



2017

A publication for friends and supporters of Hasbro Children's Hospital

Practically from the time their son Pawel was born, his parents knew he would be facing multiple surgeries. He was born with a rare genetic disorder called diastrophic dysplasia (DD), a form of dwarfism that leads to joint and bone problems, including severe, progressive scoliosis.

In the past, children with severe scoliosis at such a young age were often treated with a “growing” rod surgically attached along the spine to control the curvature. The patient would return for surgery twice a year so surgeons could manually extend the rods as the child grew. But thankfully, when it was time for Pawel’s surgery, Hasbro Children’s Hospital was utilizing a new technology that, after an initial surgery to place the rods, would allow doctors to magnetically lengthen the growing rod in an outpatient setting every three months, instead of in an operating room. The magnetic growing rod, known commercially as the “MAGEC™” rod, is a groundbreaking technology aimed at helping to treat this complicated group of patients.



Pawel’s “Magic” Growing Rods

Pawel was just seven months old when he started to develop early onset scoliosis. Hasbro Children’s Hospital Pediatric orthopedic surgeon, Craig Eberson, MD, began treating Pawel using casts and braces to control and try to correct his spinal curve. “It can be hard to get a good fitting brace with small children, so casting works better to control the curvature 24 hours a day,” Dr. Eberson explains. But Pawel’s curvature progressed quickly. Not only did he have sideways curvature, he had a rounding of his spine, known as kyphosis, which only made his condition harder to manage. Although nonoperative treatment managed to slow the progression of Pawel’s

curve, eventually it became large enough to need more aggressive treatment.

“Scoliosis doesn’t just affect the spine,” explains Dr. Eberson, “the work of breathing—opening and closing the lungs—can be very hard with a large spinal curve. Patients can also develop reflux and digestion issues, sometimes made worse by the cast or brace.” Pawel sadly struggled with both, enduring daily bouts of vomiting which required intervention so he could gain weight. But for little Pawel to get growing rods of any kind, there was one more hurdle to tackle before

continued on page 2

continued from page 1

surgery—Dr. Ebersson needed to prepare his spine by gradually correcting his 80 degree spinal curvature.

To do this, Pawel would need halo gravity traction. Using a halo surgically secured to the patient's skull, weighted traction allows for the gentle pulling of the joints and muscles to help straighten the spine. Pawel used a specially designed traction walker and traction wheelchair for almost two months.

After seven weeks in traction, four-year-old Pawel was ready for surgery. Pawel's mom Marzena says she will never forget seeing Dr. Ebersson come out after the three hour surgery and hearing him say, "He got his 'magic' rods!"

Pawel recovered quickly from the initial surgery. Now, every three months he visits outpatient imaging at Hasbro Children's Hospital for a lengthening adjustment. After an ultrasound and rod measurement, a magnet is put on his back, the adjustment is made and they go home thirty minutes later. "There's no fasting, there's no anesthesia, no overnight stays or IVs. What a big difference compared to the regular rods that require surgical adjustments every six months," says Bogan, Pawel's dad.

Today Pawel is five years old, and walking by himself. Thanks to his magnetic rods, the benefits for him reach far beyond orthopedics. His breathing has improved, his stomach has space to expand, and his daily vomiting has stopped. Marzena says, "He was always getting sick before, and now his health has really improved. He's eating and sleeping better, so he can learn better at school... things are really coming together thanks to Dr. Ebersson and Hasbro Children's Hospital!"

"This new technology is enormously beneficial, especially for children like Pawel with complex medical and developmental diagnoses. But for any child, avoiding trips to the operating room reduces infection and recovery time, while improving quality of life," says Dr. Ebersson. "Being able to offer this new technology is a great example of how Hasbro Children's Hospital is committed to bringing the very best in medical advances to our patients and their families."



Before



After



Tune in on April 5th & 6th to Put Your Money Where The Miracles Are ... At Hasbro Children's Hospital!



92 PRO-FM • Lite Rock 105 • 630 WPRO-AM & 99.7 FM • HOT 106

hchradiothon.org



Photo courtesy of East Providence Police Department

With “Good Night Lights,” Hasbro Children’s Hospital Patients Get Another Dose of Kindness

Few things in life create the type of anxiety that overcome children and their families more than a child’s hospitalization. Lives are turned upside down as minds race with thoughts of the unknown. Everyday routines simply vanish.

But for a few minutes each night, in what has become a highly anticipated event inside Hasbro Children’s Hospital, patients receive a special goodnight message from caring strangers, letting them know others are thinking of them.

Dubbed “Good Night Lights,” the effort began when Steve Brosnihan, a local cartoonist who

volunteers at the hospital, realized he could see the bus stop he bikes to after leaving the hospital from many of its windows. He’d tell patients to look for him and he’d flash his bike light to say goodnight.

Abby awaits Good Night Lights



Soon, Steve encouraged a local waterfront restaurant to begin flashing its neon sign to patients. The restaurant’s patrons also got in on the action, flocking to the outside deck to wave flashlights and their illuminated cell phones. What happened next is utterly heartwarming.

From boats stationed in Providence Harbor and some of the city’s largest hotels to a local yacht club and other area restaurants, the flashing goodnight lights have grown exponentially. In February of 2016, the East Providence Police joined the movement in their own special way.

As darkness falls each Wednesday, squad cars arrive at a parking area off Veterans Memorial Parkway across from the Providence River, facing Hasbro Children’s Hospital. In harmony, the officers turn on their cars’ headlights and siren lights. In response, the officers receive pulses of light from the flashlights of patients who were eagerly awaiting their arrival.

Though “Good Night Lights” lasts for just moments each evening, the impact felt by all involved is nearly immeasurable. It’s a happy routine the children know they can count on.

“On any given day, there are upwards of twenty children who spend the night in our hospital, many having undergone treatment earlier in the day,” says Margaret M. Van Bree, MHA, DrPH, President of Rhode Island Hospital and Hasbro Children’s Hospital. “When those lights are turned on, the smiles on the children’s faces are brighter than the illuminated sky. What makes this especially touching is they don’t even know the messengers on the other end—it’s an incredibly simple and moving display of kindness.”

Beltone New England Raises Funds to Support Hasbro Children's Hospital

For the second year in a row, Beltone New England, one of the country's leaders in hearing care, is doing something amazing to support Hasbro Children's Hospital.

Last year, across their 55 retail locations in our region, Beltone hosted its "Hear for Children" campaign, raising \$9,820 to support the purchase of specialized pediatric audiology equipment used for measuring soft sounds generated by normally-functioning nerve endings in the inner ear. The equipment plays a critical role in the audiological assessment of infants and young children.

For this year's event, that will run February through June, Beltone is partnering with Mighty Well, a company that creates medical accessories, to raise funds for The Adolescent Leadership Council (TALC). TALC provides a forum for adolescents ages 13-18 who are managing a chronic illness, enabling them to interact with peers who are going through similar experiences. Children gain insight into themselves as they develop the confidence and advocacy skills needed to navigate their medical circumstance both in the short- and long-term. The goal of the campaign is to raise \$12,000 for TALC which includes sending at least 16 children with chronic illness to the program's summer camp this coming year. Visit giving.lifespan.org/Beltone-NE2017 for more information.



 **Beltone**[™]
Helping the world hear better



Hasbro Children's Hospital
The Pediatric Division of Rhode Island Hospital
Lifespan. Delivering health with care.®

Footprints, a publication of the Rhode Island Hospital Foundation, is published for the friends and supporters of Hasbro Children's Hospital.

For more information, please contact Karli Blossom at 401-444-0394.

giving.lifespan.org/Hasbro

