

## **I. Executive Summary**

### **Introduction:**

Terminally ill children and their families spend numerous hours in a hospital room, trying to preserve as many memories as they can in their final days. In order to address the struggles of these children and their families Manchester Memorial DECA decided to organize a community service project to assist these families. We learned of a program called "Pages of Gold" from a community member, and after looking into it we knew this was a project we wanted to contribute to. "Pages of Gold", is a non-profit organization that develops scrapbooking kits to distribute to families of terminal children at Boston Children's Hospital. The memories families are able to preserve then become "Pages of Gold". The organization was started in honor of a boy, Matthew Newnan, who died from the complications of Microvillus Inclusion Disease in 2007. In order to honor their son the Newnan family put together a scrapbook of the memories they had of Matthew. Throughout their own healing process they realized how crucial this program was.

### **Description and Purpose of Project:**

The goals of our "Pages of Gold" Community Service Project were as follows:

1. To raise awareness of "Pages of Gold" and the Boston Children's Hospital
2. To raise \$500.00 for "Pages of Gold", and collect enough scrapbooking materials to make the program available to 25 families this year.
3. To make an impact on the lives of families with terminally ill children at Boston Children's Hospital.

In order to ensure our goals were achieved we planned to do the following:

- Organize a mass collection of scrapbooking materials throughout Manchester Memorial High School and the Manchester, NH community
- Promote "Pages of Gold" with posters and flyers at Memorial High School
- Host a school bake sale to raise money
- Plan a Teacher Dress Down Day to raise money and awareness

### **Project Organization and Implementation:**

In order to raise awareness of "Pages of Gold", we utilized a number of advertising mediums. We hung flyers and posters in our school to promote "Pages of Gold". We then placed a collection box in our school store where people could drop off donations. The amount of materials donated was incredibly overwhelming. It was amazing to see just how much our community stepped up to help. Along with donations of scrapbooking materials we received \$96.12 in monetary donations. Our first fundraiser was a bake sale; Memorial DECA members donated baked goods to sell and helped to run the bake sale. At the end of the bake sale we made \$267.73. The second fundraiser we held was a Teacher Dress Down Day, each teacher made a \$5 donation and was able to dress down. As a thank you they received a gold ribbon to wear for the day which is the symbol for childhood terminal diseases. They also received a handmade thank you card. We made \$365.00 at the end of the Dress Down Day.

### **Conclusion**

At the end of our community service project we collected over \$4,000 worth of scrapbooking materials and \$728.85 in monetary donations to donate to "Pages of Gold". We truly feel our DECA chapter exceeded our goals. With the contributions we brought down to the hospital it brought tears to our eyes to see just how much we had helped. We are confident our chapter has brightened the lives of families with terminal children at Boston Children's Hospital.

## **II. Introduction**

### **A. Historic background of the selected community service or charity**

The Newnan family of Chester, New Hampshire sits together looking through a scrapbook. This scrapbook however is not just any scrapbook, It is a commemorative book placed together in honor of their late son Matthew Newnan. As they sit and look through the book they are reminded of all the good times they had with their son while he was alive. It is a collection of memories from his life that fill up his scrapbook.

“Pages of Gold” is a non-profit organization started in honor of Matthew Newnan, a boy who died from the complications of Microvillus Inclusion Disease in 2007. “Pages of Gold” collects and organizes scrapbooking materials to make scrapbooking kits to give to families of terminal children at Boston Children’s Hospital. The memories families are able to preserve in turn become “Pages of Gold”.

To further more your understanding of “Pages of Gold” and how it came into existence below is the story of Matthew Newnan, the driving force behind the “Pages of Gold” organization:

In 2003, a Christmas donation and a simple wish came together to create a program that would affect a lifetime. The Child Life Specialist assigned to Matthew’s medical program was told to spend money on anything Matthew might need. The daily mission of the Child Life Program is to improve the experience of the children at the hospital by teaching coping strategies and through special activities, by doing so they can create special memories. Kirsten Fowler, Matthew’s specialist, decided to use the money to buy scrapbooking supplies. During every visit

the Newnan family was given the opportunity to scrapbook the activities they did, from playing in his room, to going to the garden, to Children's Family Day. When Matthew died from the complications of his disease in 2007, the Newnan family asked everyone touched by Matthew's life to send them their memories of their son in a story, letter, or a scrapbook page. These memories became the Newnan families "Pages of Gold".



Matthew Newnan was born in March of 1999 with Microvillus Inclusion Disease, a very rare genetic defect of the small intestine that prevented Matthew from being fed normally through his digestive tract. He had to be fed with IV nutrition called TPN. From the moment Matthew was diagnosed at two weeks of age, it was determined that he would need an intestinal transplant to even live through his first year of life. Matthew's fight for life was 24/7 as he awaited his transplant. It took no time at all for the TPN that sustained him to damage his liver beyond repair. Soon he needed a multi-organ transplant of his liver, small intestine, and pancreas.

At the age of 6 ½ months old, Matthew's health declined to the point where he had to live in the ICU until his transplant. By 7 months of age, infection and progressive liver failure had shut down his lungs and kidneys. Due to the fact that he was in multi-organ failure he was no

longer a candidate for the transplant. Within hours of this devastating news, The Boston Children's Hospital stepped up and helped Matthew by performing a procedure that could get him healthy enough for transplant. Matthew was in need of a procedure called total blood replacement. Clean blood was the only answer, blood free of the toxins that were shutting his body down. For three days Matthew received this replacement and his body was able to respond. Within no time Matthew was relisted on the transplant list. He received his transplant in January of the year 2000. Throughout his very short life he went through so much more.

The main problem he suffered after his transplant was infections of his central line. At 6 years old, two years after "Pages of Gold" was started, Matthew suffered his last struggle. It was discovered that his small intestine that was transplanted partially to his old one, wasn't working right. The Newnan family agreed to one last surgery that would completely remove the 16 centimeters that was left of his old intestine. This surgery was supposed to allow him to pass food through his stomach again. Something went terribly wrong however, everything had healed properly but his stomach could no longer process anything. His stomach was considered "dead". There was nothing left to do to help Matthew, the Newnan family decided to bring him home after six very long years at Boston Children's Hospital.

Matthew was able to stay home with the assistance of the PACT team at the Hospital; he would have at home hospice care. Matthew didn't have to visit the hospital at all in the last ten months of his life. This allowed him to enjoy himself enough to live a semi-normal life under very strict conditions. These last ten months of his life were full of good memories. These good memories fill up his scrapbook pages.

Matthew relied heavily on blood products, surgeries, machines and medicine; however it was the love he was given that kept him here for 7 years. Without the love and the help of the Boston Children's Hospital he would have never survived long enough to get through his transplant and to grow and become the delightfully funny little boy he was. Without the help he received, Matthew would have never been able to live and play, laugh or even go see a movie. Although Matthew was able to spend some of his life outside of the hospital, it was for very short periods of time. His last year of his life, at 6 years old, he was able to spend most of his time at home. There was nothing left for the doctors to do. Matthew died on February 22, 2007 after almost seven years of fighting to overcome the complexities of his disease.

The scrapbook that the Newnan family and Matthew made, has become so very important to them. The Newnan family knew that they had to do something, to continue "Pages of Gold" in honor of their son. They went to the hospital again in 2008 with one mission: to make "Pages of Gold" a real organization and to give other families the memories of their own children. The Children's Hospital of Boston, accepted the program and now officially backs "Pages of Gold".

This sadly is only one of the many stories of what goes on inside the hospital doors. Manchester Memorial DECA hopes that you are as moved as we are by Matthew's story. We hope you understand how crucial it is to preserve the memories of these children.

#### **B. Description of the local DECA chapter, school and community.**

**The Chapter:** Manchester Memorial DECA came into existence 6 years ago. It was started by Judith Johnson and has now become a well known organization throughout Manchester Memorial High School. Manchester Memorial DECA has approximately 175 members this school year, more than doubling our number of 74 members last school year. We