

Joey



In the time since his death, many of you have shared with us your memories of Joey; others have expressed how his death and memorial services affected them and their families. Many other unexpected and wonderful events have occurred since that very sad day, one of which is the establishment of the Joey O'Donnell Foundation.

This foundation, soon to be known as the Joey Fund, was created to assist in Cystic Fibrosis research and to help needy Cystic Fibrosis individuals and families. Hundreds of thousands of dollars have been contributed—a remarkable amount from many generous people. Obviously, the short and happy life of one little boy will make a big difference in the quality of life of countless other children.

We appreciate the extraordinary support and kindness we have received from so many people and we want to memorialize the experiences of the past year. Hopefully, we will soon have cause to celebrate the cure of Cystic Fibrosis. We thank you for your contribution toward that end.

Joe and Kathy O'Donnell
November 23, 1987





ystic Fibrosis . . . what did this term mean in 1974 to all but a few people gathered here today? Kathy and Joe learned that their elation over the birth of Joey would be tempered by the cruel terminal reality of the disease. No one dared predict Joey's life span; his lung damage was that severe. But Miss "K" and the Big "O" responded as we knew they would: to love and nurture this special child in a very special way.

We all became witness to an incredible human achievement. At a very early age, Joey seemed to turn his burden into a challenge—a challenge he met **every day** for 12½ years. And so his journey through life began. Many of us can recall the first night the doctors said he would not last until morning . . . Joey was just six months old. This scenario would replay over and over again for the next 12 years—and he always fooled us. He kept coming back from the brink. He seemed to love every minute of the fight.

Our days passed as well, sometimes too quickly, and often without the proper reflection on our lives and what was happening around us.

Most of us get up each morning and go about our routine, to school or work. Joey started each morning with a half hour of mist treatment and a half hour of lung searing physical therapy.

Most students at Winn Brook and Chenery rode bicycles or ran to school. Joey often got piggy-back rides from his friends from the school bus to the front door. He loved his friends and they loved him.

In the Belmont summer baseball league, most kids hit and ran with abandon. Joey (always a good hitter—which made his Dad proud) ran the bases the first year, and needed a pinch-runner the second.

Most people spend very little time in a hospital . . . Joey spent more than a year of his life at Mass. General.

We learned that God had blessed us with an unusual child. Joey would light up a room when he walked in. His eyes sparkled constantly. He exhibited an artistic talent and a well-developed visual sense. He was a great practical joker, mostly on Mom and Dad. Can't you just hear Joe saying, "Why, you . . ."

But there was more: Joey demonstrated all the special qualities of a champion:

He never quit.
He never lost his dignity.
He was never discouraged.
He never complained.
He always spoke of hope and the future, and . . .
He always thought of others first.

With his grandparents and his cousins and his friends, Joey acted in such a way that we all forgot his illness. We were pleased to be in his company, to share his special enthusiasm. He was, in Kathy's words, "my beautiful child." He was, in Joe's words, "my angel." He was, to all of us, a treasure.

Over the past six months, Joey's challenge grew. His physical activity became more limited. His lung capacity nearly gone, his heart was over-extended. He lived on courage alone. Yes, we were all there, supportive to the O'Donnell family—and did you notice—we never said "poor Joey." Rather, he was to be admired and cherished.

And then, during the last two weeks, Joey O'Donnell, he of the indomitable will to survive, achieved a vision so clear and so powerful. In a conversation with his parents, he said time on earth was like the blink of an eye and that heaven would be a special place without therapy and that his parents would meet him there. And with his active imagination, Joey said they would get there by hyper space—his favorite trick in one of the many video games at which he was so good.

I can find no way to measure or comprehend the heroic character embodied by this remarkable child. But a poem by Shel Silverstein entitled "How Many, How Much" helps me to think of Joey:

*How Many slams in an old screen door?
Depends how loud you shut it.
How many slices in a loaf of bread?
Depends how thin you cut it.
How much good inside a day?
Depends how good you live 'em.
How much love inside a friend?
Depends how much you give 'em.*

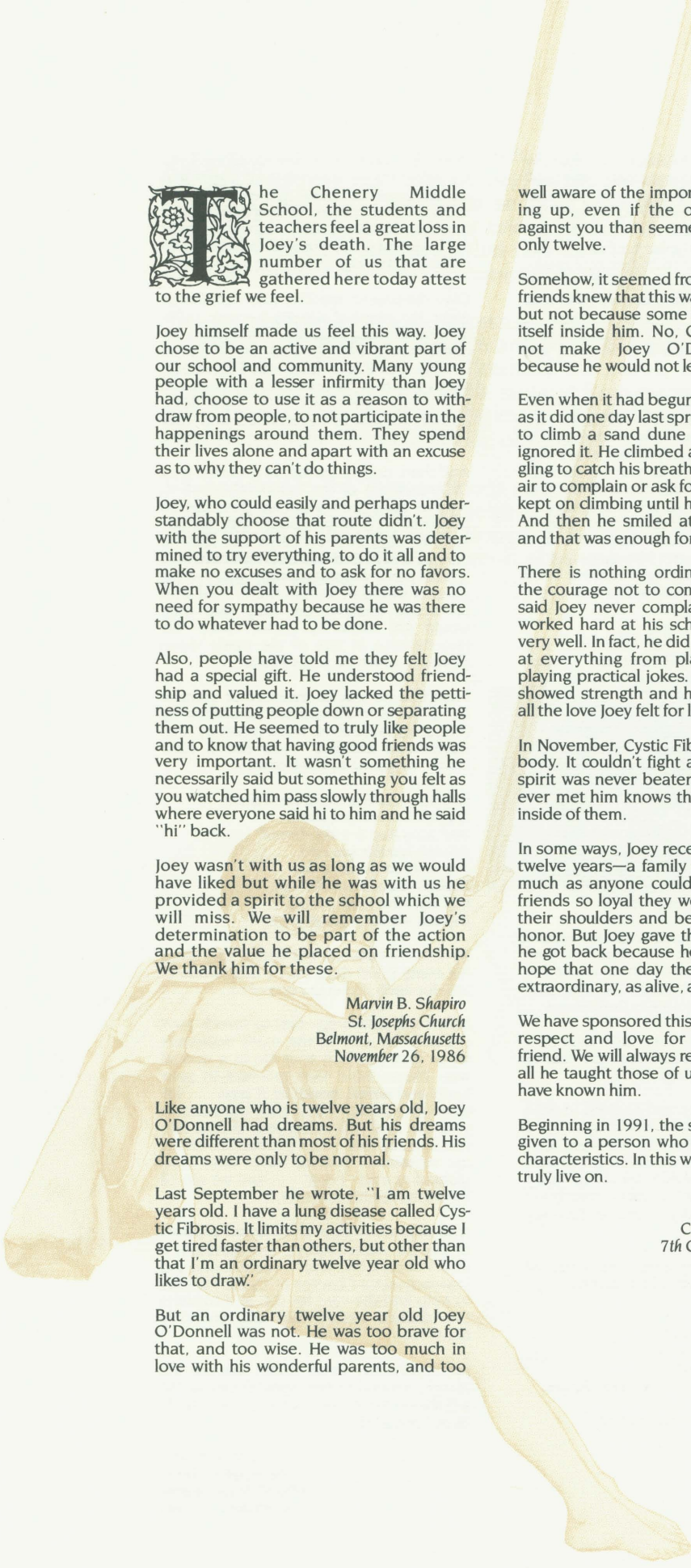
By these measures, our friend Joey lived his **many** good days with a magnitude of love for each and every one of us.

Now I ask your help—first to search your memory for one of the many moments when Joey touched your life in a special way. Please hold that moment in your heart and **never, never** let it pass . . . for there may be few other such moments in your life. And remember Joey in your difficult times as well, when you feel like giving up; remember that he never once complained or said "I quit" . . . and we are all the better for his example.

And second, I ask your renewed support of the Dr. Allen Lapeys, the Burnham 4 and 5 nurses, the John Nadeaus, and the Massachusetts Chapter of Cystic Fibrosis to help find the cure for C.F. and to claim the ultimate victory that Joey so richly deserves.

Joe and Kathy—never doubt that we will always remember how special Joey is. He will always live in our hearts and our minds as our proud champion.

Paul Del Rossi
St. Joseph's Church
Belmont, Massachusetts
November 26, 1986



The Chenery Middle School, the students and teachers feel a great loss in Joey's death. The large number of us that are gathered here today attest to the grief we feel.

Joey himself made us feel this way. Joey chose to be an active and vibrant part of our school and community. Many young people with a lesser infirmity than Joey had, choose to use it as a reason to withdraw from people, to not participate in the happenings around them. They spend their lives alone and apart with an excuse as to why they can't do things.

Joey, who could easily and perhaps understandably choose that route didn't. Joey with the support of his parents was determined to try everything, to do it all and to make no excuses and to ask for no favors. When you dealt with Joey there was no need for sympathy because he was there to do whatever had to be done.

Also, people have told me they felt Joey had a special gift. He understood friendship and valued it. Joey lacked the pettiness of putting people down or separating them out. He seemed to truly like people and to know that having good friends was very important. It wasn't something he necessarily said but something you felt as you watched him pass slowly through halls where everyone said hi to him and he said "hi" back.

Joey wasn't with us as long as we would have liked but while he was with us he provided a spirit to the school which we will miss. We will remember Joey's determination to be part of the action and the value he placed on friendship. We thank him for these.

*Marvin B. Shapiro
St. Josephs Church
Belmont, Massachusetts
November 26, 1986*

Like anyone who is twelve years old, Joey O'Donnell had dreams. But his dreams were different than most of his friends. His dreams were only to be normal.

Last September he wrote, "I am twelve years old. I have a lung disease called Cystic Fibrosis. It limits my activities because I get tired faster than others, but other than that I'm an ordinary twelve year old who likes to draw."

But an ordinary twelve year old Joey O'Donnell was not. He was too brave for that, and too wise. He was too much in love with his wonderful parents, and too

well aware of the importance of never giving up, even if the odds were longer against you than seemed fair if you were only twelve.

Somehow, it seemed from the first that his friends knew that this was no ordinary boy but not because some illness had locked itself inside him. No, Cystic Fibrosis did not make Joey O'Donnell different because he would not let it.

Even when it had begun to slow him down, as it did one day last spring as he struggled to climb a sand dune on Cape Cod, he ignored it. He climbed and climbed, struggling to catch his breath but never wasting air to complain or ask for help. Instead, he kept on climbing until he reached the top. And then he smiled at his own triumph, and that was enough for him.

There is nothing ordinary about having the courage not to complain. His friends said Joey never complained. Instead, he worked hard at his school work and did very well. In fact, he did as well as he could at everything from playing baseball to playing practical jokes. Even his art work showed strength and honor, but most of all the love Joey felt for life.

In November, Cystic Fibrosis licked Joey's body. It couldn't fight any longer, but his spirit was never beaten and anyone who ever met him knows that because it lives inside of them.

In some ways, Joey received a lot from his twelve years—a family that loved him as much as anyone could love a little boy; friends so loyal they would carry him on their shoulders and be glad to have the honor. But Joey gave them all more than he got back because he gave them hope, hope that one day they might all be as extraordinary, as alive, as loving as he was.

We have sponsored this scholarship out of respect and love for our very special friend. We will always remember Joey and all he taught those of us lucky enough to have known him.

Beginning in 1991, the scholarship will be given to a person who exemplifies Joey's characteristics. In this way, Joey's spirit will truly live on.

*Bobbie Brennen
Chenery Middle School
7th Grade English Teacher*

Measured by any standard, he was mentally the toughest person I ever met. When he was just 6 months old, the doctors told the parents of Joey O'Donnell he would not live through the night, the cystic fibrosis housed in his body would take his life then. It took the killer 12 more years to claim Joey O'Donnell as its latest victim.

When Joey O'Donnell was laid to rest in Mt. Auburn Cemetery yesterday morning, he weighed just 47 pounds, and most of that was heart. Each day of his life, when he was home, his mother gave him therapy to keep him going. Although he knew he could die at any time, he lived life as normally as he could. He never asked for a break. He never made an excuse. He did not want to be treated differently. He skated, he sailed and he played youth baseball. The first year he could hit and run the bases. The second year he could hit but had to have someone run for him. Every day he lost a little more of his life but gained the admiration of everyone who saw this kid refuse to quit. When he knew his time was up this past weekend, he looked at his mother, Kathy, first, then looked to his father, Joe, a fine athlete at Harvard a few years back, and told them: "Life goes by as quick as the blink of an eye. Before you know it, we'll all be together again. And it will be more fun. I won't have to have therapy every day anymore." Goodbye, Joey. You will always be my hero.

November 27, 1986

On a more meaningful note, the heart-breaking death of young Joey O'Donnell just before Thanksgiving has turned into a heartwarming experience for those who knew him. In less than two months since his death from cystic fibrosis, friends of the family have established a Joey O'Donnell Foundation, with all the proceeds going to the fight against CF. To date, more than \$150,000 has been contributed. If you want to pay tribute to this unusual young man, a portrait in courage throughout his 12 years, you can do so by writing to P.O. Box 272, Boston, Mass. 02101.

January 17, 1987

The legacy of Joey O'Donnell continues to grow at a remarkable rate. Joey, 12, died last fall in Belmont after a life-long battle with cystic fibrosis. The spirit of the former Little Leaguer lives on, with more than \$300,000 having been raised in his name. Tomorrow a 5-mile walk-a-thon will take place in Belmont, starting at the Chenery School Joey attended. The proceeds will go into a scholarship fund in his name for Belmont High students.

May 16, 1987

*Will McDonough
The Boston Globe.*



1,000 Celebrate the Life

The altar boy cried as a trail of smoke from burning incense within a thurible used at Benediction curled slowly about the packed cathedral. The solemn air was pierced only by prayer and the sobbing of schoolchildren and parents who had come to celebrate the life of the 12-year-old who now rested in the coffin placed directly in front of the altar at St. Joseph's Church in Belmont. His name was Joey O'Donnell and he died when his champion's heart finally tired of the long battle waged against the disease cystic fibrosis.

Across all 12 years, Joey O'Donnell fought the killer within him with enormous dignity and courage. And, Wednesday, in a church seldom as crowded except for Midnight Mass at Christmas, more than a thousand people knelt not so much in grief as to share passage with a soul whose every day and each breath gave new meaning to rituals like Thanksgiving, presently thought of as the start of a shopping season.

"When he was born, the doctor told us he'd probably never make it out of the hospital and that it would be a couple of months at most before he died," Joe O'Donnell, the father, was saying. "But he surprised us. He was always surprising us."

"Well, I probably wanted to give myself a little leeway," Dr. Allen Lapey replied. "It was absolutely one of the worst cases of CF I have ever seen. But Joey was an unusual kid. I never heard him cry. He never felt sorry for himself. He never said, 'Why me?' He never gave up."

"He didn't think of himself as a victim," Father Rod Copp had said at Mass. "He thought of himself as just a normal 12-year-old in the 7th grade."

Joey O'Donnell was born with a terminal time clock ticking inside the cells of his system. Cystic Fibrosis is a relentless and always victorious enemy of life, one that hammers away at resistance. Yet the boy constantly pushed back at fate and chose not to recognize inevitability.

And here was the hand he played every single day: More than 50 pills; a daily half hour of morning therapy that meant his mother or father massaging and slapping his chest; cups filled with phlegm and mucus coughed from lungs that worked like small, fragile straws; oxygen tubes in his nose that made him feel "like a dog on a leash" and, nearly always, a full day of school where friends fought to carry him piggyback up three flights of stairs to class.

"Did you know he was going to die?" a 12-year-old classmate was asked at Joey's wake, where more than 2,000 people came.

"No," she answered, crying. "I didn't even know he was sick. He never said anything about it."

Joey O'Donnell played Little League baseball for three years until this summer, when his lungs and legs put him on the sideline. He was a right-handed hitter with a good eye and a quick bat and because a dash to first base would exhaust his system, he had pinch-runners but he always hit.

"I like that," Joey O'Donnell had said, gleam in his eye. "Just hitting. I like that idea a lot."

of A Courageous Fighter.

"He never asked us if he was going to die," his father said. "And I don't know if he knew on Sunday. I hope I never know. That was the beauty of him: He kept telling us not to worry; that the doctors would come up with a cure; that he was just a normal kid and that's how we should treat him."

More than a year of his life was spent in the hospital and given the nature of the disease every admission could have been his last. This year alone he suffered heart failure twice but something inside—an indomitable spirit, a fighter's eye, a thoroughbred's heart—pushed back the curtain of darkness. But, no matter the courage, cystic fibrosis makes its victims renters when it comes to living.

"On Wednesday, we watched a movie," his father said. "And all of a sudden he told me he knew what heaven was. He told me heaven was different, that a long time down here was like a blink of an eye in heaven. I don't know where he came up with that."

"My son was a champion," Joe O'Donnell said. "He taught me a lot. I think he taught a lot to everyone who knew him. He knew what friendship was and he loved his friends. He was never mean and he never wanted anybody to feel sorry for him."

"I'm grateful to have known him. I used to make deals with God. I used to say, 'Give me 20 years.' Then it was 'Please give me a year. A month. A week. A day.' Then it was 'Please God, give me a smile.' You get greedy. It's human nature. But when he went in the hospital last Friday, we knew he was going to die. But here was a boy who they said 'Two months' when he was born and he said, 'No' and gave us 12 years. That was the miracle."

"And he gave us so much strength that he fooled me," said Kathy O'Donnell, his mother. "In the end, I never thought he'd really die. And when he did, it was so beautiful. It was almost as if his spirit was saying, 'Don't worry, Mom and Dad. I'm going to be all right.'"

On Sunday, in the hospital where he spent so much of his life, Massachusetts General, Joey O'Donnell drifted peacefully toward his destiny. His heart could no longer carry the burden of pushing breath through the wounded tissue of his lungs.

"We love you Joey," his mother and father kept saying.

"I love you guys too," he answered.

"Are you in any pain Joey?" the father had asked.

"Uh-uh," the boy said, shaking his head. "I'm just really tired. I'll see you guys tomorrow."

At 5:30 that afternoon, a part of Joey O'Donnell died peacefully in his parent's arms. A larger part lived on through Mass Wednesday, and the burial in a driving rain that washed across the huge crowd assembled on the gray landscape of Mt. Auburn Cemetery. But it was not death that drew them to graveside. Instead, it was the short life and big heart of a 12-year-old who used his time to teach people about the true meaning of Thanksgiving.

Mike Barnicle
The Boston Globe
November 28, 1986



Perhaps the greatest tribute to the courage Joey showed all of us is the unselfishness and dedication his memory brings out in others. The Joey O'Donnell Walkathon, held on Sunday, May 17, 1987, is a perfect example.

Holding a red and white banner decorated with hearts, a group of Joey's friends led other students from the school he attended, family members, and citizens of Belmont on a five-mile walk. The goal was to launch the Joey O'Donnell Scholarship Fund. How close did the event come to reaching that goal? Consider these impressive statistics:

- 500 people officially registered for the walk. But when the big day came, almost 1,000 people actually followed the route to support the cause and honor Joey's memory.
- On most walkathons, the average person raises about \$30. Here, the average was well over \$100.
- At the end of the day, \$37,000 in pledges had given the Scholarship Fund an exceptionally strong start.



Marie Doyle, one of Joey's teachers and a prime organizer of the event, describes how the concept came about. "It was the kids' idea. They were upset (about Joey's death) and they wanted to do something in memory of their friend. They suggested the walkathon and everyone thought it was a good idea."

A great idea might be a better term. Backed by Joey's friends, his teachers, his school and the town which officially proclaimed May 17 as Joey O'Donnell Day in Belmont, the entire event—the walkathon, the subsequent cook-out, the music, the memories, the giving—was a spectacular success.

Organizers plan to repeat the walkathon in 1988. The first scholarship, offered to graduating seniors at Belmont High School, will be awarded in 1991.

Joey O'Donnell's life celebrated with festivities planned for May 17

Joey O'Donnell Day celebrates a very special friendship. It will be observed on Sunday, May 17, in Belmont.

Joey was a seventh grader at Chenery Middle School when he died from cystic fibrosis last November.

A benefit screening of Reiner movie

Rob Reiner's "The Princess Bride"

Joey O'Donnell remembered with walk and scholarship

The film also will be preceded by a new three-minute Joey Fund trailer, designed to usher in a month-long audience collection campaign starting Friday at all theaters and General Cinema. The Joey Fund is designed to help victims of cystic fibrosis and support research. The screening will be preceded by a reception in the lobby of the Cheri at 7 p.m. Tickets, at \$50, may be purchased by phoning 542-9144. Mandy Patinkin, who stars in the film alongside Cary Elwes, Robin Wright, Chris Sarandon, Christopher Guest, Wallace Shawn and Andre the Giant, is expected to attend.

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Spirit of O'Donnell walks with marchers

By LIESA HEALY

The spirit of friendship and love was in the air last Sunday when an estimated 1,000 people marched in the Joey O'Donnell Walkathon to raise money for a memorial scholarship fund.

Holding a red-and-white banner decorated with hearts, a group of students, family members and fellow Belmontians on a five-mile walk raised \$37,000 in donations.

Although 500 officially registered for the walk, twice that number followed the route to demonstrate support for the cause and to honor the memory of O'Donnell, a much-loved, 12-year-old Chenery student who died of cystic fibrosis last November. "We had a much larger group than we ever had," said teachers from Chenery alone walked.

The idea of a walkathon shortly after Joey's death to Doyle.

Cinema Campaign

Joey Fund assists families of children with cystic fibrosis

By Cate Chapman
Alan Friedberg, president of USA Cinemas, usually does not officially endorse charities, but the life and death of Joey O'Donnell from cystic fibrosis touched him personally. Now his Boston area theaters pass the canister to fund research of the deadly disease and aid families of victims.

Participants will seek pledges and the money collected will be placed in the Joey O'Donnell scholarship fund.

Opening ceremonies, a picture and a plaque in his honor will be hung at the middle school presented for all to see. The ceremony will begin immediately following the screening and a low. Music will be provided by Jockey.

Participants will receive a picture of Joey on it and the money collected.

amount of money collected.

Walk-a-thon sponsor envelopes will be available at all of the elementary schools, at the middle school and at the high school on Friday, May 17.

Letters seeking volunteers with the smooth event will be through of A-

to help of this tents week

Joey O'Donnell Day celebrates a very special friendship. It will be observed on Sunday, May 17, in Belmont.

Joey was a seventh grader at Chenery Middle School when he died last November. His spirit will be remembered.

Joey O'Donnell day set for May 17

Plans are being made to celebrate Sunday, May 17 as Joey O'Donnell Day in Belmont (rain day—Sunday, May 31). O'Donnell, a seventh grader at Chenery Middle School, died from Cystic Fibrosis last November.

The idea was formulated by his schoolmates out of respect and appreciation for their very special friend.

A five mile walkathon through Belmont will help fund a scholarship for a senior at Belmont High School who exemplifies those qualities of courage, integrity, selflessness and maturity which Joey O'Donnell possessed.

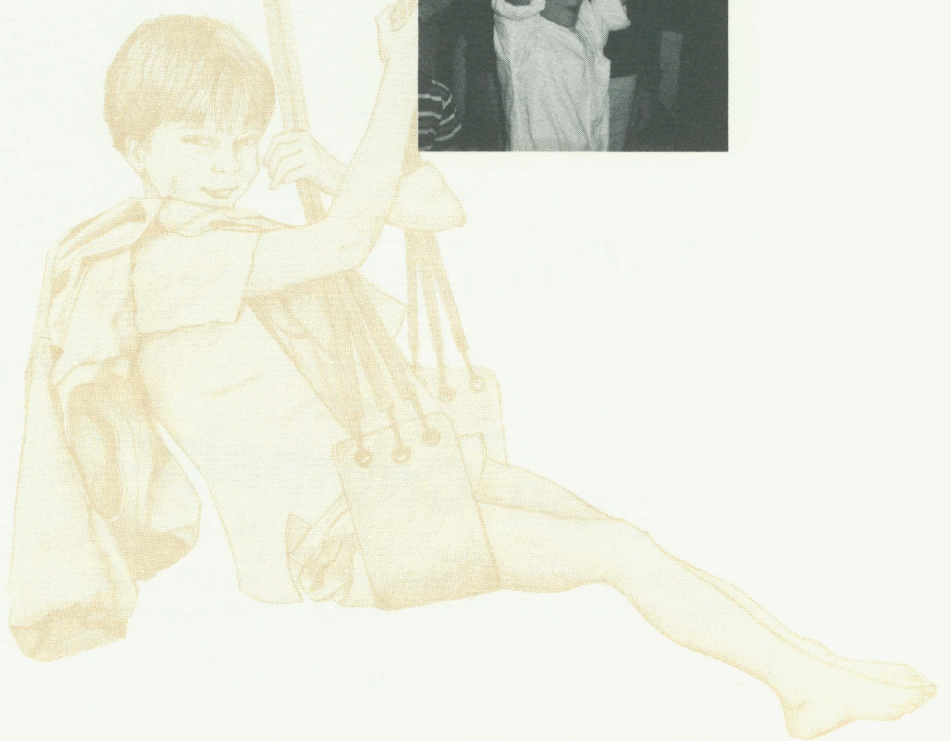
tion and interest. "You guys are just fabulous," he said, waving his arm to indicate the group of walkers relaxing in the Chenery schoolyard. "This is real testimony to the school, the spirit, and to Joey."

"On most walkathons, the average person raises about \$30," O'Donnell said. "Here, the average was well over \$100."

"I'm very proud of the kids," Doyle said. "When we brought up the idea, everyone thought it was a great idea."

...and a picture of Joey which will be hung at the Middle School. Letters will be sent home through the schools requesting volunteers. Walkathon envelopes for interested participants will be available in early May.

(Please see O'DONNELL, page 31)



"Joey was inspiration to all of us. He fought with courage and perseverance. We all have wonderful memories of Joey and in each one of us lies a bit of Joey—a special boy who touched many of our lives . . ."

"I always smiled when I was around him and even now I can smile when I think of him. He was always so pleasant to be with. That is one of the qualities that made him so special. Joey was beautiful and I will always remember him . . ."

"Joey was indeed a great example of courage and dignity for all who knew him. He was a most unusual boy. He played a great game of life with a winning smile. He was very special to me and he touched my life by his love, courage and determination to make every minute of life count . . ."

"Nothing is forgotten that is remembered, and Joey's cheeriness and brightness and sense of humor will be remembered by all of us who were fortunate enough to know him . . ."

"I have my own cherished set of memories of your unstoppable young man. He sang, he moved, he worked out his instrument parts in our various Winn Brook classrooms, despite the drain on his precious energy resources. His wisdom, his care for others, his twinkling eyes were riches that he brought to our group times together. He taught us all a lesson in courage in his gentle way . . ."

"He taught me not to be afraid. He was a great inspiration to all of us. I for one will never forget him . . ."

"The struggle goes on. It is often not quite as uplifting an experience with other patients because you don't run into people like Joey more than once, or I'm hoping perhaps twice in a career. He is our gold standard, however, and we measure psychological adaptation in other patients in relation to how he did . . ."

"I hope this doesn't make you sad, but happy—because it makes me happy to think about Joey. His face is so vivid in my memory. His little half smile, turned up nose and twinkling eyes that usually meant some devious prank was toiling about in his mind. I loved him and I would be honored if he thought of me as a friend. I know that a part of him will be in me forever . . . And, I also know that he is having a great time raising a little hell in heaven . . ."

*Excerpts of letters
from Joey's friends*

Bridge to Terabithia

Jess Aarons and Leslie Burke were very good friends even though she is a girl and beat him in a race. Before Leslie came, Jess was nothing at all. Leslie shared her feelings with Jess. They had created a world of imagination in the woods called Terabithia and Jess learned a lot through that. Jess became a brave king of the stronghold.

Leslie was swinging on the rope to Terabithia when it snapped and she fell and died. Jess was angry at first, but he realized that she would be with him always, not just her spirit but her feelings, too.

Jess built the bridge so his sister May Bell could learn from Terabithia as he had done.

Joey O'Donnell
Book Report—November, 1984

