

on the MOVE

Cancer survivor turned author



Chrystal O'Connor is reflected in a mirror at her Waterloo home May 12.

A fly settled on the O'Connors' kitchen table on an unusually warm May afternoon. As Michaelene O'Connor went to swat it, her daughter Chrystal protested.

"She won't let us kill anything, not even a fly," Michaelene said.

Maybe it's not surprising that Chrystal, 14, values the gift of life even for an insect. Chrystal's own life was almost taken away by leukemia — and now she views the world from a perspective that many people in our busy society may not.

"Appreciating the water, the trees and the air — nobody thinks about that," said Chrystal, a parishioner at St. Mary's Church in Waterloo who is completing eighth grade at St. Mary's School.

Chrystal also appreciates what other young cancer victims and their families endure, having lived the experience. So to offer support for those people, she decided in 1997 to write about her illness.

My Journey With Cancer, a 24-page booklet, was completed in late 1998. One hundred copies were produced, but interest in the book appears to be growing. Chrystal has received praise from well-wishers; been invited to speaking engagements; and gotten an inquiry from a national cancer organization about having several thousand copies of the book reproduced.

Jay was my friend ... he was my age, 7. I visited him in his room. He couldn't do much because he was too ill. He gave me a book on my birthday by Dr. Seuss, "Oh, The Places You Will Go!" I still have it. We were friends until he died. I went to his memorial service. It was outside of the hospital. We all had balloons and when it was over, we let the balloons go.

Chrystal was diagnosed with leukemia at the age of 6. She received three years of intense treatment, and the cancer has now been in remission for more than five years. However, Chrystal must still be evaluated yearly to make sure the disease doesn't return.

During the time she spent at Rochester's Strong Memorial Hospital, Chrystal made numerous friends. In addition to Jay, Chrystal was close with Christie Simonetti, a Greece resident whose plight with cancer was highly publicized as her parents sought a bone-marrow donor. Christie died in January 1993 at age 8.

In the book, Chrystal details how she would speak to Christie through an intercom, imploring her to take her medicine. She also collected donations to buy

Christie a toy jeep. Christie was recalled, dropping the jeep around the house. Christie died two weeks later.

Chrystal said she had met other young patients she met at St. Mary's who have survived their illnesses. She also learned the names of her deceased friends.

"I think of them a lot, but I'm glad that they're still here, still alive," Chrystal said.

My family played a big part in my life, especially when I had bone marrow and spinal taps ... it was like everyone was holding my hand through the pain. When my grandmother came to see me, she told my mom to go get some coffee. Then, my grandmother and I went back to the vending machines and got lots of junk food. We went back to the room and ate it all. Grandmothers are great that way.

In addition to Chrystal's narrative, the book also includes anecdotes from her family about the ordeal. Toward the back of the book, Chrystal offers tips for other children who are fighting cancer. Among them are: "Don't waste time because life is short"; and "Talk to the Lord, he will always listen."

Chrystal wrote the book at the urging of Barbara Didsbury, a language and speech therapist for the Waterloo School District who works with Chrystal. Didsbury was Chrystal's home tutor while she was undergoing treatment.

A one-year project, the book was published free of charge by Wilson Press in Seneca Falls.

Didsbury and the book idea began after she asked Chrystal, who was in seventh grade at the time, to write a paragraph about her illness.

"I saw it evolve into something more. I just kind of happened, it wasn't anything I thought up," Didsbury said.

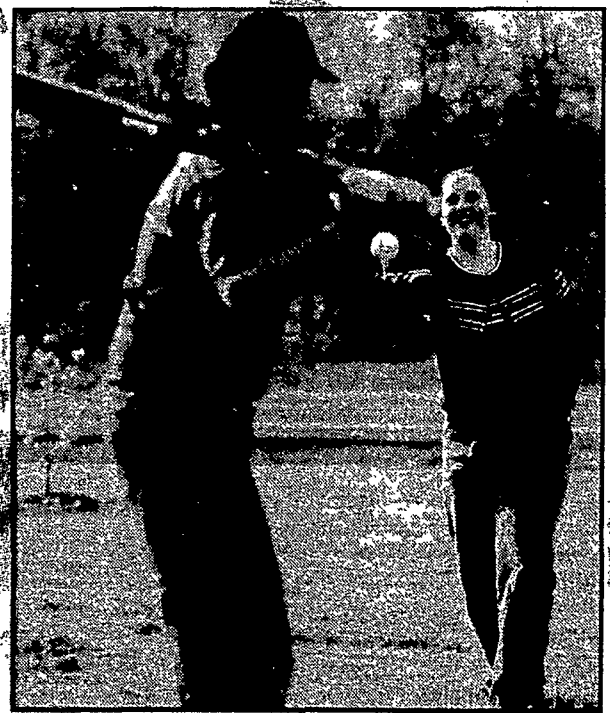
Didsbury and Chrystal's mom said that she worked hard throughout the year, recalling events and compiling a thick stack of notes that were whittled down to their current form.

"She'd be up until midnight," Michaelene O'Connor said.

“When I first found out I had cancer, I was a frightened child. No, I did not know what it meant, but I knew it was bad by looking into my parents' eyes. **”**

Story by Mike Latona

Photos by Greg Francis



Chrystal O'Connor, 14, plays baseball with brother Shawn, 11, in her Waterloo front yard.

It is like YES!!! I made it ... I AM a survivor, but I still have concerns. My big worry is am I going to have kids? I would like to have a family someday. I try not to think about the negatives. I would rather think about the positives.

Chrystal's positive focus is evident on her face: she received a school award for "best smile" three years ago.

Working with children brings Chrystal lots of those smiles. An arts-and-crafts enthusiast, she enjoys designing items for children whom she baby-sits. In addition, she aspires to be a kindergarten teacher — and is already training by serving as a volunteer aide for the kindergarten class at St. Mary's School.

"She's very warm, loving, giving. She has a real interest in others, and that was a motivation for her to write the book — to be able to help other families who are going through this," Didsbury said.

"I've always seen it with her," Chrystal's mother commented. "There was this boy in the hospital, she hovered over him like she was his mother."

Chrystal seemed a bit taken back by the publicity her book has received, saying she didn't write it for the attention.

"I don't want to say that I'm proud, but I'm glad," she said. "I never wanted it to go this far. But if a kid gets (the book) and they're sick, I'm sure I don't want any money."

COMING NEXT WEEK:

Anti-drug fun night