Casey Kaplan has the 'power'

By DON HEPNER

For Casey Kaplan, cutting her hair off was a demonstration of self determination and power. She did it before chemotherapy treatments caused it to fall out. Not having hair doesn’t dampen the spirits of this vibrant eight year old with leukemia.

Casey, who lives in Pound Ridge, will appear in a film premiere on Wednesday, Dec. 5, at 7:30 p.m., called "Soaringwords: The Power to Heal" at the Hiram Halle Memorial Library.

Casey wears a pink hat with a fake ponytail that sticks out between the listing scrap and the curved back of the hat. If she is in one of her joking moods, she will lift the trim quickly, removing hat and hair, while she grins waiting for the startled reaction of the unsuspecting onlookers.

A customized picture Casey created adorns the masterpiece in the room used as her study. On the left, the montage features a picture of her before leukemia, in the middle, during treatment; and on the right, after the cure. The before-and-after pictures show Casey with a full head of hair. The middle picture is of her without her own hair. What might be the most significant aspect of those three pictures is how she sees herself "growing" during the creative process.

"I miss school," Casey says. "But I read books. I can read grown-up people"
Casey Kaplan featured in documentary film

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books.

Mostly, Casey reads the “Betsy” series of books. “I can read a book in one a day, except when chemos makes me tired,” she said.

Teleconferencing ability between her home and her second grade class at Pound Ridge Elementary School is not yet hooked up. “We have the computer, but no wires,” Casey said with a smile that eschews frustration. “The school has the wires but no computer. Isn’t that funny?”

Teleconferencing is an interactive system that would allow Casey to talk with her teacher as well as communicate with her classmates on a real-time basis.

“If nothing else, I hope the next child that needs teleconferencing will be able to get it because of what we’ve gone through,” Michael Kaplan, Casey’s father, said.

“I miss school a lot,” Casey said.

She does get to see her friends from school. “I have play dates, but I can’t see too many kids at one time,” she said. “If they even have a runny nose, I can’t see them.”

Until February, when she hopes to go back to school, Casey’s education is not suffering.

A tutor, Lynn Huber, one of Casey’s former teachers, visits the house four times a week for two hours each session. “We get as much done in eight hours as the kids in school get done in a week,” Casey said. “They take rug breaks and recess and play games and that stuff. Mrs. Huber and I work the whole time.”

One day a week is set aside for a visit to Westchester Medical Center. For most people, that day would be an ordeal, but for Casey it is a fact of life she accepts with dignity.

Casey and her mom, Hannelore, leave the house at 8 a.m. and arrive at the hospital about an hour later. Casey’s platelet count is taken to see if she needs a transfusion to boost her immune system. Bone marrow is taken from the hip, and the spine is tapped for fluid.

Tests are run on the fluids and bone marrow to see how Casey is progressing. Ms. Kaplan waits for the results. They return home by 6 or 7 p.m.

Some of the needed medical treatment are provided at home, including physical shots that Mrs. Kaplan has learned to administer. “A doctor who is a neighbor taught me how to give shots to Casey,” Mrs. Kaplan said.

Support systems

Through all the trauma caused by Casey’s illness, the Kaplan family seems to be very stable. But looks can be deceiving. “Having a child go through this is next to losing a child, the most devastating thing,” Mr. Kaplan said. “We are on hold.”

The future looks very, very positive for Casey, however.

“At her stage, the cure rate is about 99 percent,” Mr. Kaplan said with a broad grin.

Support systems are key to recovery process for patients and for helping family members through the crisis. The Kaplans have a system that works.

“We are so lucky to live in this community,” Mrs. Kaplan said. “There isn’t anyone in this community that hasn’t brought over a present or brought over food. It has been absolutely wonderful.”

Mrs. Kaplan said that Casey’s grandmother and aunt call every day. “Grandpa calls me, too,” Casey said. “He just a little bit crazy. Just a little bit. He’s always making jokes.”

Spiritual needs count

Medical needs for patients, in many cases, are well taken care of, but the emotional, spiritual and psychological needs created by an illness are often neglected. There is no theory that states a positive, if not joyous attitude can aid recovery from any illness.

Soaringwords, a new organization designed for patients and family members who are going through, or have gone through, what the Kaplans are experiencing, was founded about two years ago.

With a concern for the mental state as a part of the curative process and recognizing what might be an emotional void caused by a serious illness, Soaringwords was founded by Lisa Honig Buksbbaum, a successful executive from New York City who gave up a lucrative career to devote her energy and time to those children inflicted with illness and the families and friends of those children who are looking to take part in the healing process.

Ms. Buksbbaum comes to Soaringwords with a dedication and commitment derived from her own experience with the death and illness of her own family members.

Ms. Buksbbaum’s brother, Gary Honig, died from an asthma-induced heart attack. Soaringwords is dedicated to Mr. Honig, who, according to his sister, loved people and life.

In addition, Ms. Buksbbaum’s father successfully battled against non-Hodgkin’s lymphoma.

During her father’s illness, Ms. Buksbbaum’s mother created inspiring signs and brought them into the hospital to lift her husband’s spirits. According to Ms. Buksbbaum, the messages to her father might have been corny, but they were always loving.

The power of these simple messages was apparent and effective. She said, “They gave dad something to look forward to and made him feel loved.”

A significant aspect of Ms. Buksbbaum’s mother’s effort was the fact that they gave her a positive role in her husband’s healing and recovery process.

Almost a year after her brother’s death, Ms. Buksbbaum’s son, Jonathan, became critically ill with rheumatic fever. He went from a healthy active child to a child who was bedridden for four months. The Buksbbaum family was regaled with tales of who had recovered from rheumatic fever and gone on to live long and healthy lives.

“At the time, my husband, Jacob, and I were desperate to talk to parents whose children had recently recovered,” Ms. Buksbbaum said.

The support system for the Buksbbaum family was terrific. Many kids made cards, sent e-mails, videos and books to help Jonathan pass the time, she said. “Jonathan made a complete recovery, and we are launching Soaringwords.org in gratitude to God and to help others maintain their faith during difficult times.”

A premiere in Pound Ridge

On Wednesday, Dec. 5, at 7:30 p.m., Pound Ridge and its friends will be treated to a film debut, “Soaringwords: The Power to Heal,” at the library. The film will feature Casey as one of the children giving testament to inspiration derived from Soaringwords. Rick Rabe, a filmmaker from Connecticut, eagerly lent his talents to the project.

“Initially, one of the board members called me and told me about the project,” he said. “The board member is a friend of mine and I said I would be willing to meet with Lisa Buksbbaum. When I met Lisa I found that this was quite an amazing organization and I found a very few people who had gathered together to do a lot of good.”

After seeing all the many people who have benefited from Soaringwords, Mr. Rabe became interested. “It was a small group of people who were doing a lot of good,” he said.

Mr. Rabe was impressed with the children who were ill. “I interviewed a lot of kids that were ill to make the film and I think it is draining, as a filmmaker, to talk to people who are going through some of the most traumatic moments of their lives,” he said. “And yet, to see the good and the uplifting of the spirit that is coming through this project was amazing and I couldn’t say no.”

Mr. Rabe was very impressed with Casey. “Casey is a wonderful child with a positive outlook, and she has a strong group of support around her.”

Healing mission

Soaringwords’ mission statement opens with, “Our Web site brings something new because it is totally focused on healing the child and the entire family. No one else is addressing the fact that when a child is ill, the entire family and extended family and extended community are in crisis.”

Soaringwords will give a sick child and his or her family the ability to communicate with other sick children and their families.

Soaringwords strengthens the pathways between mind, body, and wellness so that children and parents can take active, essential, healing roles to help cope with the illness.

One suggested way to accomplish healing takes advantage of practices created by Dr. Gerald Epstein, who is a proponent of the concept of healing visualization.

“These are exercises kids and parents can do that take less than five minutes,” Ms. Buksbbaum said. “Through visualization an energetic change in the body and a change in attitude and a lifting of the spirits takes place that opens up a pathway for healing.”

To make reservations to see the film “Soaringwords: The Power to Heal,” call Jennifer Mears Stahlkrautz at 764-9460 or Jean Mann at 764-1412.