# Community Asthma Initiative: Year Five Program Narrative

#### Introduction

Children's Hospital Boston, with the support of the Healthy Tomorrows Partnerships for Children grant, continues to refine its model for increased access to asthma care, with very successful results to date. The program continues to target children and families from specific zip codes in Boston's poorest neighborhoods, and has expanded to serve Dorchester and neighboring communities due to the success of the program. These are children whose emergency department visits or hospitalizations related to asthma suggest that the family is experiencing barriers to good asthma control. The program staff continues to find that the burden of asthma is increased when families lack the knowledge needed to control asthma, are experiencing housing issues such as mold or pests that are exacerbating asthma, and can not obtain access to referrals to specialists. The program has had success using case management to ensure that families have the services they need to help their children control their asthma, home visiting to assess environmental barriers and provide one-on-one education, and community education to increase the capacity of school personnel, health care, child care, and other providers of services to support families in asthma management. Children's is proud of the accomplishments thus far and looks forward to continuing to develop the program, and to disseminating the findings of this project to other health care providers.

# 1. Summary of Overall Project Accomplishments

The program developed by Children's Hospital Boston has demonstrated success in reducing the impact and burden asthma has on the lives of children and their families. We are confident from analysis that these outcomes are consistent, in spite of changes in season, advent of the H1N1 epidemic, and will prove that coordinated case management, home visiting, and asthma

education are the keys to reducing the burden of asthma on families and on the health care system. With the support of the Healthy Tomorrows Partnerships for Children Program, CDC REACH US, the Ludcke and Thoracic Foundations, the Office of Child Advocacy and the Program for Patient Safety and Quality this program has shown significant positive impact.

The Children's Hospital Community Asthma Initiative (CAI) has developed a case management/home visiting and community education model for increasing asthma management and reducing asthma-related hospitalizations and emergency department (ED) visits. The program provides services to children 2-18 years old living in the Roxbury, Mission Hill, Jamaica Plain, Dorchester, and other neighboring low-income communities of Boston, which have some of the highest rates of asthma. We have data from the reporting period of March 2010 through February 2011 showing care to 170 new patients, with 140 new families receiving home visits, including 164 nurse visits, 22 outreach visits, and 72 combined outreach and nurse visits. There were also 164 community meetings with over 1,800 participants, 6 large community events with over 600 participants, and 77 trainings/talks with over 1,900 participants.

Cumulatively through March 31, 2011, we have served 713 children with 340 six-month follow-ups, and 259 twelve-month follow-ups. Initial six-month and twelve-month follow-up data shows that for the children served, there were significantly reduced ED visits and hospital stays, fewer missed school days, and more children had Asthma Action Plans to guide their families, teachers, and primary care providers in their asthma care (all p< 0.001).

Components of the program which have contributed to its success include:

• case management and home visiting by nurses and Community Health Workers (CHWs) through a collaboration with Boston Asthma Initiative to provide education and home assessment by linguistically and culturally competent health educators;

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• Integrated Pest Management services which help families reduce pest infestations without

further exacerbating asthma or creating a toxic environment;

distribution of HomeSafe kits from the Boston Public Health Commission which contain

cleaning products and supplies which are designed to reduce triggers;

• an extensive community education program including recreational opportunities for

children with asthma;

• an active Family Advisory Board which guides the program staff; and

• advocacy through the introduction of legislation designed to improve care for families

coping with asthma.

2. Barriers to Progress and Strategies taken to Overcome Them

One of the barriers to progress continues to be the difficultly connecting to families for

follow-up, especially the 12-month questionnaire. Because cell phone numbers often change or

numbers are disconnected, it can be hard to reach families. In order to overcome this barrier,

CAI sends letters to families reminding them of the 6 or 12-month follow-ups. Also, there are

families that are resistant to initial outreach and/or deny the services offered by the program. In

order to overcome this barrier, the clinical director or nurse case manager calls the families 3-5

times, and if there is no response she sends letters in both English and Spanish. The clinical

director and nurse case manager watch the inpatient and emergency room computer logs and try

to meet families in person the next time they are seen, if they have not connected with the

program. They have also connected to patients while they are being seen in one of the primary

care or subspecialty clinics, or through their providers.

Children's Hospital Boston Healthy Tomorrows Partnership for Children

### 3. Progress on Specific Goals and Objectives

CAI was developed out of a need for better services for a growing number of children with asthma in some of Boston's poorest neighborhoods. Asthma is the leading cause of hospitalization at Children's Hospital Boston, and 70% of children hospitalized for asthma come from specific neighborhoods in the city with high numbers of families living in poverty.

Goal 1: Provide a comprehensive asthma program in Roxbury, Mission Hill, Jamaica Plain, and now Dorchester and other neighboring communities that improves access to and quality of asthma services for children, promotes healthy home environments, and improves asthma knowledge among children living with asthma, their families, and communities, and which is a model with potential for widespread replication.

Goal 1 Accomplishments: CAI has developed a comprehensive asthma program, which includes case management, home visiting, community education, and community partnerships. From October 2005 to September 2010, Children's had a partnership with the Boston Asthma Initiative (BAI), which is now under a larger community agency called ESAC (Ensuring Sustainability through Action in the Community) to provide home visiting services. However, since about 52% of the patients served by CAI have their primary care providers here at Children's, the program initiated Phase 3 of the project with a greater focus on the Children's medical home through monthly case coordination meetings with CHPCC and closer connection to Children's primary care providers. With the change in model, a broad search for a Community Health Worker (CHW) to work even more closely with Susan Sommer, MSN, RNC, AE-C and Massiel Ortiz, BSN, RN at Children's was initiated in September 2010. In November 2010, we hired Margarita Lorenzi, BS to be our new in house Asthma Educator/Home Visitor. ESAC/BAI continues to be a member of our broader asthma coalition.

The data we have gathered since the inception of the program points to the effectiveness of this model in reducing the burden of asthma by facilitating better asthma control. Of the 713 patients enrolled to date, we have collected six month follow-up data on 340 patients. Of these, there was a 53% reduction in ED visits following the intervention and home visiting program, a 75% reduction in hospitalizations, and a 36% reduction in limitations on physical activity. This represents a substantial accomplishment and has significantly improved the quality of life and health of these children. In addition, we see economic impact through a 39% reduction in missed school days due to asthma, and 56% reduction in missed work for parents. There was a 58% increase in the number of children having Asthma Action Plans outlining their care and management of their asthma.

We collected follow-up data on 259 families at the 12 month mark following enrollment in the program. At one year, 64% reported reduced ED visits, 79% reported reduced hospitalizations, and 32% reported reduction in limitation on physical activity. In addition, 41% reported a reduction in missed school days, and a 46% reduction in missed work time for parents was reported. These reductions have lead to a Social Return on Investment calculation of 1.46 for hospital costs and 1.73 including Quality of Life calculations over two years (benefits/program cost). In addition, there was a 56% increase in the number of children having Asthma Action Plans outlining their care and management of their asthma.

Objective	Time Frame
1.a. Approximately 100 children and families will receive	March 1, 2006-April 30, 2011
coordinated asthma services each year, and will have decreased	
asthma related admission to the hospital, and decreased	
emergency department visits. Total served: 500.	

For the 12 month reporting period of March 1, 2010 – February 28, 2011, 170 families have received case management. We were able to exceed the expected 100 families for the reporting period.

Cumulatively, as of March 31, 2011, we have provided case management services to 713 patients. Of these, 54.8% were boys, and the average age was 7.4 years with a standard deviation of 4.5 years. Of these, 549 families (77.0%) received one or more home visits. Including baseline and follow-up visits, there were a total of 142 combined outreach and nurse home visits, 230 home visits performed by an outreach worker alone, 531 nurse home visits, and 59 Integrated Pest Management visits. The cost of asthma care has been calculated for families with self-pay or co-pays were an average of \$48.75 per month for the index child. Many of these families have several members the asthma needing medications. The population served was 45.6% black, 46.8% Hispanic and 7.5% other. 70.9% of the patients use state Medicaid, called MassHealth; 65.3% had household incomes of considerably less than \$25,000/year; 25.5% preferred to speak Spanish and 1.4% African languages.

Objective	Time Frame
1.b. 50 families per year will receive home visits, including home	March 1, 2006-April 30, 2011
assessments, reduction of asthma triggers, and asthma education,	
from an existing home visiting program, the Boston Asthma	
Initiative, through increasing the program's capacity.	
Total served: 250	

In the twelve months between March 1, 2010 and February 28, 2011, 140 new families received home visits; 22 outreach home visits, 164 nursing home visits, and 72 combined outreach and nurse home visits. Based on this data and the cumulative numbers to date we have exceeded this objective for the grant year.

Objective	Time Frame
1.c. Based on 100 families per year receiving services, primary	March 1, 2006-April 30, 2011
care providers, schools, and community based services will	

coordinate services with the program, increasing communication	
and improving the continuity of care and asthma management	
planning. Total served: 500	

In this one year reporting period, through the case management program, all 170 families benefited from increased communication with primary care providers, schools and/or community resources resulting in improved continuity of care and asthma management planning.

**Goal 2:** Make communities more asthma-friendly by increasing the capacity of health care providers, schools, and community organizations to provide appropriate education and physical activity programs to children.

Objective	Time Frame
2.a. 50 community-based program staff and families will participate	March 1, 2006-April 30, 2011
in educational workshops about asthma each year in community	
settings, including opportunities offered on site in school settings.	
Total served: 250	
2.b. 50 children will participate each year in Asthma Health Project	March 1, 2006-April 30, 2011
programs (Boston Asthma Games, Boston Asthma Swim, Boston	
Asthma Camp). Total served: 250	
2.c. 30 health care providers will participate in workshops to learn	March 1, 2006-April 30, 2011
culturally competent asthma management to enhance the care of	_
children and families from various backgrounds. Total served: 150	

**Goal 2 Accomplishments:** The Community Asthma Education program provided education on asthma in a variety of venues. The Community Asthma Program Manager presented the "Asthma Basics" curriculum to child care providers, school staff, and parent groups.

**Objective 2.a**.: From March 1, 2010 to February 28, 2011, we provided 77 trainings/talks to over 1,900 participants, participated in 164 community meetings with over 1,800 participants, and participated in 6 large community events with over 600 participants. Trainings, meetings and events provide visibility for the asthma program, and are important in developing partnerships with community agencies and exceed the goals for the year.

Objective 2.b.: Asthma swim programs begin in September with many continuing throughout the year. In the past year, 30 children were enrolled in the Asthma Swim Programs. To date, about 235 children have been enrolled in the swim program. To date, the annual Boston Asthma Games have had approximately 450 participants; however, the Boston Asthma Games were discontinued this year in 2010. The Asthma day camp was discontinued in 2008 and was replaced by the Boston Asthma Summer Program. In 2010, a new Asthma Soccer Program replaced the Summer Program. The program ran for 8 weeks at the Dorchester YMCA in the summer and paired asthma education with soccer lessons with a YMCA instructor. Seven children were enrolled in the program during this first session. In addition, a new Asthma Swim program is being initiated in Dorchester and will likely begin this fall.

**Objective 2.c.**: 300 health care providers participated in 10 workshops in which Elizabeth Klements, MS, PNP-BC, AE-C taught culturally competent asthma management to enhance the care of children and families from various backgrounds, which exceeded the goal for the year.

Goal 3: Reduce disparities in childhood asthma outcomes, raise public awareness, and advocate for public policy changes to ensure that children and families have access to the educational and medical resources they need to optimally manage asthma.

Objective	Time Frame
3.a. Develop 20 new community partnerships to increase	March 1, 2006-April 30, 2008
understanding and reduce health care disparities in childhood	
asthma. Total reached: 20	
3.b. Increase individual advocacy, assisting 20 families each year	March 1, 2006-April 30, 2011
to advocate for their child's needs with landlords, health insurance	_
providers, and pharmacies. Total served: 100	

**Goal 3 Accomplishments**: The hospital engaged in new community partnerships and continues to seek ways to partner with community-based organizations to improve asthma care and access to primary care providers and specialists.

Objective 3.a.: Three new relationships were formed and some existing partnerships continued to develop this year that led to many important new connections for CAI, which met the goal for this objective. The Community Asthma Programs Manager has developed a new training relationship with the University of Massachusetts Boston Nursing Program to provide specific asthma related training to their nursing students. We continued to expand our trainings to new Head Start sites throughout the state including a new relationship with the Worcester Community Action Council Head Start Program. In addition, a new relationship is being developed with Bay Cove Human Services Intervention Project in Dorchester. The Community Asthma Programs Manager will be conducting trainings with them this spring.

In February 2008, the Boston Public Health Commission created a working group comprised of the different agencies in the city that are currently performing asthma-related home visits with the goals of: 1) identifying best practices for asthma home visits, 2) standardizing these visits across agencies, 3) identifying common data that should be collected across agencies to go into a shared registry, 4) beginning to look at a central referral mechanism, based on such factors as geography, linguistic capabilities, etc., 5) collectively strategizing and engaging the principal insurers to reimburse for these services. This group included our current partners Boston Medical Center and ESAC, as well as new partners Tufts Medical Center and the Partners Asthma Program. This group continues to convene every two weeks to carry on this facilitated process. The first pilot was completed and is being evaluated. The second pilot will consist of 150 families and will initiate the use of net books for data collection. Several members of the Children's Hospital Boston Community Asthma Initiative have participated in these meetings, including Susan Sommer, MSN, RNC, AE-C, Elizabeth R. Woods, MD, MPH, Massiel Ortiz, RN, BSN, Shari Nethersole, MD of the Office of Child Advocacy and Margarita Lorenzi, BS.

**Objective 3.b**.: In the March 1, 2010 – February 28, 2011 reporting period, 32 families have had extensive advocacy assistance with landlords, health insurance providers and pharmacies. The program has had no problem exceeding the expected 20 families receiving extensive advocacy assistance in this year of the program.

In addition to individual advocacy, the program has used the findings of this project to enhance advocacy on a policy level. In collaboration with the Asthma Regional Council, a business case for insurance companies to invest in asthma education and environmental interventions has also been developed, as well as an insurance benefits guides for providers. Using this business case, and working with the Boston Healthy Homes and Schools Coalition (formerly Boston Urban Asthma Coalition), legislation was submitted to improve insurance coverage of asthma care. This legislation allowed the coalition to identify legislative champions, including Representative Jeffrey Sanchez, House Chairman of the Joint Committee on Public Health. Sánchez subsequently secured the inclusion of an expanded pilot program within MassHealth as part of the 2011 state budget to provide high risk pediatric asthma patients enhanced coordinated care though a bundled-payment system. The team is also working on the issue of access and affordability of asthma medications. The goal is to get at least one rescue inhaler and one or more inhaled corticosteroids on the lowest tier of insurers' drug formularies. This policy change is under consideration by one private payer and we hope also to approach other payers as well.

CAI has been an active member of the Massachusetts Asthma Action Partnership (MAAP).

Over the past year, MAAP has been working in partnership with the Massachusetts Department of Public Health to develop a five year state asthma plan to serve as a roadmap for the state and

its partners to cohesively address the burden of asthma on multiple fronts. The program continues to work both individual advocacy as well as creating more systemic change.

Examples of Program Successes: The following is a case scenario that demonstrates the Community Asthma Initiative's (CAI's) program success. Jane is an 8-year-old girl with severe persistent asthma, who was enrolled in CAI during her admission to the Children's Hospital Boston's ICU. In the two years prior to this admission, Jane had four admissions due to asthma and six additional emergency department (ED) visits. In the six months prior to admission, she also missed 10 days of school due to asthma and, as a result, her mother missed 14 days of work from her part-time job.

Her mother reported that the prior school year Jane had missed more than 56 days of school. Jane has tested positive for many environmental allergies, including mouse, dog, cockroach, cat, dust mites, house dust, tree and ragweed pollen, which also were asthma triggers.

Upon discharge, Jane's mom attempted to fill one of the new asthma medications Jane was prescribed, but learned that it required prior authorization from the insurance company. The CAI nurse case manager was able to assist Jane's mom in obtaining the insurance authorization and informed her when the medicine was approved. The case manager also completed a home tutor request form so Jane could begin to receive after-school tutoring due to her frequent absences.

A home visit—which included asthma education, a review of all of Jane's asthma medications and their proper use, and a home environmental assessment to identify asthma triggers—was conducted by the nurse case manager. The family had recently moved to a pest-free apartment from a mouse-infested building. The nurse provided suggestions to reduce asthma triggers further, as well as supplies which included a HEPA vacuum cleaner and dust mite-proof pillow and mattress encasement for Jane's bed.

Soon after, Jane's mother called, saying that she had to leave her apartment and move into a shelter. The nurse ensured that Jane could continue to receive her asthma care, transferred her prescriptions to a closer pharmacy, and coordinated follow-up appointments in primary care and pulmonary.

After 12 months, Jane had three additional ED visits for mild asthma exacerbations, but no additional hospitalizations. She missed only three school days in the year, and her mother had only missed one work day due to Jane's asthma. The family is now living in a temporary apartment which is also asthma-friendly.

## 4. Staffing

Elizabeth R. Woods, MD, MPH is the Program Director, Community Asthma Program (40% effort overall, and in kind as needed for Healthy Tomorrows), as well as the Chair of the hospital's Asthma Quality Committee, and has developed and evaluated several community-based programs. She is the Associate Chief, Director of Quality Improvement for the Division of Adolescent/Young Adult Medicine, Director of Quality Improvement and Evaluation for the Leadership Training in Adolescent Health Project, the Evaluator for the Young Parents' Program, CHB, and a Professor of Pediatrics at Harvard Medical School. She oversees all aspects of the program including program development, supervision of staff and evaluation.

The program is currently staffed by a full time (100% effort, 25% supported by Healthy Tomorrows) Nurse Case Manager and now the Clinical Director for the program. Susan Sommer, MSN, RNC, AE-C is a licensed Nurse Practitioner and Certified Asthma Educator and is providing comprehensive case management services. She is fluent in Spanish and in addition to providing supervision to clinical staff also performs home visits. In addition, the program hired another full time nurse case manager in 2009 (100% effort, as needed in kind for Healthy

Tomorrows). Massiel Ortiz, RN, BSN is a Registered Nurse who is bilingual in Spanish and English, and also provides comprehensive case management services and conducts home visits. The Boston Asthma Initiative, a community based program of the ESAC non-profit organization, provided home visiting services for the program until September 2010 (100% effort, in kind for Healthy Tomorrows). In November 2010, we hired Margarita Lorenzi, BS to be our new inhouse Spanish speaking bilingual/bicultural Asthma Educator and Home Visitor (100% effort, in kind for Healthy Tomorrows).

Community education is provided by Amy Burack, RN, MA, AE-C, the Community Asthma Program Manager (100% effort, and in kind for Healthy Tomorrows). Administrative support is provided by a (60% effort overall, in kind for Healthy Tomorrows) Research and Program Coordinator, Elaine Chan, BA. Urmi Bhaumik, MBBS, MS, DSc., is the Community Health Evaluation Manager and is assisting with data collection and evaluation design (10% effort, in kind for Healthy Tomorrows).

Other staff indirectly involved in the project includes Shari Nethersole, MD, who is the Medical Director for Community Health, CHB, and Assistant Professor of Pediatrics, Harvard Medical School. She oversees the development of community programs and focuses on reducing health disparities. She ensures that the program is community focused, culturally competent, coordinated with the community health centers, and focuses on the reduction of health disparities. Elizabeth Klements, MS, PNP-BC, AE-C is the hospital's Asthma Clinical Nurse Specialist who provides oversight for the community education component of the program. Deborah Dickerson, BA, is the Director of Community Health Initiatives for the Office of Child Advocacy and works closely with CAI to plan, manage and support the program. Lisa Mannix, BA, was the Manager for State Government Relations at Children's Hospital Boston and she

works closely with MAAP, BHPC, MDPH and representatives to advocate for legislative and policy change based on the CAI findings. Lisa left Children's in October 2010, but the Manager for City Government Relations, Victor Shopov took her place as part of the team shortly thereafter.

#### 5. Technical Assistance Needs:

No technical assistance is needed. We are happy to collaborate with Healthy Tomorrows programs, AAP and MCHB staff around national and regional asthma and evaluation efforts.

# 6. Linkages Established with Other Programs

Although the program ended its contract with ESAC/BAI in September 2010, they continue to be active partners in the asthma coalition. As stated above, ESAC has an extensive history of work in the Boston community, particularly around housing issues. BAI program provides home visiting services and is an active partner in community and school educational services.

The program has an ongoing partnership with the Boston Public Health Commission (BPHC). BPHC is the program's partner in the Boston Asthma Swim, Games, and Summer Programs. BPHC is the recipient of multiple federal grants including grants from the Environmental Protection Agency for improving indoor air quality. BPHC has several asthma related programs including Asthma Prevention and Control, which systematically examines asthma and its environmental factors, and also works with families to correct problems within the home through the Healthy Homes program. CAI and BPHC meet regularly to assess how to support one another's work.

In legislative advocacy CAI worked with the Boston Urban Asthma Coalition to file HB 2236/SB 1214, An Act to Improve Asthma Management. In working with insurance payers, CAI worked with Asthma Regional Council to develop a business case for asthma care, co-sponsored

a forum for providers and payers, surveyed insurers to document current asthma benefits, and gathered data advocating with payers regarding high co-pays for asthma medications. CAI is also working with the Boston Home Visiting Collaborative to develop a consistent guideline and evaluation for asthma home visits. On October 16, 2010, working with the Family Advisory Board and the Community Coalition, CAI planned and provided a second extremely well received Community Asthma Forum at the Reggie Lewis Center in Roxbury with over 85 adults in attendance. The theme for this forum was: "Healthy Students are Better Learners: Asthma in the Schools and Preschools." Representatives from Boston Public Schools, ABCD Head Start other community organizations and a parent came to talk about asthma policies at schools, school environmental committees, and the importance of getting and staying involved with your child's asthma care at school. Most importantly, we heard directly from the adolescents and young people their experiences with dealing with asthma at school through a video that was played at the beginning of the forum.

#### 7. Project Plan

The program will continue to focus on case management, home visiting, and community education, building on its successes from the previous five years. Based on needs expressed by the Family Advisory Board and the home visiting staff, we will continue to refine the program to ensure that it is meeting the needs of families. Specific activities for the upcoming year include:

• Continued expansion of services: The Nurse Case Manager and Home Visitor will continue to receive regularly lists of candidates for the program and will make every effort to provide services to any qualified family that wish to receive them. The program will explore expansion into new low-income neighborhoods when possible, and based on results showing positive impact and obtaining expanded funding.

The case manager contacts each participating child's primary care provider and works together to assess what the child and family needs to manage the child's asthma. Depending on the needs of the family children will either be referred to or provided with the necessary services, tailored to meet their individual needs. Interventions will be tailored to the individual's needs to ensure that each family has an intervention that will work with their particular circumstances, culture, language, home environment, etc. Services to be provided will include:

- referrals to Children's Hospital Boston allergists and/or other specialists for expert evaluations and care as needed;
- o referral to existing asthma management programs and services available to the family through their own primary care provider, health insurance company, or other;
- one-on-one or group education sessions with a nurse to discuss proper use of medications and devices;
- o vaccination against the influenza (which can exacerbate asthma);
- o an individualized Asthma Action Plan to be shared with the family, school nurse, and primary care provider;
- o home visit and environmental assessment to identify and reduce asthma triggers at home;
- o advocacy assistance with landlords or housing authorities and others;
- o assistance with enrollment in health insurance, if needed; and
- a resource guide to educational, support, and physical activity programs in the family's
   neighborhood has been developed and will be updated yearly.

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Patients will also receive follow up to: review asthma management techniques and

answer questions; assess adherence to the Asthma Action Plan and identify progress on

overcoming barriers; assess new barriers; and referral to other services if needed.

• Housing issues: The program will continue to work with Integrated Pest Management

specialists to ensure that families who are coping with pest allergens in their homes have

access to remediation. While some families will need the services of an expert, for most

training by the home visitor in effective, non-toxic, and low cost solutions will be sufficient.

For a more sustainable change, the staff will work with specific housing developments to

look at ways to make changes that will impact entire buildings or developments, rather than

individual units.

Collaborations: The program will work on developing new community partnerships to build

community capacity and ensure that the community shares a "common language" of asthma

care and control. The program is currently seeking opportunities to increase access to

physical activity for children with asthma. For children in Boston's urban core, physical

activity is problematic; a recent increase in community violence has left many parents

concerned that allowing their children to play outside is unsafe, and indoor, organized

recreational activities may be cost prohibitive. Obesity and overweight, with their concurrent

health problems, are on the increase and may contribute to increased asthma symptoms. In

addition, members of the Family Advisory Board stressed that not all programs, such as

school coaches and the YMCA's or recreation centers, have staff that are aware of and

educated about asthma. We have collaborated with Greater Boston YMCAs to train staff and

to provide physical activity opportunities for children with asthma.

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 Policy Changes: CAI will continue to work with partners on legislative advocacy and systems change as well as efforts to make the program sustainable over time, improve asthma care and ensure affordable medications.

### 8. Advisory Board

CAI continues to receive input from the Children's Hospital Office of Child Advocacy

Community Advisory Board. This Board is made up of representatives from community-based
organizations and community health centers. This Advisory Board provides feedback and
guidance to all of the hospital's community health programs, including asthma. Meeting minutes
for all meetings held between March 1, 2010 and February 28, 2011 are attached (Attachment 1);
while these particular meetings did not include extensive discussion of the asthma program this
year, it has been the focus of prior Community Advisory Board meetings as the program was
being developed.

The Family Advisory Board continues to thrive. Meetings were held in March, June, September and November 2010. A range of 6-13 parents have attended each meeting and are provided food, child care, parking vouchers and given a Stop and Shop gift card as reimbursement for their time. Parents continue offer useful recommendations to the program, including improvement to educational offerings, the need for support in the Boston Public Schools, and the need for better access to medical care.

Parents were passionate about holding a second community asthma forum focusing on asthma in the school environment in which community members could come together to learn about asthma policies, school environmental committees as well as to learn ways in which they can get involved.

# 9. Sustainability Efforts

In 2007, CAI received a significant grant, \$400,000 per year for five years including indirect costs, from the Centers for Disease Control REACH US project on racial and ethnic disparities. This work will complement the work of the Healthy Tomorrows Partnerships for Children grant. The Children's Hospital Trust, which oversees all fund raising and development for the hospital, is seeking additional funding support and the Office of Child Advocacy is committed to provide the needed funds. Based on the success of the program as indicated by the data we believe that we will be successful in obtaining additional non-federal funds each year.

In addition to fund raising efforts, CAI has been working with the Office of Child Advocacy to provide evidence about the impact of case management and home visiting on health care costs. Showing the cost-effectiveness of this type of model, particularly if it reduces costly ED visits and hospitalizations, has helped us to make a case to third party payers that these should be reimbursable services. Children's Hospital worked in partnership with the Asthma Regional Council and Boston Healthy Home and Schools Collaborative, a consumer advocacy group, to develop state legislation to increase support for asthma care, home visits and education. This legislation allowed the coalition to identify legislative champions, including Representative Jeffrey Sanchez, House Chairman of the Joint Committee on Public Health. Sánchez subsequently secured the inclusion of an expanded pilot program within MassHealth as part of the 2011 state budget to provide high risk pediatric asthma patients enhanced coordinated care

though a bundled-payment service. Drs. Woods and Nethersole will serve on the Pediatric Asthma Bundled Payment Plan Advisory Committee starting in May, 2011.

#### 10. Publications/Products

CAI continues to work to disseminate information and findings of the program (see Attachment 2). In April 2010, Dr. Woods presented on "Children's Hospital Boston Community Asthma Initiative: One Year Follow Up, Adolescent Findings and Two Year Cost Analysis" at the Society for Adolescent Health and Medicine Annual Meeting which took place in Toronto, Canada. In May 2010, Dr. Woods presented "Quality Improvement Evaluation of Community Asthma Initiative: One Year Follow-Up and Two Year Cost Analysis" at the Pediatric Academic Societies' Annual Meeting in Vancouver, Canada. Then in October 2010, CAI presented "Community Asthma Initiative: An Innovative Community Based Intervention Leading to Policy Change" to the Asthma Control Program at the Rhode Island Department of Health. In November 2010 we presented on two different abstracts at the American Public Health Association Annual Conference in Denver, CO "Children's Hospital Boston Community Asthma Initiative: Reducing Health Disparities in Boston" and "Social Return on Investment from an asthma community-based case management intervention program." In addition, CAI's abstract entitled "Community Asthma Initiative: Reducing Health Disparities and Influencing Policy Change" was accepted for a presentation as well as a poster at the CDC REACH Technical Assistance Workshop that took place between March 9-11, 2011 in Atlanta, GA. Another abstract, "Adolescent perceptions of asthma and recommendation for care and messaging" was also accepted for a poster presentation the 2011 Society for Adolescent Health and Medicine Annual Meeting. Wide national dissemination of information is an important goal of the Children's Hospital Boston Community Asthma Initiative.

In addition to these abstract presentations, CAI has also submitted three different manuscripts for publication in peer-reviewed journals this year, including; 1) case management and home visiting program health outcomes, 2) cost-effectiveness of the program, and 3) our policy efforts.

This year also included a flurry of media attention (see Attachment 3) around the program sparked by an article written by Atul Gawande, MD, MPH in The New Yorker describing CAI's outcomes and the potential for cost savings for insurance companies and followed by articles in ABC News, Boston Globe, Slate Magazine, Commonwealth Magazine, Health Leaders Media, and Chest Physician. We look forward to further dissemination of information and replication of the CAI model of asthma care.

## **Attachment 1: Meeting Minutes**

Family Advisory Board Meeting March 16, 2010

Attendance: 11 parents, 8 staff

## **Community Forum (John Riordan):**

- Exercise Group >83 years old want to come and do a demonstration activity
- "Can you put together an exercise program for people [adults] like me?"
- "The forum was good and there were people from the community." "It was a good day." "There were people from the place [flu clinic] next door."
- "I would like to hear more about the triggers [dust and pollen]." An overview of asthma.
- "People were positive. It was a good turn out"
- "I think it was great. Different perspectives (parents, experts and so on)."
- "There are signs outside that say his is a smoke free area but there are people still smoking out there."
- "It would be nice to include something about cigarettes."
- "When I found out about what was in a cigarette, I was so shocked. I felt bad for everyone that had to walk by me when I smoked. I quit 15 years ago though."
- "People think they out grow asthma but really they don't. It is just that their symptoms are controlled but the asthma never goes away."
- "I think we should include more about how kids can play, swim and jump. I am one of the scaredest mom's in the world but my son goes out and plays all the sports."
- Spanish Forum??
  - o South End, Lower Roxbury, Jamaica Plain Latino communities
  - We could do the whole thing in Spanish
  - o Larger population will come if it is in Spanish
  - o "A lot of people need more information about asthma"
  - o If we did it totally in Spanish we would need help from participants like you
  - o Where Hernandez School in the South End
  - o Translation to English? Advertise as Spanish speaking only?
  - o "Why don't you have it on the same day; one room in English and the other room in Spanish?"
  - o "If it is only in Spanish you will have a lot of walkouts because AAs do not like to learn all in Spanish."
- We would like to build a large group of participants
- Timing: Saturdays, after 12 or 1, 2-4, 12-2 or 1-3
  - o "Even if you miss some people you could get a majority."
  - o "I have meetings at 10:30am"

#### **Focus Groups for Adolescents:**

- "If you mention gift cards they will come."
- "Would they just come once?"
- "If you give them a role, they will come."

- "It is good to listen to the young people. You will be amazed at what they will say."
- "Give them a leadership role."
- "Kids are smarter than you think they are."
- "You can give them a contest."
- "They could decide what they want to work on."

## **Physical Activity Opportunities:**

- "It would be nice for you to have something once a month."
- Asthma Swim program several exist
  - o Curtis Hall in JP, Dorchester House, Blackstone Elementary, Holland School
- Boston Asthma Games small handful of repeat participants each year
  - o The games will not happen this year
- Expand opportunities for more kids with exercise and asthma
- "I find parents are a lot of that blockage. It is not true, you have to give it a try."
- Every program should have a parent education component
- "When they do these activities, the coaches need to take medication in advance."
- "Kids should be able to do anything: basketball, volleyball, soccer, gymnastics, running and jumping, baseball, softball..."
- Should we have an open gym or actively teach the kids to play?
  - o "Teach them double dutch, something they don't know."
- "Basketball and double dutch so that both boys and girls can play."
  - o Should do something that is female and male friendly
  - o "Boys and girls play volleyball
- "I fear basketball due to all of the running."
- "My son is on a soccer team. His asthma acts up in the cold, sun, and when seasons change."
- Activities should take place in different communities
  - o Roxbury boys and girls club, Reggie Lewis center, YMCA, Tobin gym
  - o "The Lee school is always packed with kids."
- "YMCA register program."
- Community centers, Grove Hall, for some community centers you have to live in that community in order to use it.
- Preference? Boys and Girls Club or the YMCA?
  - o "English High School they have a track indoor and outdoor."
  - o "Reggie Lewis Center."
- Location: should be somewhere where there is public transportation, staffing and times of day
- Days of the week:
  - o Swim and gym, swim Tuesdays and Thursdays 4-6pm
- Programs should include: medications and supervision; an older group of adolescents
- "What about the younger kids?"
- 5-8 year olds can go to the Madison Park open gym, parents can play with their kids happens on Saturdays at 10am Healthy Kids/Healthy Futures; can just showup
- Doing sports, before hand you should do some education
- "Teenagers get tired easily."

- "My other daughter gets sick right away with sports."
  - o If sports are a trigger for her and she should go back to the provider; children should be able to exercise regularly.
- Most kids can play asthma friendly sports
- Some parents want to get their feet wet slowly so they can build up tolerance to playing sports.
- Kids with asthma can physical activity component

# **Children's Hospital Boston NStar Walk:**

- Any money we raise will come pack to CAI
- Can walk 2 miles or 7 miles
- \$20 registration fee, \$150 fundraising minimum
- June 13<sup>th</sup>

# Asthma Community Advisory Board Monday, May 17, 2010

Attendance: 17 members

# **Updates: BUAC -**

- Healthy Homes, Healthy Communities in Dorchester and Roxbury combining asthma and lead work in the home environment
- IPM with Head Starts
- Partnering with MassCOSH
- Dorchester House project getting Asthma Action Plans on file
- Budget cuts and the impact on custodial services at schools
- Smoke-free housing there will be a summit in July
  - o By 2013 all Boston Housing Authority developments will be smoke-free
- Parent asthma leaders as advocates and educators
  - o Showing them how they can impact their children's health

#### **Community Forum –**

- Had first forum last fall in November 2009
  - Combined testimony from parents and experts in areas of medication management, environmental issues at home and school as well as advocacy
- 2<sup>nd</sup> forum will be marketed to Spanish speaking communities in Roxbury and Jamaica Plain
  - o Location: Reggie Lewis Center, Roxbury
  - o Date: Saturday, October 16<sup>th</sup>, 2010
  - o Time: 11-2pm
  - o Lunch and childcare will be offered
- Feedback from last forum indicated particular interest in asthma issues at school
  - Schools are the number one issue because no matter what we do at home to reduce triggers, children will still have exacerbations if the school conditions are poor and all the work we do will be negated.

- Payers should also hear about this because if they are covering home visits
  which make the asthma the asthma better they would not want the school
  conditions to reduce the effectiveness of the effort that they have put into
  the home visits
- o Many schools seem to be out of code in terms of conditions
- o Should we have a whole forum dedicated to issues of asthma at schools?
- Cost-benefit analysis of the forum?
  - o Maybe doing forums with smaller more local organizations
  - o Getting people out to more unfamiliar places
- Using the forum as an organizing tool
  - o What to do with the energy that people have from the forum?
  - Example: a parent committee collected over 100 signatures for a public hearing about environmental triggers
  - o Parent liaisons → strengthening relationships with school nurses, staff, etc.
  - How can we help school nurses to connect with others to manage students' asthma
  - o Have one school that has a good environmental committee talk about how the formed the committee and things they have done so that others may be inspired to start committees at other schools?
  - Use the energy from the forum to go to the city council to advocate for budgetary concerns
  - Educating parents about what they have the power and capacity to do this kind of advocacy.
  - Dissemination of information
  - o Lead participants to become more engaged with community-based organizations
- Getting legislators involved to influence school conditions
  - At a hearing about budget cuts for janitorial staff, Felix Arroyo and others were very interested in the impact of this on school asthma exacerbations
  - o Providing statistics about school and work absenteeism
  - Everyone needs to team up to make change
  - With the short money, we need to make sure that school conditions relating to asthma is at the top of the priority list
  - o Maybe have a forum for testimonials and invite legislators, payers, etc.
  - At the last forum Councilor Yancy showed up, but if we had had more time to contact them perhaps we could get more legislators to show up
- Could we use information from Wanda's study about the schools?
  - The study is not yet at the intervention stage yet because the research has not yet been completed or published
  - Wendy will give us some preliminary data from Wanda's studies
- We want to make sure that we are not adversarial with the schools
  - Instead, we should try to connect with environmental services at schools and collaborate with them to improve conditions
  - Create a communication loop between nurse, providers, teachers, environmental committees, parents, and teenagers

- Perhaps we should stick to the more general forum like we did last time for this particular community because they have not yet had the basic education that was provided at the last forum and they may not be ready to jump to the next level yet
  - o Families still not understanding their controller medications
  - o Also hearing from a child's perspective in addition to parents and experts
- The more focused we are, the more opportunity we have for policy change
  - o Have a focused policy objective to be as effective as possible
- Forming a subcommittee to do more ongoing planning for the forum:
  - Laurita Kaigler-Crawlle, Bill Minkle, Deb Dickerson, Susan Sommer, Jerri Pratt, Elaine Chan, Amy Burack
- Other potential school related topics (besides environmental issues)
  - o Mayor's campaign for having asthma action plans on file at school
  - o Number of school nurses per school
- It would be interesting to find out what percentage of kids have asthma at each school and who has been sent to the ED from school for an asthma exacerbation
  - o But it would be hard to obtain this information unless zip code based.

# Asthma Request in State Budget -

- Payment models
- Medicaid bundled care
  - o A lot of support from Representative Jeff Sanchez
  - o Favorable action with having Senate support
  - o Many partners were involved in getting this as far as it has gone today
  - o If successful it will benefit everyone across the state
- Other policy issues that we would like to continue to work on: getting some asthma controller and quick-relief medications on the first tier of drug formularies

#### Asthma Research at CHB -

- Asthma Net Wendy Gordon
  - o Database for potential asthma patients
- Sending out a newsletter to let the community know about the progress of existing studies
  as well as upcoming ones and also explaining that research takes a long time before any
  results can be used in the community
- Will be starting their own Community Advisory Board
- Email: asthma@childrens.harvard.edu

# Family Advisory Board Meeting June 15, 2010

Attendance: 6 parents, 9 staff

### Exercise Induced Asthma Study – Dr. Jonathan Gaffin, Pulmonary Dept.

- 80% of people with asthma have symptoms with exercise
- Study is a clinical trial funded by Astra Zeneca to compare Pulmicort and Symbicort
- Study criteria:

- o currently prescribed Pulmicort or Flovent (inhaled steroids)
- o between the ages of 12 and 50
- Lasts over an 8 week span with one visit every 2 weeks
  - o Each visit takes 2.5 hours
  - o 5 visits total, \$50/visit
- · Visits include: running on a treadmill, Spirometry, breathing tests

## Asthma City Council Hearing – Victor Shopov, OCA

- Felix Arroyo identified asthma in Boston as an issue he wanted to talk about
  - What are the challenges of parents, kids, schools, etc.?
- Inviting CAI families to testify or even write letters
  - Telling stories and sharing experiences
  - o Everyone in the city is also invited to attend
- Will take place sometime in July at City Hall
- Still working on the city budget
  - o "With the severe custodian cut, the schools are going to be filthy and I am worried about my kids' asthma in BPS."
- Smoke-free housing?
  - o "I live in Boston housing. In the letter about rent was a survey about smoke-free apartments...The following week I signed my contract and asked if they were going to make it smoke free and they said no."
  - o "They said they are only planning to do smoke free for the hallways but not for the apartments."
  - o "They said that if you smoke in the apartment you could get evicted."
  - o "My neighbors smoke and all the smoke is coming in my apartment so it is like I am smoking and my daughter's asthma has been really bad lately."
  - o "If I smell smoke in the hallway, I purposely set off the smoke detector to scare the smokers away."
- If you are a resident of public housing, bring these issues up at the city hearing

# **Community Asthma Forum**

Saturday, October 16, 2010

11:00am - 2:00pm

Reggie Lewis Center, Roxbury

- Topic: school situation
- "What is our responsibility as family members and what is the responsibility of the schools?"
- Hopefully there will be new community members at this event
  - Want to cater to a diverse group
  - o Will translate appropriately
    - "Can we market to Cape Verdean populations?"
    - "We should have Haitian speakers too."
  - Open to everyone
- Are the nurses in the schools real nurses?
  - o All BPS nurses are registered nurses
  - Not necessarily the case at Head Start; they may be licensed health practitioners but not in this country

- Not enough nurses in schools
  - o "When my daughter gets sick for asthma or otherwise, she calls me and I tell her to go to the nurse, but she tells me that the nurse is never there."
- Need to have Parent Advisory Boards for the schools, environmental committees, etc.
- Don't want to be adversarial; keep in mind the good things that are happening at the schools
- Take some action, participate and affect some change
- Basic education still needed
  - Parents don't understand controller medications vs. quick relief medications and dosing
- First planning meeting will take place next week, Wednesday, June 23, 2010 from 1:00pm-2:30pm at 120 Brookline Avenue all are welcome to attend if interested

### **Head Start Focus Groups**

- Parents did not understand the difference between controller medications and quick-relief inhalers and when to use each
- Asthma education is inadequate and often not culturally or linguistically appropriate
- When kids were symptom free parents often stopped giving controller medications
- Parents also worried about the long-term side effects of the medication
  - o Some reduced dosing because of this fear
- Recommendations:
  - Any ABCD Head Start child either new or returning with a diagnosis of asthma must have a current Asthma Management Plan, quick relief medication and appropriate delivery device provided to the site health manager.
  - o Parents of all children either new or returning with a diagnosis of asthma must attend an annual asthma education training session.
  - o In addition to health care staff, classroom teachers should be required to attend an annual asthma basics workshop.
  - All health care staff should have available pictorial or actual sample of various asthma medication and delivery devices.
  - o Consider language specific sessions with appropriate interpretation.
  - Parents/guardian of any child requiring albuterol administration more than two times a week (unless otherwise indicated by the health care provider) should be contacted by the head start staff to discuss the child's asthma status and need for follow up.

# Family Advisory Board Meeting September 21, 2010

Attendance: 12 parents, 13 children, 5 staff

# **Community Asthma Forum**

Saturday, October 16, 2010 11:00am – 2:00pm

Reggie Lewis Center, Roxbury

• Topic: Healthy Students are Better Learners: Asthma in the Schools and Pre-Schools

- o Important topic because "a lot of teachers don't know about asthma. They've heard about it but they don't really know how severe it is."
- o "I've been to the principal's office at the Tobin School and she hears me but she *just* hears me. She forgets as soon as I leave the office."
- o "That is where your child goes to school, you need to stay involved."
- o "We are parents and everyone says they want to hear what we have to say."
- o "We need to empower the parent...we have to be the voice of the parents that can't and don't have time. You just don't know what happens in people's homes."
- o "You need to look at the school's environmental report. There is supposed to be a work order log so we can go back and check that it has been done."

#### • Raffle:

- o \$50 Target gift cards (2 Amy)
- o \$50 Stop and Shop gift cards (2 CAI)
- o IPM Kit (CAI)
- o Green cleaning basket (Tolle Graham)
- Networking Fair:
  - o BPHC
  - o BUAC Healthy Schools Committee
  - o Asthma Research (NEU and CHB)
  - o General Asthma Information (Beth Klements)
- Breakout Sessions:
  - o About 45 minutes long
  - o What did people learn? Action Steps?
  - o Flip charts for each table to help people get engaged
  - o Staff and panel members can move around to different tables
- Lunch to be provided by A&K Caterers sandwiches, fruit, chips, water
- Volunteers:
  - o Greeters Latasha
  - o Registration Billy, Tamikiel
  - o Food Table Billy, Lolanda, Latasha, Madelyn
  - o Clean-up Julieta, Lolanda
- Outreach:
  - o Julieta Dudley, David's Market, Ramsey Park
  - o Vivian South End, South End Library, Boston Hispanic Center
  - o Mary Whittier Street Health Center, South Bay, Dorchester House
  - Fliers were placed in each of the lunch bags given out at the Martha Eliot Health Center Health Fair
  - o Boston Neighborhood Network (BNN) free public newspaper
  - o Sending out the electronic version of the flier
  - o City councilors and legislators are being invited to attend

Asthma Community Advisory Board Monday, October 18, 2010

**Attendance:** 14 members

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# **Updates:**

- Maureen Starck interim replacement for Sue Fencer
- Planning an event to potentially take place in March a cross between the Boston Asthma Games and a Community Forum
  - o Trying to get a Boston sports team to come
- Business Case was updated as of August 2010

### **Community Forum:**

- Second forum took place this past weekend Saturday, October 16, 2010 at the Reggie Lewis Center in Roxbury
  - Theme was: "Healthy Students are Better Learners: Asthma in the Schools and Preschools"
- · Feedback
  - o Video of the students with asthma was really great
  - o Food (from AK's) was good
  - No one used the translators
- Future Forum?
  - Maybe link it with something else like other events also gathering parents or other community events
  - o Boys and Girls Club?

#### Asthma Research at Children's -

- Exercise-Induced Asthma study
  - o There was a protocol change
  - o Comparing Pulmicort and Symbicort
  - o Enrolls patients 12-50 years old
- MAAIT (Mouse Allergen and Asthma Intervention Trial)
  - o Goal is to determine if a mouse-targeted integrated pest management intervention is helpful in reducing the effects of asthma and mouse allergy in children
  - o 6-17 years old with moderate to severe asthma who have a mouse allergy
  - o Participants will receive air purifiers, professional pest management in their homes, and mattress and pillow encasements along with other incentives
- Preschool wheezers

### **Boston Home Visiting Collaborative:**

- Standardizing protocols, forms, and trainings for Community Health Workers (CHWs) conducting asthma home visits across Boston
  - o 3 home visits
  - 9 CHWs from 7 institutions Tufts now has a Cantonese/Mandarin speaking home visitor funded by a new grant
  - o Goal is to overcome payor costs and language barriers
- Evaluation of the first pilot of 25 families completed
  - Visits were helpful
  - o ACT results showed improvement
  - Room for improvement with regard to communication between providers and home visitors

- Second pilot will consist of 150 families over a 2 year time frame will begin at the end of this fall
  - o Scott Keays will be running the program with guidance from Margaret Reid
  - Some electronic versions of forms will be on the Net books (purchasing 12 Net books)
  - Online referral system not set up yet but will put a link in the Children's Asthma Registry
  - Need a lot of provider outreach to include Asthma Action Plans and encourage allergy testing

#### **Boston Public Health Commission – Smoker's Quitline:**

- Free patches to smokers 18 and older in Boston
- Trainings will be offered for basic skills for working with smokers so people who receive the training can provide counseling and bill through MassHealth
- Margaret will email flyers for the smoking cessation training sessions

#### **New Medical Home Model for CAI:**

- 54% of CAI patients receive primary care at Children's either through CHPCC, Martha Eliot or Adolescent
- Each clinic has a nurse for asthma CAI will work with them for care coordination
- Will hire an in house home visitor at Children's to work with Susan and Massiel
- ESAC/BAI still taking referrals from CAI
  - o They are getting a lot more outside referrals
  - o Covering areas contiguous to the city as well Revere, Everett, Chelsea
  - o Also referrals from MGH more from Partner's clinics
  - Hopefully there will be more Spanish-speaking capacity in the home visitor network

#### Other:

- Vitamin D and asthma not enough vitamin D in Boston/MA
- Stress levels and asthma psychosocial factors

# Family Advisory Board Meeting November 16, 2010

Attendance: 10 parents, 5 staff

#### **Updates:**

• New session for the Roxbury Asthma Swim Program starts in January for kids 6 and up

#### **Community Asthma Forum:**

- Video of the kids was really great
  - o "Communities should show the video to bring awareness to asthma."
  - We should talk to Public Affairs about how we can share the video
  - o "Maybe put it one YouTube to make it available to the community."

- o "Show the video to school nurses."
- We need to get all the releases for the video from last year so that we can get access to it
- Boston Community News "It's free and you can put anything from the community to be on there."
- Topics and speakers were very informational
  - o "The people kept our attention and were interesting."
  - Regarding the question portion: "People don't necessarily like to speak up in large groups."
  - o "My mother was quoting pieces of information she learned. I told her stuff before but I guess she had to hear it from someone else."
  - o It was good that we had back-up speakers
  - o Good to hear about the asthma protocols at Boston Public Schools
  - o "Everyone is trying to work together to make it better for kids with asthma."

#### Evaluation Results

 Numbers have not yet been crunched but we will share results at the next Family Advisory Board meeting

#### Turnout

- o Obama was at Hynes Convention Center the same day
- o A lot of people who said they were coming didn't come because of confusion with the date
  - "Some people asked 'when is the next one' because they thought it was next week"
- o Saturdays are often days for running errands and being with your kids

#### • Another forum?

- o "The more you do it the more people will come because they expect it."
- o "We should do it annually."
- o "Do something for the kids."
- "Have a website for one stop shopping about information about asthma. WGBH
  is working to create an all you need to know about asthma. We can link this to
  CAI's website."
  - "Make a list of websites and link to different sites."
- o "Something for the kids where whey are more responsible for themselves. Fun, but educational. How to use meds, when to use."
  - "So they can see other kids doing it."
  - "A child's workshop"
  - "Giving them confidence to do it themselves."
- Renee is working with the teens something like that might work with younger kids as well
- o Billboards and signage do people read it?
  - "In May maybe there will be something done from the city councilors (Felix Arroyo)...free billboards around asthma month."
- o Kids with asthma can was a good campaign
  - People were talking about it
  - A lot of people remember it and remember the message

- Campaigns like that are expensive but we can figure out other ways to spread knowledge
- We could do a fundraiser to raise money for something...make our own signs...magnets are always good
- o A good place to put out information is at Parent University
  - The next one is in January
  - There is not enough publicity about who is doing workshops or tell you enough about what the workshops are about
  - We need to work with parent engagement to make it more successful
  - Centauria Grant, Michelle Brooks
  - "My child is not going to be in school to take the MCAS if he's out for asthma. We should have a workshop for parents of BPS."
- School Environmental Committees
  - o "There should be an environmental committee for all schools."
    - We could see if Tolle Graham could come and use the Tobin School as a case study
    - "How do we make an environmental committee?"
  - o "What can we do about the Tobin School? The whole school is horrible."
    - Mary and Susan should go with Landy to talk to the Tobin School
    - Need to talk to other parents at the Tobin to see if they feel the same way
    - "We can stand outside the school to talk to parents."
    - "I called the school to see if my son was given his medicine but the nurse wasn't there so he didn't get his meds."
  - o "I had the same problem with my son at Boston Latin Academy. He missed 73 days of school. The school was not sympathetic."

### **Transportation for BPS Students with Asthma:**

- Should there be door-to-door busing for children with asthma or just for the severe asthmatics?
  - o "Depends on the severity. It should only be for the severe asthmatics."
  - o "If it only happens once in a while, then no, but if it is all the time, then yes."
  - o "Walking is good for your lungs or if you are overweight."
  - o Too many parents are taking advantage of it
  - Why do they need door-to-door?
  - o "We should stress the importance of exercise and just keep educating."
  - o "Asthma is a disability, but not one that affects transportation."
  - o "If a child's asthma is under control, there is no excuse."
  - o "Maybe we should pilot a workshop for parents who have requested transportation and provide them with information so they can really get knowledge about whether they really need it."
  - We also need to educate providers about when it is really necessary and about prescribing meds because the larger issue is getting control
  - Even with transportation, stairs at school becomes a problem because there is no elevator

#### **Attachment 2: Products and Awards**

## **Community Asthma Initiative Manuscripts:**

- 1. Sommer S, Shurtleff J, Kelly P. Chapter 10: Asthma in Adults and Children. In J. Romano, A. Lowenstein and L. Foord-May (Eds.), Teaching Strategies for Health Education and Health Promotion, Sudbury, MA: Jones and Bartlett, 2009.
- 2. Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Children's Hospital Boston Community Asthma Initiative: A comprehensive model of asthma care for health care reform. Submitted to *Pediatrics*, 11/19/2010.
- 3. Sommer SJ, Queenin LM, Nethersole S, Greenberg J, Bhaumik U, Chan E, Wilkinson RB, Dickerson DU, Woods ER. Children's Hospital Boston Community Asthma Initiative (CAI): Using Outcomes to Drive Policy Change. Submitted to *Progress in Community Health Partnerships: Research, Education, and Action*, 12/15/2010.
- 4. Bhaumik U, Norris K, Charron G, Walker SP, Sommer SJ, Chan E, Dickerson DU, Nethersole S, Woods ER. Cost effectiveness of a community-based case management intervention program for asthma. Submitted to *Public Health Reports*, 4/27/2011.

# **National and Regional Presentations:**

- 1. Woods ER, et al. YQI: Quality Improvement in Adolescent Medicine. Society for Adolescent Medicine Annual Meeting, Boston, MA, March 22, 2006.
- 2. Woods ER. Children's Hospital Boston Community Asthma Initiative. Harvard Pilgrim Health Plan, Wellesley, MA, June 28, 2006.
- 3. Woods ER. Community Asthma Initiative. Harvard School of Public Health, Boston, MA, November 15, 2006.
- 4. Woods ER, et al. From QI to Program Development. Society for Adolescent Medicine, Denver, CO, March 28, 2007.
- 5. Woods ER, Bhaumik U, Sommer SJ, Burack AB, Ebe LK, Kessler AJ, Mannix LM, Klements EM, Nethersole S. Community Asthma Initiative: An innovative community-based intervention leading to policy changes. American Public Health Association Annual Meeting, Washington DC, November 6, 2007.
- 6. Shari Nethersole, MD, Urmi Bhaumik MBBS, MS, DSc, Gareth Parry PhD, Dionne Graham, PhD. Applying Institute of Medicine Quality Domains to Measure Pediatric Community Health. American Public Health Association Annual Meeting, Washington DC, November 7, 2007.

- 7. Woods ER, Bhaumik U, Parry GJ, Sommer SJ, Wilkinson RB, Kessler AJ, Burack AB, Klements EM, Nethersole S. Evaluation of a Community-Based Quality Improvement Asthma Intervention. Society for Adolescent Medicine Annual Meeting, Greensboro, NC, March 26-29, 2008.
- 8. Susan Sommer. Integrating Asthma Education and Case Management with Home Environmental Interventions. Asthma Regional Council of New England (ARC) Conference, Boston, MA, April 17, 2008.
- 9. Susan Sommer. Motivational Interviewing and Tobacco Cessation A new approach with Motivational Interviewing. Postgraduate Course in Adolescent Medicine, Harvard Medical School, Boston, MA, May 28, 2008.
- 10. Susan Sommer. Translating the Research: Roles and Challenges for the Health System. Asthma Regional Council (ARC) Conference, Boston, MA, June 19, 2008.
- 11. Susan Sommer. Filling the Gap: A Hospital Response. Asthma Regional Council (ARC) Conference, Boston, MA, June 19, 2008.
- 12. Shari Nethersole. Health Care Provider Perspective on Working with Payers, Health Organizations and Government to Improve Asthma Outcomes. Asthma Regional Council (ARC) Conference, Boston, MA, June 19, 2008.
- 13. Woods ER, Bhaumik U, Sommer SJ, Kessler AJ, Wilkinson RB, Sesma MN, Burack AB, Klements EM, Mannix LM, Dickerson DU, Nethersole S. Evaluation of a Community-based Quality Improvement Asthma Intervention. Office of Child Advocacy Annual Poster Day, Children's Hospital Boston, Boston, MA, 2008.
- 14. Bhaumik U, Nethersole S, Parry G, Schapiro AL, Sommer SJ, Wilkinson RB, Kessler AJ, Woods ER. Cost of efficiency of a community-based asthma case management intervention program. American Public Health Association Annual Meeting, San Diego, CA, November 2008.
- 15. Dulin R, Cleghorn GD, Woods ER, Sommer S, Burack A, Kessler AJ. Two Unique Community Level Strategies to Eliminate Health Inequalities. 20<sup>th</sup> National Conference on Chronic Disease Prevention and Control, National Harbor, MD, February 23-25, 2009.
- 16. Woods ER, Bhaumik U, Parry GJ, Sommer SJ, Wilkinson RB, Kessler AJ, Burack AB, Klements EM, Sesma MN, Dickerson DU, Nethersole S. Children's Hospital Boston Community Asthma Initiative: A Quality Improvement Evaluation. Pediatric Academic Societies' Annual Meeting, Baltimore, MD, May 3, 2009.
- 17. Woods ER, Bhaumik U, Sommer SJ, Kessler AJ, Wilkinson RB, Sesma MN, Burack AB, Klements EM, Mannix LM, Dickerson DU, Nethersole S. Evaluation of a Community-based Quality Improvement Asthma Intervention. Office of Child Advocacy Annual Poster Day, Children's Hospital Boston, Boston, MA, October 19, 2009.

- 18. Woods ER, Bhaumik U, Sommer SJ, Wilkinson RB, Ziniel SI, Sesma M, Burack AB, Klements EM, Mannix LM, Dickerson DU, Nethersole S. Children's Hospital Boston Community Asthma Initiative: One Year Follow Up. American Public Health Association Annual Meeting, Philadelphia, PA, November 10, 2009.
- 19. Kahlon PS, Lyden M, Klements E, Sawicki G, Woods ER. Improving Quality of Coordinated Care across the Continuum for Asthma. NACHRI 2010 Creating Connections Conference, San Diego, CA, March 9-12, 2010.
- 20. Woods ER, Bhaumik U, Sommer SJ, Wilkinson RB, Chan E, Burack AB, Mannix LM, Sesma MN, Dickerson DU, Klements EM, Nethersole S. Children's Hospital Boston Community Asthma Initiative: One Year Follow Up, Adolescent Findings and Two Year Cost Analysis. Society for Adolescent Medicine Annual Meeting, April 9, 2010 Toronto, Canada.
- 21. Woods ER, Bhaumik U, Ziniel SI, Sommer SJ, Wilkinson RB, Chan E, Ortiz MP, Burack AB, Klements EM, Sesma MN, Mannix LM, Dickerson DU, Nethersole S. Quality Improvement Evaluation of Community Asthma Initiative (CAI): One Year Follow-Up and Two Year Cost Analysis. Pediatric Academic Societies' Annual Meeting, Vancouver, Canada, May 2, 2010.
- 22. Ortiz MP and Sommer SJ. Community Asthma Initiative Home Visit. Children's Hospital Boston Nurses Week, Boston, MA, May 6-12, 2010.
- 23. Woods ER, Bhaumik U, Sommer SJ, Mannix LM. Asthma Control Program, RI Department of Health, "Community Asthma Initiative: An Innovative Community Based Intervention Leading to Policy Change," Providence, RI, October 5, 2010.
- 24. Woods ER, Bhaumik U, Sommer SJ, Ortiz MP, Chan E, Wilkinson RB, Pizarro BL, Burack AB, Klements EM, Queenin LM, Nethersole S. Evaluation of a Community-based Quality Improvement Asthma Intervention. Office of Child Advocacy Annual Poster Day, Children's Hospital Boston, MA, October 18, 2010.
- 25. Bhaumik U, Walker SP, Sommer SJ, Chan E, Dickerson DU, Nethersole S, Woods ER. Social Return on Investment from an asthma community-based case management intervention program. American Public Health Association Annual Meeting, Denver, CO, November 8, 2010 (poster).
- 26. Sommer SJ, Bhaumik U, Chan E, Mannix LM, Ortiz MP, Burack AB, Klements EM, Wilkinson R, Dickerson DU, Nethersole S, Woods ER. Children's Hospital Boston Community Asthma Initiative: Reducing Health Disparities in Boston. American Public Health Association Annual Meeting, Denver, CO, November 9, 2010.
- 27. Woods ER, Bhaumik U, Sommer SJ, Chan E, Wilkinson RB, Ortiz MP, Burack AB, Klements EM, Dickerson DU, Nethersole S. Community Asthma Initiative (CAI): Reducing

Health Disparities and Influencing Policy Change. Centers for Disease Control and Prevention Technical Assistance Workshop, Atlanta, GA, March 9-11, 2011 (poster and workshop).

- 28. Bendzewicz R, Sommer S, Chan E, Nichols L, Bhaumik U, Woods E. Adolescent perceptions of asthma and recommendations for care and messaging. Society for Adolescent Health and Medicine Annual Meeting, Seattle, WA, March 30, 2011 (poster).
- 29. Woods ER, Bhaumik U, Sommer SJ, Chan E, Wilkinson RB, Ortiz MP, Burack AB, Klements EM, Dickerson DU, Nethersole S. Community Asthma Initiative (CAI): A Cost Effective Intervention. Pediatric Academic Societies Annual Meeting, Denver, CO, May 1, 2011.
- 30. Sommer SJ, Bhaumik U, Chan E, Ortiz MP, Lorenzi M, Woods, ER. Children's Hospital Boston Community Asthma Initiative: Addressing Environmental Allergens and Irritants in Households of Children with Poorly Controlled Asthma. American Public Health Association Annual Meeting, Washington, DC, October 29- November 2, 2011, submitted.
- 31. Woods ER, Bhaumik U, Sommer SJ, Chan E, Nethersole S. Community Asthma Initiative (CAI): A Cost Effective Intervention. The Future of Pediatrics, Chicago, IL, July 29, 2011, accepted.

Awards:	
2007	Community Health Award for leadership of providing asthma services in the urban community, Asthma and Allergy Foundation of America, New England Chapter,
	Massachusetts presented to Elizabeth R. Woods, MD, MPH
2007	Mayor Thomas Menino Proclamation, "Elizabeth Woods Day in Boston,"
	Community Asthma Initiative efforts presented to Elizabeth R. Woods, MD, MPH
	(April 12, 2007)
2007, 2008,	Nominated, Elizabeth R. Woods, MD, MPH, Martha May Eliot Award, American
2009	Public Health Association
2008	Finalist, National Environmental Leadership Award in Asthma Management,
	Environmental Protection Agency, Community Asthma Initiative
2008	Boston Urban Asthma Coalition, "Supporting Parents Voices Award," Presented to
	Amy Burack, RN, MA, AE-C (January 31, 2008)
2008	Nursing Spectrum Excellence Award, New England Area Nursing Excellence
	Awards, Presented to Susan Sommer, RNC, NP (May 13, 2008)
2009	Nominated, Elizabeth R. Woods, MD, MPH, Dean's Community Service Award,
	Harvard Medical School
2010	National Environmental Leadership Award in Asthma Management,
	Environmental Protection Agency, Community Asthma Initiative (June 17, 2010)
2010	Amy Burack, MA, RN, AE-C Action for Boston Community Development
	Community Awards Recipient for "Exemplary commitment for improving the
	lives of Boston's neediest." (Awards Ceremony – October 29, 2010)
2011	Massiel Ortiz, BSN, RN Excellence in Nursing Award in the category of
	Excellence in Education/Teaching by the New England Regional Black Nurses
	Association (Awards Ceremony – February 11, 2011)

#### **Attachment 3: Media Attention**

Now What?

By: Atul Gawande The New Yorker April 5, 2010

http://www.newyorker.com/talk/comment/2010/04/05/100405taco talk gawande

Asthma Program Helps Patients, But May Hurt Hospitals: Doctors Say Program Shows Need for

Different Thinking on Health

By: Joseph Brownstein ABC News Online April 13, 2010

http://abcnews.go.com/Health/AsthmaNews/asthma-programs-patients-hurt-

hospitals/story?id=10335142

Scourge of asthma is acute in N.E.: Treatment lags, study contends

By: Stephen Smith Boston Globe April 26, 2010

(front page, then continued on Page A5; also can be found online)

http://www.boston.com/news/health/articles/2010/04/26/scourge of asthma is acute in ne/

Little Bundles of Joy: Why do insurers ignore the most promising way of cutting health costs?

By: Darshak Sanghavi

Slate Magazine (<u>www.slate.com</u>)

April 29, 2010

http://www.slate.com/id/2252221/

Community Asthma Initiative Curbs Pediatric Asthma

By: Susan London

Chest Physician: The Newspaper of the American College of Chest Physicians

Vol. 5, No. 7, July 2010

(front page)

Breathing Easier

By: Alison Lobron

Commonwealth Magazine (www.commonwealthmagazine.org)

October 19, 2010

http://www.commonwealthmagazine.org/Investigations/What-Works/2010/Fall/Breathing-easier.aspx

A Hospital Prevents Readmissions, but Threatens Revenue

By: Cheryl Clark February 10, 2011

HealthLeaders Media (www.healthleadersmedia.com)

Children's Hospital Boston Healthy Tomorrows Partnership for Children Page 38  $\underline{http://www.healthleadersmedia.com/content/QUA-262451/A-Hospital-Prevents-Readmissions-but-Threatens-Revenue}$ 

MassHealth's bundled payment approach: A "baby step" toward broader reform State Health Watch: The Newsletter on State Health Care Reform Vol. 18 No.3, page 11-12 March 2011

http://www.mass.gov/Ihqcc/docs/shw/StateHealthWatchMarch2011.pdf