

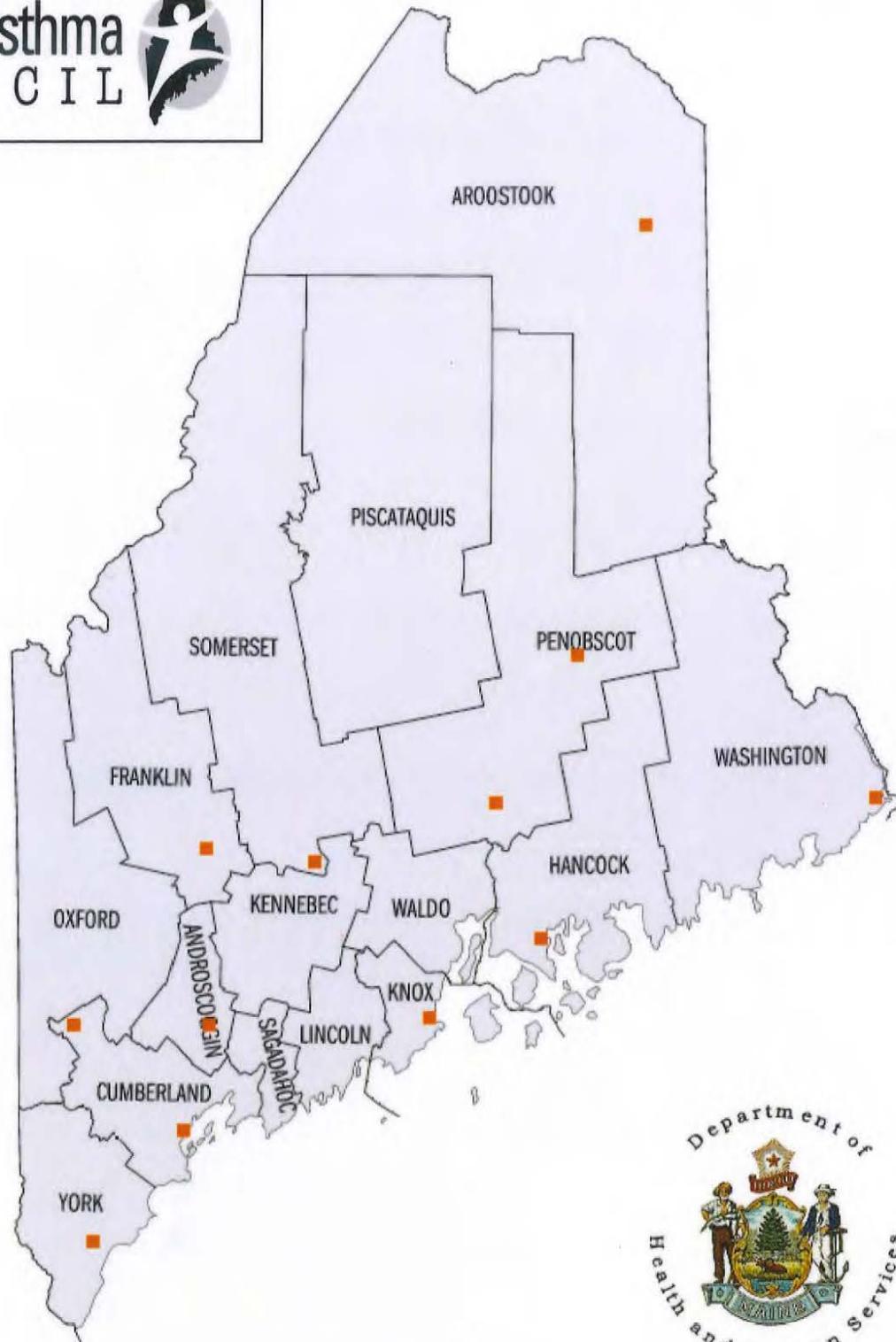
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REGIONAL ASTHMA FORUMS



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REPORT

REGIONAL
ASTHMA FORUMS

Maine

March 2004 – October 2005

Maine Asthma Prevention and Control Program

In Collaboration With

The Maine Asthma Council

December 30, 2005

Acknowledgements

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We also thank our Community Partners for sharing their time, space, and energy for these Forums.

*"There's a fire inside of everybody
Burning clear and bright
There's a power in the faintest heartbeat
That cannot be denied
Go on and trust yourself
Cause you can ride the wind
You're gonna take your dreams
Where's they've never been
There's a hero in everybody's heart"*

- Billy Gilman

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Executive Summary:

Asthma is a serious public health problem in Maine. Maine has one of the highest asthma prevalence rates in the United States. It is estimated that over 128,000 Mainers have asthma, with almost 22% of that number under 18 years of age. As such, asthma has an impact on every Maine community. It is exceedingly important, as part of the effort to address asthma, to reach out to Maine communities and to meet with people affected by asthma. By reaching out, it is possible to disseminate information, provide tools, and gather information. Regional Asthma Forums provide this opportunity to explore community level issues, strengths, and needs about asthma. We have been able to conduct Regional Asthma Forums in multiple regions of the State, from the most urban to the most rural communities.

Twelve Regional Asthma Forums took place in Maine from March 2004 to October 2005. They were held in Wells, Presque Isle, Lubec, Farmington, Lewiston, Bangor, Portland, Blue Hill, Bridgton, Rockland, Fairfield, and Lincoln. Each Forum was coordinated with community partners within the Healthy Maine Partnerships (HMP). At least 17 of the 31 HMPs (57%) were involved.

We conducted the first Forums using a primarily lecture-type format. The presenters “talked to” community participants about various aspects of asthma. Questions and discussion followed the presentations. Based on the experience of a number of Forums using this format and in response to participant comments, we changed the format to one of “talking with” community participants about asthma, actively listening to them and engaging in open dialogue on how to better address asthma at the local level. This readjustment resulted in a more productive and satisfying Forum.

Although the agenda varied slightly from Forum to Forum, the same basic principles were used: 1) Get the whole system in a room; 2) Everyone who cares about asthma in Maine is an expert and can make a positive difference; 3) Focus on common ground; and 4) Inspire action. Further, we included the following messages, information, and dialogue:

- ❖ The scope of asthma in Maine
- ❖ Introduction to the statewide Asthma Plan
- ❖ The importance of Asthma Action/Management Plans
- ❖ Tools and links to help manage asthma
- ❖ Roundtable discussions to exchange information about asthma and to find out what is important to the specific community

Several common themes regarding asthma emerged from the Forums. We found that Maine People are concerned about: support and coordination of effort; information and communication; education; the environment; and the workplace. We also found issues and concerns unique to specific areas of the state. At the statewide level, the information gathered from these Forums will allow an analysis of where to best channel resources and efforts designed to address asthma from a public health perspective.

I BACKGROUND:

The first statewide gathering concerning asthma in Maine was held in December of 1997. The American Lung Association of Maine, Maine Bureau of Health, and MaineHealth coordinated the “Maine Asthma Summit”. At that meeting it was determined that asthma is a serious health issue and that more coordinated work needed to be done to address the growing problem of asthma in Maine. As a result of that Summit, the Maine Asthma Council was formed and a successful application was made to the Centers For Disease Control and Prevention for a grant to “Address Asthma From A Public Health Perspective”. The Maine Asthma Prevention and Control Program was established by the Maine legislature, in March 2002, to administer the grant.

Plans were made to have a second statewide asthma summit in October of 2003. The purpose of the summit was to showcase progress made since 1997 and to introduce the new statewide asthma plan, called the “Public Health Action Plan for Asthma in Maine”. A poor response to calls for Summit registration caused a cancellation of that event. Although considerable work had been done in Maine concerning asthma, the Asthma Program and Asthma Council were virtually unknown to the people and communities of Maine. It was obvious that instead of expecting the people to come to a summit about asthma, we, the Maine Asthma Program in collaboration with other members of the Maine Asthma Council, needed to go out to the people. This realization prompted the concept of Regional Asthma Forums.

II PURPOSE:

The purposes of the Regional Asthma Forums were to:

1. Introduce asthma issues to the people of Maine. These issues include a description of asthma, asthma data, and how seriously asthma impacts Maine and the people of Maine.
2. Inform Maine people that there is a statewide asthma plan and how it can be used to guide asthma activities.
3. Introduce the concept of asthma management and to provide some tools to facilitate asthma management.
4. Provide connections and links for information about asthma.
5. Learn about asthma-related issues from the people of Maine, at the community level.

These purposes support the mission the Maine Asthma Prevention and Control Program, “To provide leadership for and coordination of asthma prevention and intervention activities”. They also support the roles of the Maine Asthma Council: to identify relevant data needs; identify state capacity, resources and gaps; validate the need for asthma services; facilitate discussions with other agencies and groups working on asthma issues; provide leadership on asthma issues throughout the state; advocate for policy change; and review and assess current standards of care for asthma.

III PROCESS:

A. Regional Forums

Initially, the concept of Regional Asthma Forums was to spread the word, across the state about the new statewide asthma plan (Plan). The Plan had been written and published in mid 2003 through a coordinated effort of the Maine Asthma Council and the Maine Asthma Prevention and Control Program. Representatives from that coordinated effort chose five sites, strategically located, to showcase the Plan and let Maine people know that there was a statewide effort underway to help reduce issues surrounding asthma. The decision was made to align our efforts with the existing Healthy Maine Partnership (HMP) organization as much as possible. Thirty-one local HMPs have been funded throughout the state. Each of the local Partnerships works to reduce tobacco-related chronic diseases by developing and implementing comprehensive community-level interventions that promote and support tobacco use prevention, increased physical activity and healthy eating, primarily through policy and environmental change. Since the HMPs exist to promote healthy communities, it was thought that this connection would allow us to work with an existing group of individuals, at the community level, interested in the health and wellness of community members.

The basic process was to contact the HMP Director, by phone, in or near the site chosen. Communication was then conducted by e-mail. The intention was that this person would work with the Asthma Program to publicize the Forum through e-mail lists, brochures, and notices in newsletters. It was our practice to tell the local host when and where the Forum would be held, and to send them a pre-determined agenda. The majority of these people had little idea of who we were, what we were representing, and what we were really trying to do. As a result, the interaction and support from the HMPs varied greatly.

For the first eight Forums, the agenda was basically the same. We began the Forum at noon by providing a light lunch. Presenters varied, according to availability, schedule, and travel distance. A sample Forum agenda is shown below.

- 12:00 Registration – Light Lunch
- 12:30 Welcome
- 12:45 Everyone Has a Voice, Everyone Has the Tools
- 1:00 Review of Regional and Statewide Data
- 1:30 The Statewide Asthma Plan
- 1:45 Asthma Action/Management Plan
- 2:00 Break
- 2:15 Breakout Groups/Roundtable discussion
- 3:30 Reconvene to Share Information
- 4:00 Evaluation – Adjourn

As can be seen above, the original Forum format was designed in two parts. The first half was a standard lecture style, providing information about asthma. The second half was devoted to either breakout groups or a round-table discussion.

As planning progressed, and after we experienced three successful Forums, we decided to expand our efforts. It was felt that if a total of twelve Forums were held regionally, nearly all 31 local HMPs would be able to participate, thereby covering 90% of Maine's population.

By the end of the eighth Forum, we began to experience a trend of less community participation and less involvement by the local HMP. The decision was made to change the planning and format of the last four Forums to better reflect the needs and strengths of each community. It was decided to visit with each contact and site before the Forum in order to meet the contact in person and to explain our purpose. At that meeting we requested their help in encouraging community people to attend. The local contact was encouraged to determine the Forum date and time of day best for their community. We also asked for their help in planning the agenda for the Forum. It was found that community people wanted to share, discuss, and learn more from each other. As a result, the format of the Forums was changed to more of a group discussion, with less lecture, but still supported by relevant facts, figures, and information.

At this same time, another major change involved internal planning for the Forums. For the first eight Forums, assistance with logistical arrangements was contracted and obtained through Medical Care Development, a not-for-profit organization that carries out programs and plans events to improve health and healthcare in Maine. This support involved arrangements for the venue, brochures, equipment, supplies, and food. Considering the change in Forum format, more experience of Asthma Program personnel, and better connection with the community sites, it was decided to arrange the last four Forums internally, without contracted assistance. This resulted in a less "canned" approach reflecting a more relaxed and flexible atmosphere, which was therefore more conducive to discussion and exchange of information.

Below is the agenda from our last Forum. This agenda shows changes as described above, including format and time of day.

5:00 - 5:05 Welcome
5:05 - 6:00 Asthma in Maine
6:00 – 6:10 Statewide Asthma Plan
6:10 – 6:30 It all Fits Together – Discussion and Light meal
6:30 – 7:20 Community Interaction – Asthma in our Communities
7:20 – 7:30 Evaluation - Adjourn

Forums Held:

<u>Location</u>	<u>Date</u>
Wells	March 2, 2004
Presque Isle	May 27, 2004
Lubec	June 14, 2004
Farmington	September 16, 2004
Lewiston	November 4, 2004
Bangor	January 13, 2005
Blue Hill	February 3, 2005
Portland	March 10, 2005
Bridgton	September 27, 2005
Rockland	October 5, 2005
Lincoln	October 11, 2005
Fairfield	October 27, 2005

Total attendees = 144

Average attendance per Forum = 12 (high of 26 – low of 5)

Average number of presenters per Forum = 4

B. Presenters:

Ken Huhn, Chair - Maine Asthma Council
Richard Aronson, MCH Medical Director
Dwight Littlefield, Asthma Program Manager
Kathy Tippy, Epidemiologist
Belinda Golden, Asthma Program Planning and Research Associate
Patti Roderick, Asthma Educator/Nurse
Desi-Rae Mason, Asthma Program Planning and Research Associate
Lee Scott, American Lung Association, Deputy Director
Community Members

IV RESULTS:

A. Evaluation by Forum Participants:

Participants were asked to rate usefulness of topics covered during the Forum on a scale of 1 to 4, with 1 = not at all and 4 = to a great extent.
This scale is equivalent to: Poor – Fair – Good - Excellent

Participants were also asked to, “Rate your overall satisfaction with today’s Forum”

While some variation in scoring occurred due to differing styles and abilities of the presenters, the basic value of the topic to the participants is plainly shown in Table A. People were eager to learn about tools that could be used to help manage asthma, ie, the Asthma Action Plans. They also valued the breakout or roundtable session held at each Forum. This part of the Forum afforded them an opportunity to ask questions about asthma and provide valuable information to us about their experiences, observations, frustrations, successes, and ideas. Common themes are listed under section IV. B.

It is also clear that the Forum format change, after Portland (Forum # 8), resulted in Forums that were regarded as having more value. The agenda was changed from essentially a lecture format to one of exchange of information and ideas. Although people wanted to learn about asthma, they would rather engage in discussion rather than be lectured.

All participants who filled out an evaluation form (100%), stated that they were “Satisfied” with the Forums. Overall score for all components: 3.46. This equates to a rating of 86.5% of the # 4 rating.

Table A. Forum attendee evaluation results.

Location	Purpose	Asthma Data	State Plan	Action Plan	Breakout/ Roundtable	Average Score	N*
Wells -	3.19	3.23	3.23	3.36	3.48	3.30	20
Presque Isle -	3.40	3.50	3.50	3.40	3.20	3.40	10
Lubec -	3.29	2.85	3.29	3.46	3.10	3.20	13
Farmington -	3.33	3.44	3.22	3.38	3.17	3.31	8
Lewiston -	3.22	3.22	3.33	3.33	3.75	3.37	9
Bangor -	3.50	3.40	3.60	3.70	3.50	3.54	13
Blue Hill -	3.50	3.40	3.60	3.70	3.50	3.54	8
Portland -	3.18	3.09	2.82	3.45	4.00	3.31	11
New Format	Call to Action	Asthma in Maine	It all Fits Together	Local Issues	Overall Rating		
Bridgton -	No evaluations received – combined with PTM Healthy Options Together (HOT)						
Rockland -	3.67	3.83	3.67	3.83	3.83	3.77	6
Lincoln -	3.40	3.60	X	3.60	3.60	3.55	5
Fairfield -	3.67	3.71	4.00	4.00	3.75	3.83	4
Ave. Score	3.40	3.39	3.43	3.56	3.53	3.46	107

* This number reflects actual evaluations returned, not the total number attending the Forums.

B. Common Themes

A review of 206 comments and pieces of information gathered at the Forums resulted in four common themes. No area in Maine felt untouched by asthma. Representative samples of comments for each theme are listed below.

1. Support and Coordination of Effort – 35% of the comments

Establish asthma support groups in the community; parents with kids group.
Mentor to help through the difficult times, School kids mentoring each other.
Would like a help line; Asthma help line with trained staff.
Create regional asthma groups; form an Asthma Coalition.
Need integration of care, interplay of providers, schools, hospital, community.
Need to develop the Care Model.
Lack of concerted effort, disjointed; Piggyback with other chronic diseases.
Needs to be a strong HMP–Hospital connection; develop local asthma champion.
Worksite wellness council; Insurance company’s wellness program – asthma.
Need to be sensitive to eliminating asthma health disparities.
Bring down to family level – how to manage your asthma; Getting asthma plans for each child.
Schools not responsive to needs of kids with asthma; Referrals to educators and specialist; Schools should have nebulizer and inhalers available.
Is there help for prescription drug costs; get pharmaceutical companies to help.

2. Information and Communication – 30%

Disseminate info on Best Practice guidelines, articles for physician’s library, booklets, to provider offices; plus asthma information for hospital-based needs.
Have health educator go to home – increase communication.

Information kit for schools and libraries, including educational sheets – for use in classroom and elsewhere. Provide asthma information at kindergarten registration.

Local social marketing, circulate asthma information and promote best practice guidelines for individuals in the community in local community newspapers (weeklies), with info for services for lower income folks. Communicate how to navigate health insurance system to get coverage they need.

Create an instructive interactive asthma website, including one minute asthma and video for school nurses to teach technique.

Need to share info, through HMP’s, using ITV and E-mail

Establish an asthma education resource library, with specific items. “Toys & Tools” manual for patients – with various visual aids and brochures, need asthma

toolkits – at the community level – including: resources, what can be done, activities, power point presentations, case studies

Should have a lecture series at places like - Lions Club, Town Meetings, Health Fairs, WIC, etc; An information booth at the Lobster Council–fisherman’s forum.

Provide a guide on where to get info, resource lists distributed, need opinions from those living with asthma, need to share causal factors with those with asthma, how to get help with Rx, tell where to get info on environmental pollution each day. Have asthma information in CMP/Bangor Hydro bills

Translate information for immigrant community – get an illustrator. Cultural issue more than language issue, more minority input

3. Education - 20%

Train clinicians, educate providers, so PCP provides asthma plan. Include adult asthma, and use of “air purifiers”. Use ITV – grand rounds Hospitals should offer community education focused on Asthma.

Provide presentations at workshop days for teachers - educate the educator. Need to integrate asthma into school curriculum - in small doses to digest. After school program for asthma education. Adult Ed - Open Airways.

Educate through Headstart – both kids and parents – early intervention. Coaches need to be educated about asthma.

Need to get Action Plans into Headstart, Daycare, and Preschool environments.

Hold support groups, use Public Health Nursing – asthma education as well as case management. Push education of plan and use of it.

Education at different levels – schools, worksites - ongoing asthma education in-services.

Promote education of self-management.

Connect with drug companies for community money, including asthma education.

Do a community lecture or luncheon presentation at health center for employees.

Asthma education at the community level – hard to get physician support, asthma educators, need to get into practices with action plans.

Need to teach patients, including youth, how to manage their asthma.

Send school action plans when doing the surveys (MCHS).

Have a fun-type learning day for kids – would help educate the youth about asthma. (Eastern Maine Med).

Certification programs – funding needed to go to Asthma certification

Train trainers to “systematize” education forums – not now organized

4. Environmental Concerns and the Workplace – 15%

Co-workers need knowledge too.

Action plan not available at the workplace.

Apply for MEHAF grant to address asthma in small businesses (10 or less employees) - how to best be proactive.

Concerned with building materials – offgassing – need to have information on house evaluation/building inspection. Need a “check-off” tool.

Physical Plant renovation fund – educate assessment for physical plant people.

Physical environment – getting kids involved in keeping things cleaned – “Cleanest Classroom Award”.

Problems with mold in schools/portable classrooms.

Get parents to quit smoking – need project-peer programs.

Landlords – mold, leaks, air quality - Landlords are closing rental properties.

Concerned about environmental impact of papermills.

Concerned about woodstoves – kind of wood we burn – woodsmoke.

Spring and fall pollen is a tough time.

Show how air currents move to reinforce that we are the “Tailpipe”.

C. Regional Issues

Central -

Fairfield/Skowhegan - Air quality – uncontrolled burns – connect with Health Officers in towns – need regional meetings

Lincoln - Papermill produces white stuff that gets into houses – even with doors and windows closed. Mill workers cough all winter.

Coastal -

Blue Hill - problems with boatbuilders, artists – one/two person businesses – no enforcement – unregulated – diesel – spraying

Rockland - Lobster fishermen – buoy painting – lead base

Rockland - Cement Plant – Cianbro

Eastern -

Washington County - Fish scale (pearlescence) industry (fingernail polish) for asthma impact.

Washington County - Crop dusting and field burning techniques for blueberry fields.

Northern -

Aroostook County - Northern Maine agriculture – pesticides, harvest-related injuries, protective respiratory equipment, pulp & paper, etc.

Western -

Bridgton - Low income a huge issue in our area –
Bridgton - Hancock Lumber mills –
Farmington - UMF – Smokers, diesel trucks, printing
Fryeburg – mountains – weather
Jay - International Paper

D. Summary of Strengths and Needs

Strengths – Resources

HMP (Healthy Maine Partnerships)
Healthy Community Coalition
Visiting Nurses
Hospitals
School Based Health Centers
Community
Healthcare/social services
Schools/childcare
Team approach, working together

Needs – Opportunities for improvement

Lack of knowledge of healthcare providers
Provider practices not receptive to “toolkits” or manuals
Difficult to get into physician’s offices, educate entire office
Realization of importance and seriousness of asthma in the schools
Improve school nurse to student ratio
School Nurse – has hard time with Action Plans. Difficulty getting actions plans back from doc’s offices Must advocate for the students to get plans in place.
Need Pre-school Action Plan
Lack of environmental controls related to asthma
Disjointed efforts in dealing with asthma
Need to teach asthma self management
Money issues – cost of asthma – medication costs keep rising
There are no guidelines at ER for asthma
Lack of sustainability of asthma efforts – need local coalitions
Lack of care, access to healthcare, low income, no insurance, provider knowledge, long distance to care, need written tool, cost of medication/inhalers – people sharing meds, parents do not understand instruction.
Need to capture disparate/minority data, State Plan too generic, not inclusive of underserved communities.

Community Concerns:

The Communities are:

concerned about having adequate/appropriate information about asthma
concerned about provider/physician education and knowledge
concerned about workplaces contributing to asthma
concerned about the environment
concerned about control of asthma, resulting in absenteeism from school and work
concerned about the ability of partners to work together and sustainability of effort

V. OPPORTUNITIES AND RECOMMENDATIONS FOR ACTION

A. Opportunities

The people of Maine are eager to learn about asthma. They want accurate and usable information. They want information that is readily available. They want to be provided with tools to work with. They want support and want to support each other.

It is clear that people and programs interested in addressing asthma in Maine must continue to reach out to the communities. The people of Maine need and want to be part of information, support, and action related to asthma. They want asthma friendly policies at schools, in the workplace, and in their communities. They want a healthcare provider network that is knowledgeable about asthma and one that communicates freely and easily with those in the asthma management/self-management cycle.

Most of all, the people of Maine are intelligent, interested, and eager to assist in addressing asthma. As much as possible, we need to provide that opportunity.

B. Recommendations

1. Efforts to integrate asthma information and management into Healthy Maine Partnership objectives and activities should continue. The Care Model should be used as a guide.
2. Mini-grants for asthma action at the community level should continue to be awarded. Information learned should be shared and activities replicated.
3. The Maine Asthma Council and Maine Asthma Prevention and Control Program should work together to promote community-level activities as prescribed in the Statewide Asthma Plan. These activities must include: dissemination of data, provider education, asthma self-management, environmental issues, and forming local coalitions.
4. Regional Asthma Forum participants should, 1. be kept informed and included, especially about specific issues raised at the Forums, and 2. be invited to an annual conference on Chronic Disease management, facilitated by the Chronic Disease Programs at Maine CDC.

VI. SAMPLE DOCUMENTS

**A. Maine Asthma Forum Evaluation
October 11, 2005 – Lincoln, Maine**

Please rate each section according to the following:

1. Not Useful 2. Somewhat Useful 3. Useful 4. Very Useful

Introduction: 1 2 3 4

Comments: _____

Asthma in Maine: 1 2 3 4

Comments: _____

Asthma in the
Community: 1 2 3 4

Comments: _____

Overall Rating of
The Forum: 1 2 3 4

Comments: _____

How can we improve our
Forums? _____

Profession: _____

B. **Regional Community
Asthma Forum**

“Where Every Breath Counts”

Rockland, Maine – October 5, 2005

AGENDA

- | | |
|--------------------|---|
| 5:30 – 6:00 | Welcome - Introductions
Light Buffet |
| 6:00 – 6:10 | Ken Huhn – Call to
Community Action |
| 6:10 – 6:30 | Dwight Littlefield –
Asthma in Maine |
| 6:30 – 6:45 | Dick Aronson –
It All Fits Together |
| 6:45 – 7:30 | Asthma in the Community |

C.

You are Invited to a Community Gathering: Let's Talk About Asthma

**SOMERSET HEART HEALTH, HEALTHY LIVING,
HEALTHY HORIZONS AND THE MAINE ASTHMA
PROGRAM**

Join Somerset Heart Health, Healthy Living, Healthy Horizons and the Maine Asthma Program for a community gathering to learn about and discuss the issue of asthma. We will be talking about Asthma Action Plans and sharing tools designed to help manage asthma.

Date: October 27, 2005

Time: 5:00 PM – 7:30 PM

Where: Good-Will Hinckley

Dinner will be provided!

Working together as a community, we can help reduce the number of asthma attacks through awareness and management.

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