

Sweet Charity

Spring 2019 Volume 112, Issue 1

A Good Shepherd Publication



Discovering Our Human Resources

Dear Friends,

Before retiring (for the first time), I spent many years working in human resources for another company. I came to appreciate the varied talents and character strengths we all bring to our professional and personal lives. When the road gets rough, our ability to be resilient and keep forging ahead gives new meaning to the phrase "human resources."

Through the many years that I have been involved with Good Shepherd as a board member and now interim president and chief executive officer, it has been a privilege to see the human resources of our associates, volunteers, patients, and residents shine when a beacon of light is needed most.



Drawing on their resources of expertise and compassion, every day Good Shepherd's associates rise to the challenges of those who come to us seeking hope and healing. Volunteers contribute resources of time and talent. Patients, residents and their families inspire us with their inner resources of strength and faith to triumph over great adversity.

In this issue, you will read stories that show human resources at their best. Liselly Diaz shares her story of determination to find an explanation for her son's baffling symptoms, and how Good Shepherd is helping him become stronger and more independent. Six years after their son Johnny was born prematurely, Tara and Chris Webb reflect on their journey as parents and how it brought them even closer together. And Chris Loughman talks about the stroke that his wife Gail suffered and his persistence in finding a better place for her to live, a place called Good Shepherd.

We all have human resources. How we use them says a lot about who we are. Donors like you are vital, helping us to invest in staff education, programs, technology, and charitable care. As you contemplate making a gift to Good Shepherd, know that your financial resources enable the human resources that serve to strengthen our mission.

Thank you.

A handwritten signature in black ink that reads "Gary Schmidt". The signature is fluid and cursive, with a long, sweeping underline.

Gary Schmidt, MA
Chair, Board of Trustees
Interim President & CEO

Super Boy

Luisiel Diaz was only four when he had brain surgery to stop the frightening seizures that had baffled doctors for months. Now seizure-free, Luisiel is charging full speed ahead with his super spirit and help from his friends at Good Shepherd.

4



Cover photograph: Randy Monceaux



8

Love Will Keep Us Together

After a debilitating stroke, Gail Loughman found more than a home at the Good Shepherd-Raker Center in Allentown; she found hope.



16

The Women's Circle Festive Gathering

Cozy ambiance and the warmth of friendship in an historic stone house made this annual holiday get-together special.



18

Solace for the Soul

Good Shepherd associates honor and pay tribute to colleagues past and present by funding a chapel's long overdue facelift.



Where Are They Now?

Six years ago, Johnny Webb was featured on the cover of *Sweet Charity*. Today, this handsome and engaging little boy is rocking his world.

20

Reflections By Chaplain Kelly Brooks **12**

Donor Generosity Funds New Van **14**

Gifts of Love **24**

On the cover: Luisiel Diaz and Carol Knauss, physical therapist

Our Mission

Motivated by the divine Good Shepherd and the physical and cognitive rehabilitation needs of our communities, our mission is to enhance lives, maximize function, inspire hope, and promote dignity and well-being with expertise and compassion.



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Super Boy



Liselly Diaz watched in disbelief as the little boy in the store had a temper tantrum that would mortify any mother. If it was someone else's child, as she had witnessed other times, Liselly could have walked away, quietly grateful that she didn't have to deal with the situation.

This time though, Liselly couldn't walk away. This time, the child behaving so badly was hers. But such a public display was not at all characteristic of four-year-old Luisiel, a spirited and outgoing little boy who was always happy. "I was so embarrassed with the way he was acting," says Liselly. "I didn't know what was going on."

Liselly, her husband Luis and Luisiel were on a Thanksgiving weekend trip to Atlantic City, New Jersey, in 2017, when Luisiel began acting strangely. "That weekend he got really hyper and uncontrollable," says Liselly. "He was having three or four episodes a day lasting about five minutes each, but then he would just go back to playing around."

During these episodes, Luisiel's body would stiffen and his face flush bright red. Alarmed, Liselly took Luisiel to an urgent care center as soon as they arrived home. Luisiel complained of a belly ache. An ultrasound and x-rays were needed so Liselly took Luisiel to the emergency room of a local hospital. The tests led doctors to think Luisiel might have a serious and painful condition where part of the intestine slides into an adjacent section.

Luisiel was immediately transported by ambulance to a Philadelphia hospital. "It was terrifying," says Liselly. "It was the first time he had any sort of medical condition. They



Pool therapy feels like play with Carol Knauss, physical therapist.

kept us there overnight." Another round of tests showed Luisiel was suffering from constipation. He was released the next day and sent home to fast and cleanse for 24 hours.

Luisiel's symptoms disappeared for about a week, but to his parents' dismay came back. Over the next three weeks, Luisiel was in and out of the hospital and underwent a battery of diagnostic tests. Doctors finally determined that Luisiel was actually having seizures. The cause, however, remained elusive and they were getting worse, progressing from every two hours to every five minutes. "His heart rate was going up to 200 every time and the seizures were lasting 10 minutes," says Liselly. "I was worried about him having a stroke."

Luisiel was airlifted to the Children's Hospital of Philadelphia (CHOP) where he remained for the next four months. Doctors were baffled. A more invasive approach to solve the medical mystery was needed. In a surgery that lasted several hours, neurosurgeons at CHOP drilled 15 holes in Luisiel's skull and inserted electrodes to monitor and identify the area of the brain where the seizures originated.



Luisiel with Shelby Brown, occupational therapist.

After a week of monitoring, neurosurgeons removed the portion of Luisiel's brain believed to be the source of the seizures. "Unfortunately, the seizures did not stop. I think out of all the time I spent there, that was the worst," says Liselly. "Just seeing him with a bald head and a huge scar was really rough."

As disappointing as the surgery's results were, a pathology report became a critical piece of medical evidence leading to a diagnosis that was a game changer. Luisiel had Rasmussen's encephalitis (RE), a rare neurological inflammatory disease in one hemisphere of the brain. RE most often occurs in children under 10, according to the National Institute of Neurological Disorders. Over time, RE can lead to the progressive loss of neurological functions including motor skills and speech, and eventual paralysis on one side of the body.

Neurosurgeons proposed separating the abnormal right hemisphere of Luisiel's brain

from the healthy hemisphere to prevent the seizures from reoccurring, a not uncommon surgery for children with RE. "They said this would give him the best outcome possible," says Liselly. "His quality of life would be better with the surgery than without it."

The procedure would come at a cost though. Luisiel would lose the left visual field in both eyes and fine motor skills in his left hand. He also would likely walk with a limp.

For Liselly and Luis, as difficult as it was to learn of the diagnosis, it was a relief finally to know what was causing the seizures, and that surgery was a viable option to prevent them from occurring. Here, at last, was hope.

On March 20, 2018, Luisiel had the surgery. For 12 hours, Liselly and Luis could only wait. Faith and the love of family who gathered around gave them strength. "I knew he would be okay," says Liselly who found comfort in listening to Christian music during the surgery. "We prayed a lot and had a lot of prayers coming toward us."

The results were nothing less than a miracle. "Luisiel had no seizures after that day, which was the goal," says Liselly.

On April 3, 2018, Luisiel was admitted to the Good Shepherd Rehabilitation Hospital Emily Howatt Pliskatt Pediatric Unit in Bethlehem, just a couple of miles from the Diaz's home. Luisiel's side effects from the surgery were as predicted with the left side of his body most affected.

Luisiel had to relearn everything, including how to walk. His left arm and hand were non-functioning and his left foot shook constantly. Luisiel also lost the left visual field in

both eyes and needed speech therapy to help with cognitive deficits that affected his attention span and comprehension.

Two months later, Luisiel went home. Luisiel continues to receive speech, physical and occupational therapy in Good Shepherd's outpatient Pediatrics Program where his engaging personality and spirit keep his therapists challenged almost as much as they challenge him. Using a variety of tools and techniques from warm water pool therapy to an iPad, Luisiel's balance, strength, fine motor skills, and range of motion have improved.

Luisiel also benefited greatly from the ZeroG®, a system that uses a ceiling track and harness to partially support body weight and reduce the risk of falling. Good Shepherd is the only rehabilitation facility in the area to have the ZeroG, giving patients like Luisiel an advantage in their recovery. Now Luisiel can walk and run around on his own, although always with someone keeping a close eye on the rambunctious little boy.

"He's really motivated by physical therapy and gross motor activities," says Amanda Kleckner, a physical therapist and manager of rehabilitation services for outpatient pediatrics. "Part of the reason he had so much trouble taking steps is because his brain wasn't recognizing the left side of his body, so sometimes

he would take a step putting his foot down in the wrong location making it unsafe to put weight on that foot."

Luisiel also has regained some use of his left arm and hand. "Now he can lift his arm partially or use it to help hold something," says Amanda. Speech therapy is focusing on improving Luisiel's attention span and other cognitive deficits. Soon Luisiel will start vision therapy in Good Shepherd's Vision Therapy Program.

Now five, Luisiel seems to be taking everything in stride, dashing about with seemingly boundless energy, playing video games with his father, idolizing the superhero Black Panther and looking forward to trips this summer to Dorney Park. "I'm glad his personality didn't change at all," says Liselly. "He's in kindergarten now and he's doing awesome in terms of socialization. He is super, super strong. The way he's taken everything is just incredible. Nothing can bring him down. I hope he remains that way."

Luisiel's impish grin assures his parents that he will.



*Luis, Luisiel and
Liselly Diaz at home.*

Love Will Keep Us Together

The first time Chris Loughman saw the woman who would one day be his wife it was at a popular Allentown night club. Gail Balliet was beautiful and no pushover. Chris gave it his best shot and bombed out. "I asked her for her phone number but she wouldn't give it to me," he says.

A few weeks later, when their paths crossed again at the same club, Chris's charming persistence won the day. He got the phone number and he got the girl. After dating for two years, Chris proposed to Gail in Puerto Vallarta, Mexico, while on vacation. They married on May 25, 1985. It's a date that now brings mixed emotions because on around the time of their anniversary thirty years later in 2015, Gail suffered a stroke. She was 58 years old.

Today Gail lives at the Good Shepherd Home-Raker Center in Allentown, where Chris and their beloved German Shepherd, Kobi, are favorite visitors of all the residents.

Although their married life hasn't turned out as planned, Gail and Chris are making the best of it and the love affair that began all those years ago is still going strong.



Gail is a country girl at heart, born and raised in Tamaqua, a small town in the coal region of northeast Pennsylvania. "I loved playing outside and riding my bike," says Gail. "I could go anywhere."

After graduating from high school, Gail worked as a medical secretary for 13 years. It was a job she loved. When her father needed help in the family heating oil business though, Gail dutifully answered the call and signed on as office administrator. Under her watch, the office was modernized, making it more efficient.

Gail and Chris added a daughter, Mallory, to their family in 1992. Chris also eventually joined the family oil business. Family vacations at Long Beach Island were treasured times. "We're both beach nuts and we love seafood," says Chris. During those long, leisurely summer days, Gail couldn't get enough to eat of oysters, soft-shell crabs and a favorite delicacy, cold water clams from Cape Cod.

Life settled into a comfortable rhythm. Then Gail suffered her stroke. "She had been experiencing symptoms for about two weeks leading up to the stroke," says Chris. "High blood pressure, double vision, dizzy spells. She was unsteady on her feet and had tingling on her right side. I begged her to see the doctor."

But Gail ignored the warning signs and kept going with her busy schedule at work and at home. The night of her stroke, Chris was asleep on the couch downstairs. An early riser, he didn't want to disturb Gail. "I heard what sounded like a cat outside," says Chris. "Then I realized it was inside. I went upstairs



and Gail was trying to get out of bed. She looked at me with terrified eyes."

Gail was virtually paralyzed. "I woke up and couldn't move my right side," says Gail, who speaks with great effort but is slowly improving.

Gail was airlifted to a local hospital. A blood clot had formed in Gail's basal artery, depriving her brain of blood and oxygen, and causing a stroke. Gail was flown to a Philadelphia hospital for the delicate surgery. "They told us that if she lives through this, she'll be brain dead," says Chris.

At 5 p.m. that Saturday night, the clot was removed. To everyone's immense relief, Gail survived. She spent the next month in a medically-induced coma. When she regained consciousness, Gail couldn't move any of her limbs. "She had locked-in syndrome," says Chris. "She could only move her eyes. She was on a breathing machine and had a feeding tube in her stomach. We were living by the moment. It was surreal."

After six weeks, Gail was transferred to the Good Shepherd Rehabilitation Hospital in



Allentown. Five and a half weeks later, Gail went to a nursing home in Pottsville. She remained there for one year but only had three hours of therapy a week. "They ignored her," says Chris. "She just lay in bed. She was regressing very quickly."

Discouraged by the quality of care, Chris transferred Gail to another nursing facility where she continued to languish. Chris and Mallory knew there had to be someplace better for Gail. Research on the internet and a personal referral from a family friend led them back to Good Shepherd's long-term care homes. Chris scheduled an interview for him and Gail to meet with admissions staff for evaluation. By the end of the meeting, everyone knew that Good Shepherd was the place for Gail.

It took another four months for a bed to become available. Finally in December 2017, Gail moved to the Good Shepherd Home-Raker Center in Allentown. When she arrived, Gail was depressed and kept herself

covered up with only her head visible, says Shirl Erb, a physical therapist. Helping Gail gain confidence was a priority. A motorized wheelchair was just the ticket. Now Gail was no longer confined to her bed or a bedside chair. "Giving her that piece in the beginning was very important because it let her be more social and independent," says Shirl. "I think the depression started to clear. She had been very quiet."

To the delight of her husband, daughter, her therapists, and care givers, Gail has emerged from her cocoon with a beautiful face and smile that lights up when she sees her husband and Kobi. She now goes on shopping trips and enjoys date night at the movies with Chris.

Along with building her confidence, Gail is also building her strength. She has improved her ability to shift her weight and can stand briefly with help during transfers from her bed to her chair. "We're working towards transitioning to a standing chair because her trunk balance and ability to do standing things in a functional position is improving so much," says Shirl.

In addition to physical therapy, Gail also gets some form of occupational, speech and recreational therapy every day. Therapy team members work together holistically to address Gail's physical and emotional wellbeing. Working with occupational therapist Margee Wolf, Gail is getting back to everyday tasks. "One side of her body she couldn't use at all and the other side was weak," says Margee. "So to increase her independence we had to focus on strengthening the side that was least affected with activities she could do using one hand, like washing her face, brushing her teeth and hair, and upper extremity dressing."

May is Stroke Awareness Month

Remember to act **FAST** if you or someone you know is suspected of having a stroke:

Face — Does the face droop on one side when the person smiles?

Arm — After raising both arms, does one of the arms drift downwards?

Speech — After repeating a simple phrase, does the person's speech sound slurred or strange?

Time — If any or all of the above are observed call 9-1-1 and ask for medical assistance.

Gail is learning how to do laundry and starting to enjoy light kitchen work. Once a terrific cook and cupcake decorator, Gail has made lemon merengue and stuffed Italian peppers, a family favorite, with help from Margee. Lynn Lehman, another occupational therapist, helped Gail plan and shop for ingredients to cook a special lunch for her mother.

As part of her therapy to improve the dexterity in her hands, Gail painstakingly wrote 60 Christmas cards to fellow residents and staff. "That was touching to see," says Margee.

Staying connected through social media with family and friends is important to Gail. Soon after her arrival, Maryjane Frick, another occupational therapist working closely with Gail, set her up with a computer, an adaptive keyboard she can use with one hand, and a wheelchair accessible desk in her room. Another pastime bringing Gail joy is feeding the birds and squirrels who visit on the patio outside the Raker Center. Chris set up bird feeders and Gail always has a stash of peanuts to toss out to the squirrels.

"She's just inspiring to work with," says Margee, "because I am the same age as she is, so I can relate to how hard this is to have a husband and daughter and want to get back to the things that are so important in life.

It makes us work harder when she is so dedicated and willing to try her best in therapy."

Chris and Mallory are comforted knowing that Gail is in the best possible place. "Before it was a black hole of despair," says Chris. "They've done so much for her here. Now she's optimistic about the future. We don't have to worry about Gail."

Gail and Chris Loughman at the 2018 Raker residents' Campfire Ball.



“Ask and it will be given to you; seek and you will find; knock and the door will be opened to you. For everyone who asks receives; the one who seeks finds; and to the one who knocks, the door will be opened”

Matthew 7

Reflections

— by Chaplain Kelly Brooks

Spring is one of my favorite times of year. The touch of warmth from the sun reminds us that summer is coming. It is a time of awaking for nature and for people. The sun tells the earth to wake up after months of enduring the cold winter. The trees that once appeared dead begin to bud with new growth. Flower bulbs peak through the soil and blossom into brilliant colors.

Hibernating animals instinctively come out from their winter homes to celebrate the warmth of the season. One just needs to look around to find the rebirth that comes with spring.

Spring is a spark to awaken to new life. It isn't just the spark for nature, but it can be a spark for each of us to not only see the beauty around us but also to be renewed in our life directions. It is a time to take inventory of our blessings and show gratitude for gifts seen and unseen.

In the midst of shedding our winter coats and cleaning up the yard, we need also to come out of our hibernations and experience the fullness of the world around us that God has provided.

God offers us opportunities to continually be inspired with new energy and insights through his creation and word. God



encourages us to knock and ask for renewal within our lives. He gives us opportunities to revitalize our spirit and to breathe in fresh air that feeds our souls. We need to open new doors and delight in the senses that unfold around us. When we see things with new eyes, we become aware of the beauty that is imparted to us. We only need to take advantage of the possibilities presented.

Much like spring, Good Shepherd offers sources of renewal for many people. It is through dedicated staff members, who work with a calling and excitement to bring strength and healing to patients and residents. It is through the compassion of others that sparks of healing are ignited. It brings hope in a new vision of life surrounded with blessings. The Good Shepherd not only finds

and gathers the lost sheep but also tends to their spiritual, emotional and physical growth. Daily, there is a sense of hope springing forth in progress. Kind words and smiles are the beginning of a spark sent forth from God. Good Shepherd is spring all year round.

Spring is definitely a time of wonderment for all creation. Not only does nature reflect the beauty from within, but it invites us to blossom and reflect on our lives and experiences. When we discern and assess our own life, we realize what is important; supportive family, positive friends and faith. Although there may be times of hibernation and thought, spring is always around the corner when we open ourselves to God's splendor.

“Spring is definitely a time of wonderment for all creation. Not only does nature reflect the beauty from within, but it invites us to blossom and reflect on our lives and experiences.”

Donor Generosity Funds New Van

For the 159 residents of the Good Shepherd homes in Allentown and Bethlehem, independence is essential to their quality of life. But what most people take for granted, the ability to pick up and go anywhere at any time, isn't something our residents are able to do. Safe, reliable transportation for community outings is a necessity, and with so much use, Good Shepherd's vans eventually need to be replaced.

Seeing the need for a new van, a group of our residents' family members put forth a matching gift challenge with every dollar matched up to \$70,000. Thanks to more than 500 donors who rose to the challenge, the money was raised and a beautiful new van was delivered to Good Shepherd just in time for Christmas.

The van accommodates up to four passengers in wheelchairs plus additional passengers in seats. The van will transport residents to all of the activities, family celebrations and events that are so much a part of their independence.

Linda Sheets, a resident of the Good Shepherd Home-Raker Center in Allentown, pictured here with fellow resident Brian Wright, already has a trip in mind this summer. "I want to go to the beach," she says. No doubt the van will get her there in style.

You can support our residents' independence by making a gift to the Long-Term Care Community Access Fund. Please use the envelope in this issue or donate on the web at SweetCharityOnline.org. Thank you!



Estate Planning is for Everyone!

If you hear “estate planning” and think it’s only for people older or wealthier than you—or that it’s just too confusing—you’re not alone. Estate planning is for people of all ages and economic statuses, and it doesn’t have to be difficult. A well-planned estate includes a will and ensures that your accounts, property, and other assets will go to the people and causes you care about.

Check out these common misconceptions.

Myth #1. Estate planning is complicated and confusing.

It doesn’t have to be. A qualified estate planning attorney will guide you through the process and explain everything step by step. Your estate plan provides clear instructions to distribute your assets and makes a stressful time easier for your loved ones.

Myth #2. Estate planning is only for the wealthy.

The cost of estate planning may be less expensive than you think and it can save money in the long run – in both legal fees and taxes.

Myth #3. Wills are for older adults.

If you own a home or a business, have investments or minor children, or wish to distribute assets to someone other than a spouse, you need a will.

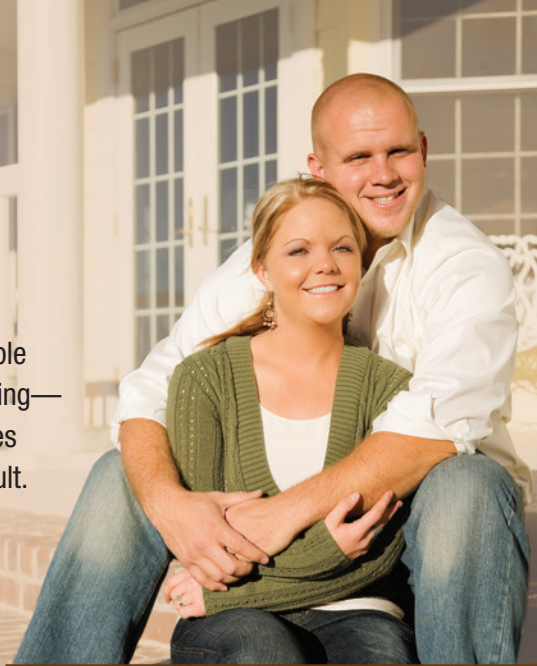
Include Good Shepherd in Your Plans

By including a gift to Good Shepherd in your will or estate plan, you create a legacy of caring that will support our mission and future. We have the expertise to work with your estate planning attorney and can suggest the right charitable giving strategy for you. Contact Jeannette Edwards at jedwards@gsrh.org or Greg Wilson at grwilson@gsrh.org or call us at 610-778-1075.

Get started today!

Call and request a free Personal Estate Planning Organizer or download your organizer at GoodShepherdRehab.org/planned_giving.

This information is not intended as legal or tax advice. For such advice, please consult an attorney or tax advisor.



WOMEN'S CIRCLE Festive Gathering



Candlelit ambience set the stage in the beautiful Laros Estate for the annual Festive Gathering of Good Shepherd's Women's Giving Circle on December 5, 2018. The event was hosted by Laura Bennett Shelton and Sharon Zondag of The R.K. Laros Foundation. Elegant hors d'oeuvres were provided by Capital BlueCross Healthy You Café and Catering.

Women's Circle members meet five times a year and hear proposals from Good Shepherd staff seeking funds for programs and staff education. Members review proposals presented throughout the year and vote on the programs they want to fund.

Wanda Kolipinski, outpatient pediatric assistive technology coordinator, presented on the need for funding to update the department's iPads which help children with communication problems be more independent. Wanda also requested funding for additional staff education in vision therapy, neuro-developmental therapy and speech therapy, and asked for funds to purchase new assistive technology that would advance pediatric treatment sessions.

Now in its tenth year, the Women's Circle began in 2009 with eight pioneering women. Since its inception, the group has grown to



70 members and contributed nearly \$500,000 to various Good Shepherd programs. The group was an honored recipient by Good Shepherd of a 2018 Distinguished Honoree award at the National Philanthropy Day Breakfast on November 15, 2018, at DeSales University.

Women's Circle chair, Anne Baum, has set a goal of reaching 100 members this year.

A tenth anniversary celebration is being planned for Thursday, June 20, at Gather in Emmaus.

For information on the upcoming celebration and joining the Women's Giving Circle, contact Dianne Spengler at dspengler@gsrh.org or 610-776-3559; or visit SweetCharityOnline and click on "Ways to Give."





SOLACE for the Soul

A hospital chapel gets a fresh look thanks to the generosity of Good Shepherd associates, and pays quiet tribute to loved ones gone but not forgotten.

Amid the daily hustle and bustle of a busy hospital, one room stands as a place for quiet reflection. Here in the Roberta Raker Hudders Meditation Chapel, residents, patients and visitors come to pray or just sit. Among those who find peace and solace in the cozy chapel with its stained glass windows is Frank Hyland, executive director and administrator of the Good Shepherd Rehabilitation Hospital in Allentown.

When Frank's mother-in-law Doris Basque died, her passing hit Frank and his wife, Diane, hard. Knowing how much Doris and the chapel meant to Frank, about 100 Good Shepherd associates contributed \$2,700 to replace the worn carpet with a gleaming new hardwood floor.

"Many of us wanted to figure out a way to show Frank how much we care," says Sue

Golden, regional director of outpatient rehabilitation, who spearheaded the fund raiser. "We thought the chapel was a place for Frank to go and be near people who were very dear to him. Church, from what I understand, was a very important part of his mother-in-law's life, so we thought it was fitting to dedicate something to her there. Nobody raised an eyebrow about giving."

The chapel was in need of more than a new floor though. Chaplain Kelly Brooks and the late Chaplain Paul Xander drew on funds from the chaplains' budget for a fresh coat of paint, a new prayer table personally chosen by Chaplain Paul before he passed away in April 2018, and new seat cushions on two benches. Two framed inspirational pictures were added; one in memory of Doris Basque and another in memory of the late Dr. Rodney "Rick" Schall, a beloved Good



Shepherd psychologist who died in August 2018 and was a close friend of Frank's. Also new to the chapel is a handcrafted baptismal font by Earl Schaeffer. The beautiful oak font had been used at the former New Jerusalem United Church of Christ in Fleetwood, where the Rev. Corrine Dautrich served prior to coming to Good Shepherd.

The renovations complete, on November 30, 2018, the chapel was blessed in a brief service officiated by Chaplain Kelly and Rev. Corrine.

"Diane and I were greatly touched and so grateful for this expression of love," says Frank. "It means so much to both of us that Diane's mother will forever be remembered. We were also moved that two of

Good Shepherd's finest, Rick and Chaplain Paul, were also honored. The renovations to the chapel are beautiful.

"I visit the meditation chapel at least twice daily, first thing in the morning and at the end of each day. It is a source of peace, inspiration, and hope for me."



Frank Hyland, rehabilitation hospital executive director and administrator, with Chaplain Kelly Brooks (center) and the Rev. Corrine Dautrich.

WHERE?

Are They Now?

JOHNNY WEBB



Since being featured in Sweet Charity in 2014, Johnny Webb has grown into a healthy and active little boy. Good Shepherd helped him get there.

"Tomorrow marks 6 years ago. The one day of the year I dread, sob and just try to forget. Everyone knows Johnny's story but very few people know the WHY..." Tara Webb posted that on her Facebook page on October 23, 2018. The "why" referred to the perilous medical journey her unborn son was about to embark on six years ago when Tara's water broke at 20 weeks, putting baby Johnny's life in jeopardy. Tara managed to hold on to Johnny for a while longer, but at 27 weeks, just seven months into her pregnancy, things took a turn for the worse.

On December 11, 2012, Johnny Webb was delivered by cesarean section. He weighed 1 pound, 11 ounces and was 13 inches long with skin so translucent you could see the veins just beneath the surface. You wouldn't have known it to look at him, but a warrior was born. In the weeks and months to follow, Johnny would need that fighting spirit to stay alive.

Six years later, and in the Webb household, December 11, Johnny's birthday, is Warrior Day. Tara and her husband, Chris, have turned painful memories when Johnny spent the first 10 months of his life in hospitals, into a day of celebration. "Instead of us just mourning, we're just so grateful to have a real live warrior," says Tara. "The menu on this day for the little boy who once was an infant too weak and fragile to eat, is Johnny's favorite foods: spaghetti and chocolate cupcakes.

The bond is strong between father and son. Chris calls Johnny his "mini-me."



Johnny keeps the 2014 issue of Sweet Charity by his bed at night.

"Instead of singing happy birthday, we sing happy warrior day," says Tara.

Johnny spent the first five-and-a-half months in the neonatal intensive care unit of a local hospital. Each breath from his tiny underdeveloped lungs was a battle to survive. In May 2013, Johnny was transferred to the Good Shepherd Rehabilitation Hospital Emily Howatt Pliskatt Pediatric Unit in Bethlehem. For Tara and her husband Chris, the next five months challenged their emotional fortitude as the pediatric rehabilitation team focused on strengthening Johnny's lungs and stamina so he could eat, suck and swallow. And, gain weight.

By the time Johnny went home he weighed 14 pounds, 4 ounces. Tara and Chris did therapy at home with Johnny, using skills taught to them by the Good Shepherd staff.

Johnny still needed supplemental oxygen and had some feeding problems, but Good Shepherd had done its job well and Johnny was in remarkably good health. "What was super amazing to me was when he was discharged from Good Shepherd that winter, never once did he need to be hospitalized for sickness," says Tara.

Johnny's sensory problems with many foods lingered. To keep him from losing weight and help with the regeneration of his lungs, Tara fortified his diet with high calorie foods like

avocados, mayonnaise and sour cream.

"Now he eats everything in sight," says Tara, rattling off a varied gastronomic list that includes cookies, chocolate milk, chicken, and waffles.

Looking at Johnny today as he races around the house playing with his brothers and sister, it's hard to imagine he once was no bigger than a ruler. "He's a daredevil, running and jumping," says Tara. "He's such a far cry from that wimpy little baby barely hanging on. Johnny is being raised to know what a fighter he is, and who is pivotal in that. Obviously Good Shepherd is in the center."

Johnny loves Peppa Pig, dancing, swimming, and "cooking" in the play kitchen at school. Johnny also loves to draw and has amassed a small library of books filled with his colorful drawings. On a recent visit to the house, as Johnny and Chris played with a toy fire engine it was hard to tell who was having the most fun. "He's a mini-me," says Chris



Johnny as a preemie in the neonatal intensive care unit.

(Below:) Johnny (center), with his family (from left) Christopher, 7; Georgia, 8; parents Tara and Chris; and AJ, 15.





(Above) Drawing is one of Johnny's favorite things to do.



(Left) Johnny playing with his sister Georgia.

with pride, noting that Johnny is very affectionate. "He likes kissing everybody and saying 'I love you.'"

Johnny is getting ready to start kindergarten in the fall. While he is on track with most of developmental skills, one goal is to improve his comprehension and speech. "We never knew if he was going to be a productive citizen of society and be able to take care of himself," says Tara, "but now we're starting to see things come together. He's very good with his social skills and he likes to do things himself."

Chris and Tara remain close with Johnny's therapists on the inpatient unit, and are grateful for all they did for Johnny and for them.

"Johnny wouldn't have been who he is today if didn't go to Good Shepherd," says Tara. "And the tools they gave us as parents really steered the train of Johnny's success. They taught us to trust that he will get there, on his own time. And he has. Everything has just come together like they said it would."

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