



“**K**nowing is not enough, we must apply. Willing is not enough, we must do.” — Goethe

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The Legacy of Alfred I. duPont
and My Son Jack

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The Legacy of Alfred I. duPont and MY SON JACK

by Albert Freedman

“**The ambulance carrying Jack and my wife, Anne, weaved through thick holiday traffic.**

A kind physician in the Emergency Room immediately recognized my son from a previous encounter. He worked thoughtfully and efficiently to stabilize Jack’s respiratory distress, ordered a chest x-ray to evaluate Jack’s lung function, and comforted both the patient and my wife. We immediately felt less anxious about Jack’s fragile condition.

I was thankful to have Jack under Dr. Attia’s care.

Two hours later, our eleven-year-old son was admitted to the Pediatric Intensive Care Unit (PICU). As Jack was wheeled through the unit on a gurney, we were greeted by a team of doctors, nurses, and respiratory therapists, many who were familiar to us and to our son. The Critical Care team worked quickly to formulate a plan. Dr. Herzog, leading the team,

knows Jack and drew from his previous experience caring for our son and other children affected by neuromuscular diseases. Supporting and enhancing the physicians’ treatment plan, Jack’s nurses and respiratory therapists worked with confidence, keen attention to detail, and with a great deal of compassion for Jack and for our family.

Twenty-four hours a day, this extraordinary team of professionals provided care for our son. They talked with our son and reassured him. They listened to what Jack himself said about his needs and respected his wishes and requests. One day at a time, Jack’s condition improved. His chest x-rays showed the left collapsed lung was expanding. Jack’s breathing became less labored. Gradually, he became more comfortable. Tonight, as I sit next to my son’s hospital bed, watching him sleep soundly, I am thankful. Six days following that harrowing ambulance ride, Jack is almost ready to come home.

Eleven years ago and miles away from here, Jack was diagnosed with Spinal Muscular Atrophy (SMA), an incurable neuromuscular disease. We were told our six-month-old baby would never be able to sit up, walk or feed himself. We were told Jack would become ill and experience respiratory distress. Our baby was given a year to live.

My wife and I were shocked, and didn’t quite know what to do or where to turn.

When our family relocated to Chester County, Pennsylvania, a friend encouraged us to consider Alfred I. duPont Hospital and Nemours Children’s Clinic for Jack’s medical needs.

Over a period of a few months, we scheduled a series of appointments with specialists. Drs. MacKenzie, Chidekal, Marks, and Proujansky assumed responsibility for Jack’s orthopedic, pulmonary, neurology and gastroenterology care. Renee Donohoe provided physical therapy consultation, Dick



Jack, his parents Anne and Albert, and his sister Cara are able to enjoy a great day during their summer vacation



(From L to R:) Christine Patille, RN, John Christie, RRT, and Brian Binck, MD wishing Jack well as he is discharged from the Pediatric Intensive Care Unit.

Lytton introduced Jack to assistive technology, and Denise Peischl and John Carter, Jr. helped us choose the proper wheelchair for our son. Each of these specialists was kind, knowledgeable and took the time to get to know our little boy. While the challenges we faced as parents continued to feel overwhelming at times, I felt thankful for the quality of care available to Jack.

A few weeks ago, Jack and his little sister, Cara, paid a visit to the hospital with me. After his scheduled appointment, Jack drove his power wheelchair through the halls with his sister hitching a ride on back. Six-year-old Cara was quiet. I sensed she was thinking about something important.

“Daddy, who is Alfred I. duPont? Why is this hospital called Alfred I. duPont Hospital?”

I thought about the best way to respond to my daughter’s question, and asked Jack to follow me in his wheelchair.

A few minutes later in the main lobby of the hospital, Cara and I stood, and Jack sat, before a statue of Alfred I. duPont.

“Tell us his story, Daddy,” said Cara.

“Mr. duPont is no longer living,” I told my children, “but when he was alive, more than fifty years ago, he made the decision to build a hospital to help children with special needs. Mr. duPont was a good person who shared what he had with others. Because of Alfred I. duPont, this hospital is here for Jack, for you, and for any other child who needs help.”

Cara thought about this for a few seconds and nodded. Jack maneuvered his wheelchair in circles around the lobby, keeping one eye on the statue of Mr. duPont. The lesson my children took from this conversation was simple — one person can make a significant difference in the lives of others.

Here in the Pediatric Intensive Care Unit at the Alfred I. duPont Hospital for Children, it’s eleven o’clock on a Friday night, three days before Christmas. I peek out the door of Jack’s room and see many familiar faces, professionals who are highly committed to their work and to the children under their care. Day after day and night after night, the nurses, doctors, and respiratory therapists, keep working. Critically ill children arrive here around the clock, 365 days a year. The hospital never closes. The PICU never sleeps.

Eleven years after being given one year to live, Jack is very much with us. Our son is a happy, intelligent, motivated child who works hard on his schoolwork and attends a special camp in the summer. He enjoys swimming, his computer, visits with friends, and driving his wheelchair through the mall. Jack’s physical disabilities are significant, but our son is not easily discouraged. He enjoys his life, and we are very proud to be his parents. Tomorrow, my wife and I will take Jack home from the hospital. We are thankful for every day with our son.

I never knew Alfred I. duPont, and until my young daughter’s question led us to his statue, I hadn’t given the man, or his life, much thought. But as my son and I spend one more night together in the building bearing his name, I’m quite sure Mr. duPont would be proud and pleased. These wonderful professionals and the thousands of children who grace this hospital — among them my son, Jack — are his legacy. ”

Albert Freedman is a proud member of the Family Advisory Council at A. I. duPont Hospital for Children.