

## FAQ For Learners

### 1. How did Almost Home Kids (AHK) get started? Who were the leaders in establishing the foundation?

- a. The concept was developed in 1992, by two mothers who were determined to keep their children out of institutions, but were exhausted due to 24/7 medical needs of their children. At this time, facilities outside of institutionalized settings did not exist that were properly equipped to provide for the complicated medical needs of children who were medically fragile.
- b. Born out of this need within the community AHK opened in 1999 and has served over 1,200 children with complex medical conditions and their families.

### 2. What is the purpose of Almost Home Kids?

- a. At Almost Home Kids, the mission is to provide transitional care in a home-like setting to children with complicated health needs, training for their families and respite care.
- b. Almost Home Kids is a short-term community based pediatric healthcare facility that brings together
- c. Medical Professionals, Recreational Volunteers, Community Providers, Sponsors, Donors, Friends, Corporate and Civic Partners. AHK is licensed by the Department of Public Health.
- d. Almost Home Kids also helps reduce costs to the state, hospitals, and families.
- e. AHK programs include transitional care, respitecare, respite transportation and emergency respite care.

### 3. What types of care programs are offered at AHK?

#### a. Respite Care

This is a short-term stay for a child who is medically fragile and/or technology dependent designed to give the child's family "a break" from the usual routine. This program can vary from being 24 hours to 14 days, as it provides the child with medical/nursing care and recreational activities in a secure and therapeutic environment. This program is meant to provide support to families in a variety of circumstances—temporary absence of private duty nursing care at home, parent illness, vacations, family emergencies, and much needed rest.

#### b. Transitional Care

This program serves as the link between hospital and home for a child who is clinically ready for discharge from a hospital, yet important factors need to be considered in order to bring the child home safely. The family may need further support through training and equipment education regarding the clinical needs of the child and/or nursing agency staffing plan.

#### c. Respite Transportation

Children who are medically fragile can be safely transported from their home to AHK, under the supervision of a medical professional, in order to receive respite care. This program is a supporting arm of the respite care program and provides an opportunity to families that did not exist, due to the inability to safely transport a child who is dependent on medical technology.

#### 4. Where is AHK located? How Do I get there?

AHK has two sites, one in Naperville and one in Downtown Chicago.

AHK Chicago  
211 East Grand Avenue 6th floor of Ronald McDonald House  
Chicago, Illinois 60611  
Phone number: (312) 229-0170



#### *Driving Directions*

**From South:** Take Lake Shore Drive north and exit Illinois (Navy Pier). At the end of the ramp, go straight ahead at the traffic light. At Grand Ave, turn left. Follow Grand Ave. to AHK Chicago Directly OR for parking follow Grand Ave to St Clair. Turn right on St. Clair, parking garage immediately on the right (AHK does not have reserved parking, so there will be a fee).

**From North:** Take Lakeshore Drive South. Exit at Grand Ave. Turn right onto Grand Ave. Follow Grand Ave to AHK or parking (as mentioned above)

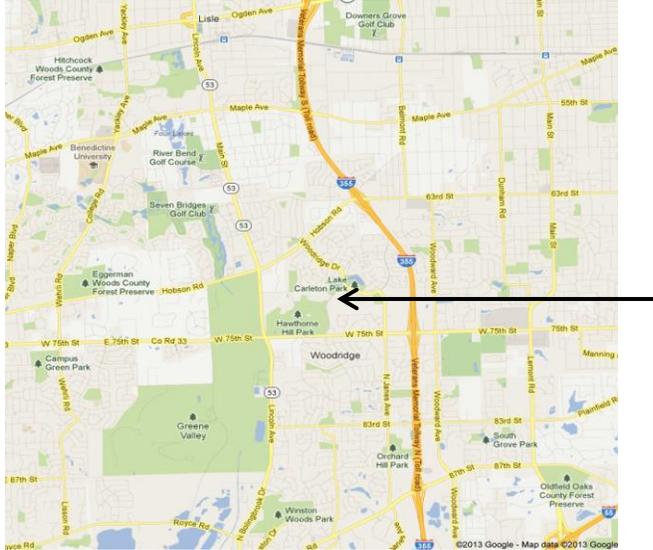
**From West:** Exit on Ohio (East) to Fairbanks (approx. 10 blocks). Turn right on Fairbanks, right onto Grand Ave. Proceed to AHK directly or parking garage (as mentioned above)

#### *Public Transport Directions*

Bus Routes that stop on Grand when Westbound and Illinois when Eastbound: #29 State, #65 Grand Bus Routes that stop on Michigan Ave (Northbound and Southbound)- 1 block west of AHK: #2 Hyde Park, #3 King Dr., #10 Science & Industry, #26 South Shore, #125 Water Tower, #143 Stockton/Michigan, #146 Inner Drive/Michigan, #147 Outer Drive, #148 Claredon/Michigan, #151 Sheridan, #157 Streeter/Michigan

CTA Train Red Line: Exit at Grand and either walk directly east for 4 blocks to AHK, or 1 block south to Illinois and catch the #29 or #65 on Illinois east to St. Clair and walk 1 block north to AHK

Almost Home Kids (Naperville)  
75721 Route 53  
Naperville, IL 60540-9528  
Phone Number: (630) 271-9155



### *Driving Directions*

Almost Home Kids is located in unincorporated Naperville. Please note that we are on a small frontage road which is off of Route 53 and not visible on the map. If using MapQuest, type in “Almost Home Kids, IL” into the Search box and select the “Almost Home Kids, Illinois 53” option to receive the best route. There is a sign that reads “Hobson Creek Estate – Private Drive”. We are the second home located between two other homes. Please see below for more detailed directions.

### **5. How is Almost Home Kids funded?**

- a. AHK is both federally and privately funded. 3 out of 4 families served at AHK are below the federal poverty level, and most qualify for government assistance (Medicaid) to help cover some of the costs of their care, including in-home nursing, physician care, medication and medical equipment costs.
- b. Each day of care at AHK costs \$850 per child to AHK, but this daily cost is only about 1/3 of the cost of acute hospital care, which is where the child would be if not at AHK. This means for every day at AHK, the IL taxpayers save 2/3 of the cost of that day, adding up to approximately \$16 million per year.
- c. AHK covers these costs for care entirely regardless of the family’s ability to pay and is reimbursed 70% of this by the state of Illinois and fundraises the remaining 30%.
- d. Since insurance and government programs do not begin to cover all of the costs associated with the level of care provided by AHK, there is a huge reliance on philanthropy. Of the private donations received, 54% is from Foundations & Corporations, 30% from individuals, 14% from in-kind gifts, and 2% from civic and religious groups.

## 6. What types of professionals work there? Specialists?

- a. AHK is team that includes Medical Professionals, Volunteers, Community Providers, Sponsors, Donors, Friends, and Corporate & Civic Partners.

**President & CEO:** Deborah A. Grisko (RN and mother)

**Clinical Staff:** Cathy Shanahan, RN, is the Senior Director of Nursing Services and Layenie Anderson, RN, is the Director of Case Management

**Medical Directors:** Dr. Peter J. Smith is the Medical Director for AHK Chicago

See <http://almosthomekids.net/clinical/medical-directors/>

In addition, a specialist in Physical Medicine and Rehabilitation (PM&R), Dr. Laura Deon, visits every other week and a specialist in Sleep Medicine, Dr. Sheldon also makes on-site rounds.

## 7. How long do children spend at AHK?

- a. For transition care, children spend up to 120 days at AHK as part of the hospital to home program.
- b. Short-term stays for respite care range from 24 hours to 14 days.

## 8. How is AHK different than hospital care?

- a. AHK is specifically designed to provide care as if the child is at home. Also, AHK's mission is not only to provide care, but also to give teaching and preparation that families need to feel comfortable taking their child home. Providing this training in an intermediate care facility such as AHK is a better use of resources and facilities and can reassure parents that they can care for their child at home without having the resources of a hospital constantly present. The home-like environment is more child-friendly and developmentally appropriate than a prolonged stay in an acute care hospital. In addition, involvement from local community members at AHK further attests to the importance of each community taking responsibility for the care of its children rather than relegating them to distant, impersonal institutions.

## 9. How is family training executed?

- a. The nursing staff directly teaches the family as they deliver care. The families have to demonstrate competency on caring for their child prior to discharge. All caregivers complete training/visitation contract and acceptance of an physician-approved medical plan of treatment. Training for the caregiver begins as soon as possible after admission and continues through the final week of discharge. During that time, the caregiver and a secondary designated caregiver provides one-to-one staff assistance and training with teaching sheets, check-off lists, and any information that is needed in the care of the child. Prior to discharge the caregiver must be able to provide independent care for the child for two 24 hour periods to ensure comfortability of the child's medical and nursing needs before leaving Almost Home Kids.

**10. Which hospitals do the children at AHK come from?**

- a. AHK receives referrals from numerous hospitals throughout Illinois and beyond state lines.

***Referring hospitals include:***

- Adventist LaGrange Memorial Hospital, LaGrange, IL
- Advocate Good Samaritan Hospital, Downers Grove, IL
- Advocate Lutheran General Hospital, Park Ridge, IL
- Advocate South Suburban, Hazel Crest, IL
- Carle Clinic, Champaign, IL
- Central DuPage Hospital, Winfield, IL
- Children’s Hospital of Illinois, Peoria, IL
- Ann & Robert H. Lurie Children’s Hospital, Chicago, IL
- Comer Children’s Hospital, (University of Chicago) Chicago, IL
- Edward Hospital, Naperville, IL
- Hinsdale Adventist Hospital, Hinsdale, IL
- Hope Children’s Hospital, (Christ Advocate Hospital) Oak Lawn, IL
- Kishwaukee Hospital, DeKalb, IL
- La Rabida Children’s Hospital, Chicago, IL
- Loyola University Medical Center, (Ronald McDonald Children’s Hospital) Maywood, IL
- Marianjoy Rehabilitation Hospital, Wheaton, IL
- Northwestern Memorial Hospital, Chicago, IL
- OSF Saint Francis Hospital, Peoria, IL
- Provena St. Joseph Medical Center, Joliet, IL
- Rehabilitation Institute of Chicago, Chicago, IL
- Rockford Memorial Hospital, Rockford, IL
- Rush University Children’s Hospital, Chicago, IL
- Rush-Copley Hospital, Aurora, IL
- Shriner’s Hospital, Chicago, IL
- Silver Cross Hospital, Joliet, IL
- St. Alexius Medical Center, Hoffman Estates, IL
- Sherman Hospital, Elgin, IL
- University of Illinois at Chicago, Chicago, IL
- Children’s Hospital of Wisconsin, Milwaukee, WI
- Boston Children’s Hospital/Dana Farber Cancer Institute, Boston, MA

**11. How successful has AHK been since opening?**

- a. Since opening, AHK has served over 950 children and their families.

**12. What are some challenges that AHK still faces today?**

- a. While the funds have been raised to construct, furnish, and equip the new facility in Chicago, operational costs for both locations and rent costs for Chicago are significant. Approximately \$1.5 million is needed every year from the private sector to balance the budget.

**13. How do you determine whether a child has complex medical conditions?**

- a. Most of the children served at AHK qualify for DSCC under a “waiver.” See [http://internet.dsccl.uic.edu/dscclroot/home\\_care.asp](http://internet.dsccl.uic.edu/dscclroot/home_care.asp) for more information.

**14. On an average day, how many professionals are on site?**

- a. There is a ratio of one RN to three children. The medical director and the PNP are on site 1-2 days per week.

**15. How long does a normal “shift” last?**

- a. A normal shift is 12 hours (either 7am-7pm or 7pm-7am).

**16. What happens after the child has completed his/her stay at AHK?**

- a. If the patient was in the transitional care program, then he/she is transported home: there the child will receive services, supports (esp. home nursing), and home therapy. b. If the patient was part of the respite care program, he/she is transported back home and restarts programs that were provided prior to respite.

**17. How many beds does each site location have?**

- a. 12

**1) 18. What are examples of the complex medical conditions most commonly seen at AHK?**

- a) This is not an all inclusive list:
- i) Neuromuscular disease
  - i) SMA
  - ii) Premature birth
  - iii) Central hypoventilation syndrome
  - iv) Metabolic disorders
  - v) Cerebral palsy
  - vi) Oncology – pre and post chemo/proton therapy
  - vii) Chromosomal disorders
  - viii) Cardiac anomalies
  - ix) Traumatic brain and spinal cord injury
  - x) Gastric anomalies – short gut syndrome
  - xi) Hospice
  - xii) Neonatal withdrawal syndrome

**19. What is the age range for the children?**

- a. Up to 21

**20. What are families trained in for transitional care?**

- Establishing physician and hospital contacts
- Troubleshooting all equipment (ventilator, feeding pumps, oxygen concentrators, etc.)
- Recognizing the signs and symptoms of respiratory distress and how to intervene
- Changing a tracheostomy tube with assistance
- Changing a gastrostomy tube or button
- Ordering equipment, supplies and pharmaceuticals

**21. What are some options to get involved with AHK?**

- a. [Keith Veselik M.D. Medical Education Program](#)  
[Elective Rotations & Observational Opportunities](#)
- b. [Volunteering](#)