C Is for Cure: A WaterFire Lighting for RI Defeats Hep C

In Honor of World Hepatitis Day
One WaterFire Torch, One Life Remembered

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I was invited by Dr. Lynn Taylor to be a torch-bearer at WaterFire last Saturday night, along with many other more worthy individuals who are on the forefront of hepatitis C research, testing and treatment.

It was an honor to represent the Rhode Island Medical Journal at the event. But as we ringed the basin of Waterplace Park, and lit one torch at a time, I thought of my brother Johnny. A flicker here, a flicker there, memories of when we were kids ignited with the flames.

He died of hepatitis C in 2000; contracted several decades prior, it is assumed, after a possible tainted blood transfusion following an auto accident when he was a teenager. He was on the waiting list in Boston for a liver transplant when he died.

To be honest, when we were little, he was what was then called a “brat.” My older brother and I were the well-behaved ones. Once the principal of our grammar school summoned me to her office. Johnny sat on a big chair fidgeting and looking quite guilty. The principal held up a ribboned ponytail he had cut off from the student who sat in front of him. “Mary, you are to tell your mother she must get control of him,” the principal directed me. That’s what they did in New York City schools then. Call in the big brother and sister. “You better not tattle,” he said as we left the office.

Then there was the time my mother went into labor prematurely. They rushed the three of us kids over to our grandfather’s house nearby. He was on his way to the courthouse, where he was a judge. He put us in the back seat of his Buick and at the court, sat us in the front row with a stern admonition to be mum when the proceedings began. I sat with my doll and combed her hair. My older brother read a book. It was not long before Johnny shot rubber bands at the plaintiffs.

Grandfather signaled to the security officer. He locked us up in a holding cell behind grandpa’s chambers. On our way home in the Buick, I protested neither I nor my doll nor Jim had done anything to deserve jail time. “You are known by the company you keep,” grandfather said sternly. “And you and Jim are your brother’s keepers. You both are older.”

As I extinguished the WaterFire torch, I thought of my late mom in her very old age who had lost her recent memory. “Where’s Johnny?” she would often ask. “He doesn’t come to see us anymore.”

“Oh, you know him, he’s probably getting into some kind of trouble somewhere,” I would answer. My siblings and I were/are Baby Boomers, most at risk for Hep C as I learned while helping Dr. Taylor with RIMJ’s July special theme: RI Defeats Hep C. Thanks to Dr. Taylor and her colleagues, the July 26th WaterFire raised awareness for so many of the tens of thousands who attended, with information and screening sites set up.

I told my sister she should get tested, since she cared for my brother at the end. She is afraid to. Then I told her there is a cure although it is expensive, right now at $1,000 a pill, for a total cost of over $80,000. “I don’t think my health insurance will cover it,” she said. “I will wait until the price drops to get tested.”

Johnny, who died of Hep C many years after this photo was taken, is on the far right; siblings Mary and James are on the left. The children in the center are the neighbors on 97th Street in New York.
WaterFire Raises Awareness of Hep C

C is for Cure: A WaterFire Lighting for RI Defeats Hep C was held July 26th on World Hepatitis Day to raise awareness, help diminish stigma, and inspire people to get tested and cured. There was also a Hep C Information and Resource Fair on the College Street Bridge and information tents for the Rhode Island Blood Center, the Rhode Island Organ Donor Awareness Coalition and the Alpert Medical School.

Torchbearers included many members of the Rhode Island medical community, who ringed Waterplace Basin at sunset to begin the lighting of 80 braziers, in an evening sponsored by Gilead in recognition of the millions of Americans suffering from hepatitis C. The C Project by Festival Ballet Providence was performed on the Waterplace Basin Stage and Gendo Taiko of Brown University and RISD played five Taiko drumming pieces as part of the opening ceremony dedicated to the spirit of healing.

Cover photo by John Nickerson,
Statehouse crowd by Jennifer Bedford,
torchbearers by Emily Gauvin,
all for WaterFire Providence

*Right:* The Torch procession leaders were
**Dr. Scott Holmberg,** Chief of the Epidemiology and Surveillance Branch, Division of Viral Hepatitis, U.S. Centers for Disease Control and Prevention and
**Dr. Lynn E. Taylor,** Assistant Professor of Medicine, Division of Infectious Diseases at the Alpert Medical School and a Rhode Island Foundation Innovation Fellow. As part of her RI Defeats Hep C initiative, she compiled a series of articles for the July issue of the Rhode Island Medical Journal. http://www.rimed.org/rimedicaljournal-2014-07.asp