



Connections

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A Newsletter for friend's of Shriners Hospital for Children

Fall 2008

Mother Finds Strength in Faith, New Friends and Shriners Hospitals

by Christina Burke

“God has given us a tremendous blessing with each of our sons, and we see it every day,” says Michelle Cain, mother of Cody, 8, and Jonathan, six months. “Cody is a wonderful big brother and is so thankful that his prayers to have a little brother have been answered.”

Cody’s little brother Jonathan is a patient at Shriners Hospitals for Children -- Philadelphia. He was born with Beals syndrome, a genetic disorder that causes the permanent fixation of certain joints and may also cause curvature of the spine and other abnormalities in the limbs, heart and eyes.

“We are so blessed that Jonathon’s story came to the attention of Fred Widmyer, a Shriner and member of the Board of Governors at the

Philadelphia Shriners Hospital,” Michelle said.

Widmyer personally explained Jonathan’s case to Randal Betz, M.D., a world renowned orthopaedic surgeon and chief of staff at the Philadelphia Shriners Hospital. After just one week, Janet Cerrone, physician assistant, contacted the Cain family to set up an appointment.

“As Janet and I were e-mailing back and forth, she told me ‘once you’re in Shriners Hospitals, you’re family,’” Michelle said. “We’ve found that Shriners Hospitals treats and cares for the whole situation and the needs of the whole family.”

For now, Dr. Betz is focusing on the curvature in Jonathan’s spine and will fit him with a flexible back brace. During future visits, Jonathan will be seen by pediatric hand specialists who will likely fit him for splints to help extend his fingers and possibly his knees.

Jonathan at six months. He was born with Beals syndrome, a genetic disorder that causes a number of abnormalities.

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Welcome

Harold J. P. van Bosse, M.D. is our newest general pediatric orthopaedic surgeon. Most recently, Dr. van Bosse was an attending pediatric orthopaedic surgeon, at New York University Hospital for Joint Diseases and New York University Medical Center, New York. Dr. van Bosse brings his expertise of arthrogyposis to Shriners Hospital for Children.

Arthrogyposis is a non-progressive disease, but one that causes deformities in the developing child. His responsibilities at Shriners Hospital will include seeing patients in the outpatient clinic, performing surgery, and starting new centers of excellence in arthrogyposis, Prader - Willi syndrome and clubfoot.

Kristin Fizur, R.N., B.S.N., is the new director of critical care. In this role, she will be responsible for overseeing nursing staff and the day-to-day operations in the newly relocated pediatric intensive care unit. Ms. Fizur will also work with the patient satisfaction, performance improvement in designated areas, and patient flow throughout the hospital. She looks forward to being a representative of nursing leadership and all associated educational programs and projects related to critical care and emergency response.

Lori King, PT, Ph.D., PA-C is responsible for assisting the attending physicians staffing the outpatient clinics. She will be evaluating both new and returning patients, handling pre-operation evaluations, pre-admission histories and physicals. In addition, she will provide casting, ordering x-rays, helping to plan patient's care and educating patients and their families about their child's condition. King will also collaborate with other clinicians, including therapists, orthotists and prosthetists, social services and nursing.

Spotlight

National Nurses Week was held May 6-12. During this week, we honored our nurses for all of their hard work and dedication to our patients and unveiled our new nursing vision. It states, "*Nurses at SHC-Philadelphia are recognized and respected for excellence through professionalism and compassionate care for patients with pediatric spinal cord injuries and orthopaedic specialty care, while fostering collaboration, communication and independence in our premier facility.*"

The **Philadelphia Magazine, Top Doctors** may issue featured The List citing the 366 best local doctors in 55 different specialties. Dr. Betz is listed under the heading of orthopaedic surgery and Dr. Kozin under hand surgery. Congratulations top docs!

The 12th annual **Christmas in July** was a huge success again this year! The Philadelphia Chapter of Centurions, a police-organized motorcycle club rode nearly 500 strong. They delivered toys and raised funds to date totalling nearly 50,000 dollars to benefit patients at SHC. Special thanks to everyone who participated in this event.

The **World Congress on Disabilities Expo**, the world's leading disability event, is dedicated to making a difference in the lives of people with disabilities, their families and professionals who work with them. For two days in July exhibitors displayed their products and services in Reading, PA. along with Shriners Hospitals.

Judith Cline-Junkins, **Grand High Priestess** recently made a stop in Philadelphia with the Oriental Shrine, a ladies group. While here, the group enjoyed an ice cream party with the patients and families.

LuLu Shriners Golf tournament had another successful year... This year's theme was "We do it for the Kidz." Over \$25,000 was raised for the hospital. The national anthem was sung by a special guest appearance from Timmy Kelly, a patient at Shriners Hospitals.

This summer we launched the second phase of SHCIS, called **e-Merge**, another component of our electronic medical records (EMR) programming. **e-MERGE** improves the way we capture and record patient data by creating a permanent, easy to access record.

This summer headquarters for Shriners Hospitals for Children launched a **new website** to reflect our new branding and marketing efforts. You can find the website at www.shrinershospitals.org Take a look around and navigate your way through the new layout and design.

The David Letterman CBS jumbo screen in **Times Square**, New York ran 30 second SHC spots every hour for two months. It was great exposure for Shriners.

Shriners Hospitals for Children ranked as one of the top three most-trusted nonprofit organizations in a recent survey of wealthy individuals conducted by the **Luxury Institute**, an independent research firm.

In November 2007, the PGA TOUR announced that Timberlake would become the host of the TOUR's Las Vegas event, which was renamed the Justin Timberlake Shriners Hospitals for Children Open. Timberlake becomes the 14th celebrity in TOUR history to host an event, joining the likes of Bob Hope, Frank Sinatra, and Sammy Davis, Jr. The October 17 concert is one of several events during tournament week that will benefit Shriners Hospitals for Children. Timberlake is also hosting a Celebrity Pro-Am on Wednesday, October 15, at TPC Summerlin, the host site of the golf tournament. For more information on the event, visit [HYPERLINK www.jtshrinersopen.com](http://www.jtshrinersopen.com).

The annual **expanded board day** was on September 18th, 2008. Hospital presentations, displays and tours were held for over 200 guests. The annual luncheon honored our drivers for their many hours of service.

New PICU Opens

Shriners Hospitals for Children - Philadelphia announces the grand opening of a 2,300 square foot pediatric intensive care unit (PICU) to provide exceptional critical care services to our patients. Our pediatric critical care physicians include; Barry Evans, MD and Steven Nemerson, MD. The unit director is Kristin Fizur, R.N., B.S.N., along with a new team of 12 registered nurses staffing the unit around the clock. We welcome everyone to the team here at SHC.

The PICU includes five private beds with ample space for family members to stay close to their loved ones while critical care needs are met. This newly licensed unit is a big step in fulfilling the hospital's commitment to provide the best care to children and families.

The official ribbon cutting ceremony

The PICU's formal ribbon cutting ceremony was held on September 17, 2008. Special guest Ralph Semb, Chairman of the Shriners Hospitals for Children Board of Trustees, was here to officiate the ceremonies. The event included a behind the scenes video showing off the PICU's high tech features. Following the ceremony, employees, patients, families and guests enjoyed an assortment hot hors d'oeuvres and desserts.



The PICU's nursing station



Photo left (l to r), Dr. Barry Evans, pediatric intensivist, Ernie Perilli, hospital administrator, Rick Gallier, vice chairman, Board of Governors, Ralph Semb, Chairman of the Shriners Hospitals for Children Board of Trustees, Maria DeMarco, director of patient care services, Kristin Fizur, director of critical care services.



Photo right (l to r), Rick Gallier and Ralph Semb officially cut the ribbon for the new PICU.



Continued from page 1.

It's not only the excellent care and compassion that mean so much to the Cain family, but also the fact that Shriners Hospitals makes it available at no charge.

"We have insurance, but we still face substantial out-of-pocket costs for Jonathan's future care. What a blessing that Shriners Hospitals provides their services, including transportation, meals and lodging free to us!" she says.

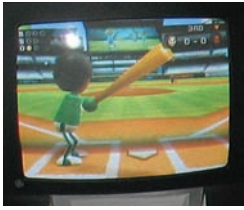
Recently, Michelle and her husband had another blessing enter their lives. Through Shriners Hospitals, they were connected to two other families with children who have Beals syndrome. The support and friendship they've experienced is helping them stay positive about the future.

"To not know anyone else with the same condition as your child is a lonely feeling," Michelle said. "Our new friends - one of them is an adult living with Beals Syndrome - are very encouraging about Jonathan's future."

"It's meant so much to us to get to know people living with the same experiences. Just one more blessing from Shriners Hospitals."

Donors in Action

Wii are so excited at Shriners!



Patients are very excited to get their hands on the newly donated Nintendo Wii's. They were a gift from the Daughters of the

Nile, Dorcas Temple #129, Altoona, PA. They were given with the anticipation of the patients being able to play games such as bowling, tennis and baseball, all with the swing of a wrist.

This state-of-the-art game console comes to life with its distinguishing feature—the wireless controller. The one-handed remote has a sensor able to detect motion and rotation in three dimensions. The high sensitivity simulates a more life-like experience for the players.

The teen lounge is full of laughter and cheers when patients are playing Wii together; especially the boxing or baseball games. Wii tournaments have become a regular event at the hospital so don't be surprised if there is chatter about who just won at bowling or golf without ever leaving the hospital!



Jose (I) and Michael are thoroughly enjoying Wii, the latest game system at Shriners Hospitals.

Sawyer Family Strums for Shriners

The Sawyer family recently presented the hospital with an \$800.00 donation. Geraldine Barrett (left), fiscal services department and Terry Diamond (right), development director were present to receive the check. The Sawyer's raised the money performing at a bluegrass festival.



Giant Card Brings Smiles to Philadelphia Shriners Hospital

Recently, the kids at the Philadelphia Shriners Hospital received a flood of get well wishes from Shriners Hospitals supporters around the country.

In April, headquarters asked our supporters to electronically “sign” a giant get well card for kids. The goal was to have 1,000 people sign the card -- and we were overwhelmed by the response we received. Nearly 2,500 caring people signed the card!

The giant card, which reads “We hope you're up and chasing rainbows again real soon,” was delivered to the our hospital in late June and was received with many, many smiles!

Thank you for showing our kids how much they mean to you! Your support and encouragement are helping kids defy the odds and overcome unimaginable obstacles.

We hope to give you the opportunity to do something similar for more children in our hospitals very soon.



Singing for Tomorrow

Michael Francis, 16, is a native of Antigua, located in the Caribbean. His travels brought him to Philadelphia to help correct his scoliosis. In addition to surgeries and quality care while at Shriners, Michael also received the gift to explore his passion for music through the music therapy program.

The program offered through *Arts at Your Side*, is a community service initiative of the Arts and Quality of Life Research Center at the Boyer College of Music and Dance at Temple University and funded through a grant by the Christopher Reeves Foundation that supports an innovative songwriting program for inpatients. It is lead by Dr. Joke and other instructors.

The music therapy program offers individual songwriting sessions to help children express their feelings and help them cope. With the help of a music therapist, each child creates and records original songs about their unique perspectives and experiences often relating to their disability. They may also share their hopes for the future.

Michael spent four months at Shriners and he was able to build a relationship with instructor Michael Viega and with music. Since middle school, Michael has been involved with music but he never really took it seriously. But now, going into eleventh grade, he does take it seriously. He has a passion and is inspired to make high-quality beat boxes, write lyrics and sing songs. He often brainstorms by listening to diverse types of R & B, hip-hop and techno. Artists Michael enjoy include; Chris Brown and Little Wayne, but he also likes to create his own style of music. He isn't afraid to sing about anything or write his own lyrics.

In addition, Michael has learned to work with a computer program called Garage Band, supported on Apple computers. The program uses a variety of different instruments, without bringing all the equipment along. It allows you to create, edit, enhance and make music cds just the way you want.

Instructor Michael Viega realizes the importance of music therapy. "It creates a safe environment for them. They feel like a kid and not a patient at a hospital," says Viega.

Michael Francis' created his own show name -- *Michael Fresh*. He wrote two songs while in music therapy and recently held his first concert here in the teen lounge.

Shriners Hospitals for Children is grateful to be the recipients of a grant from the *Arts at Your Side* program. The arts experiences and arts engagement may positively influence patients, by soothing, healing and instilling hope.

Michael Francis (left), music therapist works with patient Michael to create a song. Michael is passionate about his music and really has his own style.



■ We Get Letters

It is very uplifting to see the great stories you write about the children whose lives are affected and improved by the care at Shriners Hospital. The main reason I donate to Shriners is to offer something back for the care I received from 1958-74 for the problems associated with right talipes equino varus, a clubbed foot.

Thanks to the care of the Shriners Hospital in Philadelphia, I have been able to enjoy a full and active life. Despite the limitations of my right foot, I have been able to compete as four years in Division I gymnastics (team captain - two years; four letters) and compete nationally in gymnastics, play amateur/semi-professional football in England and field hockey where I trained for the Olympics in 1984 and was on the coaching staff in 1992.

I graduated summa cum laude in 1982 (West Chester State College, BS Health and Physical Education), magna cum laude in 1990 (Temple University, BS Physical Therapy) and finally, with a Doctor of Medicine from the Uniformed Services University of the Health Sciences in 2001. I am currently working as an Army physician.

I am married to another Army physician who is currently deployed to Iraq. Between us, we have seven children, all in very good health.

I appreciate everything that Shriners Hospital did for me. Please let me know if there is anything I can do for you.

Sincerely,

Michael Koznarsky, MD
MAJ, MC, USA



Shriner makes 500th trip transporting patients to Shriners Hospital for Children

Recently, Charlie Willer, a member of Salaam, the north Jersey chapter for Shriners in Wayne, N.J., made his 500th trip to Shriners Hospital for Children in Philadelphia. Willer started his career in “volunteering” as a first aid squad member eventually becoming president of the first aid council. He also taught driver safety for the squad. He loves helping people and when he could no longer keep up with the fast pace of an emergency situation he looked for other ways to help. As a member of Salaam, Willer could volunteer as a driver for Shriners Hospitals driving children who need medical care to the hospital. “I may not have a truck with flashing lights, but I am able to keep doing what I love and I still feel productive,” Willer said.

Accompanying Charlie on the special trip was fellow Shriner Bill Preuninger. Charlie is from the Salaam Shrine Center in Livingston. He drives local patients and families from North Jersey to the Shriners Hospital for Children in Philadelphia for their appointments. We presented Charlie with a plaque and had a special celebration for his 500th trip.

Bill Prueninger shown with Charlie Willer who received his 500th trip award. Congratulations!

Participation of Supporters Crucial to Continued Success

Since the first hospital opened in 1922, employees, Shriners and other supporters have made it possible for Shriners Hospitals to provide care to more than 865,000 children at no charge. Many things have changed since 1922 - there are now 22 hospitals providing care to more than 125,000 children each year - but the success and evolution of this great philanthropy still depends on the dedication of the people who support the organization’s mission.

Working together, employees, Shriners and other supporters are crucial to ensuring the organization remains open to change that builds on tradition to guide future success.

Jack, Hope and “Molly the Pony”

Noble Jack Robinson, who volunteers his time at the front desk of the rehabilitation area at Shriners Hospitals for Children, was moved by Thumbelina’s (the world’s smallest horse) recent visit. He did some research and found out about Molly, an 18-year-old pony with a prosthetic leg. Molly has a book explaining her life and all the galloping she has been able to do with the leg. Noble Jack graciously donated four books to the hospital to be placed in various waiting areas. Seen in this photo are Noble Jack and Hope, a patient. Hope was so excited to have the book read to her by Noble Jack. She loves ponies and never heard of an animal with a prosthetic leg! Thanks Noble Jack!



The World's Smallest Horse gallops into SHC By: Stephanie Spagnola

Recently a neighing horse named Thumbelina greeted the patients, families and staff. She is a dwarf chestnut mare standing at 17.5 inches tall and weighing 58 pounds, and was certified by Guinness World Records as the "World's Smallest Living Horse," in July 2006, and maintains that record today. She is cited as the smallest horse in 55 million years.

Thumbelina was a great visitor, she stayed still and allowed many children to pet her and even posed for pictures. It was a great day for her to get out of the barn and visit the patients at Shriners Hospitals.

"Each year, Thumbelina heads out in the Thumbby-mobile to visit sick, needy, troubled, disabled and abused children," said Kay Goessling, co-owner of Goose Creek Farms, a miniature horse farm in St. Louis, MO where Thumbelina was born. "She lives in their hearts and brings them hope and joy even in their most difficult times."

Goessling, along with her husband Paul, established the Thumbelina Charitable Foundation in conjunction with the tour to raise money and awareness for children's charities and organizations.

"We salute these organizations and all who volunteer their time to help children in need," said Goessling. "In fact, this foundation was originally established to channel the world's affection for Thumbelina toward worthy charities and the missions for which they strive."

Thumbelina is a part of the Thumbelina Children's Tour to bring hope and comfort to tens of thousands of suffering children. She has millions of fans in over 150 countries, providing a source of hope to children who must overcome challenging health obstacles. As she has survived her early challenges of being a "dwarf mini," Thumbelina is perfectly healthy today and is an

inspiration to all needy children. They are currently on tour of the Shriners Hospital for Children during the 2008 year.



From left to right: Mike Goessling, Thumbelina, and Shriners patient Gracelyn

Thumbelina Fun Facts

Breed: Dwarf miniature horse

Type: Chestnut Mare

Birthday: May 1st, 2001

Home: Goose Creek Farms in Missouri

Height: 17 1/2 inches or 44.5 centimeters tall

Weight: 57 pounds that is not very heavy for a horse. Other miniature horses can weigh between 175 and 225 pounds. A regular sized horse can weigh 1000 pounds.

Diet: 1 cup of grain twice a day and a few handfuls of hay.

Mission: To make the world a better place for kids.



Surprise! Sea World on Wheels is here...

On a recent surprise visit, Sea World on Wheels made an appearance at Shriners Hospital for Children. Noble Austin Kear ran into the Sea World on Wheels group in his office building elevator. When asked what brought them to Philadelphia, they replied, we just finished doing an early morning radio show and have a few hours until the next stop. Austin suggested making a visit to Shriners Hospital for Children to bring some cheer to the kids. He was so impressed that they took him up on the offer. With a few quick phone calls to SHC and lots of cooperation from hospital staff, the impromptu party was thrown together in less than 25 minutes. Sea World trainers were very excited to be able to see the children. They were all touched that they could brighten up someone's day. They were even able to have one of the talking birds say "Happy Birthday to Kyliegh" in his native language! Patients enjoyed all sorts of birds, an anteater and a fun filled, educational visit with the Sea World group. Overall, it was a great surprise for the children at Shriners!



Sea World trainer brings unusual animals for the patients to enjoy.

Hospital Statistics 2007

Admissions:	1,551
Outpatient clinic visits:	10,956
New applications approved:	2,180
Operations:	932
Average stay:	4 days

Go Phillies!

Take me out to the ballgame, buy me some peanuts and Cracker Jack...It is one of the many tunes that was heard on a recent trip to the Philadelphia Phillies game. A group of patients and families accompanied by staff were able to view a great game of baseball. Some of the group had never been to the new Philadelphia Phillies stadium; they had great seats! The tickets were donated to the patients of Shriners by the Philadelphia Phillies organization. It gave the patients and families an opportunity to get out and about in the great city of brotherly love.



Pictured is a group of happy patients, families and staff taking a break from watching the game, it was a great time had by all!



Shriners Hospitals
for Children™

Dean R. Shacklett	Chairman, Board of Governors
Ernest N. Perilli	Administrator
Randal R. Betz, MD	Chief of Staff
Kathleen Goodstein	Editor
Christina Burke	Contributors
Stephanie Spagnola	
Brian O'Doherty	Photographer

Connections is published quarterly for the friends of Shriners Hospitals for Children - Philadelphia.
3551 North Broad Street
Philadelphia, PA 19140
Phone: 215.430.4000

Please send comments or suggestions to
E-mail: kgoodstein@shrinenet.org or
215.430.4058

