THE CATAclySMIC BLIZZARD OF '78 still haunts New Englanders. It was what many called the “mother lode” and remains the benchmark by which all other nor’easters are judged. So when Mother Nature unleashed Juno on Jan. 26 and 27, yielding some 25 inches of snow in Boston, memories of that monumental snowstorm were front and center as MGHers rallied just as they did 37 years ago.

"Back in '78, I had nothing to do with snow removal," says George MacNeil, director of MGH Buildings and Grounds. "A lot of people just stayed once they were here. I remember helping out in any way we could."

The response to Juno was no different. With a state of emergency and travel ban in effect, some staff worked full shifts, others slept at the hospital and many covered shifts for those who could not make it in. Because the hospital was at 100 percent capacity, staff worked tirelessly to admit patients waiting for inpatient beds while coordinating with case managers to find ways to safely discharge patients.

“Despite the challenges, staff responded amazingly well, as they have so many other times,” says Paul Biddinger, MD, medical director for MGH Emergency Preparedness. Adds David Reisman, senior administrative director of Emergency Preparedness, “We had to access the labor pool, but people were willing to volunteer. Staff went out of their way; many came in early prepared to stay for several days and were incredibly flexible to do what they needed to do for patients.”

Buildings and Grounds staff was among the many employees who put in extra hours. MacNeil says 53 employees from all trades remained at the hospital for two days, operating in shifts.

“We set limits for the guys, depending on what they were doing, so they got the proper rest,” says MacNeil. “The problem with this storm was that it was relentless. It was like we were fighting three or four storms. How the MGH deals with snow removal is different than a shopping mall or business. The hospital can't shut down. We continually have to clear all of our walkways and entrances so that the facility remains accessible, safe and secure at all times.”

Jeanette Ives Erickson, RN, DNP, FAAN, senior vice president for Patient Care and chief nurse, says the entire MGH community came together. “The storm didn't mean a day off or a chance to sleep in,” she said. “For many it meant extra shifts, and several nights sleeping on cots. This kind of dedication and commitment is what makes the MGH a special place.”
New MGHfC clinic offers treatment for rare disorder

MASS GENERAL HOSPITAL FOR CHILDREN (MGHfC) will soon open the world’s first Pitt Hopkins Syndrome (PTHS) Clinic. Made possible by a generous donation from Nancy LeGendre and Walter Herlihy, parents of two young women with PTHS, the clinic will focus on providing knowledge-based medical care and serving the comprehensive medical needs of individuals with the disease.

A rare genetic disorder affecting a specific gene called TCF4, PTHS is characterized by developmental delays, limited speech, extreme breathing problems, seizures, gastrointestinal issues and distinctive facial features. Affected individuals typically exhibit a happy demeanor characterized by frequent smiling, laughing and excitability. The number of identified patients with PTHS worldwide has increased from nearly 350 in 2013 to more than 3,000.

With the creation of the clinic, individuals with PTHS and their families will have access to multiple subspecialists, broad-based medical resources and the opportunity to contribute to a biorepository critical to laboratory research into the syndrome at the MGH.

“Our goal here is to provide families with answers,” says Ron Thibert, DO, MsPH, co-director of the PTHS Clinic. “The clinic’s purpose is to further understand and diagnose Pitt Hopkins Syndrome. Bringing patients with similar diagnoses to a dedicated clinic will allow us to develop in-depth expertise and practice guidelines and also help us expand our clinical knowledge and experience in managing the specific problems these patients might experience over their lifetime.”

Adds Nancy LeGendre, “We are extremely pleased to have this opportunity to support the opening of the Pitt Hopkins Syndrome Clinic. It is frightening and life-altering to learn that your child has a rare disorder. Naming their syndrome was our first step, and now we are hopeful the clinic at MGHfC will provide symptomatic care and one-stop directed medical treatment so children and adults with Pitt Hopkins Syndrome can live full, healthy and active lives.”

Before mutations in the TCF4 gene were discovered to be the cause of the syndrome in 2007, diagnosis relied exclusively on medical history and physical examination. Genetic testing was available, but a need for clinical suspicion limited testing to the most profoundly affected patients.

“There is currently an evolving genetic picture of rare disorders,” says David Sweetser, MD, PhD, co-director of the PTHS Clinic at MGHfC. “Expanded genetic screening, which includes gene panel testing and whole exome sequencing, has vastly improved our ability to make the diagnosis. While the true incidence of Pitt Hopkins Syndrome still remains to be determined, we are now learning that there is more variability in this condition than originally thought. We hope to better understand the genotype, keep track of the exact mutation and see how this might correlate with certain clinical features.”

The clinic will work closely with MGHfC’s Angelman Clinic to identify and recruit patients. A number of those now genetically determined to have PTHS were previously diagnosed with Angelman Syndrome, and the syndromes share many of the same medical and developmental concerns.

For more information about the Pitt Hopkins Clinic at MGHfC, call 617-726-6540.
Delivering with a midwife

NOW IN ITS 21ST YEAR, the MGH Vincent Obstetrics and Gynecology Nurse-Midwifery Service delivers 26 percent of the babies born at the hospital and participates in the national benchmarking efforts of the American College of Nurse Midwives, where all clinical outcomes are documented. Recently, the MGH was involved in a public service announcement – put together by the college's Massachusetts affiliate that appeared during an episode of “Call the Midwife,” a public television series chronicling the lives of midwives and their families in London's East End during the 1950s. Marie Henderson, CNM, MSN, director of the MGH Nurse-Midwifery Service, explains how midwifery has evolved and is an integral part of a multidisciplinary team at the MGH.

What is the role of the midwife?
A nurse-midwife provides gynecological care, family-planning services and primary care for a woman throughout her pregnancy, delivery and post partum. Midwives are experts in normal labor and delivery and are trained to identify any deviations from normal. Midwives promote immediate skin-to-skin contact after birth, breastfeeding within the first hour of life and the bonding of the family unit. After the birth of her baby, we encourage the woman to care for herself and her family by leading an active lifestyle and making appropriate nutritional choices.

What is the history of midwifery at the MGH?
When the MGH opened in 1821, obstetrical patients were not admitted. Women of means and middle-class women had their babies at home. Hospitals were for destitute women who had no safe place in which to give birth. Before the 20th century, traditional midwives were informally trained and attended almost all births. Physicians who attended birth in 1821 were “practitioners of midwifery” and went into the patients’ homes. In the state of Massachusetts, midwifery had been very (Continued on page 4)

‘Do your job’

FORMULA FOR SUCCESS: Three words of wisdom from Patriots head coach Bill Belichick have become a mantra for the team's journey to the Super Bowl: “Do your job.” The omnipresent pledge has hooked passionate Patriots fans, many of whom proudly don T-shirts with the words emblazoned in large, bold print. On Jan. 16, mascot Pat Patriot brought the slogan to the MGH, recognizing employees who have gone above and beyond, including Hiyam Nadel, RN, CGC, nursing director of the MGH Vincent Obstetrics and Gynecology Service, and Firdosh Pathan, RPh, of the MGH Pharmacy. Pat presented both employees with two tickets to the AFC Championship game against the Colts and “Do your job” gear. During his visit, Pat also stopped by to see patients at MassGeneral Hospital for Children.

Tickets to the big show

GO PATS! Two lucky MGH employees are heading to Super Bowl XLIX to watch the Patriots take on the Seattle Seahawks. Christine Weiand, RN, an inpatient nurse, and Erika McCarthy, a marketing manager in Neurology, won the chance to travel to Arizona in a special raffle for employees. More than 9,900 raffle tickets were sold, with proceeds benefitting the MGH Fund. Weiand and McCarthy each received two roundtrip airline tickets, four nights of hotel accommodations at the Patriots team hotel, two tickets to the Super Bowl at the University of Phoenix Stadium, two tickets to the Patriots Welcome Reception, admission to pre- and post-game parties, and official Patriots, and Super Bowl XLIX gear.
A new generation of scientists

THE TIMITY SCIENCE FAIR is one of the many events postponed this week due to the blizzard. Timity Middle School eighth-grader Peace Idahor is not surprised by the impact of weather on daily life. His science fair project with supervisor Omar Lopez, a systems manager from the MGH Physical and Occupational Therapy Department, researched the effect of weather on attendance.

Each winter — as a component of the MGH/Timity Partnership, a program of the MGH Center for Community Health Improvement — James P. Timity Middle School seventh- and eighth-graders collaborate with MGH mentors on science projects and poster displays. Participating students compete in a schoolwide science fair. Students with exceptional projects are selected to compete in a citywide science competition. The program is now in its 25th year.

Originally from Nigeria, Peace and his family came to the U.S. in 2010. Peace said school was extremely hard at first. While he spoke English, some local Nigerian words are not used in this country, and his accent was hard for others to understand. When Peace transferred to the Timity School in the sixth grade, he joined the debate team.

Peace says this experience made a big difference. “The training and preparation I used to make my argument improved my ability to express myself and my confidence that others understood what I was saying.”

Lopez has been a volunteer with MGH Youth Programs for seven years, but this fall was the first time he worked with a student on the science fair project. “I thought I would give it a shot,” says Lopez. “I don’t have a science background, but I found that that was not an impediment, and I’ve enjoyed the friendship we’ve built up over the course of this project. We’ve had great conversations about all the science challenges and seeing where my mind takes him as he identifies questions that Peace was interested in.”

Peace said, “I also enjoyed my weekly meetings with Omar.”

Adds Lopez, “The best part of this experience is watching Peace explore science challenges and seeing where his mind takes him as he identifies the answers.”

The Timity Science Fair has been rescheduled for Feb. 2. For more information on MGH Center for Community Health Improvement programs, visit http://www.massgeneral.org/cchi/.

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Delivering with a midwife

(Continued from page 3)

restrictive. The Commonwealth didn’t issue licenses for nurse midwives to practice until 1977. Seventeen years later, Obstetrics was established at the MGH along with a multidisciplinary team that included a midwife to provide midwifery care to the low and moderate-risk childbearing population.

How has midwifery evolved?

There are 15 midwives at the MGH who continue to be the newest members of the Advanced Practice of Registered Nurses (APRNs) and also leaders in what can happen at the legislative level. The latest regulations of the Board of Nursing states midwives no longer need a supervising physician to practice midwifery but do need a clinical relationship with a physician. One aspect of my job is to make midwifery visible to the MGH community. I want women to know midwifery care is a great option for childbearing.

Do you think the series “Call the Midwife” has helped the public better understand midwifery? The series portrays caring, educated and professional women who demonstrate the midwifery skill set and have a clinical relationship with an obstetrician. We chose to do a public service announcement because we wanted viewers to know that midwifery care is an option in this state, and at the MGH.

For more information about the MGH Nurse-Midwifery staff, visit http://www.massgeneral.org/obgyn/staff/midwives.aspx.