate the information successfully in other communities. The program was modified to collaborate with local opinion leaders, to find leading physicians to provide the sessions, and to develop a standardized program disseminated by the train-the-trainer model. The program has sought the endorsement of local medical organizations to gain physician buy-in, and it added a segment on documentation, coding, and billing for asthma education. Mail surveys, chart audits, and parent interviews are being used to collect annual data on patient outcomes and changes in physician knowledge, attitude, and behavior.

Issues that remain to be addressed are the acceptance of “well” asthma visits by patients, the variety of health care providers involved in asthma education (e.g., nurse educators), and how to attract physicians who are “late” adopters to attend the seminars.

Discussion

- Plans for the future depend on the RWJF. Currently, evaluation and dissemination must be carried out at the same time. The train-the-trainer program, based on the results of the first study, is being disseminated nationwide (beyond the 10 evaluation sites) in collaboration with Allies Against Asthma and the CDC. This program has reached almost 900 physicians. Results from the second study are available for the first year.
- Development of a model for allied health care providers has been proposed. Focus groups have been conducted with these providers.
- Alternative education—e.g., through the Internet, recorded messages, and telephone counseling sessions—might encourage patients to return to well asthma visits.

PATIENT-PROVIDER COMMUNICATION AND ADHERENCE TO ASTHMA THERAPY (Dr. Cynthia Rand)

Dr. Rand, director of the Johns Hopkins Center for Adherence Research, talked about the effect of breakdowns in patient-provider education on adherence to asthma therapy. First, she reviewed research on patient-physician communication. This research provides strong evidence that such communication is poor. Physicians do 60 percent of the talking, and the conversation rarely addresses psychosocial issues. Fifty percent of the time, physicians do not name the medication being prescribed or give dosing instructions. Poor communication may contribute to health disparities in minority populations, with unintentional racial biases that might lead physicians to underestimate asthma severity and underprescribe medications. Patients may be reluctant to express expectations and preferences, and they may distrust the physician. Language barriers and patients' low levels of health literacy play a role in both patients' misunderstanding and their difficulty following therapeutic regimens.

Essential elements of physician-patient asthma communication include addressing the following questions:

Does the patient understand the prescribed regimen? Multiple studies have shown that, after they leave the physician's office, patients forget about one-half the information given to them. This percentage is worse if the information is surprising or distressing. Poor patient comprehension and recall contribute to unwitting nonadherence. For example, poor comprehension can lead to poor MDI technique, even after teaching—furthermore, the quality of the technique tends to decrease even more between visits.

A study by Boulet (1998) asked Canadian users of inhaled corticosteroids (ICS) about their perceptions of this treatment and found they had significant misunderstanding. Language, education, and cultural differences may increase the likelihood of unwitting nonadherence and contribute to health disparities.

In 2000, a study by Vargas found discrepancies of 61 percent between physicians' reports and parents' reports of asthma medication regimens.

A qualitative study by Schillinger (2003) focused on audiotaped communication between 38 physicians seeing 74 patients who had both diabetes and low levels of health literacy. The study examined the association between the patients' glycemic control and the physicians' application of a communication strategy—explaining new concepts, assessing patient recall and comprehension, clarifying and tailoring information, and reassessing recall. Patients whose physicians assessed recall/comprehension were more likely to have A1c levels below the mean. This study provides a model for communication about and treatment of asthma.

Does the patient have concerns about following the treatment? “Intelligent” nonadherence is when patients deliberately alter or discontinue therapy. This often occurs because they feel better, have concerns about side effects, perceive the therapy to be ineffective, fear addiction, and consider that less medicine is the best medicine. Primary nonadherence is when the patient never picks up the therapy. A telephone survey by Chambers et al. (1999) asked 800 adult patients why they did not use ICS. Reasons were “I use it only when I need it” (52 percent), “I don’t like using medicine unless I feel sick” (33 percent), “I don’t want to use steroids” (27 percent), and “I feel fine” (no percentage given).

Rickert et al. (2002) reported physician–patient discordance and patient rejection of therapy among symptomatic children ages 6–12 with a history of ED use for asthma. The majority of patients did not have ICS prescribed. About 30 percent of the time, parents and physicians were discordant about ICS use. The only significant predictor of concordance was asthma beliefs. Even when therapy was prescribed, more than one-third of patient caregivers did not report using a prescription, and this discordance was related to their beliefs.

Is the patient adherent to the treatment on an ongoing basis? A high level of disagreement is found between physicians' assessment of patient adherence to regimens and actual reality—adherence is not much better than 50 percent. A study by Van Ganse et al. (1997) asked physicians whether their patients were on ICS and the patients' level of adherence. There was 74 percent agreement between what the physician thought the patient was taking and the reality.

When Sherman et al. (2000) looked at concordance between physician assessment and pharmacy refill data they found 50 percent overall agreement. For a qualitative study of physicians treating hypertensive patients, Steele et al. (1990) audiotaped interactions of physicians and patients. Patients admitted their nonadherence to regimen to the research assistant but not to the physician. Typical interactions included close-ended questions that assumed adherence and closed the door to sharing concerns and worries about the regimens.

Dr. Rand noted that Dr. Cabana had provided some steps for improving physician–patient communication. She also said that PACE was one of the few controlled studies demonstrating that improving the quality of communication improves outcomes and acceptance. PACE also showed that effective communication does not take longer.

Conclusions

Dr. Rand concluded that gaps in communication may result in the patient's misunderstanding or mistrusting the prescribed regimen. Physician–patient communication may be particularly poor with low-income minority patients. Poor communication can result in decreased patient

adherence to treatment, thus leading to increased morbidity. Improving communication between providers and patients requires using, teaching, reinforcing, and supporting information-intensive and interactive educational strategies. Physicians should not just present information but listen to patients. Physicians must also tailor and address patients' concerns with a revised message that meets the patients' needs.

Discussion

- It takes a village. Other asthma educators might include nurses, pharmacists, and respiratory therapists. Reimbursement policies would provide incentives for the health care system to do this.
- Research on the use of community health workers has shown mixed results. Dr. Rand said she was not aware of studies that compare asthma education provided by physicians and by other health care providers, but this comparison would be worth exploring. Her own dissertation research examined patient communication and satisfaction with obstetricians and midwives; midwives provided better communication.
- Not only paid professionals have an effect. Studies in high schools have shown that 9th graders were more receptive to health information from 11th graders than from paid educators.
- Schools continue to be an underutilized setting for education. For example, personnel in the school could review the asthma regimen with the child and family, then call the physician to confirm the regimen.
- Underuse of ICS may be due to failure to prescribe ICS optimally.

COMMUNITY APPROACH TO PATIENT EDUCATION (Ms. Judith C. Taylor-Fishwick)

Ms. Taylor-Fishwick is with the Center for Pediatric Research in Norfolk, Virginia, (a grantee of the Allies Against Asthma). She described the Asthma Ambassador Program, an outreach project targeting public housing programs in three ZIP codes in southeast Virginia. This community-based intervention evaluates the needs of disadvantaged, hard-to-reach children who have asthma and who live in public housing. The program uses a variety of approaches to find children: following up on referrals from physicians and school nurses, emergency rooms, and home visiting nurses; and going door-to-door in the projects.

The program started with 144 children and now includes 180. Most of the children are on Medicaid, 53 percent are male, 99 percent are African American, 56 percent had at least one ED visit in the last 12 months for asthma, 83 percent had no asthma action plan, 33 percent are taking ICS, 13 percent are taking oral steroids, and 18 percent are taking Singulair.

Caregiver concerns include the child's performance in normal daily activities (29 percent), not being able to lead a normal life because of asthma (30 percent), and side-effects of medication (36 percent).

The Ambassador Project interviewed 10 local women living in the projects. These women were trained about basic asthma messages, how to communicate with clients, and how to deal with conflict. Four of the women were selected to work as Asthma Ambassadors. Each Ambassador is asked to make a minimum of four educational home visits with an enrolled family. Home visits do not replace physician care. The Ambassadors convey information to the children's caregivers about asthma, different types of medications, recognition of symptoms and triggers, and asthma action plans. The family is given a standard action plan and is told to bring it to their physician. When it is completed and signed by the physician, one copy goes to the school nurse. When the caregiver signs the asthma action plan, they agree to have the school nurse communicate with the physician.

At the four home visits, the Ambassadors talk about (1) the importance of asthma action plans, (2) triggers and warning signs, (3) use of controller medications and spacer technique (using a video to inform the family and child), and (4) the asthma action plan and the importance of an asthma diary.

After learning about the family's concerns and priorities, the Ambassador fills out a family outcomes form to identify goals. Educational resources include *A Parent's Guide to Asthma* (booklet), low-level literacy materials, and a checklist for asthma triggers (used by the Ambassador in the child's home). The Ambassador works with the family to identify questions and concerns to take to the physician. A medical information release form allows the program personnel to talk with the physician and home health nurse.

The Ambassador also brings other resources to the family: a spacer; the spacer video; "freebies" such as a T-shirt, magnet, bookmark, gift vouchers; and information about special events. The "Asthma ladies" are known in the community and make referrals between families.

Three Ambassadors now cover 5 housing projects and 100 clients. A nurse supervisor oversees the program and holds weekly case conferences with the Ambassadors to review the issues and families. The Ambassador Project Coordinator provides program oversight. The program is linked to other community partners, such as churches, the PACE program, housing directors, school nurses, other insurance-based home visiting programs, EZ Breathers, and pharmacists.

Discussion

- Getting permission to review the action plan is very important. The action plan is on the Internet, and copies will be sent to the meeting attendees.
- Program evaluation consists of two surveys given at baseline and at 12 months. The survey evaluates topics such as medication use, quality of life, and parent/caregiver confidence about managing the child's asthma.

- Sustainability will be achieved by linking with managed care organizations (MCOs). The program is looking for funding.

ASTHMA EDUCATOR CERTIFICATION (Dr. Carlos Camargo)

Dr. Camargo said that the mission of the National Asthma Educator Certification Board (NAECB) is to promote optimal asthma management and quality of life among individuals who have asthma, their families, and their communities by advancing excellence in asthma education. The Board was formed in 2001 with help from the ALA and other organizations. The first exam was posted on September 19, 2002. The exam includes 175 questions (150 actual test questions and 25 pretest items). It has gone through extensive testing to ensure that it represents what asthma educators do in this country.

The 3.5-hour exam can be taken online at more than 100 secure sites in H&R Block Centers. The Candidate Handbook includes sample questions and references. Exam categories include the asthma condition (20 percent), patient and family assessment (26 percent), asthma management (almost 50 percent), and organizational issues. To be eligible to take the exam, people can be licensed or credentialed professionals from categories such as physician, physician assistants, nurse, respiratory therapist, technologist, pharmacist, social worker, health educator, and an open category—anyone who provides asthma education counseling and coordination and has a minimum of 1,000 hours of experience.

People from all these groups except social workers have taken the exam. Respiratory therapists and nurses are the professionals most frequently represented. The first-time pass rate is 70–75 percent. For the entire group, the pass rate ranged from 46–100 percent. There are now almost 500 certificants; their names are posted on the NAECB Web site (www.naecb.org).

In spring 2003, ongoing exam development and evaluation will continue, and the second exam will be released. A scholarship program was started, and the AE-C trademark (Asthma Educator-Certified) was secured. In fall 2003, activities will include release of the Reimbursement Web site, election of new board members, and analysis of the first year's candidates.

Dr. Camargo described the Reimbursement Web site, which will include information on Medicare guidelines for coding, billing, and reimbursement; a glossary of terms; medications, including tips for getting medications for indigent patients; an overview of one third-party payer; and a State-by-State description of coding. Users will be able to go on the Web site and click on "Edit" to enter comments. Categories under Medicare will include pulmonary procedures, rural health clinics, home health nursing, medical equipment and supplies, and new codes specific to Medicare on health and behavior assessment. The goal of the Web site section on Reimbursement is to share tips on how to obtain payment for asthma education. The section was written for administrators who need to keep the program solvent. There is also information by State (for five States thus far).

Discussion

During the discussion, the following issues were raised:

- Nurses and respiratory therapists come from a wide range of asthma programs.
- Certification does not assess skill or knowledge on smoking cessation.
- For the MCO section, in the States that are major players, people are asked to describe their codes and program, with the goal of sharing information. Launching the Reimbursement Web site will prompt these persons to review the information.

SUBCOMMITTEE REPORTS

School Asthma Education (Dr. Lani Wheeler)

Dr. Wheeler reported that the School Asthma Education Subcommittee celebrated the publication of an update for the *Managing Asthma Guide for Schools*. This will be posted on the NAEPP Web site's School Corner.

The Subcommittee is working on the following projects:

- “Is the Asthma Action Plan Working?” is an assessment tool designed for school nurses. This will be a guide to organizing information, sharing it with PCPs, and helping families get better care. The tool is not designed for use with every child with asthma—only with those experiencing difficulty. Revisions will be made to the document, with help from the National Association of School Nurses. The draft will then go to the Subcommittee for review and approval.
- A Self-Carry Guidance Document will define the parameters that go into decisionmaking about whether to allow students to self-carry asthma medications. Although the Subcommittee promotes the idea that schools permit self-carrying of medications, this policy should be based on a physician assessment, parental permission, and input from the school nurse. The document lists factors the PCP should consider to determine whether a specific student should self-carry medications. This document will be revised and reviewed by the Subcommittee.
- A standard protocol/flow chart for managing asthma episodes is in the process of development. The flowchart focuses especially on the situation when a child does not have an asthma action plan or an albuterol inhaler in school. Only 20–25 percent of students with asthma have a quick-relief inhaler in school. When a child who does not have an inhaler has an episode at school, schools may take various actions—call 911, call the parent to bring an inhaler, or supply nebulizers and medications for students who have diagnosed asthma. Other school programs have obtained donated inhalers from MCOs and have used the inhalers for any child who has a physician's order on file. Because of the many issues associated with this effort, subcommittee member organizations are not equally comfortable with all these options. Once agreement is reached, the document will be finalized.
- The Subcommittee decided to form a new workgroup to focus on physical education teachers and coaches. The goal is to increase their knowledge, attitudes, and

behaviors with regard to exercise-induced asthma. The Work Group will provide a coordinated approach and will work with the national organizations for physical educators to help develop the formats that are the most useful for their membership.

Discussion

- A CDC survey found that only a few States allow self-medication in schools. The Subcommittee is not working on this issue directly. Ms. Christy Olson said that Allergy and Asthma Network/Mothers of Asthmatics, Inc. is addressing this issue. A Bill (HR 2023) is now in the House of Representatives, and efforts are being made to hold a hearing to establish the benefits of the self-carry policy.
- Some schools are experimenting with regular administration of controller therapy for children whose families do not administer medication reliably at home.

PROFESSIONAL AND PATIENT–PUBLIC EDUCATION (Dr. William Storms)

Dr. Barbara Yawn first thanked and congratulated the Coordinating Committee members and NHLBI staff who contributed to the very successful cross-disciplinary National Asthma Conference held in June 2003.

Dr. Storms reported that the Subcommittee heard the following presentations:

- Dr. Seymour Williams discussed “Key Clinical Activities To Quality Asthma Care,” produced by the CDC to help public health departments deal with Medicaid managed-care contracts. The document is a simple short version of the NAEPP’s asthma guidelines and can be used by any managed care contractor.
- Dr. Rachelefsky discussed a handout that is a supplement to *Pediatric Asthma: Promoting Best Practices*, produced by the American Academy of Allergy, Asthma, and Immunology (AAAAI). He described several sections of the new document, including Can Your Child Go to School Today? (a page that physicians can give to patients) and Asthma Tips for Travel, Vacations, and Holidays With Your Child. The document will be available on the AAAAI Web site after the first 8,000 copies are sold at \$10 a copy. The document is designed to be copied (there is no copyright).
- Ms. Andrea Greiling and Dr. Leslie Boss discussed prehospital management of asthma in transport settings. The guidelines do not address this topic; every State, county, and city has different rules. A working group will be established to develop a standard approach, which might eventually become a sample protocol for prehospital management of asthma.

Ms. Schmidt summarized the following additional activities:

- An effort began several years ago to identify and organize resources for asthma education. Dr. Denise Dougherty leads the project and is working with the Council

for Excellence in Government Fellows to explore whether to establish a NAEPP partnership project.

- A checklist has been developed to serve as a “job description” for new NAEPP Coordinating Committee members. Members should send their comments to Dr. Yawn or Ms. Schmidt. A goal is to develop a bulleted list organized according to highlights, decisions, and follow up actions.

PATIENT EDUCATION: WHAT’S NEXT?

In this segment, members had an opportunity for to provide the NAEPP with directions for patient education.

- Dr. Yawn will send members’ comments about issues related to patient education in rural populations. This document might be the basis for a Working Group to address the issues. Asthma in adults is another topic that deserves attention.
- Dr. Rachelefsky suggested that the NAEPP should revisit the possibility of holding a national asthma campaign directed at patients and the public (modeled after a campaign done in Australia/New Zealand). Physicians may be the wrong target for education. A Working Group might explore this suggestion further.
- Dr. Rachelefsky noted that, according to data from a project that he directs for RWJF, most patients who go to the ED for pediatric asthma care have mild/intermittent asthma. He suggested focusing on asthmatics who come to the ED rather than on minority or underserved patients who have severe asthma.
- Another neglected population is the elderly and adult patients with asthma. The elderly have the highest asthma mortality. Adults who are older than age 35 and smoke may also have COPD and reactive airway disease, so they do not present a “tidy” asthma profile. This population warrants specialized education and intervention.
- Dr. Luna suggested the need for a summary of the critical elements of a patient education program. Dr. Rand added that “best practices” could be disseminated.
- The CDC is working on a project to identify the best research on asthma education and to make those materials and methods widely available. The Wee Wheezer program for children less than 7 years of age is now available as a package, in both English and Spanish, through the Asthma and Allergy Foundation of America (AAFA). This program has been adapted to the Wee Wheezers at Home program which targets public health workers who in turn take the program to parents in the home.
- Much time is spent on educating the physician. Instead, change the focus to projects (either research or standardization of processes) aimed at enabling and empowering patients to communicate better with their physicians.

RESEARCH TRANSLATION (Dr. Michael Schatz)

Dr. Schatz provided an overview of work on *Managing Asthma During Pregnancy: Recommendations for Pharmacologic Treatment—Update 2004*. He noted that asthma is probably the most common potentially serious medical problem to complicate pregnancy. (About 7 percent of pregnant women have asthma.) Based on new evidence, the report will update an earlier report (1993).

Dr. Schatz highlighted some major findings, organized by drug category, based on data from the last 10 years:

- **Inhaled beta-agonists.** More reassuring data are available on short-acting beta-agonists; albuterol was the most-studied drug. Few data are available relative to long-acting beta-agonists used during pregnancy, but their inhaled delivery rate and efficacy support their use.
- **Inhaled steroids.** Data suggest these drugs' efficacy in preventing exacerbations of asthma during pregnancy. More reassuring safety data have been provided; extensive data for budesonide are available from the Swedish Medical Birth Registry.
- **Oral steroids.** Meta-analyses for four case-control studies suggest a fourfold increased risk of oral clefts with first trimester exposure to these drugs. There may be other increased risks, but there are questions about the indication and timing of the use of these drugs. For other possible increased risks (preeclampsia, preterm birth, and low birth weight), it is harder to differentiate between the risk from the steroids themselves and the risk from the severe asthma for which the steroids were used. The risks of severe uncontrolled asthma (maternal death, fetal death, or both) still outweigh the risks of using these drugs, but we now have the tools to prevent the need for oral steroids.
- **Other drugs.** Generally reassuring data are available for theophylline, and an additional study is reassuring for cromolyn. Minimal data are available from studies on leukotriene in humans. Animal studies are reassuring for some receptor antagonists (montelukast, zafirlukast) but not for zileuton.

Dr. Schatz reviewed the major changes in preferred medication treatments from the 1993 report and the current draft on approaches to step therapy.

- **Mild persistent asthma:** Use low-dose ICS (more data are available for budesonide).
- **Moderate persistent asthma:** Three options are: (1) medium dose ICS, (2) low-medium dose ICS + long-acting beta-agonists, and (3) low-medium dose ICS + theophylline (although continued discussion suggests that this treatment will probably be moved to “alternative” status).
- **Severe persistent asthma:** Use high-dose ICS and long-acting beta-agonists plus oral prednisone if needed.

The new draft differs in several ways from the earlier document. Some drugs will be singled out within a class (e.g., budesonide and albuterol) because of the availability of more gestational data. Medium-dose ICS or combination therapy will be considered co-equal choices for moderate-persistent asthma. Greater consideration is given to theophylline due to both its long-time use and reassuring data in humans.

Discussion

- Ms. Schmidt said that the NAEPP has a distribution plan for the report. It will be sent to the V.I.P. mailing list. Electronic notices will be sent to the coalitions and to medical professionals, including obstetrician-gynecologists. Member organizations could help to market the report. A concise executive summary of the report will provide a quick reference.
- Information on the systemic bioavailability of inhaled drugs was not part of the evidence review. A participant suggested that manufacturer information on this topic be included in a bioavailability table.

SURVEILLANCE UPDATE (Dr. Stephen Redd)

Dr. Redd provided an update on plans for national surveillance of asthma. He noted that some gaps identified a few years ago have been filled in. A long-term goal is to chart progress to know what else needs to be done.

Dr. Redd noted that prevalence of asthma has risen in the last 20 years and now possibly is stabilizing. Over the years, measures of burden have also increased, but these too have stabilized and even declined for some measures. A disparity in outcomes persists, as African Americans have much higher rates of mortality, hospitalization, and ED visits. Age-adjusted mortality data for 1979–2001 show that most asthma mortality occurs among older Americans, particularly those older than age 35 and those older than 65 in minority populations.

Dr. Redd mentioned several changes that may affect data collection. Between 1980 and 1996, a single question assessed current asthma prevalence; starting in 1997, two questions assessed lifetime prevalence and one on attack prevalence. The question for assessing current asthma was modified in 2001. Also, in 1999, the International Classification of Diseases (ICD)-9 began to be implemented—with a 90 percent concordance with ICD-10.

Healthy People 2010 included eight objectives related to asthma. One was to decrease mortality/hospitalization/ED visits by 50 percent. Another was to improve intermediate outcomes, such as education, management plans, and inhaler use (with an implied focus on patients with severe asthma). Dr. Redd noted that there is no target to reduce prevalence of asthma because there is no strategy to accomplish that. There are also no targets for less-severe outcomes, such as increased quality of life or decreased symptoms measured in the last 2 weeks.

The CDC has national data on prevalence, deaths, hospitalization, ED use, and outpatient visits—but these data are inadequate to plan or to evaluate State or local interventions. Except for mortality data, geographic specificity is lacking and a time lag occurs between when the

event happened and when it was reported. The CDC is in the process of implementing three initiatives to obtain State data: working with States to evaluate existing data; developing and implementing telephone surveys, such as the Behavioral Risk Factor and Surveillance System (BRFSS) and the National Asthma Survey (which is being field tested in five States); and developing new tools for tracking 2002 data. Information is available on the CDC Web site. Efforts have been made to decrease the interval between reporting and making the data available to the public.

The BRFSS led to an Asthma History Module; State-level data provide the opportunity to calculate a case fatality rate for asthma. The information makes it possible to examine not only prevalence but the severity and management of asthma. The National Asthma Survey uses the same sampling frame as the National Immunization Survey, includes all ages, and provides an opportunity to ask more questions about asthma. The challenge is achieving an adequate response rate.

The CDC has initiated several innovations in asthma surveillance: a combined surveillance and intervention project at the University of South Carolina, Michigan State University, and Northwestern University; work with California, Illinois, and Michigan to develop a system for reporting mortality and additional data on deaths due to asthma; and work with Miami-Dade County and Northwest Kaiser on a surveillance system for new-onset cases of asthma. The CDC has funded asthma programs designed to improve surveillance activities in 33 States plus the District of Columbia and Puerto Rico. CDC's asthma program includes: (1) a focus on schools in the Division of Adolescent and School Health, and (2) collaboration with the National Institute for Occupational Safety and Health (NIOSH) on work-related asthma.

Dr. Redd mentioned the following recent developments in asthma data and surveillance:

- The Health Resources and Services Administration is funding a State-level model of asthma prevalence in children for all States.
- New questions are being added to the National Longitudinal Survey of Youth.
- The National Health Interview Survey includes an asthma surveillance supplement with questions to answer HP 2010 objectives.
- The BRFSS 50 Cities Program will provide city-level data on prevalence of asthma.
- The AHRQ's Health Care Utilization Project (HCUP) has compiled data for some States on hospitalization related to asthma.

Dr. Redd said that these efforts will help in planning and evaluating the success of surveillance efforts, but a lot of work remains.

COMMUNITY INITIATIVES UPDATE (Ms. Linda Doctor)

Ms. Doctor gave a preview of a video clip—a RWJF national news story on asthma coalitions that will be distributed to local media outlets. The story will highlight what coalitions can do to

help control asthma and inform people where a coalition may be near them. Information is available on about 160 asthma coalitions to date—for example, those sponsored by the NAEPP, CDC, RWJF, California Endowment—but a number of local coalitions are funded by health departments, and others lack substantial resources.

Ms. Doctor reported that the public education campaign of Allies Against Asthma has a new Web site, Coalition Connections, which can be accessed from the homepage, www.alliesagainstasthma.net. Coalition Connections will allow people who see the RWJF news clip to locate and connect to local coalitions in their area by clicking on their States. Ms. Doctor demonstrated the Web site, noting that a Resource page will be added, including the Resource Bank—a collection of about 600 materials (educational and program tools) that people have submitted. The Web site also includes information on evaluation of the materials. A companion document on quality information is being developed. Ms. Doctor said that she would appreciate feedback on any of the resources.

MEMBER HIGHLIGHTS

Ms. Janice Nolan said that the ALA would like to develop a forum for discussion of national-level policy issues related to asthma. She asked members to contact her if they wish to participate; a consensus agenda is needed to advance plans for such a forum.

Mr. Bob Axelrad reported that the EPA has launched a new wave of its national Asthma Awareness Campaign, developed in conjunction with the Advertising Council. Begun about a year and a half ago, the campaign received \$100 million in donated media time in its first year. It was one of the top 10 public service announcements aired. Working with the Legacy Foundation and the Advertising Council, the EPA is developing a second campaign related to smoke-free homes. Other EPA activities are related to research and the EPA's program on outdoor air pollution. The EPA also funds many organizations to help with programs targeting communities, schools, day care facilities, and homes.

Dr. Yawn reported that the American Academy of Family Physicians (AAFP) is in the second year of a program on asthma. A pharmaceutical company funds the program. AAFP has established coalitions for adult asthma patients and will determine how to translate this effort to other local activities. The AAFP has also worked with several of the NAEPP asthma coalitions.

Mr. Mayrides thanked the CDC for the intervention that developed and validated the Wee Wheezers program. He reported that the AAFA is developing a public policy initiative on health disparities (especially in minority children). The first draft has been reviewed by some Coordinating Committee members. A second draft will be out early in 2004. Anyone who wishes to participate in the project is invited to contact AAFA.

ANNOUNCEMENTS AND ADJOURNMENT

Ms. Schmidt announced that the next meeting will be held September 20, 2004. She added that NHLBI is in the process of updating NAEPP's patient education publications, *Facts About Controlling Your Asthma* and *You Can Control Asthma*.

She thanked the members for their participation and adjourned the meeting.

APPENDICES

APPENDIX A

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM (NAEPP) COORDINATING COMMITTEE MEETING NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI)

Hyatt Regency
One Bethesda Metro Center
Bethesda, Maryland
December 8, 2003
8:30 a.m. to 1:00 p.m.
Agenda

8:00 a.m.	Registration and Coffee	
8:30	Welcome and Opening Remarks	Ms. Diana Schmidt
8:40	Involvement of the Asthma Team in Patient Education Pharmacists Take an Active Role	
	<ul style="list-style-type: none">• Institutional Settings• Community Settings• Discussion	Dr. Leslie Hendeles Dr. Dennis Williams Full group discussion
9:05	Current Patient Issues	
	<ul style="list-style-type: none">• Transition to Non-CFC Inhalers• ALA Petition• Discussion	Dr. Robert Meyer Ms. Fran DuMelle Full group discussion
9:30	Patient-Provider Partnerships	
	<ul style="list-style-type: none">• Can Better Communication Affect Patient Outcomes?• Patient-Provider Communication and Adherence to Asthma Therapy• Discussion	Dr. Michael Cabana Dr. Cynthia Rand Full group discussion
10:30	Break	
10:45	Community Approach to Patient Education	
	<ul style="list-style-type: none">• Asthma Ambassador Program Allies Against Asthma: Hampton Roads, Virginia• Discussion	Ms. Judith C. Taylor-Fishwick Full group discussion
11:00	Asthma Educator Certification	
	<ul style="list-style-type: none">• An Update• Discussion	Dr. Carlos Camargo Full group discussion
11:15	Subcommittee Reports	
	<ul style="list-style-type: none">• School Asthma Education• Discussion	Dr. Lani Wheeler Full group discussion

	<ul style="list-style-type: none">• Professional and Patient–Public Education• Discussion	Dr. William Storms Full group discussion
11:30 p.m.	Patient Education: What’s Next?	Full group discussion
11:45	Research Translation <ul style="list-style-type: none">• Update on Asthma and Pregnancy Report• Discussion	Michael Schatz Full group discussion
Noon	Surveillance Update	Dr. Stephen Redd
12:15	Community Initiatives Update <ul style="list-style-type: none">• Allies Against Asthma: Public Education Campaign	Ms. Linda Doctor
12:30	Member Highlights <ul style="list-style-type: none">• Roundtable	Full group discussion
12:50	Announcements	
1:00	Adjourn	

The next NAEPP Coordinating Committee meeting is scheduled for September 20, 2004.

APPENDIX B

**NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM (NAEPP)
NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI)
COORDINATING COMMITTEE**

**Participant List
December 8, 2003
Members Present**

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY
Kevin Nellis (for Denise Dougherty, Ph.D.)

ALLERGY AND ASTHMA NETWORK/MOTHERS OF ASTHMATICS, INC.
Christy Olson, M.S., R.N., AE-C (for Nancy Sander)

AMERICAN ACADEMY OF FAMILY PHYSICIANS
Barbara P. Yawn, M.D.

AMERICAN ACADEMY OF PEDIATRICS
Gary Rachelefsky, M.D.

AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS
Gabriel R. Ortiz, M.P.A.S., PA-C

AMERICAN COLLEGE OF ALLERGY, ASTHMA, AND IMMUNOLOGY
William Storms, M.D.

AMERICAN COLLEGE OF CHEST PHYSICIANS
John Mitchell, M.D., F.A.C.P.

AMERICAN LUNG ASSOCIATION
Janice Nolen (for Noreen M. Clark, Ph.D.)

AMERICAN MEDICAL ASSOCIATION
Paul V. Williams, M.D.

AMERICAN NURSES ASSOCIATION
Karen Huss, R.N., D.N.Sc.

AMERICAN PHARMACEUTICAL ASSOCIATION
Dennis M. Williams, Pharm.D.

AMERICAN PUBLIC HEALTH ASSOCIATION
Pamela J. Luna, Dr.P.H., M.Ed.

AMERICAN SCHOOL HEALTH ASSOCIATION
Lani S.M. Wheeler, M.D.

AMERICAN SOCIETY OF HEALTH-SYSTEM PHARMACISTS

Leslie Hendeles, Pharm.D.

AMERICAN THORACIC SOCIETY

Stephen C. Lazarus, M.D.

ASTHMA AND ALLERGY FOUNDATION OF AMERICA

Mo Mayrides (for Bill McLin)

COUNCIL ON STATE AND TERRITORIAL EPIDEMIOLOGISTS

Sarah Lyon-Callo, M.A., M.S.

NATIONAL ASSOCIATION OF SCHOOL NURSES

Linda Wolfe, R.N., M.Ed.

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION, CDC

Sarah Merkle, M.P.H.

NATIONAL CENTER FOR ENVIRONMENTAL HEALTH, CDC

Leslie P. Boss, Ph.D.

NATIONAL CENTER FOR HEALTH STATISTICS, CDC

Lara Akinbami, M.D.

SOCIETY FOR ACADEMIC EMERGENCY MEDICINE

Carlos A. Camargo, M.D., Dr.P.H.

SOCIETY FOR PUBLIC HEALTH EDUCATION

Judith Taylor-Fishwick, M.Sc. (for Estelle Bogdanoff, M.P.H., CHES)

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

David E. Jacobs, Ph.D.

U.S. ENVIRONMENTAL PROTECTION AGENCY

Bob Axelrad

U.S. FOOD AND DRUG ADMINISTRATION

Robert J. Meyer, M.D.

Members Absent

AMERICAN ACADEMY OF ALLERGY, ASTHMA, AND IMMUNOLOGY

Gail Shapiro, M.D.

AMERICAN ASSOCIATION FOR RESPIRATORY CARE

Thomas J. Kallstrom, F.A.A.R.C.

AMERICAN ASSOCIATION OF OCCUPATIONAL HEALTH NURSES

Pam Carter, R.N., C.O.H.N.S.

AMERICAN COLLEGE OF EMERGENCY PHYSICIANS

Richard M. Nowak, M.D., M.B.A., F.A.C.E.P.

AMERICAN COLLEGE OF PHYSICIANS

Scott A. Wolf, D.O., M.P.H., F.A.C.P.

ASSOCIATION OF STATE AND TERRITORIAL DIRECTORS OF HEALTH PROMOTION
AND PUBLIC HEALTH EDUCATION

Barbara L. Hager, M.P.H., C.H.E.S.

NATIONAL BLACK NURSES' ASSOCIATION

Susan B. Clark, R.N., M.N.

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES, NIH

Kenneth Adams, Ph.D.

NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH, CDC

Gregory R. Wagner, M.D.

NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES, NIH

J. Patrick Mastin, Ph.D.

NATIONAL MEDICAL ASSOCIATION

Michael Lenoir, M.D.

NHLBI AD HOC COMMITTEE ON MINORITY POPULATIONS

Ruth I. Quartey, M.A., R.R.T.

U.S. DEPARTMENT OF EDUCATION

Debra Little

Doris Sligh

National Heart, Lung, and Blood Institute

James Kiley, Ph.D.
Diana Schmidt, M.P.H.
Lenee Simon, M.P.H.
Ellen Sommer, M.B.A.

Guests

Ann Clark, J.D.
Rachel Flores, M.P.A.
Peter Gergen, M.D., M.P.H.
Rita Goodman, M.S., R.N.C.
Teri Kranefeld
Lee Petsonk, M.D.
Alisa Smith, Ph.D.
Robert Venezia, Dr.P.H.

National Aeronautics and Space Administration
American Lung Association
National Institute of Allergy and Infectious Diseases
Health Resources and Services Administration
American Lung Association
Centers for Disease Control and Prevention
U.S. Environmental Protection Agency
National Aeronautics and Space Administration

Invited Speakers

Michael Cabana, M.D.
Linda Doctor
Fran Du Melle
Cynthia Rand, Ph.D.
Judith Taylor-Fishwich
Michael Schatz, M.D., M.S.

Contract Support Staff

Judith Estrin, M.A.
Paula Murrain, M.P.H.
Teresa Wilson, M.P.H., R.N.

APPENDIX C

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM (NAEPP) NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI) SCHOOL ASTHMA EDUCATION SUBCOMMITTEE

Meeting Summary December 7, 2003

Present: Dr. Lani Wheeler (chair), Dr. Leslie Boss, Dr. Mary Brasler, Ms. Dana Carr, Ms. Sandra Fusco-Walker, Dr. Karen Huss, Dr. Pam Luna, Ms. Sarah Merkle, Ms. Katherine Pruitt, Dr. Gary Rachelefsky, Ms. Diana Schmidt, Dr. Alicia Smith, Dr. Paul Williams, Ms. Linda Wolfe. **NHLBI Staff:** Ms. Diana Schmidt. **Contract Support Staff:** Ms. Judith Estrin, Ms. Teresa Wilson.

INTRODUCTION (Ms. Diana Schmidt)

Ms. Schmidt welcomed the Subcommittee members and asked them to introduce themselves.

NAEPP UPDATES (Ms. Schmidt)

Ms. Schmidt noted that members should have received copies of *Managing Asthma: A Guide for Schools; Key Clinical Activities for Asthma Care*; and *Guidelines for the Diagnosis and Management of Asthma—Update on Selected Topics, 2002*. Member comments on *Update on Pediatric Asthma: Promoting Best Practice Guidelines* have been received, and the Science Base Subcommittee is reviewing the comments on medications. *The Report of the Working Group on Asthma During Pregnancy* is also being updated; members will receive copies for review after the Science Base Committee clears this document.

Ms. Schmidt said that the NAEPP will incorporate comments; those that cannot be incorporated will be discussed with the organizations that made the comments. If an organization feels that it cannot support the document if its comments are not included, it has the option not to put its name on the document.

Member organizations can request copies of the school guide from the NAEPP. The PDF file for the Guide is not yet on the NAEPP Web site, which is being redesigned.

Dr. Lani Wheeler said that several resources, including Tools for Schools, need to be updated in the Pediatric Guide. She asked members to suggest other resources and organizations that could be added.

OTHER PROPOSED ACTIVITIES

Proposed Special Issue of the *Journal of School Health* (Dr. Lani Wheeler)

Dr. Wheeler reported that the *Journal of School Health* is interested in publishing a report that reviews formal research on asthma as well as case studies (lessons learned) that usually do not get published. Subcommittee members will be asked to review the papers for consideration.

Ms. Schmidt said that NHLBI has been involved in several school research projects, some of which have been published—but improved dissemination of results to the field is needed. A new proposal is to establish a steering group to create an outline for a special journal issue or a journal supplement. An extension of this effort could be to develop a speaker panel that would present at conferences of national organizations that are vested in school asthma issues. The panel presentations would be modified to fit the specific needs of each organization. Committee members reacted positively to this proposal; one noting the advantage of a speaker panel where each participant could address his or her specialty, offering the latest findings in school-based research. To pursue this project would take considerable resources from the NAEPP, and given competing priorities, it may not be feasible.

Dr. Wheeler added that if funding is available, NHLBI and the CDC's Division of Adolescent and School Health (CDC DASH) could collaborate on the project. The goal is to implement the project in 2004.

WORK GROUP REPORTS (Dr. Wheeler)

Feedback on Action Plan for School Nurses

The group discussed the latest version of "Is the Asthma Action Plan Working: A Tool for School Nurse Assessment." Dr. Wheeler noted that this project started as a revision of the tool developed for social workers by the National Intercity Asthma Project. The National Association of School Nurses (NASN) was developing something similar and has taken the lead on refining the Action Plan. The latest version incorporates minor changes since the last version was sent for review.

The document is designed for school nurses to use to assess a child's current situation and to determine whether a referral to a physician is needed. The nurse would not do the assessment for every child with asthma—only those with indications that their asthma is not under control. The tool could be modified for use by parents, who would interact with the school nurse. It includes a place for the nurse's signature because she/he is the one doing the assessment (a doctor's signature is not required).

Subcommittee members suggested a series of changes and additions to the draft. They suggested including a description and examples to the definition of long-term control medications. It was noted that the intention is to indicate where the school nurse may need to give the medication, but the nurse may not be at the school all the time.

The NASN will be asked to revise the document, and the new version will be disseminated to the entire Subcommittee for approval. The approved version will be formatted with the NAEPP and NASN logos and be placed on the Web sites.

Self-Carry Guidance

Dr. Wheeler referred to the latest version of the Self-Carry Guidance. She noted that this document, which provides guidance about which children should self-carry medications, could be helpful in a training program to help new pediatricians decide whether self-carrying is appropriate. The new draft reflects changes suggested by the NASN, including two questions that emphasize a focus on the individual student and not on the policy of self-carrying. Among the changes is the addition of a bullet to ask whether the district has a policy that allows self-carrying. Dr. Wheeler sees a problem with the last change because this document would be used only in a community where there is such a policy. The policy issue is addressed in other documents (e.g., the Guide for Schools).

Another participant suggested that the wording of the bullets should be more positive—e.g., “All students who are able should be encouraged to self-carry an inhaler”—rather than listing the reasons they should not self-carry.

Dr. Wheeler noted that State nurse consultants suggested adding a bullet about the need for students to keep their medication in their possession at all times and not leave it where it is available to other students.

Suggestions for Asthma Services at School included adding, “Have medications been provided in an appropriate and timely manner by school staff?” and “How accessible is the medication at all school-sponsored events (including off-site activities)?”

Other issues raised were whether an extra inhaler, kept in the school office, should be mandated and whether emergency medical system (EMS) response time is relevant, because calling 911 might not help quickly enough with asthma attacks.

Dr. Wheeler thanked the members for their feedback and said that she would revise the document and send them the new version.

Stocking Inhalers in Schools

Dr. Wheeler reported that a Work Group was established to discuss the possibility of recommending that schools stock inhalers because students are not self-carrying reliably. One idea is to develop an issue paper that describes how this is working in some jurisdictions and how costs are covered. For example, Nebraska has put nebulizers and albuterol in every school and has trained people to use them; New Jersey has put nebulizers in all schools. This Work Group cannot be an NAEPP project because some members (e.g., the NASN) are against the policy of stocking inhalers. Ms. Linda Wolfe said that NASN’s policy on medications is that every order is individual for each child. A NASN taskforce is working on this issue.

The goal of NASN's flowchart is have children work closely with health care providers who would direct their care. Emergencies are different—the NASN is open to accepting a role for school nurses if regulations allow it. The flow chart will be disseminated to the Work Group members electronically.

It was noted that some families cannot afford inhalers, and some medications have relatively short expiration dates. Nurses in high schools favor the stocking policy because they want students covered but do not have room to keep 200 inhalers at school.

The NAEPP is working on a protocol that would include stocking inhalers, but it cannot move on this issue because of lack of consensus. *How Asthma-Friendly Is Your School?* recommends having a standard policy to use in the event a child has an asthma attack.

PARTNER UPDATES

American Lung Association (Ms. Katherine Pruitt)

Ms. Pruitt reported that the ALA released its Asthma-Friendly Schools Toolkit—a binder with recommended strategies and resources for a comprehensive approach to managing asthma in schools. This management is considered the responsibility of the community—not the schools. Topics in the Toolkit include school health services, recommended policies, environmental management, appropriate physical activity, and appropriate asthma education in schools. The resources are intended for nonschool entities, such as local lung associations and asthma coalitions, to help schools put the appropriate comprehensive management plan in place. The first printing of the Toolkit was sent to local lung associations and partners.

The Toolkit was developed in partnership with the American Academy of Pediatrics, NASN, and the National Education Association's Health Information Network. The materials will be in the public domain and will be available on the ALA Web site, presumably by January. CDC-DASH funding will establish eight pilot sites where local lung associations will work with asthma coalitions to conduct a 2-year study of the Toolkit use (processes and outcomes).

The ALA also has developed a database template—the Asthma Incidence Reporter (AIR) database—intended for use by schools to track students with asthma. The database will include information—with tracking over time—about how often students come to the nurse's office, use their inhalers, and make ER visits. The database can be used to generate standard reports. Several trainings for the use of the database have been held with local lung associations and their coalition partners, and it has been well-received.

The School Nurse Asthma Management Program (SNAMP) (Ms. Linda Wolfe)

Ms. Wolfe said that the NASN received a cooperative agreement from CDC-DASH in 2001 to develop SNAMP, a 1-day training program to educate school nurses about school-based asthma management of students in grades K–12. The goals of this program are to: (1) increase the number of asthma action plans developed and implemented for students who have asthma, (2) increase the extent to which asthma action plans include members of the coordinated school health program, (3) integrate asthma management throughout school activities, (4) increase

school nurses' collaboration with community organizations, and (5) increase school nurses' awareness of policies that affect asthma management.

In the first year, an advisory group provided direction about the content for the SNAMP training program and resource manual. The group also met after the first pilot study was completed. In years 2 and 3 of funding, a manual was developed, and four pilot sites were established in both urban and rural settings. The SNAMP program was presented at the NASNs national conference in Cincinnati in June 2003.

Training covers essential knowledge of asthma management; obtaining and implementing asthma action plans and nursing care plans for students with asthma; managing asthma triggers; suggestions for working with school faculty, staff, and the larger community; and planning for their specific school site implementation.

The manual has been submitted to the CDC for review. In spring 2004, a train-the-trainer program will be held. Additional funding is proposed for the following year to triple the number of nurse trainers.

Centers for Disease Control and Prevention (Ms. Sarah Merkle)

Ms. Merkle reported that the CDC sponsored two expert panels in the last year to focus on evaluation of school asthma programs and develop a logic model to suggest short-term and long-term outcomes. She distributed the draft Logic Model for Planning and Evaluating Local Education Agency Efforts To Help Schools Address Asthma. Ms. Merkle noted that long-term outcomes (e.g., improved academic performance of students with asthma) cannot be achieved by schools alone. She will also send the draft to members electronically.

American School Health Association (ASHA) (Dr. Wheeler)

Dr. Wheeler said that the American School Health Association (ASHA) will shortly issue a new journal, *Health in Action*, primarily designed for school staff. Although not designed to provide definitive information on managing asthma in schools, it offers another approach for people who want to learn more. The journal includes articles on many other topics such as mental health issues, physical activity, etc.

Allergy and Asthma Network/Mothers of Asthmatics, Inc. (Ms. Sandra Fusco-Walker)

Ms. Fusco-Walker said that Allergy and Asthma Network/Mothers of Asthmatics (AAN/MA) and the EPA are developing a program called Home School and Play. Eight volunteers have been trained by school nurses to work with school districts. Each of these volunteers will work with five families, providing in-home assessments, phone followup, and education. After 3 years, groups with 1, 2, and 3 years of training will be assessed.

AAN/MA presented its metered-dose inhaler (MDI) study at the American College of Chest Physicians conference in November 2003. A phone survey indicated that people often are using albuterol inhalers until nothing comes out. They do not know they should be counting doses, and 8 percent of those surveyed ended up calling 911 because the inhaler was actually empty. This

problem is being publicized so that health providers can educate patients about the need to count doses.

The AAN/MA is also working with States to change laws to protect students' rights to self-carry medications. Currently, 26 States do not have such laws in place. AAN/MA is lobbying to get HR-2023 passed. This law would provide future funding to States that have laws in place protecting students' rights to carry, as long as liability is covered. Ms. Wolfe added that the Delaware did not push for a law but changed the Department of Education regulation (which has the effect of a law) to allow students to carry inhalers and epinephrine pens.

Environmental Protection Agency (Dr. Alisa Smith)

Dr. Smith said that the EPA is working to strengthen the asthma component in the its Tools for Schools Kit and Resource Guide to reflect the programs that exist. The EPA also produced *Indoor Air Quality Tools for Schools Program: Benefits of Improving Air Quality in the School Environment*. The booklet, available as hard copy or on the EPA Web site, covers general issues about indoor air quality and student performance, mold, and asthma (including some references to the science of asthma).

Asthma and Allergy Foundation of America (Dr. Mary Brasler)

Dr. Brasler said that the AAFA continues to work, with EPA funding, to offer an education program for child care providers, including those who are Spanish-speaking. Under a CDC-DASH cooperative agreement, AAFA also continues to offer the Power Breathing program for teens. This program provides updates on the asthma guidelines for allied health professionals. AAFA also offers materials (a folder and handouts) for school staff, coaches, and physical education teachers. Many students say that exercise is a main trigger for asthma attacks.

FUTURE ACTIVITIES (Dr. Wheeler)

Dr. Wheeler asked the group to identify gaps—such as target audiences that need materials or different formats for materials. During the discussion, the need for an education model for physical activity teachers and coaches was raised. Ms. Pruitt said that a lung association in Wisconsin has developed a training module for this target audience and also provided an exercise component for *Health in Action*. The module is being disseminated nationwide. The NAEP might be able to incorporate the module with other materials, which could be packaged to reach students of physical education. The Dean of the School of Physical Education at the University of Maryland has expressed interest in this activity.

Dr. Wheeler noted an opportunity to establish a Work Group in this area. The following members volunteered to serve on the Work Group: Dr. Mary Brasler, Ms. Dana Carr, Dr. Pamela Luna, Ms. Sarah Merkle, Ms. Katherine Pruitt, Dr. Paul Williams, and Ms. Linda Wolfe.

Dr. Luna suggested another means to address the challenge of getting information out to parents and professionals—i.e., through newsletters. She suggested that short articles for these audiences could be shared among member organizations. Most organizations will allow their

articles to be excerpted if credit is given. Members can provide electronic versions of such pieces (along with permission to use them) to Ms. Schmidt, who could then send them to the entire membership. Members can check with their organizations' communication directors to see if they can share their articles.

ADJOURN

Dr. Wheeler asked for corrections to the membership list. Ms. Wolfe offered to provide a directory of school nurses. The next meeting will be held September 20, 2004.

Dr. Wheeler thanked the members for their participation and adjourned the meeting.

APPENDIX D

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM (NAEPP) NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI) PROFESSIONAL AND PATIENT/PUBLIC EDUCATION SUBCOMMITTEE

Meeting Summary December 7, 2003

Present: Dr. William Storms (cochair), Dr. Barbara Yawn (cochair), Dr. Leslie Boss, Dr. Mary Brasler, Ms. Andrea Greiling, Dr. Leslie Hendeles, Ms. Christy Houle, Mr. Tom Kallstrom, Dr. Stephen Lazarus, Ms. Sarah Lyon-Callo, Dr. John Mitchell, Mr. Kevin Nellis, Ms. Christy Olson, Mr. Gabriel Ortiz, Dr. Gary Rachelefsky, Dr. Stephen Redd, Ms. Judith Taylor-Fishwick, Dr. Dennis Williams, Dr. Seymour Williams. **Guest:** Dr. Robert Venezia. **NHLBI staff:** Ms. Diana Schmidt. **Contract support staff:** Ms. Paula Murrain, Ms. JoLane Thomas.

WELCOME AND INTRODUCTIONS

Dr. Storms and Dr. Yawn thanked participants for attending and asked them to introduce themselves to the rest of the group.

THE NATIONAL CONFERENCE ON ASTHMA 2003

Dr. Yawn reported that the National Conference on Asthma 2003, held in June, was quite successful. NAEPP received positive feedback, and several other meetings have resulted from the conference. One of the most important developments was that representatives of coalitions attended, not just physicians and nurses. Video presentations of all plenary sessions were Webcast (www.asthma2003.net). To access the meeting Webcast, enter the site, go to Live Webcast, and click on the link for videocast.nih.gov. Then click on *past events*, then on *conferences*, and select *Number 3*. Scroll down to National Conference on Asthma to click on *days 3, 2, and 1*. Material is still being added to the site. Eventually, it will be possible to do a search and go to each speaker. At this time, Dr. Yawn said, there are no plans to produce a hard-copy summary of the meeting. Smaller groups are planning to document some components, and some participants have scheduled followup meetings. All agree that it is necessary to plan the next meeting well in advance.

One participant commented that the target audience for this kind of meeting can and should be expanded in the future. Another participant raised a concern about the existence of enduring materials. A Web site is passive, the participant felt, and other materials should be available. It would also be useful to know who attended. A summary should be targeted to laypersons as well as to physicians. It was noted that pharmaceutical companies get materials out slowly, and Dr. Yawn stated that a comprehensive meeting summary would take a year or so to produce. A full report may be possible; certainly, NAEPP needs to improve ways of letting people know what happened. Dr. Yawn reiterated her concern about costs and the need to approach planning via the NIH Roadmap initiative. NHLBI should receive the recognition for this successful conference.

Members of coalitions came to the conference wearing their coalition hats, so to speak. One participant suggested an e-mail survey. Such a survey may not provide anything elaborate but can be used in a variety of ways. Debate followed concerning how often this conference should be held. Several people had worried about whether the meeting would work. Many of those who spent enormous amounts of time in planning the last conference are not willing to expend that intense level of work for another 3 years.

A participant commented that if planning doesn't begin in the near future, momentum could be lost, and opportunities could slip away. It is necessary to plan in 2005 for 2008 and to be vocal about this planning. Dr. Yawn noted that the National COPD Conference did attract the attention of politicians, and careful planning can generate similar interest for future conferences.

Decision

It should be recommended to the full NAEPP that another conference be conducted as soon as possible, because a conference fills a niche that other meetings do not fill. Dr. Storms added that if it were a good meeting, people would talk about it. Dr. Yawn will draft a recommendation and prepare a letter to the Acting Director of NHLBI. She would welcome persuasive suggestions from others.

KEY CLINICAL ACTIVITIES TO ACHIEVE QUALITY ASTHMA CARE: APPLICATION IN THE FIELD (Dr. Seymour Williams)

Dr. Williams reported that *Key Clinical Activities in Quality Asthma Care* has been published after careful and extensive review. The purpose of the document was to provide an opportunity to understand better quality care in various environments. It was published in March 2003 and audiences include the general public, practitioners, coalitions, benefits managers and third party payors.

A PDF file was sent to all public health programs. It is hoped that the document will be useful as a teaching tool for professional education. It is being used in a variety of settings and as an informational tool by other organizations (such as the Asthma Coalition) and initiatives. One process that exists because of contract specifications is called "the request for information." The report can be used to help various entities, such as States and employers, understand quality control.

One participant expressed his concern that the measurements were not adequately defined, so they are being set by insurance companies. These guidelines should come from NAEPP, not from insurance companies. "Close medical followup," for example, is being interpreted by some as 3 days and by others as 5 days because it is not defined in the book. These companies' requirements tend to be more rigorous.

Consumers should be driving this issue, said another participant. Collaboration with patients and consumers is essential to understanding the full effect of the information. One participant noted that this illustrates why translational research is so essential. Much discussion occurs about "bench to bedside"; now it is time to think about "bedside to community." Practitioners say this is not possible, but the major reason may be that they have not have been provided with a

package that is usable or practical. NAEPP may need to give the push. Translational work primarily may mean involving the patient, but some other translational pieces exist, too. Although primary clinical activities are a good start, the dilemma is how they can be turned into a research project that demonstrates how to make these materials usable to both practitioners and their patients.

AMERICAN ACADEMY OF ALLERGY, ASTHMA, AND IMMUNOLOGY (AAAAI) PATIENT EDUCATION HANDOUTS (Dr. Gary Rachelefsky)

One barrier is that asthma education is not easily obtainable and is not reimbursable, yet it is desperately needed. The Robert Wood Johnson Foundation (RWJF) has produced 8,000 user-friendly pamphlets, but they cannot be distributed because of cost. The pamphlet is targeted to professionals and those who care for asthma patients. It will eventually be available on the AAAAI Web site, www.aaaai.org. A participant noted how comprehensive these handouts were -- that one area not discussed in any educational materials except this one is how to prepare for sleepovers and campouts.

ALLIES AGAINST ASTHMA RESOURCE BANK (Ms. Christy Houle)

Ms. Houle noted that this project has been sponsored by RWJF. She explained that the Resource Bank (www.asthmaresourcebank.com) is, in effect, a clearinghouse for a variety of information, grouped into four basic categories:

- Asthma-related educational materials (422)*
- Asthma programming resources (138)
- Survey instruments (92)
- Coalition-related materials (41)

Several search methods may be used to locate materials: a general search, a fast search, a search by keyword, and an advanced search that allows the visitor to refine areas of specific interest (specific audience, language, literacy level, and ethnic background). Future plans for the site include incorporating tools to evaluate asthma education materials (both by content and by appeal) and mounting a database of asthma programs.

One participant asked who would staff this project. At the moment, a graduate student is the staff. Another participant noted a lack of videos on asthma for adults, although there are numerous videos for children. Are there common of requests for things that do not yet exist? Ms. Houle responded that there are many requests for environmentally related tools, but few exist. Videos are easy to make, as well as inexpensive, and pharmaceutical companies are often willing to provide the product. Assessment of the site and its resources is an interesting question. At present, visitors to the Web site can link to a feedback form.

* Figures in parentheses are items available as of November 2003.

THE AHRQ ULTIMATE TOOLKIT: HOW CAN WE MAKE IT USEFUL? (Ms. Diana Schmidt)

Ms. Schmidt and Dr. Dougherty developed a draft of the asthma patient education toolkit that is intended to maximize patient self-management skills and to promote comprehensive asthma care. A handout outlined five tiers of patient education and proposed tools for each of those tiers. If the NAEPP were to agree on a list of tools to include in each tier, then a next step could be to review currently available tools that fit each item on the list and select the best examples with which to stock the toolkit. A prerequisite to moving forward on this concept would be to have the various organizations and societies who would use the toolkit buy into the process from the very beginning. If developed, the contents of the resultant tiered toolkit would be posted on the NHLBI Web site and the sample tools would be downloadable.

Dr. Robert Venezia from NASA said that his organization has interest in developing asthma education tools for patients. One participant encouraged the members to develop a marketing plan and determine the audience before expending a great deal of time on this concept. Dissemination is critical; if the toolkit cannot be disseminated in such a way that various audiences will use it, then it should not be done. Participants encouraged the designers to include case studies and similar topics that illustrate how to implement a toolkit. An enormous amount of material on asthma is already available to patients via the Internet and other resources; it might be more useful to teach individuals how to access existing information

PREHOSPITAL MANAGEMENT OF ASTHMA IN TRANSPORT SITUATIONS (Ms. Andrea Greiling and Dr. Leslie Boss)

Ms. Greiling opened by noting that the number of Emergency Department (ED) visits for asthma in the United States in 2000 totaled 1.8 million; 465,000 people were hospitalized for asthma during the same year. Asthma is among the most common reasons people request ambulance transportation, and it is critical to understand what interventions occur during this ride. Because prehospital management of asthma is often less than adequate, standardization of prehospital asthma management protocols is needed. At present, the Emergency Medical Service (EMS) system has no formal structure, Federal oversight, or centralized funding. Instead, EMS programs are monitored on a State-by-State basis. Education requirements, standards of practice, ambulance vehicle specifications, and dispatching qualifications and procedures all differ among local jurisdictions.

A literature review turned up five population-based studies evaluating EMS asthma protocols in a geographical location, three case-controlled studies measuring the clinical effectiveness of various treatments, and five systems-level profiles of EMS models that specifically addressed asthma emergency management. Administration of treatment varied by the training level of the personnel, the EMS model used (two-tiered versus all Advanced Life Support [ALS]), geographical setting (urban versus rural), and local legislation and politics. The conclusions of the literature review (1) indicated that prehospital treatment of asthma varies within States and (2) supported the contention that standard protocols should be instituted.

The Asthma Guidelines state specifically “[t]he Expert Panel recommends that prehospital providers administer supplemental oxygen and inhaled short-acting bronchodilators to patients

who have signs or symptoms of asthma. ALS units should have available an inhaler plus spacer/holder chamber and/or nebulizer for beta-agonist administration.”

Four critical questions need to be addressed by an expert panel, which can then develop a best-practice, prehospital treatment algorithm for acute asthma and identify the appropriate mechanism for implementing the algorithm:

- Does an adequate prehospital treatment guideline exist that can be implemented nationally?
- Is it possible to design a treatment algorithm that can be recommended for use nationwide?
- How is treatment appropriately implemented within EMS systems?
- Does the Professional Education Subcommittee have a potential role in this activity?

Town meetings are planned in February and June 2004, after a working group has been designated. The Department of Transportation is providing considerable support for this effort and has launched its own initiative.

Participants discussed the importance of having an EMT trained to administer emergency treatment for acute asthma episodes. However, each State and county would have to approve this policy at its own level. Florida already has a statewide mandate.

The question of diagnosis also is a problem. Can an EMT diagnose symptoms correctly and not administer medications that might present some risk? For example, if a patient in coronary heart failure, with symptoms similar to an acute asthma attack, were administered albuterol, the results could be disastrous. With a specific document and appropriate training, the EMT could apply specific guidelines. It is important to train firefighters as well, and it is critical to address the needs of rural areas. Members of the subcommittee can work with various organizations to help them develop a document.

The Subcommittee recommended that NAEPP partner in this project in some way and develop a document that will address this issue.

THE ROLE OF NAEPP MEMBERS (Ms. Diana Schmidt)

To followup a discussion at a previous meeting, Ms. Schmidt reviewed the expectations of NAEPP in relation to the individual roles of its members. These expectations are to:

- Bring information from the organization you represent to the NAEPP. This information could include program priorities, agendas, research, news, and opportunities.
- Keep your organization informed about asthma issues discussed at the meeting; share the postmeeting information summary; encourage continued commitment to and support of asthma activities by your organization.

- Participate in discussions as an expert in your area. Join and attend meetings of one of the NAEPP subcommittees.
- Provide input into discussions of the subcommittees and the Coordinating Committee from the perspective of the organization and the constituency you represent.
- Collaborate and partner with member organizations in developing new asthma initiatives and in coordinating existing asthma activities.
- Take the lead or participate in project development work groups between meetings, as appropriate and feasible.

A critical part of this effort is taking uniform messages back to member organizations. Members are encouraged to add any other material that their organizations may consider appropriate.

MEMBER EXCHANGE

The CDC and Council of State and Territorial Epidemiologists (CSTE) have been holding conference calls regarding asthma surveillance using Medicaid. They are looking into the feasibility of using Medicaid as a data source and trying to determine what indicators might be appropriate. Jim Taylor has been facilitating these calls. There is no official timeline on when anything will be produced via this effort, but it wanted the Subcommittee to know it was underway.

Over the last 10 months, the Steps to a HealthierUS Initiative has been underway via the DHHS Secretary's office. This is a program that has targeted grave health conditions; its goal is to develop specific strategies for promoting ways to improve these conditions (such as exercise and proper nutrition). Asthma is part of this effort, although it is unclear exactly how it fits in. For FY2004, 15 grants have been funded. More information will be provided to the Subcommittee in the near future.

APPENDIX E

NATIONAL ASTHMA EDUCATION AND PREVENTION PROGRAM (NAEPP) NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI) FEDERAL LIAISON GROUP ON ASTHMA MEETING

Meeting Summary December 8, 2003

Present: Ms. Diana Schmidt (cochair), Dr. Lara Akinbami, Mr. Bob Axelrad, Dr. M. Beth Benedict, Dr. Leslie Boss, Dr. Ann Clarke, Dr. Peter Gergen, Ms. Rita Goodman, Ms. Carol Greene, Dr. Karen Huss, Dr. David Jacobs, Dr. Woodie Kessel, Dr. Hillel Koren, Ms. Susan Lyon Stone, Ms. Sarah Merkle, Dr. Robert Meyer, Ms. Nanette Pepper, Ms. Katherine Pruitt, Dr. Gary Rachelefsky, Dr. Stephen Redd, Dr. Alisa Smith. **Guests:** Dr. Ann Clark, Mr. Robert Venezia. **Contract Support Staff:** Ms. Teresa Wilson, Ms. Judith Estrin

WELCOME AND INTRODUCTIONS

Ms. Schmidt welcomed the Federal Liaison Group on Asthma (FLGA) members and guests and asked them to introduce themselves.

FLGA PROGRESS: STATUS REPORT

Ms. Schmidt noted that FLGA activities have been following the priorities established for FLGA's Report to Congress in 2001:

1. Gather, analyze, and disseminate asthma data;
2. Enable optimal functioning of children with asthma in school and child care settings;
3. Develop and evaluate community-based interventions;
4. Enhance guidelines implementation; and
5. Improve understanding of asthma prevention through research on the causes of asthma and its exacerbations.

The FLGA explores what individual Federal agencies are doing in these areas and identifies opportunities for collaboration. FLGA has spent time on all the issues listed above.

FOCUSED DISCUSSION: ASTHMA INTERVENTIONS (Dr. Leslie Boss)

Dr. Boss noted that, at the last meeting, the group discussed the status of ongoing asthma intervention research through October 2002. More than one-half the intervention research is funded through the National Institutes of Health (NIH); additional research is funded by other Federal agencies and outside groups. Apparently no attempt was made to identify and fill gaps in intervention research from a cross-agency viewpoint. The FLGA might be the group that could do this.

One goal is to increase the implementation of scientifically sound asthma interventions in diverse communities. To do this, we need to know what existing science-based interventions are available for implementation in community settings, what has been learned through asthma intervention research, what asthma research is currently in the pipeline, and what interventions are needed in communities. A searchable database now shows what research is being funded. To provide a framework for discussion, Dr. Boss asked how to accomplish the following:

- Identify the research gaps and agree on research priorities
- Direct scarce asthma intervention resources to identified gaps
- Utilize alternative research approaches in addition to controlled trials
- Update efficiently information on newly funded and completed intervention research
- Learn and act on research findings quickly but without affecting the ability to publish the information
- Provide even modest funding to help further evaluation and documentation of the best interventions appropriate for more widespread implementation
- Identify intervention approaches that should be packaged for widespread implementation
- Promote the use in communities of interventions that are already available and scientifically sound

Discussion

During the discussion, the following comments were made (grouped here by topic):

Community Issues

- At the community level, we expect an intervention with a targeted outcome to solve the problem, but other factors (e.g., access to care) can influence the outcome. A framework is needed to determine which piece of the puzzle addresses what.
- Each community might have the resources to address different aspects of asthma. Modifying an intervention might change the outcomes, so ongoing evaluation is required.
- We need community buy-in—getting physicians to participate. Will physicians do as well after the research is over?

Other Federal Efforts and Collaborations

- Multiple agencies and organizations are funding asthma research; in some cases, they may be independently doing the same types of things. These efforts need to be coordinated better.
- The CDC Division of Adolescent and School Health (CDC DASH) has funded intensive evaluation to tease out the aspects of an intervention that make a difference.
- The CDC sponsors conference calls to examine State-based data for asthma. The CDC and the Centers for Medicare and Medicaid Services (CMS) have held conference calls to interact with States on asthma analysis. This effort may lead to a training session.
- Head Start criteria dealing with asthma care in children have been distributed to Head Start programs nationwide. It might be useful to look at similar best practices in schools and at the environmental aspects that influence asthma.
- The EPA has dozens of asthma projects on indoor air quality; it requires that projects achieve results, but many results end up being anecdotal.
- The EPA Office of Research and Development has a focused asthma strategy. One project measures exposure to coarse and fine particles; this project leverages an NIH program.
- FLGA has not worked with the Task Force on Community Preventive Services (a non-Federal group of experts in public health convened by the Department of Health and Human Services [DHHS]) but has used its abstracting form. Asthma was too complex for the Task Force's model.
- The DHHS Steps to a HealthierUS Initiative (12 grantees and \$15 million) provides an opportunity to share research projects and technical assistance to succeed at implementation.

What We Need To Know

- Some States have higher asthma prevalence than others. What factors influence this difference?
- We need investigator feedback on what happened to interventions after the research was completed as well as what the researchers are doing now.
- What happens when people ask for a certain kind of information or intervention and it does not exist? For example, a need has been expressed for interventions addressing Native American and Chinese American populations. On the other hand, should research in urban schools be prohibited because so much research has been done in this area?

What Could the FLGA Do?

- Make sure that we get the information from research to the people who need it. We could have a greater effect by agreeing on gaps and figuring out how to fill them.
- Share the information from the NIH process already in place to identify research priorities. This could inform how Federal agencies decide which asthma research to fund.
- Explore the feasibility of going to the States for information on asthma education in schools.
- Update the inventory of projects that was developed for the FLGA Report to Congress 2 years ago; tell how much progress has been made. FLGA should be able to assess to what extent the research is overlapping or complementary, as well as areas for potential collaboration. The gaps should be obvious. Using Dr. Boss's framework, the group could analyze the inventory and make it not just a report to Congress but something to learn from. This would be a big undertaking.
- Conduct an analysis across research and results, and identify a Federal research agenda for asthma. Two Federal reports in 2000—the report of the President's Task Force on Environmental Health Risks and Safety Risks to Children, and the Action Against Asthma Report—put in place a research strategy. One problem is that so much activity is occurring but there is no one place to access all the information of what works for asthma.
- Conduct meta-analysis or a Cochrane review for similar projects in different settings. This would help identify the elements that work. A report on the findings would provide useful information. This type of project would require resources.
- Share the latest information on member agencies' projects.
- Maintain State contacts for sharing information and interventions at the local level.
- Share information for the next request for proposal (RFP) cycle when the Omnibus Bill is passed in 2004 and RFPs are available to fund asthma research.
- Determine what is a major focus. One suggestion was to concentrate on three domains: (1) disparities in outcomes by geography, race, age, etc., (2) variability in quality of care, and (3) what works in patient education.
- Develop a core Web site on (1) what works for asthma in terms of scientifically rigorous interventions and (2) what might work for asthma, according to anecdotal evidence. (Tools for Schools has provided both scientific and anecdotal evidence.) A clearinghouse for interventions could synthesize lessons learned about outcomes and point to sources of other information.

- Determine whether to meet between the four regular meetings—via electronic mail, conference calls, or committee meetings. Conference calls would allow sharing information on ongoing projects (the information would be kept confidential).

Ms. Schmidt noted that members have many ideas and will probably need to meet between regular meetings to make progress. A working group was formed to further examine the issues related to ways of better coordinating efforts relative to intervention research.

PROPOSAL TO COORDINATE WITH THE ASTHMA WORK GROUP

Mr. Bob Axelrad described the President's Task Force on Environmental Health Risks and Safety Risks to Children. Cabinet secretaries are members, and the Task Force is cochaired by the secretary of HHS and the administrator of the EPA. The Task Force, established in 1997, initially focused on several priority areas, including asthma. An Asthma Workgroup, cochaired by Mr. Axelrad and Dr. Stephen Redd, was charged with putting together an asthma strategy and an initiative focusing on environmental triggers and children. The Asthma Workgroup's Report, dated September 10, 2003, reports on asthma activities across the Federal government and is organized by the priority areas established in 2000. Under the Bush Administration, a Schools Work Group was formed; it focuses on developing an interagency inventory and strategy.

Mr. Axelrad and Dr. Redd suggested that, since the goals of the FLGA and the Task Force are the same and many of the same people are involved, the two groups might be combined to speak with one voice. This combination would offer the opportunity to present asthma issues to senior staff at the Department level, and it would also broaden input to the reports. The FLGA has greater breadth and is the appropriate body to coordinate the asthma effort.

Participants made the following comments:

- Would the meetings need to be longer to accommodate environmental subject matter?
- It makes sense to have the same people gather at the same time. But the FLGA has a bigger scope than the Task Force, and its focus should not be narrowed. Mr. Axelrad said there is no intention to limit the FLGA. It would provide an opportunity to report to the President's Task Force on all Federal activities on asthma.
- Ms. Schmidt said some administrative issues remain. The Task Force is at the cabinet level, while the FLGA is at the level of the NHLBI.
- Several members said they do not see a problem with the proposal, but would need to check with their respective agency about who would represent the agency at a combined FLGA/Task Force-Asthma Work Group meeting—a staff person or a political appointee.

Ms. Schmidt asked FLGA members to consider the implications of the proposal relative to their own agencies to discuss at the next meeting.

ADJOURN

Ms. Schmidt said that the next meeting will be held in April or May 2004. She thanked the participants and adjourned the meeting.