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## The Therapeutic Camping Needs Of Children: The Hole-In-The-Hills At Wa-Shawtee

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**THE THERAPEUTIC CAMPING NEEDS OF CHILDREN:  
THE HOLE-IN-THE-HILLS AT WA-SHAWTEE**

**Preliminary Report  
March 1, 2008**

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**EXECUTIVE SUMMARY**

This executive summary of the preliminary report documents the major findings, to date, of the first two components of a needs assessment being conducted for the Hole in the Hills at Wa-Shawtee (HITH). The purpose of the study is to determine if a new,

medically-equipped and professionally-staffed therapeutic camp in the Great Plains region of the Midwest has the capacity to be a success. There are almost 3.5 million children between the ages of five and seventeen in the 6-state HITH region,<sup>1</sup> an unknown number of whom are seriously-ill and/or have special medical conditions and health care needs, who could potentially benefit from a therapeutic camping facility.

The first two completed sections of the needs assessment are: 1) an inventory of existing camps and camp programs for selected pediatric conditions in the 6-state catchment area and 2) an inventory of the population to be served, including the prevalence of priority illnesses/conditions and the levels of unmet need or potential camp demand in the HITH region. The remaining two components of the assessment, which will be included in the final report are: 3) the identification and ranking of the needs of seriously-ill children in the priority disease groups, and 4) the identification and ranking of the needs of these children's parents and families.

## NEEDS ASSESSMENT FINDINGS

The major findings of the needs assessment are as follows:

### 1. Inventory of Camps and Camp Programs

- The priority disease groups identified by HITH are autism, asthma, cancer, cerebral palsy, diabetes, epilepsy/seizure disorders, heart/cardiovascular and juvenile arthritis.<sup>2</sup>
- A total of 49 camps in the region were identified that provide 105 camping opportunities for “special needs” children in the priority disease groups.<sup>3</sup>
- In the past 12 months a total of 8,371 children with serious illness/conditions were provided recreational opportunities by the camps in the HITH region.
- The total number of camping opportunities for children *by priority illness/condition* and the total numbers of children currently served by camps in the region are shown below in Table 1, columns 2 and 3.

**Table 1**  
**Total Unmet Demand for Camping Opportunities by Priority Disease Groups**  
**In the Hole-in-the-Hills Region**

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<sup>1</sup> There are 3,419,951 children ages 5-17 in the six-state region that includes Iowa, Kansas, Minnesota, Missouri, Nebraska and South Dakota (*Annual Estimates of the Population, July 1, 2006, U.S. Census Bureau*).

<sup>2</sup> Information collected on camping opportunities and disease prevalence among children in 17 disease groups initially investigated identified 65 camps. The HITH board of directors used this information to narrow the list to 8 priority disease groups for additional study and evaluation.

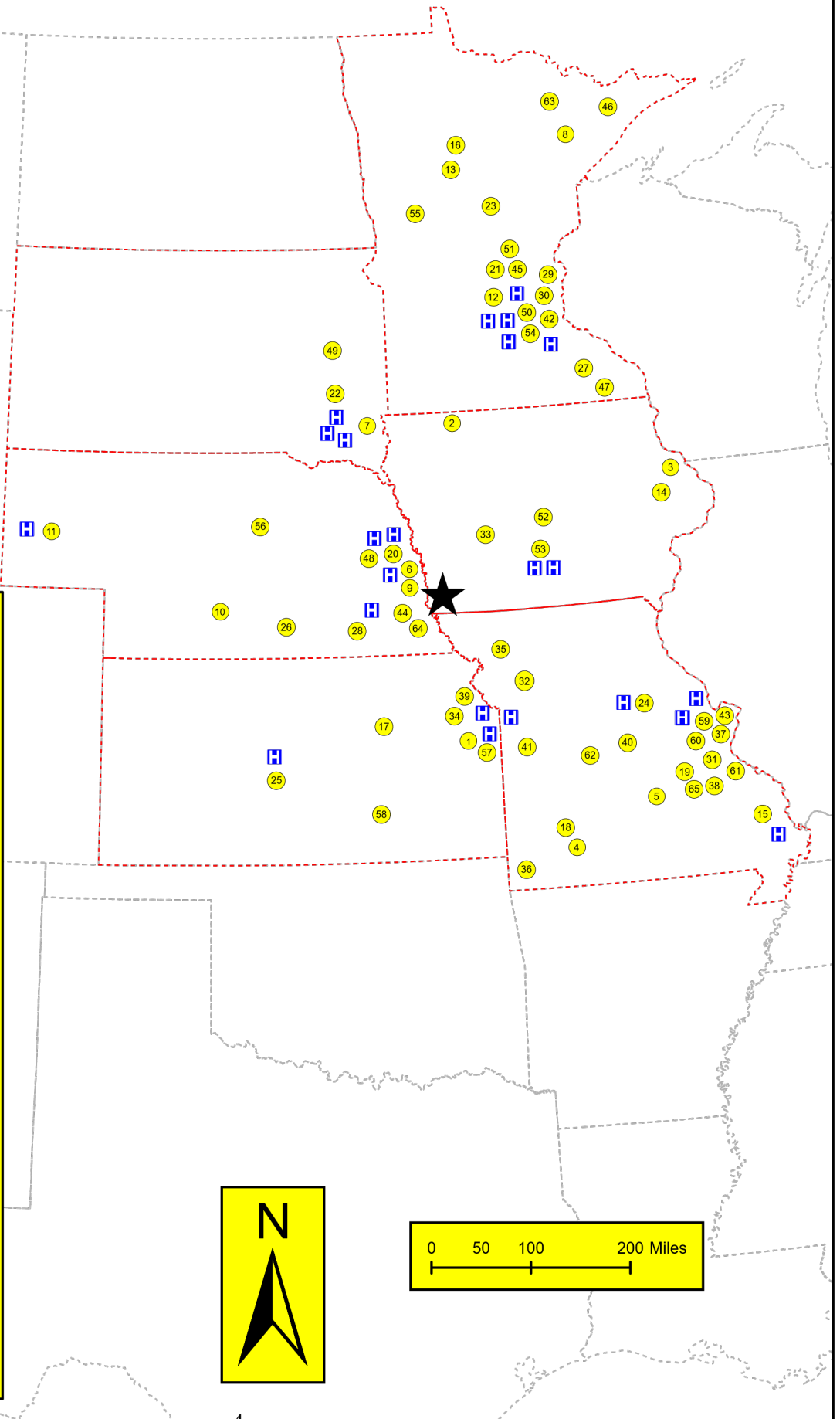
<sup>3</sup> Over one-fourth of the camps (26.2%) offer services for two or more of the HITH disease groups of interest. “Camping opportunities” refer to the cumulative total of disease groups served by all 49 camp sites, rather than the offering of a number of different types of camps and/or camp dates for any one disease group in a given year.

<b>DISEASE GROUP RANK Unmet Camp Demand</b>	<b>Number of Camping Opportunities in HITH Region</b>	<b>Children Served By Camps in HITH Region</b>	<b>Children Eligible for Camps HITH Region</b>	<b>Unmet Camp Demand in HITH Region</b>
<b>1. Autism</b>	15	<b>1,405</b>	<b>13,903</b>	<b>12,498</b>
<b>2. Heart/ Cardio</b>	8	<b>504</b>	<b>8,034</b>	<b>7,530</b>
<b>3. Diabetes</b>	18	<b>1,673</b>	<b>6,992</b>	<b>5,319</b>
<b>4. Asthma</b>	14	<b>892</b>	<b>4,889</b>	<b>3,997</b>
<b>5. Epilepsy /Seizure</b>	12	<b>966</b>	<b>4,787</b>	<b>3,821</b>
<b>6. Cerebral Palsy</b>	15	<b>1,456</b>	<b>5,096</b>	<b>3,640</b>
<b>7. Juvenile Arthritis</b>	1	<b>20</b>	<b>3,419</b>	<b>3,399</b>
<b>8. Cancer [Includes Leukemia]</b>	22	<b>1,455</b>	<b>4,103</b>	<b>2,648</b>
<b>TOTAL</b>	105	<b>8,371</b>	<b>51,223</b>	<b>42,852</b>

- Map 1 on the following page shows the locations of all 65 special-needs camps and the 23 children's hospitals in the HITH region. The maps for each of the eight priority disease groups are provided in Chapter I of this report.

# MAP I: Youth Camp Locations

- Camps**
- 1 - AAFA Superkids Asthma Day Camp
  - 2 - Avera McKennan (Foster YMCA) Asthma Camp
  - 3 - Camp Albrecht Acres
  - 4 - Camp Barnabus
  - 5 - Camp Black Hawk/Carpe Diem (Sunnyhill Adventures)
  - 6 - Camp Brave Hearts
  - 7 - Camp Bring it On
  - 8 - Camp Buckskin
  - 9 - Camp CoHoLo
  - 10 - Camp Comeca
  - 11 - Camp Cosmo Diabetic Camp
  - 12 - Camp Courage
  - 13 - Camp Courage North
  - 14 - Camp Courageous of Iowa
  - 15 - Camp DAY Break
  - 16 - Camp Discovery (Autism Society of MN)
  - 17 - Camp Discovery/KA-DI-DA-CA
  - 18 - Camp Earthworks
  - 19 - Camp EDI (The Gloria Hirsch Camp)
  - 20 - Camp Floyd Rogers
  - 21 - Camp Friendship/New Hope (Friendship Ventures)
  - 22 - Camp Gilbert (Sanford Children's Specialty Clinic)
  - 23 - Camp Hand in Hand (Autism Society of MN)
  - 24 - Camp Hickory Hill
  - 25 - Camp Hope (ACS KS)
  - 26 - Camp Hot Shots Central
  - 27 - Camp Jornada
  - 28 - Camp Kindie
  - 29 - Camp Odayin
  - 30 - Camp Oz (Epilepsy Foundation of MN)
  - 31 - Camp Quality Central MO
  - 32 - Camp Quality Greater Kansas City
  - 33 - Camp Quality Heartland
  - 34 - Camp Quality Kansas
  - 35 - Camp Quality Northwest MO
  - 36 - Camp Quality Ozark
  - 37 - Camp Rainbow
  - 38 - Camp Redbird
  - 39 - Camp Shing (Epilepsy Foundation of KS & West. MO)
  - 40 - Camp Sunrise (ACS MO)
  - 41 - Camp Super Breathers (Cass Med. Center)
  - 42 - Camp SuperKids (ALA of MN)
  - 43 - Camp SuperKids (ALA of MO)
  - 44 - Camp SuperKids (ALA of NE)
  - 45 - Camp We-No-Wheeze Central
  - 46 - Camp We-No-Wheeze North
  - 47 - Camp We-No-Wheeze South
  - 48 - Camp Without Barriers (Easter Seals NE)
  - 49 - Camps 4 R Kids Foundation
  - 50 - Courage Center (Camping Dept)
  - 51 - Cristo Vive International
  - 52 - Des Moines YMCA Camp
  - 53 - Easter Seals Camp Sunnyside
  - 54 - Eden Wood Center
  - 55 - KAMP KACE
  - 56 - Kamp Kaleo
  - 57 - Kansas City Diabetes Camp at Camp Shawnee
  - 58 - Kansas Jaycees' Cerebral Palsy Ranch
  - 59 - Missouri Children's Burn Camp (Burns Rec. Support Groups)
  - 60 - St. Louis SCD Camp
  - 61 - Sunnyhill Adventures
  - 62 - Wonderland Camp Foundation
  - 63 - YMCA Camp du Nord
  - 64 - YMCA Camp Kitaki
  - 65 - YMCA Camp Lakewood (YMCA of the Ozarks)



## 2. Population To Be Served (Disease Prevalence and Unmet Demand)

- A total of 51,223 children, ages 5-17, are estimated to be eligible to attend special needs camps for one of the priority illnesses/conditions in the HITH region. *The total prevalence of each priority illness/condition in the region is shown in Table 1, column 4.*
- The eight priority disease groups selected by HITH have the highest rates of prevalence (among the 17 diseases/conditions studied<sup>4</sup>) in the 6-state catchment area, as follows:

Autism (.407%)  
Heart/cardiovascular (.235%)  
Diabetes (.204%)  
Cerebral palsy (.149%)  
Asthma (.143%)  
Epilepsy/Seizure Disorders (.140%)  
Cancer (.120%)  
Juvenile Arthritis (.100%)

- The *total unmet need or potential camp demand*, calculated by subtracting the number of children in the HITH region currently attending camps (8,371) from the total number eligible to attend (51,223), is 42,852 children.
- The total unmet camp demand *for each of the priority illnesses/conditions* is summarized graphically on the following page in Figure 1.

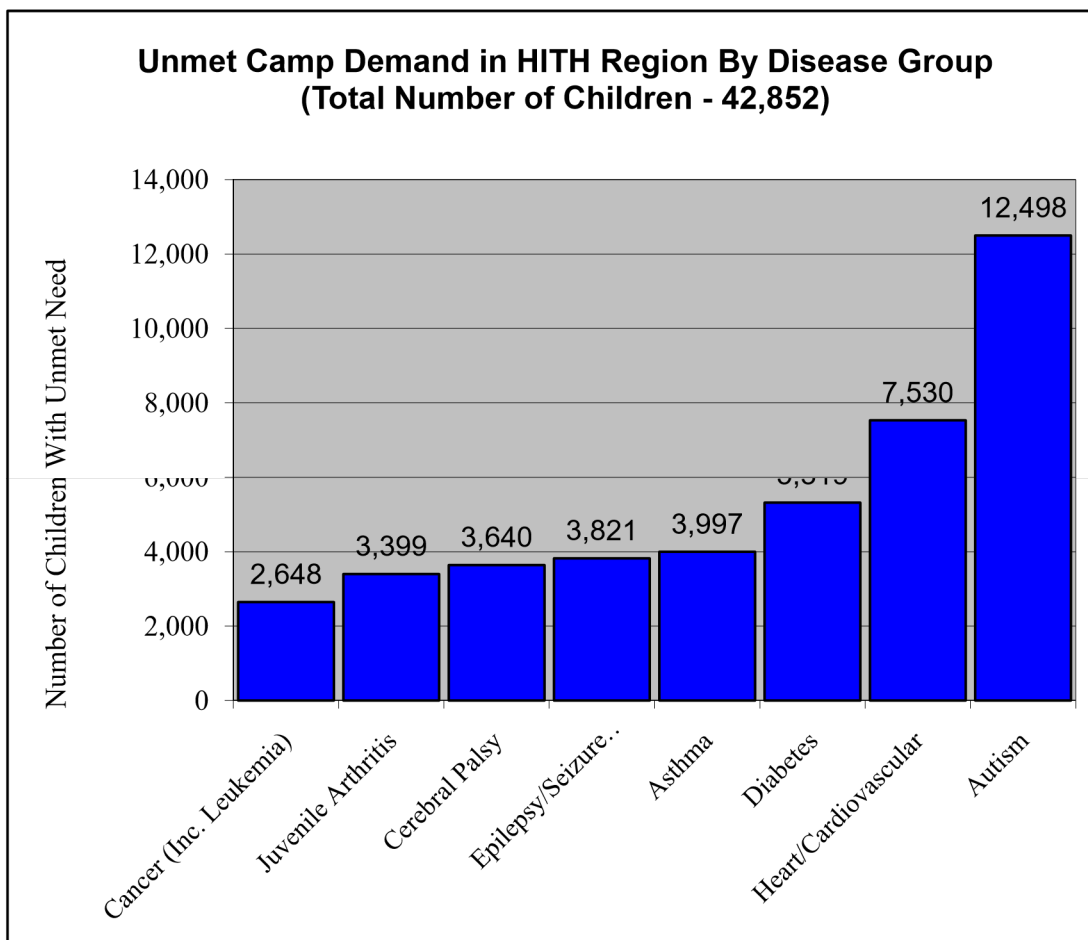
<sup>4</sup> Numbers in parentheses are the prevalence rates of the illnesses/conditions among children in the HITH region. For example, (.407%) means there are an estimated 407 children with autism per 100,000 population, ages 5-17, in the 6-state area.

The other disease groups studied in the assessment and their prevalence rates in the HITH region include: HIV/AIDS (.008%), burns (.020%), multiple sclerosis (.020%), spina bifida (.020%), cystic fibrosis (.024%), blood disorders (hemophilia, sickle cell, other) (.026%), brain injury (.041%), muscular dystrophy (.049%), and organ transplants (.067%).

### **Number of Camp ,s Children Served, and Unmet Demand in the Hole-in-the-Hills Region By Disease Group**

**Disease Group Number of Children Served Number of Unmet (Ranked By Unmet  
Camping By Camps in Children in Camp  
Demand) Opportunities HITH Region HITH Region Demand**

Disease Group	Number of Children Served	Number of Unmet (Ranked By Unmet)	Opportunities	HITH Region	HITH Region	Demand
Cancer (Inc. Leukemia)	22	1,455	4,103	2,648		
Juvenile Arthritis	1	20	3,419	3,399		
Cerebral Palsy	15	1,456	5,096	3,640		
Epilepsy/Seizure Disorders	12	966	4,787	3,821		
Asthma	14	892	4,889	3,997		
Diabetes	18	1,673	6,992	5,319		
Heart/Cardiovascular	8	504	8,034	7,530		
<u>Autism</u>	<u>15</u>	<u>1,405</u>	<u>13,903</u>	<u>12,498</u>		
<b>Total</b>	<b>105</b>	<b>8,371</b>	<b>51,223</b>	<b>42,852</b>		



**3. Summary and Conclusions**

- The needs assessment conclusively demonstrates that there are more than sufficient unmet needs and potential demand in the HITH region (42,852 special-needs and seriously-ill children) for a new, medically-equipped and professionally-staffed therapeutic camp to be a success.



- In fact, the number of children with unmet camping/recreation needs in each of the eight (8) priority disease groups, ranging from autism (12,498) to cancer (2,648), is more than twice the number sufficient to support at least one medical specialty camp (using a camp standard of over 1,000 children per camp).<sup>4</sup>

## I. INTRODUCTION

This preliminary report documents the findings, to date, of a need assessment conducted for the Hole in the Hills at Wa-Shawtee (HITH). The purpose of the study is to determine if a new, medically-equipped and professionally-staffed therapeutic camp in the great-plains region of the mid-west has the capacity to be a success. There are almost 3.5

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<sup>4</sup> See *Assessing the Therapeutic Camping Needs of California's Children: The Painted Turtle Project*, by The California Children's Health Foundation/California Children's Hospital Association (1998), page 10.

million children between the ages of five and seventeen in the 6-state HITH region,<sup>5</sup> an unknown number of which are seriously-ill and/or have special medical conditions and health care needs, who could potentially benefit from a therapeutic camping facility.

The Association of Hole in the Wall Camps (AHWC) requires that a needs assessment for proposed facilities be completed as part of its application and review process for membership. According to the AHWC, this most important of first steps should provide developing camps with the critical information necessary to make informed decisions to best serve the needs of seriously ill children and their families. The information gathered in the assessment is designed to establish the legitimacy of the project for resource procurement and allocation, community involvement and support and discussions with potential partners such as regional hospitals, medical and social-work professionals, voluntary disease-group organizations and existing camps. The findings and information in the preliminary report are structured and presented in ways to be of most use to the HITH governing board at this time in the development process. In particular, this includes the selection of priority illnesses and conditions, focusing remaining research tasks in the final stages of the assessment and other decision-making.

The following chapter presents the results and findings of two of the four major areas of investigation in the therapeutic-camping needs assessment. It also describes the research design and methodologies employed in the collection and analyses of assessment information. Finally, the conclusion of this preliminary report discusses the needs-research tasks that remain to be completed for the further development and successful completion of the Hole-in-the Hills at Wa-Shawtee.

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<sup>5</sup> There are 3,419,951 children ages 5-17 in the six-state region that includes Iowa, Kansas, Minnesota, Missouri, Nebraska and South Dakota (*Annual Estimates of the Population, July 1, 2006, U.S. Census Bureau*).

## **II. NEED ASSESSMENT METHODOLOGIES AND FINDINGS**

The HITH needs assessment is organized around four major and over-lapping areas of investigation: 1) an inventory of existing camps and camp programs for selected pediatric conditions in the 6-state catchment area, 2) an inventory of the population to be served, including the prevalence of priority illnesses/conditions and the levels of unmet need for each, 3) the identification and ranking of the needs of seriously ill children for each priority disease group, and 4) the identification and ranking of the needs of the children's parents and families.

These areas of study often overlap due to the combination of research methods employed to gather necessary information and the fact that data gathered at early stages in the research process is needed before later stages can be initiated or completed. The methods employed include an internet search of camps and camp programs for children with

special needs, a telephone survey of camp and program directors, the collection and analysis of hospital/medical facility treatment information, interviews with key medical and social-work providers, and focus groups of families of children with serious-illnesses and conditions.

## **A. INVENTORY OF CAMPS AND CAMP PROGRAMS**

The investigation of existing camping opportunities for children with serious illnesses/conditions that have special healthcare needs examines 17 disease groups of interest to HITH: asthma, autism, blood disorders, brain injury, burns, cancer, cerebral palsy, cystic fibrosis, diabetes, epilepsy/seizure disorders, heart/cardiovascular, HIV/AIDS, juvenile arthritis, multiple sclerosis, muscular dystrophy, organ transplants and spina bifida. Two previously-conducted needs assessments were suggested as useful demonstration models for the HITH study by AHWC<sup>6</sup> and relevant comparisons are presented as part of this report.

### **1. Methodology**

The camp inventory was initiated via interviews with key medical and socialwork personnel at Children's Hospital in Omaha, NE (see Attachment A, Interview Protocol). This was followed by an extensive internet search of camps for children with special needs in the 6-state region, which included data collection from numerous camplocator sites for children.<sup>7</sup>

A search was also conducted by disease group which usually led to sites for nonprofit advocacy/service organizations (such as the American Lung Association, [www.lungusa.org](http://www.lungusa.org)). These agency sites frequently contained links to camps by state

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<sup>6</sup> The two studies are *Assessing the Therapeutic Camping Needs of California's Children: The Painted Turtle Project*, by The California Children's Health Foundation/California Children's Hospital Association (1998) and *Needs Assessment for a Camp in Redmond, Washington*, by Herbert Research, Inc. (2006).

<sup>7</sup> Several of these sites offer web-pages and links that identify camps serving children with special needs by disease group: The American Camp Association (<http://find.acacamps.org/>), Family Village ([www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)), KidsCamps.com, Therapy/Respite Camps for Kids (<http://wmoore.net/therapy.html>), SummerCamps.com and VerySpecialCamps.com.

chapter or other specialized camp-locators (for example, The Consortium on Children's Asthma Camps, [www.asthmacamps.org/asthmacamps/](http://www.asthmacamps.org/asthmacamps/)).

All relevant information obtained through the interviews and web-based search (for example, camp name and location, contact information, disease groups served, cost, the availability of financial assistance, ages served, number of children served per year, etc.) was entered into an electronic database. Once the search was complete, all of the camps/camp directors in the database were called and asked to participate in a short telephone survey.

The telephone survey instrument (see Attachment B) was designed to verify the internet-based information collected, fill in any existing information gaps in the database and provide more detailed information about the camp, the clients they serve, the number of referrals they make, etc. The survey also contained questions to measure the camp directors' perceptions of the needs of children and families, the need for a new medical camping facility and their willingness to participate and coordinate with HITH.

Finally, camp sites for each disease group and children's hospital locations were geocoded using the Geographical Information System (GIS) Arcmap. Such software is useful to identify population patterns that might be important in priority disease-group selection, marketing, staffing, collaboration and other important decision-making.

## **2. Findings**

The inventory process identified 65 camps offering recreational opportunities to "special needs" children with conditions/illnesses of interest in the 6-state region. Of these, 48 camps (73.8%) offer children's services for only one of the 17 disease groups, while 17 camps (26.2%) offer services for two or more. One camp in the region serves special needs children in 12 of the 17 disease groups, another serves 11 of 17 and another serves 10 of 17.

In our inventory and analysis the recreational opportunities afforded by multipliedisease-group camps are treated equally with the opportunities provided by camps that serve only

a single disease group. To do so, the different recreational opportunities provided by the YMCA Camp at Boone, Iowa, for example, for children with asthma, cancer, cystic fibrosis or diabetes are counted as four camping opportunities at a single camp site.

Altogether, the 65 camp sites in the region offer a total of 143 camping opportunities for children in the 17 disease groups of interest.<sup>8</sup> In the past 12 months a total of 10, 686 children with serious illnesses/conditions were provided recreational opportunities by the camps in the 6-state HITH catchment area.

Table 1 summarizes the number of camping opportunities and number of children served by camps by disease group in the HITH region. It also provides comparisons to the numbers of children served for each, if data were available, in the California and Pacific Northwest assessments.<sup>9</sup>

**Table 1.  
Children Served by Camps in Selected Disease Groups in the Hole-in-the-Hills and Comparative Regions**

<b>DISEASE GROUP</b> (Number of Camping Opportunities)	<b>Children Served By Camps in HITH Region</b>	<b>Children Served By Camps in California &amp; Pacific Northwest Region</b> (CA) (NW)
<b>1. Asthma (14)</b>	<b>892</b>	874 (CA) 549 (NW)
<b>2. Autism (15)</b>	<b>1,405</b>	n/a
<b>3. Blood disorders (6)</b> [Includes hemophilia, sickle cell, other]	<b>119</b> [53 sickle cell, 66 non-specified]	429 (CA) [214 hemophilia, 215 sickle cell] 90 (NW) [40 hemophilia, 50 sickle cell]
<b>4. Brain Injury (6)</b>	<b>545</b>	n/a

<sup>8</sup> Stated another way, “camping opportunities” in this report refers to the cumulative total of the disease groups served by all 65 camp sites, rather than the offering of a number of different types of camps and/or camp dates for any one disease group in a given year.

<sup>9</sup> The California study reported numbers served by camps for 9 conditions/illnesses, the Pacific Northwest region study (which encompassed the states of Alaska, Idaho, Montana, Oregon and Washington) reported on 11, while the HITH region examined 17.

When only numbers of children with matching conditions/illnesses are considered, HITH-region camps served about the same number of children (3,355) as California camps (3,430) in 6 disease groups. HITHregion camps served almost double the number of children (6,731), however, as were served in the Pacific Northwest region (3,508) in 11 matching disease groups.

There were 5,274,908 children in California and approximately 1.9 million in the Pacific Northwest region, ages 6-16, at the time those assessments were made, compared to 3,418,951 ages 5-17, in the HITH region.

<b>5. Burns (4)</b>	<b>233</b>	430 (CA)
<b>6. Cancer (22) [Includes Leukemia]</b>	<b>1,455</b>	1,262 (CA) 654 (NW)
<b>7. Cerebral Palsy (15)</b>	<b>1,456</b>	n/a
<b>8. Cystic Fibrosis (2)</b>	<b>118</b>	0 (NW)
<b>9. Diabetes (18)</b>	<b>1,673</b>	1,445 (NW)
<b>10. Epilepsy/Seizure Disorders (12)</b>	<b>966</b>	160 (NW)
<b>11. Heart/Cardiovascular (8)</b>	<b>504</b>	160 (CA) 61 (NW)
<b>12. HIV/AIDS (3)</b>	<b>152</b>	275 (CA) 13 (NW)
<b>13. Juvenile Arthritis (1)</b>	<b>20</b>	39 (NW)
<b>14. Multiple Sclerosis (7)</b>	<b>316</b>	n/a
<b>15. Muscular Dystrophy (9)</b>	<b>832</b>	497 (NW)
<b>16. Organ Transplants (0)</b>	<b>0</b>	n/a
<b>17. Spina Bifida (0)</b>	<b>0</b>	0 (NW)
<b>TOTAL (143)</b> (Totals for matching disease groups)	<b>10,686</b> <b>(3,355)</b> <b>(6,731)</b>	3,430 (CA) 3,508 (NW)

The greatest numbers of children served by camps in the HITH region are those with the following illnesses/conditions: diabetes (1,673), cerebral palsy (1,456), cancer (1,455), autism (1,405), epilepsy/seizure disorders (966), asthma (899), and muscular dystrophy (832). The fewest children served are those with: organ transplants or spina bifida (0), juvenile arthritis (20), cystic fibrosis (118), blood disorders (119) and HIV/AIDS (152).

The total number of camps and camping opportunities by state in the HITH region are shown in Table 2. The state of Missouri provides the largest number of both camps (20) and camping opportunities (43) in the region, about 30% of each; followed by Minnesota with 18 camps and 38 camping opportunities or about 27% of each.

South Dakota has the fewest number of camps (3) and opportunities (4) and Kansas has slightly more with 7 each. Interestingly, Iowa (6) actually has five fewer camps than Nebraska (11), but these provide 29 (20.3%) of the camping opportunities in the HITH region compared to (22) or 15.4% in Nebraska.

**Table 2.**

## Number of Camps and Camping Opportunities in the Hole-in-the-Hills Region

STATE	Number Camps (%)	Camping Opportunities (%)
Missouri	20 (30.8%)	43 (30.1%)
Minnesota	18 (27.7%)	38 (26.6%)
Nebraska	11 (16.9%)	22 (15.4%)
Kansas	7 (10.8%)	7 (4.9%)
Iowa	6 (9.2%)	29 (20.3%)
South Dakota	3 (4.6%)	4 (2.8%)
<b>TOTAL</b>	<b>65 (100.0%)</b>	<b>143 (100.1%)*</b>

\*Does not equal 100.0% due to rounding

Geo-coded camp site data showing the camping opportunities for each disease group are summarized in the following series of maps. Map 1 shows the locations of all 65 camps and 23 children's hospitals in the region HITH region. Maps 2 through 16 show the camp sites where recreational camping opportunities are available for 15 of the 17 disease groups of interest.

The proposed site of the Hole-in-the-Hills Camp (shown by a star on the GIS maps) is approximately 35 miles south of Omaha, Nebraska along Interstate 29 in Iowa and was formerly the home of the Wa-Shawtee Girl Scout Camp. This 65-acre site located in the Loess Hills was donated to HITH by a private benefactor with the stipulation that it be used to benefit children or the land would revert to the State of Iowa and be added to the adjoining Waubonsie State Park.

An examination of the geo-coded data shows that *in toto* most camps, as one might expect, are clustered around the main population centers. The centers also contain or are near the greatest number of children's hospitals identified in each state, this pattern being most apparent in Minnesota, Missouri, Nebraska and Kansas.

When camping opportunities for individual disease groups are considered, this same pattern generally holds true, but with certain exceptions. These exceptions include autism, blood disorders, brain injuries, cerebral palsy, epilepsy/seizure disorders, heart/cardiovascular conditions, HIV/AIDS and muscular dystrophy in Iowa; burns in



Nebraska; cerebral palsy in Kansas; and epilepsy/seizure disorders and HIV/AIDS in Missouri.

In Iowa, where camping opportunities for 8 disease groups are not located near identified children's hospitals, further investigation may be warranted. One possible explanation for the anomaly may be that the two camp sites in the eastern portion of the state that provide numerous camping opportunities for multiple disease groups, are actually near a hospital facility providing specialized services to children in that part of the state, but that facility that has not yet been identified by HITH.

## **B. POPULATION TO BE SERVED (DISEASE PREVALENCE-UNMET NEED)**

In the health sciences "prevalence" is most commonly defined as the number of cases of a disease present in a specified at-risk population at a given time. Prevalence rates for each disease group examined in this report are shown as a percentage of the atrisk youth in the HITH region, as well as for the California and Pacific Northwest comparison regions.

By applying these rates to the number of children at risk in the HITH region (3,418,951 children ages 5-17), the estimated numbers of children eligible or the total demand for special needs camps for each disease group could be determined. Unmet need or demand for each condition/illness can then be calculated by subtracting the number of children currently attending camps (see Section A) from the total number eligible to attend.

### **1. Prevalence of Selected Pediatric Conditions**

Prevalence rate estimates for the 17 conditions/illnesses of interest in the HITH region were determined, in most cases, by using of the mean (average) of rates in the California and Pacific Northwest region assessments, adjusted for regional differences. The mean rate of prevalence for each disease group in the two western-region assessments was adjusted for the HITH region by adding or subtracting the difference between western and mid-western hospitalization rates (when data were available).

For example, the statewide prevalence rate of asthma in California (see Table 3), was .115% (.115% = 6,089 children, ages 6-16 / 5,274,908 children ages 6-16 in California), while the rate in the Pacific Northwest was determined to be .120%. The mean of the two prevalence rates is .118% (.118% = .115% + .120% / 2). A comparison of the rates of hospitalization for asthma in the two regions revealed that the rate was 21% higher in the mid-west (16.7 per 10,000 population in the mid-west compared to 13.8 in the west).<sup>10</sup> Adjusting the mean of the prevalence rates in the assessments by this amount (.118% x 21% = .025%) equals an estimated prevalence rate of .143% for the HITH region (.118% + .025% = .143%).

For disease groups where the prevalence rate was only available from one comparison assessment, the lower of the California or the Pacific Northwest region rate and the national prevalence rate was used, to produce more-conservative estimates. When rates were not available from the western-region comparison assessments (such as for autism, brain injury, cerebral palsy, multiple sclerosis and organ transplants), national prevalence rates were applied.

Table 3 depicts the total prevalence (number of children affected) and prevalence rate of each disease group in the HITH region, as well as those of matching groups in California and the Northwest region. The total prevalence of the 17 illnesses/conditions in the HITH region is an estimated 60,626 children who are eligible for special-needs camping opportunities.

The eight highest rates of prevalence of serious conditions/illnesses in the HITH region are autism (.407%), heart/cardiovascular (.235%), diabetes (.204%), cerebral palsy (.149%), asthma (.143%), epilepsy (.140%), cancer (.120%) and juvenile arthritis (.100%). The six lowest prevalence rates were HIV/AIDS (.008%), burns (.020%),

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<sup>10</sup> See *Vital and Health Statistics, Series 13, Number 162, "National Hospital Discharge Survey: 2004 Annual Summary with Detailed Diagnosis and Procedure Data"* (Table 18, page 32), Centers for Disease Control and Prevention, National Center for Health Statistics (October 2006).

multiple sclerosis (.020%), spina bifida (.020%), cystic fibrosis (.024%) and blood disorders (hemophilia, sickle cell, other) (.026%).

**Table 3.**

**Children Affected by Selected Disease Groups and Prevalence Rates in the Hole-in-the-Hills and Comparison Regions**

<b>DISEASE GROUP</b>	<b>Number of Children HITH Region (Prevalence Rate)</b>	<b>Number of Children California and Northwest Region (CA) (NW) (Prevalence Rate)</b>
<b>1. Asthma</b>	<b>4,889 (.143%)</b>	6,089 (CA) (.115%) 2,004 (NW) (.120%)
<b>2. Autism</b>	<b>13,903 (.407%)</b>	n/a
<b>3. Blood disorders</b> [Includes hemophilia, sickle cell, other]	<b>889 (.026%)</b>	1,122 (CA) (.021%) 595 (NW) (.016%)
<b>4. Brain Injury</b>	<b>1,390 (.041%)</b>	n/a
<b>5. Burns</b>	<b>684 (.020%)</b>	1,059 (CA) (.020%)

<b>6. Cancer</b> [Includes Leukemia]	<b>4,103</b> <b>(.120%)</b>	3,038 (CA) (.058%) 2,703 (NW) (.140%)
<b>7. Cerebral Palsy</b>	<b>5,096</b> <b>(.149%)</b>	n/a
<b>8. Cystic Fibrosis</b>	<b>820</b> <b>(.024%)</b>	477 (NW) (.024%)
<b>9. Diabetes</b>	<b>6,992</b> <b>(.204%)</b>	5,021 (NW) (.260%)
<b>10. Epilepsy/Seizure Disorders</b>	<b>4,787</b> <b>(.140%)</b>	3,418 (NW) (.177%)
<b>11. Heart/Cardiovascular</b>	<b>8,034</b> <b>(.235%)</b>	13,456 (CA) (.220%) 1,957 (NW) (.101%)
<b>12. HIV/AIDS</b>	<b>274</b> <b>(.008%)</b>	397 (CA) (.006%) 220 (NW) (.011%)
<b>13. Juvenile Arthritis</b>	<b>3,419</b> <b>(.100%)</b>	1,932 (NW) (.100%)
<b>14. Multiple Sclerosis</b>	<b>695</b> <b>(.020%)</b>	n/a
<b>15. Muscular Dystrophy</b>	<b>1,675</b> <b>(.049%)</b>	937 (NW) (.049%)
<b>16. Organ Transplants</b>	<b>2,292</b> <b>(.067%)</b>	n/a
<b>17. Spina Bifida</b>	<b>684</b> <b>(.020%)</b>	1,169 (NW) (.059%)
<b>TOTAL COMBINED PREVALENCE/DEMAND</b>	<b>60,626</b> <b>[17 Disease Groups]</b>	25,161 (CA) [6 Disease Groups] 20,433 (NW) [11 Disease Groups]

Matching by disease-groups, HITH prevalence comparisons with western-region assessments reveal that 18,873 children were affected by six (6) of the same illnesses/conditions of interest in the California study, a prevalence rate of .006% (.006% = 18,873 / 3,418,951), while 25,161 or .005% (.005% = 25,161 / 5,274,908) were affected by the same conditions in California. Similarly, 36,566 HITH-region children (1.07%) were affected in 11 matching disease groups, compared to 20,433 or 1.08% (1.08% = 20,433 / 1,900,000) in the Pacific Northwest study.

## 2. Unmet Need for Therapeutic Camps

Once the number of children meeting camping eligibility criteria (total demand for special-needs camps) was determined for each disease group, estimates were derived for total unmet camping needs. Unmet need being calculated by subtracting the number of children currently attending camps (met demand; see Section A) from the total number eligible to attend.

Table 4 summarizes, in descending order, the total unmet need/demand for camping opportunities for children for each disease group in the HITH region, as well as the total numbers and rankings for the comparison groups. There are a total of 49,940 children eligible for special-needs camps in the 6-state who are not currently having these needs met.

**Table 4.**

### **Total and Ranking of Unmet Demand for Camping Opportunities for Selected Disease Groups in the Hole-in-the-Hills and Comparison Regions**

<b>DISEASE GROUP (Ranked by Unmet Demand)</b>	<b>Children Served By Camps in HITH Region</b>	<b>Children Served By Camps in California &amp; Northwest (CA) (NW)</b>	<b>Children Eligible for Camps HITH Region (CA) (NW)</b>	<b>Unmet Camp Demand HITH Region (CA) (NW) (Rank)*</b>
<b>1. Autism</b>	<b>1,405</b>	n/a	<b>13,903</b>	<b>12,498</b>
<b>2. Heart/ Cardio</b>	<b>504</b>	160 (CA) 61 (NW)	<b>8,034</b> 13,456 (CA) 1,957 (NW)	<b>7,530</b> 13,296 (CA) (1) 1,896 (NW) (4)
<b>3. Diabetes</b>	<b>1,673</b>	1,445 (NW)	<b>6,992</b> 5,021 (NW)	<b>5,319</b> 3,576 (NW) (1)
<b>4. Asthma</b>	<b>892</b>	874 (CA) 549 (NW)	<b>4,889</b> 6,089 (CA) 2,004 (NW)	<b>3,997</b> 5,215 (CA) (2) 1,455 (NW) (6)
<b>5. Epilepsy/ Seizures</b>	<b>966</b>	160 (NW)	<b>4,787</b> 3,418 (NW)	<b>3,821</b> 3,258 (NW) (2)
<b>6. Cerebral Palsy</b>	<b>1,456</b>	n/a	<b>5,096</b>	<b>3,640</b>

<b>7. Juvenile Arthritis</b>	<b>20</b>	39 (NW)	<b>3,419</b> 1,932 (NW)	<b>3,399</b> 1,893 (NW) (5)
<b>8. Cancer [Includes Leukemia]</b>	<b>1,455</b>	1,262 (CA) 654 (NW)	<b>4,103</b> 3,038 (CA) 2,703 (NW)	<b>2,648</b> 1,776 (CA) 2,049 (NW) (4) (3)
<b>9. Organ Trans-plants</b>	<b>0</b>	n/a	<b>2,292</b>	<b>2,292</b>
<b>10. Brain Injury</b>	<b>545</b>	n/a	<b>1,390</b>	<b>845</b>
<b>11. Muscular Dystrophy</b>	<b>832</b>	497 (NW)	<b>1,675</b> 937 (NW)	<b>843</b> 440 (NW) (10)
<b>12. Blood disorders [Includes hemophilia, sickle cell, other]</b>	<b>119</b>	429 (CA) 90 (NW)	<b>889</b> 1,122 (CA) 595 (NW)	<b>770</b> 693 (CA) 505 (NW) (6) (8)
<b>13. Cystic Fibrosis</b>	<b>118</b>	0 (NW)	<b>820</b> 477 (NW)	<b>702</b> 477 (NW) (9)
<b>14. Spina Bifida</b>	<b>0</b>	0 (NW)	<b>684</b> 1,169 (NW)	<b>684</b> 1,169 (NW) (7)
<b>15. Burns</b>	<b>233</b>	430 (CA)	<b>684</b> 1,059 (CA)	<b>451</b> 629 (CA) (7)
<b>16. Multiple Sclerosis</b>	<b>316</b>	n/a	<b>695</b>	<b>379</b>
<b>17. HIV/ AIDS</b>	<b>152</b>	275 (CA) 13 (NW)	<b>274</b> 397 (CA) 220 (NW)	<b>122</b> 122 (CA) 207 (NW) (9) (11)
<b>TOTAL</b>	<b>10,686</b>	3,430 (CA) 3,508 (NW)	<b>60,626</b> 25,161 (CA) 20,433 (NW)	<b>49,940</b> 21,731 (CA) 16,925 (NW)

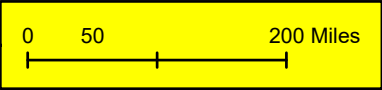
\*The comparison assessments examined 10 disease groups in California and 12 in the Pacific Northwest (hemophilia and sickle-cell were separate disease groups in these studies while combined in the HITH assessment). The other diseases studied in California were inflammatory bowel disease (3), kidney disease (5) and liver disease (8).

The greatest unmet needs/demand for camping opportunities in the HITH region, expressed in total numbers of children, were for those with autism (12,498), heart/cardiovascular conditions (7,530), diabetes (5,317), asthma (3,997), epilepsy/seizure disorders (3,821) cerebral palsy (3,640), juvenile arthritis (3,399) and cancer (2,646). Maps 2-9 show the existing therapeutic camps for these eight (8) disease groups (which

were later selected by the HITH board of directors as priority conditions for further investigation and assessment), as well as the children's hospitals in the regions. Maps of the camps for children in disease groups with lower levels of unmet need are provided in Attachment C.

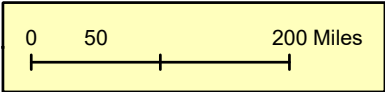
## Map 2: Youth Camps for Autism

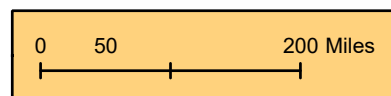




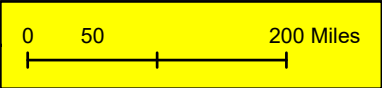
Map<sup>23</sup>: Camps for Heart/Cardiovascular

## Map 4: Youth<sup>24</sup> Camps for Diabetes



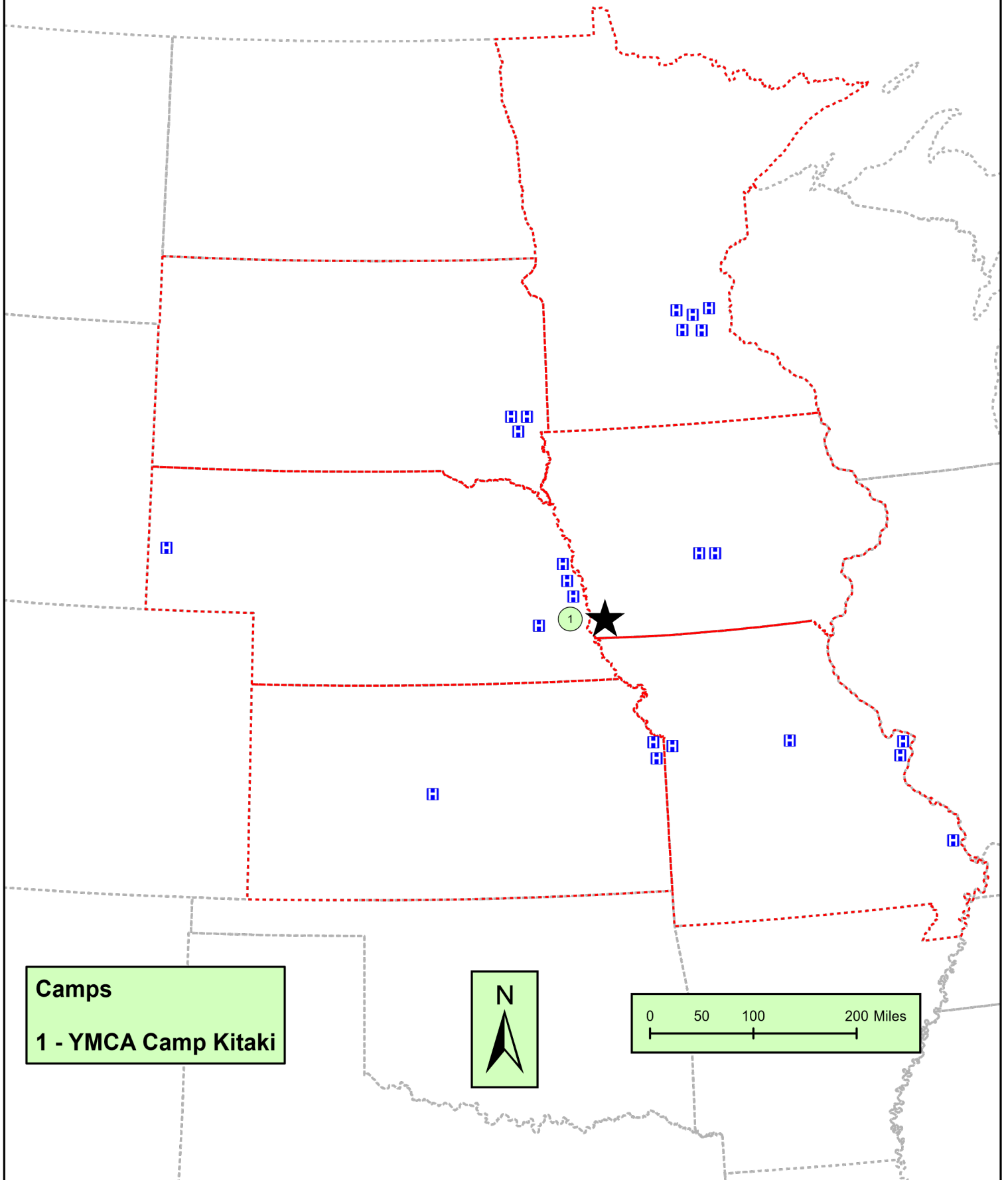


# Map 6: Camps for Epilepsy/Seizures

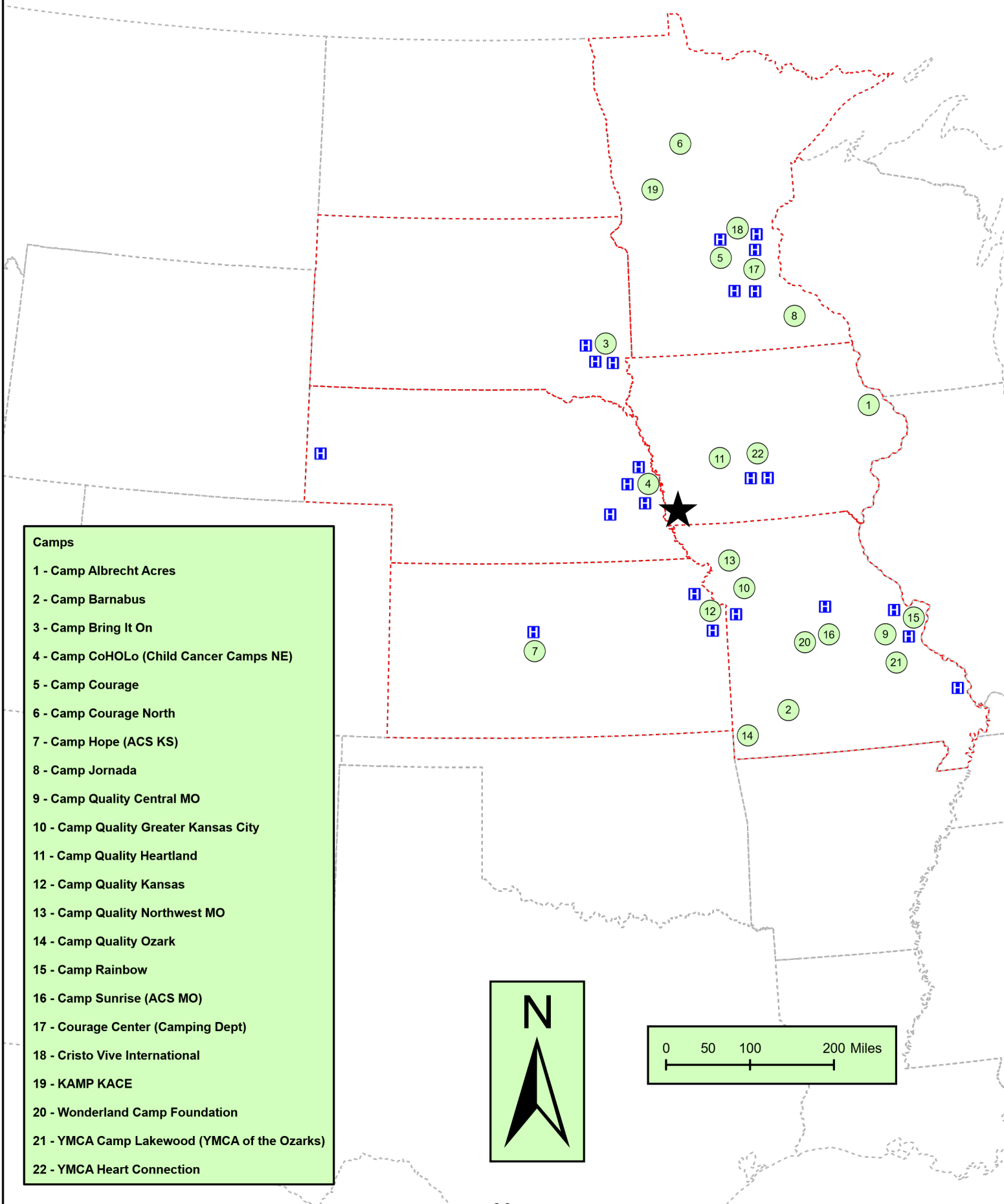


# Map 7: Camps for Cerebral Palsy

# Map 8: Camps for Juvenile Arthritis



# Map 9: Youth Camps for Cancer



- Camps**
- 1 - Camp Albrecht Acres
  - 2 - Camp Barnabus
  - 3 - Camp Bring It On
  - 4 - Camp CoHOLo (Child Cancer Camps NE)
  - 5 - Camp Courage
  - 6 - Camp Courage North
  - 7 - Camp Hope (ACS KS)
  - 8 - Camp Jornada
  - 9 - Camp Quality Central MO
  - 10 - Camp Quality Greater Kansas City
  - 11 - Camp Quality Heartland
  - 12 - Camp Quality Kansas
  - 13 - Camp Quality Northwest MO
  - 14 - Camp Quality Ozark
  - 15 - Camp Rainbow
  - 16 - Camp Sunrise (ACS MO)
  - 17 - Courage Center (Camping Dept)
  - 18 - Cristo Vive International
  - 19 - KAMP KACE
  - 20 - Wonderland Camp Foundation
  - 21 - YMCA Camp Lakewood (YMCA of the Ozarks)
  - 22 - YMCA Heart Connection

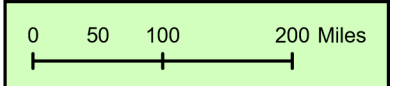
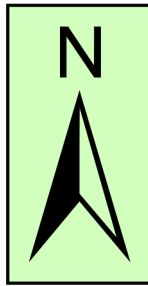


Table 5 shows the percentages of unmet and met demand of the illnesses and conditions of interest in the HITH and comparison regions. The disease groups are listed in descending order of percentage of unmet demand (% unmet demand = unmet demand / total demand) in the HITH catchment area.

**Table 5.**  
**Percent Unmet Demand for Camping Opportunities for Selected Disease Groups in the Hole-in-the Hills and Comparison Regions**

<b>DISEASE GROUP RANK</b> <b>Percent Unmet Demand in HITH Region</b>	<b>Unmet Demand HITH Region</b> <b>Number (%)</b>	<b>Met Demand HITH Region</b> <b>Number (%)</b>	<b>Unmet Demand Comparison Assessments (CA) (NW)</b> <b>Number (%) (Rank)</b>	<b>Met Demand Comparison Assessments (CA) (NW)</b> <b>Number (%)</b>
<b>1. Organ Transplants</b>	<b>2,292 (100.0%)</b>	<b>0 (0.0%)</b>	n/a	n/a
<b>2. Spina Bifida</b>	<b>684 (100.0%)</b>	<b>0 (0.0%)</b>	1,169 (NW) (100.0%) (1)	0 (NW) (0.0%)
<b>3. Juvenile Arthritis</b>	<b>3,399 (99.4%)</b>	<b>20 (0.6%)</b>	1,893 (NW) (98.0%) (3)	39 (NW) (2.0%)
<b>4. Heart/ Cardiovascular</b>	<b>7,530 (93.7%)</b>	<b>504 (6.3%)</b>	13,296 (CA) (98.8%) (1) 1,896 (NW) (96.9%) (4)	160 (CA) (1.2%) 61 (NW) (3.1%)
<b>5. Autism</b>	<b>12,498 (89.9%)</b>	<b>1,405 (10.1%)</b>	n/a	n/a
<b>6. Blood Disorders</b>	<b>770 (86.6%)</b>	<b>119 (13.4%)</b>	693 (CA) (61.8%) (6) 505 (NW) (83.2%) (3) [other 3?]	429 (CA) (38.2%) 90 (NW) (16.8%)
<b>7. Cystic Fibrosis</b>	<b>702 (85.6%)</b>	<b>118 (14.4%)</b>	477 (NW) (100.0%) (2)	0 (NW) (0.0%)
<b>8. Asthma</b>	<b>3,997 (81.6%)</b>	<b>892 (18.4%)</b>	5,215 (CA) (85.6%) (2) 1,455 (NW) (72.6%) (6)	874 (CA) (14.4%) 549 (NW) (27.4%)



<b>9. Epilepsy/ Seizures</b>	<b>3,821 (79.8%)</b>	<b>966 (10.2%)</b>	3,258 (NW) (95.3%) (5)	160 (NW) (4.7%)
<b>10. Cerebral Palsy</b>	<b>3,640 (71.4%)</b>	<b>1,456 (28.6%)</b>	n/a	n/a
<b>11. Diabetes</b>	<b>5,319 (71.1%)</b>	<b>1,673 (28.9%)</b>	3,576 (NW) (71.2%) (10)	1,445 (NW) (28.8%)
<b>12. Burns</b>	<b>451 (65.9%)</b>	<b>233 (34.1%)</b>	629 (CA) (59.4%) (4)	430 (CA) (40.6%)
<b>13. Cancer</b>	<b>2,648 (64.5%)</b>	<b>1,455 (35.5%)</b>	1,776 (CA) (58.5%) (5) 2,049 (NW) (75.8%) (8)	1,262 (CA) (41.5%)  654 (24.2%)
<b>14. Brain Injury</b>	<b>845 (60.8%)</b>	<b>545 (39.2%)</b>	n/a	n/a
<b>15. Multiple Sclerosis</b>	<b>379 (54.5%)</b>	<b>316 (45.5%)</b>	n/a	n/a
<b>16. Muscular Dystrophy</b>	<b>843 (50.3%)</b>	<b>832 (49.7%)</b>	440 (NW) (47.0%) (11)	497 (53.0%)
<b>17. HIV/AIDS</b>	<b>122 (44.5%)</b>	<b>152 (55.5%)</b>	122 (CA) (30.7%) (9?) 207 (NW) (94.1%) (6)	275 (CA) (69.3%)  13 (NW) (5.9%)
<b>TOTAL</b>	<b>49,940 (82.4%)</b>	<b>10,686 (17.6%)</b>	<b>21,731 (CA) (86.4%)</b>  <b>16,925 (NW) (82.8%)</b>	<b>3,430 (CA) (13.6%)</b>  <b>3,508 (NW) (17.2%)</b>

Those disease groups with the highest percentages of unmet demand (over 70%) in the HITH region are: organ transplants and spina bifida (100.0%), juvenile arthritis (99.4%), heart/cardiovascular (93.7%), autism (89.9%), blood disorders (86.6%), cystic fibrosis (85.6%), asthma (81.6%), epilepsy/seizure disorders (79.8%), cerebral palsy (71.4%) and diabetes (71.1%). Those with the lowest percentages of unmet demand are HIV/AIDS (44.5%), muscular dystrophy (50.3%), multiple sclerosis (54.5%), brain injury (60.8%), cancer (64.5%) and burns (65.9%).

A comparison of the levels of total met camping demand to unmet demand in the HITH and comparison regions reveals very similar ratios for therapeutic camping. The HITH (10,686 met to 49,940 unmet) and Pacific Northwest (3,508 met to 16,925 unmet) met demand ratios were both about 1:5 (one child whose needs are being met for every five children with unmet needs), while the ratio of about 1:6 in California (3,430 met to 21,731 unmet) was somewhat worse.

### **3. Conclusions and Recommendations**

In the past 12 months in the 6-state region, 60,626 children in the 17 disease groups, ages 5-17, had conditions and illnesses that would make them eligible to attend the Hole-in-the-Hills camp. A total of 10,686 of these children attended special needs recreational camps during this time period, leaving 49,940 children with unmet needs who are potential camp participants.

Nine of the disease groups, ranging from autism (12,498) to organ transplants (2,292), each had more than twice the number of children sufficient to support at least one medical specialty camp (using a camp standard of over 1,000 children per camp).<sup>11</sup> The total number of potential campers from these 9 disease groups total 45,144 or an average of 5,016 per group.

Both the number of disease groups and the total number of children with unmet needs, exceed the numbers reported in the two comparison assessments. The California assessment identified 4 disease groups meeting the 1,000 children/camp threshold, totaling 22,774 children or an average of 5,694 per condition. The Pacific Northwest study revealed 7 conditions meeting the threshold, totaling 15,295 children with unmet needs or an average of 1,699 children per condition.

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<sup>11</sup> See *Assessing the Therapeutic Camping Needs of California's Children: The Painted Turtle Project*, by The California Children's Health Foundation/California Children's Hospital Association (1998), page 10.

An examination of the disease groups served by existing Hole in the Wall camps in 2006 shows that the Painted Turtle camp at Lake Hughes, California now serves 11 disease groups.<sup>12</sup> Altogether, the 8 Hole in the Wall camps in the U.S. and Europe serve children from over 40 disease groups, ranging from 6 disease groups served at the Hole in the Wall Gang Camp in Ashford, Connecticut to 15 disease groups at the Victory Junction Gang Camp in Randleman, South Carolina.<sup>13</sup> The average number of disease groups served per camp is 8.5.<sup>14</sup>

Clearly, these findings show there are more than sufficient numbers of children to support at least one medically-equipped and professionally-staffed camp in the Hole in the Hills region. In addition to the nine disease groups identified (each of which by itself could form the basis of the 1,000 children/camp threshold), we also recommend the inclusion of spina bifida among the initial priority disease groups for further investigation in the remaining aspects of the needs assessment. There are currently 684 children affected with spina bifida, and more significantly, no camping opportunities for them were identified in the HITH region, resulting in 100% unmet need.<sup>15</sup>

### III. REMAINING RESEARCH TASKS

Using the information gathered for this preliminary report, the HITH board of directors narrowed the list from 17 disease groups of interest initially investigated to

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<sup>12</sup> From the Association of Hole in the Wall Camps, 265 Church St., New Haven, Connecticut 06510.

<sup>13</sup> The remaining camps are *Camp Boggy Creek*, Eustis, Florida; *Barretstown*, Ireland; *L'ENVOL pour les enfants europeens*, France; *Double "H" Hole in the Woods Ranch*, Lake Luzerne, New York; and *Over the Wall*, England.

<sup>14</sup> Four of the camps list hemophilia, sickle cell anemia and/or other blood disorders as separate disease groups; one of the camps lists cancer and leukemia as separate groups. These conditions and their numbers are combined in the totals shown in this report.

<sup>15</sup> Other conditions with somewhat larger numbers of children, but for which considerable efforts are already being made to meet their needs (resulting in lower percentages of unmet need) were blood disorders (770, 89.9%), brain injury (845, 60.8%) and multiple sclerosis (843, 50.3%).

eight (8) conditions selected for further study and evaluation. These include: autism, heart/cardiovascular, diabetes, asthma, epilepsy seizure disorders, cerebral palsy, juvenile arthritis and cancer (including leukemia).

These disease groups will now be the focus of the two major areas of investigation yet to be completed: 1) the identification and ranking of the needs of seriously-ill children, and 2) the identification and ranking of the needs of the families of these children. While a considerable amount of work on these assessment components was conducted as part of the inventory of camps and study of the population to be served in the HITH region (see Chapter II), important research tasks remain, the results of which will be presented in the final report.

The final report will include results of already-completed interviews at Children's Hospital in Omaha, Nebraska for several of the disease groups, yet to be completed interviews with medical professionals and staff at the University of Nebraska Medical Center, as well as at other hospitals, community-health organizations and professional associations in the HITH region. Finally, the report will also contain additional campdirector survey and parental focus group results on unmet familial needs, existing barriers and attitudes/ perceptions, which are necessary for the further development and successful completion of the Hole in the Hills at Wa-Shawtee.

**ATTACHMENT A**

**Interview Protocol**

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**MEMORANDUM**

DATE: April 17, 2007

TO: Rhonda Ervin, Children's Hospital Rehabilitation Manager

FROM: R.K. Piper, UNO Center for Organizational Research and Evaluation (CORE)

RE: Protocol for Gathering Information for Hole in the Hills Needs Assessment

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Below is a protocol for gathering important information about and/or from special needs children, their families, health professionals, medical organizations, service providers, potential partners and community stakeholders. This information is being collected to determine if a new camp near the Omaha-Council Bluffs Metropolitan area,

for children with serious illnesses or life-threatening conditions, has the capacity to be a success.

The protocol is organized to gather information in four (4) key areas: an inventory of existing camps and programs for special needs children within the five-state region, an inventory of the population of children and families to be served, identification and ranking of the needs of children with priority illnesses/conditions and identification and ranking of the needs of families of special needs children.

**Hole in the Hills at Wa-Shawtee: Needs Assessment Protocol**  
**Agency: Children's Hospital (Rhonda Ervin, Manager)**

Inventory of Existing Camps and Programs for Special Needs Children

1. *The Hole in the Hills organization is envisioning that the children's camp will initially serve those from the following disease groups: cancer, leukemia, organ transplants, autism, HIV, sickle cell anemia, diabetes and heart/cardiovascular disease.*

*Are there other disease groups you believe should be included in this list? Should they be considered as higher-priority than some of those currently on the initial list?*

2. *Are you aware of any existing camps or programs in the five-state target area (Iowa, Nebraska, Missouri, South Dakota and Kansas) that meet the envisioned needs of special needs children and families? Are there any that meet at least some of their needs?*

*How about in the larger Midwest region?*

3. *Do you know the contact persons for these camps/programs? And do you have their contact information?*

*If not, do you know who would?*

4. *Do you have any additional thoughts, suggestions or comments about existing camps/programs for special needs children? What about future efforts by Hole in the Hills to partner with existing camps/programs?*

*Or about the Hole in the Hills project in general?*

*Are there any particular individuals or organizations you can think of that might be interested in participating in or supporting the Hole in the Hills camp?*

Inventory of the Population of Children and Families to be Served

1. *Do you have information on the total number of children in the five-state area (and the larger Midwest region) who have the priority illnesses/conditions? Does this include information on their (and their families') demographic characteristics?*

*Do you know who else would have this type of information?*

2. *What about information on the total number of children not being served by camps?*

*Do you know who else would have this information?*

3. *What do you think are the main reasons why these children are not being served?*

*Probe: Is it due to: parental choice, physician choice, lack of information, children too sick or vulnerable to be cared for, cultural or language barriers, distance to existing camps, lack of perceived benefits, other family priorities/obligations, the cost of existing opportunities, or other reasons (please explain)?*

4. *Who else should we talk to in order to gather information about these populations of children and their families?*

*Do you have any other thoughts, suggestions or comments here?*

#### Identification and Ranking of the Needs of Children with Priority Illnesses/Conditions

1. *What do you think would be the most important needs of children with each of the priority illnesses/conditions we identified above: (cancer, leukemia, organ transplants, autism, HIV, sickle cell anemia, diabetes, heart/cardiovascular disease and any others)?*

2. *Do these needs vary for each illness/condition according to gender, age or other characteristics?*

*Do you know who else would have this type of information?*

3. *Overall, based on the information you have about existing camps/programs and the populations not currently being served, what do think should be the priority needs [which illnesses/conditions and types of children/families] addressed by the Hole in the Hills camp?*

*Can you rank these from highest priority to lowest priority?*

#### Identification and Ranking of the Needs of Families of Special Needs Children

1. *What do you think are the most important needs of families with each of the priority illnesses/conditions we identified above: (cancer, leukemia, organ transplants, autism, HIV, sickle cell anemia, diabetes, heart/cardiovascular disease and any others)?*

*Would these needs most-likely include: transportation and lodging, opportunity to meet with other parents of special needs children, availability of counseling services, respite care, educational and health programs, independent living skills, social activities, assertiveness training, wellness programs, sibling camp/program opportunities?*

*Are there other family needs you can think of?*

- 2. Do these needs vary for each illness/condition according to gender, age or other characteristics of the children and/or their families?*

*Do you know who else would have this type of information?*

- 3. Overall, based on the information you have about existing camps/programs and the populations not currently being served, what do think should be the priority needs for families [which illnesses/conditions by types of children/families] addressed by the Hole in the Hills camp?*

*Can you rank these from highest priority to lowest priority?*

- 4. Finally, do you have any last thoughts, suggestions, concerns, questions or comments about the Hole in the Hills camp development effort?*

#### Documentation.

- 1. Collect and/or make arrangements for any future collection of data, information or documentation discussed in this interview.*
- 2. Additional notes or instructions for follow-up activities.*



**ATTACHMENT B**

**Telephone Protocol  
Camp and Organization Survey**

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**MEMORANDUM**

DATE: June 18, 2007

TO: Special Needs Children's Camp Directors  
Disease-Group Organization Directors

FROM: R.K. Piper, UNO Center for Organizational Research and Evaluation (CORE)

RE: Protocol for Gathering Existing Camp and Disease-Group Organization  
Information for Hole in the Hills Needs Assessment

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Camp (City/State): \_\_\_\_\_

Sponsoring Agency/Organization: \_\_\_\_\_

Director: \_\_\_\_\_

Telephone: \_\_\_\_\_

*Hello,*

*This is \_\_\_\_\_ with the University of Nebraska at Omaha. We are conducting a needs assessment for the development of new camp in the mid-west for special needs children who are seriously ill or have life- threatening conditions. May I speak with [name or \_\_\_\_\_ Camp Director]?*

- 1. If not available, ask when is the best time to call back to reach him/her**
- 2. If no answer, note date/times of 3 attempts**  
\_\_\_\_/\_\_\_\_ \_\_\_\_/\_\_\_\_ \_\_\_\_/\_\_\_\_
- 3. If answering machine, leave message starting with the first two sentences above, then say, I'm all calling to speak with the [name or \_\_\_\_\_ Camp Director]. I would appreciate it if he or she could call me at [(402) \_\_\_\_\_] or if I am not in, please leave me a message letting me know the best times to call back. Thank-you!**

*This needs assessment study is being sponsored by the non-profit Hole in the Hills organization in conjunction with Children's Hospital of Omaha. We would like to ask you a few questions to get your perceptions. This usually takes about 12 minutes.*

[pause]

**If interviewee wants more information:** Ask if they have heard of Paul Newman's Hole in the Wall Camps for seriously-ill children and say the needs assessment is to determine if there is sufficient need for a similar camp to be successful in the mid-west. If they still have questions you cannot answer, ask if the project director could call them back.

### **Inventory of Existing Camps and Programs for Special Needs Children**

1. First, our search of the internet shows that your camps serve children with the following disease group(s) *[note all those that apply on calling sheet prior to calling]*:

1. Asthma/respiratory
2. Autism
3. Blood disorders
4. Brain injury/organ transplants/burns
5. Cancer
6. Cerebral palsy
7. Diabetes
8. Epilepsy/seizure disorders
9. Heart/cardiovascular
10. HIV/AIDS
11. Multiple sclerosis
12. Muscular dystrophy
13. Other \_\_\_\_\_
14. Other \_\_\_\_\_

Is this correct and are there other special needs children your camps serve?  
*[note all those that apply]*:

2. *[If more than one disease group]* Do children in the various disease groups all attend camp together?

1. Yes
2. No

If no, which disease groups have separate camps? *[note on calling sheet]*

3. Does your camp *[agency]* partner or collaborate with any particular agencies *[camps]* for each disease group (such as the American Lung Association for asthma camps, Easter Seals for autism camps, and so forth)?

1. Yes *[note on calling sheet by disease group]*
2. No

Do you have their contact information? *[note here or on sheet]*

4. Approximately how many children do your camps serve each year? *[note by disease group on sheet]*
5. What is the duration of your camps *[note by disease group on sheet]*?
  1. More than one week
  2. One week
  3. Less than one week
  4. One to two days
6. Are your camps *[note by disease group on sheet]*?
  1. Sleep-over
  2. Weekend or
  3. Day camps
7. Do other family members attend camps with their children?
  1. Yes *[If yes, note by disease group on sheet]* 2. No
8. What are the costs of your camps *[note by disease group on sheet]*?
 

Is financial assistance available? 1. Yes *[note by disease group on sheet]* 2. No
9. What is the age range of the children in your camps *[note by disease group on sheet]*?
10. Do your camps currently serve seriously-ill children and those with lifethreatening conditions who require on-site medical facilities and staff?
  1. Yes *[If yes, note by disease group on sheet]* 2. No
11. Do you collaborate with any hospitals or other medical institutions to provide necessary medical and mental-health care and supervision?
  1. Yes            2. No

If yes, which ones? \_\_\_\_\_
12. To what degree are you satisfied with the medical and mental-health care and supervision that is provided?
  1. Very satisfied
  2. Somewhat satisfied
  3. Somewhat dissatisfied
  4. Very dissatisfied
13. Do you believe the medical and mental-health care and supervision at your camps could be improved? 1. Yes 2. No

If yes, what are the most important problems that need to be addressed (*for each disease group*)? \_\_\_\_\_

14. Do you currently have to turn any children away from camps or refer them elsewhere, due to the severity of their medical conditions, other needs you cannot meet or for other reasons?

1. Yes      2. No

If yes, about how many children per year do you have to turn away [*note by disease group on sheet*]?

Of these, about how many do you refer to other camps? [*note by disease group on sheet*] ?

15. Do you believe there are seriously-ill special needs children not adequately being served by camps in the mid-west? 1. Yes 2. No

If yes, what particular groups of children come to mind?

16. Which of the following do you think are reasons they are not being adequately served (*circle all that apply*)?

1. Costs are prohibitive for many families
2. Distances to the camps are too great
3. There are not adequate medical facilities and staff on-site
4. There are not adequate medical facilities and staff within a reasonable distance
5. Parents are reluctant to have seriously-ill special needs children attend camps
6. There is a lack of camps or camp openings
7. Other reason(s): \_\_\_\_\_

17. Which of the following are barriers for seriously-ill, special needs children and their families attending therapeutic camps in the mid-west (*circle all that apply*)?

1. Too few camping opportunities for certain age groups
2. Too few camps that are sufficiently language and culturally diverse
3. A lack of psychological counseling or life-skills learning opportunities at camps
4. A lack of appropriate recreational opportunities for children with serious illness or severe conditions at camps
5. A lack of camps that include families and siblings in their programs
6. A lack of information about camps for certain disease groups
7. A lack of family resources to attend camps

Are there any other barriers that you can think of?

1. Other: \_\_\_\_\_

2. Other: \_\_\_\_\_

18. Overall, do you believe a new children's camp is needed in the mid-west that can meet the complete medical and mental health needs of seriously-ill children?

1. Yes      2. No      3. Not Sure

19. Do you have any final thoughts, suggestions or comments about a new camp in the mid-west for children who are seriously-ill or have life-threatening conditions?

20. Do you think your camp [agency] would be interested in working with Hole in the Hills and Children's Hospital in the future?

1. Yes      2. No      3. Not Sure

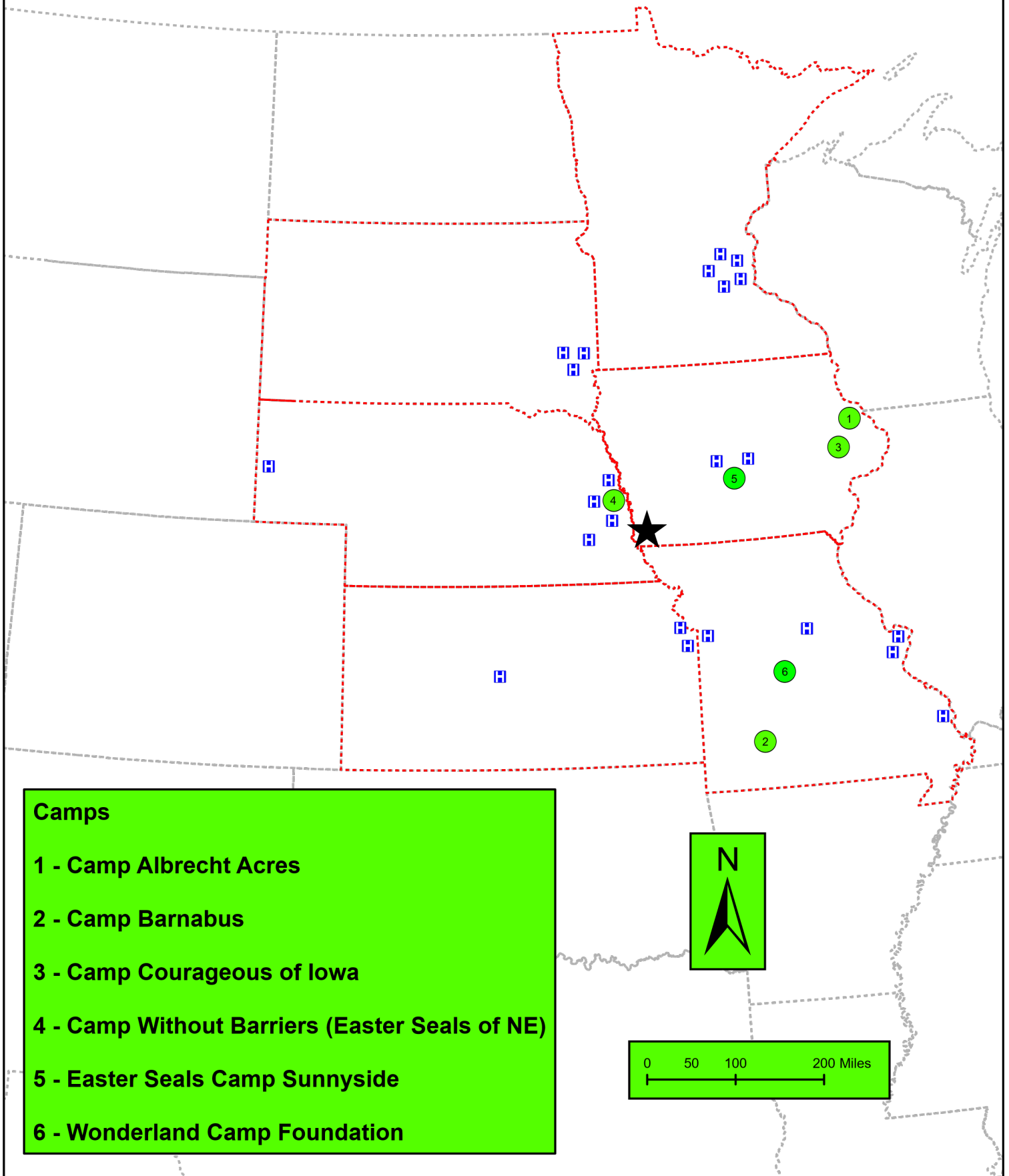
Can you think of any other camps, organizations or groups that might be interested in working with the Hole in the Hills camp?

*Thank you so much for participating in our study!*

**ATTACHMENT C**

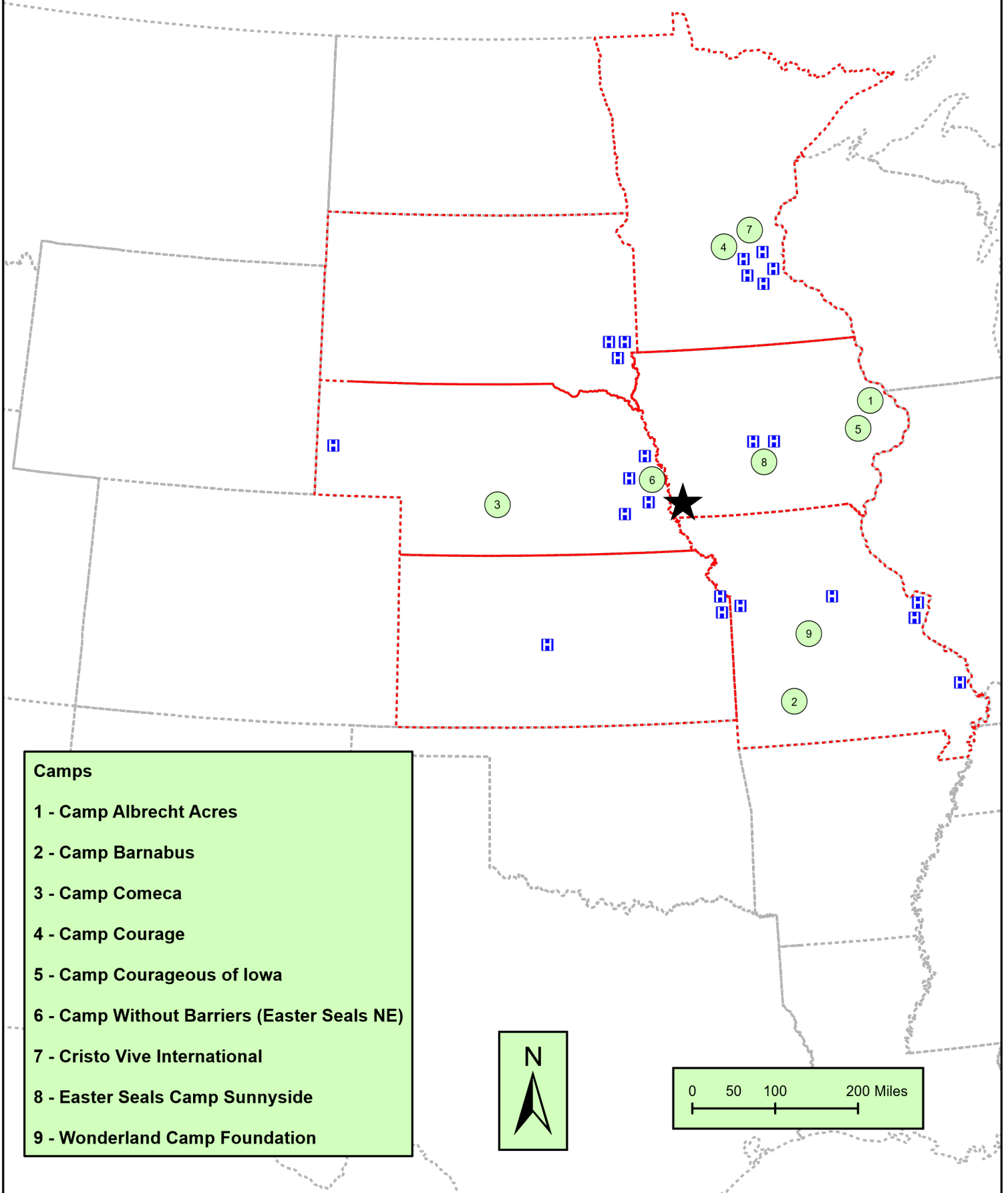
**Maps of Camps by Disease Groups and  
Children's Hospitals**

# Map 10: Camps for Brain Injuries





# Map 11: Camps Muscular Dystrophy



# Map 12: Camps for Blood Disorders

