

# **Parents of Children with Asthma Final Report**

**Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil**

**August 26, 2002**

## **Introduction**

The American Lung Association (ALA) received a grant from the Center for Disease Control (CDC) that focuses on improving the quality of life and outcomes of children with asthma in Minneapolis and St. Paul. The grant is part of the national “Controlling Asthma in American Cities Project.”

As a piece of the overall grant, the American Lung Association contracted outside evaluation<sup>1</sup> consultants to conduct a series of focus groups with parents of children that have been diagnosed with asthma. Eight focus groups and three key informant interviews were conducted in Minneapolis and St. Paul from June through August 2002. The focus groups collected information related to the educational needs of the families, factors that influence patient outcomes, and health care system issues that impact a family’s ability to manage asthma. Focus group participants were recruited to reflect racial-ethnic, socio-economic and educational diversity. One group was conducted in Spanish, and key informant interviews were conducted in Somali and Hmong. Details on recruitment and findings from individual focus groups follow in this report.

## **Key Findings**

Information from the focus groups and key informant interviews are summarized and presented below. Individual focus group reports are found in Appendix A.

### **BACKGROUND ON THE CHILDREN’S ASTHMA:**

The children with asthma ranged from the ages of five months to seventeen years old and had mild, moderate, and severe asthma. Some children received care from their pediatricians, asthma or pulmonary specialists, while teams of specialists handled severe cases. Medical treatment for asthma included use of preventative and controller medications, and hospitalizations. It is significant to note high asthma rates in one group (FG3), ten of the eleven families present had multiple children with asthma, and the other family was a single child family.

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<sup>1</sup> Dr. Jane Maland Cady and Dr. Gale Mason-Chagil conducted the focus groups for the ALA.

## EDUCATIONAL RESOURCES DESIRED BY FAMILIES

- **Parents overwhelmingly wanted support groups for parents and for asthmatic children of all ages. They indicated that they liked sharing with and learning from other parents that have experience with asthma. Many groups indicated that they would also like to have an informed asthma expert present as a resource for questions and concerns.**
  - I think that the people I have been in contact with, like support groups, other parents affiliated with this, of kids that are asthmatic, are experienced about knowing what to do and what not to do. Like I didn't know that when my baby first got sick that I had to rip up the carpet and stuff, and then one of my friends said, well if you take up the carpet and get rid of your animals and do this and this...I think that I learned a lot from other people that were going through the same situation.
  - They should have support groups for just the kids, so they don't have to feel different, or have to feel left out, or feel so afraid.
- **Parents wanted more educational opportunities such as classes and camps for parents, asthmatic children of all ages, children without asthma, teachers, daycare workers, recreation center staff, school staff, school nurses, neighbors and family members. Group classes might not be effective in the Somali community (KI1). Parents desired affordable and subsidized classes and camps covered by insurance and other organizations.** Parents suggested that education on asthma should be as common as CPR, and that everyone should understand and recognize asthma.
  - You know, think about it, a lot of kids have it [asthma], and they teach about sex, why shouldn't they teach them about asthma. Why can't my kids go to high school to learn about asthma?
  - Education and communication is a huge deal, that is the only way we are going to get it out to each and every person out there, because even if you are not a parent with an asthmatic child you might be a grandparent with an asthmatic child in the future. We all need this kind of education. Especially schools and hospitals, hospitals need to become more of an in between, and not be so nonchalant about [children] having asthma.
- **All families wanted quality one-on-one time with doctors and nurses to better understand asthma.** They wanted doctors to take more time to get to know the patient, to assess the symptoms and diagnose the patient's condition, and to inform the family more fully about their child's asthma and treatment options. In addition, the ability of medical staff to communicate effectively with non-English speaking parents and children is critical (KI1, KI2, FG7). Parents (FG2) indicated that they would like to have an asthma case manager or asthma clinic (FG6) that would help them address the management of asthma and integrate all the individuals involved with their children's asthma
  - The doctors need to give more detail. They hear the same thing [from patients] 20,000 times a day and they don't explain well enough to each patient. Everyone is different.
  - The doctor is the one seen to be the "wise-man" [to Somali's], the one who knows. Nurses too [are respected], they do a lot of teaching.
  - I like learning from the doctors. I want to know what they are doing
- **Parents suggested a variety of formats to learn about asthma, which differed based upon experience with asthma and individual educational levels.** Individuals with children with mild asthma conditions or whose children were newly diagnosed with asthma wanted more easily accessible and practical information presented via videos and pamphlets, or other simple reading materials. Individuals with children diagnosed with moderate to severe

asthma were more interested in knowing the most recent research on asthma, including drug therapy and causes and cures of asthma. Information about asthma should be communicated orally for cultures with oral traditions, such as Somali (KI1) and Hmong, via radio, television, video, or one-on-one.

- For someone that has a child with asthma, nothing is new.
  - Who the hell is going to have time to sit down and read when your baby can't breathe?
- **Many families were satisfied with asthma related support organizations and information, while a few families suggested that environmental advocacy and lobbying groups should focus on asthma and air quality issues (FG2). A few families also desired more information on the effects of air quality on asthma, as well as holistic medical perspectives of asthma (FG2, FG5).**
    - I've dabbled with the ideas of holistic healing. I want to stop the problem. I want them to stop focusing on the medicine part of it and the after care, and fix the problem.
    - They should focus on preventative medicine. They could get a statement from doctors regarding air quality. The AMA finally said something about gun violence, why can't they talk about air quality?
    - Environmental groups need to get behind the increase in asthma issue.

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Parents with asthmatic children are impacted emotionally and socially. Parents commented that they worried about their children, some felt angry, some felt frustrated, they missed work (some even lost jobs), many parents lost sleep at night, and some spent extra time trying to be an advocate for their child with schools, clinics, and hospitals.**
  - I became very angry and wondered why this is happening to me, am I being punished? It was very frustrating for my husband and I. We'd say, "Here you take him, I don't know what to do." It was tiring and emotional and trying and horrible.
  - It's just hard for me. I miss work. It's hard on both of us. I don't trust anyone but my husband or I. When she coughs I know she is going to get it.
  - But it does sort of change your life because I'm always apprehensive that he is going to over exert or get exposed to something, you know and that it will spiral. It certainly changed the way we plan our activities, or the way we monitor him, and the freedom we give him, whether he can go to a friends house, or if the day care has equipment, sorting through it all has been pretty confusing for us. We've been able to manage it and we've avoided hospitalization for last year and a half which I am thankful for, but it still comes up
  - It seems like it is a common diagnosis so people sort of dismiss it, and yet it colors your whole life, especially like going out to a restaurant, it is terrifying.
- **Some parents restricted children's activities, while others did not.** For example, some children did not participate in sports, social outings, visiting friends and family, or sleepovers because of their asthma. If they did, they educated others about asthma and made sure their support systems could respond to an asthma flare-up.
  - My son has a friend that would like him to stay overnight, but the parents smoke and I don't let him.
  - I explain to all Pete's friends. They all know what to do. They know how to use the nebuliser. You know if he wakes up at night they all know how to put the medicine in and they just give it to him, so that way he can spend the night somewhere, and if he needs help all his friends know how to help him.

- **Most parents believed that they were ultimately responsible for managing their children’s asthma. This included medical care, administering medicine, arranging proper support and medical care in their children’s daily activities. However, when it came to identifying a flare-up some parents believed that they were responsible for intervening, while other parents believed that it is the child’s responsibility to manage their asthma by communicating with the parent, or other caregiver, when they don’t feel well.** The identification of symptoms and the administration of medication was not always age dependent, although the older the child, the more they tended to assume these responsibilities.
  - I told my son, your health is your responsibility. I can help you with it, but you are going to have to tell me when you feel uncomfortable. Anything that makes you feel uncomfortable, even when he was three, you have to tell me. That is him taking his responsibility too. All through his life I told him, you have to manage your health if you have diabetes. It is your life. I told him talk to me, talk to anybody, talk to the daycare provider. Because there are a lot of times that they aren’t even with you. A lot of time in the day they are visiting a friend, or visiting a relative, or are at daycare, or at school, and you have to tell somebody if you don’t feel well. You have to know how to read your symptoms inside yourself.
  - He’s not mature enough to say he wants his medicine.
  - My daughter is 17 so she is really responsible for hers, and she takes it seriously, but any little thing she reacts to it. But my other daughter is different.
  
- **The parents were very knowledgeable about reducing triggers in the home, and when possible, they improved or changed their home environment.**
  - When my baby started having all these upper respiratory problems, they tried to tell me it was the dust, it was the house, so we de-housed our house, you know. I got rid of all the carpet...you know, anything you can do to try and help your kid breathe because my baby at that point was gasping like [gasp, gasp, gasp], and when you are a mom and your baby is gasping you will do whatever it takes.
  
- **Some parents were concerned about the side effects and use of steroids and other medications, while others believed they were necessary to effectively control their child’s asthma. Several families spoke of the difficulty of treating asthmatic children with multiple medical conditions (FG2, FG4, KI2).**
  - They said that the steroids could inhibit his growth, so we don’t know if he is going to grow up and be as big and strong as we hoped him to be... We were told that he had to take his medicine twice a day for the rest of his life. I don’t actually follow that, but it’s horrible to be told that you are going to have to give your child something like that...forever...I’m really angry.
  - When they told me about my son, that he was going to have to take the meds for the rest of his life, I looked at the doctor and said, “I don’t think so, he’s only seven.”
  - If you have a chronic illness, you have to face facts, you have to look at your day and see what you have to do to manage. My son needs to take something or he is in rough shape.
  
- **The majority of parents said that they work to treat their children's asthma symptoms at home with reliever medications. If these efforts were not adequate, they would seek outside medical attention for their children. Parents then visited clinics, urgent care clinics, and made emergency room visits. Several focus groups (FG6, FG8) said that asthma was so serious that they would call the ambulance to ensure that their children received appropriate care in a timely manner.**

- Calm them down first, you gotta' get them calm. Then you treat them with a medication, and if that doesn't work, you call 911, or go to the hospital.
- I call 911 so the ambulance come and treat them right away. ... If you have real chronic asthma you only have like four minutes to get air into your lungs.
- **Some parents consistently used an asthma action plan, yet many did not. Some did not understand them (KI1) or were not informed about them by their doctors (FG4).**
  - I heard you say about a plan...I went to the doctor and I didn't get a plan. I just have to make my own plan.
  - Not many Somalis know how to use the asthma action plan, or what is this for. It is one of those many things from the hospital. They end up in the trashcan.
- **Some parents accept the fact that their children have asthma, while others resist the idea that the symptoms of asthma constitute a chronic disease (FG4, FG8, KI1, KI2).**
  - The biggest problem is to admit that their child has asthma. They will say that my child has cold, maybe the flu at the worst, but not asthma. It's a big challenge to understand that their child has asthma.
  - I don't know if I am in denial because I don't want my son to be sick. I have a hard time accepting it. I think that I should get a second opinion, because you know besides tracking it with a peak-flow meter, there is no actual test, am I right?

#### **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **Many parents expressed the desire to have consistent medical providers for their children because of relationships that they developed over time and improved understanding of the medical history and unique family situations.**
  - My kids have the same doctor since they were both born. They've never really had any problems. [If you go to a different doctor.] they have to learn their history and all this and that. They've had the same doctor since day one.
  - My pediatrician has spent a lot of time with me, I'm very satisfied with her, and my allergist is really good too, but the few times we were in the hospital I felt like the doctors were in and out and every time one came in, it was a different doctor, and you had to tell your story all over again, and my regular doctors are great.
- **Parents wanted doctors and nurses to provide quality medical care. This included a thorough understanding of asthma, taking time to fully diagnose and discuss treatment options in understandable ways, and being friendly and empathetic. It is important to continue to provide interpretive services to families with English as a second language (FG7, KI1, KI2).**
  - Sometimes when the doctors treat a kid, [they] give him a prescription and never really tell the parent what is going on. ... The prescription, they say give him this at this time, but that's it. But they don't really tell you, make you feel comfortable like you're getting the information, that it's about your child or about my child. You got a right to know.
  - Can I ask you something; I don't understand the basis of this. I take my son into urgent care, and he is not getting any better with the nebuliser, so a doctor, that of course he has never seen before, puts him on Prednizone. The nebuliser didn't work. Let's just say it wasn't asthma, and the nebuliser didn't work because let's say it is pneumonia. Why would an urgent care doctor do that? And then he tells me, you've got to find a

pediatrician. So I went to the pediatrician and I told him I didn't like the Prednizone. I want to go to a specialist.

- **Parents said that doctors do not diagnose asthma consistently. Some doctors diagnosed asthma while others would not. The child's age sometimes seemed to be factor in the diagnoses.**
  - My thirteen month old was diagnosed at four months. The doctors really don't want to diagnose asthma at that age. He gives her the neb every time she is wheezing and it might or might not be asthma.
  - They gave me the asthma treatment because technically they can't diagnose as asthma until they are over two, but they give you the asthma treatment and everything that goes with the asthma. They can't call it asthma, but they know... they see the symptoms and everything, but legally they can't call it asthma, until after two.
  
- **Overwhelmingly, parents said that health insurance or medical assistance was necessary for them to care for their children's asthma. Some people were very satisfied with the prescription coverage and support for equipment; however, others were not because the co-payments were expensive, the number of prescriptions was limited, or insurance company changes limited access to coverage. Some parents felt that providers were biased against people with medical assistance and as a result families did not receive timely or quality services (FG3, FG4, FG6).**
  - My daughter had to have medication for school, but they would only let us have one inhaler. Because if they don't have the inhaler at school they can't use it, they can't use someone else's inhaler.
  - I have to follow protocol. I have to call the nurse line about whether to come in and sometimes you have to wait up to two hours to hear back. You have to get prior authorization for an ER visit otherwise it is the patient's responsibility. That happened to me once.
  
- **Many parents felt that they had to be advocates for their children within the healthcare system for a variety of reasons, while others followed the diagnosis and treatment of the doctors with little challenge (FG3, FG7, FG8, KI1, KI2). Serving as an advocate included deciding whether treatments were appropriate for their children and intervening to encourage or discourage specific prescriptions.**
  - I was taking him to Y hospital, and I kept telling the doctor. "I think he has asthma," ... ever since he was like two months [old] and I took him to all his well-child check-up, and the doctor told me, "Well I'm the doctor. I know." He doesn't. So, I said, "well okay, when something happens to my son and there is lawsuit. I think you'll be bothered to check it out." He gave us Prednizone for a week and it still didn't clear up. And then I switched him over to Z hospital, cause he had a severe asthma attack.
  - No, he is not on them [steroids] no longer. I took him off, because it was too strong for his body. It used to have him zoned out.
  
- **Parents wanted quality medical care available to their children at school. They preferred that full-time nurses be available to assist their child throughout the day, but many schools had part-time nurses. Parents also suggested that day care providers, recreational center workers, teachers, and other school staff be knowledgeable about the symptoms and intervention strategies for asthma. Parents questioned individual school policies related to the administration of medicines at school.**

- One of my sons...he left his inhaler at home and he needed it and he told the teacher that he needed his inhaler. "Oh," the teacher said, "you go home and get it." He said, "YES!" He was about to walk home and he was barely breathing, in the cold. Now if that teacher were educated enough to know that when you are having an attack, you can't be walking anywhere. Luckily, they were able to get her [emergency contact person] and she was to go to the school. ... "I'm not going to give him permission to walk home. He is wheezing, it's cold outside, and he is walking by himself. I'm going to come, I'm going to get him, we are going to get the inhaler and I'll bring him back to school." ... The staff really needs to be educated on how to handle asthma cases when they are having an attack what to do.
- I think they should educate the schools, the teachers and those who are working in the school, not just the teachers, but the people in the cafeteria, the childcare people, the people who monitor the playground, they should educate them to be able to detect a time when a kid is in trouble and know what to do when a kid is in trouble. So that is something that we need really bad and they should get on it right away, if they have my say so.

## **Methods**

ALA grant project managers and evaluation consultants collaboratively developed the focus group protocol and framework for conducting the focus groups (See Appendix B). They also worked together to develop a recruitment plan and share community contact names.

### **RECRUITMENT**

The evaluation consultants contacted over 35 community based organizations, school programs, medical clinics, and hospitals. Each organization collaborated differently with helping recruit the focus group participants. Some distributed a generic flyer that advertised the focus groups and provided a phone number at the ALA to contact if individuals were interested. Others recruited participants for the groups from their clients (See Appendix C). A list of the organizations contacted and recruitment methods used is presented in Appendix D.

After individuals indicated interest in focus group participation, the ALA, the evaluation consultants and/or the collaborating organization contacted them with specific times and dates of the focus group. In some cases, a confirmation letter was sent; in other cases confirmation was made by phone. Individuals received 35 dollars, a light meal, on-site childcare, and transportation reimbursement as incentives for participation.

### **FOCUS GROUP DETAILS**

As previously stated, the goal of the focus groups was to talk with parents that have children with asthma who lived in Minneapolis and St. Paul. Five focus groups were conducted in St. Paul and five focus groups in Minneapolis. Evaluation contractors and ALA staff aimed to recruit participants that represented the racial-ethnic distribution of reported asthma cases; however, participants were not actively recruited to attend specific racial-ethnic focus groups. Thus, most groups represented a mix of race-ethnicities. The only groups that were organized for specific racial-ethnic groups were the Spanish-speaking group, the Hmong group, the Somali group, and one African American Group in Minneapolis. In summary, we interviewed 94 parents that have children with asthma, and provided child care for 81 children. The percentage of the total for each racial-ethnic group follows.

| <b>Racial-Ethnic Identification</b> | <b>Number of Individuals in Focus Groups/Interviews</b> | <b>Percentage of Total Participants (%)</b> |
|-------------------------------------|---|---|
| African American                    | 40  | 43  |
| American Indian                     | 10  | 11  |
| Asian (Hmong)                       | 2   | 2   |
| Caucasian -                         | 18  | 19  |
| Latino                              | 23  | 24  |
| Somali                              | 1   | 1   |
| <b>TOTAL</b>                        | 94  | 100   |

More complete details about focus group locations, collaborating organizations, and make-up of groups may be found in Appendix E.

## **LESSONS LEARNED**

The focus groups were advertised as opportunities for parents to learn more about their children's asthma. This was a very effective approach because many parents arrived at the focus groups wanting to learn more and expecting to participate in an asthma class. Since people were very interested in learning more, available resources were shared with them. For example, brochures on asthma from the American Lung Association were provided for them and the Family Asthma Project was explained and they were able to sign-up. Parents were also asked to sign-up if they were interested in serving on a parent advisory committees for the larger asthma project in the future.

Effective recruiting methods and attractive incentives were two other major factors that lead to the successful completion of eight focus groups and three key informant interviews. General flyers were successful in recruiting families for several focus groups; however, recruiting through established organizations or existing groups was much more effective (e.g. Asthma Camp, Sharing and Caring Hands, Family Medical Center-Hennepin County). Results were more effective when clinic and social service organizations personally invited clients to participate. The two exceptions to this were the Somali and Hmong communities where personal invitations yielded little interest.

The low turn out for Somali and Hmong focus groups needs to be studied further. There may be cultural reasons that parents were not inclined to participate in a focus group or to discuss asthma. For example, a key informant said that Somalis do not come to classes (KI1). It was suggested that a Somali group be convened in a residential community by resident from that community (KI1). Also, perhaps Hmong parents showed little interest in participating because they do not believe asthma is a chronic disease since symptoms are often intermittent; therefore, parents did not see the purpose in meeting (KI2).

One theme that developed from the focus groups was that doctors diagnosed asthma differently. This problem may have influenced the outcome of the Hmong group. A clinic worker began inviting Hmong families to the focus group. Initially she thought she had 100 families with asthmatic children to contact. In the end, only 12 children were diagnosed with asthma. The others were diagnosed with bronchitis and difficulty breathing. The differential nature of asthma diagnosis was also apparent with the Spanish-speaking group. The clinic invited families to participate because the record showed that they had an asthmatic child. However, two families,

of sixteen total, said that they did not know why they were invited to the group because they had never heard, or understood from their child's doctor, that they had asthma .

Generally, one to three days before the group, participants to reminded of the time and date in a phone call, and provided directions. Some participants received letters, but generally, phone call reminders without a letter were very effective ways of encouraging parents to attend. In the beginning groups were arranged for both the morning and the early evening, but the evening groups were the most popular.

We felt that the incentives consisting of 35 dollars, a meal/food and on-site childcare were attractive to families and greatly influenced the overall turn out of the focus groups. It was important to make it clear to participants that the cash incentive was limited to one per family, as often a couple would attend the group together. None of the parents rejected the cash incentives, though some people expressed surprise that they were offered. Childcare was provided on site with at least one childcare worker for each five to seven children. Problems developed when a single adult was left to care for too many children. During the reminder phone call we asked parents how many children they were bringing, however, often parents brought more children than they initially reported. Also, the flyer should clearly state that the childcare is provided "on-site" and facilitators should clearly explain to participants that they will not be reimbursed for childcare in their home. Overall, the most effective entertainment for the children was pizza, a juice box and a cartoon video. We also had age appropriate toys, group games (such as hang man or other word games), drawing, and board games.

### **Summary**

Parents provided detailed quality information based on their experiences related to educational resources desired by families, factors that influenced patient outcomes, and healthcare systems issues that impact a family's ability to manage asthma. Parents stated that more education was needed for themselves, their children, and people who care and educate their children. Parents also said that having children with asthma impacted everyone in the family, including the asthmatic child, the parents, and siblings. Finally, parents said that access to insurance and insurance policies that ensured quality care for their children was key to managing their children's asthma. The result of these focus groups will be used to adapt and improve the care of children with asthma in Minneapolis and St. Paul.

**Appendix A.**  
**Focus Group Reports and Key Informant Interviews**

# Parents of Children with Asthma Focus Group One Report

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
June 11, 2002

## Key Findings

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

The parents in this group had a total of nine children with asthma. They ranged in age from three years old to nine years old. Five of the children were diagnosed with RSV between four and six months old while the other four were diagnosed between one and two years old. The children's asthma was described as mild to severe. One child had been hospitalized for asthma within one month of the group. The children were prescribed inhalers, nebulisers, and given oxygen when needed. They were also using the following drugs: Albuterol, Prednizone, Singulair, Pulmicort, Advair, Cromolyn.

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **Parents wanted to learn information from a variety of sources, including doctors, books, the internet and other parents.** One parent said that when her child was diagnosed they already had previous experience with siblings and her own parent, which helped her manage her child's asthma.
  - I like the books. I get some information from my doctors, but I don't 100% rely on them. Because they kind of go with what the hot medication out there now is. So when YY drug came out, "oh let's try YY." Now there is ZZ drug, "let's try ZZ drug." So everything new that comes out, they want to try. So I'll just read about it, maybe go on the internet, and talk to other parents.
  - If I'm bored I do research on the internet...if I have questions about [something] I'll ask their doctor because she has worked really closely...because their physician has been seeing them both since they were babies.
  
- **Parents reacted differently to the information provided to them by their children's doctor.** Several parents said that they were tired of hearing the same basic information from their healthcare providers and receiving the same pamphlets on reducing triggers and how to administer drugs. At the same time, some parents did not understand how to run the equipment.
  - What makes me mad is, you know that your child got asthma, every time you go in, they tell you the same stuff, over and over again, every visit. Tell me something. Tell me how to get rid of it, don't keep telling me about the medicine. Make sure he is not around smoke.
  - Every time you go in, "Does anyone smoke?" I'm like, "nobody smokes around the child," you are telling them right to their face, "nobody smokes around them, it just comes on when it wants to come on."
  - That breathing thing, where you take the test for breathing, I guess there is a brochure on how many breaths you can take, and they go so many times. I mean I still can't tell that.

- **Several parents said that their insurance providers offered asthma classes.** One parent said that a class on the drugs was helpful, but other parents said that the classes should not be mandatory because they were very well aware of the drugs and how to run the equipment.
  - Like the brochures they give you, you know you already know that...[they tell me] no "you have to go to this class. You have to go to a pharmacy class now. That's recommended." They supposed to teach you about the medicines and them things...I already know. They say it's mandatory now.
  - I've already had to deal with it, why do I got to go sit in on a class and learn how to plug in a machine and turn a button on?
  
- **Parents said that mutual support from other parents would be beneficial for them.**
  - Other parents...it seems like it's easier if people are all knowing about the same thing. Then going some place and everybody is trying to get all the answers from one person. And everybody here...see like word about of mouth right here, we learned about the asthma pillow, learned about all these different kinds of inhalers.
  - 'Cause I figure you learn more from people in your community or from wherever, as long as it's a group, you can discuss what you had and what they had, and there you go.
  - Them doctors give you the machine, show you how to work it and give you all the pretty much the same kinds of meds. That's the teaching they give you. You learn more from talking to other parents, people that have it and experience.
  
- **Nurses who visited the home also helped parents learn about asthma, in addition to providing resources to support the family.**
  - But then when she started getting sick that's when we asked the nurse to continue to come in and show me the right way of handling the equipment...And when to call the doctors, and when not to call them?
  - I don't have a phone upstairs and I can't keep running up and down the stairs to get to the phone, so they got us one of these cell phones that you keep in your house and like if your baby has an attack, you push a button and it will connect you to the health connection or something.

## **FACTORS THAT INFLUENCE PATIENT OUTCOMES**

- **Parents had ideas about the causes of their children's asthma.** The most prevalent idea in the group was that smoking during pregnancy might have caused the asthma, while one parent disagreed and said that one of her children is fine despite the fact that she smoked during pregnancy. Other causes cited included heredity, lead dust and the changes in weather.
  - I think it has something to do with us being pregnant, how well we eat, because my brother has asthma very bad, and don't none of his four kids have it. I think it has to do with how we treat ourselves when we are pregnant, what we eat, and like smoking, being around people who smoke, and stuff like that.
  - I didn't smoke and I wasn't around smoke while I was pregnant. So I mean, how my son got it?
  - What I'm wondering [is] if it's hereditary.
  - When we moved into our first apartment after she was born, I thought maybe it was my fault we were doing the lead project, they were teaching us how to dust the things and clean the air conditioner out. You know, if you don't clean your air conditioner out and things can get into their lungs. ... She started getting sick, I mean she was just constantly throwing up and you could see her ribs start going in and out. She had to be at least three

to four months old, tiny, and to see her ribs get sucked in like that, to be heaving like that. I'm like freaking out, the paramedics came and got her, her breathing wasn't normal. I was thinking, what am I doing, what did I do to her.

- **Parents said that they had to be advocates for their children's asthma within the medical system.**
  - I was taking him to Y hospital, and I kept telling the doctor. "I think he has asthma," ... ever since he was like two months [old] and I took him to all his well-child check-up, and the doctor told me, "Well I'm the doctor. I know." He doesn't. So, I said, "well okay, when something happens to my son and there is lawsuit. I think you'll be bothered to check it out." He gave us Prednizone for a week and it still didn't clear up. And then I switched him over to Z hospital, cause he had a severe asthma attack.
  
- **Parents were generally aware of the triggers of their children's asthma and worked to reduce the triggers in their homes.** Common triggers included: smoke, dust, weather changes, cleaning detergents, and head colds. Families made many changes to their home including use of asthma pillows, special pillowcases, vaporizers/humidifiers, and cleaning regularly. Moving to residences with cleaner air quality helped one family.
  - There is no smoking in my house. You either have to go outside or you don't come in period. Get mad if you want to, you know what I'm saying? Because dang, my son has asthma ... no smoking period.
  - I think a lot of it has to do with, I was in that lead the project, too. That's when mine was getting a lot of his treatment because they were trying to get the lead out of my house, so it was really bad. After we moved out of that last house, he pretty much slowly quit having to use the nebulisers and taking the medicine.... The dust, plus the smoking.
  - You can't avoid asthma, but you can probably reduce it by cleaning a little bit more and getting a little bit more fresh air.
  
- **Some parents said that when their child had a flare-up, they offered the child hot tea or coffee.**
  - Outside if he is running for a long time, overactive, he'll have an asthma attack, but this may sound weird, if my son is having an attack, I give him hot tea. I was giving him coffee.
  
- **Parents said that they were responsible for managing their children's asthma, but parents said that children as young as five years old were able to administer their own medicine.**
  - It was my responsibility to keep him away from the things that would make him have to do his nebulisers, because he was on the Albuterol, the treatment, it used to scare me because he would do a treatment and he would lay there and his eyes would roll in the back of his head, it used to be scary watching that. I used to tell the doctors, he acts funny when he gets that treatment and stuff. They said that that was normal.
  - I monitor him, but he knows exactly what to do and when he needs it, I don't have to tell him any more. If it's time to take one, he'll automatically go to his drawer, pull it out....at about five [years old], and he knows to take alcohol and wipe them out and wipe the mask off.
  - My daughter knows [how to use the equipment] but she hasn't been on the meds over six months, so I kinda' think she is growing out of it. My baby he hasn't been on the nebulisers much either. It's just when the seasons change and I have to do everything for

- him, he's still too little. ... [but] he knows how to put the medicine in and put the mask on and sit down and do it himself, but I have to help him.
- I am, but like she said the machines are easy. I'm sure if she was taught she'd learn real easy 'cause everything is premixed.
- **Some parents were concerned about the use of steroids and overuse of medications by the children.**
    - I could see that the more steroids that she was taking, the more harder it was for her to stay up and her brain start working, but ever since we took her off them, you know, I guess she is alright now.
    - I had to take my son's inhaler away from him 'cause he was depending on it like 24/7. "I need it Mom, I gotta' breathe." It was all in his head, so I only want to give it to him when I see him wheezing, otherwise he *will* use it anytime he can.
  - **Parents recognized that asthma manifested differently for each person, and the parents said that they knew their child's illness better than anyone.**
    - Everybody cases is different. Like my son, he can run and play, play sports, I mean, his asthma doesn't affect him like that.
    - They [school people] don't understand the characteristics [of her child's asthma] to watch for. Like with every kid they are different.

#### **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **Consistent and quality medical care is very important to parents.**  
*Parents said that they were happy when their children received treatment from the same doctor.*
  - My kids have the same doctor since they were both born, they've never really had any problems. [If you go to a different doctor] they had to learn their history and all this and that. They've had the same doctor since day one.

*Doctors diagnosed asthma differently.* Many of the children in this focus group were first diagnosed with RSV as infants, and later the doctors began to call the illness asthma.

  - Most of them [RSV cases] were not being diagnosed as asthma, but that's what it was being treated as, they had like upper respiratory problems.
  - [When do they call it asthma?] When they get older...when they become dependent on inhalers and nebulisers.
  - [Child was diagnosed with asthma] when he went in for a cold, at the clinic. Because he had been getting sick, and I switched doctors because they should have known that when he was little [that he had asthma], and they didn't, so I switched clinics, and then they told me.
- **Parents questioned the authority and procedures of doctors related to their children's asthma.**
  - The doctor's really don't know all that much. Maybe they know what they're doing, but sometimes they put him on too high of a dose. They give him too much.

- **Parents expressed concerns about the cost of medication and wanted to know more about programs that could help them pay for their children's medication.**
  - The funding to pay for it. ... it's costly, their medication.
  - They are like eighty bucks, depends on what kinds they have on them.
  - I had a question. Is there any kind of program out there to help pay for children on asthma. If you don't have medical assistance?
  - It can be kind of spendy. I pay out of pocket.
  
- **Insurance companies and healthcare providers have expectations for the families that some parents said might not be reasonable, while other families were very happy with the equipment and support provided by their insurance providers.**
  - The nebuliser thing, came off the insurance thing. So when the first daughter was not having the attacks any more ... when I had the second daughter [three years later] they expected me to have all this stuff still. ... the machine had to be cleaned. I took it in to them, they were supposed to have it cleaned for me, or replace it with a new machine. I didn't have the mask, the tubing was just filled with dust, and hot water didn't clean it. So we just left it at his mom's house. So they were trying to say, "Well, we can't charge the insurance company because you've already had this machine and you had all the stuff to it." ... I couldn't bring her down here ... for every two hours or run to them and say that she needs a treatment, so that's when a nurse came back to visit us. She brought that machine [and took it], if she needed it in the middle of the night and [I] take her downtown to the hospital.
  - Like, if I'm missing a piece, I just call this phone number and they come out, they'll come out and clean it, when I ask for a piece, they bring it. They'll bring a filter, too.
  
- **The process of medication clearance for day care providers and schools sometimes interfered with a child's medical treatment.**
  - You got to have to doctor's permission. You got to sign a release form for their children, for the [day care] providers to give them medicine. My baby was sick one day but they would not give her medicine....By the time I got her, she was [breathing heavy], you know.
  - I have had to sign something for the nurse at school. Your doctor fills out this asthma thing, you just bring it.
  
- **Parents said that teachers, school staff, day care providers and others who care for children needed to be educated about asthma the treatments.**
  - My son's teacher took his [inhaler] away. Because she caught him doing it in class. Like he is supposed to step up out of the class and go do it in the hallway. If he is having an attack he'll do it right there.

# Parents of Children with Asthma Focus Group Two Report

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
August 26, 2002

## Key Findings

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

The children with asthma ranged from the ages of one year to sixteen years old and had mild, moderate, to severe asthma. Some children received care from their pediatricians, or asthma or pulmonary specialists. Medical treatment for asthma included use of preventative and controller medications and hospitalizations. The parents in this group (all mothers) were a mix of racial-ethnic groups, with one African American, one Hispanic, and seven Caucasians.

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **Parents wanted educational support groups for parents, children with asthma and siblings. Parents who had participated in a support group made positive comments about them.**
  - I like learning from other parents
  - They should have parent groups – new [asthma] parents with old [asthma] parents.
  - I have to admit, I have noticed they have given me so many pamphlets and support groups, and I have been educated more this year on asthma. I think it is a great responsibility on the clinics, on the doctors to give you and your child this type of information
- **Parents wanted asthma education for the general public.**
  - Education and communication is a huge deal, that is the only way we are going to get it out to each and every person out there, because even if you are not a parent with an asthmatic child you might be a grandparent with an asthmatic child in the future. We all need this kind of education. Especially schools and hospitals, hospitals need to become more of an in-between, and not be so nonchalant about [children] having asthma.
- **Parents wanted quality one-on-one time with doctors and nurses in order to better understand asthma and their child's treatment.** Those parents who had one-on-one attention with their care providers were very satisfied with the interaction. Others suggested that there is a need for an asthma care manager or case manager, particularly for new asthma families.
  - They really need to educate the parent, when you are in there with the child and you don't know what is going on and they are doing all this and that and giving them this medication and that, you need to ask them why. My first question whenever they prescribe something for my son is, what are the side effects of that medication? What are you doing to my child? I work in the hospital and I am one of the rudest people there is when it comes to my kid. I'm sorry; this to me is an experiment, what they are doing to our kids.

- I like learning from the doctors. I want to know what they are doing
- We have a nurse that calls once a month and she really cares and keeps on the meds and is it working.
- **Families wanted more information on the effects of air quality on asthma, as well as holistic perspectives of asthma.**
  - They should do modeling for air quality or research for asthma incidences and air quality.
  - [They should] focus on preventative [care], get a statement from doctors regarding air quality, the AMA finally said something about gun violence, why can't they talk about air quality?
  - I've dabbled with the ideas of holistic healing. I want to stop the problem. I want them to stop focusing on the medicine part of it and the after care, and fix the problem.
- **Families wanted support for asthma from other organizations and networks. They suggested that environmental lobbying groups begin to focus on asthma and air quality issues.**
  - Isn't there a lobbying group, an arm of the ALA that somebody could get behind all the parents of children that have asthma, to do some lobbying for air quality?
  - Environmental groups need to get behind the increase in asthma issue.
  - The MPCA should have air alerts daily.

## **FACTORS THAT INFLUENCE PATIENT OUTCOMES**

- **Parents with asthmatic children are impacted emotionally and socially. Parents commented that they worried about their children, some parents felt angry, some felt frustrated, they missed work, some felt all aspects of their life were impacted, and some spent extra time trying to be an advocate for their child with schools, clinics, and hospitals.**
  - I have a nineteen year old with asthma and a seven year old. Basically, I've been traumatized by it, since he was four months old. Just now it's getting under control. It's been pretty bad.
  - I found out about asthma on his first birthday. When my child started turning different colors and stopped breathing, I took him to the emergency room and found out he had asthma. It was very scary . . . I don't let him participate in a lot of activities which I know is wrong, you know when you experience your child in the hospital for a week you tend to change your perception about how and what a child can do.
  - I lost my job. I went to the ER three times per week and couldn't go to work.
  - But it does sort of change your life because I'm always apprehensive that he is going to over exert or get exposed to something, you know, and that it will spiral. It certainly changed the way we plan our activities, or the way we monitor him, and the freedom we give him, whether he can go to a friend's house, or if the day care has equipment, sorting through it all has been pretty confusing for us. We've been able to manage it and we've avoided hospitalization for last year and a half, which I am thankful for, but it still comes up.
  - It seems like it is a common diagnoses so people sort of dismiss it, and yet it colors your whole life, especially, like going out to a restaurant it is terrifying.
  - We have an action plan for babysitters, the school nurse, and teachers. We found two babysitters with asthma so they are really tuned into the kids.

- **Some parents restricted children's activities, while others did not.** Parents worried about the impacts on their children of limiting activities.
  - We aren't really encouraging him to play sports and I wonder what kind of social impact that will have on him by not playing sports.
  - I feel kind of weird because I don't keep my kids in on hot days, or cold days, they all play sports. Actually my five year old is down playing soccer right now. My sixteen year old was about two when he was diagnosed with asthma and the doctor said let him do what he can. All my kids play sports and they take their nebulisers.
  - We try not to restrict sports even though he has a moderate case of asthma, so we don't restrict him because sports, especially for boys, is so important
  
- **Some parents identified various causes of asthma, and others had many questions about the basic causes of asthma.** The grouped listed issues of air quality and genetics as causes.
  - How many other people experienced this [asthma diagnoses] around that time. I have no family history of asthma. The coal burning plants, particularly by the high bridge, started burning at 100 % capacities at that time. It's a turn of the century plant, unregulated, grand fathered in. This one is able to function. It is right about that time that summer that it started eeking out all sorts of particulate matter that he [her son] started coughing at night in July, but we didn't really have it diagnosed until December. [crying] I'm really angry about the air quality in the Twin Cities. I know it could be better. Exxon and the rest of them, they have so much money, and their shareholders in their company are not suffering. But our children are.
  - I worry about air quality. I used to live in Chicago and he was constantly sick. I moved to the suburbs and he got better, and then I moved here and he got better. Until recently, I started noticing that I had to pay more attention.
  
- **Parents believed that they were ultimately responsible for managing their children's asthma.**
  - The doctor has specifically told me he is old enough to use the inhaler and I don't think so. I am having a really hard time letting him go, and I think it will affect him in the long run, I think it will be a negative effect, but I am really scared.
  - I always trying to catch the asthma early, so he won't have to do to the hospital.
  
- **The group was very knowledgeable about reducing triggers in the home and when possible they improved or changed their home environment, but within limits**
  - I had to change my whole house. We bought an air purifier for 500 dollars. It helps but it made me angry. Here is my poor baby suffering, what can you do when you are watching your poor baby suffer? What can you do? Get angry with the doctors?
  - On the other hand I am not going to change my lifestyle so much that I create this pure environment for my child so he won't be able to cope.
  - We've altered our environment and give our 18-year-old cat a bath twice a week.
  
- **Some parents were concerned about the side effects and use of steroids and other medications, while others believed they were necessary to effectively control their child's asthma.**
  - They said that the steroids could inhibit his growth, so we don't know if he is going to grow up and be as big and strong as we hoped him to be. We were told that he had to take his medicine twice a day for the rest of his life. I don't actually follow that, but it's horrible to be told that you are going to have to give your child something like that...forever...I'm really angry.

- When they told me about my son, that he was going to have to take the meds for the rest of his life, I looked at the doctor and said, “I don’t think so, he’s only seven!”
- But now it’s like Singulair, Albuterol, you know all these meds can’t be good for him either, you know it just makes you wonder. That is what makes me angry is I am a person that doesn’t take any kind of medication and I have to be dying to even take a Tylenol, you know, that’s me. Now he is on four to five different meds and I just keep him on the meds and that seems to help, you know because I don’t want to be in the emergency room either.
- If you have a chronic illness, you have to face facts, you have to look at your day and see what you have to do to manage. My son needs to take something or he is in rough shape. If he doesn’t, he is in rough shape.

## **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY’S ABILITY TO MANAGE ASTHMA**

- **Consistent and quality medical care is very important to parents.**

*Parents describe consistent and quality care as doctors and nurses that took time with patients and families, got to know them and their unique situations, were empathetic, knowledgeable, and answered questions.* The group emphasized the importance of working with the same doctor, particularly a specialist. Those that had consistent care were very satisfied, as opposed to those that did not work with the same doctor, or have confidence in that doctor’s diagnoses.

- Do I stick with my family practice doc? Do I see the specialist? Do I watch him? Even though I have gotten good care, I have a lot of questions.
- Doctors need to spend more time with patients to better diagnose what they have.
- My pediatrician has spent a lot of time with me, I’m very satisfied with her, and my allergist is really good too, but the few times we were in the hospital I felt like the doctors were in and out and every time one came in, it was a different doctor, and you had to tell your story all over again, and my regular doctors are great.
- Doctors need to be more involved with their patients.

*Parents recommended creating an integrated team of public health professionals to help families that have children with asthma.*

- We need medical providers, care managers, social workers working together with those doing research and advocacy work. [They should] talk with physicians, in urgent care, clinics and ER’s so that they can make it all kind of fit together so that we aren’t having to fit all of the pieces of the puzzle together.

- **Affordable insurance coverage is important to families.** Several parents worried about the cost of medication.
  - I don’t understand why our country has the highest prices for their medications.
- **It was important for families to have schools with full-time nurses or other trained health professionals.**
  - We need better staffing and funding for school nurses.
  - When schools don’t have a school nurse, who is there to administer medications?

# Parents of Children with Asthma Focus Group Three Report

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
August 26, 2002

## Key Findings

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

The children with asthma ranged from the ages of five months to seventeen years old and had mild, moderate, to very severe asthma. Medical treatment for asthma included use of preventative and controller medications and hospitalizations. According to the parents, some of the children were born with asthma, while others developed it at different ages. The families sought medical help from the homeless shelter clinic, their regular clinic doctors, specialists, and one family had a nurse from Colorado that called monthly. The parents were a mixed racial-ethnic group, with nine African Americans, and five Caucasians. There were four fathers and ten mothers present. Ten of the eleven families present had multiple children with asthma, and the other family was a single child family. In the shelter, there are ninety-two families, and over thirty signed up to participate in the focus group, thus indicating a high asthma population of over thirty percent

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **Parents wanted more classes for parents and children with asthma. They suggested that the classes target parents, young children with asthma, teenagers with asthma, and the general population.**
  - You know, think about it, a lot of kids have it [asthma], and they teach about sex, why shouldn't they teach them about asthma. Why can't my kids go to high school to learn about asthma?
  - If the schools talked about it more the kids who don't have asthma would know how serious it is also
  - I think that people that don't have asthma should have the same information as the people that do.
  - There should be classes for teenagers and little children; all kids with asthma should attend class.
- **Families indicated that they liked learning from people that had experience with asthma, such as doctors, nurses, and other parents with asthmatic children.**
  - We learn from doctors and nurses, they know all about it.
  - I like to learn from adults, like somebody that has been there, that knows.
- **Parents suggested a variety of formats to learn about asthma including videos, reading materials and brochures, but they were not unanimous about the most desired format.**

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Having a child(ren) with asthma emotionally and socially impacts the parents and asthmatic children.**

*Parenting is impacted in a variety of ways with an asthmatic child.* Quality time with the children is limited because parents smoke away from their children, and parents worry about responding to the needs of all their children.

- I don't smoke with them in my presence, but then I'm always shooing them away because I am smoking, you know.
- I got four little ones, and when Sherry has got to do her treatment every four hours, it's to round up the other three and do a treatment on Mary. You know I manage it that's not the problem, but I'm just worried about in case Mary has a real bad one in the middle or the night or at 1:30 in the morning, I've got to dress all four of my kids and take them with me. I'd like help with this.

*Some parents restricted children's activities, while others did not.*

- It seems like every activity they want to do, they can't do. I just don't understand.
- You can't limit what they do, either they are too young, or they won't listen.

*Children with asthma often feel differently than their peers, particularly when they are teenagers.*

- The school too, our kids are a little bit older and we have one that takes it serious and the one that carries a pump and they are ashamed to do it in front of the other kids, they say the other kids aren't carrying it around, and they are hiding it in their lockers and stuff.
- My boy said, "it's not cool," and I said, "If you need it you need it."

- **Parents said that they and their children did not always understand the seriousness of asthma or recognize signs of a flare-up.**

- My daughter doesn't take this seriously. They don't do this in Illinois, they just give you the asthma pump. There are a lot of things the clinic here told us that we didn't know and they just diagnosed my ten year old with it too, and I don't think he takes it serious. A lot of kids don't take it serious
- I didn't take it seriously, you know, like my kids wheezed a lot. I couldn't tell. I thought they were just tired a lot.
- Doctors need to make us aware that it is really serious.

- **Some parents were aware of various causes of asthma, while others were not.** Some parents believed that you could only be born with asthma, and others believed that it was something you developed after birth. In some cases, different doctors provided conflicting information about the causes of asthma. Parents listed genetics, air quality, chemicals in the environment, and the weather as causes of asthma.

- I thought you had to be born with it; I didn't think it was something that just occurs.
- A doctor told me you aren't born with asthma; you just develop it over time.

- **Some parents believed that they had to manage their children's asthma, particularly when the children were younger. Children had different responses to managing their asthma.** Some parents also felt it was not possible to limit children's activities to prevent flare-ups.

- My one daughter won't do her nebuliser. She won't do her inhaler. She don't care, but my other daughter is totally the opposite. She will take her medicines when she is supposed to, my one daughter needs it more and the other is basically out of it.
  - They have been doing their own medicine for a long time.
  - They are bigger and so when they feel like they can't handle it they tell me.
- **Some individuals in the group were somewhat knowledgeable about reducing triggers in the home and when possible, they implemented those changes. Others were not aware of techniques such as the use of dust mite covers on mattresses and pillows.** Reducing triggers included; quitting smoking, limiting all smoke around children, limiting after effects of smoke around children, limiting smoke from fireplaces and campfires; limiting outdoor activities when weather triggered flare-ups, reducing mold and mildew, and having no pets.

## HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA

- **Consistent and quality medical care was important to most parents.**

*Parents described quality care as doctors and nurses that took time with patients and families to help them understand the scope of asthma. For those families with more severe asthma cases, specialists provided important care. Few families had been with the same doctor, but those that did commented on the importance of continuous care.*

- This clinic explains everything, stuff that I didn't even know. They break it down for you.
- We never seem to have a problem getting in. We had the same doctor for the girls forever.

### **Emergency Room staff should take asthma flare-ups more seriously**

- The ER needs to take asthma serious. Everybody else is more important. I think most of us here, you know you take them to the emergency room, you've done everything you possibly could by that time and nothing is working and then you are sitting there looking at your kid going through the same problem of not breathing and the doctor is not really doing anything about it either.

*Some parents perceived that hospitals and clinics prioritized care based upon their insurance provider. Families with particular insurance programs said that they received inferior care, such as longer waits for appointments and at the emergency room.*

- When I take her to the clinic down here they tell me the same thing, that you've got to get her in as soon as possible, when they find out what kind of medical insurance I got, then they start booking me out for a month later.
- Even with the medical center, I called to make my daughter an appointment the day before yesterday and because she is not wheezing, she just needs another pump and they want her to see a physician and her appointment isn't until August. I just want a pump for now and I will deal with the doctors in August. If she has an asthma attack, they recommend that I take her to the emergency room, and well it might not be so severe as getting to the ER and she just might need her pump.
- The specialty clinic is hard to get in to it takes a long time.
- A lot of these places like doctors and clinics, they need to stop frowning on insurance, so what if it is one insurance, or another, or whatever. I know someone has got to pay the

doctor bills, but that's why they give us insurance, because we can't afford the doctor bills anyway.

- **Parents wanted schools, preschools, and daycare facilities to be prepared to respond to the needs of children with asthma.** For example, they wanted clear policies regarding the use of prescription drugs and knowledgeable staff that could identify and treat asthma conditions.
  - At the schools, the nurse keeps her pump. So if she is going to have an asthma attack, she can get that asthma pump, and she is not allowed to walk around the schools with her asthma pump. They are afraid of another kid that don't have asthma getting it. If my child has an asthma attack and she is on the third floor on this side, and the nurse is in the basement on the other side, you know it is defeating the purpose of needing the pump.
  - I noticed that they said they can't keep their inhalers, and I know some schools have sent out some literature that kids can keep those now and I think it is important. I think a child knows how to responsibly use it
  - The doctor said it would be okay for her to run around in gym, it wouldn't harm her, but I think they need to put it on the school, you know, because they take it for granted, I don't want to end up coming to the hospital because she didn't take her asthma pump, or she wasn't paying attention to her breathing, running around.
  - My doctor sent a note, my kids go to Head Start, and now they have to a treatment there too.

# Parents of Children with Asthma Focus Group Four Report

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason Chagil  
August 26, 2002

## Key Findings

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

The children with asthma ranged from the ages of one year to seventeen years old and had mild, moderate, and severe asthma. Some children received care from their pediatricians, asthma or pulmonary specialists, or teams of specialists treated severe cases. Medical treatment for asthma included use of preventative and controller medications, and hospitalizations. Changes in the seasons influenced the type and amount of medicine given to control and prevent asthma flare-ups. Several of the children were diagnosed with asthma as infants. The parents, all female, were a mixed racial-ethnic group of six African Americans, three Native Americans, and three Caucasians.

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **All parents wanted support groups for parents and asthmatic children of all ages..**  
Many parents perceived the focus group as a support group and used it as such. Parents represented a range of experience and understanding about asthma, from those with children newly diagnosed to those having considerable experience with their children's asthma and with specialist care. Many questions were asked regarding diagnoses, use of medications, and reducing asthma triggers in the home. Those with some knowledge or opinion shared their ideas freely.
- **Parents wanted support for their children, specifically more asthma camp opportunities, especially for teenagers.** Most of the parents agreed that it was particularly important for teens with asthma to receive support because of the prevalence of peer pressure and struggles with self-image.
  - I wish they had a camp for teenagers.
  - At the same time, I still wish they had camps for teens. That is when body image and being different is important, and you might want to try and start denying your asthma because it is not cool, or macho for a guy, so having that as an outlet for a teen, I think it should go until 18. You know he went two years at 12 and 13, and by the time he figured things out, he was too old to go anymore, and he would have been a great counselor for the next group of kids.
  - One or two more groups that the kids could go to, more than just once a year in the summer.
- **Parents wanted access to free and affordable camps.**
  - The camp should be free. We couldn't go if we had to pay.

- **Families wanted quality one-on-one time with doctors and nurses to better understand asthma.** They wanted doctors to take more time to know the patient, to be with the patient, and to inform them more fully about their child’s asthma. When doctors did so, parents were very satisfied, particularly those families working with specialists.
  - The learning is a lot of times put on yourself. Again, I got a pamphlet and a little book to read, and was told to give him a medicine, and that is it.

## **FACTORS THAT INFLUENCE PATIENT OUTCOMES**

- **Parents with asthmatic children are impacted emotionally and socially. Parents commented that they worried about their children, they missed work, and some spent extra time trying to be an advocate for their child with schools, clinics, and hospitals.**
  - It hurts us real bad to see our babies not do the things that other kids do.
  - It’s just hard for me. I miss work. It’s hard on both of us. I don’t trust anyone but my husband or I. When she coughs I know she is going to get it.
  - It is important to be assertive. What I would do is draft a letter at the beginning of the school year and let them know on paper. Copy the principal as well as the school district that you have given instructions to the nurse as to what you want to happen, and then if my child comes home and has seen you, but you haven’t let me know in some way, then I would notify the school board. Anytime they medicate your child it is supposed to be on record.
- **Some parents restricted children’s activities, while others did not.** For example, some children didn’t participate in sports or social events because of their asthma.
  - It’s hard to deal with a child like that when she wants to go to Valley Fair, but I can’t allow it. I don’t want to make my mistake and she can do it this time, but not the next time, because if something did happen.
- **Some parents were aware of various causes of asthma, and others had many questions about the causes.** This group discussed a variety of causes including; roaches and bugs, smoking, smoking during pregnancy, genetics, and using Vick’s vapor rub on the child as a baby. Others questioned the causes, noting some people smoke a pack a day, and their children don’t get asthma. Others wondered if it could come at any age.
  - I’ve heard, I don’t know where, that a lot of inner city kids have asthma, rather than those in other smaller places.
  - This doctor told me, “If you want to smoke fine, but don’t kill your kid.”
- **Some parents believed that they were responsible for managing their children’s asthma, while other parents believed that it was the child’s responsibility to manage asthma by communicating with the parent, or other caregiver, when they did not feel well.** The responsibility of managing the asthma was not always age dependent. Some parents taught their children from a very young age that the child was responsible for communicating about their asthma. Other parents have teenage children that still relied on the parent to administer medications or to intervene when the child did not feel well.
  - She’s seventeen. I shouldn’t have to be keeping after her, “Take your medicine, take your medicine.”
  - I have to do the same thing with my thirteen-year-old daughter. She will see me nebulising my youngest daughter and she will come to me and say, “Mom, I’m coughing

- and my chest hurts,” she doesn’t know how to use a nebuliser since she is five? I say, “Why do I have to tell you that, you’re 13, why do I have to tell you something you know
- I told my son, your health is your responsibility. I can help you with it, but you are going to have to tell me when you feel uncomfortable. Anything that makes you feel uncomfortable, even when he was three, you have to tell me. That is him taking his responsibility too. All through his life I told him, you have to manage your health if you have diabetes. It is your life. I told him talk to me, talk to anybody, talk to the daycare provider. Because there are a lot of times that they aren’t even with you. A lot of time in the day they are visiting a friend, or visiting a relative, or are at daycare, or at school, and you have to tell somebody if you don’t feel well. You have to know how to read your symptoms inside yourself.
- **The group was very knowledgeable about reducing triggers in the home and when possible they improved or changed their home environment.** Reducing triggers included; quitting smoking, limiting all smoke around children, limiting after effects of smoke around children, no plug-ins, using lemon juice and baking soda for cleaning products, no carpet, no perfume, keep them healthy as possible, bundled up, prevent colds, no pets, and no air fresheners.
    - I am doing everything I can because I don’t want nothing to happen to my baby, nothing, and anything I can do I do it.
    - It was me or the habit and I kicked the habit.
  - **Some parents were concerned about the side effects and use of steroids and other medications, while others believed they were necessary to effectively control their child’s asthma.** For example, some parents indicated that the use of the inhalers and steroids was better than having their children sick, yet others believed that there had to be alternatives and were interested in trying new medicines.
    - I know this cough when it comes. This urgent care doctor put him on Prednizone, and I was really concerned about it because I don’t like Prednizone.
    - I hate to see any child be on medication that young.
  - **Parents did not consistently have or use written asthma plans.** Some families were very familiar with and used written asthma plans. Others had their plans “in their heads.” Another family did not know about written asthma plans, and thought she had to create her own, because the doctors did not discuss them with her.
    - I heard you say about a plan...I went to the doctor and I didn’t get a plan. I just have to make my own plan.

## HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY’S ABILITY TO MANAGE ASTHMA

- **Consistent and quality medical care was very important to parents.**

*Parents described consistent and quality care as doctors and nurses that took time with patients and families, got to know them and their unique situations, were empathetic, knowledgeable, and answered questions.* The group emphasized the importance of working with the same doctor, particularly a specialist. Those that had consistent care were very satisfied, as opposed to those that did not.

- I have had pretty good luck with the schools and the doctors as well. I've kept my child's same pediatrician, even though he [the son] is over six feet tall and 170 pounds. He'll be sixteen.
- When you go to the emergency room or urgent care you never get the same doctor.
- My granddaughter has the same doctor and the same school. She has been to asthma camp twice now and we have a nurse visiting. I'm pretty happy about it. Everything is okay.
- The doctors should take more time with the patients.
- Doctors need to be looking at it [the unique situation of the asthma patient] from a personal standpoint because everyone's got a different gig. It always seems that they look at it like there is mom and a dad and a dog and a house, and not everyone is like that.
- My kids and I have good doctors, thank you, Jesus.

***Doctors diagnosed asthma differently.*** All members of the group echoed the importance of finding the best doctor for their child. If families were getting conflicting diagnoses and were troubled by that, the participants in the focus group encouraged them to get another opinion.

- Can I ask you something? I don't understand the basis of this. I take my son into urgent care, and he is not getting any better with the nebulisers, so a doctor that of course he has never seen before puts him on Prednizone. So what's the basis of this? Let's just say it wasn't asthma, and the nebuliser didn't work because let's say it is pneumonia. Why would an urgent care doctor do that? And then he tells, you've got to find a pediatrician. So I went to the pediatrician and I told him I didn't like the Prednizone. I want to go to a specialist.

- **Consistent and quality insurance coverage was important to families.** About half of the parents were satisfied with their insurance coverage, and the others were not.

***Parents wanted consistent coverage when insurance companies experienced transitions.***

- When YY Medical Group goes through a transition, you suffer. It's not supposed to be about us, we shouldn't suffer. I'm paying for health care, and even if we weren't paying for health care, somebody is.

***Insurance companies should have prescription coverage that is more reflective of real-life circumstances.*** Parents commented that companies should provide several inhalers for children who live in split homes, or an extra inhaler to leave at school.

- My daughter had to have medication for school, but they would only let us have one inhaler. Because if they don't have the inhaler at school they can't use it, they can't use someone else's inhaler.
- I think [insurance companies need] better understanding about giving extra medications, you know, understanding if your child has to go to a split home.

***Insurance companies should be more supportive of the community.*** For example, ZZ Medical Group pays for asthma camp and provides other important community services.

- ZZ Medical Group is Johnny on the spot. You get more information from them. You get more things like this from ZZ Medical Group.

- **It was important for families to have schools with full-time nurses or other trained health professionals that practiced good communication with the families of the children with asthma.** There was a discrepancy as to how schools dealt with asthma related regulations, such as use of inhalers and reporting nurse visits to the families.
  - If there is no school nurse, there has to be somebody there responsible for a medical emergency.
  - I had a really bad incident with my school nurse this past winter. My daughter was sick. I think it had to do with the cold air and her bus stop is three blocks away, and she had to walk to it. So when she arrived at school her asthma started to kick in. And the nurse was there but she was too busy talking to another co-worker while my daughter was there. And she didn't say, "Can I help you Kate?" because she knows my daughter really well. And she just let Kate stand there and suffer. And when Kate came home I could tell because her eyes were glassy and watering and she always bites her bottom lip when she has a hard time breathing. And she told me, "Mommy, I tried to tell the school nurse but she didn't pay no attention to me," and I was so furious. The school nurse called and apologized many times and she even got Kate's bus to come and pick her up at the front door. I was just so furious. She could have collapsed.
  - I love my daughter's school to death, but I have had to harp and harp and harp to the school nurse, "So okay if my daughter has to come to see you for anything, whether it is to wipe her nose, or for an asthma attack, you don't have to call me, I will give you a form, all you have to do is sign it and say Mary was here. Give it to Mary and have her give it to me." To this day she still does not do that.
  - Mary needed her inhaler, and my boyfriend took it to school to give it to her, and because he wasn't Mary's legal guardian, he wasn't allowed to give her the inhaler. I was at work and I couldn't give it to her and they didn't tell me that.

# Parents of Children with Asthma Focus Group Five Report

Prepared for the American Lung Association  
by Jane Maland Cady/Gale Mason-Chagil  
August 26, 2002

## Key Findings

### BACKGROUND ON THE CHILDREN'S ASTHMA:

The children with asthma ranged from the ages of one year to seventeen years old, and had mild, moderate, and severe asthma. Children received care from pediatricians, asthma specialists, and teams of specialists treated severe cases. Medical treatment for asthma included use of preventative and controller medications and hospitalizations. Changes in the seasons influenced the type and amount of medicine given to control and prevent asthma flare-ups. Their parents were a mix of racial-ethnic groups, with five being African American, one multi-racial, and two Caucasian.

### EDUCATIONAL RESOURCES DESIRED BY THE FAMILY

- **Parents said that there should be education for parents, children with asthma, children without asthma, daycare workers, recreation center staff, teachers, school staff, school nurses, neighbors and family members.** Parents commented that education on asthma should be as common as CPR. Everyone should recognize when an asthma attack is starting.
  - Daycares and preschools should have in-services on asthma. Teachers and aides need to know the signs.
  - Show films so kids are more supportive, so they know to tell someone if another child is having an asthma flare-up.
  - Asthma is a thing these days, it's everywhere, and kids want to play. Rec[reaction] center staff should know about asthma, and each rec[reaction]. center should have a nebuliser.
  - There should be education for the children too. You know what, my son is in first grade and if he had to wear the mask with his peers it might make him uncomfortable. You know how they show little films; well they could do one on asthma, so that maybe the kids could learn to be more supportive and sensitive to that type of thing.
- **Parents unanimously wanted support groups for parents and children with asthma, as well as support groups for the children themselves.** Many looked at the focus group as a support group. They believed that it was important to share with and learn from others that had similar experiences with asthmatic children, particularly other parents. They also felt it was very important to have a support group for the asthmatic children, so that they would have a place to express their fears, worries, and concerns.
  - I think that the people I have been in contact with, like support groups, other parents affiliated with this, of kids that are asthmatic, are experienced about knowing what to do and what not to do. Like I didn't know that when my baby first got sick that I had to rip

- up the carpet and stuff, and then one of my friends said, well if you take up the carpet and get rid of your animals and do this and this... We got rid of pets we had for four years, and that was like putting your pets out, you know, I think that I learned a lot from other people that were going through the same situation.
- They need support groups for parent and child so that they can learn to work together to vent your frustrations as well as the child's.
  - They should have support groups for just the kids, so they don't have to feel different, or have to feel left out, or feel so afraid.
  - Kids should get in a group to talk about their asthma, because he gets scared.
- **Families wanted quality one-on-one time with doctors and nurses to better understand asthma.** They wanted doctors to take more time to know the patient, to be with the patient, and to inform them more fully about their child's asthma. When doctors did so, parents were very satisfied. Many believed that nurses could take more time to share with the patient than doctors could.
    - Nurses are great; we had one visit once a week.
    - The doctors need to give more detail. They hear the same thing [from patients] 20,000 times a day and they don't explain well enough to each patient. Everyone is different.
    - Dr. S[mith] is really good. He has asthma and that really helps. Other doctors don't take time to look at the chart.
  - **Parents preferred to learn about asthma in formats such as pamphlets, DVD's, videos, and one-on-one.** They were not interested in "big, thick" books; rather they preferred to be presented practical and basic information. Several parents indicated that it would be helpful to see what an asthma attack looked like and what to do about it on DVD or video.
    - Who the hell is going to have time to sit down and read when your baby can't breathe?

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- ***Parents with asthmatic children are impacted emotionally and socially. Parents commented that they worried about their children, some felt frustrated, some became more permissive with their children, sleeping arrangements and quality of sleep were also influenced.***
  - Sometimes I get frustrated, and I find myself getting frustrated with him, because he will wait until the last minute and comes running in from the outside and says, "I can't breathe, I can't breathe," then he takes his medicine and he is okay. It also frustrates me because he doesn't want to be on the machine because it takes a minute, I'll ask if he is finished and he'll take half of it and say, "yeah" and go run outside. Two hours later, he says he can't breathe and I say, "you didn't finish it," and it gets really hard because I am a single parent.
  - He don't want to be too far from me. If he is in his room he gets too scared that I won't hear him. He gets real scared. He's had it all these years and he still gets frightened. He wakes up twice a night and gets on his machine. He'll come in the room and he'll say, "Mom, Mom, I can't breathe," and he is just scared to death. So it is hard for him to spend a night at a friend's house, you know, he has to take his nebuliser everywhere he goes. He just gets scared.

- **Some parents restricted children’s activities, while others did not** For example, visiting friends or having sleepovers was limited or required education for the friends of children with asthma.
  - I explain to all Pete’s friends. They all know what to do, how to use the nebuliser. You know if he wakes up at night they all know how to put the medicine in and they just give it to him, so that way he can spend the night somewhere, and if he needs help all his friends know how to help him.
  - My son has a friend that would like him to stay overnight, but the parents smoke and I don’t let him.
  
- **Parents were not always aware of the various causes of asthma.** In this focus group, most participants believed that it was a genetic condition and that the environment had some impact on asthma. They did not discuss other possible causes.
  
- **Parents believed that they were ultimately responsible for managing the children’s asthma, but that the children needed to share some responsibility for communicating with the parent when they didn’t feel well.** Parents believe that children can over medicate or not complete medication because of distractions or other desires, such as wanting to return to play. Managing asthma also meant making sure that the children had adequate support and proper medical care at schools, friend’s homes and other places they go.
  - It’s [managing the child’s asthma] highly stressful and sometimes I just want to cry.... I tried to explain the importance of doing it right, but it is just a lot of responsibility on me and him. I tell him he needs to communicate when he is having difficulty if I don’t notice.
  - He tends to want to ignore it.
  
- **Parents were concerned about the use of steroids.** Most of the parents reported that they took the children off steroids as soon as they saw an improvement in the asthma flare-up, even though it might not be the required medical protocol.
  - I don’t like steroids. I won’t use it on my boys.
  - Pete has it too but I don’t like to give it to him, he’s already ADHD, the steroids and the ADHD, he just bounces if over the walls. I quit [using steroids] because I can’t handle all that energy”.
  - I don’t use that stuff, they gave him some, but he is already high energy.
  
- **The group was very knowledgeable about reducing triggers in the home and when possible, they improved or changed their home environment.** When asked about what they did to reduce asthma flare-ups in their homes, the group responded nearly in unison, “Clean, clean, clean.” They supplied the following examples: used dust mite covers, removed carpet, weekly or bi-weekly dusting, wash mattresses and carpets weekly, no pets, no smoking, new windows, new fans. It was not always financially possible for families to make changes to their environment, such as putting in hard wood floors, installing air conditioning, or moving to an “asthma friendlier” place. They also were aware of environmental factors to reduce asthma flare-ups in others’ homes
  - When my baby started having all these upper respiratory problems, they tried to tell me it was the dust, it was the house, so we de-housed our house, you know, I got rid of all the carpet...you know, anything you can do to try and help your kid breathe because my baby at that point was gasping like [gasp, gasp, gasp] and when you are a mom and your baby is gasping you will do whatever it takes

## HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA

- **Parents wanted consistent and quality medical care. They described such care as doctors and nurses that took time with patients and families, got to know them, were empathetic, knowledgeable, answered questions, and educated them about asthma and treatment options.** The group felt it was very important to continue to work with the same doctor. They complained of inconsistent and inferior care when they changed clinics and/or doctors.
- **Families wanted consistent and quality insurance coverage.** Some parents were content with their insurance coverage, but most were not.
  - I have no problems with my insurance; I have no problems with my doctors.
  - I hate XX Medical Group.

*They noted differences in coverage between insurance companies, such as medication restrictions, protocol and care coverage. These differences greatly impacted the quality of medical care received.* For example, parents first treated asthma flare-ups at home. Then when needed the parents followed insurance protocols, such as first calling nurse lines to get authorization for which clinic to go to such as urgent care or the emergency room. Sometimes clinics that were authorized were far away or inconvenient for families.

- I have to follow protocol. I have to call the nurse line about whether to come in and sometimes you have to wait up to two hours to hear back. You have to get prior authorization for an ER visit otherwise it is the patient's responsibility. That happened to me once.
- I think it starts at the top. It is the people that are in charge of providing health care. I mean I think it is awful that you get yours free and I have to pay. I think it... this HMO crap is out the door. When we should really be more concerned for the welfare of the kids, the dictators are up there deciding which hospital you can go to and which clinic you can't. I think it starts at the top. If you have established yourself and your family in one facility and they know you, how come if you have to change to a different HMO, all of a sudden every doctor is a new person in your face? It is like being ripped open naked.

*Prescription regulations were not always practical or useful for parents.* For example, families stated that they needed easier access to inhalers, and coverage for multiple inhalers for children who lived in more than one home. Also, it could be cumbersome to get a refill on an inhaler. Some insurance companies required the families to make a visit to the doctor to get the prescription to be refilled. Parents would like to be able to just pick up the refill each month without the visit. For others, the inhalers do not always last a month when they are used more frequently, but the refill is restricted by refill dates. According to one family, XX Medical Group authorizes premix medications for school, but not at home, so that when a child has an asthma flare-up at home, it is more difficult to respond to it quickly.

- **It was important for families to have schools and daycares with full-time nurses or trained health professionals that communicate clearly with the families of the children with asthma. Parents wanted them to have equipment in easily accessible places.**
  - There's a lot [of responsibility]. You have to keep up with the medicines, and you know like school, when he started kindergarten, they had a part time nurse, and I said, "That is not going to work". What if my son has an asthma attack in the afternoon, and the nurse is only there in the morning? And I said, "Do you have a nebuliser here", and they said,

“Yes, on the 3<sup>rd</sup> floor”, and I said, “If my son is having an asthma attack what are you going to do? You can’t leave my son alone while you run up to the third floor, find the key, get the nebuliser, and come back and stuff,” so they got a full time nurse at the school, and they got the nebuliser in the office on the first floor.

- **Some families indicated that they wanted doctors to be more informed about food allergies and their impact on asthma.**
  - Doctors should let parents know about watching what your kids eat, like dairy products. The need more information about studies regarding food allergies.”

# Parents of Children with Asthma Focus Group Six Report

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
July 18, 2002

## Key Findings

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

Children ranged in age from four to ten years old and had mild to severe cases of asthma. Two children were diagnosed at five to six years old, three children were diagnosed at six months old, and the others were diagnosed when they were one to two years old. Doctors diagnosed most of the children with asthma during visits to the clinic or Emergency Room for breathing difficulties or head colds. One child was diagnosed during a routine check-up, and one parent brought the child's breathing problem to the attention of the school nurse who diagnosed the asthma. The parents said that their children used inhalers and nebulisers and some children were on steroids. The only asthma drugs that the parents cited were Flovent and Prednizone. Focus group participants were mainly mothers, but there was one grandmother and a fiancée who also attended the focus group.

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **Most parents wanted to learn about their children's asthma one-on-one from doctors. Written information was not as useful because it did not account for different levels of asthma understanding.** Several parents said that they wanted less clinical responses from their children's physicians and more personal conversations about the children's health.
  - My doctor's a good doctor she helped me with out a lot of stuff she shouldn't help me out on. She gave me a lot of information.
  - Maybe it would be better in an appointment with the parent and the doctor, everyone wants to hear what the doctor [says].
  - Written information that is mailed to a parent is not always read, and it's not always appropriate for their understanding, they may have a big long word, and I don't even know how to pronounce it...On a more personal level, they [doctors] are going to come down to my level to make me understand, instead of sending me some literature or information.
- **Parents said that they were generally not happy with the explanations they had received from their doctors about using equipment and administration of medication.** One mother said that she wanted the doctor to talk less about "what's in the books" and to be more personable and share his/her personal opinions related to the child's asthma condition.
  - Sometimes when the doctors treat a kid, give him a prescription and never really tell the parent what is going on...[regarding] the prescription, they say, "give him this at this time," but that's it. But they don't really *tell* you, make you feel comfortable like you're getting the information, that it's about your child or about my child. You got a right to know.
  - Outside from being a doctor, [I want to hear] from your own opinion, you have something in common with this, give me your feedback.

- They could explain to you what the deal is, all I got thrown at me was a machine, and what time to give it to him, all that and they didn't tell me nothing about nothing.
- **Parents wanted to share with other parents coping with asthma in similar situations, perhaps involving the guidance of a knowledgeable professional.** Several parents said that their insurance providers offered asthma classes in which parents were able to share with each other.
  - It's very helpful to talk to other people about it, not just the doctor, but some knowledgeable professionals and some parents who have been experiencing this.
  - [In the class] we were just talking the way we are now, with everyone else.
- **Parents wanted their children's school to provide asthma related information, including classes for students and meeting individually with parents.**
  - [At her school] they had the training and the class. They showed her how to use it [medication], what it was for. They have a whole little class. Everybody that gets asthma, they take them into this little class. They give them a training on the medicine. She liked it. They made it fun.
  - I went to the school, when I mentioned it to the nurse, right then and there she set me up with an appointment...and she sat with me for like two hours and this was after school, five o'clock when I got off of work, she made it whatever time was available to me. We sat there for two hours talking about asthma, and what she was going to give her and send the child to the class earlier that day already, and let her know. I mean I think that's good. That's good. Every school should be like that.
  - [Have meetings at] the schools because the parents is more likely not to run down to that hospital or to some buildings to a meeting, but they will go to a school more.
- **Parents thought that teachers and school staff should be educated about asthma, and how to cope with asthmatic children who also have ADHD.**
  - The teachers even [should] take courses and be more informed ... make them go through a training.
  - They need to be more educated at school, as far as, for the kids who have asthma and ADHD together. They have to be more educated.

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Having a children with asthma emotionally and socially impacted the parents, asthmatic children and their siblings.**

*Families, including non-asthmatic children, were impacted in a variety of ways by a child's asthma.*

- [Her other children ask] "when we go there, can Henry go there?" Because when he is on steroids he can't go into big crowds or anything like that. "Is he going to end up sick again?" Little things like that ... [the other children ask] "Is he going to get sick next week? Can we go to Valley Fair? Does he have to stay home?" You know what I mean? It's hard.

***Parents said that they generally did not limit their children's activities as way to prevent flare-ups.***

- We used to live across the street from a park and we liked to go there and there is a little pond or lake or something like that. [I'd say] "No you cannot go there," and... then he is over there every other day...and I tried to keep him in the house a lot, but I do let him do what he wants to do.
- **Parents had various ideas about what caused their children's asthma.** Two children were born prematurely and the parents felt that this may have lead to the development of asthma.
  - When my daughter was about two, it developed from a peanut in her lung. She had ate peanuts, and choked on it and got in her lungs. And two years old that's when they found out that she had developed asthma from that. That's what the doctor said.
  - I thought about it; maybe could be smoking, like if the parent smoked when you are carrying your child. At that time, when you are carrying the baby and the baby is developing, and you are sending messages and all, everything through to the baby. That may have a lot to do with it, I'm not sure.
  - Asthma is hereditary on his dad's side.
- **Parents believed that they were ultimately responsible for managing their children's asthma, but that the children needed to share some responsibility for administering their own medication.**
  - My son goes and does it on his own, he knows how to use it, but ultimately it all boils down to you [the parents].
  - I kind of like coach him a little bit. Because I know when his asthma may tick off and when it's not, just as far as the type of play that he does, so I just kinda' tell him, we have to watch for it...[during] basketball, baseball...to know when to give himself his medicine.
  - Now that he is learning how to use the nebulisers, he knows when it's coming on, and he'll stop his activity.
- **Parents were concerned about the side effects of steroids.** Many of the parents reported that they stopped giving their children steroids as soon as they saw an improvement in the symptoms, even though it was against medical protocols, because they did not like the side effects of the medication.
  - It's a steroid. It does a lot more damage than it does good.
  - No, he is not on them [steroids] no longer. I took him off, because it was too strong for his body. It used to have him zoned out.
- **Some children do not want to take their asthma medicine.**
  - At this age [ten years old] he has the Flovent that helps prevent it [flare-ups], but he is very stubborn about taking it. And I think it does help him if he does it consistently, but he doesn't *want* to, so that's a struggle of ours.
  - Well, I did [give the child steroids], because it helped open up the lungs to breathe... she cried, she said, "I don't want it." She makes me cry.

- **The group was very knowledgeable about reducing triggers in the home and, when possible, they improved or changed their home environment.** Parents reported using dust mites covers, avoiding smoking around the child and in the home, avoiding use of strong cleaning chemicals around the child, not having pets or avoiding certain types of indoor plants. They used air purifiers, special vacuums, and vaporizers. It was difficult to cope with second hand smoke from neighboring apartments.
  - Clean, clean, clean....clean-up.
  - It's kind of hard because I'm a smoker and I have to go outside to smoke, things like that, but I do it for him.
  - I can't afford to put this in the house, because everything they don't want you to have you can afford, while everything they *do* want you to have, is too expensive.
  - As soon as my son gets in the area of getting close to our apartment, he does this [breathing very heavily], because the smell, whoa ... smoking. It's so heavy in that one end of the hall it smells smoke ... the building people are [saying] like "No smoking in the hallways," but there is no one is smoking in the hallway, it's just weeping out of the apartment.
  
- **Parents were not clear about asthma treatment options, especially as it related to testing for allergies.**
  - I feel like the doctors just want to keep treating the symptoms rather than finding out what the cause is.....To me they really discouraged the allergy testing. Because they said, that there are so many things that can be allergic to, and it's hard to find. It's kind of a trial and error thing, they made it sound like it [would be too much for him]. ... Well I don't know, you don't want to put him through something he doesn't need, but you don't know what to think. I don't feel like I got a lot of information from the doctor.
  
- **Parents said that during a flare-up they administered medications at home and then sought medical attention, or they sought medical attention immediately because of the seriousness of asthma.**
  - Calm them down first, you gotta' get them calm. Then you treat them with a medication, and if that doesn't work, you call 911, or to the hospital.
  - I call 911 so the ambulance come and treat them right away If you have real chronic asthma you only have like four minutes to get air into you lungs.

#### **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **Consistent and quality insurance coverage is important to families.** Some parents were content with their insurance coverage, but most were not.

##### *Payment protocols are not always clear to parents.*

- What's that got to do with my kids, I don't know, but they won't see them at YY hospital, because that's where they was going, but their dad got a medical bill, so they won't see my kids. I tried to tell them, that that don't have nothing to do with my kids.

*Parents said that they had difficulty accessing care because sometimes they were not eligible for public assistance but, at the same time, they did not make enough money to pay medical bill.*

- Sometimes you make too much money to qualify for medical assistance, and not enough to pay a \$218 bill.
- **It is important for families to have schools and daycares with full-time nurses or trained health professionals that communicate clearly and regularly to the families of the children with asthma.**
  - It's more secure to know that the school knows what's going on [with my child's asthma].
  - 'Cause some of the schools are starting to get those nurses offices in there where they fully check your child out at school. So it's real nice I think for the school to really know a lot...they have a school nurse and then they have a regular nurse and they are there *all* day. I mean they sign your kids up. They call you at home, [and ask] "do you want us to give your kid a physical? We'll set up a day." They do all this at our school.
  - You might see her [school nurse] two days out of the week, if you are lucky.
- **Parents commented on how important it was to have medical release forms signed so childcare providers and school people would treat their children's symptoms.**
  - The school wanted me to sign a paper saying it was okay to give it [medication] to him.
  - The school nurses called me, "she is having an attack, I need to sign these forms." I said, "if you don't give her help, you are going to have to sign these forms!" Because I had to sign that form [and I hadn't], I had to come leave work, go down and give her medication.
- **Many parents said that people who receive medical assistance are treated less promptly and with less respect by medical staff and receptionists than people who had insurance through their jobs.** Parents said that people on medical assistance had to wait longer in the waiting room than people with insurance and people with insurance were checked-in before people on medical assistance.
  - You coming for a problem you are not coming in to get disrespect like, or to be treated like you are beneath them.
  - They are not treating people right. This medical system is out of control... At BB Medical Hospital, they do treat you different if you on medical assistance, versus you having a job. I pay for my insurance with my job now and it's way different [than before, when I was on medical assistance].
- **Parents said that doctors were not as educated about asthma as they needed to be.**
  - [We need] more doctors that know more about asthma.
  - Now the hospitals have changed, the doctors are dealing with that one field, and that one field only. But when you have an emergency they may call some doctors that's there for bones only, and they are trying to suggest something for asthma, they have no clue about what's going on. And that's what happens at AA hospital a lot.

- **Parents felt that the doctors were not confident in their diagnoses and treatments, and sometimes their children were being treated as guinea pigs.**
  - And the thing that the doctors always say to a parent or anybody is "let's *try* this." It's not that, "I'm going to give you this, and this should work for this", it's always, "let's try this and if that don't work, we'll *try* that."...[then the doctors say,] "it may not be asthma, it might be bronchitis," or "he just got a cold." I've heard that. I've heard that.
  - Sometimes they are [using us] like guinea pigs.
  
- **Parents wanted to have asthma specialty clinics that provide training and classes for parents and children.**
  - Have more specialists: I was thinking...Maybe they should have a clinic for asthma available somewhere.
  - Clinic about asthma, it's just a whole day, that you come in there, they teach you about asthma, they give you a little medicine.

# Parents of Children with Asthma Focus Group Seven Report<sup>2</sup>

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
August 5, 2002

## Key Findings<sup>3</sup>

A bilingual moderator conducted this group in Spanish. The data was translated in English during the analysis.

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

Twenty-two parents were present during the focus group representing sixteen families with asthmatic children. Mothers and fathers represented five families while mothers represented the remaining families.

The children were diagnosed with asthma as early as eight months old and as late as sixteen years old, and currently the children were between eighteen months old and seventeen years old. The children's asthma symptoms ranged from mild to moderate with only one severe case in the group. Parents mentioned that only two or three of the children had had flare-ups in the past year.

The parents did not use medical terminology to describe their children's medical treatments. Ten of the parents said that they had an *aparato* (equipment) or a nebuliser in the home and six children had *maquinitas* (little machines) or inhalers. Several parents mentioned that their children used Albuterol.

Please note that the clinic recruited children who were diagnosed with asthma from their clients lists, however two parents were not clear why they had been invited to the meeting on asthma, because they had never heard or understood an asthma diagnosis from their child's doctor. One of the mothers began to contribute to the focus group because she said that the medications her child received were similar to the other, asthmatic children. However one mother did not participate in the conversation.

One family who attended did not speak Spanish, so a key informant interview was completed with them in English. Their perspectives are also included in this report.

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<sup>2</sup> Clinic staff recruited the families to participate in the focus group. The goal was to have eight-ten families in attendance, therefore, based on previous experience and advice from the clinic staff twice as many families were recruited with the assumption that approximately one half of the people would not attend. In the end, all of the families attended which could be due to their interest in asthma and/or the attractiveness of focus group incentives, among other reasons.

<sup>3</sup> There were 22 adults, and up to 7 infants and children, in the room during the focus group. The size of the group complicated the data collection in at least two ways. First, in order to complete the focus group protocol in a timely manner follow-up questions were kept to a minimum; therefore the answers for this group were considerably less detailed than the other smaller groups. Second, clarity of the two tape recordings was sacrificed because participants were not positioned near a microphone and background noise from the large group interfered with sound quality.

## EDUCATIONAL RESOURCES DESIRED BY FAMILIES

- **All the families said that the best way for them to learn about asthma was from their doctors and from written pamphlets materials.**
  - From my point of view all methods of learning about asthma are important. I have heard a lot of important things from other people here today, but for me the pamphlets are the more informative way to learn. I try to understand and follow the steps that they outline. I take notes from the pamphlets about things I don't understand and then during a doctor's visit I ask the doctors. I have gone to the meeting where presenters give the orientation about asthma. Sometimes they don't have the correct information, so I prefer to speak directly with my doctor.
- **Parent support groups were strongly supported. At the same time, some parents also debated the virtue of having Spanish language videos on asthma that they could review in their homes.** Many parents thought having a video that they could review at home was a good idea, but others said that they would not have time to watch it and they preferred to be able to ask questions from an expert source.
  - We are noticing there are different types of asthma symptoms, and watching a video that tells us specifically what asthma is would help us know the difference between regular coughing. Or a conversation like we are having today would help us understand more about asthma.
  - Having an expert give a presentation will be helpful, because if you have a video you cannot ask questions. If a doctor facilitates a discussion group for parents, the doctor can help educate the parents on what to do about their children's asthma, but the ideal format for me is a dialogue among parents.

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Parents had few ideas about what caused their children's asthma.** Parents said that the asthma may be caused by pollution such as bad air quality and garbage. Also, one woman felt that her child had asthma because she ate ice when she was pregnant.
  - Contamination, like the garbage around, in Chicago there was a lot of smoke.
- **Parents did not name the asthma drugs that their children used and showed a general lack of awareness about when to use inhalers and nebulisers.** Ten families reported having nebulisers in the home and six families reported having inhalers. However, at least five families said that they had not used the equipment in the home. One of the problem parents cited was that they were not clear how asthma symptoms differed from regular coughing and as a consequence they did not know when to use the machine. Other parents said that the child had not had a flare-up that required the use of nebulisers or inhalers.
  - [Referring to a nebulisers] I don't remember what it's called ... but it's the equipment that you use with the nose.
  - They also gave me that the little machine [inhaler] to use, but I never used it because my child only got sick that time I went to the clinic.

- **Most parents believed that they were responsible for managing their children's asthma, but some parents mentioned that doctors, clinics and asthmatic children, especially as they got older, had roles to play in asthma management.**
  - We feel that as parents, we can help the child avoid the things that the doctors say will bring on the asthma symptoms. If the cold air affects the child, that's one thing that we can try to avoid.
  - I think it's the responsibility of the mother or father, but I'm both the mother and the father at one time. I worked at night, and I always called her to see if she took her medicines, and some times she had not taken it ... and so that affected her also, she needs to take the medicine as prescribed.
  - I think it's the mother and the father, and also the doctors and also the children when they are growing.
  - I help them, but they don't know, they don't know because they are too small. The older one is a bit older but also he teaches his sister by telling her how to ... the little one is too small.
  - Also, I try to teach my child so that he can be independent because when he goes to school, he has to remember the time of his medication and what type of medication he has to take, as prescribed by the doctor.
  
- **The group was knowledgeable about reducing triggers in the home and when possible they improved or changed their home environment. A theme was that the cold weather, having a cold, or feeling cold led to asthma symptoms in the children. Therefore, many of the parents said that they bathed their child less often than normal in order to avoid the chance that the child would feel chilled.** Some parents also cited common asthma triggers including, dust, pollen, smoke, and pets. Parents said that they tried to eliminate problems through cleaning the home, and not allowing smoke or pets in the home. One mother said that her child was not allergic to anything in the home, so she did not change the home environment.
  - I think the parents have the responsibility to care for the children, and avoid things in the house that harm them, by vacuuming the house and cleaning the house. These things should help the child live a normal life, live a healthy life. With these simple steps it should help all these breathing problems.
  - We try not to smoke on the house. No one smokes in the house. If visitors come they have to smoke outside, not inside.
  - We also use the vaporizer. We put it in a bed room.
  - We clean the dust very often.
  
- **A parent said that they try not to cater to the child so much that the child would not be able to function in normal conditions.**
  - We have also avoided bathing him very often in very warm water, as the asked us to do, because the child has to get used to the normal temperature, the normal environment. The doctor suggested that we should do that, but we thought that we have to let the child develop his own resistance and get used to the normal temperature. Before we were avoiding taking the child out of the house because of the cold temperature, but we don't do that any more.

## **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **Most of the children did not have regular asthma flare-ups.** Two families said they had experience flare-ups so serious that they had called the emergency room.
- **Parents said that communication and access to interpreters was a barrier they experienced in caring for their children's asthma.** One parent said that she and her child had to wait 1-2 hours for an interpreter to arrive at the emergency room.
  - I feel the most difficult issue is communication, the language.
- **Parents said that access to insurance was a barrier for them. Several parents said that the insurance companies would not provide insurance for one or more of their children, and they were not clear how to resolve the problem.**
  - The insurance [is a problem]... because my job does not cover my daughter. This is my problem.
- **Parents said that transportation to and from medical visits was a problem for them.**
- **Doctors diagnosed asthma differently, and parents were often confused about the diagnoses.**
  - I came because my daughter has asthma, or so they tell me. For two years now, she has been receiving the asthma treatments. But the doctors tell me that maybe she has it and maybe she doesn't. We continued with the treatments. The last visit we had, they told me that he didn't have asthma... My daughter got sick in May, so I took her to the emergency room. There they began connecting her to the equipment that helps respiration and since then she has been sick. Since then they send all the equipment with us and I have it at the house. Now I give treatments in the house, alone, we don't go to the doctors, but she hasn't gotten sick again since then.
  - My daughter had a cough in her chest, I thought it was bronchitis so I took her to the doctor, and then they said that she had asthma. They didn't say specifically that she had asthma, it didn't seem like it in the beginning ... I don't know [if it's asthma] we just have the machines at home and we don't use them.
- **Several parents wanted the healthcare system to keep them updated on the most current treatments available for asthma.**
  - Hospitals should update parents about the new treatments that are available for asthma.

# Parents of Children with Asthma Focus Group Eight Report

Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
August 8, 2002

## Key Findings

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

Families who participated in the focus group categorized their children's asthma as mild, moderate and severe. Two families reported that they had children with severe asthma, two reported moderate and four reported mild cases of asthma. The children with asthma ranged in age from 1 one to fifteen years old. Several parents had more than one child with asthma, and several of the children with asthma were adopted. When several of the children were infants they were treated as if they had asthma, one as early as six weeks; however, doctors did not diagnose the asthma until approximately after the age of two. All the children had inhalers and many of them had nebulisers in their home. Two of them used peak flow monitors when needed. Children received medical attention for their asthma from family practioners, peditricians, and specialists. Medical treatments that the children received included inhalers, nebulizers, Albuterol, Advair, Singular, and Prednizone. Nine mothers participated in the focus group. Three were African American and six were Liberian immigrants.

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **Parents said that they unanimously supported the idea of support groups for both parents and children with asthma.** Parents said that they wanted to develop networks with other people who were experiencing the same issues with their children's asthma in order to share information and ideas.
  - Talk to friends or family that go through the same thing.
  - I think more forums like this. I think like a support system with other parents who are going through it and then in that way...more and current information and updates. That would be nice.
  - Having support group for both parents and kids.
- **Parents wanted educational resources for their children such as camps, classes at school, and other opportunities for children to learn how to manage their asthma.** One family had attended the ALA Asthma Camp and a class offered by their insurance provider on how to cope with dust in the home.
  - I wish the kids can get a chance, maybe to do a class or to learn about it in school, somewhere where they can learn how to take responsibility for it, and learn more about their own body and their illness, and because their doctor said it's something that they are going to be with for a long time, he doesn't see them growing out of it, he said that some kids will grow out of it at a certain age, but their's, it just continues so they have to accept it and learn how to live with it.
  - You [could] do a healthy eating workshop, sports workshop. Instead of only having basketball camp or soccer camp.
  - I think more classes, because they don't talk about asthma [for parents and kids.]

- If they do more about asthma in schools, 'cause there are a lot of kids in school that have asthma. The nurse at the junior high school my kids go to said, "whoa, there are tons of asthma people that have to come in for inhalers, they have to stand in line at lunch time to get inhalers before they go out for recess? So if they were doing more education in the schools for the kids, it'll help them to learn more.
- **Parents said that camps and other educational opportunities needed to be affordable.**
  - I forget the name of the people who sponsor the asthma camp, one year the kids went to that. But they had fulltime nurses there, everybody knew about [asthma], they learned a lot about what they can do with the asthma, a lot of kids, the parents tend to be more protective, that they can't run, they can't jump, they can't do this because they are having an attack. So the kids learn how to do these things living with asthma. I thought it was really nice. They should have more affordable ones. So that everyone can be able to take part in them.
- **Parents suggested using media as a way to communicate with children with asthma and the general public.** Parents said that the educational resources for asthma should be made available to children in media they use regularly such as games, video games or children's magazines. Parents also suggested that newspaper or magazine articles highlight asthma as a way to educate the broader public.
  - It had a whole article on asthma, so if you see a kid that you know and that you read about the whole and everybody starts to read, I think that helps the family.
- **Most parents wanted to learn about their children's asthma from doctors either during appointments or on the phone.**
  - I got 90% of my information from the doctor. I just call, if something I don't know or the reaction is different to something, I just call...I leave a message and he'll call me back.
  - I get a lot of information from him [the doctor] because he has been treating them since they were three years old. So we got videos from him, sample things, and like when the Advair came out, he showed us how to use it and told us what it was. I got a lot of information from him.
  - Most of the information I get it from the pediatrician.
- **In addition to learning one-on-one from their doctors parents wanted to receive written information (e.g. pamphlets, newsletters) and videos from their clinic, insurance providers, their children's school, or through the internet.**
  - We get mailings too...I don't know, they [insurance provider] must pass out the information out or something, because sometimes we'll get like a newsletter in the mail, with something new that has come up, or we'll just get it out of the blue.
  - I read a lot, I like to go on the internet, so I like to use the computer. I like to do research on the computer.
  - X Insurance Company puts out a first aid book that's really good, for everything, and they have a section on asthma...if all the insurance or health care companies could do that, that would be really good.
- **Parents wanted to receive current information about basic research and treatments for asthma.**
  - Research...everything that comes out, whether it's printed, or talked about on TV, or in news articles or doctor's visits.

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Having a child(ren) with asthma emotionally and socially impacted the parents and child(ren) with asthma.** Parents mentioned they did not sleep deeply as they were listening to their children's breathing in the middle of the night, and their work was affected when they had to go to the clinic often with their child.

### *Parents' quality of home and work life was impacted in a variety of ways with an asthmatic child.*

- At night I'll wake up. Right now it's so hard to sleep with my door shut, 'cause a lot of time, I will hear that heavy wheezing at night and I know that someone is in there in trouble, so I got to get up, go wake that person up, you know, have them do the nebuliser, and then go back to bed. It's always like you always got one ear outside, trying to be alert and not to sleep too deeply.
- I keep an extra ear out all the time to hear if they are wheezing.
- I get nervous about the breathing, especially when you are sleeping, they're asleep. You don't want to fall asleep all the way, they might stop breathing and then you'd be in trouble.

### *Parents said that their work was affected if children had to often go to the doctor.*

- Work, if they go often and frequently, if you have to work a lot. Sometimes you know that they need to go and you say, "well I can't take another day off." So I have to wait and take them later in the evening, to urgent care or something like that, when they could have gone to the clinic in the morning, but since you can't take so many days off work, you have to wait.
- If you have a child with asthma and when you work somewhere where people don't understand, they don't have kids either, they don't understand where you are coming from. It's a problem.

- **Most parents said that heredity was the major cause of their children's asthma, but several parents mentioned other factors.** Several parents said that the children contracted RSV as infants, which could have contributed to the development of asthma. An adoptive parent mentioned that the mother smoked and used drugs when she was pregnant which may have lead to health complications, including asthma, for the children.

- It runs in my family. My brother has it really bad. My sister has it *really*, really, bad....Fred's mom, you know has to be hospitalized sometimes, and then my daughter's dad has it very bad.
- I think mine is more hereditary, my sisters have asthma. I have two sisters that have asthma besides me....and all my three kids have it, so I believe that is what it is in my case.
- Their medical history says that their mother was smoking a lot when she was having them, and she was using drugs also, and they were both premature [with RSV.]

- **One parent said that caffeine appears to help her child's asthma.**

- It's funny my five year old likes coffee, and I don't give her coffee, but she...feels good when she drinks coffee, but my oldest sister that has asthma, she is a caffeine fiend. I found out that people that suffer from asthma, caffeine helps them....especially if she is not feeling too good.

- **All of the parents said that the parents were responsible for managing their child's asthma; however, several parents of teenagers said that they hoped that their child would take more responsibility for the management.**
  - I think right now I'm responsible because they are still young.
  - I think it's the parent's responsibility, up to a certain age, I mean, once the child becomes a teenager they have to learn to take responsibility more....Mom and Dad wouldn't be there all the time.
  - If I don't follow what the doctors say, they will not get well, or they will get into trouble so I think I am responsible for that.
  - I do all the work. They don't do anything. They don't even know sometimes when they need their medication. I have to figure it out....I got to tell them take your medicine, do this do that, you know, and over and over, every day....I'm trying to get them to take responsibility for their own medication, cause that's the only way. "You guys need to know when you need to take your inhaler. You got to know that you will need it during the day, so take it with you when you go out." And that's the hardest part....But I think when they learn to take responsibility for it, they can live with it. But they have to learn how to be able to do it themselves.
  
- **Some parents were aware of the triggers for the children's asthma, while others had their own theories.** Come parents said that weather triggered severe asthma in their children, but the type of weather that was a problem differed. Parents said that different foods, dust, insect and rodent feces, and pests were triggers for their children's asthma.
  - I think it is better for him during the winter because the air is not as humid.
  - It's triggered by cold, when she gets a cold. She is very sensitive to a lot of things, and certain food she can't eat. [peanut butter]...Usually it doesn't trigger until she has a cold and then it's really, really, bad ...I'm a smoker but I try not to smoke around her, dust mites, mold, that kind of stuff.
  - Fur, anything that's furry, he gets red in the face, can't breathe, and congestion, that's really bad, when he gets near fur.
  - I know that the insects, like roaches, droppings from mice, and stuff like that, they tell you to stay away.
  
- **The parents were very knowledgeable about reducing triggers in the home and, when possible, they improved or changed their home environment.** The parents said that they cleaned with special attention to coping with dust, and they used vaporizers, humidifiers, filters for heat vents and air purifiers. They also got rid of pets.
  - So we bought some type of covering for their pillow and their mattress, allergy free. We cover their mattress and pillows with it. They have learned to clean it themselves. I show them how to do it, every two weeks they have to use the suction on their pillow and their beds. They are also very, very allergic to animals, cats and dogs. ... they help to mow the grass but they have their inhaler before they go out and help.
  - I do all that to keep the air clean and in the winter I try to use the humidifier and the vaporizer.
  - We had a rabbit. We had to get rid of our rabbit, because of that. We had to give it away.

- **Most people tried to care for their children's asthma flare-ups in the home and then, if it was not successful, they took the child to the Emergency room or the Urgent Care.**
  - We have passed emergency so much, so when he has problem, show me what to do when they have, and I can usually get them to the hospital, or if it's really bad, then I'll just have to call the ambulance. [But she has not ever had to do that.]
  
- **Parents had different levels of understanding of asthma symptoms and medications. Some parents were very knowledgeable and listed names of all the drugs and knew the symptoms well, while others did not.**
  - How do you know when a child has asthma? When my son was little, I did not know he had it and he was breathing kind of funny, and you know, by me being kind of young, I was kind of worried, like, I know he's not supposed to breath like that. So I took him in and they told me he had RSV....And they told me he might have asthma, so they gave me that asthma machine, I keep forgetting that name of it, and Albuterol.
  - It was hot that day, it was real hot that day, and he started breathing funny again. I didn't take it seriously 'cause, I didn't see his ribs, but when we got downtown...he was breathing worse than what he was, so I took him down there when I got to the hospital, the lady was like, "thank god you brought him, because he won't have made it if you would have brought him any later." 'Cause they basically told me that if I would have brought him later, he would have died on me. So that's why I'm so glad that I brought him in, it scared me, you know being young, and a single mom...[seven months old]
  
- **One parent expressed resistance to the doctor's diagnosis of asthma.**
  - He was having an attack. The doctor gave me Albuterol and I kept saying, "no, he don't have asthma. No he's just got allergies real bad." ... I figured he wasn't breathing because the allergies were bothering him.

## **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **Doctors diagnosed asthma differently.** According to parents, children were diagnosed with asthma at different ages. Generally, they treated the symptoms in infants as asthma, but doctors did not call it asthma until the children were toddlers.
  - They don't label it asthma when they are so small. He's only a year old.
  - They gave me the asthma treatment because technically they can't diagnose it as asthma until they are over two, but they give you the asthma treatment and everything that goes with the asthma. They can't call it asthma, but they know...they see the symptoms and everything, but legally they can't call it asthma, until after two.
  
- **Parents felt that the time they waited at Emergency Rooms and Urgent Care to see a doctor limited their ability treat their children's asthma.** Parents said that they had to wait for hours to see a doctor when their children was having trouble breathing.
  - [A barrier is] The time you wait in the emergency room and urgent care.
  - I'll tell you what happened to me once, my son, when he had the RSV, I didn't even know what RSV was at that time. He was only 6 weeks, and I took him to Urgent Care and they told me to wait... called 911 at the Urgent care. I wasn't going to wait, and then all the doctors were, "okay we're sorry, we're sorry." It was too late, I saw the ambulance, I said take my son to the hospital. You know? So we were at Urgent Care, we were waiting, he wasn't breathing, they tell me I gotta' wait?!? So I called 911, I used their phone.

- **Parents said that access to insurance was important in their ability to care for their children's asthma. Insurance companies should have prescription coverage that is more flexible in understanding life circumstances of families.**
  - And those medicines are expensive. If you didn't have insurance to pay for them, that can be almost not affordable.
  - But I tried to get two Albuterol for my son because he was going to be out of town, he [physician] was like, "No, I can't do that."
  - Anytime you need a new mask. It's not a problem.
  
- **Parents said that it was important to have full-time nurses or other trained health professionals in the school, who communicated regularly and clearly with the families of the children with asthma. Parents wanted training about asthma for all people who interact with the child, including teachers, child care providers, playground monitors, etc.** Parents said that their children's health is at risk when providers are not trained to recognize symptoms and intervene with the children.
  - A lot of parents either write a note that they can't go until they have the inhaler, and if they forget it and they don't bring it, they can't participate. And if they don't tell the teachers, or the doctors and the nurse, and they go ahead anyway, that's when they end up in the nurse's office and having to go home.
  - One of my sons...he left his inhaler at home and he needed it and he told the teacher that he needed his inhaler. "Oh," the teacher said, "you go home and get it." He said, "YES!" He was about *walk* home and he was barely breathing, in the cold. Now if that teacher were educated enough to know that when you are having an attack, you can't be walking anywhere. Luckily, they were able to get her [emergency contact person] and she was to go to the school...."I'm not going to give him permission to walk home. He is wheezing, it's cold outside, and he is walking by himself. I'm going to come, I'm going to get him, we are going to get the inhaler and I'll bring him back to school."...The staff really need to be educated on how to handle asthma cases when they are having an attack, what to do.
  - I think they should educate the schools, the teachers and those who are working in the school; not just the teachers, but the people in the cafeteria, the childcare people, the people who monitor the playground, they should educate them to be able to detect a time when a kid is in trouble and know what to do when a kid is in trouble. So that is something that we need really bad and they should get on it right away, if they have my say so.

# Parents of Children with Asthma Somali Key Informant Interview

Prepared for the American Lung Association  
by Jane Maland Cady/Gale Mason-Chagil  
August 26, 2002

## Key Findings

A key informant interview with a Somali parent replaced the Somali focus group due to a low number of participants. The individual interviewed is the parent of a child with asthma and experienced in working with Somali families in medical institutions. The information offered included personal comments and reflections on other Somali families that have children with asthma

### EDUCATIONAL RESOURCES DESIRED BY FAMILIES

- **According to the key informant, Somali families needed different kinds of educational materials, based upon their experience with asthma and individual educational levels. Preferably, information should not be communicated to the family during an asthma flare-up.** For beginning asthma information, videos and pamphlets are good sources of information, but it is also important to have access to the most current research. Books are desired as they provide more detailed information.
  - For someone that has a child with asthma, nothing is new.
  - It is good to tell them about asthma and how to manage it when they don't have an asthma episode. If you tell them when the child is sick it might be falling on deaf ears.
- **Somali families wanted one-on-one time with doctors and nurses to better understand asthma. The clinic visits should always include an educational component.**
  - The doctor is the one seen to be the "wise-man", the one who knows. Nurses too, they do a lot of teaching.
  - Somalis will not attend class.
  - When they come to the clinic there should always be an educational component with the provider.
- **Information about asthma should be communicated orally via radio, television, or one-on-one.** This is a culturally appropriate way to communicate with Somalis who depend largely on oral means of communication.

### FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Somali families may not readily accept that their children have asthma; and therefore, may not follow protocol for care of asthma. In general, it is more acceptable for older adults to have asthma, but when children demonstrate asthma symptoms, many families view the symptoms as just a cold or the flu.**

- The biggest problem is to admit that their child has asthma. They will say that my child has cold, maybe the flu at the worst but not asthma. It's a big challenge to understand that their child has asthma.
  - The most important thing to do is convince the parents that their child has asthma. Once this is acknowledged, it is important to teach them how to manage asthma.
  - Depending on the parent's knowledge, they accept that their child has asthma. They go to their experience with older people coughing and wheezing and the idea of a child that has asthma is new to them. They may not feel that these are asthma symptoms. If it is an older person they will accept that they have asthma but not a child.
- **The parent believed that it was his/her responsibility to manage the child's asthma.** This included: scheduling doctor visits, taking the child to the doctor, administering with the correct dose of prescribed medications at the correct time, taking away asthma triggers, and working with the school to care for the child with asthma.
    - He's not mature enough to say he wants his medicine...He gets sick sometimes when he is at school but he doesn't ask for his medicine. Sometimes he will get sick at school, and he needs his medicine, and then he will vomit and the school will call me, and I go there and pick him up and take him home and give him his medicine and then he will be all right.
- **The family was very knowledgeable about reducing triggers in the home and when possible they improved or changed their home environment.** Reducing triggers included; no smoking, no pets, dressing warmly in cold weather (when child is vulnerable), no incense, frequent vacuuming, frequent cleaning, limiting second hand smoke. Since a move from an older apartment infiltrated by second-hand smoke, the child's asthma improved considerably.
    - Anything that might trigger asthma is a no-no.
- **The parent was knowledgeable about how to manage asthma flare-ups, yet noted that other Somali families did not know how to use an asthma action plan.** The key informant's family used reliever medicines and followed an asthma action plan regularly.
    - Not many Somalis know how to use the asthma action plan, or what is this for. It is one of those many things from the hospital. They end up in the trashcan.

## **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **Doctors and interpreters need to provide culturally appropriate health care delivery.** It can be difficult for Somali's to communicate with the health care team because of language barriers and cultural sensitivities.
  - For the Somali parents it is really scary...if they are told this is a chronic disease and it may never go away that is very scary, but if you are told that this asthma is the kind of disease you can manage, it is very different.
- **Affordable and quality insurance coverage is important to families.** It is important to have access to insurance and good coverage, particularly for prescriptions. This family could not always afford the reliever medication, and thus did not always follow prescribed medical care.

- Expense is a real problem because there is no solution for it. If I cannot afford to buy the controller medicine, then that is it, I will not buy it. For those on medical assistance, it is not a problem for them. Whatever they need they can get it.
- It is a financial burden on me to keep the child on controller medicine. It costs me a lot of money. I know he needs the medicine, but sometimes, I can't afford [it].
- **It is important that school care providers, such as nurses, teachers, and administrative staff understand and recognize asthma.**
  - School nurses should have a brochure or guide in their office. They should have something for the teachers. If the teacher has a child with asthma, they should learn to know the symptoms.

# **Parents of Children with Asthma Hmong Key Informant Interviews**

**Prepared for the American Lung Association  
by Jane Maland Cady and Gale Mason-Chagil  
August 13, 2002**

## **Key Findings**

Two Hmong parents with asthmatic children participated in individual key informant interviews. One interview was conducted in Hmong and one was conducted in English.

### **BACKGROUND ON THE CHILDREN'S ASTHMA:**

One parent had a six year old child who, in addition to severe asthma, had severe mental disabilities. The mother said that she did not know what caused the child's asthma or mental disabilities. She said perhaps he was born with the problems or the doctors caused the problem when they gave him "too much medicine" during a emergency room visit when he was seventeen days old. The child uses the "machine," or nebuliser, twice a day and he also takes syrup when he is not feeling well, however the mother did not know the names of the drugs. The only drug name she cited was Amoxicillan. She explained that the doctor prescribed Amoxicillan when the child had ear infections.

The second parent said that they found out that his eight year old son had asthma when he was about eighteen months old. The father said that the child woke up one day wheezing and then over the course of a couple of weeks, it worsened. When they took the child to the doctor, they were told that he had asthma. When he had flare-ups earlier, he used the nebuliser but it made him vomit and therefore he would not use it regularly. The child had always had a moderate or mild case and had not had a flare-up in four years.

### **EDUCATIONAL RESOURCES DESIRED BY FAMILIES**

- **Parents preferred to learn information about their children's asthma from the doctor.**
  - Sometimes...from the doctor, sometimes the doctor says when he has very difficulty breathing, he should sleep on his belly....that helps him....for the head to be high, it really helps slow the breathing and the coughing.
  - We learn from the doctor....The big source is probably from the doctor....We ask questions. What do we do? How bad? Or what do we do in that situation?
  - The doctor is the biggest thing for me. 'Cause me and my wife with our kids, every time they are sick, we don't know, we just take them to the doctor. We ask questions. We explain what's wrong, we ask questions. So that's how we now....When we go there, we take pamphlets.
- **Some parents would like to read materials in English while others preferred to read materials in Hmong.** The younger parent said that he would like to read books in English to learn about asthma, however, the older mother was able to read only Hmong.
  - We like to read so probably books [would be helpful]....I can't read Hmong. I can speak Hmong.

- **One parent said that she learned information about asthma management from friends and discussed the information with the doctor.**
  - I heard about it, and then I explained to the doctor...I didn't know the name, but I explained it to the doctor and he kind of got the idea.
- **The parent who had a child with severe asthma learned a great deal through a home-visiting program. A medical professional, sponsored by her insurance company, came to her home every week for three months.**
  - I had an in-home visiting doctor, that comes and tells me how to use the equipment..

## FACTORS THAT INFLUENCE PATIENT OUTCOMES

- **Having a child(ren) with multiple medical needs, including asthma, emotionally and physically impacts the family.** One child required constant supervision because in addition to asthma, he had developmental delays. A home health care aid worked with him regularly, and was trained in coping with his asthma.
  - I have a very difficult time taking care of my son because he can't...everything I have to do for him, taking his shoes off, and clothes on, taking a bath, feeding. So it's very difficult.
- **One parent was not clear about the scope and impact of a specific medical treatment offered by the child's doctors.**
  - The time that I went to X hospital for my son, I asked them to give him a stronger medicine. They said that they had a medicine that will cure the difficulty breathing, but once it's cure and once it reoccurs again, they can't fix it. I wondered if that was true or not?
- **Both parents said that they were responsible for managing their children's asthma.**
  - When it comes to difficult times, it is me. For regular days its health care assistant.
  - Me and my wife, both of us. My wife knows it more than I do, because she is much more into the kids, than I am, but we both are....He will be more comfortable with my wife.
- **Parents were aware of triggers for their children's asthma and worked to reduce the triggers in their home.**
  - In the cold weather, every time we take him to school, we have to cover him with a blanket. If you don't do that, then the cold gets into his lungs and it seems like his throat feels very itchy and he start coughing really bad.
  - We use a humidifier....It tends to help me control my son's difficult breathing.
  - It's a four-plex, so if they are smoking in one apartment, it goes through the heat vent or something [into another apartment.]
- **One parent said that when the child was having severe flare-ups, they limited his activities.**
  - We don't let him run around so much, because we think it might trigger the heavy breathing, so we take him for walks and let him play on the walks, but no hyper running around.

- **One parent said that she trusted the doctor's advice and gave the prescribed medicines to the child. The other parent also listened to the doctor advice but was more cautious about giving the child medicines, and selected not to give the child medicine against medical advice, favoring home remedies, a glass of water and fresh air.**
  - We ask him what's wrong, you are breathing so heavily, you are wheezing? That's what we do, we give water and we try to calm him down, get him to lay down, relax him....We'd tell him to drink water. We think maybe his throat is dry or maybe the air is bad. We give him water and tell him to take a deep breath and go outside [for fresh air].
- **A small child did not want to use the nebulisers or inhalers.** One parent said that his eighteen month old son did not like to use the nebulisers.
  - When he tried it a couple of times, then he feels like he is going to throw-up once the medicine goes inside him, he feels like he is going to throw up, he won't want to do. You can't really make him do it....So we just didn't use it.
  - I think they prescribed on of those hand inhalers, but that didn't work either, it didn't work that way either. He won't want to use it. So every time you say, "use the inhaler." He'll start crying or run and hide.
- **Both parents said that they did not know where the asthma came from, except that some children have it and others do not.** One parent said that in the Hmong language there was a term that referred to a condition similar to asthma, but it was not clear what the term referred to, for example, was it a disease, a relatively common condition, or a reference to a type of cough.
  - I'm not sure. I think maybe...he was born that way.
  - Some kids just have it.
  - I have no idea. One day he wake up and he start wheezing, and a couple of weeks later, breathing heavier and heavier, and it just goes away and come back later.

### **HEALTH CARE SYSTEM ISSUES THAT IMPACT A FAMILY'S ABILITY TO MANAGE ASTHMA**

- **One mother did not comment directly on the importance of consistent medical care, but she did use the name of the doctor that regularly treated her son while she did not know the names of the drugs he was taking for his asthma.**
- **One parent was very happy with the medical system and her access to interpreters.**
  - I think it's convenient that I can go to the hospital at any time when my kid's having difficulty breathing and the medicine that they prescribe helps my kid. So it's convenient to see the doctor in the hospital.
  - I have a translator that goes with me, so I pretty much understand. [Interpreter provided by the hospital/clinic]
- **Both families make clinic appointments for the asthma, but one attended the emergency room when the child was in distress.**
- **Insurance coverage is important to families.** Both parents said that insurance was a major factor in their ability to provide medical care for their children. One parent received public assistance, the other family received insurance as a work benefit.
  - For her friends, they had to go and buy it, but for her she just had the doctor prescribe it and they covered for that machine.

- They don't pay 100%. So you are pretty much paying 20% of it. So sometimes with the many medical visits you have to pay the bills that are pretty much high. ... part of the visit, the machines, the equipment, everything. Like you got to pay 20% out of whatever the cost is.
- **Both parents expressed interest in finding a cure for asthma.**

## **Appendix B. Focus Group Protocol**

## AMERICAN LUNG ASSOCIATION – ASTHMA STUDY FOCUS GROUP PROTOCOL

Jane Maland Cady, Ph.D., and Gale Mason-Chagil, Ph.D.

### **Recruitment Procedures**

We are recruiting parents who have one or more children who are diagnosed with asthma at schools, clinics, community centers, and ALA asthma camps in Minneapolis and St. Paul. One primary recruitment strategy is to distribute flyers/letters to asthmatic children and their families through agencies who regularly interact with them. Parents who express interest in participating in the study would contact a phone number on the ALA flyer/letter for basic information about the project. The ALA representative would then give us a list of interested parents and we would contact them by phone to answer specific questions and arrange with them a convenient time and date for the focus group. If they consent to participate in a group we will remind them in phone call a day or two before the focus group. Parents will also be asked if they would like a letter outlining the details of the focus group and a map (if necessary), and confirmation letters will be sent upon request.

Our goal is to conduct 10 focus groups with 8-12 individuals each that reflect the racial-ethnic and distributions based on national data on childhood asthma. The sessions will last 1.5 hours approximately and will be tape-recorded.

We will conduct the focus groups in at ALA-MN in St. Paul and, if possible, community-based locations in Minneapolis and St. Paul, such as community centers and clinics

Incentives for the focus group include 35 dollars per family, childcare, food, and transportation.

### **Focus Group Event**

#### **Arrival, Informal Discussions, Refreshments**

##### **Introduction**

Good Evening and welcome to our session tonight. Thank you for taking the time to join our discussion tonight/today of childhood asthma. My name is \_\_\_\_\_ and I am an independent program evaluation representing the American Lung Association. Assisting me is \_\_\_\_\_. **[If the ALA staff is present, we should introduce him/her also.]** We are attempting to gain information about your experiences, as a parent or guardian of a child or children with asthma. We have invited people from throughout Minneapolis and St. Paul (or the specific contact agency) to share ideas.

You were asked to participate in our group because you all have a child or children with asthma. We are very happy that you have decided to join us here tonight/today.

Tonight we will be talking about the experiences you have had helping your child or children manage their asthma. We are particularly interested in how asthma has affected your family and your perspectives on caring for your child's or children's asthma. Remember, there are no right or wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said.

Before we begin, let me remind you of some ground rules. Please speak up-only one person should talk at a time. We are tape-recording the session because we do not want to miss any of your comments. If several are talking at the same time, it will be difficult to hear the tape and we

will miss some of your comments. Please be assured that everything said here today is completely confidential. Keep in mind that we are just as interested in negative comments as positive comments, as the both provide valuable perspectives.

Our session will last about an hour and a half, and we will not be taking a formal break. We all have name tags to help us remember each other's names. So, let's begin. First, let's go around the circle and.....

**Introductions – (10 minutes)**

1. Please introduce yourself, the age(s) of your child(ren) who has(have) asthma and let us know you found out that your child has asthma?
2. What do you think caused your child's asthma?

**Management of Asthma (20 minutes)**

3. What type of medical care has your child received?  
[Do they use controller medications, reliever medications (inhaler), written action plan, have they had spirometer test, have they used a peak flow meter.]
4. What steps have you taken at home to reduce your child's asthma symptoms (triggers)?  
[examples: mattress covers, got rid of pets, pillow covers, vacuum more frequently, etc.]
5. Who do you think has the most responsibility in caring for your child's asthma and can you describe these responsibilities?  
[What is your role in caring for your child's asthma? What is your child's role in caring for his/her asthma?]

**Asthma Related Educational and Community Resources (20 minutes)**

6. What is your favorite way to be given information about asthma, for example, books, pamphlets, videos, one-on-one teaching, or classes?
7. In what setting would you like to receive this information?  
[One on one, group, from Doctor, in clinic, at home, at school, on-line]

**Access to Healthcare (20 minutes)**

8. Where do you go and what do you do when your child has an asthma flare-up?
9. What affects your ability to get medical care for your child's asthma?  
[e.g. access (get to see the doctor when you want to), enough time with the doctor, get questions answered, provide information in a way that's easy to understanding, what do you do with your other children, are you able to keep your appointments, transportation, clinics, ER, urgent care differences, etc.]  
[Do you think the instructions by the doctors and nurses are clear?]

**Concluding Statement (5 min)**

10. In conclusion, please suggest two – three ways that the health care system could better help you care for your child with asthma? (Go around the circle for all to speak).

**Conclusions**

We would like to thank you for coming and sharing your valuable time so that we could learn more about families of children with asthma. Your thoughts and experiences are very important and provide valuable information that will be used to improve the quality of life (better term) for families such as yours.

If anyone is interested in participating in a Parent Advisory Council for this grant you may give us your name and number and we will pass this on to the ALA, who will contact you about this opportunity.

You can pick up an envelope on your way out of the door from [Assistant Moderator Name] with a small gift for participating tonight. As you pick up your envelope you may sign the form with first name and last initial. If you need travel reimbursements, also talk with [Gale/Jane] as you leave. We also have information for you on asthma that you may take with you (or could there be a nurse present?). We also have some information on the Family Asthma Program. If you are interested you may put your name on a list and someone from the program will contact you. If you have any other questions you may let us know and we will pass them on to the American Lung Association.

### **Post Analysis Session**

Discuss session with moderator, assistant moderator, and ALA staff present. Use notes from discussion sheet for analysis.

### **Materials to Bring:**

- Tape recorder
- Microphone
- Extra tapes and Batteries
- Name Tags
- Refreshments
- List of participants with phone numbers
- Incentives
- Information on Asthma

## **Appendix C. Focus Group Flyers (General and Somali)**

# Parents of Children with Asthma

## Please Join Us for a Focus Group Discussion and Information Sharing About Childhood Asthma

- Purpose:** Meet other parents from Minneapolis and St. Paul who have one or more children with asthma, discuss the role your child's asthma plays in the life of your family, and learn how other families effectively cope with their child's asthma.
- When/Where:** Attend a meeting at one of several sites around Minneapolis and St. Paul during May, June, and July 2002. We will find a time and place that is convenient for you to attend. Each meeting will last approximately 1.5 hours.
- You receive:** Support and information from other parents to help you effectively cope with your child's asthma. In addition, you will receive \$35 cash, food, the cost of transportation, and on-site childcare, if needed.
- Interested Parents:** Please call Amy at 651-223-9567 for more information about attending one of these groups in St. Paul or Minneapolis.
- Sponsored by:** The American Lung Association of Minnesota

# Waalidiinta Soomaaliyeed ee Carruurtoodu Neefta Qabto

## Fadlan Nagala Soo Qayb Gala Faaqidaadda Kulan Kooxeed Iyo Aqoon Is-Weydaarsi Ku Saabsan Neefta Carruurta

**Ujeeddada:** La kulan waalidiin kale oo reer Minneapolis ah, kuwaas oo leh carruur neef qabta, Faaqid kaalinta neefta ilmahaagu ka cayaarto nolosha qoyskaaga, Barona sida wax-ku-oolka ah ee ay qoysaska kale u la qabsadeen neefta ilmahooda.

**Goorma/Xaggee:** Khamiista, Agoosto 8deeda 6:00 fiidnimo – 8:00 fiidnimo.  
Xarunta Beesha Sabathani, oo ku taal: 310 East 38<sup>th</sup> St., Minneapolis

**Waxaad Ka Helidoontaa:** waalidiinta kale taageero iyo macluumaad kaa caawiya sidaad si wax-ku-ool ah ula qabsan lahayd neefta ilmahaaga. Intaa waxaa dheer 35 doolar oo caddaan ah, cunno, kharajka gaadiidka, iyo carruurta oo meesha laguugu hayyo, haddii loo baahdo.

**Waalidiinta danaynayow:** Fadlan kala xiriira shaqaalaha Sabathani wixii war dheeraad ah oo ku saabsan kulan kooxeedka telefoonka (612) 821-2300.

**Waxaa Soo Qaban Qaabiyey:** Ururka Sambabada ee Maraykanka, Qaybta Minnesota

## **Appendix D. Recruitment List**

**RECRUITMENT LIST**

| <b>ORGANIZATION</b>   | <b>METHOD OF RECRUITMENT</b>  | <b>NUMBER OF FLYERS DISTRIBUTED</b>                              |
|---|---|--|
| American Indian OIC   | General flyers  | Distributed by organization                                      |
| ALA Asthma Camps  | Letter of invitation  | Distributed by organization                                      |
| Asthma Initiative – Minneapolis Public Schools                            | General flyers to school nurses to students to parents  | 1000   |
| Asthma Initiative – St. Paul Public Schools                               | General flyers to school nurses   | Distributed by organization                                      |
| Association for Advancement of Hmong Women                                | General flyers, Personal recruiting, Specific Hmong flyer   | Distributed by organization                                      |
| Dorothy Day Center  | Announcement over the public address system to clients  | N/A  |
| Children's Initiative, St. Paul   | General flyers  | Distributed by organization                                      |
| Children's Respiratory and Community Care Specialists (CRCCS) Minneapolis | General flyers  | Distributed by organization                                      |
| Children's Hospital Pulmonary Clinic, St. Paul                            | General flyers  | Distributed by organization                                      |
| Children's Hospital, Minneapolis  | General flyers  | Distributed by organization                                      |
| Early Childhood Family Education – Minneapolis<br>3 locations             | General flyers and newsletter   | Distributed by organization                                      |
| Early Childhood Family Education – St. Paul                               | General flyer to all of the teachers and sites in St. Paul  | Distributed by organization                                      |
| Glenwood-Lyndale Community Clinic   | Personal recruiting   | N/A  |
| Head Start - Minneapolis  | Specific flyers   | Distributed by organization                                      |
| Head Start – RAP St. Paul   | Wrote letters to families of asthmatic children asking them to participate                                  | Approximately 100 letters sent.                                  |
| Health Start Clinics St. Paul Schools                                     | General flyers to all school site clinics   | Distributed by organization                                      |
| Healthcare for the Homeless – St. Paul                                    | General flyer that was distributed at clinics in homeless shelters throughout St. Paul, personal recruiting | Distributed by organization                                      |
| Heart of the Earth School, Minneapolis                                    | Flyer to every student  | 250  |
| Hennepin County Family Medical Center                                     | Specific Spanish language flyer- recruited in clinic, and phone calls                                       | Distributed by organization                                      |
| Home Visiting Nurses – Ramsey County                                      | General flyers  | Distributed by organization                                      |
| Hmong American Partnership  | General flyers, and Specific Hmong flyer  | Distributed by organization                                      |
| La Clinica  | Flyers  | Never distributed did not secure research approval at the clinic |
| Lao Family Community of MN  | General flyers to aftercare classes they conduct, Specific Hmong flyer                                      | Distributed by the organization                                  |
| Loaves and Fishes, St. Paul   | Flyers  | Distributed by the organization                                  |
| Martin Luther King Center   | General flyers  | Distributed by the organization                                  |
| Minnesota Visiting Nurses Association                                     | General flyers through classes, daycare center visits   | 350  |
| Model Cities, St. Paul  | Flyers  | Distributed by organization                                      |
| Model Cities, St. Paul  | Phone calls to parents of clinic patients   | 13 families called   |
| Pediatric Clinics at Hennepin County Medical Center                       | General flyers  | Distributed by organization                                      |
| Pulmonary Offices, Minneapolis  | General flyers  | Distributed by organization                                      |
| Staub Pediatric Clinic-Riverside  | General flyers  |  |
| Sabathani Community Center, Minneapolis                                   | Specific flyer, phone calls from organization, personal invitation  | Distributed by organization                                      |
| Sharing and Caring Hands  | Specific flyers   | Distributed by organization                                      |
| Women Infants and Children (WIC) – Minneapolis                            | General flyers distributed at Clinics   | 30   |
| Women Infants and Children (WIC)– St. Paul                                | General flyers distributed at clinics   | Distributed by organization                                      |

## **Appendix E. Focus Group Details**

**FOCUS GROUP DETAILS**

| <b>TITLE</b>                                  | <b>DATE (TIME)</b>         | <b>PLACE</b>   | <b>PRIMARY CONTACT ORGANIZATION OF PARTICIPANTS</b>    | <b>Number of Participants (Childcare)</b> | <b>R/E Distribution</b>   |
|---|----------------------------|--|--|---|---|
| FG1   | 6/11<br>(6:00 – 7:30))     | Corcoran Park-<br>Minneapolis                          | Minneapolis School Flyers/Heart<br>of the Earth        | 8<br>(2)                                  | African American - 2<br>American Indian - 6<br>Asian-<br>Caucasian -<br>Latino -    |
| FG2   | 6/18<br>(6:00 – 7:30)      | ALA- St. Paul  | St. Paul Flyers, ECFE Contacts                         | 9<br>(8)                                  | African American – 1<br>American Indian -<br>Asian-<br>Caucasian - 7<br>Latino - 1  |
| FG3   | 6/24<br>(7:00 – 8:30)      | Mary’s Place – Minneapolis.                            | Sharing and Caring Hands                               | 13<br>(9)                                 | African American - 9<br>American Indian -<br>Asian-<br>Caucasian - 4<br>Latino -    |
| FG4   | 6/27<br>(6:00 – 7:30)      | ALA- St. Paul  | ALA Asthma Camps                                       | 12<br>(9)                                 | African American - 6<br>American Indian -3<br>Asian -<br>Caucasian -3<br>Latino -   |
| FG5   | 7/1/02<br>(6:00-7:30)      | ALA- St. Paul  | St. Paul Flyers – Schools, Head<br>Start, Clinic       | 8<br>(16)                                 | African American - 5<br>American Indian - 1<br>Asian -<br>Caucasian – 2<br>Latino - |
| FG6   | July 18<br>(6:00 – 7:30)   | ALA- St. Paul  | St. Paul Flyers,<br>Minneapolis School Flyers          | 10<br>(14)                                | African American - 8<br>American Indian -<br>Asian -<br>Caucasian - 2<br>Latino -   |
| FG7   | August 5<br>(4:30 – 6:00)  | Hennepin County Family Medical Center -<br>Minneapolis | Hennepin County Family Medical<br>Center - Minneapolis | 22<br>(23)                                | African American -<br>American Indian -<br>Asian -<br>Caucasian –<br>Latino - 22    |
| FG8   | August 8<br>(4:00 – 5:30)  | Sabathani Community Center – African<br>American       | Sabathani Community Center                             | 9   | African American - 9<br>American Indian -<br>Asian -<br>Caucasian -<br>Latino -     |
| Somali Key<br>Informant<br>Interview<br>(K11) | August 8<br>(6:00-8:00)    | Sabathani Community Center - Somali                    | Sabathani Community Center                             | 1   | Somali - 1  |
| Hmong Key<br>Informant<br>Interviews<br>(K12) | August 13<br>(6:00 – 7:30) | Model Cities Health Center                             | Model Cities Health Center                             | 2<br>(1)                                  | Hmong - 2   |

