

Growing Hope by Cultivating Community Support:

Accessible, Long-term Fundraising for the Kosciusko Cancer Care Fund

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Abstract

The Kosciusko County Cancer Care Fund provides assistance for non-medical-treatment expenses for cancer patients and families. The Fund offers assistance in areas such as mortgage payments, utilities, food certificates, home repairs, lodging, and more, in sums in excess of \$175,000 each year. This assistance is vital for families facing mounting medical treatment costs for cancer that can reach amounts of \$500,000 or more over the course of the disease. In addition to exceptional medical treatment costs, more than 12% of Indiana's population does not have health insurance. The costs of treating cancer can create a significant financial burden for anyone, leading to unpaid bills and a lack of funds that distract a patient from healing properly and seeking necessary treatment. With increasing demand for assistance, we propose ideas for long-term, accessible fundraising opportunities to support the Fund in the future.

We propose the concept of "White Out Cancer" for a fundraising theme, which will represent all cancer types. Short-term ideas include the sale of white silicone wristbands and white "White Out Cancer" t-shirts, where all proceeds go directly to the Fund. We also propose a program promoting local children to save "Change for Cancer", donating collected change to the Fund and promoting Fund awareness. There are also opportunities for involving local businesses in a "round-up" program, rounding bills to the nearest dollar and donating the extra change, or offering an evening where a percentage of sales go back to the Fund. Long-term, we aim to explore housing for cancer patients visiting Indianapolis and a community fundraising event. To promote prevention and Fund awareness, we will incorporate educational opportunities and screenings into each fundraising opportunity. If awarded the \$1,000 grant, those funds would support start-up costs and promotion for our short-term ideas.

A Personal Account

My name is Stuart Floyd. My wife, Heidi, and I have always pursued financial freedom. In Chicago, I worked as a computer engineer. By the age of 26, I became the Vice President of Technology for a hundred million dollar insurance company. In the spring of 2002, we felt so comfortable with our savings that I changed careers. We moved to Fort Wayne, Indiana, to follow my dream of becoming a Christian minister.

As part of the program, we served a one year residency in a local church. In the Fall of 2004, I was serving in Lockport, Illinois, when my wife surprised me with some news. She thought that we were expecting a child. She set up an appointment with her doctor to confirm it. While at her doctor's office, she told the doctor that, though, it is probably nothing, she found this lump. The doctor confirmed that, indeed, there was something good growing inside of her. She was pregnant. The doctor also established the fact that she has something bad growing inside of her; an aggressive, malignant tumor.

Through some serendipitous guidance and direction, Heidi found a doctor at the Simon Cancer Center in Indianapolis, Indiana, who treated her and our baby son, Noah. They were one of a handful of research hospitals in the country who had a new and life-saving form of chemotherapy that would not break the placental wall or harm the baby in any way.

Six years later, our son, Noah, is a survivor. He made it through the flood of chemotherapy. My wife, Heidi, now works at the Vera Bradley Foundation to raise money, and I am happy to serve the community of Warsaw as a Christian minister. However, none of this would be possible if it weren't for the financial contributions of hundreds of people. Within the first year, Heidi had a round of chemotherapy, two surgeries, radiation treatments, and much

more. The total cost exceeded \$250,000. Even with medical insurance, our savings was wiped out.

In no time, we went from a savings surplus to receiving daily reminders of our debts from creditors working on behalf of medical personnel and hospitals. At one particularly low point, I decided to quit and go back into the computer industry to support the family. That week, I received a check in the mail and a note from a community support group in my hometown. They had been baking noodles and selling them for over a year. They heard about our situation and wanted to support us. That \$10,000 check completely changed the course of our lives. It was just enough to buy food for my family and pay utilities for the rest of the year. Even more importantly, it let us know that people cared.

Our total costs now exceed half a million dollars. Few, if any of us, could do this on our own. Community support groups like the Kosciusko County Cancer Care Fund do so much more than provide funding to people who are fighting for their lives. They provide hope. Without the support of a Fund like the Kosciusko County Cancer Care Fund, we would not be where we are today. They change lives.

The Cost of Cancer

Treating cancer places a significant cost burden on any individual or family, regardless of insurance coverage. According to the National Cancer Institute's 2007 Cancer Trends Progress Report, the total economic burden of cancer in 2004 was an estimated \$190 billion. The four most common cancers in 2004 were lung, breast, colorectal, and prostate. The average

individual cost of breast cancer treatment is \$23,078 in the first year of treatment, \$62,856 for the last year of life, and an average of \$2,207 per month for all other times. The average individual cost of lung cancer treatment is \$60,709 for the first year of treatment, \$93,921 for the last year of life, and an average of \$7,861 per month for all other times. The average individual cost of colorectal cancer is \$51,570 for the first year of treatment, \$85,095 for the last year of life, and an average of \$3,877 per month for all other times. The average individual cost of prostate cancer is \$19,710 for the first year of treatment, \$62,242 for the last year of life, and \$3,201 per month for all other times (National Cancer Institute n.d.). Oftentimes, cancer treatments extend over long periods of time, leading to mounting medical costs.

While insurance coverage helps off-set medical expenses for many individuals, not everyone has the privilege of coverage at the time of diagnosis. In Indiana, between 2008 and 2010, the number of individuals without insurance coverage was 813,000, representing approximately 12.8% of the state's population (U.S. Census Bureau n.d.). The trend of insurance coverage has continued in a negative direction from 2007 – 2010, according to the U.S. Census Bureau, with the number of uninsured individuals increasing 2.4% in that short timeframe. The National Cancer Institute also notes in its Progress Report that Medicare does not cover some cancer expenses, such as oral medications commonly used to treat breast and prostate cancers. The additional out-of-pocket costs for such Medicare recipients can amount to an additional 10% of expenses above the average individual treatment costs (National Cancer Institute n.d.). As demonstrated by these statistics, the medical care required for cancer treatment alone is a significant financial burden, thus creating a growing demand for the services of the Kosciusko County Cancer Care Fund.

An Understanding of the Kosciusko Cancer Care Fund

The Kosciusko County Cancer Care Fund (KCCCF) was established in 1999 with the goal of raising funds to assist individual cancer patients residing in Kosciusko County (K21 Health Foundation n.d.). The Fund helps to ease financial difficulties so that cancer patients and their families can focus on recovery and treatment. Oftentimes, the spouse must also take time off of work to be a caregiver for the cancer patient, which can create financial difficulty for the family with mounting medical bills. In an interview with Cindy Knafel, KCCCF Board Member, we learned that her personal battle with cancer amounted to \$480,000 of medical bills, which would burden a family of any financial status. The Fund is administered by the K21 Health Foundation and is advised by an all volunteer committee. The Committee's mission statement is "We are dedicated to reducing the challenges facing cancer patients and their families by financially assisting them during their fight" (K21 Health Foundation n.d.).

The KCCCF supports families of all classes and backgrounds, and it serves patients undergoing treatment for any type of cancer. The areas of assistance offered by the fund are: Rent/Mortgage, Utilities, Food Certificates/Supplements, Prescription Medications, Car Payments/Rentals, Gas Certificates, Health/Life Insurance, Screenings, Car Insurance/Repairs, Wigs/Prosthesis, Home Insurance/Repairs, Lodging, and other miscellaneous expenses (K21 Health Foundation n.d.). The Fund essentially supports all of those expenses that exist outside of the medical treatment setting. According to Knafel, the K21 Health Foundation approaches each patient and family by asking "What would you like us to pay?" K21 is conscious of patient and family needs and will utilize funds wherever they are needed for that individual family.

They do not budget capped amounts of funds for individual types of assistance, because each family's need is unique and unpredictable.

Since its inception, the Fund has paid out more than \$1.5 million to more than 1,000 families of all classes and backgrounds. In 2011 alone, the Fund distributed \$179,072.55 to 110 Kosciusko County families. Based on 2011 figures provided by the K21 Health Foundation, 90.7% of the Fund payments were applied toward rent/mortgage (54.0%), utilities (22.6%), prescription medications (5.2%), car payments/rentals (4.7%), and gas certificates/transportation costs (4.2%). The fund has supported up to 18 different communities within Kosciusko County, and it served 11 of those communities in 2011. The most highly supported communities in 2011 were Warsaw (62.0%), Winona Lake (8.4%), Silver Lake (6.6%), Leesburg (4.7%), and Claypool (3.8%) – amounting to 85.5% of the total funds dispersed that year. Exact figures and dollar amounts are provided in Appendix A (K21 Health Foundation 2012).

A reserve is maintained to allow for overages, and it was dipped into in 2011 (C. Knafel, personal communication, January 31, 2012). When asked about the Fund having enough supply to meet the demand, Knafel explained that there are many “deep pockets” within the community who care about the Fund and likely would not let it run dry; however, without those individuals the Fund may be at a fringe point for having the financial capacity to meet the increasing number of demands. Since 2005, KCCCF payments to families have increased an astounding 226%, from \$79,165.34 to \$179,072.55 (K21 Health Foundation 2012). Frugality is important to the Fund and KCCCF Committee. 97% of funds raised go directly to “hope” – providing direct assistance to families. Only 3% of funds raised are utilized for administrative

and printing costs (C. Knafel, personal communication, January 31, 2012). Low administrative costs are made possible, because the Fund is administered by K21 Health Foundation.

Current Committee Fundraising Efforts

The current KCCCF Committee diligently raises money to support the on-going efforts of the Fund. Currently, a significant amount of their fundraising comes from annual Gala & Golf Benefit and Idol Nite events, in addition to living trusts, corporate support, individual donations, and more (C. Knafel, personal communication, January 31, 2012). While these two annual events are incredibly successful in raising funds, they are also higher-dollar opportunities to give. Our group identified a lack of accessible funding options for those wishing to donate to and support the Fund in smaller ways. Our group also recognized the significant impact a large number of small donations could have on the Fund. With anticipated increased demand for KCCCF assistance, additional avenues for funding should be explored that reach a larger number of citizens. Many Kosciusko County citizens are not aware of the KCCCF, or how it works, making public education is a key component of future fundraising efforts.

Short-term Opportunities for Community Support

Our biggest obstacle is awareness. How many people are aware that there are agencies out there that are willing to help when needed to provide financial, emotional, or physical support? The

problem is agencies such as the Kosciusko Cancer Care Fund cannot do provide this support without the help of the community, largely through fundraising.

A fundraising idea that seems to be quite popular is selling silicone wristbands. We have all seen the different color bands on peoples wrists representing specific causes. Since there are numerous colors representing the wide spectrum of cancer, we felt it appropriate to have one color to represent all cancers, white to “White Out Cancer”. The wristbands can be purchased for \$1.00 each and sold for \$3.00 each, therefore raising \$2.00 to the Kosciusko Cancer Care Fund per sale.

By talking to area schools and businesses like Martin’s Supermarket we could set up a small area that could be used to advertise the wristbands and possibly even white t-shirts with the words “White Out Cancer”, to represent cancer of all kinds. While selling those items, we could also have a mobile mammogram opportunity set up and pamphlets available to make people aware that not only is cancer out there and annual physicals are important, but we can also make them aware that there are services out there for those in need and how to find those resources for help.

Another fun idea is “Change for Cancer”. How many of us go to the store and get change handed back to us and we just throw it into our pockets or purse? Instead, individuals can be encouraged to throw it into a bowl at home and save the change to help the Kosciusko County Cancer Care Fund. This is also a fun idea for young people to help. How many of us have heard our children say, “that sounds great but what can I do to help, I’m too little?” Kids can help and feel like they, too, are “growing hope” by adding their loose change that they may find in couch cushions, in car seats, or on the floor into a container in their room or in their classroom at school. The children involved could proudly carry deliver the container to the Kosciusko County Cancer Care Fund administrators to show that they would like to give their money to help give someone the hope they need. If awarded the \$1,000 grant, we could purchase containers to put in the schools for the kids to put their loose change

in. It may help these kids to understand that they too can help “Grow Hope by Cultivating Community Support”, since they, too, are an important part of the community.

Along with the “Change for Cancer”, we could work with the local businesses (supermarkets and restaurants) to implement a “round-up” program, where your bill or purchases is rounded to the next dollar, and the rounded change is donated to the Kosciusko County Cancer Care Fund. We can also try to encourage area restaurants to participate in what is called “Give Back Nights”, where on a certain day/night of the week they will take a percentage of sales and donate it to a cause. A couple of the restaurants in town, Ruby Tuesday and Hacienda, already have such programs.

Long-term Opportunities for Community Support

Many of us know someone who has had to be away from home for an extended period of time, due to either them or a family member’s extended treatment for cancer. The cost to that person or family can become overwhelming, as they have to not only travel (if it is a distance away), but also pay the hotel cost for an extended stay.

One long-term idea that we discussed was purchasing a home, or even building one, through a program similar to Habitat for Humanity. It would be a home where the patient and/or family members may stay while they or their family member is seeking advanced cancer treatment. In one of the rooms, we could have a memorial wall where people can sign either their name or loved ones name, or write a little something in memory of them. The obstacles with this, of course, is the expense of either buying or building the home, the insurance coverage, who will manage the property, and who will maintain the home. This idea would require the partnership of a long-term, significant community funder.

Almost everyone loves to go to concerts. Another long-term idea we discussed was a concert to benefit the Kosciusko Cancer Care Fund. We could even incorporate a 5k run and children's activities to make it an all day event and end with a concert in the evening. We could either charge one fee for everything or charge individually for the 5k run and the concert. We could also set up booths offering tests for different cancers and have pamphlets available for people to remind them of the importance of yearly exams. Of course there are a few obstacles with this, also. We would need to address where this would all take place, the cost of the band (unless an artist would perform for a low cost or for free), and advertisement.

In either case, these ideas will take more time, effort, and funding support to accomplish. With the help of the community and individual leaders, they are not impossible. After all, the best way to spread the word is through contacts, and who better to get the word out than the leaders of the community, including KLA members past, present, and future!

The Importance of Education in Fund Raising

We can all see from the personal story and the financial information above that fundraising is essential. However, as a group, we would be remiss if when raising funds we did not provide education to Kosciusko County residents on cancer prevention, screenings for early detection, and counseling for cancer patients and their loved ones. So many lives could be changed if they never got the diagnosis of cancer, or their cancer was found early, decreasing treatment needs and increasing chances of survival.

Cancer prevention starts with a healthy diet and lifestyle. The American Cancer Society pamphlet *Choices for Good Health* states "It's true: A diet and physical activity help reduce cancer risk." Oh no, all those things your Mom told you growing up are true! You should eat your vegetables! Sitting in front of that TV/computer is not how you should spend your day. Go outside and play! (But wear

sunscreen and a hat.) Oh, and smoking is bad for you! I know that last one is a big one for those that smoke. The American Cancer Society Pamphlet “When Smokers Quit”, talks about benefits of quitting. Did you know 20 minutes after you quit smoking that your heart rate and blood pressure drop? Twelve hours after quitting your carbon monoxide level drops to normal? Two weeks to three months after quitting, your circulation improves and your lung function increases? One to nine months after quitting, your coughing and shortness of breath decrease? One year after quitting, the risk of heart disease is halved? Finally, ten years after quitting, the lung cancer death rate is about half that of a continuing smoker?

Early detection decreases the treatments needs and increases the chances of survival, sometimes by up to 50 percent. Wow, why wouldn't we all go to the doctor and get screened for thing like skin cancer, breast cancer, cervical cancer, prostate cancer and colon cancer? We are afraid, unaware, or just too busy. Did you know that the Warsaw Cancer Center offers free skin cancer and prostate cancer screenings? Did you know that the American Cancer society has numerous pamphlets on screening and its benefits? Did you know that colon cancer begins with a growth (polyp) and that most people who have polyps removed never get colon cancer? There are so many “Did you know questions we could ask”. We believe that education about what screenings are available, where to go to get these screenings, and why you should get these screenings, should be an essential part of our fundraising awareness opportunity that will also draw attention to the Fund..

Counseling opportunities are also important. Patients and their families go through infinite changes. They deal with fear, anger, loss of income, loss of lifestyle, and the unknown. Talking with a counselor, talking with other cancer patients, and talking with other families all promote a more positive and healthier patient and family.

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