



**A Foundation Dedicated to the Care, Comfort and Cure of Children with Brain and Spinal Cord Tumors.**

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Maya Manley  
*Secretary*

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*Director of Clinical Neuro-Oncology  
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Making Headway is a 501(c)(3) not-for-profit foundation.

*Top: Tena Walton with her husband Keith and son John.*

*Below: Sara Chaiken (right) celebrating her birthday in the playroom with her best friend Alex Beran.*

**Hello From The Office!**

*A Message from Tena Walton, Office Administrator*



*I can hardly believe that four years have gone by—four years since I joined Making Headway. As I think most of you know by now, I'm the English one with the funny accent at the end of the telephone!*

*It has been wonderful for me to work daily with Maya and Edward and to try to help them a little in the magnificent job that they do with Making Headway. I know from the occasions when I have had the opportunity to speak with you, be it in person or on the telephone, how much Making Headway means to each of you. It really is an honor and a privilege to be involved, if only in an administrative capacity.*

*One of my greatest joys is helping those wonderful parents who organize fund raisers for Making Headway. I am thinking of people like Jeannie and Greg Trunz, Allison's mom and dad, and their Tulip Festival Dinner Dance; of Diane and Pat Ryan, Elizabeth's parents, with their Little Bit of a Walk; of Maira Hernandez-Kinloch, Matthew's mom, who transforms her birthday into a fundraiser; of Tracey and Stephen Casale, Sophia's parents, who organize the Fore-A-Difference Golf Tournament; of Cheryl and Chris Coutts, Morgan's parents, who created Casino Night with their friends, Chris and Jim Caci; and Robin and Chuck Magner, Riley's parents, who put together Riley's Walk. We are so very grateful to all of them for the magnificent work they do for Making Headway. And, of course, I cannot forget my lovely Shira Antonoff, Sarah's mom. On a very regular basis, Shira drives from her home in New Jersey to volunteer in the office. Thank you, Shira! You make such a difference.*

*And to all of you, who inspire me in my work—thank you, for being you, for your strength and fortitude. Please don't forget to check our web site at [www.makingheadway.org](http://www.makingheadway.org), where we regularly post not only our support group notices, but also Making Headway's forthcoming events.*

*I look forward to continuing my work in the office. And while we go through our transition from the INN at Beth Israel, please know that if I can help, in whatever capacity, at any time, I am only a phone call away at (914) 238-8384 or email me at*

[tena@makingheadway.org](mailto:tena@makingheadway.org)





## Giving Graciously

Throughout the year, Making Headway receives countless contributions from individuals, groups, organizations and companies. These gifts help us in fulfilling our mission to provide care, comfort and support to families of children with brain and spinal cord tumors. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of this year's gracious giving include the following:

**Children with Hearts at I.S. 285**, Brooklyn donated \$350 in memory of **Susan and Donald Don's** daughter **Rachel**. The **5th Grade Class at Solomon Schechter Day School** of Bergen County, NJ, chose Making Headway to be the recipient of their class Tzedakah project. They donated \$118 in memory of **Sarah Antonoff**. On the occasion of her wedding, **Dana Costello** donated \$350.

A first-class yacht cruise on *The Jewel* was donated by **Marisa and Richard Stadtmauer**, friends of Making Headway founding members, **Elisa and Clint Greenbaum**. 40 Making Headway families enjoyed perfect weather and a delicious lunch as they cruised for three seafaring hours around the lower end of Manhattan.

**Rachel Meyer** (age 10), **Andrew** (age 8) and **Mitchell Lipman** (age 11), raised \$200 one hot summer afternoon for Making Headway by sweeping out neighbors' cabanas and accepting donations for a good cause. Good afternoon! Beautiful placemats were made by children at the **Grafflin Elementary School** in Chappaqua, NY, and enjoyed by children at the hospital. In memory of **Stephanie Potts**, **Dawn Brown** donated \$400 plus a matching gift in lieu of wedding favors.

Happy Birthday to **Matthew's** mom, **Maira Hernandez Kinloch**, who—once again—celebrated by hosting a tea party and raising \$2,162. **The Associates Club** of Acordia in Morristown, NJ—where **Emily's** dad, **Tony Ousouljoglou**, is an account manager—raised \$140 on their Dress Down Day.

In memory of **Kenneth Thomson's** birthday, toys were donated for the Day Hospital playroom from **Ellen, Peggy, Alexis, Tom, Cecilia** and **Kevin**. **Catherine Martyn** and **Jerome Cappellani** favored Making Headway with a donation of \$3,500 in lieu of favors at their wedding. 🌸

## School Partnerships: Parents, Advocates and Schools Working Together to Promote the Well Being of Children

By Patricia Weiner, Educational Consultant



All children are entitled to develop to their fullest potential through the benefits of healthcare and education. Developmentally, school offers the opportunity to be industrious and develop a strong sense of self. Psychologically, school connotes normalcy and familiarity. Academically, skills are mastered. At school, children meet new friends, discover how to interact with other children and adults, and learn about themselves.

Children who have been treated for brain and spinal cord tumors are at risk for academic difficulties. It is distressing for a child who has been through so much medically to return to school with a new set of challenges. And, while all children with special needs have a federal right to a free and appropriate public education (FAPE) in the least restrictive environment (LRE), working out what your child needs takes advocacy and persistence.

One of my roles as an educational consultant is to help families overcome the barriers to an appropriate education for their child. Together with Dr. Rebecca Mannis, I am available through Making Headway to help you understand the needs of your child and how to work with the school so that your child receives the services to which he or she is entitled. Parents know their children best and together we can help build partnerships with schools and medical teams. I am honored to be working with the Making Headway Foundation. 🌸

### Tips for Parents: Advocating for Success

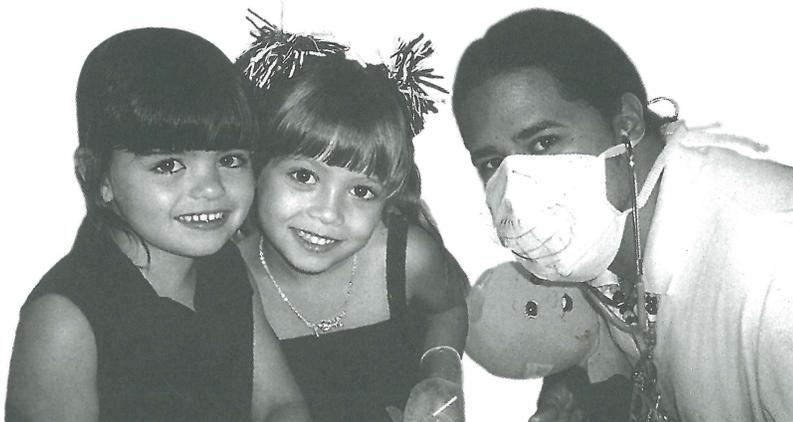
- **Know** your rights.
- **Become** informed about how your child's illness impacts his or her education.
- **Be** an active participant in your child's Individual Education Plan (IEP) team. (And, if you are not sure about something the Committee on Special Education (CSE) says, DON'T sign the IEP.)
- **Call** Making Headway at (914) 238-8384! We can help you navigate the complex educational system.

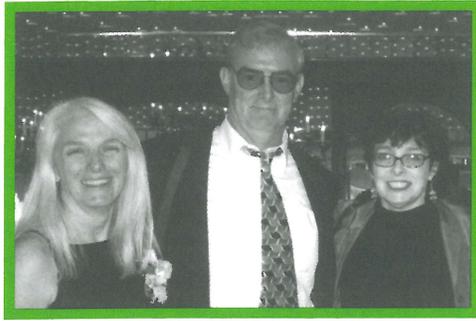
*Patricia Weiner is a special educator and child life specialist, with expertise in educational law. She has spent over thirty years advocating for children and their families and is currently on the faculty of Bank Street College in New York.*

*Top left: Adam the Clown with members of the Rasmussen and Giles families on the yacht cruise.*

*Top right: Educational consultant Patricia Weiner.*

*Below: Child Life Specialist Jose Acevedo with Tiffany Romano and Kayla Wentink preparing for surgery.*





## Allison Trunz Remembered, Honey Shields Honored

In April, Jeannie and Greg Trunz hosted the 7th annual “All-is-onE” Tulip Festival Dinner Dance at the Swan Club on Long Island in memory of their daughter Allison. 295 people attended and raised over \$160,000 for Making Headway. This year’s dinner dance journal honored Honey Shields, who made the 10th floor at Beth Israel North a wonderland for the children.

It’s hard to believe that seven years have passed since the first dinner dance. It’s always a bittersweet evening that honors Allison and breaks Jeannie and Greg’s hearts all over again. For them, the dinner dance is a time to connect with friends and show them the pain involved for the families. The sorrow and the beauty of it all bring a gentle mercy that is palpable by the end of the evening. For any parent, Jeannie and Greg embody our worst fear and greatest hope—an unbearable loss and an incomparable humanity. Making Headway is honored again and again by their generosity and moved by their example. 🌻

## “A Little Bit” Goes a Long Way

When 9-year old Elizabeth Ryan was diagnosed with an inoperable brain stem tumor, Dr. Fred Epstein sadly said there was nothing he could do. With all his compassion, Dr. Jeffrey Allen couldn’t offer more hope in terms of treatment: the tumor had spread all over. Six months later, on December 2, 1998, Elizabeth lost her battle.

Even in the depths of their sorrow, Elizabeth’s parents, Diane and Pat, countered their grief with the determination that others should not suffer as they had. Transforming their loss into something positive and tangible, they came up with *A Little Bit of a Walk* to raise money for

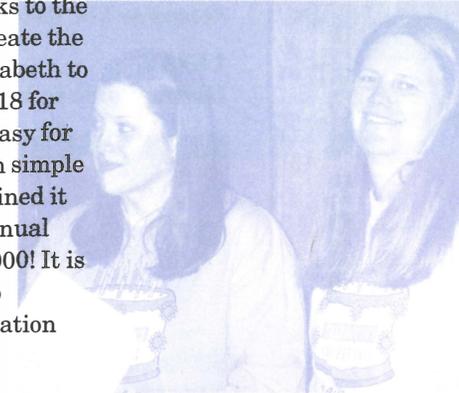
Making Headway. “A little bit” had been Elizabeth’s nickname and it speaks to the humble purpose of the walk: to create the opportunity for all who knew Elizabeth to remember and celebrate her. At \$18 for individuals, \$40 for families, it’s easy for everyone to participate. With such simple ambitions, the Ryan’s never imagined it would be so successful: the 6th annual walk this past spring raised \$23,000! It is Making Headway’s great honor to earmark the Ryan’s generous donation toward research. 🌻

## Riley’s Walk: Toward Hope

During this year’s Family Fun Day, a beautiful 7½-year old red-head volunteered to play the evil witch during Goowin’s Balloowins annual performance of “Snow White and the Seven Dwarfs.” How could anyone have imagined that this little pixie, playing the witch with glee and giggles, had received intricate surgery as a baby by Dr. Fred Epstein?

Every year since, Riley Magner’s grateful parents, Robin and Chuck, have organized *Riley’s Walk* in Boston. For the past two years, *Riley’s Walk* has raised money for Making Headway to express the Magner’s heartfelt connection to New York and the wonderful people who got them through an impossible time. More than anything, though, *Riley’s Walk* has been about hope. For anyone whose child has been diagnosed with a brain tumor, hope in the form of Riley’s smiling face gets us through each day.

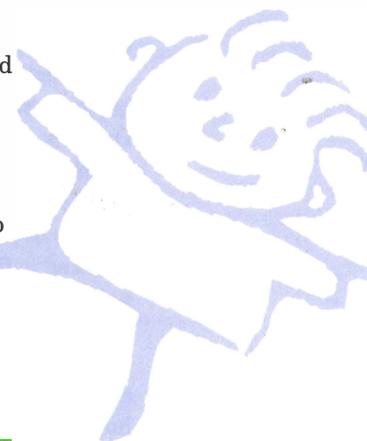
This fall, *Riley’s Walk* will end after six years. Robin says she feels sad to give it up but so, so blessed. We all hope that for Riley, this becomes a distant memory in a childhood filled with glee and giggles. For their part, Robin and Chuck will never forget. Nor will Making Headway. 🌻



Above: Diane Ryan (right) with co-organizer and best friend Colleen Byrne at A Little Bit of a Walk.

Left: Honey Shields with her brother Bob and sister Rose at the Tulip Festival Dinner Dance.

Bottom: Robin and Chuck Magner with their son Kyle at Riley’s Walk.



## Superkids

Stories by Elizabeth Buttke

### LINA

#### Giving voice to hope



Being an only child and the only grandchild of two sets of grandparents, Lina was surrounded by boundless love from the moment she was born. Yet even those adoring adults were surprised to learn, when Lina was three, how incredibly gifted their little girl was. They knew she was bright. But they never suspected her IQ was 160-plus, until she was tested for school.

Lina's musical talent was equally impressive. Barely over a year old, Lina was able to hum the theme from *Sesame Street*. By the time she was seven, she sang so beautifully that she was accepted into the Children's Chorus of the Metropolitan Opera.

But in a few short years, Lina's life would take a dramatic turn. Her music teacher began to feel that Lina lacked discipline because she failed to practice enough and she was putting on weight. Lina was also having trouble remembering lyrics. What seemed like lack of motivation was noted by Lina's middle school teachers as well. Her grades were on the decline, no longer in sync with her capabilities.

As practicing psychologists, Lina's parents, Sophia Richman and Spyros Orfanos, explored every possibility they could think of to explain what was happening. Eventually, they arranged for a battery of psychological tests—and were shocked to find Lina's IQ was over 60 points lower than before.

Just as baffling were physical changes they observed in Lina. She developed a slight limp and strange gait, and started holding pencils with an awkward grip that affected her handwriting. When they consulted a neurologist, he recommended an MRI.

The result was a devastating diagnosis. The MRI revealed a tumor as big as an

orange deep within Lina's brain—which somehow Lina herself seemed to sense two months before the dreaded discovery. In an uncannily prescient poem titled "Darkness" Lina wrote, "The beauty that surrounds me is closing in."

Although the tumor was benign, its location made it life-threatening, requiring immediate surgery. While most of the tumor was removed successfully, Lina was left with learning difficulties and impaired peripheral vision. But she never let anything get her down.

Since her surgery, Lina has graduated from high school and college, interned as a music therapist at the INN—where she herself had been treated by Dr. Allen—and just completed a year of social work in graduate school. On top of all that, she is happily pursuing a career in music—with an upcoming singing tour and a CD album. (It can be sampled at [www.linaorfanos.com](http://www.linaorfanos.com)).

Ever the optimist, Lina even took what most would consider a fearful setback in stride. This past January, a routine MRI revealed Lina had developed another brain tumor, a tiny pituitary adenoma. Treatable with medication, the tumor is now gone and Lina is still very much on the go.

Lina's ability to survive whatever traumas she faces may well be inherited from her mom Sophia, who not only survived the Holocaust as a hidden child, but had the strength and courage to write an uplifting memoir, *A Wolf in the Attic*—even as she helped Lina in the fight of her own life. How well they both triumphed over tragedy may best be expressed by an untitled poem Lina wrote while vacationing in Greece after her surgery:

*A young girl  
sits outside a home  
far away from her problems.  
A relaxing breeze  
cools her head  
and the  
music that is played  
calms her.  
Pussy willow flows in the  
wind.  
Everything is  
calm.  
The song may stop  
but the music still  
continues.* 

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This newsletter is dedicated to our donors and supporters, whom we celebrate every day.

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Top: Lina Orfanos.

Below: Clinical Research Assistant Jeena Chacko with Juan Ochoa.

