

Momentum.

Mary Free Bed Rehabilitation Hospital Foundation Newsletter

Volume 19 / Summer 2019

Mary Free Bed[®]
Rehabilitation Hospital Foundation



UPCOMING EVENTS

July 12-14
**Midwest Wheelchair
Tennis Championships**
MVP Athletic Club, Crahen

July 22-26
**Junior Wheelchair
Sports Camp**
Grand Valley State University

Sept. 7
**Rhoades McKee Reeds
Lake Triathlon**
(Mary Free Bed is
charitable beneficiary)
East Grand Rapids

Sept. 17
**A Mary Evening at
One Trick Pony**
Fundraiser to support
Mary Free Bed's Stroke
Program
One Trick Pony

Nov. 2
**Thrive – Mary Free Bed
Foundation Gala**
DeVos Place

WHAT'S NEW

YOUNG STROKE SURVIVOR SHARES HOW REHABILITATION TURNED 'DOUBTS INTO DREAMS'

Lauren Ziegler is a 21-year-old college student who loves to work out and prides herself on living a healthy lifestyle. When she woke up Dec. 6 to get ready for class, the Grand Valley State University senior knew something was seriously wrong.

"I kept collapsing, and I wasn't able to get back up off the ground," said Lauren, who was able to crawl to her phone and call her sister for help.

After Lauren arrived at Spectrum Health Butterworth Hospital, doctors determined she had experienced a massive stroke that caused paralysis on one side of her body and a host of other complications. Spectrum's team worked to save her life, and two weeks later she was medically stable and ready to begin acute rehabilitation at Mary Free Bed.

When she came on Dec. 18, Lauren couldn't stand without assistance or care for herself. During the next several weeks,

she participated in the Stroke Program's high-intensity gait training to regain strength and endurance. Lauren initially struggled to take steps without support, but slowly and steadily made huge gains.

High-intensity gait training has been the focus of a long-term collaborative research study to identify rehabilitation protocols that facilitate better and faster recovery from a stroke, particularly walking. The study, in its fifth year, has included 461 patients.

Lauren worked diligently in physical, occupational, speech and recreational therapy, focused on meeting her goals.

"As the weeks went on, I began to believe I would walk out of the hospital," said Lauren (pictured above), who shared her journey of survival with 300 guests at the *Let Freedom Spring* luncheon on May 15, the Mary Free Bed Foundation's

annual fundraiser. "Then I began to believe that walking wasn't good enough – I wanted to run."

Her team provided those challenges and encouraged her along the way, helping her battle to achieve that goal. When she graduated from Mary Free Bed on Jan. 25, Lauren did run out of the hospital.

She continued to make strides in outpatient therapy near her Detroit-area home and plans to return to GVSU to finish her undergraduate degree before pursuing an advanced clinical degree.

"I'm not certain what my future would look like without Mary Free Bed," Lauren said. "I have determination and faith, but without the intensive therapy and specialized care, I don't think I would be back in the gym, attending school,

Continued on page 2

A MARY TOUR

Join us for a tour of Mary Free Bed. Space is limited, and reservations are required. Email foundation@maryfreebed.com, or call 616.840.8137.

Tours begin at 11 a.m. July 23, Aug. 14, Sept. 17 and Oct. 16.

living in my own apartment, and I certainly don't think I'd have the hopeful outlook that I have now."

Last year, the Mary Free Bed system of care treated 1,454 stroke survivors in its inpatient programs. Led by a physician who specializes in stroke rehabilitation, the team uses innovative therapies and technology to develop a personalized care plan for each patient. The program exceeds national benchmarks for the number of patients able to return home or to a homelike setting.

"Mary Free Bed is on the leading edge of stroke care," CEO Kent Riddle told attendees.

The high-intensity gait training study, a collaborative effort between Mary Free Bed's Center for Research & Innovation and the Shirley Ryan Ability Lab in Chicago, has proven to show early intervention facilitates better, faster recovery.

The Stroke Program treats patients of all ages, from children to adults. And now, Mary Free Bed experts can treat babies shortly after they're born.

When an adult has a stroke, the symptoms are recognizable and its effects obvious. Rehabilitation begins immediately, and many adults recover mobility and function.

It's difficult to detect a stroke in babies, something that often leads to cerebral palsy. Experts in the Mary Free Bed Kids Early Development program are trained to perform an emerging technique called General Movement Assessment that analyzes movement patterns. GMA can detect neurological problems and help clinicians diagnose cerebral palsy much sooner. Early diagnosis and intervention are key to improving a child's capabilities and reducing the lifetime cost of care.

"This is brand new in the field of medicine," Riddle said. "We're really excited about it."

'FULL PEDS AHEAD' INITIATIVE BETTERS ACCESS TO CARE, CREATES BRIGHTER FUTURES

Improving the lives of children and teens with disabilities has been an important part of Mary Free Bed's mission for more than a century. Recently renamed Mary Free Bed Kids, the hospital's specialized pediatric programs and services were developed and continue to evolve with our youngest patients in mind.

Mary Free Bed is the only inpatient rehabilitation hospital in Michigan with a unit just for children and teens. Each year, the hospital provides comprehensive rehabilitative care for about 130 inpatients and specialized outpatient services and resources in Grand Rapids and Holland.

"Full Peds Ahead – An Initiative for Kids at Mary Free Bed" is a robust undertaking to improve access to care. The Mary Free Bed Foundation launched the initiative to raise \$10 million over the next 10 years. It's the catalyst to grow Mary Free Bed pediatric programs and increase support for uninsured and under-insured children. The Foundation is also embarking on an effort to increase the Pediatric Endowment to \$20 million over the same 10-year period to fund the program in perpetuity.

While Mary Free Bed Kids provides care for young patients recovering from a wide range of illnesses and injuries, the program includes new and expanding specialties. Here's a glimpse:

AUTISM

- Autism Spectrum Disorder is a developmental disability that can cause behavioral, communication and social challenges. The number of kids diagnosed with ASD is growing rapidly, according to the Centers for Disease Control and Prevention, which estimates that one in 59 children in the United States has it.
- Mary Free Bed Kids offers specialized diagnostic and intervention services for children with ASD and other neurodevelopmental disorders.

Treatment may include Applied Behavioral Analysis, a scientific model of care that uses specialized interventions to build necessary skills and reduce or eliminate problem behaviors.

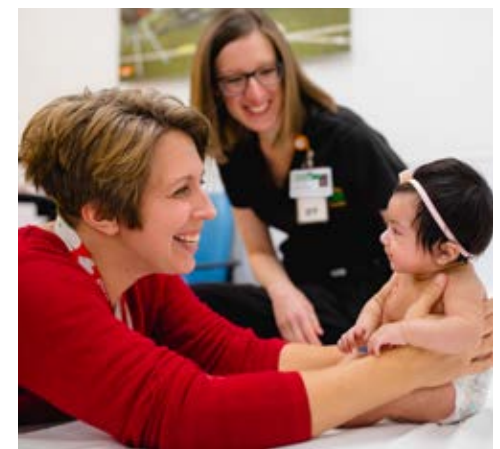
- Mary Free Bed recently became an Approved Autism Evaluation Center, having met criteria developed by Blue Cross Blue Shield of Michigan and Blue Care Network to provide comprehensive assessments to make or confirm an Autism Spectrum Disorder diagnosis.

CEREBRAL PALSY

- The most common childhood motor disability, cerebral palsy affects one in 323 children in the United States, according to the CDC. It primarily affects movement and posture, but also can cause problems with vision, hearing and speech.
- Mary Free Bed Kids provides comprehensive rehabilitation and a proactive rehabilitation plan to promote movement, self-care and communication skills.
- Children with muscle spasticity caused by cerebral palsy or other movement disorders may find help in the Advanced Management of Pediatric Spasticity Program, a collaborative partnership with Helen DeVos Children's Hospital

CHRONIC PAIN

- Chronic pain – defined as persistent and recurrent – doesn't always have a physical source. The most common conditions are headaches and musculoskeletal or abdominal pain. Sometimes it's associated with a long-term illness or health condition; sometimes there's no known cause.
- Mary Free Bed is in the process of developing comprehensive, multi-disciplinary program to assess and treat children with chronic pain.
- Specialists will work with patients and their parents to develop a personalized



rehabilitation plan that incorporates innovative treatments such as physical and occupational therapies combined with cognitive behavioral therapy, a mindfulness-based treatment approach.

EARLY DEVELOPMENT

- Babies learn skills and grow at different rates, but parents concerned about their baby's growth or development can be evaluated by the Mary Free Bed Kids Early Development team.
- Specialists provide comprehensive medical assessments for babies from birth to the age of three to determine if development is normal or to identify a problem that suggests services and support are needed.
- Experts are trained to perform an emerging technique called General Movement Assessment that analyzes movement patterns in babies three months old and younger. The non-invasive test can detect neurological problems and help clinicians diagnose cerebral palsy much sooner.

To learn more about supporting Full Peds Ahead at Mary Free Bed, please contact Darrow Goodspeed at 616.840.8196 or darrow.goodspeed@maryfreebed.com.

STORIES THAT MOVE YOU



EVERLYN THRIVES IN FACE OF RARE DIAGNOSIS OF OSTEOGENESIS IMPERFECTA

Evelyn Franchetti is a typical 3½-year-old. She loves singing and dancing, princesses and puppies.

When she arrives at preschool, Evelyn looks around the classroom and declares “These are my friends!” before scampering off to play, protected by her bright red walker.

The happy-go-lucky little girl doesn’t need the device to help her walk. It’s a shield.

Evelyn has osteogenesis imperfecta, a rare condition commonly known as brittle bone disease. OI is a genetic condition characterized by bones that break easily, sometimes from as little as a sneeze or a hug. According to the Osteogenesis Imperfecta Foundation, at least 20,000 people in the U.S. have OI.

Evelyn was diagnosed in utero when doctors noticed a fracture in one of her femurs during an ultrasound.

The diagnosis wasn’t a surprise to Drew and Dawn Franchetti. Drew has OI, and Dawn has achondroplasia, another rare genetic condition that affects the musculoskeletal system. It’s the most common form of dwarfism. There’s no family history of either condition.

“When we were interested in starting a family, we met with a geneticist,” Dawn said. “We learned our child had a 25 percent chance for only OI or achondroplasia, 25 percent chance of not receiving either gene or a 25 percent chance of receiving both.”

Dawn’s obstetrician ordered monthly ultrasounds to monitor the baby’s growth.

“When her bones started to develop, we noticed the fracture,” Dawn said. When Evelyn was born, the geneticist visited the Franchettis in the hospital and confirmed she also has achondroplasia. “With proper medical treatment, people with OI can live fulfilling lives.”

Evelyn’s journey with Mary Free Bed began when she was about five months old.

They worked with Mary Free Bed Orthotics & Prosthetics + Bionics clinicians, who fit Evelyn with a cranial remolding helmet to help her head grow correctly. Evelyn’s pediatrician referred her for physical therapy to develop strong muscles and safe movement.

“This is our third round of physical therapy,” Dawn said. “The first was to help with rolling over and lifting her head, the second to sit independently and stand, and now she’s a champion at walking.”

Julie Honeycutt, Evelyn’s physical therapist, said she continues to meet her goals.

“When we got started, Evelyn was so fragile and mom was so afraid,” said Julie, who explained the need to minimize fractures and strengthen a variety of muscle groups, prevent contractures and maintain a straight spine.

“This needed to be done slowly, but increasingly so Evelyn could do as much as she could with her muscles,” Julie said.

“This was attained by gentle, graded and specific handling techniques, and lots and lots of teaching and repetition.”

The walker was ordered for support and protection in crowded environments.

“We can’t risk her getting knocked down,” Julie said. “She still falls occasionally and can catch herself, but we still have much more work to do, so she can be safe.”

Evelyn, for one, likes her visits to Mary Free Bed: “I like to play with the baby. I like the rocket. Julie is funny.”

Her physical therapy is part of an extensive medical care plan that includes infusions every four months to strengthen her bones. She also sees a geneticist, endocrinologist, orthopedist, pulmonologist and a cardiologist, who monitor her as she grows.

“Although we try to lead a ‘careful’ life, Evelyn has all the drive and more of an average 3½-year-old,” Dawn said. “She may be tiny and have fragile bones, but she loves to play, dance and sing! No one should be afraid to say hi and become a friend.”

While Evelyn hasn’t experienced additional fractures, Dawn and Drew know she’s fragile and are diligent about safety. Working with Julie has been “so impactful,” Dawn said.

“There’s always going to be a concern, but we can’t live in fear either. Our hope for her is that she leads a fulfilling life and learns that even with differences she can do anything she sets her mind to.”

MAKING A DIFFERENCE



Brad Kaufmann, Mike Avendt, Maria Besta, Jocelyn Dettloff, Laura Dulay, Patrick Lonergan, Tom Welch

FIFTH THIRD BANK JOINS COMMUNITY PARTNERSHIP PROGRAM

When selecting organizations to support in the communities it serves, Fifth Third Bank looks for those that may help its own employees and customers. Its mission to strengthen families and build strong communities complements Mary Free Bed's mission to restore hope and freedom through rehabilitation so people can achieve their highest level of independence.

That's why Fifth Third joined Mary Free Bed Foundation's Community Partnership Program.

"We are fortunate to have Mary Free Bed serve our community and the state of Michigan," said Tom Welch, regional president at Fifth Third Bank. "Mary Free Bed is rooted in caring and has a long history of helping people and their families rebuild their lives. Fifth Third Bank is honored to be part of it."

This year, Fifth Third will support Mary Free Bed's Wheelchair & Adaptive Sports Program and *Thrive*, the Mary Free Bed Foundation's gala.

The foundation's Community Partnership Program offers businesses the opportunity to support Mary Free Bed Rehabilitation Hospital at a significant level and gain greater visibility in the community and among its network members. To learn more about becoming a Community Partner, contact Laura Dulay at laura.dulay@maryfreebed.com or 616.840.8729.

GIFTS & GRANTS

DEVYN'S DEFENDERS

Eight-year-old Devyn Whitney has a pink prosthetic leg decorated with pretty sugar skull owls that glow in the dark. It drew a lot of attention on a hot day last summer, when Devyn and her family visited an art fair in their hometown of St. Joseph. And not in a good way.

"I was scared and sad, because people were staring at me," said Devyn, who was born without a fibula, a rare condition known as fibular hemimelia. She also was missing several bones in her hands, feet and toes.

She had several surgeries, including the amputation of her lower right leg. Five months shy of her third birthday, Devin was fit for her first prosthetic. She's had 10 since.

"Her amputation has never stopped her," said her mom, Stephanie Watkins.

While the experience at the art fair was difficult, it prompted Devyn to want to help other kids like her. The family decided to raise money for Mary Free Bed's Center for Limb Differences, where Devyn has been a patient since she was a baby, and sell bracelets with the words "Devyn's Defenders."

"It's gone above and beyond what we thought would happen," Stephanie said of the community's support for current and former patients.

Stephanie, Devyn and her twin brother, RJ, recently presented a check for \$1,600 to Dr. Michael Forness, above, and other members of Devyn's team at the Center for Limb Differences. It will be used to help fund the center's annual picnic.



ART WITH HEART

The DeMann family of Hopkins celebrated their daughter Madison's first birthday by accepting donations to make another child's day brighter.

Madison, who was diagnosed with torticollis (a shortening or tightening of the neck muscle that causes the head to twist to one side) a few weeks after she was born, participated in physical therapy and was fit by Orthotics & Prosthetics with a cranial helmet.

"We wanted to do something to give back, since Madison has been so overwhelmingly blessed with love and gifts during her first year of life," said her mom, Lydia, who invited guests to Madison's birthday party to bring art supplies for Mary Free Bed pediatric patients.

Lydia and Madison presented the donation to child life specialist Mariah Bruff, left, and foundation Annual Fund director Jocelyn Dettloff.



THANK YOU

The Mary Free Bed Foundation is grateful for the significant support from the following generous donors and organizations:

AdvisaCare
Airway Oxygen
CareLinc Medical
Edward N. and Della L. Thome Memorial Foundation, Bank of America, N.A., Trustee
Fifth Third Bank
Fremont Area Community Foundation

Frey Foundation
Gillett Family Foundation
Grand Haven Area Community Foundation
Korff Foundation
Lake Michigan Credit Union
Lewis and Norma VanKuiken
Meijer Foundation

Perrigo Company Charitable Foundation
Pete and Anne Eardley
Peter C. and Emajean Cook Foundation
Saladin Shriners
Take His Hand Foundation
Trace 3
United States Tennis Association, Inc.

A MARY EVENING AT OLIVE'S

Friends stopped by Olive's Restaurant on Wealthy Street in East Grand Rapids on May 1 to eat, drink and be merry. Proceeds from the popular annual event benefitted the Betty Bloomer Ford Cancer Rehabilitation Program.



Laura Puff, Brad Kaufmann, Tim Pietryga, Ingrid Cheslek, Mindy Whiteside, Leslie Shanlian



Leslie Shanlian and Terence Reuben



Deb and Mike Damstra, Darrow Goodspeed

LET FREEDOM SPRING

The annual luncheon May 15 at Frederik Meijer Gardens & Sculpture Park drew 300 guests, who donated \$70,000 for Mary's Mission to restore hope and freedom to patients.



Pam Buschle, Audrie and Lauren Ziegler



Betty Yeiter, Kate Dernocoeur, Pat Macholan, Tasha Blackmon



Joan Kullgren, Julia Tittley, Suzy Gill, Ellen Nelson, Susan Steketee

A MARY EVENING ON WEALTHY FEATURING PROSTHETICS, PAWS AND PARTNERSHIPS

Guests enjoyed hors d'oeuvres and beverages while strolling around the Mary Free Bed lobby on May 9 to meet some of the hospital's expert clinicians and learn about just a few of the programs and services for patients and their families.



WHERE ARE THEY NOW?

CARE GRANTED: GABRIEL USES PERSONAL EXPERIENCE TO HELP OTHERS

Gabriel Grant was an 18-year-old high school graduate looking forward to going to Grand Rapids Community College to play golf as a walk on. But when a tire blew on the car he was riding in, Gabriel's life took a different path.



Gabriel broke his neck and became a quadriplegic in the 2009 crash. After spending a month in an acute care hospital, he went to Mary Free Bed to start his journey to independence. He spent the next year participating in therapy, first as an inpatient. He was one of the first patients to stay at the Inn at Mary Free Bed, which allowed him to practice living independently and continue with outpatient therapy.

To stay connected to athletics, Gabriel joined the Rolling Thunder, Mary Free Bed's quad rugby team. Two years later, Gabriel's dream of playing collegiate sports became a reality when he was offered an athletic scholarship to play quad rugby at the University of Arizona.

During his recovery, Gabriel struggled to find quality home care. That personal experience led him to build his own home-care business, Care Granted, in 2016. Gabriel also has worked with ArtPrize to improve the event's accessibility.

What's on the horizon for Gabriel? Marrying his fiancé, Angel, in November, continuing Care Granted operations and focusing on accessible housing.

"I am an entrepreneur at heart, and there needs to be more accessible housing available in the city of Grand Rapids," said Gabriel, who now splits his time between Phoenix and Grand Rapids. "After I left Mary Free Bed, I lived in downtown Grand Rapids until moving to Arizona. I loved being part of the action. And people with disabilities need to be part of the action."



Gabriel and his father, Frank, golfed together in the foundation's 2018 golf outing.

JULIE CELEBRATES MILESTONES AFTER SURVIVING MASSIVE STROKE

On an April day 10 years ago, Julie Scheving's life changed. The former Holland resident experienced a massive stroke that limited her ability to talk and move. But when she began her rehabilitation journey at Mary Free Bed, Julie took steps to get her life back. And she's done just that.

A decade later, Julie returned to Grand Rapids – armed with tasty treats – to visit her team and offer her thanks. She swapped stories with therapists and nurses, and shared encouragement with current patients on their path to recovery.

"You'll never be the same again," Julie said. "But you will find a new normal, a better way. I think I see life better now than I did before."

To watch a video about the reunion, please visit maryfreebed.com/the-right-motivation.



Julie Scheving (center) talks with a patient and physical therapy assistant Glenn Tamminga.

GUILD HIGHLIGHTS

KIDS, ADULTS TAKE ADAPTIVE WHEELS FOR A SPIN AT BIKES FOR THE REST OF US

Bike rides are a summer staple, and Mary Free Bed wants to ensure everyone can join in the fun. The 24th annual Bikes for the Rest of Us, sponsored by the Mary Free Bed Guild, will help to make that possible.

More than 80 children and adults with disabilities were paired with therapists who assisted in matching their physical needs with the most appropriate cycling equipment. Whether the children or adults sustained a life-altering injury or illness, or were born with a disability, the event made it easy for families to try multiple bikes and find the best fit.

“An adaptive bike is going to give Violet a lot of freedom that she has never had before,” Cynthia Pratt said about her daughter, Violet, who participated in the April 27 event.

More than 70 volunteers participated, including Mary Free Bed therapists, nurses, staff and guild members. The event featured cycling equipment demonstrated by local and regional bike shops, medical equipment suppliers and manufacturers.

“We’re here to support participants and help offset their cost – through the generosity of our guild – for a bike that’s adapted just for them,” said Maria Besta, manager of Mary Free Bed’s Wheelchair & Adaptive Sports Program.

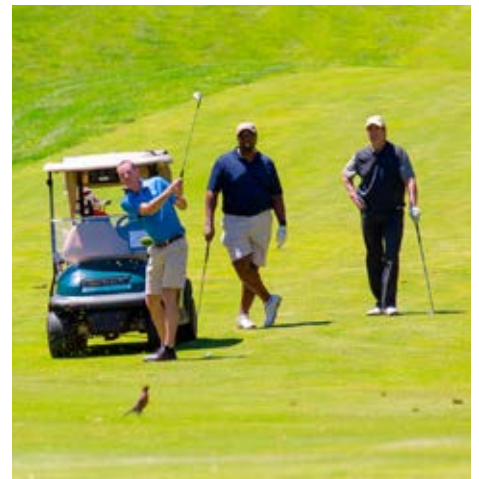
The guild contributes to the purchase price for children and adults with a disability who received Mary Free Bed services and demonstrated financial need.



Congrats to the amazing athletes who participated in the May 11 Amway River Bank Run. It's the largest road race in the country and the only race in the world to offer a 25K wheelchair division. This marked the 30th consecutive year the Mary Free Bed Guild has sponsored the wheelchair division and the 14th for the handcycle division.

WHEELCHAIR & ADAPTIVE SPORTS

More than 220 golfers teamed up to support Mary Free Bed Wheelchair & Adaptive Sports during the annual Golf Outing June 3 at Thousand Oaks. Generous individual donors, businesses and foundations provide 95% of the funding for WAS, which offers competitive teams, clinics and classes for people with disabilities.



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CONTACT

Phone: 616.840.8137

Web: maryfreebed.com/foundation

Email: foundation@maryfreebed.com

STAFF

Timothy J. Pietryga

Vice President, Advancement

Darrow Goodspeed

Major Gifts and Donor Relations Director

Brad Kaufmann

Director of Planned Giving

Jocelyn Dettloff

Annual Fund Director

Laura Dulay

Sponsorship and Events Manager

Kelly Fitzgerald

Administrative Assistant

Help us to be even more "green." Email foundation@maryfreebed.com to receive this publication electronically.

To be removed from our mailing list, please call 616.840.8137.

WISHLIST

The Mary Free Bed Foundation often receives requests from clinicians for specialized equipment and technology to help patients during their rehabilitation journey. If you'd like to fulfill a wish, please contact Darrow Goodspeed at 616.840.8196 or darrow.goodspeed@maryfreebed.com.

Activity-based toys – Cash donations of any amount will be gratefully accepted to purchase toys, such as a picnic basket, cash register, farm and toys for a camping.

Free-standing grab bar (\$200) – Used for balance in therapy.

Pediatric Moon Swing (\$315) – Addresses bilateral coordination, balance, strength and vestibular input.

Large tumble form rolls (\$600) – Designed with effective rehabilitation and fitness applications in mind; used in positional and neurodevelopmental training and for patients with special needs.

Go Baby Go ride-on toy cars (\$1,000 per car, 12 requested) – The Go Baby Go program, in conjunction with Mary Free Bed Orthotics & Prosthetics, modifies battery-operated, ride-on toy cars for children 1-4 years old with disabilities. The modified cars provide ways to explore, play with their peers, ride along with siblings and interact with their parents in innovative ways.

Educational materials for children with feeding difficulties (\$1,500) – Nutrition information guides, specialty nutrition plates, placemats, feeding cups and totes for patients to take home; assist in teaching and reminding both children and their parents about proper nutrition and healthy eating habits.

Enthermics blanket-warming cabinet, blankets (\$3,600 each, four requested) – A blanket warming cabinet stores and warms linens, blankets, hospital gowns and sterile intravenous (IV) and surgical irrigation fluids in a medical environment. A warm blanket can ease anxiety and stress our patients feel during their recovery.

FINAL NOTES

- Have you remembered Mary Free Bed in your estate plan? If so, let us know. Contact Brad Kaufmann, director of Planned Giving at 616.840.8898 or brad.kaufmann@maryfreebed.com.
- Mary Free Bed's Marketing Department won a PProof award from the West Michigan chapter of the Public Relations Society of America for its creative and artistic work on materials for the foundation's *With a Mary Heart* Employee Giving Campaign.

