Pediatric Asthma Action Plan

A Comprehensive Community Plan to Address Pediatric Asthma for the City of Buffalo

A CALL TO ACTION

- The people of Buffalo have a unique opportunity to improve the quality of care and the quality of life for asthmatic children and families living in poverty.
- This report describes the effects of pediatric asthma on the Buffalo community and includes the information you need to join the effort to combat this widespread community health issue.
- This is your opportunity to take action and make this Pediatric Asthma Action Plan a reality.

Community Health Foundation of Western and Central New York

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Why should the City of Buffalo focus on the issue of pediatric asthma?

Pediatric asthma is an issue that demands Buffalo's attention, as the situation is particularly dire. Community statistics illustrate the critical need to address pediatric asthma in the City of Buffalo now:

- More than **60 percent of children in Buffalo live in poverty, and one-fifth of them are also asthmatic.**

- Buffalo remains in the top 100 — and number two in New York State — **most challenging places to live with asthma,** according to the Asthma and Allergy Foundation of America.

- Recent studies have **linked Buffalo's asthma problem to environmental toxins,** the Peace Bridge area, and other hazardous waste materials and industrial sites.

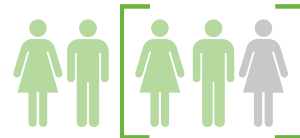
Nationwide surveys have found:

- **Asthma is a leading chronic condition** among children in the United States today.

- **Asthma is far more pervasive within communities of poverty.**

- **Asthma that is controlled allows children to participate** in typical childhood activities relatively worry-free.

More than three out of every five children in Buffalo live in poverty. At least one of them also suffers from asthma.



Background

Coming Together

Great things happen when communities come together to address important issues. That's why the Community Health Foundation positioned itself as the catalyst for the creation of a comprehensive community plan to address pediatric asthma in the City of Buffalo.

Almost two years ago, the Foundation initiated this effort by convening a community-based task force including pediatric health care providers, organizations, and dozens of community leaders and other stakeholders who wanted to help improve the quality of life and care for asthmatic children and their families in Buffalo. The group was charged with developing a community-based plan that would embrace a collaborative and coordinated approach to addressing the challenges of pediatric asthma.

Specifically, task force members assembled for four work sessions in order to:

- Develop a shared understanding of the impact of pediatric asthma in the City of Buffalo
- Review current initiatives intended to help asthmatic children and their families
- Identify the best practices found in research and other community-based pediatric asthma initiatives that have been implemented throughout the United States
- Craft specific goals, objectives, and strategies for a community-wide asthma plan
- Assemble work groups tasked with achieving the goals, objectives, and strategies defined in the community plan

As part of the development process, the group also discussed the key components found in other successful community-based programs and agreed on the necessity of broad community buy-in, cross-sector leadership, and a sustained effort. They further determined that the plan would need to identify the responsibilities for participating work groups and organizations and establish mechanisms for accountability, effective communication, and information sharing.

Community Voices

At the request of the task force, the Community Health Foundation hosted several focus groups in Buffalo neighborhoods where pediatric asthma is particularly prevalent. In these groups, parents of asthmatic children spoke of the challenges they face on a daily basis. The key areas of concern and common problems that the parents highlighted both informed and helped guide the development of this plan.

Community leaders and parents of asthmatic children supported the need for a community-based plan that embraced a collaborative and coordinated approach to addressing the challenges of pediatric asthma.

Pediatric asthma is a community health issue that can be addressed in a coordinated and comprehensive manner here in Buffalo.

Introduction

Letter from Ann Monroe

President Community Health Foundation of Western and Central New York

I am very pleased to introduce the **Comprehensive Community Plan to Address Pediatric Asthma for the City of Buffalo.** This plan represents the collective work of many individuals and organizations over the past 24 months and belongs to the Buffalo community. But a plan is only the beginning. The community's sustained effort, commitment and creativity will be required to achieve the effective and enthusiastic community collaboration needed to help Buffalo's asthmatic children reach their full physical, emotional, and academic potential.

The Foundation has a long-standing commitment to improving the health of children in Western and Central New York communities of poverty. As the third poorest city in the country, Buffalo contends with sub-standard living conditions, low wages and literacy levels, and increasing dependence on costly emergency room care for routine health needs and avoidable crises. Combine these systemic challenges with a population of children where more than three of five live in poverty and one in five has asthma and you can see why the Foundation chose to make this issue a priority.

When we began exploring possibilities for addressing these challenges, we discovered many programs and organizations trying to help asthmatic children and their families in our community. However, they often functioned in crisis mode, struggling from day-to-day, operating in isolation of other stakeholders, and closing their doors or canceling programs when funding ceased. Insufficient coordination among stakeholders was also resulting in wasted resources. Because leadership across sectors had not emerged, there was no standardization of care and no uniform way to measure trends and results of existing pediatric asthma work.

Also, through an environmental scan of other communities, we discovered that successful community-based pediatric asthma programs share several key components. These include: broad community buy-in; cross-sector leadership; sustained efforts; clarity of roles and responsibilities; mechanisms for accountability and effective communication; and information sharing.

Thus, in May 2007, an active work group of interested and committed participants began the development of a purposeful, collaborative, and outcome-driven community plan for impacting pediatric asthma in Buffalo through clear and feasible implementation strategies. While the Community Health Foundation remains invested in carrying out the plan, we cannot do it without full involvement of the Buffalo community. **Please join with your colleagues in this call to action to achieve better health for our children.**

First things first, adopting a framework

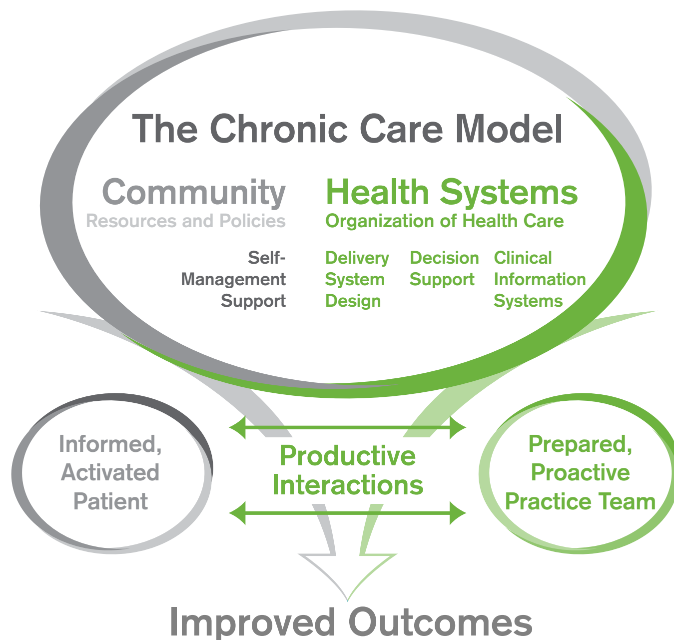
The Chronic Care Model

Pediatric asthma impacts children and their families most directly. However, this chronic disease also affects the communities in which asthmatic children live, receive medical attention, and attend school. The Community Health Foundation and the task force understand the importance of adopting a framework that considers these realities.

At the Foundation's recommendation, the group considered and adopted the *Chronic Care Model* developed by Dr. Ed Wagner and the MacColl Institute. The model recognizes that the patient, providers, community, and health systems must work together to ensure the best outcomes and quality care for the patient – this model can be applied to the treatment of any chronic illness.

The model supports a coordinated effort by identifying the elements of a health care system that are most essential to facilitating high quality care and treatment of a chronic disease, such as pediatric asthma.
The elements include:

- Health Systems
- Delivery System Design
- Decision Support
- Clinical Information Systems
- Self-Management Support
- Community



For more detailed information on the Chronic Care Model, visit:
http://www.improvingchroniccare.org

Components of successful community asthma plans

In developing the Buffalo community asthma plan, the task force and Community Health Foundation sought to learn from successful plans implemented elsewhere in the country. They gained valuable insight from the *Asthma Health Outcomes Project (AHOP)*, which was conducted by the Center for Managing Chronic Disease at the University of Michigan's School of Public Health. The project was funded through a cooperative agreement with the Indoor Environments Division of the U.S. Environmental Protection Agency.

Asthma Health Outcomes Project (AHOP)

AHOP sought to better recognize and understand the hallmarks of successful asthma programs. The project's goal was to identify common themes and features of asthma programs that both addressed links between asthma and the environment and reported a positive impact on asthma-related health problems.

To distinguish itself from traditional academic research projects, *AHOP* used a combination of literature searches and grassroots efforts to identify successful community asthma plans. The researchers conducted a global effort by asking communities from around the world to participate in the nomination process. Between 2003 and 2005, *AHOP* catalogued more than 500 asthma programs from across the United States and around the world.

The project also surveyed the 223 programs that reported improving at least one asthma-related health outcome. This effort allowed *AHOP* to identify the common features in communities that most effectively **decreased emergency room visits, improved quality of life, and saw fewer missed days of school or work.**

AHOP found that the communities with the highest success rates had implemented asthma programs that addressed environmental triggers through extensive coordination between health care providers and local communities. The most successful programs dealt with the environmental factors that exacerbated asthma symptoms using a variety of approaches, including education for health care providers and intensive home visits with follow-up support to families.

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Components of successful community asthma plans

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How the *AHOP* informed our planning process

At the time the task force was first convened, *AHOP* had just released its preliminary study results. Therefore, the task force actions and assessments were based on *AHOP*'s Preliminary Field Report, which focused on the 111 programs that published results in peer-reviewed journals.

AHOP's preliminary quantitative analyses suggested that programs are more likely to report a positive impact on health outcomes if they:

- Work with health care providers.
- Have close ties to the communities they seek to assist.
- Collaborate with other agencies or institutions.
- Follow established steps of program development in order to meet the needs of the community.
- Are tailored to meet individual participants' needs, particularly when it comes to sensitivity to environmental triggers.

AHOP's final report entitled, "Asthma Programs with an Environmental Component: A Review of the Field and Lessons for Success," published in December 2007 confirmed their preliminary findings. In doing so, *AHOP*'s final report also validated the Buffalo task force decision to create a plan that is collaborative, clinically connected, and community-centered.

To learn more about the *Asthma Health Outcomes Project* and to download a copy of the final report, visit: **www.asthma.umich.edu.**

We're not in this alone

While *AHOP* provided invaluable insight into the **components of successful pediatric asthma plans,** the task force continued to seek out other programs and strategies for combating pediatric asthma. We researched and synthesized information about what other communities around the country were doing to help us develop an effective community asthma plan for Buffalo.

In the course of our research, we were surprised to find that while many communities were implementing programs to manage their local pediatric asthma challenges; the programs focused on school, home, or provider education programs separately and were *not* targeting all three at the same time.

We found only one example of a program that provided support to community-based coalitions that were implementing **comprehensive pediatric asthma management programs;** that program was the *Allies Against Asthma* program.

Allies Against Asthma

Allies Against Asthma, a national program funded by the Robert Wood Johnson Foundation, provided support to community-based coalitions that were implementing comprehensive pediatric asthma management programs. Between 2000 and 2006, the *Allies* program awarded $12.5 million to support seven community-based coalitions, their targeted activities, and site-specific program evaluations. Coalition efforts included improved access to and quality of medical services, education, family and community support, and environmental and policy initiatives. The primary aims of the program were to:

- Reduce hospital admissions, emergency room visits, and missed school days.
- Enhance the quality of life of children with asthma.
- Develop a sustainable strategy for asthma management in the community.

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We're not in this alone

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The components of successful asthma programs identified by *AHOP* were also incorporated in the *Allies Against Asthma* program. All foundation funding for all *Allies Against Asthma* coalitions ended in July 2006, evaluation and dissemination activities are expected to continue past 2008. The Robert Wood Johnson Foundation is currently working with the University of Michigan to complete the evaluation of this initiative.

We anticipate that the final report on the *Allies Against Asthma* initiative will serve to further promote the community-based coalition model for implementing successful pediatric asthma programs. For more information on the *Allies Against Asthma* research visit: **http://www.asthma.umich.edu/About_Allies/Evaluation/findings.html**.

Allies Against Asthma participant communities

Buffalo, and many of the *Allies* communities, share similar issues including high asthma rates, particularly in communities of color and poverty and fractured systems of care. *Allies Against Asthma* participant communities included:

- Seattle, WA
- Milwaukee, WI
- Long Beach, CA
- Washington, DC
- Philadelphia, PA
- Norfolk, VA
- San Juan, Puerto Rico

All of these cities encompass highly industrialized areas, generating tons of environmental pollutants each year. All of these cities have large populations living below the federal poverty line and many of the children are without access to ongoing preventive health care. Buffalo shares most of these same characteristics, which prompted the task force to replicate many of the *Allies'* goals, objectives, and strategies in its own plan.

Thus the Buffalo Pediatric Asthma Action Plan objectives include:

- Reducing hospital admissions, emergency room visits, and missed school days;
- Enhancing the quality of life for children and families living with asthma; and,
- Developing and implementing a sustainable strategy for asthma management in the Buffalo community.

Goals, Objectives, and Proposed Strategies

The task force and Community Health Foundation want to emphasize the importance of including extensive community outreach, home-based interventions, health literacy, and a focus on prevention and using existing resources efficiently, as major components of the Buffalo plan. In addition, we must ensure there are uniform metrics in place to measure pediatric asthma outcomes.

Community Participation

Community participation in developing and implementing the Pediatric Asthma Action Plan in Buffalo is critical to its success. As such, the task force and the Foundation asked the Buffalo communities that have been directly adversely impacted by pediatric asthma to evaluate and prioritize the proposed goals and objectives based on their understanding of Buffalo's pediatric asthma needs and concerns, as well as the focus group results.

Here are the goals identified by the community participants in order of priority:

Goal One: Develop a sustainable strategy for asthma management in the community.

Goal Two: Optimize care delivery and training for providers.

Goal Three: Improve self-management skills among children and families.

These goals are consistent with the Chronic Care Model framework and reflect the *Asthma Health Outcomes Project's (AHOP)* principles of successful asthma programs. Other communities, such as the *Allies Against Asthma* communities, have met similar goals using a variety of strategies. These communities can serve as models and mentors in the development of similar strategies for Buffalo. **On the following pages we will elaborate on the objectives along with some sample strategies that can be used to achieve these goals in Buffalo.**

The Buffalo Pediatric Asthma Action Plan

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The Buffalo Pediatric Asthma Action Plan

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The Role of the Community Health Foundation

The Community Health Foundation is committed to supporting the work of the task force as it continues developing the Pediatric Action Plan for Buffalo. At the same time, the Foundation is actively seeking a local entity that can assume the day-to-day responsibility of overseeing the implementation and ongoing activities related to implementing the plan and measuring outcomes. The Foundation will continue to convene the work groups until a new entity is identified.

The Need for Operating Principles

The task force also agreed that the work groups needed operating principles to guide them in communication, leadership, and collaboration. In particular, the task force saw a need for principles defining members' roles and distributing tasks and responsibilities among them.

Some of the *Allies Against Asthma* communities provided models for doing this. For example, in Seattle, the King County Asthma Forum's strategic plan included a formalized structure with clearly delineated committee structures and functions, decision-making rules, and a conflict resolution mechanism. This approach was adopted from: **http://www.metrokc.gov/health/asthma/bylaws.htm.** Interviews and a closed-ended coalition member survey revealed the effectiveness of these coalition-building efforts.

Goal One

Develop a sustainable strategy for asthma management in our community.

The task force agreed on the importance of training children and their caretakers to respond to asthma attacks and the needs of asthmatic children.

Successful Examples

The *Allies Against Asthma* communities offer a useful model for doing this. Each *Allies* community created a standardized asthma action plan. In addition to providing instructions for medication use and physician contact information, this one- to two-page color-coded document lists specific steps to take when asthma symptoms occur.

The document is distributed to schools, childcare providers, family members, and other individuals that asthmatic children may come in contact with. This activity's success depends on input from parents and other caretakers.

Task force members also wanted to include strategies that family members and caretakers can use at home to identify and assess their asthmatic children's needs. Several standardized protocols for home care can be found in the *Allies Against Asthma* communities. For instance, the Milwaukee Healthy Homes Demonstration Project educates families and provides home and allergy testing, and the King County Asthma Forum's Master Home Environmentalist© Program trains volunteers to reduce exposure to asthma triggers in the home. More information on these programs can be found on the *Allies Against Asthma* web site (see link on next page).

The Need for Cultural Competence

Projects like these necessitate cultural competence in recruiting and training workers and educating families. The task force also emphasized the importance of recruiting asthma community workers who understand and can effectively interact with the community they serve. King County Asthma Forum, for example, recruited and trained multilingual community members to visit families and provide education, resources, and case coordination to improve asthma management.

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Goal One

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The Role of Public Policy

Community-based efforts alone may not guarantee quality asthma care. As the task force discussed, local and state legislative policies — including housing ordinances and environmental policies — may need to be changed as well. The following *Allies Against Asthma* communities have produced policy changes that benefited asthmatic children in their communities:

- King County Asthma
- The Long Beach Alliance for Children with Asthma
- The National Capital Asthma Coalition

For more details on these communities' successes, please visit the *Allies Against Asthma* web site: **http://www.asthma.umich.edu.**

Engaging the Community

Effective asthma management in Buffalo will require greater community participation. Activities that can increase involvement include:

- Conducting interviews with key informants
- Arranging meetings with community leaders and key organizations
- Holding community summits
- Conducting focus groups
- Inviting media coverage to all work group events

Allies Against Asthma communities offer useful examples for putting these activities into practice. To learn more, visit **http://www.asthma.umich.edu/.**

Goal Two

Optimize care delivery and training for providers.

The second goal requires implementing a consistent asthma care education program for providers. Several task force members expressed an interest in implementing the Physician Asthma Care Education (PACE) program in the community (see link below).

The PACE program is an interactive, multi-media educational seminar designed to improve physician awareness, ability, and use of communication and therapeutic techniques for reducing the effects of asthma on children and their families. This two-part program also teaches physicians how to document, code, and improve asthma counseling reimbursement. Two studies have already substantiated the PACE program's effectiveness. These studies, along with the full PACE curriculum, is available at: **http://www.nhlbi.nih.gov/health/prof/lung/asthma/pace/index.htm.**

Other Training Models

Allies Against Asthma programs provide additional training models. Fight Asthma Milwaukee, for instance, offers a six-hour asthma management seminar that helps nurses, office managers, medical assistants, outreach workers, and health profession students improve the asthma management education they provide to clients and their families.

Fight Asthma Milwaukee has also championed a Teach Asthma Management workshop for nurses, clinic staff, and health educators. The workshop provides guidelines on asthma care and demonstrates teaching techniques and communication methods to help families improve self-management. A modified version of the workshop has also been used to train public school nurses.

To entice providers to attend training sessions, the task force recommended offering incentives such as Continuing Medical Education, Continuing Education credits, or free meals. Pre- and post-course tests or surveys could help gauge the success of training programs.

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Goal Two continued

The Need for Clinical Care Coordination

Task force members also noted a need to facilitate clinical care coordination for participating families. Community meeting participants agreed that a trained advocate for the child and/or family should be identified before case management services begin.

Alianza Contra el Asma Pediátrica en Puerto Rico's Clinical Care Coordination Program provides one useful model. The program, which was adapted from a local managed care asthma disease management program, links nurse coordinators, community health workers, and clinicians to assess, refer, and follow up with patients and their families.

As noted in Goal One, all training and educational materials for health professionals and families and children must consider cultural needs. Because Buffalo's poor and ethnically diverse communities are hardest hit by asthma, any asthma care and education must be sensitive to the needs, practices, and interests of different cultures. Task force members were interested in following the lead of many *Allies* communities, which have held cultural competency workshops for service providers.

Goal Three

Improve self-management skills in children and families.

The task force felt strongly that the Buffalo community plan must empower children and their families to manage their asthma. To do this successfully, the work groups will need to investigate the necessary types of education, as well as the outlets where such education can be provided. Education programs and materials must account for the literacy levels and cultural differences of patients and their families.

Resource Centers

Many task force members also stressed the importance of developing both a physical and virtual asthma resource/support center to provide education and coordinate services. Given the costs and logistics associated with such centers, the working groups will need to research currently operating asthma resource/support centers further.

Some communities that have established resource/support centers include:

- Alianza Contra El Asma Pediátrica en Puerto Rico distributes a community bulletin in their target area.
- CINCH in Norfolk, Virginia, which features revolving hands-on, interactive education stations that teach asthmatic children and their families about asthma management.
- Long Beach Alliance for Children with Asthma situated its Asthma Resource Center in the heart of the priority community to give residents access to basic asthma information, resources, and referral services.
- King County Asthma Forum offers a toll-free, bilingual support line that connects asthmatics to community and medical resources.
- Philadelphia *Allies Against Asthma* uses an integrated telephone-based intervention to provide information, referrals, service coordination, and follow-up assistance to families of asthmatic children. Coordinators follow each participating family for four months and provide long-term support services.

Next Steps

Over the next 18 to 24 months, the Community Health Foundation will assist in convening the work groups.

The Community Health Foundation will work to ensure that each work group has clearly delineated leadership and communication channels and that each committee defines its role and distributes tasks among team members. To increase community outreach efforts, each work group will arrange interviews with key informants, as well as meetings with other community leaders and key organizations. Each committee will also help ensure that service providers demonstrate cultural competency.

Organizing

Based on the goals identified in this action plan, the task force and Community Health Foundation have identified the following work groups:

- **Community Sustainability** will focus on Goal One: Develop a sustainable strategy for asthma management in our community.
- **Provider Training and Care** will focus on Goal Two: Optimize care delivery and training for providers.
- **Education** will focus on Goal Three: Improve self-management skills in children and families.

As these work groups convene they will have the opportunity to define their own roles and tasks. The following are some suggested committee activities –

Community Sustainability

- Disseminate the National Heart, Lung, and Blood Institute's 2007 guidelines in a user-friendly format; these guidelines could be shared in the form of written guidelines, workshops, or PowerPoint presentations.
- Discuss methods for ensuring the plan's dissemination to all appropriate caregivers.
- Collaborate with the Community Sustainability work group to review home care protocols and determine the best plan for identifying allergens in the home and helping families eliminate these allergens (or, at the very least, minimizing exposure to them).

- Recruit families and other culturally competent workers to be trained on implementing the home care plan and sharing it with others.

Provider Training and Care

- Select appropriate training facilities and faculty to teach the Physician Asthma Care Education (PACE) curriculum.
- Use materials and resources from the *Allies Against Asthma* communities.
- Examine other workshops and identify facilities that are well equipped to provide workshops for health care providers and community advocates.
- Investigate case management services and develop a process for identifying a child advocate in the family.

Education for Children and Families

- Identify and evaluate available asthma education programs that target families and children.
- Select asthma education programs for community-wide use (including families and children).
- Review programs for cultural competency and literacy levels.
- Research currently operating asthma resource/ support centers (similar to those implemented by the *Allies Against Asthma* communities).

Monitoring local, state, and national policies

All committees will be charged with monitoring local, state, and national policies that might influence the ability to achieve the plan's goals. Committees can propose policies and work with the appropriate agencies to ensure policies exist that will promote the community plan and impact pediatric asthma in Buffalo.

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Next Steps

Each work group will play a critical role in implementing a community plan that enables Buffalo's asthmatic children to thrive.

Next Steps

continued

This is your opportunity to take action and make this Pediatric Asthma Action Plan a reality.

How You Can Help

Task force members may volunteer for committees of interest to them. **Interested participants may choose to participate in more than one committee.** Volunteers may also make referrals and recommend other members. This can help ensure that the work groups represent all facets of health care, community-based organizations, and parent groups.

Early in the process, groups may need to meet frequently. With express permission of all group members, the groups may hold ad hoc meetings via conference call or e-mail. To ensure good attendance, work groups should hold meetings at community centers and other locations that are convenient for all members. If meeting sites are not conveniently located, work groups should provide transportation for community members, including parents, advocates, and other childcare providers.

The asthma plan will be launched and monitored over the next 24 months. As the work groups strive to achieve the four goals outlined by the task force, they may develop additional ideas, goals, and objectives. Progress on the community plan's goals and objectives will be measured and reconfigured as needed.

Currently, the Community Health Foundation is looking into ways that it can support the plan to combat pediatric asthma in Buffalo, both over the next 24 months and on into the future. The next steps that the Buffalo community takes will be crucial to the plan's success. By embracing a collaborative approach to pediatric asthma, the people of Buffalo have a unique opportunity to improve the quality of care and the quality of life for asthmatic children and families living in poverty. Please join the Buffalo community in making these visions a reality.

The people of Buffalo have a unique opportunity to improve the quality of care and the quality of life for asthmatic children and families living in poverty.

Task Force Members

The task force played an invaluable role in developing the community asthma plan. We are grateful for the input and guidance of all of the task force members, including:

- Asthma Coalition of Western New York
- Buffalo Public Schools
- Catholic Health System
- Catholic Independent Practice Association
- Center for Asthma and Environmental Exposure at the University at Buffalo
- Community Action Organization of Erie County, Inc.
- Community Health Center of Buffalo, Inc.
- Diocese of Buffalo, Department of Catholic Education
- Erie County Health Department
- HealthNow New York, Inc.
- Fidelis Care
- Head Start
- Independent Health
- Jericho Road Family Practice
- Kaleida Health
- Northwest Buffalo Community Health Center, Inc.
- Univera Healthcare
- University at Buffalo Department of Family Practice
- Western New York Public Health Alliance
- Women's & Children's Hospital of Buffalo
- Amber Slichta, Program Officer, Community Health Foundation

Consulting Team

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Download and **share** copies of the plan.

BUFFALO COMMUNITY
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