

# *St. Jude Patient Family Reference Resource*



*Finding cures. Saving children.*

## 16. Focusing on Hope

## Focusing on hope



The staff of St. Jude Children's Research Hospital believes that hope is essential to life. Hope can directly affect the well-being of young patients by helping them make the best of difficult moments.

It can also help them make some sense of having a serious illness. Dreams, wishes and goals point toward today or the future, and hope is what drives those thoughts. Without hope each day can seem uncertain or even scary. Having hope, for themselves or others, helps children and teens cope with hardships.

To help you and your family foster and maintain hope during this trying time, Patient Care Services and Behavioral Medicine offer this important section of the Patient Family Reference Resource.

"The nice thing about hope is that you can give it to someone else, someone who needs it even more than you do, and you will find you have not given yours away at all."

*Maya Angelou, author*

## What is hopefulness?

The St. Jude Hope Research Translation Team has defined hopefulness as a personal, comforting and sustaining belief that life has meaning even in difficult times. It is also a belief that something good can happen for you or for others. Hopefulness is inside each of us. It can be influenced in both good and bad ways by those around us. Suffering and feeling alone or unappreciated can make it hard to focus on hope.

**Some factors that help us to be hopeful include:**

- Believing in yourself,
- Trusting the good intentions of others,
- Faith in God, and
- Being close to others.



## Offering real hope

In 1962, the first patients admitted to St. Jude Children's Research Hospital were not expected to live. A part of their treatment was devoted to helping ease the physical and emotional pain of dying. By 1975, St. Jude could offer almost half the patients real hope of survival.

A major change occurred at St. Jude in the mid-1970s. Staff members moved away from an emphasis on how to best deal with death and dying. They chose instead to focus on finding the best means of promoting life and quality living.

**H**aving faith

**O**ffers us comfort and joy

**P**eople sharing a dream that their child will be cured

**E**verlasting love from all of us at St. Jude



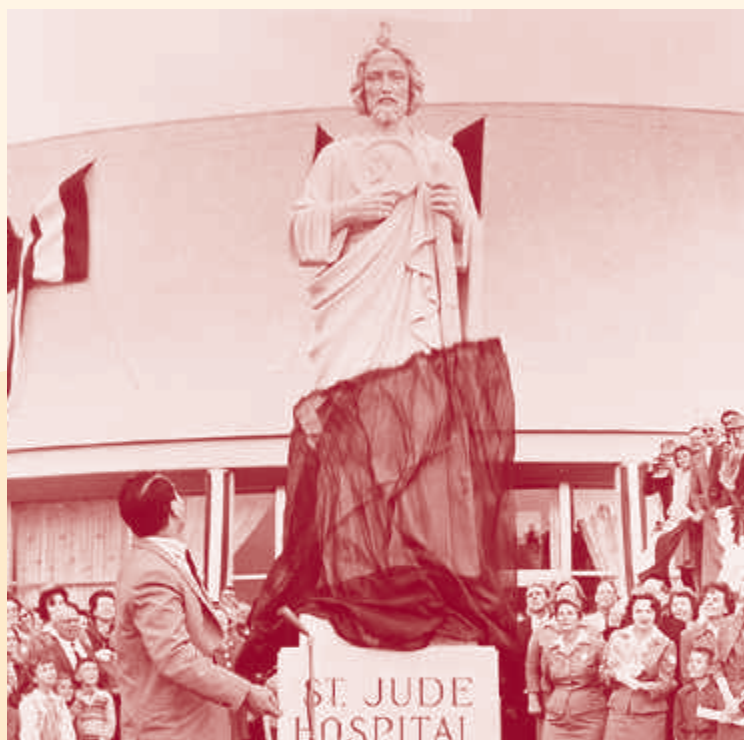
## The hope of one man's dream



“Help me find my place in life, and I will build you a shrine where the poor and the helpless and the hopeless may come for comfort and aid.” In the midst of the depression, a struggling radio actor put his last \$7 on the alter and offered this prayer on his knees in a Detroit church before a statue of St. Jude Thaddeus, the patron saint of hopeless causes.

Danny Thomas later built St. Jude Children's Research Hospital because he believed passionately that “no child should die in the dawn of life.” St. Jude staff members will continue to pursue this dream until every catastrophic childhood illness in the world has been eliminated.

To learn more about Danny Thomas' story of faith turn to section 14 of this notebook.



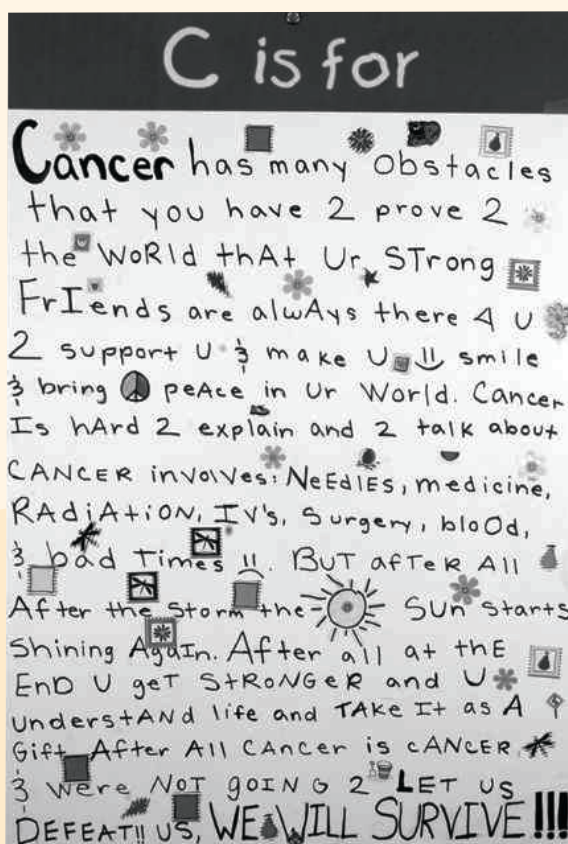


## Alphabet of hope

*An Alphabet about Kids with Cancer* was written by **Rita Bergland** after her 4-year-old son had been diagnosed as having brain cancer in 1989. Her alphabet is a book that explores the many emotions of families who have children with cancer. The book provides information on many topics such as living, dying, radiation and others that parents might find hard to explain to their children. The Children's Legacy of Colorado published the book in 1994.

Using the book as a model, St. Jude child life specialist Heather Haluska asked teen patients and their brothers and sisters to start their own alphabet. Since then, other patients not just teens have been writing and illustrating their own letters. A display of the alphabet can be viewed in the first floor of the ALSAC Tower near the cafeteria. The alphabet changes periodically with letters and art work created by new patients.

- A** aches
- B** body
- C** cancer
- D** dying
- E** exceptional
- F** feelings
- G** guilt
- H** healing
- I** intensive care
- J** joy
- K** kids
- L** living
- M** medicine



- N** needles
- O** operation
- P** parents
- Q** quiet
- R** radiation
- S** siblings
- T** transfusions
- U** understanding
- V** visualize
- W** wishes
- X** x-ray
- Y** yo-yo
- Z** zowee

## St. Jude Quilt of Hope

“Quilts, like diaries, are an accumulation of bits and pieces of the maker’s life, a repository of ideas, hopes and feelings.”

*Roderick Kiracofe, author*

The St. Jude Quilt of Hope is beautifully displayed in the Patient Care Center. The wall features 4 quilt panels with squares made by patients, survivors, staff, volunteers, and friends of St. Jude. Each square tells a story ranging from expressions of gratitude to sorrow. By viewing the panels you will see how the pieces gather to tell the “big” story of St. Jude. The St. Jude Quilt of Hope includes more than 50 panels, and all panels are rotated through the display. For more information, visit [www.stjude.org/quilt-of-hope](http://www.stjude.org/quilt-of-hope) or e-mail [quilt@stjude.org](mailto:quilt@stjude.org).



## Ways to encourage hope

### **In your child:**

- Find activities that keep your child in touch with friends and family—making a list of friends and family, writing letters, sending e-mail or calling them.
- Help your child manage anxiety by finding out how much he wants to know about his disease and treatments.
- Make time for fun—rent a favorite movie, go to a ball game, eat favorite foods, encourage play time, etc.
- Ask your child, “What are you hoping for today?”
- Ask your child, “What makes you feel the best?” Remember: You are your child’s greatest supporter.
- Encourage your child to take part in the treatment plan. For example, your child can help with making some decisions or help change the dressing on a Hickman line.
- Focus on your child’s abilities rather than disabilities.
- Help your child make friends within the St. Jude family.
- Encourage your child to keep doing schoolwork and to continue thinking about future education and career goals.





## Ways to encourage hope

### **In yourself:**

- Ask yourself, “What am I hoping for today?”
- Keep a daily journal or notebook. Each day, write 2 things that were good today and 1 hope for tomorrow.
- Learn about your child’s illness and treatment. It will help reduce your anxiety of the unknown.
- Remember to add some humor to each day. Laughter is a good cure-all for the “blues.”
- Seek support and make new friends within the St. Jude family.
- Make time for fun activities and pamper yourself—rent a favorite movie, go to a ball game, eat favorite foods, get a haircut, manicure or massage, etc. A short break can improve your outlook.
- Call the HOPE Hotline at ext. 4999 (495-4999) for a daily dose of hopeful insights.



## Resources for hope



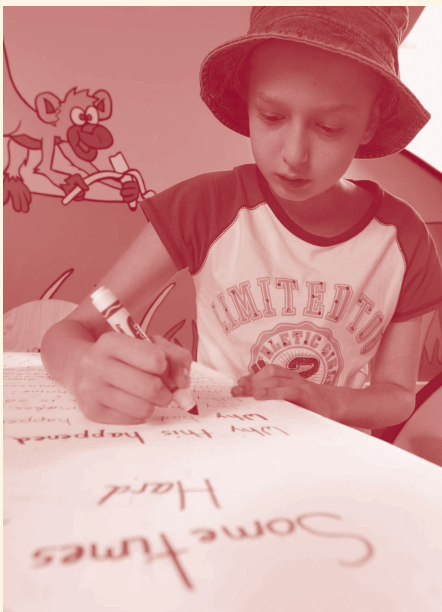
- Call the HOPE Hotline at ext. 4999 (495-4999) for a daily dose of hopeful insights.
- The Patient Care Center Chapel, located near the south waiting area (D section), is open 24 hours a day.
- The Danny Thomas/ALSAC Pavilion Chapel is available when the pavilion is open—Sunday through Friday, 8 a.m.–4 p.m., and Saturday, 10 a.m.–4 p.m. The pavilion is closed on holidays.
- The Danny Thomas Memorial Garden is located behind the pavilion and has the same operating hours.
- The Linda R. Hajar Family Resource Center, located on the second floor of the Patient Care Center, is open 24 hours a day.
- St. Jude offers an educational series of handouts for patient families called Do You Know. Ask your clinician for a copy of the Do You Know titled “Focusing on Hope.”
- If you need assistance with spiritual needs, ask to speak with a hospital chaplain or call Chaplain Services at 495-3672.
- Journaling books are for sale in the Patient Care Center Gift Shop, or you can just buy a small notebook to use for this purpose.



## Reflections of hope

### *St. Jude*

*By Hanna Haghayeghi, 11-year-old St. Jude patient*



*Hanna Haghayeghi*

When I first came to St. Jude  
I was really scared.

Then I met the doctors  
And I knew they really cared.

They said that the treatment would be really tough  
But I'm lucky because 6-8 months should be enough.

During my biopsy, the doctors had a scare  
soon I awoke in intensive care.

The nurses helped me when I was in pain  
They told me to keep still as they stuck my vein.

I had 29 pokes in just 2 weeks  
That was enough to give me the creeps.

Now I have a Hickman line  
And that is doing just fine.

Sometimes during my therapy I thought I might die  
During those times, I would scream and cry.

I have three to five months of treatment to go  
Although the treatment seems to go rather slow.

I can't wait until the day I get out  
When it happens I'll scream and shout.

St. Jude will always have a place in my heart.  
They have been there for me right from the start.

## Reflections of hope



*Lauren Nunes*

### HOPE

*by Lauren Nunes, 14-year-old St. Jude patient*

I am something that you seek  
When no one likes you and  
Your family thinks you're hopeless.

I am something that you seek  
When everyone is in despair and  
Everything goes wrong.

I am something that lifts you up  
When you are down and  
When you are ready to give up.

I am something that will never die  
And is with you wherever you are.

I am something that if you are only  
Hanging on by a string,  
I will pull you up.

I am something that if you have  
Led a bad life and want to change,  
I will redeem you.

I am a feeling.  
All you need to get through the tough times,  
I am HOPE.



## Reflections of hope

*Claire Reed wrote this poem soon after her frightened 9-year-old daughter learned that she had osteosarcoma, a type of bone cancer, in her left leg. "The poem was written for Shaina, but it was based on Shaina's feelings and thoughts. So it really is her poem, too," says Claire. Mother and daughter recited these words each night at bedtime until Shaina's disease went into remission.*



*Shaina Reed and her mother, Claire*

### ***Side by side***

Side by side  
Mommy and me—  
Together we'll get through this,  
Just wait and see.

Mommy stays with me  
Day and night.  
I'm not afraid  
'Cause it'll be alright.

Side by side  
Every day we pray  
That things will get better  
And go my way.

Cancer is a mean  
And ugly cell.  
Chemo will kill it,  
And make me well.

I miss basketball  
And cheerleading too.  
Shopping at the mall  
And going to school.

Someday I will run  
And jump and play.  
There is no price  
That's too high to pay.

Side by side  
A lot of people do care.  
Side by side  
Good wishes we share.

Side by side  
One day at a time.  
Side by side  
It's gonna take time.

## Reflections of hope



*Katelyn Atwell and her mother, Sharon*

For the past two years,  
God has been closely monitoring me.  
For the past two years, he has  
used YOU to fulfill my destiny.

For the past two years, your looks of grave  
concern have changed to astonished delight.  
For the past two years, my eyes have gone  
from complete darkness to blessed sight.

For the past two years, tube feedings  
gave way to “real food” eating.  
For the past two years, I went from  
complete silence to the joy of speaking.

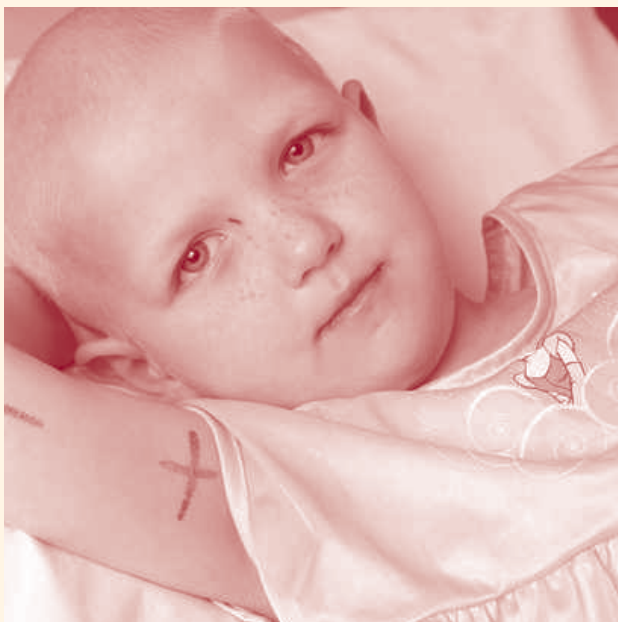
For the past two years, you have watched me  
go from lying to sitting,  
sitting to standing,  
standing to now taking steps.

For the next one hundred years I could never find  
the words to say “Thank You” for getting me  
through the past two years.

All my love

*Katelyn Atwell, 15-year-old patient*

## St. Jude Stories of Hope



*Makayla Woods*

### ***Makayla Woods***

February 23, 2001, was one of the worse days of my life. My daughter Makayla was diagnosed with Neuroblastoma. It's a type of solid tumor most commonly found on the adrenal gland. I had to make one of the biggest decisions that would not only change my life but my family's as well. We chose to come to St. Jude after being told it was the best place for Makayla to have treatment. When we arrived at St. Jude I finally realized she was facing a life and death situation that I had no idea about. Now, after 13 months of treatment my family and I have learned that all the advice we had gotten was right. St. Jude does wonderful work and has the child's best interest at heart. The doctors

and nurses work miracles in this hospital everyday. I can understand that the road ahead is unknown and no one can understand that feeling unless they have been there. I know that without Jesus we would not have made it through the good and bad days that cancer can present you. There will be good times and bad times down this road that is unknown but you have a very special child. All of these children are special in their very own way. You are in the very best place possible. Faith, hope and love will see you through it all. Take it one day at a time. Enjoy all of the days we have whether they are good or bad. Keep in mind that God didn't promise us a perfect life; just His perfect love.

Tucked in the *Bible's* wonderful passages of triumph and tragedy is a short but compelling piece that is turned to again and again to restore hope—*Psalm 23*.

You and your family are in our prayers,  
*The Makayla Woods Family*

## St. Jude Stories of Hope



### ***Sarah Johnson***

My name is Sarah Johnson, and I am from Peoria, Illinois. In August of 2000, I began my year as a high school freshman at Peoria Notre Dame High School. I led the life of an active fourteen year-old, maintaining good grades, hanging out with my friends, and playing my favorite sport, soccer.

During the week before I was diagnosed, I was feeling fatigued and had fevers at night. Now that I look back on that week, I cannot believe that I had been playing in a soccer tournament a week before I was diagnosed! I had no idea

that in a matter of days my life was about to change forever. On November 10 at the St. Jude Affiliate in Peoria, I was diagnosed with Philadelphia Positive Acute Lymphoblastic Leukemia (ALL). I was transferred to St. Jude Children's Research Hospital in Memphis on November 12 where I began treatment immediately.

When I first found out that I had cancer, I was shocked. The possibility that I would have cancer, especially at my age, had never crossed my mind. I was scared because I did not know what chemotherapy was at the time, and the only thing I knew was that cancer was a serious illness. The complex procedures that I would have to go through to be able to be healthy again were a mystery at that point. All I knew was that my life would never be the same.

I was never upset or mad at anyone for getting cancer, because I knew that God had a plan for me. I knew that, if anything, St. Jude was the best place for me to be. The first day that I was at St. Jude, the doctor came in to tell my parents and me about all of the side effects from the chemotherapy. It was at this point that I realized I could die, and I was very scared.



While it was very hard to hear the doctor talk about all the possible complications, I kept in mind that he had to mention everything from the worst to the best things that could happen. The next Sunday was my birthday, and I was still in the hospital. I was very excited because my sister, Amy, my aunt, and my uncle were coming to visit. That was the last fun day I would have for quite awhile. The chemotherapy itself was not that bad; the side effects were the awful part. After a while, I was sick of throwing up and feeling nauseated all the time, but I just kept telling myself that it was only temporary. I tried to maintain a positive outlook on things no matter how difficult they seemed.

During therapy, keeping in touch with my friends with phone calls and e-mail helped me through the hard times. It made me feel like I was still connected to home, even if it was only in a small way. I found out in December that after I finished my chemotherapy I would need a bone marrow transplant. Because I am an adopted Korean, the doctors started looking for an unrelated donor for me. I was very lucky that they found one match for me.

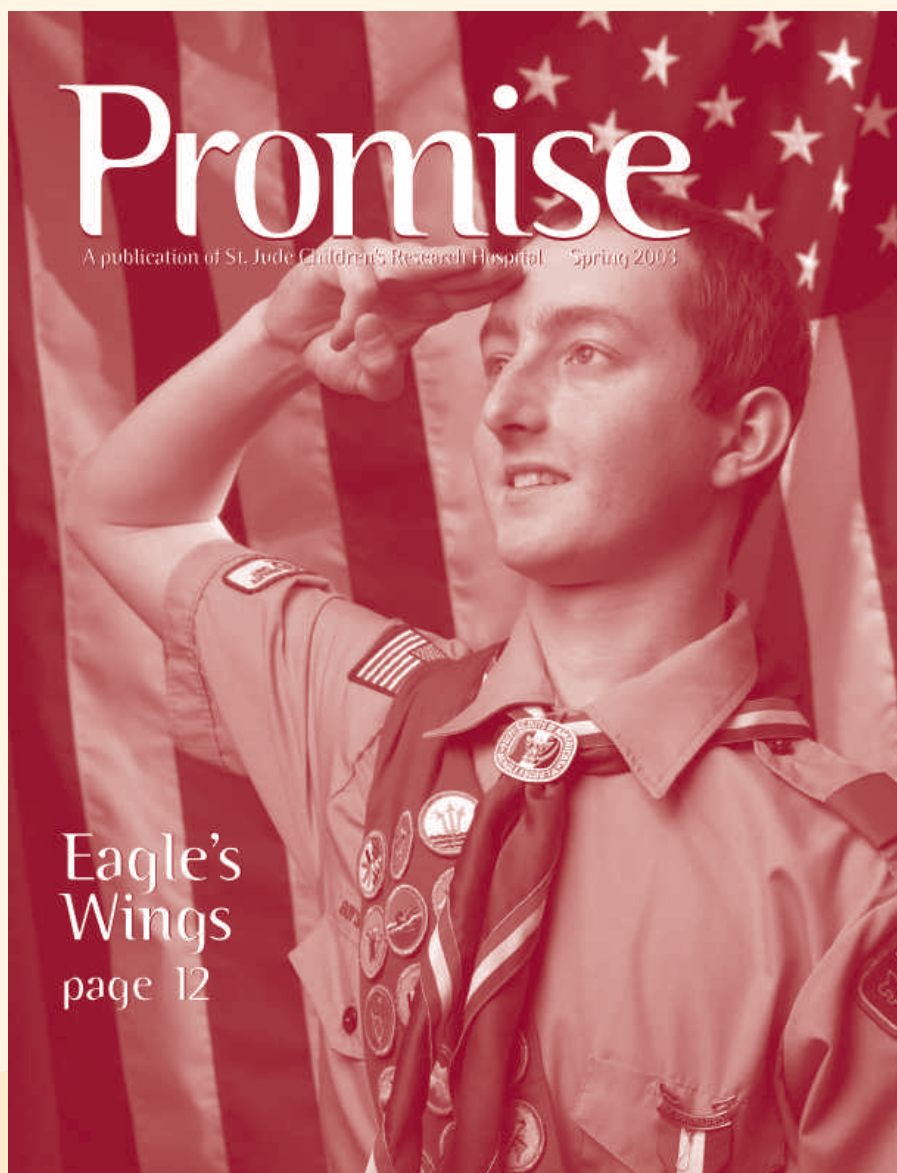
***“My battle with cancer has been an enlightening one, and now I am ready to start my new life cancer free.” Sarah Johnson***

On May 3, I was admitted to begin my high-dose chemotherapy and radiation to kill the last cancerous cells in my body. This process prepared my body for the bone marrow transplant. The transplant took place on May 11. After the procedure, all my family and I could do was hope and pray for a successful outcome. The days seemed very long, especially since I felt so awful. It was a very slow and difficult recovery from the bone marrow transplant, but I just took it one step at a time.

I am happy to report that shortly after Day 100 I was able to return home, thanks to the St. Jude Affiliate in Peoria. I know that I would not have been able to come home as quickly if it were not for the friendly nurses and doctors who gave personal attention to my well-being while in Memphis. Through this experience, I have learned not to take life for granted. I have realized that family and friends are very important to me, and that when life throws you a curve ball, you have to hit a home run. There are so many blessings in disguise out there. I would have never met all of my new friends in Memphis if I had not gotten sick. I also found it extremely important to be optimistic. I always found the brighter side of things, even when it was tough to find one. My battle with cancer has been an enlightening one, and now I am ready to start my new life, cancer-free.

## Stories of hope from *Promise* magazine

The St. Jude Children's Research Hospital Public Relations department produces a quarterly magazine for promoting the hospital to high level donors, corporate partners, peer institutions and national media outlets. *Promise* magazine is a showcase of the work performed at St. Jude. It always includes an uplifting and often inspirational patient profile. We have included some of these articles for your enjoyment.



## Your journal of hope

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## Your journal of hope

This image shows a full page of blank, cream-colored lined paper. It features horizontal ruling lines spaced evenly down the page. At the bottom, there is a decorative orange wavy border that spans the entire width of the page. The paper is otherwise empty of any text or markings.



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