

## When the Hospital Looms: HMS Eases the Trauma



William "Buddy" Hackett made a full recovery from surgery early this year and happily rejoined his friends and school routines. Here he enjoys reading a book in class with assistant teacher Jessica Clay.

Sixteen-year-old William "Buddy" Hackett entered the hospital in January for spinal fusion surgery. His parents had alerted Buddy's HMS team to the upcoming surgery.

The news triggered team activity. Their goal was to provide support for Buddy and his family before and throughout hospitalization and recuperation and to gather the information that would allow for his smooth reintegration into his HMS program.

Staff help to prepare the child and his parents for what to expect and are experienced in planning for and accommodating a child's

readjustment period when he returns. Throughout this stressful experience, everyone contributes to helping families get through a difficult time, while remaining respectful of parents and their child's privacy.

HMS's social worker can facilitate communication with other families whose children have gone through the same procedure. Nursing Services, together with physical, occupational and speech therapists, developed a Post Operative/Post Hospitalization Summary and Orders form that outlines questions parents should ask of physicians and hospital staff.

"We were impressed—HMS thinks of the parents as much as the child," says Bill Hackett. "They do for the family as a whole."

HMS prepares the youngster in different ways, depending on the amount of notice and the child's level of comprehension. Karen Turek, recreation therapist, talks with the student, reads books about going to the hospital, perhaps makes a calendar marking when he is in the hospital and when he will return, or plays with a stuffed animal to illustrate events like getting a needle or to identify the body part that will undergo surgery.

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## Inglis Foundation Honors HMS with 2010 Award

HMS has received the 2010 Inglis Award for Continuing Excellence from the Inglis Foundation. The award honors the performance of nonprofit organizations in the Philadelphia region that enhance the quality of life for people with physical disabilities, thus supporting the Foundation's mission.

Together with four other honorees, HMS received a \$20,000 award and was recognized during a ceremony and reception held at Inglis House in May. A group representing HMS parents, students, staff, administration and the board attended the ceremony to accept the award on behalf of the school.

The Inglis Foundation helps people with physical disabilities to live life to the fullest and with maximum independence and mobility through day and residential programs, employment assistance and care management.

## Watch HMS on WHYY-TV's Arts Experience!

Dance/movement therapy at HMS was featured on WHYY-TV's *Experience* spot, airing numerous times in May. You can still watch it on online in WHYY's video library at <http://video.whyy.org/program/1100712934>.





## Executive Director's Message

By Diane L. Gallagher, PhD

Interest in HMS's specialized programs remains high. We regularly share our expertise with special education professionals, families and other interested individuals and organizations. Our new website is an effective tool, offering anyone seeking resources for a child with complex needs resulting from brain injury information about our programs as well as our services beyond the school's walls.

Most recently, we hosted a day-long visit by representatives of Kuwait's Ministries of Education and Public Works to show how HMS's programs and physical plant benefit our students. Kuwait is designing a large campus that will serve youngsters with a range of developmental disabilities. Working with educational and architectural design consultants in the US, Kuwait selected HMS among seven US sites as resources in their planning process.

HMS encourages staff to present their experiences at conferences and workshops. Social worker Nancy Hale presented "I Want to Ride the Roller Coaster" this spring, with HMS parents Kerri and Brian Hanlon, Megan Guthrie, Verna Hart and Janine Blythe, at the Philadelphia Regional Conference on Developmental Disabilities. I recently participated in UCP's (United Cerebral Palsy) annual conference in Chicago, and HMS reached out to many visitors at the Abilities Expo in Edison, NJ.

This fall, dance/movement therapist Rachel Federman-Morales will present "Patterns of Connection: A Dance Mosaic" about HMS's collaboration with Drexel University at the American Dance Therapy Association's national conference. Classroom teacher Cheryl Leask was invited to join Pennsylvania Department of Education's panel charged with examining the Standards Aligned Curriculum and Assessment. She will represent Pennsylvania's students with the most significant disabilities for whom standardized testing is typically inadequate.

In September HMS will host a symposium for special education professionals, "Serving All Our Students: Meeting the Needs of the Student with Complex Disabilities," with participation from PA's Bureau of Special Education. We look forward to continuing to share our wide experience and to exchanging ideas with colleagues.

## Register for HMS's September Symposium for special education professionals

**"Serving All Our Students: Meeting the Needs of the Student with Complex Disabilities"**

Earn CEUs

September 28, 9:00 am to 5 pm, at PaTTAN's King of Prussia facilities.

Register now online at <http://hmsschool.org/news-events/calendar/symposium>.

## Remembering HMS Family Members with Affection

Two individuals with long HMS ties died this past spring. HMS remembers them with respect, affection and appreciation for their many contributions to school life.

Reverend William McKean, who served as HMS's chaplain for 37 years until his retirement in 1993, died on April 4. Compassionate with both students and staff, Rev. McKean brought an ecumenical spirit to his HMS role. He was concerned for students' feelings and needs and was an excellent listener. Through the years, both he and his

Drexel Hill congregation supported HMS in numerous ways.

Kathleen Ross, who died on May 23, was an HMS nurse for 20 years from 1987 to 2007, primarily serving resident students in the evening. A clear thinker and communicator, she provided stability to the evening program and was vigilant on students' behalf. Always looking for ways to improve the program, she provided helpful input for nursing considerations when HMS planned Harris Hall, the school's new residential wing.



## Talented Artists

Sean Hanlon and occupational therapist Janice Barbour share enthusiasm for a colorful flower painting on opening day of HMS's Annual Art Show. Sean and his schoolmates voted for their favorite works.



## Something Magical Returns

HMS's Greg Viola (center) belts it out with Germantown Friends School pals Louis Bartholetti (left) and Matt Overholser during a performance of "Blue Lou and the Belly Fish" in the 28th year of the two schools' joyful collaboration.

## HMS Participates in *How Philly Moves* Public Art Project

HMS dance/movement therapist Rachel Federman-Morales and student Elisheva Apple will be part of a new public-art initiative of Philadelphia's Mural Arts Program that promotes "gateways to the city." *How Philly Moves*, an approximately 50,000 square-foot mural, will cover the parking decks at Philadelphia International Airport, providing a colorful welcome for travelers on Rte. I-95.

The joy of dance—infectious, universal and providing a shared community bond—will reflect Philly's lively arts scene. A diverse range of dancing figures from the Philadelphia region, whose energetic movement will be visible even at 60 miles per hour, will inhabit the vibrant mural.

Artist Jacques-Jean Tiziou has designed the mural which incorporates his photography and is

scheduled to be dedicated in June 2011. In the preliminary design phase, Mr. Tiziou brought together over 70 dancers and a team of volunteers to produce a photographic series that helped to shape his design concept for *How Philly Moves*. An invitation then went out for applicants to participate in an additional photo session, allowing up to two dancers per applicant. HMS responded, and the school's representatives were among those selected to be photographed.

*How Philly Moves* will include a documentary film and a permanent exhibition inside the airport's public space which will explain the context for the project. Every dancer who participated in the photo sessions will be included in the permanent exhibition, if not in the outdoor mural.

## Dance at HMS Expands with Drexel Collaboration



Sruly Guttman (center) and his dance partner from Drexel University, together with other dancers in the collaboration, perform "Patterns of Connection: A Dance Mosaic" during HMS's Volunteer Recognition Evening.

Twelve HMS dancers and 12 students from Drexel University performed together at our Volunteer Recognition Evening in April. "Patterns of Connection: A Dance Mosaic," choreographed by HMS dance/movement therapist Rachel Federman-Morales, pulled the two groups into one-on-one partnerships that fostered meaningful relationships and exuberant dance forms. The year-long, after-school collaboration was the first with Drexel's dance ensemble.

It follows a seven-year relationship with *fusion2*, the student company of DanceFusion, a West Philadelphia company, that pairs middle- and high-school dancers with HMS students. They work together weekly throughout the year toward a performance at the Painted Bride Art Center as part of *fusion2's* annual concert.

"The whole process is so rich for everyone," says Ms. Federman-Morales, who draws a distinction between her weekly dance/movement therapy sessions with each classroom and the after-school wheelchair-dance class collaborations. With *fusion2* and Drexel "we're working toward a final product, so in the end we have this piece we've created over time and now we get to perform it. Having

that performance is empowering for everyone involved."

Both Drexel and *fusion2* students describe their experience at HMS in glowing terms. They comment on the joy HMS dancers take in the program and appreciate the opportunity to develop a close relationship with their partners. Fifteen-year-old Kerian Pearson of *fusion2* took satisfaction in helping her HMS age mates experience a range of movement and expression they would not be able to achieve on their own. Drexel's Ashley Jacobs says, "I can honestly say that I learned things about myself and about working in a partnership from my amazing partner Sam that I could not have learned any other way...We had challenges as a partnership but we worked through them using dance as our problem-solver and way of communication."

Ms. Federman-Morales emphasizes that these collaborations give HMS students a chance to build relationships beyond the HMS community and to have fun with peers from outside the school. Drexel wants to continue the collaboration, and Ms. Morales hopes to perform next year in the Mandell Theater where Drexel's dance department showcases their annual performance.



### Top Chefs

Students enjoyed a diverse range of Guest Readers this year, including two chefs from the Four Seasons Hotel who brought cookies for students to decorate. Emily Aiello (center) opts for frosting and M&Ms from among the toppings, with a little assist from her teacher Emily Gureckis and executive chef Rafael Gonzalez.





## Parents Corner

"Finding the Sweet Spot"

By Amy Warmflash

When asked how long Jordana, my nearly 18-year-old daughter has been in a power chair, I am hard pressed to answer. "Always," I often reply, although that is not quite correct. Jordana is presently in her first power chair. It's approximately 3 years old. But this wasn't the beginning of her power mobility.

Jordana has been at HMS since she was five years old. Her HMS team has been putting her in power since she was old enough and big enough to fit. They collectively have tried numerous hand controls, head controls, leg controls, and remote-assist control. In Jordana's early days, when distractibility was a major obstacle, they even rigged a "blinder" out of a cardboard box to keep her focus straight ahead. It was a sight, but it worked.

Regardless of Jordana's age or stage, they tried and tried again. I cannot say what the precise moment was, but the OTs and PTs found that marriage of skill, will and equipment...they were patient, they were persistent and they found the "sweet spot." The same story applies to her communication device—and together these two skills, so marvelously honed at HMS, have given her the power, pun intended, to experience the world in a more complete way.

We'll take some credit. We live with the consequences of power mobility: the weight of the chair we now transport, another battery needing nightly recharging, the sloppy driving which has led to scarred walls and doors, and even a broken toe from being run over. We happily accept it all for the freedom, self determination and joy that have resulted.

HMS promoted Jordana to "independent" driver this year, a developmental milestone worthy of shouting from the rooftops. She is now a young woman who can express herself physically in the world, on her own terms, on her own, having found her sweet spot. How very, very sweet it is.

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They choose things he can bring to ease the hospital stay. Ms. Turek prepares a "goodie bag" of supplies—play dough to squeeze away pain, bubbles to help with deep breathing and to pop as a distraction, perhaps joke books or a cd of the child's favorite music or a "magic wand" to touch the places that hurt. She may add activities on his communication device to take his mind off hospitalization—"I want to watch TV," "play a game," "take a walk."

The child's teacher may talk about an upcoming hospitalization in class, if appropriate. Kevin Rafferty, who works with older students says, "Sometimes there's even more anxiety for classmates—they envision themselves in that hospital situation. If they're constantly asking about it, I know they're mulling it over."

Surgical procedures can limit the child's ability to communicate in the hospital—casting or positioning changes may restrict access to his communication device. His speech therapist might plan pre-hospital training with a different mode of communication—a language board or pictures—or a different way for the child to access a scanning switch. Depending on the planned procedure, a therapist may also gather baseline data pre-surgery to compare with post-hospitalization changes.

When a youngster enters the hospital, HMS remains in touch. Staff members close to the child visit with the parents' okay. Classmates send cards and drawings. The social worker places photos in the hospital room picturing the student in school and at his best to show hospital staff the child's abilities when well. Someone from physical therapy typically stops in to fine-tune wheelchair adjustments for new positioning or body height. Staff check in regularly with parents.

At school, therapists are preparing for the student's return. They order equipment to accommodate post-surgery needs and plan for alternate positioning in the classroom so the student can participate in his program rather than remain in bed.

"The therapists were so involved, they couldn't have done anymore," say the Hacketts, whose son recuperated at home for three weeks before a gradual return to school.

On Buddy's first day back, the Hacketts participated in a meeting of the full team to share post-hospitalization information and to discuss plans for their son's readjustment to school. They spent time with Mary Anne Bayne, director of nursing services and CNAs, who practiced Buddy's wheelchair transfers and personal care.

"It's the team approach that makes it happen," says Barri Alexander, physical and occupational therapy coordinator—"education, the therapies, nursing, the child's CNAs. HMS is good at getting the child back into his program. We can make a lot of classroom accommodations... Success depends on good communication with the family and the staff team."

"Communication is what it's all about," agrees Ms. Bayne. "We need to know what's key to making the student comfortable... And HMS has the ability to do that with round-the-clock nurses to manage pain and wound care and in-house therapists. It's routine for HMS."

For residential students, HMS also gathers information on changes in nighttime routines: bathing and toileting, sleep positioning, pain control, dietary and feeding changes and specialized equipment. Nurses encourage parents' evening calls for updates on their child.

When an emergency illness results in hospitalization, preplanning is impossible. But, support to the family and child is even more

important. All other HMS protocols remain in place during the student's recuperation and return to school.

It takes time for a youngster to heal, adjust to body changes and get back up to speed in school. HMS's team flexibly accommodates these challenges. Teachers work at the child's pace. Therapists adjust training sessions and equipment in response to surgical procedures—staff are alert to changes in lung capacity and respiration, swallowing and feeding, positioning and access. Weekly rounds, together with informal team information-sharing, keep staff and the family up to date.

A child's hospitalization is always stressful. But HMS's expertise, caring and flexibility make a tough situation more bearable.



### HMS School News

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A publication of HMS School for Children with Cerebral Palsy, dedicated to reporting about student life, school programs and important events.

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HMS School is nonsectarian, admitting children from any locality without regard to race, religion, gender or country of origin.

The Mission of HMS School for Children with Cerebral Palsy is to educate, nurture, and care for children and youth with motor impairments who may also have other disabilities resulting from brain injury with the goal of assisting each individual in achieving his or her maximum potential. HMS School aims to facilitate independence and improve the quality of life for its students in a safe and secure environment so they can lead fulfilling, stimulating lives in their present and future environments.

