

**Consortium of Children’s Asthma Camps
Assessing the Value of Asthma Camps Study
March 2005**

The Consortium of Children’s Asthma Camps (Consortium) Board of Directors commissioned Jill Heins Nesvold, MPH to conduct a study, from mid-September 2004 through mid-March 2005, to determine the value of asthma camps. This study aimed to identify the future opportunities for asthma camps and determine the Consortium’s role in this future direction. Through correspondence with Consortium Board members, “value” was defined to include:

- Reach, including the number of campers, gender, race/ethnicity, socioeconomic status, asthma severity rating, geographic representation, and new or returning camper
- Cost, including direct costs, in-kind volunteer hours, and in-kind donations
- Impact on children’s asthma symptoms and/or asthma management
- Access to the asthma medical community
- Access to the health plan community
- Opportunities for organizational fundraising
- Positive public image
- Altruistic motives
- Organizational tradition

To answer the overarching question, “what is the value of children’s asthma camps,” the following guiding study questions were developed in conjunction with the Consortium Board:

1. What is the value of asthma camps as perceived by:
 - Local sponsors, including American Lung Association affiliates
 - Camp directors
 - Health care professionals staffing the camps
 - Parents/guardians of children with asthma who attend asthma camps
2. What is the asthma education curriculum context and delivery format?
3. What is the experience in assessing value of other health-related camps in the U.S.?
4. What impact does attending asthma camp have on a child’s asthma management?

Methods:

A multi-method, retrospective study was conducted. Using multiple methods makes findings valuable to multiple stakeholders. In addition, the strengths of one method can offset the limitations of others. The following data collection methods were used to assess the value of children’s asthma camps.

1. Key Stakeholder Interviews - Twenty-six interviews were conducted, via telephone or in-person, with children’s asthma camp stakeholders. Stakeholders represented established and new camps, small and large camps, organizations that recently quit sponsoring asthma camps, and Consortium of Children’s Asthma Camp Board members and consultants. The asthma camp roles of the stakeholders ranged from camp director/coordinator, medical director, medical

volunteer, organization board member, parent of camp participant, and high-level leadership/administrative oversight.

The interviews were conducted between September 29, 2004 and November 1, 2004. The interviews varied from 10 minutes to 45 minutes in length, depending on the role of the stakeholder, their familiarity with asthma camps, and their willingness to share details. See Attachment A for the *Key Stakeholder Interview Protocol* and Attachment B for the *Stakeholder Interview Summary*.

2. Review of published and unpublished literature - The extensive literature search identified 26 articles or manuscripts¹, written in English, between 1981 and 2001. The purpose of identifying all published articles, regardless of when published, was to: 1) capture all (or as many as possible) of the published articles regarding the impact of children's asthma camps since asthma camps' beginnings in 1967 and 2) to ensure a sufficient number of peer reviewed journal articles from which to draw conclusions. See Attachment C for the *Review of Published and Unpublished Literature on Children's Asthma Camps*, Attachment D for a chart of the *Evidence Regarding Impact of Children's Asthma Camps*, and Attachment E for the *Bibliography*.

3. Interviews with other chronic disease specific children's camps - Directors of the Children's Oncology Camping Association, Diabetes Camping Association, and American Diabetes Association Camping Programs were interviewed in November 2004 regarding their experience in assessing the value of camps. See Attachment F for the *Summary of Interviews with Non-asthma Chronic Disease Camps for Children*.

4. Online Survey of Asthma Camp Directors - An online survey was developed to collect a variety of information about asthma camps in the United States, including general camp information, camper demographics, staffing patterns, budget information, asthma education provided through camp, and community outreach. This survey was piloted tested with two asthma camp directors. Adjustments were made based on pilot test comments. The final survey was first distributed on Monday, October 4, 2004. Camps were contacted either via email or phone at least four times requesting that they complete the online survey. Surveys were accepted until Friday, January 21, 2005.

Seventy-five (75) surveys were completed for a return rate of 62%. The response rate was based on 121 verified asthma camps (defined as having a contact name, phone number, and/or email address in the Consortium database after personal contact with a camp staff person between October 2004 and January 2005). See Attachment G for the *Online Survey* and Attachment H for the *Children's Asthma Camps Online Survey Summary*.

5. Parent Interviews - Ten interviews were conducted with parents of children who attended a 2004 asthma camp. Eight of the parents were from Minnesota (November 2004) and two from California (February 2005). See Attachment I for the *Asthma Camp Parent Interview Protocol* and Attachment J for the *Summary of Parent Interviews*.

¹ These 26 articles include one national presentation and one nationally presented poster session.

Key Study Findings:

Both children's diabetes and oncology camps have been challenged to define their value.

Based on the experience of children's diabetes camps, it would be beneficial for asthma camps to see this as an opportunity to increase the use of best practices, measure their impact, refine their procedures, and take asthma camps to the next level.

Children's asthma camps provide a variety of experiences that children with asthma could not receive anywhere else, including:

- Feeling of normalcy
- Opportunity for intensive asthma education
- Opportunity for a total camp experience
- Independence from their parents/primary caregiver
- Opportunity for kids to be kids
- Opportunity to build the child's socialization skills, self-confidence, and self-esteem

Stakeholders perceived that asthma camps are valuable for a variety of reasons, including:

- Provide intensive asthma education for children with asthma
- Opportunity for interaction with peers
- Opportunity to experience a camp specifically for them
- Further the development of the child
- The sponsoring organization and asthma community receive benefits from asthma camp such as connections to the medical community, ambassadors for asthma, and a feel good experience

The **moderate to high level of evidence** regarding children's asthma camps, in the published and unpublished literature, indicates that asthma camps can increase parent and child asthma knowledge, increase a child's locus of control, improve their self-efficacy and attitude about their disease, improve their asthma-related behavior and pulmonary function measures, and improve their metered dose inhaler and peak flow meter technique. The literature also indicates that asthma camps decrease child's anxiety, symptoms, exacerbations, school absences, emergency department visits, and hospitalizations. Two studies indicated cost-savings of over \$2,000 per child in the year following asthma camp participation.

Camps are managed by organizations with extensive experience and by minimal paid staff.

Camp is an institutionalized tradition within many organizations. Of camps responding to the online survey, 62% reported more than 10 years of experience. Of camps who responded to the online survey and who have a designated staff person whose responsibility is to direct camp activities, 75% have an employed coordinator at or less than 0.3 FTE. Camps are also staffed by a variety of health care professionals who have volunteered their time and expertise.

While campership is decreasing annually, campers are most often returning campers and from limited income families. The average number of campers per camp has consistently decreased since 2000. In 2004, less than half of campers (45.2%) were new (first time campers).

54.8% of camps reported that at about two-thirds (61%) of their campers were from limited income families.

The components of asthma education are fairly consistent across camps, while the duration of education, curricula used, and use of asthma action plans is not. While almost all camps cover asthma basics, types of asthma medications and how they work, when to take asthma medications, what to do in case of an asthma episode, and triggers, “how to use your asthma action plans” is not taught consistently. This could be due to the fact that less than half (46.6%) of camps require an asthma action plan prior to attending camp. A standard asthma education curriculum was used by less than half of camps. The average number of hours of group or individual asthma education varied greatly from 0-2 hours to more than 8 hours.

Parents are not familiar with what asthma education camps are teaching to their children. Half of camps reported that they provide parent/care provider education through brief sessions pre-camp or at the time of drop-off or pick-up. Few camps provided sibling education. Based on interviews with parents, parents do not understand what education is provided to their child during asthma camp. Therefore, parents may not be able to reinforce these messages after camp or follow through with their role in asthma management.

Through the generous support from pharmaceutical companies, the verification of a family’s socioeconomic status prior to providing financial assistance, charging a registration fee, and seeking out health plans to cover members’ registration fees, asthma camps should be able to balance their budgets. The average 2004 camp expenditures (\$35,805) and average income (\$35,097) reported were virtually equal. Pharmaceutical companies provide generous support for camps. The 2004 average per camp pharmaceutical contribution per camp was \$4,860. Only seven camps indicated they required verification of family’s socioeconomic status prior to providing financial assistance. The remaining camps indicated that financial support was provided simply based on parent request. Only 15 camps (20.5% of respondents) indicated that they do not have a camp registration fee.

A variety of local camp evaluations and research projects have been conducted.

While the majority of camps conduct some type of evaluation, it is primarily limited to participant satisfaction and process evaluation. Forty-seven camp directors indicated through the online survey that they conducted one or more of the following types of camp evaluation:

- Pre-post test of children’s asthma knowledge and skills
- Pre-post (or simply post-test) of parent’s asthma knowledge
- Post-camp participant and/or parent satisfaction survey
- Evaluation of the asthma education content and delivery

Only six camps reported that they conducted some type of impact evaluation, such as pulmonary function testing or cost-benefit analysis.

At least eight asthma camps have closed in recent years for a variety of reasons, including:

- Inability to recruit new campers
- Lack of financial resources
- Change in organizational focus away from direct service
- Camp facility closed and inability to identify another appropriate facility

- Intentional mainstreaming of children with asthma into existing, non-specialty camps.

Stakeholders reported a variety of impacts that would occur if their organization quit sponsoring asthma camps.

- Organizations would lose a fundraising opportunity
- The sponsoring organization’s public image would be negatively impacted
- Sponsoring organizations may lose their volunteer base
- Closing asthma camps would significantly impact children with asthma

Future Opportunities for Children’s Asthma Camps:

This study provides a number of opportunities for the Consortium and individual asthma camps to consider, including:

- Standardizing evaluation methods and tools for use by asthma camps, including participant satisfaction tools, process evaluation, and impact evaluation. This would allow evaluation results from multiple camps to be aggregated and for broader themes and generalizations to be made.
- Encouraging verification of financial need prior to providing financial assistance to a child. The Consortium may want to recommend requiring that parents need to provide a federal tax form 1040, line 36 for evidence of household income.² A sliding scale fee and/or family circumstances (recent unemployment, single family household, etc.) may be appropriate after proof of household income.³
- Encouraging all asthma camps to have a registration fee. Through the online survey, many camp directors indicated that they do not set a camp registration fee. This may reduce these camps’ opportunity for revenue. Without a registration fee, it would be difficult to request a health plan to cover the costs associated with their members who attend camp or a family with the ability to pay to pay for their child’s camp.
- Providing guidance (other camp’s experiences on who to contact, information to provide to the health plan, etc.) to camps on how to seek registration coverage from health plans for their members who attend camp.
- Stressing the importance of reaching new campers and targeting children with persistent asthma. Through the online survey and stakeholder interviews, several camp directors reported that in the last year(s), their camp had no new campers and that they did not limit the number of years a child could attend camp. Similarly, many camp directors reported that their campers only needed a diagnosis of asthma, regardless of severity or level of asthma control, to attend camp. By simply filling a camp with any child with

² Form 1040, line 36 is the proof required by the American Diabetes Association. Personal communication with American Diabetes Association Camp Program Director March 2005.

³ Recommendation by the American Camping Association. Personal communication March 2005.

asthma, camps are reducing their opportunity to impact children and families in most need of asthma education and management.

- Addressing returning campers by recommending a limited number of years that campers can return and suggesting on how to best utilize returning campers as peer educators and mentors. The Diabetes Camping Association has a successful model – a continuum of involvement – where children with diabetes are first campers, then peer educators, then junior counselors, then counselors. This provides more role models and therefore more impact.
- Continuing to stress a minimum number of asthma education hours provided to children with asthma. While the Consortium recommends a minimum of one hour of asthma education per day, it is unclear from responses by camp directors that this minimum is provided.
- Developing a recommendation requiring a written asthma action plan prior to attending asthma camp and as one component of the asthma education curriculum. The asthma action plan is the only component of asthma education that is not being consistently taught, based on responses to the online survey by camp directors. In addition, only 46.6% of camps reported that they do not require an asthma action plan prior to attending camp.
- Conducting a multi-site, long-term impact study starting prior to camp and up to one-year post camp. Measures should include children’s knowledge, asthma management skills, pulmonary function, school attendance, health care utilization, and cost-benefit.
- Developing, piloting, and evaluating the impact of a mid-year asthma education refresher/booster for children who attend asthma camps. Both stakeholders and parents indicated that children with asthma would benefit from a “mid-year refresher/booster”. Suggestions for this refresher included a winter “camp” where summer campers could be reunited for one day of asthma education and peer support.

Study Limitations:

Several limitations of the research regarding children’s asthma camps exist. First, the retrospective design of this study relied on data that had already been gathered and individuals’ memories and documentation of their 2004 asthma camp experience. Second is the unknown fidelity among and between the asthma education curriculums at children’s asthma camps. In other words, it is difficult to generalize the findings from individual asthma camp studies because of the variations in intensity, duration, standardization, content, and delivery format of the asthma education at children’s asthma camps. Third is the lack of well-designed, long-term studies of asthma camps. We simply do not know the length of time camps change asthma management behavior, if there is another factor responsible for impacting children’s health, etc. The design of future evaluation and research studies regarding children’s asthma camps should take these limitations into consideration.

Attachment A

Consortium of Asthma Camps Stakeholder Interview Protocol

Name:

Date:

Hello, I am Jill Heins calling on behalf of the Consortium of Asthma Camps. The Consortium Board is undertaking a study to determine the value of asthma camps. I would like to ask you several questions about your experience and perceptions of asthma camps. Do you have about 10 minutes?

All information you provide to me is confidential and will only be shared in aggregate. No comments will be attributed to you or your organization. May I ask you several questions?

How long have you been involved with asthma camps?

What is your role with asthma camps?

What does an asthma camp experience provide to children with asthma that they could not receive anywhere else?

In your opinion, what makes asthma camps valuable?

Has your asthma camp conducted any evaluations/research that has not been published? If so, would I be able to access that information? How?

If there would no longer be an asthma camp in your community, what would be the impact on:

- Your organization
- The public
- Children with asthma and their families
- The medical community
- The media

For health care providers:

How has your involvement with asthma camps impacted your day-to-day practice as a health care provider?

For camp directors:

What is the motive of your organization to sponsor asthma camps?

How has the asthma camp community assisted you with the building of community partnerships that has impacted other work of your organization?

To what extent does your community expect your organization to provide direct service to the community?

Do you use camp to promote fundraising opportunities for ALA (example might be Asthma Walk)?

What is the impact asthma camps have on other fundraising for your organization?

Attachment B Stakeholder Interview Summary

The Consortium of Children's Asthma Camps Board of Directors commissioned a study, beginning, mid-September 2004, to determine the value of asthma camps. This multi-method study included interviewing key stakeholders involved with children's asthma camps. This document describes the process and key findings from those interviews.

Methods:

Twenty-six interviews were conducted, via telephone or in-person, with children's asthma camp stakeholders. A stakeholder was defined as someone who would do their job differently tomorrow, based on study findings presented today; a sponsoring organization representative; or a key leader in the asthma camp community. The Consortium of Children's Asthma Camps Executive Director originally developed a list of stakeholders representing established and new camps, small and large camps, organizations who recently quit sponsoring asthma camps, and Consortium of Children's Asthma Camp board members and consultants. This list was supplemented through stakeholder recommendations or referral of the interview to another individual. The asthma camp roles of the stakeholders ranged from camp director/coordinator, medical director, medical volunteer, organization board member, parent of camp participant, and higher-level leadership/administrative oversight.

The interviews were conducted between September 29, 2004 and November 1, 2004. The interviews varied from 10 minutes to 45 minutes in length, depending on the role of the stakeholder, their familiarity with asthma camps, and their willingness to share details.

The stakeholders were queried about their role, length of involvement with asthma camps, perception of what the children, families, health care professional volunteers, and organizations receive from camp, their perception of the value of asthma camp, what the impact would be on various sectors if their camp was eliminated, organizational motives for sponsoring camps, partnership development, educational components of camp, camp budget, and the impact camp has on their organization's fundraising efforts.

Findings:

A variety of themes emerged from these stakeholder interviews. Below is a summary and supporting statements for each theme. To maintain confidentiality of the interviewee, organizational names were withheld.

Stakeholders perceive that children's asthma camps provide a variety of experiences that children with asthma could not receive anywhere else.

Feeling of normalcy: 14 (54%) stakeholders indicated that by attending asthma camps, children with asthma have the opportunity to spend significant time with other children with asthma. This allows the children to feel normal and realize there are other children with asthma just like them.

- "It provides a realization that they are not alone."

- “Children find they are not all that different from other children.”
- “They receive a feeling of inclusion. They aren’t alone in the world.”

Opportunity for intensive asthma education: 14 (54%) stakeholders indicated that by attending asthma camps, the children receive quality, intensive asthma education in a variety of formats.

- “We provide one-hour of asthma education per day. The lessons are reinforced throughout the day. The education is age appropriate.”
- “We provide one-hour of formal education per day. Then the lessons are integrated into camp day through different formats. There is direct teaching through one nurse per cabin, small group activities based on age, large group activities, and one-on-one teaching if needed.”

Opportunity for a total camp experience: Fourteen (54%) stakeholders shared that asthma camp provides children with asthma a total camp experience in a medically safe environment.

- “The children are able to fully participate in the camp experience.”
- “The children are at camp and safe with their disease.”
- “Camp is an opportunity for children with asthma to enjoy the outdoors free of worry and restrictions due to their asthma.”

Independence from their parents/primary caregiver: Nine (35%) stakeholders indicated that asthma camp provides an opportunity for children to develop self-confidence and independence from their primary caregiver.

- “Often, camp is the first time away from home for this child because of medical concerns.”
- “They gain confidence. They learn they can be away from their primary care providers. As a Mom, I gained independence that someone else can take care of my child. It is difficult to give up your most prized possession for one week.”
- “Children learn ‘I can help take care of my asthma without my parents’.”

Opportunity for kids can be kids: Eight (31%) stakeholders mentioned that asthma camp provides children with asthma an opportunity to do activities that they are not normally able to do because of their disease.

- “We do things they are not normally able to do, such as swimming and sports.”
- “We never let kids use asthma as an excuse not to participate.”
- “Our purpose is to show kids what they can do with controlled asthma.”
- “Kids can be kids.”
- “Camp is a unique ‘I can do’ attitude.”

Opportunity to build the child’s socialization skills, self-confidence, and self-esteem: Five (19%) stakeholders shared that asthma camp assists in the personal development of the child.

- “Children gain self-assurance.”
- “The children build their confidence level for asthma self-management so they can leave home and go to mainstream camps in the future.”

Other benefits of the asthma camp experience mentioned by stakeholders included:

- Camp provides an opportunity to reach children from limited-income and inner-city families. (4)
- Children often cannot attend a mainstream camp because of their asthma. (3)
- There is a positive impact on the parents and families ability to manage asthma. (2)

Stakeholders perceived that asthma camps are valuable for a variety of reasons.

Stakeholders perceived the greatest value of asthma camp to be an opportunity to provide intensive asthma education for children with asthma: Twelve (46%) stakeholders described the opportunity to provide asthma education as camp's greatest value.

- "Camp is an alternative source for asthma education, skill building, and changing asthma-related behavior."
- "To kids, camp is a great experience coupled with great education on management."
- "We have medical volunteers teach children how to manage asthma outdoors, to pre-treat, carry and use rescue medications, use spacer properly, zones, medications, triggers, and how to identify early warning signs."
- "It is a typical camp experience plus asthma education."

Opportunity for interaction with peers: Six (23%) stakeholders indicated that interaction among peers with asthma is the greatest value of asthma camp.

- "Children see their peers also have asthma."
- "Camp shows children they are not alone and not weird."

Opportunity to experience a camp specifically for them: Five (19%) stakeholders indicated that having a camping experience specifically for children with asthma is the greatest value.

- "Every kids dreams of going to camp and staying away from their parents overnight."

Further the development of the child: Four (15%) stakeholders mentioned that the value of children's asthma camps is the development of the child's independence and self-esteem.

- "Children excel individually, they learn not to be embarrassed."
- "We teach that children with asthma can achieve anything!"
- "Camp builds independence and stretches their horizons."

The sponsoring organization and asthma community also receive benefits from asthma camps: Four (15%) stakeholders mentioned that the value of asthma camp is reaped by the sponsoring organization and broader asthma community.

- "Asthma camp is the cornerstone of building the asthma community. It connects (my organization) to the medical community, it provides a research opportunity, and it is a direct service of our organization for the public to see."
- "Camp sends the public message that asthma can be controlled. Camp sends little ambassadors for asthma out."
- "It is a feel good experience for (my organization), volunteers, and families of kids with asthma."

- “Camp provides a ‘warm fuzzy’ product to do fundraising.”

A variety of local camp evaluations and research projects have been conducted.

Seventeen (65%) of the stakeholders mentioned that one or more evaluations or research projects had been conducted through the asthma camp with which they were involved. Examples of the types of evaluation or research conducted at individual camps includes:

- Pre-post test of children’s asthma knowledge and skills (5)
- Pre-post (or simply post-test) of parent’s asthma knowledge (4)
- Post-camp participant and/or parent satisfaction survey (4)
- Evaluation of the asthma education content and delivery (2)
- Post-camp quality of life questionnaire (2)
- Cost-benefit analysis (1)

Please see the summary of published and unpublished research for a description of the above research activities and related findings.

Stakeholders indicated the primary motive for their organization to sponsor asthma camps is to help children with asthma (10 or 38%).

- The following testimonial was written on the back of one camper’s post-camp satisfaction form. She has severe persistent asthma and had low self-esteem. She wrote this when she was 14 years old. “I have been coming (to asthma camp) since I was eight. Before then I was rejected from others and had no self-confidence. Since I have gone, I have made my first best friends here, and have felt special, and no longer have to hide my disease from others. Without this camp, I would not be the person that I am today. I can’t thank everyone enough for giving me a place I think of everyday and smile because of the memories and lessons I have come back with. I love it with all my heart and soul. I will never forget it or the people that helped me to enjoy my life.”

Other organizational motives for asthma camp provided by stakeholders included:

Tradition (4):

- “We continue because of tradition. Tradition needs to be woven into the foundation of an organization.”
- “For some organizations, it may simply be tradition. It is expected by the volunteers.”

Part of organizational mission (2):

- “So many things we do are not visible to the community. This one is visible.”
- “Camp is a visible manifestation of carrying out (my organization’s) education mission.”

To fill a community need (2):

- “No one else was doing it. Parents were calling with concerns and asking where they could send their children.”

Publicity/outreach (2):

- “The hospital started camp because it was good publicity, a win-win situation, and provided huge outreach to the community.”
- “Camp is marketing tool, it brings in donors and cash.”

Three of the stakeholders indicated that they did not know their organization’s motive for sponsoring asthma camps.

The asthma camp experience impacts the day-to-day practice of health care providers in a variety of ways. (Note: All but one of the health care providers interviewed were physicians.)

- “When I see kids away from the office, it is a real world experience and I see real behaviors.”
- “I get to know what kids are like in the real world. The clinic is an artificial environment. Camp makes me more aware of the real life challenges and barriers.”
- “Camp reinforces the idea that you must teach something three times.”
- “I have a special bond with the kids I also see at camp. This is what I do everyday, then I go to camp for three days a year.”

Asthma camps provide organizations the opportunity to develop community partnerships.

Stakeholders often first described partnerships as financial sponsorships (6 or 23%).

- “In 2005, camp will be paid for completely by the Kansas City Royals. People will donate for kids.”
- “The Minnesota Vikings donate \$100 for each touchdown they make throughout the year.”

Several unique, non-financial partnerships were described by stakeholders.

- “The four largest health care organizations, Children’s Hospital, National Jewish, Kaiser, and come together annually to develop the asthma education curriculum.”
- In (our state), four hospitals provide the volunteer medical staff while on the hospital payroll. How? We simply asked!”
- “We work with prep programs (RN and RT) to have the students volunteer at camps. They learn a lot!”

Two stakeholders described partnerships that extend beyond camp.

- “When we go into a community for camp, we talk with the elected officials. We interact with these folks in a close manner. It feels like we are doing something together. We work with the elected officials in a non-policy/advocacy manner. It sets the stage for the remainder of the year. Later, they may listen or support (my organization’s) policies or bills.”
- “The University School of Respiratory Science Center sends two MDs to camp. One of them is the camp director. This makes for good partnerships outside of the clinic setting. We were able to partner on a COPD project later. This wouldn’t have happened without our previous partnership experience.”

The extent to which stakeholders believed there was a community expectation for their organization to provide direct service varied.

- “It is part of the expectation. If the community donates money, it is expect there is a program or specific result.”
- “This is our 19th year. It is the expectation of the community that we hold camp. Period.”
- “There is no strong community expectation. The city government doesn’t have a clue that we do camp. However the asthma community feels strongly about camp.”

Asthma camp impacts the fundraising efforts of an organization

- All stakeholders indicated that their sponsoring organization raises money for asthma camp.
- Fundraising in some organizations is often done in the name of asthma camp.
- Fundraising for asthma camp is relatively easy.
- Fundraising may or may not meet the camp budget. Stakeholders indicated that fundraising usually meets the out-of-pocket expenses, however it is reportedly less common that fundraising cover the administrative/support staff time.
- Three of the stakeholders questioned whether all of the money raised under the heading of asthma camp goes directly into a camp specific budget.
 - “We always fundraise in the name of kids with asthma and asthma camp. Not all funds raised in the name of camp go to the camp budget.”
 - “We combined two of our overnight camps. Before, all of our funds went to (an organization) to be managed. We started questioning what happened to the surplus. Now, these two camps are going to get their own tax ID number. Another (camp in our state) had the same experience and now has their own tax ID number and system.”

Raising funds for camp may not translate into raising funds for other issues.

- “Asthma camp for children is a very easily understood sell. Money for research is more difficult. You can’t translate the \$500 for camp into \$500 for research.”
- “It is easier to raise money for kids than research animals.”

Stakeholders reported a variety of impacts that would occur if their organization quit sponsoring asthma camps.

The sponsoring organization would be impacted (18 or 69%):

Organizations would lose a fundraising opportunity. (8)

- “Other physicians in my community would set up their own camps and use (my organizations’) volunteers and fundraising partners.”
- “People identify us with asthma camp, it is an easy way to raise funds.”
- “We would loose something valuable for fundraising and partnerships.”

The sponsoring organization’s public image would be negatively impacted. (7)

- “It would decrease our public image.”
- “It benefits (my organization). It is the most visible thing we do.”
- “Our organization would lose their direct tie to the family. We would lose passion if we get too far away from the patients. It would hurt (my organization’s) reputation.”
- “For the amount of money raised, (this organization) does almost nothing for the allergy/asthma community. There is very little activity this (organization) does for asthma. (This organization) fundraises to be an entity. Once per year they hold a dinner to raise funds, then we don’t see them again in our community for a year.”
- “Without camp, (my organization) is just fundraising to be an entity. There is a perception of too many staff without something good to do.”

Sponsoring organizations may lose their volunteer base. (5)

- “We would lose our medical and lay volunteers.”
- “Camp connects and brings new medical professionals into camp and (my organization).
- “We would lose health care professionals as volunteers. This is the entry into volunteers for other programs.”

Closing asthma camps would significantly impact children with asthma. (13)

- “(My organization) would lose a great program that benefits kids.”
- “It would cause a void for a lot of the kids. Many are repeat campers.”
- “We wouldn’t be able to educate kids, because these kids are not involved with other community programs.”

Other comments made by stakeholders regarding closing asthma camps included:

- Camp provides respite care for parents. (3)
- Asthma camp is their organization’s only asthma-related or largest program. (2)
- Stakeholders indicated that they would expect to see kids in more acute or severe settings. (2)
- “It would free up staff time for other projects.” (1)

Summary:

Stakeholders perceived asthma camp to be a valuable opportunity to provide intensive asthma education to children with asthma in a medically safe, family-friendly, and peer-to-peer environment. In addition to sponsoring organizations being able to help kids with asthma, asthma camp also provides an excellent fundraising, partnering, volunteer recruitment, and public/medical community outreach opportunity.

Attachment C

Review of Published and Unpublished Literature on Children's Asthma Camps

A review of published and unpublished literature⁴ was conducted as one component of the Consortium of Children's Asthma Camps' study to determine the value of asthma camps. The extensive literature search identified 26 articles or manuscripts, written in English, between 1981 and 2001. The purpose of identifying all published articles, regardless of when published, was to: 1) capture all (or as many as possible) of the published articles regarding the impact of children's asthma camps since asthma camps' beginnings in 1967 and 2) to ensure a sufficient number of peer reviewed journal articles from which to draw conclusions.

Four articles were excluded from the literature review because they did not directly evaluate the impact of children's asthma camps. Faivelson, 1993 compared in-patient hospitalization education with in-patients who received their usual care; Ponder, 1993 described a life-threatening exacerbation at an asthma camp and the medical response; Punnett, 1993 was a retrospective descriptive design to identify what factors differentiate children in terms of their reactions to camp experiences; and Wilson, 1993 randomly assigned adult patients with asthma to a variety of educational formats, including camp.

The most common types of published articles include a detailed description of children's asthma camps (Alaniz, 1995; Alaniz, 1999; Parrish, 1980; Silvers, 1992; and Consultant, 1993); a description of volunteer staff training (Beder, 2000); and testimonials/expert opinions regarding the benefit of children's asthma camps (Seeler, 1990; Sosin, 1991; and Tinstman, 1981). Welch, 2002 and the Consortium of Children's Asthma Camps piloted a Universal Health History Form with three different camps to characterize the type of children attending camp. These descriptive journal articles did not evaluate children's asthma camps or measure outcomes.

The following is a summary, grouped according to outcome measures, of the literature identified. The chart, *Summary of Evidence Regarding Impact of Children's Asthma Camps*, illustrates the types of study designs and the reported outcomes measured.

Use of camp nursing services: Bloch, 2001 conducted a retrospective descriptive study of 156 children, ages 3-16 years, with asthma who attended a large, outdoor, non-specialty, eight-week day camp. The data retrieved from the camp nursing records indicated that 9.4% of the children had asthma. Of the children identified with asthma, 10.9% received scheduled daily asthma medication administered by camp nurses; 78.9% needed two or more doses of PRN asthma medications during camp, and 13.5% presented, at least once, to the camp nursing office during the camp season with asthma-related respiratory complaints. Of the 35 visits to the camp nursing office for acute asthma problems, 20% of those visits required the child to leave camp. A total of 765 doses of asthma medications were given (scheduled and PRN) during camp. According to Bloch, "children with asthma used an ample amount of camp nursing services (therefore) sound nursing systems and camp policies must be in place to facilitate frequent change in daily scheduled medication regimens. In addition, adequate nursing staff is necessary to meet the

⁴ These 26 articles include one national presentation and one national poster session.

needs of the children with asthma as well as the various nursing needs of other campers.” Bloch voiced concern that while many “day camps are required by local laws and accreditation agencies to have first-aid stations, they are not required to have professional nurses on site.” Since children with asthma have been shown to use an ample amount of camp nursing services, it is important to determine if a camp’s health and first-aid procedures are sufficient for children with asthma.

Parent and child asthma knowledge: Six studies indicated an increase in child and/or parent asthma-related knowledge (Brazil, 1997; Meng, 1998; Penza-Clyne, 2003; Plante, 2001; Robinson, 1985; and Weisberg, 1995). One article reported a measurable decrease in family stress related to the child’s asthma after attending a three-week out-patient children’s asthma camp (Brazil, 1997). Weisberg, 1995 reported an increase in family communication after camp.

Self-efficacy: The literature indicates mixed findings regarding the impact of asthma camps on self-efficacy. Alaniz, 1999 reported no statistically significant differences in overall asthma self-efficacy scores among 27 adolescents who attended a one-day, six-hour day camp. However, there were differences on the teens’ ability to manage asthma pre-camp and one-month follow-up on several specific questions/areas: while exercising; in the doctor’s office; breathing improperly; while afraid; and when angry. Similarly, Penza-Clyve, 2003 found that self-efficacy does not change as a function of camp. The author suggested that because the post-test is immediately at the end of camp, the children have not been confronted with opportunities to manage their asthma. Contrary to the above, Buckner, 2002-3 found that self-efficacy and resilience increased at six weeks post camp ($p < 0.05$) for 16 teens (ages 12 – 15) who participated in asthma camp.

Locus of control: There were also inconsistent findings regarding children’s asthma camps’ ability to increase a child’s locus of control (defined as a child’s willingness to take their asthma medications) (Robinson, 1985; Weisberg, 1995; and Hazzard, 1986). Robinson, 1985 found a statistically significant increase from pre-camp to immediate post-camp and three-months post-camp in the child’s locus of control. Weisberg, 1995 reported an increase from pre-camp to immediate post-camp in the child’s “mastery over asthma” (defined as a child’s feeling of control over their asthma). Hazzard, 1986 found no statistically significant differences between the control and interventions groups.

Self-esteem/Self-concept: While four studies reported a decrease in the child’s anxiety and improved attitude toward their disease (self-esteem or self-concept) after asthma camp (Brazil, 1997; Briery, 1999; Plate, 2001; and Robinson, 1985), Hazzard, 1986 found no statistically significant differences between the control and interventions groups.

Asthma management techniques: Four studies reported improved asthma-management techniques. Improvements in metered dose inhaler technique was reported by Brazil, 1997; Fitzpatrick, 1992; and Kelly, 1998. Improvements in peak flow meter technique were reported by Kelly, 1998 and Meng, 1998. Increased use of breathing/warm-up exercises was reported by Brazil, 1997 and Fitzpatrick, 1992.

Meng, 1998 reported that parents felt that their children had learned to take responsibility for their asthma management and the children had increased confidence about their self-management (this definition is very similar to self-efficacy and self-concept; however, Meng, 1998 defined them differently). Parents noted that the effects of the asthma education lasted about six-months. The parents recommended that a booster education program at the mid-year point between camps would be beneficial.

Pulmonary function: Decreased asthma symptoms were also reported after camp. Chipps, 1984 monitored the daily pulmonary function of the child with asthma during an eight-week residential summer camp for children with asthma. Overall, pulmonary function improved and symptom scores dropped during camp. Significant increases in pulmonary function occurred after the second week at camp. The author questioned whether this was due to changes in the environment or more consistent administration of medications while at camp.

Symptoms: Brazil, 1997; Chipps, 1984; and Weisberg, 1995 reported decreased asthma symptoms after children attended asthma camps. Brazil, 1997 reported this decrease in symptoms lasting a minimum of three months post-camp. Chipps, 1984 and Sekaros, 1993 both reported a decrease in exacerbations between pre and post-camp surveys.

School absences: Five studies reported decreased school absences after attending asthma camps (Brazil, 1997; Fitzpatrick, 1992; Kelly, 1998; Meng, 1998; and Sorrells, 1995). Kelly, 1998 found that school absenteeism decreased from a total camper cumulative of 266 days for the year prior to attending asthma camp to 188 days the year after asthma camp.

Health care utilization: Decreased health care utilization was identified by five authors. Kelly, 1998; Meng, 1998; Fitzpatrick, 1992; Sekaros, 1993; and Sorrells, 1995 reported a decrease in emergency department visits after attending asthma camps. Kelly, 1998 and Fitzpatrick, 1992 measured a decrease in hospitalizations after participation in asthma camps. In the most recent of these studies, Kelly, 1998, found that emergency room visits due to asthma, in the year prior to camp compared to the year following camp, decreased by 59% while asthma-related hospitalizations decreased by 83%.

Cost-savings: Only two studies measured the financial impact of children's asthma camps (Fullman, 2002 and Kelly, 1998). In comparing data collected in the year prior to and following asthma camp attendance, Kelly, 1998 found that health care utilization savings total \$2,014 per child enrolled in asthma camp. Similarly, Fullman, 2002 compared the differences between return camper and first-time camper mean scores for emergency department visits, hospitalizations, and missed school days. Based on local average costs, the total savings per child per year who attended asthma camp was \$2,618.

Discussion: The published and unpublished evidence regarding children's asthma camps indicates that asthma camps can increase parent and child asthma knowledge, increase a child's locus of control, improve their self-efficacy and attitude about their disease, improve their asthma-related behavior and pulmonary function measures, and improve their metered dose inhaler and peak flow meter technique. The literature also indicates that asthma camps decrease child's anxiety, symptoms, exacerbations, school absences, emergency department visits, and

hospitalizations. Two studies indicated cost-savings of over \$2,000 per child in the year following asthma camp participation.

Children's asthma camps achieve a high level of science-based prevention. The literature base regarding children's asthma camps was compared to the public health definition of "science-based prevention," defined as "approaches that have been developed and evaluated using scientific-processes. These programs are grounded in a clear theoretical foundation and have been carefully implemented and evaluated. The evaluation findings have been subjected to critical review by other researchers and the program has been replicated in a variety of settings with the desired results".⁵ Asthma camps also reached a level of moderate evidence-based medicine (definition of strong evidence-based medicine is several relevant, high-quality scientific studies with homogeneous results). Asthma camp studies have been successfully replicated in several settings, across multiple target populations with consideration for age, gender, race/ethnicity, and geographic context.

Several limitations of the research regarding children's asthma camps exist. First is the unknown fidelity among and between the asthma education curriculum at children's asthma camps. In other words, it is difficult to generalize the findings from individual asthma camp studies because of the variations in intensity, duration, standardization, content, and delivery format of the asthma education at children's asthma camps. Second is the lack studies utilizing control or comparison groups. The third limitation is the length of time between testing in the time-series design studies. Most time-series studies implemented post-tests immediately after camp and then at one to three months post-camp. Therefore, the long-term impact of camp on children's asthma is unknown. The design of future evaluation and research studies regarding children's asthma camps should take these limitations into consideration.

⁵ Mulhall, P and Hays, C. Research-based Prevention: A Pyramid for Effectiveness. Center for Prevention Research and Development, Institute of Government and Public Affairs, University of Illinois.

Attachment D

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Please insert *Evidence Regarding Impact of Children's Asthma Camps* here.

Attachment E

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Attachment F

Summary of Interviews with Non-asthma Chronic Disease Camps for Children

As part of the Consortium of Children's Asthma Camps' study to assess the value of asthma camps, directors of the Children's Oncology Camping Association, Diabetes Camping Association, and American Diabetes Association Camping Programs were interviewed in November 2004 regarding their experience in assessing the value of camps. The following is a summary of those conversations.

Children's Oncology Camping Association:

The director of the Children's Oncology Camping Association explained that he just returned from a national oncology camping association meeting where, for the first time, they discussed oncology camps' current status, their impact on children, and their future direction. "We are at the same place asthma camps are."

According to the Children's Oncology Camping Association, the American Cancer Society has begun questioning their future support of oncology camps. Children's oncology camps, led by local volunteers, are breaking support from the American Cancer Society and starting their own camps. "This is causing a shake-up. Volunteers believe in [oncology camps] enough to take on the challenge." These "break-off" camps are often private, non-profits and have a variety of sponsors such as the Ronald McDonald House, foundations, and local hospitals. By breaking away from American Cancer Society, they are no longer bound to the American Cancer Society camping guidelines.

The Children's Oncology Camping Association's next steps will be to take the comments from this 2004 national conference and identify a future direction. They are looking to the National Camping Association for ways to standardize oncology camps nationwide. "For 20 years oncology camps have been independent and autonomous. We are now asking them to all work together." The Children's Oncology Camping Association is also encouraging camps to begin to collect "hard data to support a recovery rate."

The diabetes camp experience:

The experience of children's diabetes camps has two perspectives, that of the American Diabetes Association (ADA) and that of the Diabetes Camping Association (DCA). The ADA shared that in 1986, the ADA looked at how to best reach their mission, changed their structure from state affiliations to a national system, and hired consultants to assess the pros and cons of supporting children's diabetes camps. Through this process, the ADA identified liability of camps to be a large concern. As a result of this process, ADA greatly reduced their support for children's diabetes camps. From the DCA perspective, "about a dozen years ago, ADA choose to pull away from camps."

Then in 1997-1998, ADA brought together a task force to again look at children's diabetes camps. ADA looked at the percent of donor dollars that was spent on children's diabetes camps versus other programming (including Type II, research, parent education, and pre-diabetes education) and what services of camp might be redundant in the community (examples include

peer-to-peer education and parent support groups). The task force recommended continuing diabetes camps with some modifications.

ADA developed standards for the camps in which ADA's is still involved. Requirements of these camps include: a balanced budget (including direct expenses, staff/administration, and overhead); scholarships provided only after verification of financial need; issues of safety and liability are addressed (medical malpractice insurance and sexual molestation coverage); camps are accredited by the National Camping Association (which means all residency camps need to be a minimum of five days); "sound human resource practices" (defined as background checks for staff and volunteers); standardized staff and volunteer orientations; and standardized medical practice guidelines.

ADA indicated that "some camps split from ADA." For those camps that obtained their own 501.c.3 status, ADA agreed to market the camps through the ADA website and provide limited financial support if the camp has insurance, background checks, and is American Camping Association accredited.

The DCA saw this process differently. The DCA shared that "ADA learned a lesson. Once camps started to be independent, form their own board, and have their own finances, there was a big impact on ADA because they could not claim they provided any tangible service. ADA lost a huge number of volunteers and dollars." DCA indicted that ADA set up guidelines and now have the "best of both worlds."

Prior to this process, "diabetes camps never looked at outcome measures" stated the director of the DCA. The Joslin Diabetes Center in Boston is collecting outcome measures (primarily A1C) on diabetes camps. Ron James, MD from the Missouri Diabetes Camp is looking at international diabetes camp outcomes.

The DCA has developed a successful model for staffing camp. "The most successful diabetes camps are the ones were a child is a camper, then junior camper, then a counselor. It puts a different perspective on camp – a continuum of involvement. This provides more role models and therefore more impact." This model has also reduces staffing expense and increases buy-in and commitment. "With everybody involved in camp having diabetes, it is easier to get financing." No longer are you doing "camps for poor little children with diabetes."

DCA provides networking, sharing of resources, problem solving, funding-raising advice, and coordinating of evaluation/research for diabetes camps.

Some of the fundraising lessons learned by the DCA include:

- "If someone is in competition for donated dollars, look at the parent's view. Yes, they want the disease gone, but since their child has diabetes, they want their child to have a happy, healthy life."
- Produce a promotion video with parent and child testimonials about camp.
- Develop a long-term relationship with a nationwide service organization. Diabetes camps have formed a relationship with the Lions Club. Volunteers and DCA court the

Lions Club throughout the year. They conduct about 50 presentations per year to Lions Club service groups to develop a personal, face-to-face relationship.

Attachment G

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Please insert *Children's Asthma Camp Study* here.

Attachment H

Children's Asthma Camp Online Survey Summary

An online survey was developed and distributed as part of the Consortium of Children's Asthma Camps' (Consortium) study to determine the value of asthma camps.

Methods:

The online survey was developed to collect a variety of information about asthma camps in the United States, including general camp information, camper demographics, staffing patterns, budget information, asthma education provided through camp, and community outreach. This survey was piloted tested with two asthma camp directors. Adjustments were made based on pilot test comments. The final survey was first distributed on Monday, October 4, 2004. Camps were contacted either via email or phone at least four times requesting that they complete the online survey. Surveys were accepted until Friday, January 21, 2005.

This survey took significantly longer to distribute and collect than anticipated, primarily due to the lack of up-to-date information on the Consortium database. This database of camps in the United States is maintained by the Consortium; however, the responsibility for updating individual camp name and information has been the responsibility of the individual camp. Camps are able to update their information at any time and the Consortium sends several reminder prompts throughout the year. Through the distribution of this survey, it was found that not one of the camps listed in the database had complete correct information. Therefore, significant time was spent contacting the individual camp or the local American Lung Association affiliate to verify the correct camp information. The positive result is a very up-to-date Consortium database and a realization that the Consortium cannot passively rely on individual camps to update their camp information.

Seventy-five (75) surveys were completed for a return rate of 62%. Excluded from this response rate are two surveys completed by asthma camps in Mexico. The response rate is based on 121 verified asthma camps (defined as having a contact name, phone number, and/or email address in the Consortium database after personal contact with a camp staff person between October 2004 and January 2005). An additional 10 asthma camps are listed in the database, but were unable to be verified (total asthma camps in the U.S. believed to be 131). The results of this online survey were analyzed using Microsoft Access.

Summary of findings from the online survey:

- 75% of camps who have a designated staff person whose responsibility is to direct camp activities, have a staff coordinator at or less than 0.3 FTE.
- 62% of camps responding have more than 10 years of experience.
- The average number of campers per camp has consistently decreased since 2000.
- 70.3% of camps are residential and last an average of 4.9 days.

- 45.2% of respondents indicated more than half of their 2004 campers were new.
- 41.9% of respondents indicated more than half of their 2004 campers were returning campers.
- 47 respondents indicated that they conducted one or more of the following types of camp evaluation: pre-post test of camper knowledge; pre-post test of camp pulmonary functioning; survey of camper and/or parent satisfaction; and post-camp survey of staff/volunteer satisfaction.
- Six camps reported that they conducted some type of research or evaluation beyond pre-post tests or participant satisfaction.
- 54.8% of respondents reported that at least 61% of campers were from limited income families.
- Seven respondents indicated they required documentation/verification of family's socioeconomic status. The remaining respondents indicated that financial support was provided based on parent request.
- 22.7% of respondents indicated at least 61% of campers were from the inner-city or at-risk neighborhoods.
- Camps are staffed by a variety of professionals and disciplines.
- Few camps provide CME/CEU opportunities for their medical staff.
- 15 camps (20.5% of respondents) indicated that they do not have a camp registration fee.
- The average 2004 camp expenditures (\$35,805) and average income (\$35,097) reported were also equal.
- Average 2004 total pharmaceutical contribution per camp was \$4,860.
- The average number of hours of group or individual asthma education varied greatly from 0-2 hours to more than 8 hours.
- A set asthma education curriculum was used by less than half of camps.
- Less than half (46.6%) of camps require an asthma action plan. "How to use your asthma action plans" are not covered as consistently as other asthma management components.
- Few camps provided sibling education. Half of camps provided parent/care provider education through brief sessions pre-camp or at the time of drop-off or pick-up.

- Most camps received publicity or media coverage for their 2004 camps.

List of the Children’s Asthma Camp online survey questions and related responses.

Do you have a designated staff person whose responsibility is to direct camp activities?

Yes = 69 (92%)

No 6 (8%)

Responses to this question = 75

If yes, what percent FTE is this designated camp staff person or how many hours devoted to camp coordination?

Less than 0.2 FTE = 25

0.2 to 0.29 FTE = 9

0.3 to 0.39 FTE = 2

0.4 to 0.49 FTE = 1

0.5 to 0.59 FTE = 2

0.6 to 0.69 FTE = 3

0.7 to 0.79 FTE = 1

0.8 to 0.89 FTE = 0

0.9 to 0.99 FTE = 1

1.0 FTE or more = 1

Responses to this question = 45

How many years has your organization been offering asthma camps?

0 – 5 years = 18 (24.3%)

6 – 10 years = 10 (13.5%)

11 – 15 years = 12 (16.2%)

16 – 20 years = 4 (5.4%)

More than 20 years = 30 (40.5%)

Responses to this question = 74

* Due to rounding, total = 99.9%

Have you conducted any research or evaluation of you asthma camp?

Yes = 56 (75%)

No = 19 (25%)

Responses to this question = 75

How many children attended your camp....

In 2000?

Total = 3,154 campers; mean camper per camp = 67.1

Responses to this question = 47

In 2001?

Total = 3,112; mean camper per camp = 64.8

Responses to this question = 48

In 2002?

Total = 3,307; mean camper per camp = 60.1
Responses to this question = 55

In 2003?

Total = 3,616; mean camper per camp = 57.4
Responses to this question = 63

In 2004?

Total = 3,876; mean camper per camp 56.2
Responses to this question = 69

The remaining questions and responses were based on the 2004 camp experience.

What type is your camp?

Residential = 52 (70.3%)

Day = 19 (25.7%)

Mainstream = 1 (However in the following question, five camps described their camps as residential mainstreaming.)

Other = 2

Responses to this question = 74

If day or residential, number of days?

Number of days	Number (percent) of camps
1	2 (2.9%)
2	1 (0.1%)
3	10 (14.5%)
4	10 (14.5%)
5	20 (29%)
6	18 (26.1%)
7	8 (11.6%)

Responses to this question = 69

* Due to rounding, total = 98.7%

What requirements must the children meet in order to attend your camp?

- Daily medications consumed = 35
- Camper must have a certain level of asthma severity = 29
- New diagnosis of asthma (defined as diagnosis within the last year) = 4
- Other = 29

Please describe the details of your requirements:

- 9 reported accept children with moderate to severe asthma

- 36 indicated child only needs to have diagnosis of asthma
- 3 indicated preference to moderate/severe, but will accept any child with asthma.

Do you require a written asthma action plan for your campers?

Yes = 34 (46.6%)

No = 39 (53.4%)

Responses to this question = 73

What percent of your 2004 campers were:

New asthma campers:

0 – 25% = 3 (7.1%)

26 – 50% = 20 (47.6%)

51 – 75% = 8 (19%)

76 – 100 = 11 (26.2)

Responses to this question = 42

* Due to rounding, total = 99.9%

Returning campers:

0 – 25% = 9 (20.9%)

26 – 50% = 16 (37.2%)

51 – 75% = 16 (37.2%)

76 – 100 = 2 (4.7%)

Responses to this question = 43

What ages were your 2004 campers:

- 73% of respondents indicated that their campers were between 8 and 13 years of age.
- 16% of respondents indicated that their campers were between 6 and 7 years of age.
- 6.5% of respondents indicated that their campers were between 14 and 15 years of age.

If other, please describe:

- Counselors in training
- High school students
- Junior counselors
- Parents

Gender of 2004 campers:

Approximately half of 2004 campers were male and half female.

What percent of your 2004 campers were from limited income families?

0 – 20% = 12 (19.4% of respondents)

21 – 40% = 6 (9.7%)

41 – 60% = 10 (16.1%)

61 – 80% = 18 (29%)

81 – 100% = 16 (25.8%)

Responses to this question = 62

What documentation did you require for proof of income (i.e. How did you determine the camper's socioeconomic status)?

Seven respondents indicated they required documentation/verification of family's socioeconomic status. The remaining respondents indicated that financial support was provided based on parent request.

What percent of your 2004 campers were from the inner-city or at-risk neighborhoods?

0 – 20% = 24 (36.4% of respondents)

21 – 40% = 12 (18.2%)

41 – 60% = 15 (22.7%)

61 – 80% = 7 (10.6%)

81 – 100% = 8 (12.1%)

Responses to this question = 66

Do you provide the counselors for your camp?

Yes = 47 (64.4%)

No = 26 (35.6%)

Responses to this question = 73

Do you go to a facility that provides camping expertise and staff counselors?

Yes = 39 (54.2%)

No = 33 (45.8%)

Responses to this question = 72

How is your asthma camp staffed (Please check all that apply.)?

Camps are staffed by a variety of professionals and disciplines, including (in rank response order):

1. Respiratory therapists
2. Nurses
3. Allergists
4. Pediatricians
5. Nurse practitioners

Other types of camp staffing included:

- Child and family psychology
- Nursing, RT, and pharmacy students
- College students
- Local high school students
- Girl Scouts
- Former campers
- U.S. Marines

Is your medical staff:

- Volunteer – 52 (71.2%)
- Paid – 3 (4.1%)
- Combination of volunteer and paid – 18 (24.7%)

Responses to this question = 73

What was your 2004 camp budget (expenditures) (including designated staff time but excluding in-kind contributions or volunteer hours):

Budget expenditures reported by 55 camps totaled \$1,969,291; average \$35,805 per camp.

* Four additional camps expenditure totals were excluded because they did not include staff costs.

What was your total 2004 camp income (including all registration fees, grants, contributions, etc. but excluding in-kind contributions or volunteer hours):

- 51 camps reported a total 2004 camp income of \$1,789,954; average \$35,097 per camp.
- Income ranged from \$1,700 to \$95,000.

How is your camp funded? (Check all that apply.)

- Donor contributions = 59
- Grants from foundations = 53
- Grants from pharmaceutical companies = 48
- Partnerships with other agencies and organizations = 43
- Fee for service = 33
- Fundraisers = 22
- General operating budget = 21
- Asthma Walk = 17
- Health Plan (HMO) = 11
- Government funds = 2
- Other = 8, including:
 - \$20 application fee
 - Local medical students conduct a 5K run/walk and proceeds go to asthma camp
 - Children's Miracle Network
 - Local hospital provides funds

What as your 2004 camp registration fee?

- The range of camp registration fees was between zero and \$650.
- 15 camps (20.5% of respondents) indicated that they do not have a camp registration fee.
- Health plan/insurance covered part of all of registration fee = 12 camps (17.9%)
- Sponsorship offered to child = 50 camps (72.5%)

Do you receive pharmaceutical sponsorship for camp?

Yes = 53 (79.1%)

No = 14 (20.9%)

Responses to this question = 67

Please list the pharmaceutical companies who sponsored your camp in 2004.

The following pharmaceutical companies were the most frequent sponsors:

- GlaxoSmithKlein sponsored 19 camps
- Astra Zeneca = 14
- Sepracor = 12

Please indicate the total amount of pharmaceutical contributions in 2004.

A total pharmaceutical contribution of \$189,552 was reported by 39 camps (average contribution of \$4,860).

Please estimate the total number of volunteer health care professional staff hours for your 2004 camp.

Total volunteer hours reported by 58 camps = 52,648 hours or 907 hours per camp.

Do you provide CME/CEU opportunities for staff?

Yes = 13.8%

No = 86.2%

Please estimate, in dollars, the amount of in-kind contributions (products, services, prizes, etc.) your camp received in 2004.

48 camps reported a total of \$289,708 in in-kind contributions; average was \$6,036.

How many hours of group asthma education did your campers receive in 2004? (check one)

0 – 2 hours = 4 (6%)

2 – 4 hours = 15 (22.4%)

4 – 6 hours = 15 (22.4%)

6 – 8 hours = 21 (31.3%)

More than 8 hours = 12 (17.9%)

Responses to this question = 67

How many hours of individual asthma education did your campers receive in 2004? (check one)

0 – 2 hours = 32 (47.8%)

2 – 4 hours = 24 (35.8%)

4 – 6 hours = 4 (6%)

6 – 8 hours = 3 (4.5%)

More than 8 hours = 4 (6%)

Responses to this question = 67

* Due to rounding, total = 100.1%

Did you use a set asthma education curriculum during your 2004 camp?

Yes = 33 (48.5%)

No = 35 (51.5%)

Responses to this question = 68

If yes, what was the name of the curriculum?

- 10 respondents use and/or modify *Open Airways for Schools*

- Many reported using a combination of existing curriculum or developing their own.

What components of asthma management were covered during your 2004 camp? (check all that apply)

- Asthma triggers and other environmental controls = 69
- What are the types of asthma medications = 69
- What is asthma = 68
- What to do in case of an asthma episode = 68
- When to take asthma medications = 66
- How do asthma medications work = 64
- How to use your written asthma action plans = 49

Did you provide sibling education during your 2004 camp?

Yes = 9 (13%)

No = 60 (87%)

If yes, please describe: If sibling education was provided, it was often not directed at siblings, but was part of a family retreat or session.

Did you provide parent or car provider education during your 2004 camp?

Yes = 34 (50%)

No = 34 (50%)

Responses to this question = 68

Please describe the parent session: 24 respondents reported the parent session was either pre-camp, at drop-off time, or during pick-up.

Did you receive publicity or media coverage for your 2004 camp?

Yes = 56 (82.4%)

No = 12 (17.6%)

Responses to this question = 68

Please describe the type of media.

- Newspaper = 50
- Radio = 21
- TV = 18
- Other = 9, including included with hospital advertisements and posters in physician offices.

What would happen to the asthma camp in your community if your organization would no longer support it?

Close = 34

Find another sponsor = 7

Other = 1

Unknown = 26

Do you have plans to increase the age limits for children attending your asthma camp?

Yes = 4 (5.9%)

No = 64 (94.1%)

Responses to this question = 68

If yes, to what age? The four respondents are increasing the age of the campers..

Do you have plans to decrease the number of days of your camp in 2005?

Yes = 5 (7.6%)

No = 61 (92.4%)

Responses to this question = 66

Do you have any other plans to change the style/delivery of your asthma camp in 2005?

Changing location – 5

Adding asthma action plan -2

Sibling camp added -1

Attachment I Asthma Camp Parent Interview Protocol

Hello, I am Jill Heins with the American Lung Association of Minnesota. I am calling on behalf of the Consortium of Asthma Camps. We are undertaking a study to determine the value of asthma camps.

It is my understanding that _____ attended asthma camp this summer. I would like to ask you several questions about your experience with asthma camp.

All information you provide to me is confidential and will only be shared in aggregate. No comments will be attributed to you. May I ask you several questions?

How would you describe asthma camp to the parent of a child with asthma?

What is the best thing that your child got from asthma camp?

How has participating in asthma camps impacted your child with asthma? (Decrease hosp/Ed/symptoms/school absenteeism, improve his/her ability to understand asthma as a disease, improve ability to recognize symptoms, improve ability to take meds, improve social opportunities such as sleep-overs, trips, field trips, etc.)

After asthma camp, how did what he/she learned about asthma impact your child's:

- **Ability to take meds:**
- **Ability to recognize their asthma symptoms:**
- **Asthma symptoms and episodes:**
- **Self-management:**

How did attending asthma camp impact your child socially?

What is the best thing that you and the rest of your family got from your child attending asthma camp? (Prompts might include: respite care, opportunity to give other children care, increased family knowledge of asthma, decreased stress, reduced missed days from work.)

How has asthma camp changed your role in managing your child's asthma?

Why have you sent your child to asthma camp more than one time?

Is there anything else about your child's asthma camp experience that you would like to share with me?

Thank you for your time!

Attachment J

Summary of Parent Interviews

Ten interviews were conducted in October 2004 with parents of children who attended asthma camps during the summer of 2004. Eight of the parents were from Minnesota and two of the parents were from California. Parent interviews were terminated after the first ten because little insight was being gained. While parents indicated that their children enjoyed asthma camps and they would recommend asthma camps to other parents of children with asthma, the parents simply were not aware of the asthma-related education provided to their child during camp.