

CHILD

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graduated from Bethesda-Chevy Chase High School, said part of the book came from contemporaneous material such as the journal she kept during the PGD experience and e-mail updates to friends and family during Henry's bone marrow transplant. After Henry died, she said she wove those together and "added Henry and his spirit and who he was as a person," which she said helped her deal with the loss.

"I spent almost 24 hours a day with Henry the last couple years of his life," she recalled. "It was an incredibly intimate relation-

ship, and after he died, I still had a need to spend a lot of time with him. Writing about him fulfilled that need."

"It was painful, but also a beautiful way to remember everything that was so wonderful about Henry," she said, noting that the book is "infused with those good times" with her son.

Strongin said, though, that she still is unable to write about the final few days of Henry's life; to tell that part of the story, she used blog entries her husband wrote at the time.

Fanconi anemia, like Tay-Sachs, is considered a Jewish genetic disease because Ashkenazic Jews

are disproportionately affected, said Strongin, who belongs to Adas Israel Congregation in D.C.

According to the National Institutes of Health, while about 1 in 300 people in the U.S. carry the gene, 1 in 90 American Jews of Ashkenazi descent have the faulty genes. Both parents have to be carriers for the child to inherit the disease.

The condition leads to blood failure, which necessitates a bone marrow transplant by the time a child is 6 or 7 years old.

Prenatal testing told them that Henry's younger brother, the now-13-year-old Jack, would be born without the disease. But the chance of producing an embryo with the bone marrow match, but without Fanconi, was only 18 percent, and nine cycles of in vitro fertilization did not produce a pregnancy.

It was not easy going through IVF, especially those knowing that the life of one of their children hangs in the balance.

"It was an absolute real-life race against time," said Strongin. "That sense of urgency [was] paired with higher and higher stakes as time went by," as she and her husband watched Henry's blood counts

drop. But Strongin said she always looked to Henry and wondered, "What did I have to complain about?"

Henry eventually had a bone marrow transplant from an anonymous donor, but complications resulted. He died not long after his seventh birthday. As a menorah burned in his hospital room, his final words before being placed on a ventilator were "Mom, this is a very bad last night of Chanukah."

They would be his last words; Henry died a few days later.

Since Henry's death, Strongin, a former non-profit executive, has created the Hope for Henry Foundation. The organization fills a need Strongin saw during Henry's illness: hospital resources that lift children's spirits and allow them to "laugh and have fun." The foundation, operating in hospitals in the D.C. area, Baltimore and Philadelphia, provides patients with such things as birthday parties, iPods and cameras that allow them to send pictures to their friends.

And even after he was gone, Henry was still having an effect on others. At the young boy's funeral, one of his doctors from Georgetown University Hospital sat down next to a then assistant rabbi at Adas Israel. Dr. Ali Mendelson



and Rabbi Jeremy Winaker were engaged a year later, with Max Henry Winaker born in 2007.

"It was so beautiful," said Strongin about the name. "It was such an incredible honor."

This article is made available to the Jewish Press through the JTA news service cooperative.

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SLEEP

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she says. "It can lead to a power struggle between parent and child."

Mezrah says that if children wander into the parents' bedroom during the night, they should be walked back to their own bedroom.

"The child needs to feel comfortable in his or her own space," she says, and not get in the habit of intruding on parents' intimacy.

In her book Mezrah outlines an entire program, day by day, on getting babies to sleep. Some local residents have found relief for their own families by taking her advice. One of those is Jodi Jacolow of Tampa, the mother of two toddlers, who told the *Jewish Press* that she and her husband, Steven, have worked together on incorporating Mezrah's suggestions into their lives.

"I started my two children on her plan, one at six weeks and one at birth," she said. "By 10 weeks they

were both sleeping through the night," Jacolow said. Mezrah also helped the couple transition their 20-month old son from a crib into his new bed.

"She suggested having a celebration of the new bed with balloons and a cake and making the transition into a party," Jacolow said. "It worked."

Leni Sack, director of the Tampa JCC pre-school program, witnessed another of Mezrah's tips, one that may sound bizarre to some. Sack said her 3-month-old granddaughter tended to scream in her car seat.

Sack's daughter Amy had tried to calm the infant with all kinds of music to no avail. In came Mezrah with the suggestion to try one other — rap music — and it did the trick. "The strong rhythm of rap music helped settle the baby down," Sack said.

Mezrah said a happy family life, where no one is sleep-deprived, is possible for most.

"Just try to be one step ahead of your child's needs as well as your own," she says.



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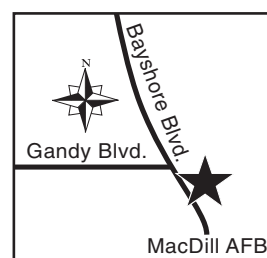
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