

Chair Carruthers, Ranking Member Liston, and members of the subcommittee:

One Hundred Twenty Five Thousand families are raising a child with a life-threatening medical condition across the State of Ohio, according to Nationwide Children's Hospital. Imagine raising a child with cancer, diabetes, cystic fibrosis, or another life-threatening condition. Families in this situation face numerous challenges everyday: how are we going to keep our household budget, how are we going to provide a happy childhood for all of our kids, and most importantly, how am I going to keep my child well or maybe even alive? Will my child ever just feel like a kid again?

That's where A Kid Again steps to the plate. A Kid Again provides monthly Adventures for children with life-threatening medical conditions across the State of Ohio- providing families an opportunity to allow their child with a medical condition to experience joy while also allowing the entire family unit to come together for quality time once every single month. To date, A Kid Again has more than 20,000 Ohioans enrolled in all 88 counties.

I would like to tell you a story about Hannah. Due to her medical condition, Hannah was born with one lung. This condition has created massive obstacles and challenges for Hannah and her family. During her seven years of life, Hannah has spent over six months in the hospital. These are six months where Hannah wasn't surrounded by her family or loved ones. These are six months where Hannah's mom, Meredith, was separated from her son's. Can you imagine how difficult it was for those boys to have had six months of their lives without their mom or sister at home. Imagine how scary it is to see an ambulance pull up to your house to whisk your little sister away to Nationwide Children's Hospital. This is why A Kid Again is imperative for our families. A study conducted by Nationwide Children's Hospital concluded that 77% of A Kid Again families are more connected as a family unit because of our monthly programming. Another, study conducted by the American Academy of Pediatrics concluded that 80% of parents raising children with life-threatening medical conditions see their marriage end in divorce. A Kid Again keeps families together and wraps them in support when they need it most.

We would like to thank Representative Sweeney for drafting an amendment to include A Kid Again in the State Budget for 1.5 million dollars per fiscal year. Here's how that funding will support A Kid Again families, like Hannah's. We will bring Adventures closer to home for the families we serve in hard to reach parts of the state, allowing us to provide a better and more holistic experience for all our families- regardless of their zip code. Additionally, we will create a new position to serve A Kid Again families throughout Ohio. The new Community Connector position will work alongside our families to connect them to resources that are provided by local charities or even help them enroll in a benefit or programs already funded by the State of Ohio. Resources that families previously didn't have the time or know how to take advantage of. This new position will shorten the time to resources for the 20,000 individuals we serve across the state. This is important to note, because we serve more than 300 conditions and not all of those conditions have a non-profit to support them. That is why A Kid Again Community Connector will deepen the impact of the 20,000 individuals we serve. This funding will allow us to support our families in a holistic manner and connect them to vital resources that can improve the quality of their lives.

At A Kid Again, 91 cents of every dollar we receive is reinvested back into local economies across Ohio. A Kid Again supports families raising children with life-threatening medical conditions and promotes that great State of Ohio.

Chair Carruthers, thank you for the privilege of speaking to the subcommittee today. We would greatly appreciate the support of all subcommittee members on this amendment.

_____ moved to amend as follows:

1 After line 123868a, insert:

2 "GRF 600551 Job and Family Services Program Support \$1,500,000
3 \$1,500,000"

4 In line 123874, add \$1,500,000 to each fiscal year

5 In line 123914, add \$1,500,000 to each fiscal year

6 After line 124180, insert:

7 **"Section 307.____. JOB AND FAMILY SERVICES PROGRAM SUPPORT**

8 The foregoing appropriation item 600551, Job and Family
9 Services Program Support, shall be provided to A Kid Again to
10 support families raising children with life-threatening medical
11 conditions."

12 The motion was _____ agreed to.

13 SYNOPSIS

14 **Department of Job and Family Services**

15 **Sections 307.10 and 307.____**

16 Appropriates \$1,500,000 in each fiscal year in GRF ALI
17 600551, Job and Family Services Program Support. Requires these
18 funds be provided to A Kid Again.



Helping Ohio families raising a child with a life-threatening condition

A Kid Again increases mental wellness, social connectedness, and positive health outcomes of Ohio families.

We offer year-round, cost-free Adventures so families can set aside their financial pressures and struggles of raising a child with a life-threatening condition to create vital, fun-filled memories that strengthen their family bonds and community connections.

- Focuses on entire family (includes siblings, parents/guardians)
- Continuous service; not a one-time event for families



“The time together as a family is so necessary and I’m just so busy and overwhelmed...days like these are saving our family right now.”

Summary: A Kid Again

20,000

Ohioans enrolled

88

Counties served

300+

Medical conditions served, including ones so rare that no other organization supports them

55%

Enrollment growth in 2022

1995

Founded in Ohio

89%

Of funding spent on programming

91%

Reinvested in local economy

Demonstrated sustainability

2022: \$1,000,000 requested and received from Franklin County Public Health

2023: \$500,000 requested

Nationwide Children’s Hospital study validates impact

- 95%: emotional well-being improved
- 89%: child’s quality of life increased
- 77%: tighter family bond
- 58%: child’s physical health improved

The Need

~720,000

Ohioans in a family raising a child with a life-threatening condition

Funding Ask

\$1.5 million a year (FY24 and FY25)

Support family programming

- Ensure Adventure programs impact all 88 counties
- Increase support of high health disparity groups

Support program staffing

- Sustain service delivery
- Foster community building to reduce social isolation
- Ensure effective family onboarding to maximize well-being and mental health benefits

Increase impact through community connectors

- Shorten time to vital resources for a large, pre-existing community that considers us a trusted advocate



A KID AGAIN

EVALUATION OF A COMMUNITY-BASED THERAPEUTIC RECREATION PROGRAM FOR CHILDREN WITH LIFE- THREATENING CONDITIONS

September 27, 2016

Prepared by:

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The Research Institute at Nationwide Children's Hospital

EXECUTIVE SUMMARY

Despite improvements in life expectancy, childhood chronic illnesses impose an immense burden on children, families, and society. In addition to financial costs, children with chronic illnesses and their families are at a heightened risk for social, emotional, and behavioral difficulties.¹⁻³ In order to mitigate these potentially negative outcomes, the A Kid Again[®] organization fosters hope, happiness, and healing for families raising kids with life-threatening illnesses. They do this through year-round, fun-filled adventures that allow children with life-threatening illnesses to feel like A Kid Again.

A Kid Again[®] holds multiple fun and kid friendly adventures for children with life-threatening illnesses and their families. Some of these adventures include major sporting events, zoos, science centers, gaming restaurants, outdoor recreational play centers, and holiday parties. Children are given an opportunity to “give illness a time out” and just be kids for a day. Parents are able to socialize, find affinity, and seek support from other parents who are in a similar situation. Most importantly, the family is given the opportunity to spend quality time together at an event, which may not have been possible without the help of A Kid Again[®].

Between September of 2012 and November 2014, A Kid Again[®] in partnership with the Research Institute at Nationwide Children’s Hospital, directed a pilot study to examine the impact of A Kid Again on children with life-threatening illnesses and their families. Conducted independently by a top pediatric research center, the study utilized interviews and surveys with parents, children, and siblings enrolled in A Kid Again[®] to gather information on the families the organization serves and outcomes that may be associated with program participation. Additionally, family members reported on their satisfaction with A Kid Again[®] and generated suggestions for how the program could better suit their needs. In order to best assess and evaluate the program, two phases of the study were conducted.

In Phase One, assessments were conducted in the homes of members recruited from the Central Ohio chapter (i.e., within 50 miles of Nationwide Children’s Hospital). In depth surveys and qualitative interviews were utilized to better understand families’ overall program satisfaction, as well as satisfaction with support, accessibility, communication, and interactions with staff/volunteers. The impact of both length (i.e., time since enrollment) and density (i.e., number of activities attended in the previous year) of involvement were examined in relation to a variety of family psychosocial outcomes. Specifically, quality of life; coping strategies; social, emotional, and behavioral functioning; as well as family functioning were assessed using standardized questionnaires to better understand how families of children with life-threatening illnesses benefitted from the A Kid Again[®] program.

Contact was attempted with 218 families to participate in the first phase of this study, and data were obtained from 79 families. Of these families, 78 mothers, 52 fathers, 79 children, and 67 siblings participated. Half of the children participating in the study were diagnosed with cancer, 13% were diagnosed with sickle cell disease, and 37% had another diagnosis (e.g., cystic fibrosis, spina bifida, complex chronic conditions). On average, children and families had been involved in the program for about 5 years and were very satisfied with the adventures and the support gained from their involvement in the A Kid Again[®] program. They were also very

satisfied with accessibility, communication, and interactions with staff/volunteers. When asked about areas for improvement, families and children requested more appropriate adventures for teens, better accessibility for children with disabilities (e.g., wheelchairs), and increasing opportunities to volunteer.

In Phase Two, a statewide, online survey was conducted to examine parents' perceptions of how the A Kid Again[®] program affected their own and their child's emotional well-being, overall enrichment, social well-being, resilience and coping, health condition, and health choices. Survey links were emailed to 1,431 families and 385 complete responses were received. Of the families that participated in Phase Two, 45% children had a cancer diagnosis, 7% were diagnosed with sickle cell disease, and 48% had another diagnosis. Families in this sample had been involved in the program for about 6 years. Data suggested that when families attended more events in the past year, both parents and children reported significantly higher emotional and social well-being and experienced better health-related outcomes.

Overall, the evidence collected suggests that families benefit greatly from their experience with A Kid Again[®]. The program not only helped children who have life-threatening illnesses feel more engaged and supported in their community, but other family members benefitted as well. This suggests that A Kid Again[®] is accomplishing their mission "to foster hope, happiness, and healing for families raising kids with life-threatening illnesses." Previously, the A Kid Again[®] program had anecdotal evidence of the positive outcomes that families experienced as a result of the program. However, these outcomes are now supported through both survey and semi-structured interview data with families. Because this is the first study to examine the impact of a therapeutic recreation program on families, our hope is that the data collected will help facilitate national expansion of the organization and additional research on these types of programs.

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STUDY OVERVIEW

Community-based programs, such as A Kid Again[®], are thought to promote better integration for children with chronic conditions and provide support, education, and respite for families.

However, no research to date has examined the impact of therapeutic recreation programs that provide multiple brief, but ongoing, opportunities for families of children with life-threatening illnesses. The goal of this study was to obtain preliminary data on the impact of A Kid Again[®] on family outcomes and to explore associations between program involvement and demographic, physical, psychosocial, and healthcare factors. We expected that higher levels of involvement in A Kid Again[®] would be associated with better physical, psychosocial, and healthcare outcomes for children and parents.

In order to evaluate these factors and the impact of A Kid Again[®], our study was conducted in two separate phases:

Phase One: Over 1,600 families are currently enrolled in A Kid Again[®], however, only children and their parents who lived within a 50 mile radius of the study center were recruited to participate in the first phase of the pilot study. To ensure that the sample was representative of all families in the program, 125 families were randomly selected for recruitment with the goal of reaching 100 families. Due to outdated contact information, the research team expanded the pool of potential families to 218, and reached 148 of those families, of whom 79 participated. To be eligible for Phase One, children had to be between the ages of 5-18 years old and have at least one English speaking parent. Eligible families were asked to complete a battery of measures assessing demographic, physical, psychosocial, and healthcare factors. Furthermore, there was a semi-structured qualitative interview to assess program satisfaction.

Phase Two: In order to acquire statewide data about A Kid Again[®] families, 1,431 online surveys were sent via email to all families enrolled in the program that had a valid email address on file. Using REDCap[™], a reliable online survey application, 385 parents completed a survey assessing the impact of AKA on the psychological and physical well-being of both themselves and their child with a life-threatening illness.

This study was a collaborative effort between A Kid Again[®] and the Center for Biobehavioral Health at the Research Institute at Nationwide Children's Hospital. The Center for Biobehavioral Health, located in Columbus, Ohio, has extensive experience in developing strategies to assess and enhance the psychological, social, and physical health behaviors of children affected by a variety of severe and life-limiting illnesses. Dr. Cynthia Gerhardt, director of the center, and her research team, conduct federally-funded research, both nationally and internationally, regarding family adjustment to cancer and end-of-life care in addition to other pediatric conditions (e.g., sickle cell disease, juvenile idiopathic arthritis, and traumatic brain injury). To ensure the quality

of the data collected, the research team developed a study protocol of reliable and extensively validated measures (See Appendix A for more information). Data were analyzed and interpreted by the research team at Nationwide Children's Hospital. Guided by previous research demonstrating the negative impact that chronic illness can have on adjustment in children and families, and the potential benefit of therapeutic recreational programs, surveys were created to specifically assess how involvement in A Kid Again[®] was related to family outcomes (e.g., emotional well-being, quality of life). Phase One of the study was initiated during September 2012 and Phase 2 was initiated during March 2014. Because families were randomly recruited locally for Phase One and all families received the survey for Phase Two, characteristics of this sample are considered to be fairly representative of families enrolled in the program (see Appendices D and E).

RESULTS

Results from this study indicate that A Kid Again® had a widespread positive impact on families, and led to improvements in their social, emotional, and even physical well-being. By participating in the monthly adventures, parents and children were able to improve their self-confidence and sense of empowerment, and create unique memories that would last a lifetime. Additionally, families felt that the adventures led by A Kid Again® were a welcome distraction from the daily care demands of having a child with a life-threatening illness. Parents were especially satisfied with the holiday party, Kings Island, the Columbus Zoo, Charles Penzone's Mother-Daughter Makeover, and the Clippers game—just to name a few. Children with life-threatening illnesses and their siblings were most satisfied with Magic Mountain, Kings Island, and Miracles and Magic adventures.

Overall, parents believed the adventures fostered a safe and easily accessible environment in which their child was able to truly feel like “a kid again.” Families also felt a sense of community and acceptance as a result of the program because they were able to interact with other families facing similar situations. Thus, the data suggest that A Kid Again® is accomplishing their mission “to foster hope, happiness, and healing for families raising kids with life-threatening illnesses.”

A more detailed overview of the results from both Phase One and Phase Two of the study are discussed below. Supplemental information can be found in the Appendices.

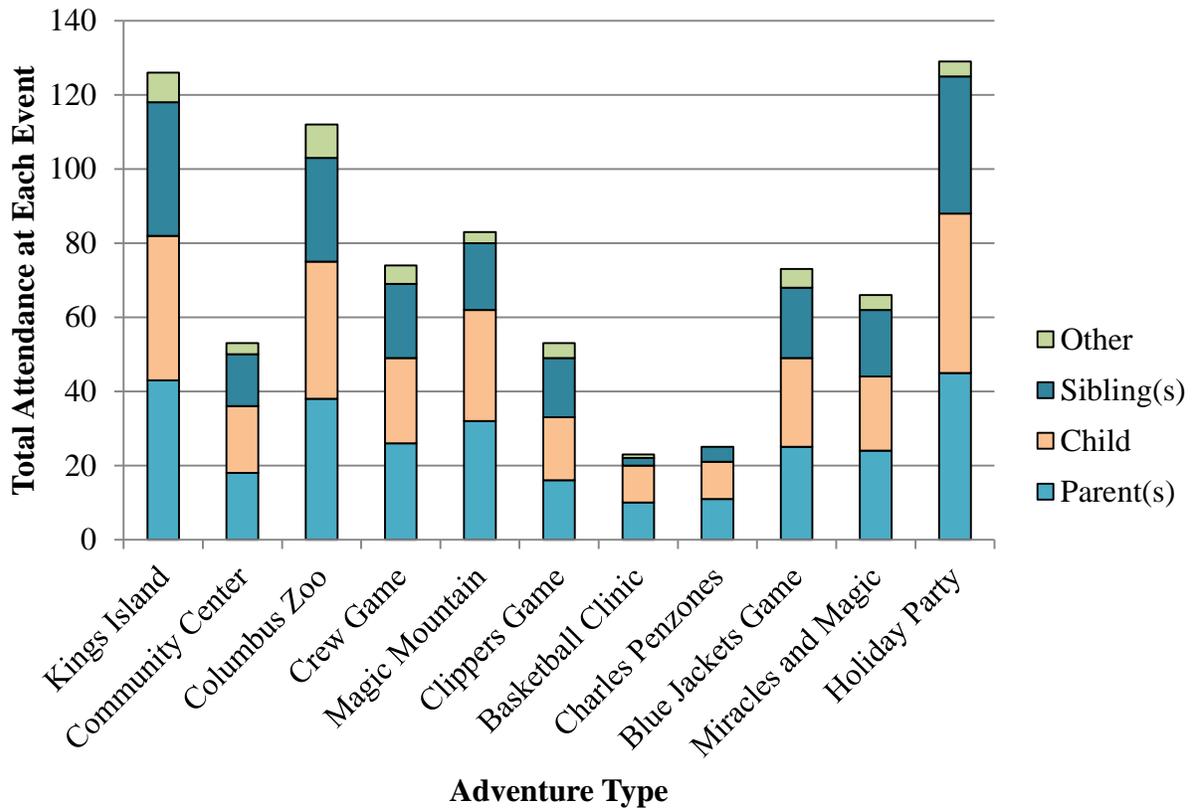
Phase One

Seventy-nine local families participated in Phase One of this study, including 78 mothers, 52 fathers, 79 children, and 67 siblings. The aim of this initial phase was to characterize program involvement, describe overall satisfaction with the program, examine child health outcomes and associations with program involvement, and identify families who benefit most from A Kid Again®. Interview data provided information regarding aspects of the program that families either liked or disliked, and provided families with an opportunity to offer suggestions for improvement.

Program Involvement

On average, families participating had been involved in A Kid Again for 4.7 years. They attended approximately 37% of A Kid Again® adventures during the previous year (ranging from 0 to 89% of adventures per year). The figure below demonstrates the distribution of children, siblings, and parents that attended each adventure throughout the year.

Figure 1: Phase One Adventure Attendance



Program Satisfaction

Children, parents, and siblings were asked to rate their overall satisfaction with the program, as well as individual aspects of the program based on a Likert scale ranging from 1 (*not at all satisfied*) to 4 (*very satisfied*). Overall, parents and children have been very satisfied with the A Kid Again® program. Table 1 below depicts program satisfaction for parents, children, and siblings.

Table 1: Mother, Father, Child, and Sibling Program Satisfaction

	Mother Satisfaction	Father Satisfaction	Child Satisfaction	Sibling Satisfaction
Very Satisfied	80%	90%	85%	84%
Somewhat	15%	10%	15%	11%
A Little	4%	-	-	5%
Not at all Satisfied	1%	-	-	-

Satisfaction with Adventures

Families and children were most satisfied with the following components of A Kid Again® adventures:

- *Type and number of adventures or activities offered for children with medical conditions*
- *Type and number of adventures for siblings and parents*
- *The age-appropriateness of adventures for children*

Table 2: Mother, Father, Child, and Sibling Satisfaction with Adventures

	Mother	Father	Child	Sibling
The type of adventures or activities offered for children with medical conditions	3.7	3.9	3.8	-
The number of adventures offered for children with medical conditions	3.7	3.9	3.8	-
The type of adventures for siblings	3.6	3.8	-	3.6
The number of adventures for siblings	3.6	3.9	-	3.6
The type of adventures for parents	3.3	3.6	-	-
The number of adventures for parents	3.2	3.5	-	-
The age-appropriateness of adventures for children	3.6	3.8	-	-
When adventures are scheduled	3.5	3.6	3.6	3.2
Refreshments or meals provided during adventures	3.4	3.6	3.4	3.3

Regarding specific adventures, Mothers and fathers were most satisfied with the Kings Island, Columbus Zoo, and Holiday Party adventures. Similarly, children and siblings most frequently attended and were most satisfied with the Kings Island, Magic Mountain, and Holiday Party adventures. Figures 2, 3, 4, and 5 below depict families' satisfaction with each of the specific adventures.

Figure 2: Mother Satisfaction with Adventures

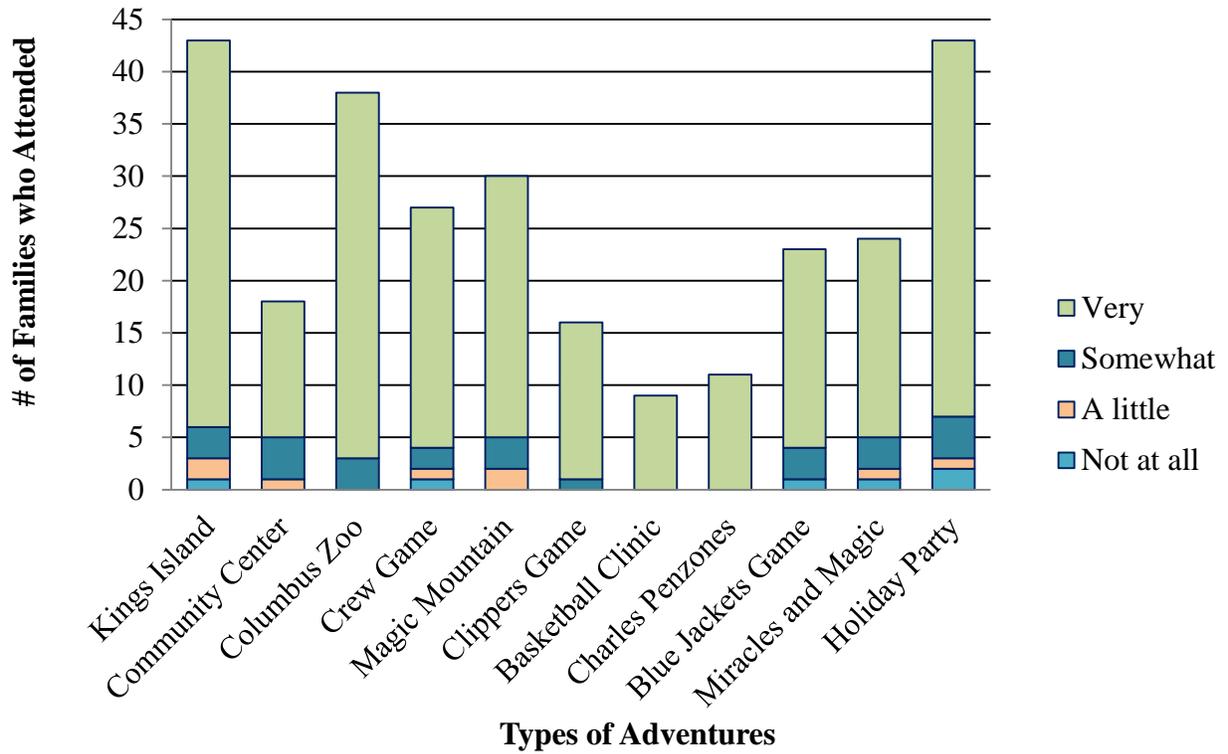


Figure 3: Father Satisfaction with Adventures

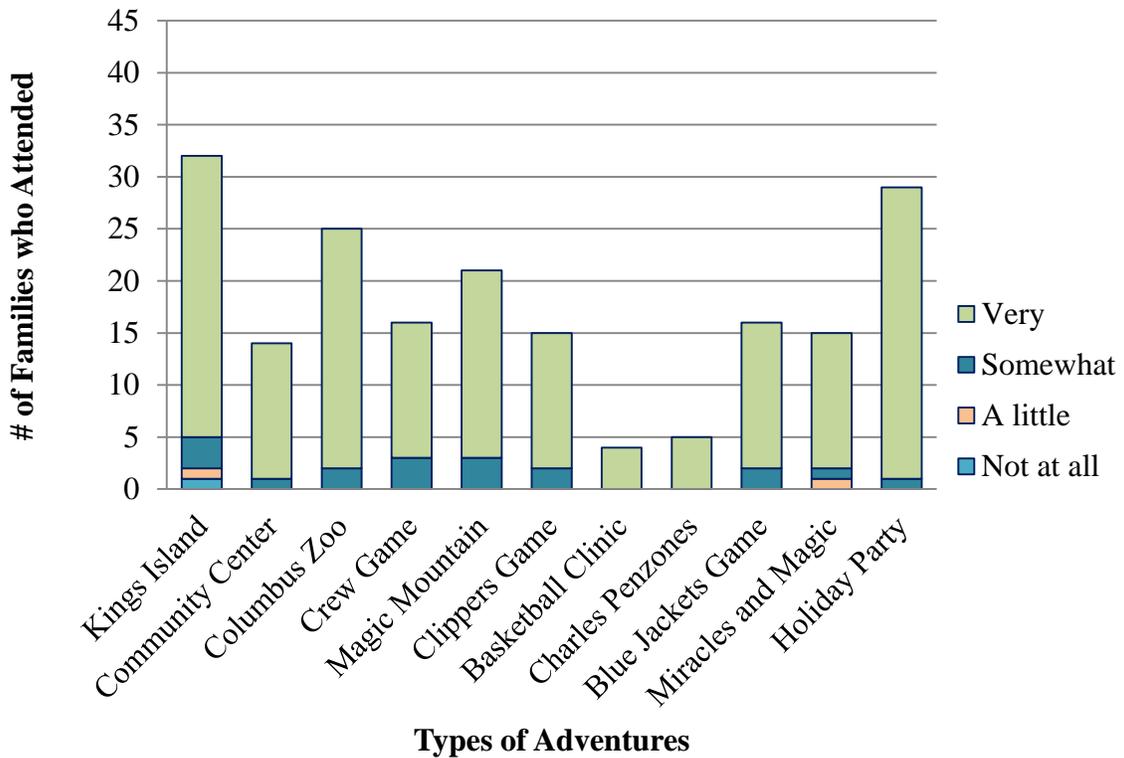


Figure 4: Child Satisfaction with Adventures

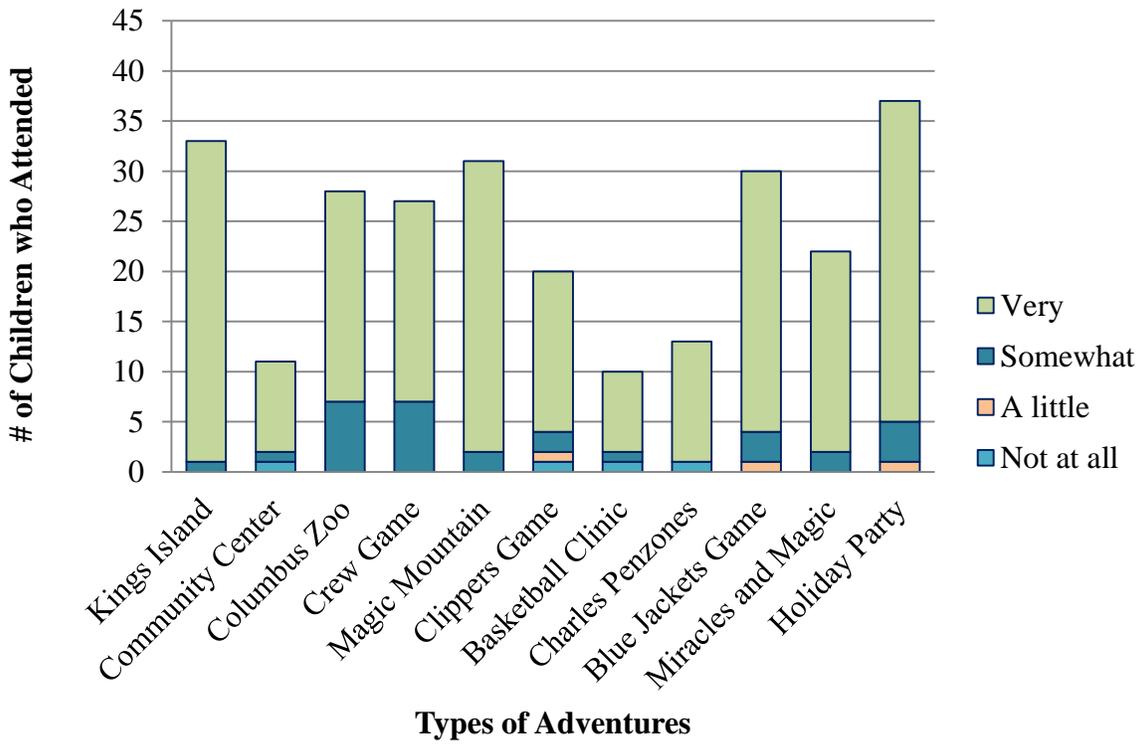
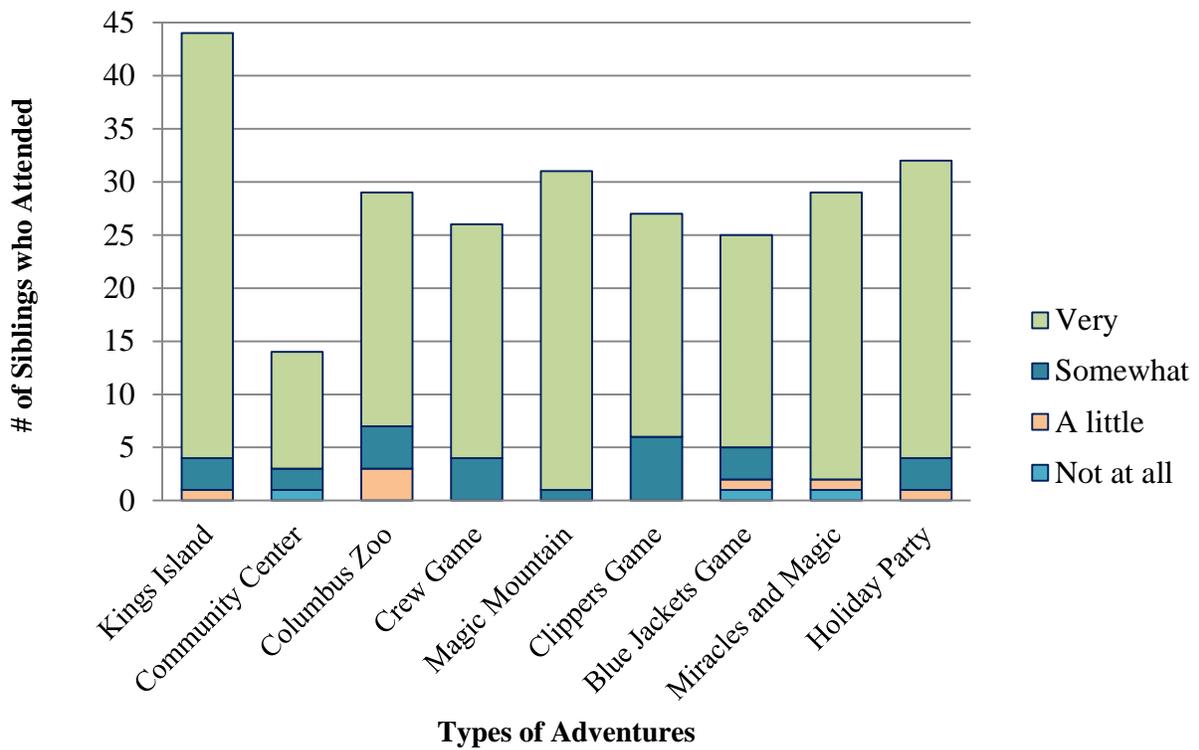


Figure 5: Sibling Satisfaction with Adventures



Satisfaction with Support

Overall, families and children were very satisfied with the amount of support that A Kid Again[®] provided for them. Parents found more support through interacting with other families, while children and siblings found more support through their own involvement in A Kid Again[®] (See Table 3). A Kid Again[®] offered support to families through:

- *The availability of emotional support through involvement in A Kid Again[®]*
- *The availability or helpfulness of educational resources through a Kid Again[®]*
- *The opportunity provided by A Kid Again[®] for a break or respite from your normal routine*
- *Opportunities to interact with other families through A Kid Again[®]*
- *Opportunities to interact with other healthcare professionals through A Kid Again[®]*

Table 3: Mother, Father, Child, and Sibling Satisfaction with Support

	Mother	Father	Child	Sibling
The availability of emotional support through your involvement in A Kid Again	3.2	3.6	3.8	3.8
The availability or helpfulness of educational resources through A Kid Again	3.1	3.5	3.1	3.1
The opportunity provided by A Kid Again for a break or respite from your normal routine	3.6	3.7	3.8	3.7
Opportunities to interact with other families through A Kid Again	3.6	3.8	3.4	3.3
Opportunities to interact with other healthcare professionals through A Kid Again	3.0	3.4	-	-

Satisfaction with Accessibility and Communication

In general, families were satisfied with the accessibility and ease with which they were able to participate in adventures (See Table 4). Specifically, families were most satisfied with the following:

- *The safety of adventures for children*
- *The initial application process to enroll a child in the program*
- *Overall communication from A Kid Again[®]*

Table 4: Mother, Father, Child, and Sibling Satisfaction with Accessibility and Communication

	Mother	Father	Child	Sibling
How easy it is to travel or get to adventures	3.4	3.6	-	-
How easy or accessible it is for children to participate in adventures	3.6	3.8	3.8	3.5
The safety of adventures or activities for children	3.8	3.9	-	-
How soon you are notified of upcoming adventures	3.6	3.7	-	-
How often you are notified about adventures	3.6	3.7	-	-
The way in which you are notified of adventures (e.g., phone, mail, email)	3.7	3.8	-	-
The initial application process to enroll your child in the program	3.8	3.8	-	-
Overall communication from A Kid Again	3.7	3.9	-	-

Satisfaction with Staff and Volunteers

Staff and volunteers have a large impact on families’ experience with A Kid Again[®]. Families were generally very satisfied with the A Kid Again[®] staff and volunteers. After partaking in adventures, families and children experienced the “ripple effect” and felt more inclined to volunteer both inside and outside of the organization (See Table 5). Families were also satisfied with the following aspects of A Kid Again[®] personnel:

- *The staff’s willingness to answer questions*
- *The friendliness and helpfulness of the A Kid Again[®] staff and volunteers towards parents, siblings, and A Kid Again[®] children*
- *Quality of interaction and supervision during adventures*

Table 5: Mother, Father, Child, and Sibling Satisfaction with Volunteers

	Mother	Father	Child	Sibling
The staff’s willingness to answer questions that you and your family may have?	3.8	3.9	-	-
How friendly and helpful A Kid Again staff is toward your children	3.9	4.0	3.8	3.7
How friendly and helpful A Kid Again staff is toward you	3.9	4.0	-	-
The quality of your interactions with A Kid Again volunteers	3.7	4.0	3.9	3.8
The supervision provided to children during adventures	3.6	3.7	-	-

Qualitative Interviews

Qualitative interview data from Phase One asked children and parents: “What do you like best about A Kid Again?”, “What do you not like or think could be better?”, and “What ideas do you have for alternative adventures?” Overall, parents and children thoroughly enjoyed A Kid Again® and made excellent suggestions to increase the effectiveness of the program, while voicing ideas for new adventures for future families to partake in. Aspects of the programs that parents, children, and siblings enjoyed most were:

- *It helps my child fit in and feel normal*
- *It brings our family closer together*
- *Helps us connect with families in a similar situation*
- *Allows us to do things we normally couldn’t afford*
- *Allows us to have fun and get a break from the illness*

While the A Kid Again® program is successful in terms of providing an environment in which a child is able to feel like a kid again—families voiced suggestions to make the program more effective and better accommodating:

- *Better communication and advertising about adventures*
- *More accessibility for children with disabilities (i.e., wheelchairs)*
- *More appropriate adventures for teens*
- *Include siblings over 18 and/or a friend for teenagers*
- *Keep events smaller in order to foster family interaction*
- *Eliminate process of buying tickets for food, games, etc.*
- *Increase opportunities to volunteer*

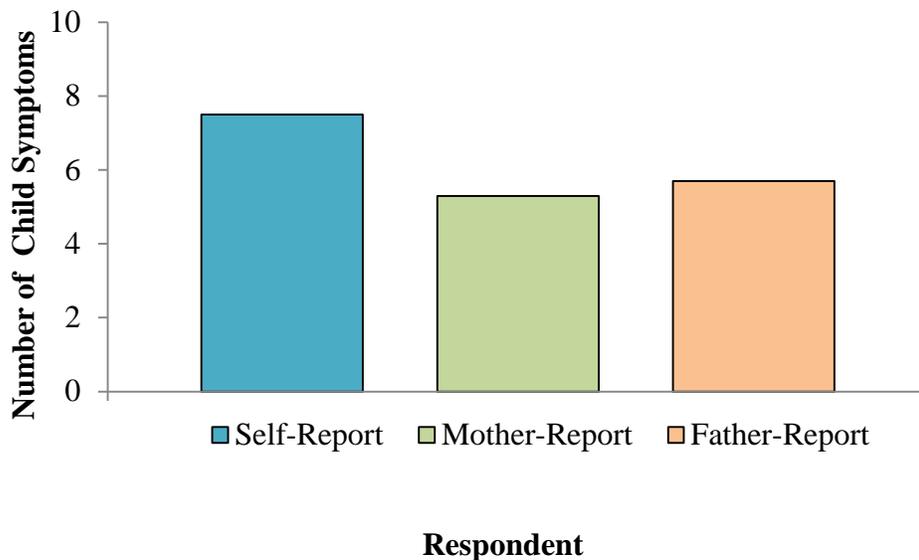
Families also made suggestions for future adventures. While these are completely up to the discretion and funding of A Kid Again®, families took the time and effort to produce ideas in which to better the program and promote a fun, enriching environment:

- *Halloween party*
- *Family dinner or picnic*
- *Fair with ride passes*
- *Movie night*
- *Waterpark*
- *Concert*
- *Circus*
- *Arcade*
- *Camping*

Child Health Outcomes

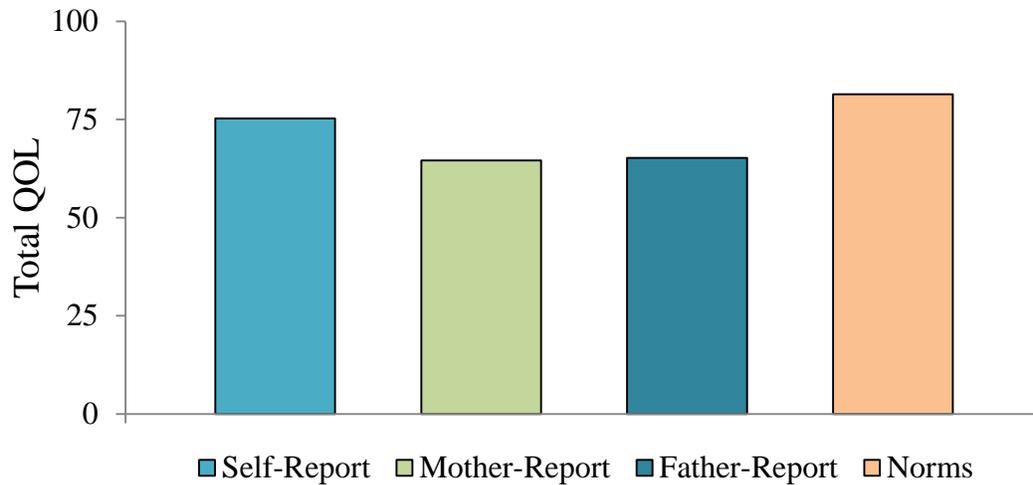
Symptoms

On average, children reported experiencing about seven illness-related symptoms and parents reported about six illness-related symptoms during the two days prior to survey completion. Analyses also indicated that children who reported experiencing more symptoms were more involved in the A Kid Again® program (i.e., attended more events during the past year). This suggests that the organization is not only best serving children who are the sickest, but potentially improves the physical well-being of children.



Quality of Life

Both children and parents reported that the child with a chronic illness had a poorer quality of life than established norms for healthy children, in which average scores are 83-84. Additionally, poorer quality of life was associated with greater density of involvement in A Kid Again[®] (i.e., attended more events during the past year). Once again, this suggests that families with the sickest children are benefitting the most from A Kid Again[®].



Emotional and Behavioral Functioning

Although most children in the A Kid Again[®] program did not report experiencing substantial emotional (e.g., anxiety, depression) or behavioral (e.g., aggression, rule-breaking) problems, a subset was experiencing difficulties. Interestingly, greater satisfaction with the A Kid Again[®] program was related to fewer emotional difficulties in children. This is encouraging and suggests that the program may positively affect emotional well-being in children with life-threatening illnesses.

Phase Two

For Phase Two, we received 385 responses from statewide surveys emailed to A Kid Again[®] parents regarding emotional and social well-being, overall enrichment, resilience and coping, health and physical conditions, and health conditions. On average, families were involved in A Kid Again[®] 5.6 years, with 24% of the sample being involved for 8 or more years. Ninety-three percent of the participants in Phase Two had attended A Kid Again[®] adventures in the past year.

This phase of the study closely examined the impact of family involvement in A Kid Again® on the various outcomes for children with life-threatening illnesses and their families. Outcomes were measured using parent self-report and parent-report of their child. The results listed below are grouped into several broad categories and represent general results relative to our measured outcomes. Given that A Kid Again® has three regional locations (i.e., Central, Northern, and Southwest), statistical analyses were run to determine whether the impact of A Kid Again® differed between sites. Quantitative results for each outcome are presented below.

Impact on the Child

Emotional Well-Being

Involvement in A Kid Again® was designed to foster a sense of empowerment in children and improve their ability to rebound from difficult set-backs and challenges pertaining to their illness. Research suggests that these characteristics are adaptive when dealing with the stress of an illness and help to prevent more serious mental health issues in the future. Notably, **over 95% of parents reported that the A Kid Again® experience contributed to improvements in the emotional well-being** of their child by fostering feelings of joy and happiness (See Table 6). Similarly, between 75% and 85% of parents believed that because of the A Kid Again® adventures, their child experienced:

- *Decreased feelings of fear or worry (75%)*
- *Less depression or sadness (83%)*
- *Increased self-esteem (85%)*
- *Enhanced feelings of hope (85%)*

Table 6: Impact on Children’s Emotional Well-Being

As a result of our family’s involvement in A Kid Again, MY CHILD has had....		Not At All	A Little	Some	A Lot	Item Mean
Emotional Well-Being	More joy or happiness	0%	4%	25%	70%	3.65
	More hope	3%	12%	41%	44%	3.25
	More positive feelings about himself/herself	4%	13%	39%	45%	3.24
	Less depression or sadness	5%	12%	38%	45%	3.22
	Less fear or worry	7%	18%	36%	39%	3.08

Table 7: Differences in Emotional Impact between Regions

Region	More Joy Mean	More Hope Mean	More Positive Mean	Less Depression Mean	Less Fear Mean
Central	3.68	3.30	3.32	3.24	3.13
Northern	3.78	3.41	3.34	3.28	3.06
Southwest	3.64	3.33	3.20	3.19	3.06

* No significant differences were discovered between regions regarding the emotional impact of the program for children.

Enrichment

The A Kid Again[®] program enriches the quality of children’s lives by providing a positive outlet for children to simply enjoy being a kid. **Eighty-nine percent of parents believed that their child’s quality of life improved** through the A Kid Again[®] experience and **96% of parents reported that through A Kid Again[®], their child had the opportunity to behave, act, and feel like a kid again** (See Table 8). Involvement in A Kid Again[®] also enriched children’s lives in other ways through each of the following:

- A shift in focus away from the illness and toward an optimistic anticipation of having something to look forward to (98%)
- A positive distraction from the medical environment and its demands (90%)
- A unique experience in which to celebrate something positive related to their illness creating a chance to feel special (97%)

Table 8: Impact on Children’s Enrichment

Because of our family’s involvement in A Kid Again, MY CHILD has had....		Not At All	A Little	Some	A Lot	Item Mean
Enrichment	A chance to feel special	0%	3%	14%	83%	3.80
	A distraction or break from the clinic/hospital	3%	7%	25%	65%	3.52
	Something positive to look forward to	0%	2%	13%	85%	3.83
	An opportunity to be a kid again	0%	4%	17%	79%	3.74
	Better quality of life	3%	9%	30%	59%	3.44

Table 9: Differences in Enrichment between Regions

Region	Feel special Mean	Distraction Mean	Positive Mean	Be a kid again Mean	Better QOL Mean
Central	3.85	3.54	3.85	3.75	3.50
Northern	3.88	3.69	3.94	3.91	3.47
Southwest	3.76	3.49	3.82	3.73	3.39

* No significant differences were discovered between regions regarding the impact of the program on children’s enrichment.

Social Well-Being

The A Kid Again[®] program provided children with numerous adventure opportunities to establish relationships with other children in similar situations (See Table 10). Additionally, the program fostered communication and socialization between families, which promoted a sense of belonging and community. In fact, **88% of parents reported an increase in compassion felt toward others**. The A Kid Again[®] experience also enhanced the social well-being of children through creating:

- An increased sense of enhanced social support from others (79%)
- An experience in which the child felt greater acceptance by other children and adults in the community (83%)
- An increased desire to give back and help others (86%)
- Stronger connections and relationships with other children with a similar health status (80%)

Table 10: Impact on Children’s Social Well-Being

Because of our family’s involvement in A Kid Again, MY CHILD has had....		Not At All	A Little	Some	A Lot	Item Mean
Social Well-Being	More social support from others	5%	16%	38%	41%	3.15
	More compassion toward others	3%	10%	36%	52%	3.36
	Greater acceptance by others	5%	12%	36%	47%	3.25
	A desire to give back/help others	2%	12%	33%	52%	3.35

	A stronger connection with other parents or children like my child	4%	15%	28%	52%	3.28
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Table 11: Differences in Social Well-Being between Regions

Region	More SS from others Mean	Compassion Mean	Great acceptance Mean	Give back Mean	Stronger connection Mean
Central	3.15	3.36	3.30	3.33	3.24
Northern	3.34	3.34	3.44	3.47	3.47
Southwest	3.15	3.38	3.21	3.35	3.29

*No significant differences were discovered between regions regarding the program’s impact on children’s social well-being.

Resilience and Coping

Involvement in A Kid Again[®] fostered a sense of empowerment in children and improved their ability to cope with challenges pertaining to their illness (See Table 12). Cultivating adaptive coping strategies in children with chronic illnesses is important given the downstream effects it can have on their mental health. **Seventy-seven percent of parents believed that their family was closer** as a result of participating in A Kid Again[®]. Other gains were:

- A sense of increased family strength (86%)
- Greater sense of empowerment and control in life (86%)
- Feelings of increased self-confidence (78%)
- Increase ability to cope with the illness and situation (81%)

Table 12: Impact on Children’s Resilience and Coping

Because of our family’s involvement in A Kid Again, MY CHILD has had....		Not At All	A Little	Some	A Lot	Item Mean
Resilience/Coping Ability	A sense that our family is closer	4%	10%	36%	51%	3.34
	A feeling that our family is stronger	5%	10%	35%	51%	3.32
	Greater sense of empowerment or control in life	7%	18%	34%	41%	3.09

	More self confidence	6%	16%	37%	41%	3.14
	Greater ability to cope with the illness and or/situation	5%	14%	33%	48%	3.25

Table 13: Differences in Resilience and Coping between Regions

Region	Family is closer Mean	Family is stronger Mean	Empowerment and control Mean	Self-confidence Mean	Cope with illness Mean
Central	3.40	3.39	3.13	3.14	3.34
Northern	3.41	3.44	3.41	3.38	3.41
Southwest	3.35	3.30	3.04	3.15	3.18

*No significant differences were discovered between regions regarding the impact of the program on children’s resilience and coping.

Health and Physical Condition

In addition to children’s social and emotional well-being, results suggest that A Kid Again® may have enhanced children’s overall quality of life (See Table 14). **More than half of parents felt that their child’s health condition improved** through the A Kid Again® experience.

Additionally, between 50% and 58% of parents attributed the following improvements to A Kid Again®, including:

- All over better physical well-being (58%)
- More energy (57%)
- Increase in physical strength (50%)

Table 14: Impact on Children’s Health and Physical Condition

Because of our family’s involvement in A Kid Again, MY CHILD has had....		Not At All	A Little	Some	A Lot	Item Mean
Health /Physical Condition	Better physical well-being	19%	23%	37%	21%	2.61
	More energy	22%	22%	37%	20%	2.55
	More physical strength	27%	24%	32%	18%	2.40

	Fewer clinic or hospital visits	45%	17%	22%	16%	2.09
	Less pain or physical symptoms	39%	20%	24%	17%	2.19

Table 15: Differences in Health and Physical Condition between Regions

Region	Physical well-being Mean	More energy Mean	Physical strength Mean	Fewer medical visits Mean	Less pain/symptom Mean
Central	2.63	2.59	2.36	1.97	2.05
Northern	2.66	2.50	2.44	2.28	2.53
Southwest	2.56	2.55	2.39	2.10	2.19

*Significant differences were found between sites regarding pain and physical symptoms, where parents in the northern chapter reported their children had greater improvements in pain, and children in the southwest chapter had less impact on physical well-being.

Health Choices

Given that research shows a strong connection between health attitudes and physical disease, the potential impact of A Kid Again® on children’s health behaviors is of extreme importance (See Table 16). Notably, **74% of parents attributed some of their child’s behavioral and attitudinal changes regarding their health** to A Kid Again®. Many parents also believed that A Kid Again® had a positive impact on their child through:

- A positive turning point in treatment (55%)
- An increase in desire to improve his or her health behaviors (57%)
- Greater willingness to comply with treatment and treatment protocols (56%)
- Improvement in health behaviors and choices made regarding health (57%)

Table 16: Impact on Children’s Health Choices

Because of our family’s involvement in A Kid Again, MY CHILD has had....		Not At All	A Little	Some	A Lot	Item Mean
Health Choices	A better attitude about his or her illness or condition	8%	18%	38%	36%	3.02

	A positive turning point in treatment	27%	18%	30%	25%	2.54
	A stronger desire to improve his or her health behaviors	21%	23%	31%	26%	2.62
	Greater willingness to comply with treatment	24%	20%	29%	27%	2.58
	Improved health behaviors/choices	23%	21%	32%	25%	2.59

Table 17: Differences in Health Choices between Regions

Region	Better attitude Mean	Positive treatment Mean	Improve health Mean	Comply with treatment Mean	Improved behaviors/choices Mean
Central	3.06	2.56	2.64	2.61	2.61
Northern	3.09	2.72	2.75	2.78	2.81
Southwest	2.98	2.45	2.58	2.50	2.51

*No significant differences were discovered between regions regarding the impact of the program on children’s health choices.

Impact on the Parents

Emotional Well-Being

Similar to the findings for children, the A Kid Again[®] program resulted in a variety of positive outcomes that are in line with the A Kid Again[®] mission. **Ninety one percent of parents experienced more joy and happiness as a result of their involvement** (See Table 18). Sixty-eight percent or more of parents affirmed that the experience provided by A Kid Again[®] enhanced their emotional well-being through the following ways:

- *An increase in feelings of hope (84%)*
- *An increase in self-esteem (77%)*
- *Less depression or sadness (75%)*
- *Less fear or worry associated with their child’s health (68%)*

Table 18: Impact on Parents' Emotional Well-Being

As a result of our family's involvement in A Kid Again, I have had....		Not At All	A Little	Some	A Lot	Item Mean
Emotional Well-Being	More joy or happiness	1%	7%	29%	62%	3.52
	More hope	6%	10%	30%	54%	3.33
	More positive feelings about myself	8%	15%	30%	47%	3.17
	Less depression or sadness	8%	16%	33%	42%	3.10
	Less fear or worry	12%	21%	30%	38%	2.93

Enrichment

Involvement in A Kid Again[®] enriched parents' quality of life by giving them adventures to look forward to and allowing them the opportunity to bond with one another. A major finding of this study was that **99.7% of parents reported that A Kid Again[®] provided them with unique opportunities to see their child be a kid again** (See Table 19). Ninety-two percent or more of parents believe that the program enriched their lives by providing:

- *Positive memories that will last forever (98%)*
- *A distraction or break from the clinic or hospital (88%)*
- *An experience in which to look forward to (97%)*
- *An event that was otherwise impossible (93%)*

Table 19: Impact on Parents' Enrichment

As a result of our family's involvement in A Kid Again, I have had....		Not At All	A Little	Some	A Lot	Item Mean
Enrichment	Positive memories that will last forever	0%	1%	10%	88%	3.86
	A distraction or break from the clinic/hospital	5%	8%	17%	71%	3.54
	Something positive to look forward to	1%	3%	12%	85%	3.81
	An opportunity to see my child be a kid again	1%	4%	12%	83%	3.76

	An experience that was otherwise not possible	2%	6%	13%	80%	3.71
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Social Well-Being

A Kid Again® not only enriched parents’ lives and improved their emotional well-being, but it also gave them a chance to form connections with families facing similar life challenges (See Table 20). As a result, **over 90% of parents also reported feeling more compassionate towards others and a strong desire to “give back.”** Overall, A Kid Again® improved the social well-being of parents through the following:

- *Greater acceptance by others (79%)*
- *More social support from others (73%)*
- *A stronger connection with other parents and children experiencing similar situations and struggles (82%)*

Table 20: Impact on Parents’ Social Well-Being

Because of our family’s involvement in A Kid Again, I have had....		Not At All	A Little	Some	A Lot	Item Mean
Social Well-Being	More social support from others	9%	17%	29%	44%	3.09
	More compassion toward others	2%	7%	27%	64%	3.54
	Greater acceptance by others	7%	14%	30%	49%	3.21
	A desire to give back/help others	1%	5%	26%	68%	3.61
	A stronger connection with other parents or children like my child	5%	14%	24%	58%	3.34

Resilience and Coping

Finally, the support provided by A Kid Again® facilitated adaptive coping in parents and provided them with a sense of resilience (See Table 21). **Ninety-four percent of parents reported that the skills they gained from A Kid Again allowed them to better cope** with their child’s illness or condition. Additionally, A Kid Again® successfully provided an opportunity to renew and strengthen family bonds which produced outcomes such as:

- *A sense that their family is closer (87%)*
- *A feeling our family is stronger than before (86%)*
- *Greater sense of empowerment or control in life (76%)*
- *Increase in self-confidence as a parent (77%)*

Table 21: Impact on Parents’ Resilience and Coping

As a result of our family’s involvement in A Kid Again, I have had....		Not At All	A Little	Some	A Lot	Item Mean
Resilience/ Coping Ability	A sense that our family is closer	3%	10%	33%	54%	3.38
	A feeling that our family is stronger	4%	10%	31%	55%	3.36
	A greater sense of empowerment or control in life	8%	15%	32%	44%	3.12
	More self-confidence as a parent	7%	15%	31%	46%	3.17
	Greater ability to cope with the illness and situation	6%	15%	31%	49%	3.22

USE OF THIS INFORMATION

The ultimate goal of this study was to enhance services to promote resilience in children, siblings, and parents affected by life-threatening illnesses. The results of this study are based on quantitative and qualitative measures of the impact that A Kid Again[®] has on families and children involved in the program. While feedback was overwhelmingly positive, steps are being taken to continually improve the A Kid Again[®] experience for families. The present data can be used to justify the impact of the organization for funding foundations, individuals, or corporate sponsors. The data represents aggregated results of an online survey and qualitative interviews from home visits from Phase One, as well as survey results from Phase Two, and should be presented in that context. Percentages can be stated as presented, or in relative context (e.g., “a very high percentage” rather than “90 percent”).

Parents’ highly positive responses about A Kid Again[®] demonstrate the extent to which the organization is accomplishing its mission to “foster hope, happiness, and healing.” Surveys show that families are highly satisfied with programming. Interview data suggests that through the monthly events, children were able to fit in, feel normal, and truly be a kid again. Family members grew closer, while also forging new bonds with other families in similar situations. Children involved in A Kid Again[®] were able to experience an opportunity otherwise not possible and give illness a time out.

This research evaluation of the effectiveness of A Kid Again[®] characterizes the impact of the organization on children and families affected by life-threatening illnesses. The goal was to enumerate the benefits of A Kid Again[®] and to better support the potential nationwide expansion of the program. Here we present compelling evidence that the A Kid Again[®] organization should spread beyond Ohio to similarly enhance the lives of children with life-threatening illnesses across the country.

The following quotes demonstrate some of the positive effects that A Kid Again[®] had on the lives of parents and children alike.

“It made me happy – just very, very happy!” [What about it made you happy?] “It made my family spend time with each other and we get to do some stuff that we don’t get to do that much.”
– Child

“It’s kept us together through a really difficult time” – Dad

“It opened my eyes to not only how special they are, but how special the world is...where they can find some place where they can fit in.” - Dad

“It gave our kids the chance, not only our sick child, but our other children as well, to just really have no stress, no concerns, just a fun time.” - Mom

FUTURE DIRECTIONS

This study was an important step in identifying the impact of A Kid Again[®] on Ohio families, and lays the groundwork for additional prospective and longitudinal research. In general, families believed that the program had a significant, positive impact and helped to foster hope, happiness, and healing. While largely successful, there are several areas in which to improve A Kid Again[®] in order to better serve families. Parents and children believe the next steps for A Kid Again[®] should be to improve access to events (specifically children in wheelchairs), better communication of the timing/destination/adventure further in advance, and to provide more adventure opportunities for children and families. Parents also suggested developing more age-appropriate adventures for teenagers to attend, and allowing the accompaniment of older siblings (over 18) or a friend. Finally, parents and children agreed that smaller events would be most beneficial and would help to foster more family interaction.

We anticipate that the data collected in Phase One and Phase Two of this study will facilitate a larger and more in depth study to better understand the impact of the A Kid Again[®] program. Future studies will allow us to prospectively examine the effectiveness of A Kid Again[®] over

time in a more geographically diverse sample and to identify additional factors associated with child and family outcomes after involvement in the program. Future steps might include increased collaboration with other community organizations in order to maximize the quality and scope of services, while enriching the lives of as many children and families as possible. As a whole, the data collected will help to ensure that the A Kid Again[®] organization remains successful and faithful to their mission, and will help us to achieve our ultimate goal of expanding this organization to other communities nationally.

APPENDIX A

STUDY DEVELOPMENT AND DATA COLLECTION

Study Development

Between September 2012 and November 2014, researchers at Nationwide Children's Hospital conducted the following protocol in order to develop an appropriate battery of measures for families to complete during Phase One of the study.

- Contact with researchers at Nationwide Children's Hospital was initiated by A Kid Again[®] leadership to discuss the possibility of conducting a program evaluation.
- Funding was obtained from a donor and supplemented by a grant from the Columbus Foundation.
- A review of current, relevant literature was conducted to characterize themes and identify constructs of interest.
- Researchers at Nationwide Children's Hospital deliberated and discussed previous findings in order to select appropriate measures. Decisions were guided by several general principles. First, measures had reasonable reliability and validity, and could be self-administered. For parents, all measures required no more than a 7th grade reading level. Lastly, child and adolescent measures were selected that could span the developmental framework proposed for the project.
- A series of qualitative questions were also created to obtain additional information and feedback about families' experiences with A Kid Again[®].
- A satisfaction questionnaire was developed based on previous work and tailored to meet the needs of the organization. Feedback from board members was used to refine the measure before use.
- A final meeting was held with members of both A Kid Again[®] and researchers from Nationwide Children's Hospital to finalize the complete protocol for both study phases.
- Approval for Phase One was obtained from the institutional review board (IRB) at Nationwide Children's Hospital, and the study commenced in family homes beginning September of 2012.
- Phase Two involved a survey on REDCap (Research Electronic Data Capture), which is a secure, web-based application designed to collect and manage research data (Harris et al., 2009).
- Phase Two was exempt from IRB approval due to the anonymous nature of the online survey and commenced in March 2014.

As stated above, appropriate measure were selected for this study based on several key factors including reliability, credibility, administration type, and reading level. Parent and child measures are as follows:

Measures Completed by Children:

- Memorial Symptom Assessment Scale (MSAS): Assesses the presence or absence of a variety of physical and psychological symptoms (e.g., pain, fatigue, worry), which have been found most prevalent in youth with chronic illness. Follow-up questions assess the frequency, severity, and distress associated with the symptom.
- Pediatric Quality of Life (PedsQL): A self-report examining health-related quality of life for children ages 5-18 in four domains of functioning: physical, emotional, social, and school.
- Self-Perception Profile for Children (SPPC): Evaluates children's perceptions of their proficiencies in six domains: scholastic and athletic competence, social acceptance, physical appearance, behavioral conduct, and self-worth.
- Youth Life Orientation Test (YLOT): Assesses self-perceptions and dispositional optimism and pessimism.
- Benefit Finding Scale (BFS-C): Children rate their perceptions of potential benefits of their illness based on how well these items describe their own experience.
- Social Support Scale for Children (SSSC): Child perception of social support from family, close friends, peers, and teachers.
- Child Report of Parenting Behavior Inventory-Revised (CRPBI-R): Assesses the child's perception of mother and father parenting behaviors.
- Satisfaction Survey & Qualitative Questions: Children were asked several open-ended questions at the end of the assessment to obtain qualitative feedback about their experience in A Kid Again[®] (e.g., what they liked best, what should be better, what else should A Kid Again[®] do for families). Answers were coded for thematic content.

Additional Measures for children 10+:

- Youth Self Report (YSR): Assesses the emotional and behavioral problems in adolescents including internalizing problems (i.e., anxiety and depression), externalizing problems (i.e., aggressive, hyperactivity, and noncompliant), and social competence (friends, activities, school).
- Parent Adolescent Communication Scale (PACS): Assesses the effectiveness and openness of communication between the parent and child.
- Response to Stress Questionnaire (RSQ): Assesses coping with stressful events and involuntary stress responses.

Measures Completed by Mothers and Fathers

- Demographic Questionnaire: Measures the basic background characteristics of the family, for example: (a) parent and child age, race, ethnicity; (b) parental marital status, number of children, education, occupation, and income; and (c) family spiritual/religious involvement.

- Memorial Symptom Assessment Scale (MSAS): (see above). Each parent provided reports of their child's symptoms.
- Pediatric Quality of Life: (see above). Each parent reported on their child's symptoms using a proxy version of the PedsQL.
- Child Behavior Checklist: Assesses the emotional and behavioral problems of children including internalizing problems (i.e., anxiety and depression), externalizing problems (i.e., aggressive, hyperactivity, and noncompliant), and social competence (friends, activities, school).
- Self-Report Forms – 36 (SF-36): Assesses parents' quality of life based on seven domains: physical functioning, role physical, social, bodily pain, mental health, role emotional, vitality, and general health to form physical and mental health determinants.
- Caregiver Strain Questionnaire (CSQ): Assesses the impact on parents of caring for a child with special needs. Factor scores include: caregiver strain, internalized feelings and negative feelings directed externally.
- Response to Stress Questionnaire: Assesses coping and involuntary stress response to examine: primary and secondary coping, disengagement coping, involuntary engagement, and involuntary disengagement.
- Parent Behavior Inventory / Communication Scale: Assesses perceived levels of parental care and overprotection.
- Family Environment Scale: Assesses the social environment of a family in three domains: interpersonal relationship, personal growth and system maintenance.
- MOS Social Support Survey: Assesses emotional, informational, appraisal, and affectionate support as well as positive social interaction.
- Life Orientation Test / Benefit Finding Scale: Assesses the perception that positive contributions were made to one's life by the experience of being diagnosed with and treated for cancer.
- Satisfaction Survey & Qualitative Questions: Assesses the satisfaction with the A Kid Again® program through Likert scaling, as well as several open-ended questions at the end of the assessment to obtain qualitative feedback about their experience in A Kid Again® (e.g., what they liked best, what should be better, what else should A Kid Again® do for families). Answers were coded for thematic content.

Data Collection Methods: Phase One

A Kid Again[®] provided access to their program rosters where Dr. Gerhardt's team determined the potential eligibility of families for the study. Children who are eligible must: (a) be enrolled in A Kid Again[®] (i.e., with a life-threatening illness), (b) be 5-18 years old; (c) have at least one English speaking parent; and (d) live within 50 miles of the study center. A letter was mailed to 218 randomly selected families that met eligibility criteria to describe the study and inform the family that they will be phoned to determine their interest in participating. Two weeks later, the study coordinator called the families to explain the purpose, risks and benefits of participating. Research team administered the initial surveys in family homes with children and parents at a time that was convenient for them. Initial visits lasted about 2-2.5 hours. The goal was to have about 100 families participate.

Parents and children ages 9 or older provided informed consent and assent prior to completing surveys. All children (ages 5-18) who are able to provide self-report were asked to complete measures, and families completed surveys in separate rooms to ensure privacy. Respondents were asked to complete measures of functioning (e.g., physical symptoms, quality of life, social support), as well as several qualitative questions to obtain additional information and feedback about their experience in the program. Of the 148 families who were able to be contacted, 79 (53%) chose to participate in Phase One of the study. Following completion of questionnaires, all participating families were mailed a thank you letter and a check for \$50. Each child also received a \$10 gift card. After this initial phase of data collection, families had the option to schedule a subsequent 1-1.5 hour visit to collect additional data from parents and siblings about sibling functioning. Again, families were reimbursed for their time.

Data Collection Methods: Phase Two

The second phase of the study involved acquiring more statewide data about A Kid Again[®] families. Online surveys were sent via email to all families enrolled in the program that had a valid email address on file. This resulted in emails sent to 1,431 families. Using this survey, parents reported on the impact of the program on the psychological and physical well-being of both the child with a life-threatening illness and themselves. Three-hundred and eighty-five parents completed the online survey, which was a 27% percent response rate.

Data from both Phase One and Phase Two was independently analyzed by researchers at Nationwide Children's Hospital. Results from the program evaluation were presented to board members at A Kid Again[®].

APPENDIX B

CHILD CHARACTERISTICS

PHASE ONE

Age of A Kid Again® Child

Age	Number	% of Total
5-7 years	13	17%
8-10 years	13	17%
11-13years	20	24%
14-16 years	25	32%
17-19 years	8	10%
Not reported	0	0%

Gender of A Kid Again® Child

Gender	Number	% of Total
Female	34	43%
Male	44	56%
Not reported	1	1%

Race/Ethnicity of A Kid Again® Child

Category of Race	Number	% of Total
White	52	66%
Black or African American	22	28%
Other	3	4%
Not reported	1	1%

Category of Ethnicity	Number	% of Total
Hispanic or Latino	2	3%
Not Hispanic	75	96%
Not reported	1	1%

Condition of A Kid Again[®] Child

Condition	Number	% of Total
Cancer	40	50%
Sickle Cell	10	13%
Other	29	37%

PHASE TWO

Age of A Kid Again[®] Child

Age	Number	% of Total
1-3 years	21	5%
4-7 years	81	18%
8-11 years	106	24%
12-15 years	122	27%
16-19 years	72	16%
20+ years	11	2%
Not reported	34	8%

Gender of A Kid Again[®] Child

Gender	Number	% of Total
Female	191	43%
Male	223	50%
Not reported	33	7%

Race/Ethnicity of A Kid Again[®] Child

Category of Race	Number	% of Total
White	332	74%
Black or African American	56	13%
Asian	2	1%
More than one race	16	4%
Other	6	1%
Not reported	35	7%

Category of Ethnicity	Number	% of Total
Hispanic or Latino	12	3%
Not Hispanic	401	90%
Not reported	34	7%

Condition of A Kid Again[®] Child

Condition	Number	% of Total
Cancer	187	42%
Sickle Cell Disease	29	7%
Other Health Condition	198	44%
Not Reported	33	7%

Healthcare Utilization

Healthcare Utilization	Mean	SD	Range
Hospitalizations	0.8	1.8	0-11
Days in Hospital	2.8	6.9	0-29
Outpatient Visits	20.3	26.0	0-119
Urgent Care Visits	0.4	0.9	0-5
Emergency Department Visits	0.5	1.1	0-6
Billed Charges from NCH	\$62,586	\$164,735	\$583.25- \$1,263,246

APPENDIX C

PARENT CHARACTERISTICS

PHASE 1

Gender of A Kid Again® Parent

Gender	Number	% of Total
Female	34	43%
Male	44	56%
Missing	1	1%

Marital Status of A Kid Again® Parent

Marital Status	Number	% of Total
Single, Divorced/Separated, or Widowed	17	22%
Married	52	66%
Remarried	2	2%
Living with Someone	4	5%
Missing	4	5%

Race and Ethnicity of A Kid Again® Parent

Race	Number	% of Total
White	51	65%
Black or African American	20	25%
Other	2	2%
Missing	6	8%

Category of Ethnicity	Number	% of Total
Hispanic or Latino	1	1%
Not Hispanic	49	92%
Not reported	33	7%

Number of Events Attended by A Kid Again® Parent

Number of Events	Number	% of Total
0	10	13%
1	7	9%
2	10	13%
3	19	24%
4	14	18%
5	6	8%
6	3	4%
7	4	5%
8	5	6%
Missing	1	1%

Annual Family Income of A Kid Again® Parent.

Annual Family Income	Number	% of Total
Under \$25,000 per year	17	23%
\$25,001-\$50,000 per year	19	26%
\$50,001-\$100,000 per year	27	37%
\$100,001 or more per year	10	14%

PHASE TWO

Gender of A Kid Again® Parent

Gender	Number	% of Total
Female	383	86%
Male	32	8%
Missing	32	7%

Race/Ethnicity of A Kid Again[®] Parent

Race	Number	% of Total
White	346	77%
Black or African American	52	12%
More than one race	8	2%
Other	7	1%
Missing	34	8%

Category of Ethnicity	Number	% of Total
Hispanic or Latino	5	1%
Not Hispanic	409	92%
Not reported	33	7%

Age of A Kid Again[®] Parent

Age	Number	% of Total
19-24 years	6	1%
25-30 years	8	2%
31-36 years	106	22%
37-42 years	119	27%
43-49 years	136	31%
50+ years	75	9%
Not reported	34	8%

Marital Status of A Kid Again® Parent

Marital Status	Number	% of Total
Single, Divorced/Separated, or Widowed	91	20%
Married	305	74%
Living with Someone	19	4%
Missing	32	7%

Annual Family Income of A Kid Again® Parent

Annual Family Income	Number	% of Total
Under \$25,000 per year	73	19%
\$25,001-\$50,000 per year	95	25%
\$50,001-\$100,000 per year	153	40%
\$100,001 or more per year	57	15%
Missing	7	1%

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