



Ronald McDonald House Charities of Southern California

Camp Ronald McDonald for Good Times

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Introduction to Ronald McDonald House Charities of Southern California

In 1980, RMHCSC opened the region's first Ronald McDonald House near Children's Hospital Los Angeles, followed by the start of Camp Ronald McDonald for Good Times in 1982. Over the next 35 years, RMHCSC opened six more Ronald McDonald Houses near major pediatric hospitals across the region. Today, RMHCSC houses have a total of 175 guest rooms that serve more than 17,000 family members every year; RMHCSC Camp is nationally recognized for its year-round, residential oncology camp programs.

Throughout the world, the Ronald McDonald House Charities partner with local hospitals serving critically ill children to strengthen community approaches to family-centered care. Our Houses and Family Rooms allow parents to remain close to their children during hospital stays, have a space to rest and care for themselves, and connect with other families that face similar challenges and fears. All of this ensures that parents are in a healthier frame of mind when it comes time to make decisions about their child's care.

In Southern California, we have deepened our approach to enhancing family-centered care through our camp program, Camp Ronald McDonald for Good Times. “Camp” functions year-round and was designed to help children build their self-esteem, self-reliance and independence after experiencing cancer.

Camp Ronald McDonald for Good Times:
“Where Healing Happens”

Camp Ronald McDonald for Good Times (“Camp”) is the only year-round camp focused on the needs of children with cancer and their families in Southern California. For over thirty-five years, Camp has been on the forefront of designing medically supervised programs that respond to the needs of the pediatric oncology community. Today, we are one of the world’s largest oncology camp programs, serving over 1,600 campers every year from all over our region with fun-filled, medically supervised, cost-free camp programs. We also host the first Spanish language camps in the nation to support our Southern California based Latino families impacted by childhood cancer.

All of our programs are offered at our 60 acre facility in Mountain Center near Idyllwild, which is comprised of 14 cabins (200 beds), a pool, activity areas, hiking trails, a multi-use dining hall and meeting space, Ed Rasky Archery Range, Jackson Fishing Pond and a “Med Shed.” The “Med Shed” is our comprehensive Health Care Center, where all of our campers’ medical needs are attended to 24/7 while at camp. We are in the midst of finalizing plans for a new cabin village, as well as a new amphitheater for performances and various activities.

Family Camp (which is the focus of our Project Impact interviews and evaluation) is offered to families of children with cancer ages 0-8. Families with children older than 8 years of age who are considering Summer Camp are also encouraged to attend Family Camp so they can familiarize themselves with the site, staff and program. Six Family Camp sessions are conducted in English and two are conducted in Spanish. The weekend- long camp is designed to be fun and

supportive for all members of the family. Parents and children engage in activities that encourage teambuilding and bonding. Families form new bonds, find new support systems and build friendships and relationships that last during their child’s treatment and beyond. Whether a child has an amputated leg, is using a wheelchair or walker, or has compromised vision, staff and volunteers are trained to ensure everyone can participate in camp programming. Activities at Family Camp include: archery, basketball, soccer, hiking, fishing, arts & crafts, nature exploration, music/dance, and more. The goal of our Family Camp program is to create a sense of community and belonging among families living with childhood cancer.

As a result of attending Family Camp, we intend to impact families in the following ways:

1. **Families reconnect and reestablish a sense of normalcy.** Family Camp allows families to get away for a weekend for what serves for many as the only vacation they take each year. Families have time to relax, rebuild and strengthen family bonds. They are provided opportunities to return to a sense of normalcy – play, laugh, eat meals, and talk together again – to participate in everyday activities that were put on hold during treatment.
2. **Families build relationships and support networks with other families.** Family Camp allows families to meet other families going through the cancer journey – some on the same road, some where they once were, and some where they hope to be one day. Families connect with one another, build long-lasting friendships, and develop relationships that serve as peer support networks they lean on after Camp is over.
3. **Families are informed and empowered to move forward in their cancer journey.** Family Camp allows families the opportunity to be part of a safe and supportive environment where questions and conversations are welcomed. Volunteer counselors facilitate safe and engaging activities where kids

are allowed to be kids again, and where parents can see firsthand the benefit of Camp in the lives of their children. Parents are given the time to meet with other parents and staff to ask advice, share resources, or express successes and challenges around their cancer journey.

Evaluation Methodology

The aim of our evaluation was to see what kind and quality of impact Family Camp is having on the families that attend. To understand this, we explored two broad research questions:

1. What kind and quality of impact are we having on families with children facing cancer?
2. What aspects of our program are causing this impact?

Over the course of the project, we (a) developed and refined our ideas of intended impact and indicators, (b) designed and implemented a mixed methods outcome evaluation using both qualitative and quantitative means to collect and analyze data, (c) identified findings, and (d) considered the implications to those findings for program improvement and innovation.

This project began with a focus on the work of identifying and clarifying the intended impact of Family Camp. Once the ideas of impact had been developed, we used the Heart Triangle™ model to identify qualitative and quantitative indicators of impact focused on the mental, behavioral and emotional changes families experience that indicate we are achieving our impact. We then used these indicators to design a qualitative interview protocol and a quantitative questionnaire to measure our progress toward achieving our intended impact.

Qualitative Data Collection and Analysis

For the qualitative portion of the evaluation, we designed an in-depth interview protocol to gain data about the structural, qualitative changes resulting from our program. We used a purposeful stratified sampling

technique to select a representative sample from the population we serve. Our population size was 121. Our sample size was 12 and we drew our sample from the following strata of our population:

- Families who attended Family Camp in 2018
- Families who attended Family Camp one or more time with the last two years

Our interview team consisted of Camp Ronald McDonald for Good Times' Executive Director Fatima Djelmane Rodriguez, Development Director Marlene Stang, Program Director Chadwick Edwards and Program Associate Shannon Edwards.

We then convened one-on-one interviews lasting from between 45 minutes and one hour in length with a sample from the identified strata of the population. Interviewers took notes during the interviews and filled in the notes immediately after the interview to obtain a substantive rendering of the interview.

We analyzed the data inductively using a modified version of thematic analysis. Interviewers implemented the first three phases of thematic analysis (becoming familiar with the data, generating initial codes and identifying themes) for each interview. The interviewers familiarized themselves with the data by reviewing the data from each interview four times, each time thinking through a different aspect of what the data reveal about the research question. The data were then bucketed into four categories to serve as an initial set of codes. Finally, initial themes were generated based on the pervasive insights from the data. This process allowed us to interpret the meaning and significance of the data from each interview.

Next, we brought all of the data analyses and initial themes together and implemented the next two phases of thematic analysis (reviewing themes, defining and naming themes). We reviewed the initial themes as a team to identify the overarching themes that emerged from the full scope of our data analysis to illuminate the collective insights and discoveries. We mapped these themes visually and examined them in

various ways to gain greater definition of the features of the themes, causes and catalysts of the themes, new or surprising insights related to the themes, and relationships between the themes that were revealed in the data. We then determined the most significant and meaningful discoveries and brought them forward as findings to be described in the final phase of thematic analysis, this report.

Quantitative Data and Analysis

For the quantitative portion of the evaluation, we designed a questionnaire to collect data on our quantitative indicators of impact. We administered this instrument via Survey Monkey to 121 families that had attended Family Camp one or more times within the past 2 years and received a response from 21 families, a 17.35% response rate. The data were analyzed primarily using measures of central tendency. We identified key insights, patterns, and gaps within the data and incorporated these discoveries into the related findings.

The most significant discoveries from this evaluation are described in the findings that follow.

We narrowed our study to focusing on the impact of Family Camp for the families we serve. For the qualitative portion of the process, we interviewed a total of 12 families both in person and over the phone. We focused on families that have attended Camp at least twice to better assess Camp's impact over time. Interviews were conducted by Camp's Executive Director, Development Director, Program Director and Program Associate. Data from the survey has been folded into our findings from the qualitative interviews.

Findings

Finding 1: Game Changers

Key Insight: Camp Ronald McDonald for Good Times is a place where families first encounter other parents and volunteers who can share life-changing resources for their children and their families.

Description

The data reveal that for a lot of parents Family Camp is the first time they hear about resources to support their child and family. Being catapulted into the medical world is daunting for every family we spoke to and is especially overwhelming when they are also dealing with the emotional trauma of having a newly-diagnosed child. Even for families who have access to more resources and a formal education, the data showed that families were all exposed to new information and resources when they came to Family Camp.

When families were asked “What are the three most helpful new resources that you learned about at Camp?” on our quantitative survey, answers provided by our survey respondents ranged from the practical (i.e. “How to request a ‘child life’ worker at hospital in-patient visits.”) to program-based resources like “Capes and Crowns” (a non-profit that provides one-of-a-kind fantasy photo ops to children with illnesses) and “The Sunshine Kids Foundation” (a non-profit that provides meaningful group activities and emotional support to children with cancer.)

In our interviews, many parents described a variety of resources they discovered through attending camp. One parent learned that Camp could connect her and her family to Family Support Services (FSS, a therapy program offered at the Ronald McDonald Houses), so now she's going to look into it utilizing this service. Another family also learned about the Ronald McDonald House Charities of Southern California Family Support Services through Camp and have told others about the benefits of the resource for them as parents and for their children. One parent shared, “The medical western health system is not taking a holistic approach to healing. They don't look at the whole body, just the diagnosis. The psychological ability to move on in the world is difficult, but FSS and Camp help alleviate that for us.” For one of our parents, Family Camp was the first time they learned of resources to help with their son's struggles in school. They shared, “I heard about the 104 plan and IEP. I had no clue about

all that before Family Camp. [Thanks to Camp], I was able to get [my son] more time. We just got a 104 plan set up, so that he can do better.”

Significance

The data revealed that Camp is a valuable place where families learn new information and gain access to resources. This is significant because families may not receive information about resources for remission and survivorship from their medical providers, whose primary concern is treating disease. We also realize that families need ongoing support outside of Camp as well so that they can continue to be informed of and connected to more holistic resources. What this would look like (a bricks and mortar facility or online support network, for example) requires further discussion. The cancer journey does not end at remission, so resources and support are needed throughout the child’s life.

Possible Responses

- Create an online forum for parents.
- Add a resource tab to our website.
- Provide families with a resource binder when they first join Camp.
- Include a resource corner in family newsletter that is distributed currently.
- Host quarterly family meetings at the RMHCSC houses as an additional touch point for parents.

Finding 2: Cancer Unites Us

Key Insight: Regardless of race, gender, sexual orientation, or socioeconomic status, our campers are able to find common ground in their cancer journeys.

Description

Interviewees across the board shared that Camp is a place where their children are able to leave their diagnosis at the door and just

be themselves. Cancer gives the children and families a seemingly instantaneous bond even though many of these children and families would not necessarily interact with one another “down the mountain” due to their various differences. As one of our parents put it, “Families at Camp just get it.”

In our quantitative survey, parents responding to the question “How many new families in similar situations as yours did you meet at Camp?” the answers ranged from “1” to “over 100”; approximately one-third of respondents, however, stated numbers in the 5-10 range. From this we can deduce that although our respondents represented a diverse array of racial and socio-economic groups, at Camp they find common ground in their journey through cancer. Our quantitative data also indicates that a majority of families stay connected with one or more of the families they meet at Camp. In responding to the question “How many of those families have you connected with since Camp?” approximately 74% of respondents indicated 1 or more; only 26% indicated “none” or “0.”

A parent shared that Family Camp was the first time they met a family with a child who had the same diagnosis as her son. For this parent, this connection was significant in that it showed them they were not alone, that this could happen to anyone. As they shared, “Our connection with these families is priceless.” Another family, shared that Camp has reshaped their view of the LGBTQ community. Where they were once reluctant to commune with anyone who identifies as LGBTQ, they now embrace everyone they meet at Camp. In fact, they shared that their Camp experience was so transformative that they decided to leave their church because of the exclusionary doctrine (against the LGBTQ community) it preaches. Another parent, described how cancer unites their family to other families despite geographical distances. They shared that they regularly visit other families who live farther than 50 miles away from them to stay connected.

Significance

Given that cancer is a unifier, we see that creating a safe space for community and fellowship along the cancer journey is powerful. For the 26% of families who reported not staying connected to any of the other families they met at Camp, we have identified possible responses such as creating an online forum for parents and hosting quarterly family meetings at the RMHCSC houses as an additional touch point for parents (see below). While some might suggest that programming should be tailored to address the differences between campers, it's not necessary because campers feel relieved to be in a community where others understand their experience with cancer, regardless of other differences in their lives. Camp's role then is to create a culture of inclusivity where families are able to heal and return to a renewed sense of normalcy.

Possible Responses

- Check in with families who only come to camp once to determine why they've made the decision not to return.
 - Questions to these family would focus on ways to meet their needs better and probe to ensure they felt included and part of the community.
- Create an online forum for parents.
- Host quarterly family meetings at the RMHCSC houses as an additional touch point for parents.

Finding 3: What If? What If? What If?

Key Insight: Although navigating through childhood cancer/and survivorship creates stress and isolation, Camp creates a community of support and teaches families how to move beyond “what if, what if, what if.”

Description

As one parent explained, childhood cancer puts families on an emotional roller coaster. There are so many unknowns that can send

parents into a tailspin of fear. Camp provides parents and children with tools to remain present and focused on the moment. Program elements such as walking in nature, playing games, being disconnected from technology, and spending quite time together outside of the normal daily responsibilities gives campers an opportunity to practice self-care and mindful engagement in present activities as opposed to worried thinking.

Evidence of this finding was expressed when they shared their emotional distress at learning that their son's recent urine test revealed abnormalities. When they began to ask themselves, “what if questions,” they found grounding in their son's ability to calmly face their upcoming meeting with his doctor to discuss the test results. Their son expressed his own conviction that no matter what the results, they could handle dealing with them. This parent credits Camp with giving their son this ability to be confident and remain present without spiraling into worries about the future.

Though all of the families we interviewed expressed a significant decrease in stress during and soon after Camp, they did express the need for suggestions and ways to implement Camp activities that reduces stress into their daily family life. Camp is very effective, however, in helping families ease back into a normal daily rhythm even as they continue to face cancer. This is evidenced by the fact that in responding to the question “How true is the following statement? I am more confident in my ability to resume normal life activities as a result of camp,” nearly 52% of respondents answered “extremely.”

Significance

This finding is significant because Camp program elements instill mindfulness in campers which has a domino effect within families. Children are able to pass their stress reduction techniques to their parents and vice versa. This helps to reduce pain and isolation within families, so that no one family member is carrying their load alone.

Possible Responses

- Create a test workshop/presentation at one Summer Camp session and one Family Camp session provided by FSS where they focus on stress relieving/mindfulness techniques that can be used down the mountain.
- At Family Camp closing ask parents to share how they plan to take some of the practices they've learned and participated in at Camp when they go home.
- Provide families with a one sheet that gives ideas on integrating family unifying activities into their daily lives.
- Have families pair up and commit to one goal around mindfulness and one goal around family unity, share those goals with each other, and set a check in date when families will follow up with each other to hold each other accountable to those goals.

Finding 4: Where Healing Happens

Key Insight: Camp is as much a part of the cancer healing process as surgery, chemo therapy, radiation, and various other treatment modalities.

Description

Interviewees referenced suffering from Pediatric Traumatic Medical Stress and that though cancer is in the body of one child, the entire family is impacted by the disease. Not only must children heal from the cancer in their own bodies, but siblings and parents must heal from the trauma of diagnosis, treatment and survivorship as well. One parent shared that “Camp was where my healing process started,” since it was where they could first talk about their deepest, most intimate feelings. Our quantitative data suggest that Camp is instrumental in helping others discover a new comfort level in discussing aspects of their cancer journey. When asked the question “How much more comfortable are you with talking to other families

about your struggles, challenges, and fears since coming to Camp?” the largest percentage of respondents (just over 42%) responded “a lot.” And another parent shared that although their son missed years of schooling due to cancer treatment, his son is mentally and emotionally able to perform at grade level because of the confidence, advocacy skills, and determination he learned at Camp.

Significance

Our data reveal the importance of the mind body connection and the power of Camp to be a critical healing modality for children who would otherwise experience physical, mental and emotional developmental delays. Healing is equally important for siblings and parents who suffer from emotional and psychological trauma because of the cancer diagnosis and treatment since they serve as a child’s primary support network. When asked the question “How true is the following statement? Now that I’ve attended Camp, I am able to manage my daily stress levels,” only 4% of respondents said “not at all.” This is particularly noteworthy because in responding to the question “How true is the following statement? Before coming to Camp, I was able to manage my daily stress levels.” nearly 15% of respondents replied “not at all” – a much larger percentage.

The data show that the pediatric oncology community would benefit from recognizing the strong connection between the mind and the body as children and their families heal from cancer and using the camp modality as part of the patient and families’ care plan. Furthermore, toward this end, our volunteer doctors and nurses are at the front lines of taking their learnings from Camp and sharing them with colleagues to transform the practice of pediatric oncology within their field.

Possible Responses

- Further explore ways to formalize a medical volunteer ambassador program that helps promote the healing value of Camp.

- Create an awareness building campaign that shares the healing impact of Camp.
 - Social media focused 30 second videos that provide campers an opportunity to share how Camp has impacted their healing process.
 - Before and After posts on social media.
- Present at medical conferences to talk about how and why Camp is a critical part of the healing process.
- Identify medical researchers within our volunteer base who might be willing to assist us in publishing Camp's findings around how the Camp experience contributes to a child's healing from cancer.

Finding 5: Inspired Authenticity

Key Insight: The program inspires youth to discover and be their best authentic selves and teach others to be and do the same.

Description

The data reveal that campers are provided with tools and an environment that empowers them to build confidence, safely push past their fears, embrace their true selves and create space where others can do the same. One example given was by one parent who shared that their son had a new found confidence and an ability to advocate for himself in school. His teachers have in turn remarked that it is a pleasure to have him in class. Camper parent shared that they see a huge difference in themselves since coming to Camp. Here children are “leaders amongst their friends” and, as a result, they all have a “brighter future.” Their daughter, in particular has tried new sports she would otherwise not have tried and even advocated that she be given additional opportunities before being cut from team. Once she was cut from the team, her parent shared, “The ‘failure’ did not devastate her because at Camp she learned as long as you tried, that’s what counts. Camp did that for her.”

One parent shared that Camp has changed how she believes her son should be treated. The inclusivity that defines Camp's programming is now the gold standard for this parent and their family. When their now homeschooled son (do to his increasing physical needs), was not included in his 6th grade class' graduation ceremony, this parent contacted the principal and let them know this is not acceptable. They credit Camp with helping them realize what their son deserves and the importance of advocating on his behalf. Our quantitative data reveal that other parents have also discovered a newfound confidence in their ability to advocate for their children. When asked the question “How true is the following statement? I am a better advocate for my child and family since leaving Camp.” the largest percentage of parents (just over 40%) responded with “extremely.” And when asked the question “What is one thing you've done to advocate for your child or family since coming to Camp?” survey respondents revealed that their advocacy not only relates to their child's care (i.e. “Speak up more to doctors when I'm concerned about something”) but also larger systems change (i.e. “I've been less afraid advocating for the full cleanup of the Santa Susana Field Lab.”).

One camper parent shared that their son gains more confidence in himself each year by going to Camp. This parent said, “There's a comfort in knowing someone is always there for him. There is no other place he has in his life where he can be like that. He's starting to branch out and get more independent at Camp. He's gaining confidence that he's actually someone. The counselors care and make him feel that he is somebody – someone to actually care besides mom and dad shows he's actually worth it.” Our quantitative data reveal that the confidence that children gain at Camp even inspires their parents to push past their fears about sending them off to week-long summer sessions by themselves once they reach the age of 9 and graduate out of Family Camp. In responding to the question “Have you sent your child to summer camp as a result of having attended Family Camp?” the majority of respondents (nearly 60%) said “yes.”

Significance

The intentionality in which programming is implemented—from the vetting and training of volunteers to the inclusion of all campers in activities regardless of physical or mental abilities, to name a few—can be used as a model for other youth and family camps. One parent shared that they attended another camp with their son and found the difference notable. He wasn't included in many activities and had they not been present, he would have had a horrible time.

Possible Responses

- Explore partnerships with other nonprofit organizations to replicate Camp's model.
- Create a mentorship program where WOLPers or camper graduates support young campers to continue nurturing their growth and development once their down the mountain.
- Create a “spread the love down the mountain” tip sheet so campers have tools and examples of things they can do in their community to set an example for inclusivity.

Finding 6: Cancer is the Best Worst Thing

Key Insight: Because cancer led our families to Camp, it effectively opened their eyes to possibilities, areas of personal growth and a newly formed family. They credit cancer then for finding these blessings.

Description

The data reveal that families value the friendships they form with other families who are also experiencing childhood cancer. They also expressed how Camp was the first place where they felt an overwhelming sense of love, inclusion, and support. They have been amazed to witness remarkable changes within themselves and their children that they credit to Camp—many of them now see cancer as a hidden blessing as a result. Several families noted that their

biological extended family and friends disconnected from them when their child was sick. Camp became a home away from home and a place where many have formed new families and a support network. One parent stated, “We’ve been through crap. Some parents have lost kids, but we’re all on a journey together. We have such a strong Camp family and to be able to go to reunions and sit in circle and say hi and be together...it’s priceless. Those are our people.”

The experience of attending Family Camp also awakened many of our respondents to the importance of spending quality time with one another. When asked “How much more time do you spend together as a family each week since you came to Camp?” the largest percentage of respondents (just over 48%) stated 4-6 hours. Family Camp also sparks creativity and discovery within the family unit, as is evidenced by responses to the question “What new activities have you tried since Camp in order to spend quality time with one another?” Answers ranged from recreational activities (i.e. “card games, walks, chess, beach day, lunch out” and “we bought a bow and arrow set!) to forming more positive habits (i.e. “cell phone free time.”) In other words, families are not only adopting activities they practice at Camp into their daily lives, but they are also implementing Camp’s emphasis on eliminating distractions in order to be more present to friends and loved ones.

Significance

It was surprising to hear parent’s think of cancer as a blessing considering it is a disease that could end their child’s life and results in a life long journey of checkups, latent affects, and uncertainty. This finding underlines the human need for connection and Camp’s ability to foster and grow human connection. In a world that is increasingly disconnected because of our modern lifestyle (i.e. divisive politics, technology, time constraints, geographic boundaries, racial/social economic differences, etc.), Camp’s culture of unity is profoundly needed and life changing for our families who have added barriers because of childhood cancer.

Possible Responses

- Create a family ambassador program to help recruit potential new families.
- Create an online forum for parents.
- Add a resource tab to our website.
- Provide families with a resource binder when they first join Camp.
- Include a resource corner in family newsletter that is distributed currently.
- Host quarterly family meetings at the RMHCSC houses as an additional touch point for parents.

Steps Forward

The qualitative findings from our evaluation project were informative and inspiring. Camp is also undergoing a needs assessment process which this project will inform. Once we gather the data from the larger needs assessment, we will then determine programmatic changes, shifts, and/or additions we would like to make over the next five years to deepen our impact and best respond to the evolving needs of our community.