



Life-Lines

A quarterly newsletter on leukemia & other related blood disorders

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Medical Play Therapy

A Prescription for Health

Do you remember when you were a child and you woke up on a summer morning with an entire day spread out before you? And do you recall the excitement and joy of letting that day unfold and filling it with play – creative, imaginative, and spontaneous play?

Experts in such things pretty much agree that play is an important part of health and development. And it's not a new idea. Even Plato observed that you can tell more about a person in an hour of play than in a year of conversation.

But what is the value of play when a child is ill, subjected to countless medical procedures, and just doesn't feel like playing? The answer: Combining the two can be an empowering and therapeutic prescription.

Play can provide a healthy outlet for a child's anxiety. Play time, both structured and spontaneous, gives children an opportunity to escape from the constraints of a physically demanding regimen and allow their imaginations to soar. Play also allows the child a sense of mastery and control. While in treatment, the child is often the passive follower. But it is in play that he or she can take control, create the story, and call the shots, literally as well as figuratively.

Sheila Morris, Meg Rescorla, and Jenni Gretzema, have witnessed it time and again. All are Certified Child Life Specialists (CCLS) with the University of Michigan Comprehensive Cancer Center and C.S. Mott Children's Hospital where they work with children and adolescents to ensure healthy development, even during illness and treatment. Their group is comprised of ten Child & Family Life professionals who are members of the Pediatric Hematology & Oncology health care team.

The process begins at diagnosis, often before treatment actually begins. The challenge is to prepare the child and family for treatment and identify coping strategies before difficulties arise. Planning is an integral part of caring for the child. The program goal is for the entire family to come out healthy, recognizing that siblings can also feel confused, isolated, and afraid.

"We're here to help both the child and the family cope by supporting them throughout their medical experiences," Sheila explains. "Our team is very aware that childhood should be a growth-focused, spontaneous, creative, and fun time for children, and we try to preserve as much of that as we can as the children and their families confront the challenges of illness and treatment."

The Child & Family Life Program at C.S. Mott was established in 1922, one of the first such programs in the nation. Over the years, the program has expanded from a hospital school and activities focus to a comprehensive range of Child & Family Life services that includes all pediatric specialties.

"Medical play therapy gives the children opportunities to master their experiences," explains C.S. Mott's Child Life Specialist Jenni Gretzema. "Often these children feel they have no control over what's happening to them, and the play interventions provide many insights and coping techniques."

One of the ways to address the stress and anxiety of treatment is through medical play therapy, with dolls as patients and the child patient taking the role of doctor.

Jenni recalls a six-year old boy who was so terrified of his frequent Neupogen shots that he would build a fortress of his IV poles to hide behind when it was time for the shots.

"He was upset, scared, and angry," recalls Jenni. "So we worked



*Shane McFarland, a 3-year old from Saginaw, during play therapy with Child Life Specialist Jenni Gretzema at C.S. Mott's Child & Family Life Program.
(Photo by Juliet Fuller, UMHS Public Relations and Marketing Communications)*



President's Corner

Hitting the Marks

As you read this column, the 2007 new year is long past and the promise of spring and summer beckon just ahead. But as I write today, the year is still fresh. I'm feeling retrospective still, about 2006. What did we learn that can help us better serve our

families and prepare for what lies ahead?

The CLF that you see is this newsletter arriving every few months. You hear the compassionate voices of our staff when you call us or when the Patient Services staff call you to ask how you are doing. You might find a CLF check that helped to pay for a medical expense or your last trip to the hospital. Or maybe you see us as the special needs request that got the car repaired or rent paid.

That's the side of CLF that most see but it's what goes on behind-the-scenes that make everything possible. We are always striving to improve – to better understand your needs and more effectively respond to them – and at the same time, do everything possible to ensure that CLF will be there for tomorrow's families as we have been for today's and yesterday's.

We are a bit obsessed about checking with the families we serve to make sure our services are on target. We strive to learn more about what your needs are. Although we do invest in research to find a cure and improve medical treatment and we devote occasional issues of *Life-Lines* to new developments in treatment and research, CLF's primary focus is supporting families throughout their struggle. That is truly where our expertise lies.

One of our behind-the-scenes people is Louise Derry. At one time, Louise headed our Patient Services department and launched several innovative programs. She also created "Stepping Stones" and continues to be responsible for annual updates and production of this resource that CLF provides to each new family. Although Louise "retired" from leadership of the Patient Services program in 2001 in order to take on a new career – motherhood, she still works for CLF to address our needs assessment and evaluation efforts. So it is due, in part, to Louise's work that CLF has so effectively met the needs of families we serve.

Last year, we undertook a different approach to determining how effectively CLF services were addressing the needs of families. Although we at CLF think about our work in relation to the various services we offer, (each designed to address a particular set of needs) families see us as just – CLF. We asked Louise to reconfigure our evaluation process to present CLF in that way to families. The results confirmed those assumptions and also gave us some valuable insights about some of the strategies we employ. Most interesting was a summary statement at the end of the evaluation report:

"Of all the programs and services offered by CLF, respondents were most satisfied with the time spent interacting (via phone, e-mail, and in person) with CLF's Patient Services staff. In fact, these interactions between families and staff members were rated as the most helpful in the overall coping process (as compared to other CLF programs and services)."

This is interesting because it indicates that how we deliver service is at least as important, if not more so, than what we deliver to families. The research also reveals that the most sought after information or educational service families received from CLF is how to negotiate through caregiving and how to cope with all the various practical and emotional challenges that come.

So as science devotes itself to solving the medical riddles – people need help. In the many years that CLF has studied how best to do that, we find that the support people require today has changed little from when we first started to research coping in the late 1980s. What has changed is the priority and resources CLF devotes to this focus.

So, how well is CLF hitting those marks in this latest evaluation? Well, here are the findings on a scale of 1 to 5 with 1 being "strongly disagree" and 5 being "strongly agree."

Impact Description	Score
CLF has had a positive impact on the way we cope with this diagnosis/treatment/its issues	4.27
CLF is important to us as we deal with diagnosis/treatment/its issues	4.23
CLF provides useful programs and services for families dealing with leukemia/lymphoma, etc.	4.46
CLF has a "user friendly" registration process	4.41

So, what do we think about an average rating of 4.34? Well, we are very encouraged. But we also see room for improvement. Stay tuned.

Glenn R. Trevisan



2007 Radiothon Highlights

WCSX's JJ & Lynne's 28-Hour Radiothon, presented by Rock Financial, broadcasting "live and local" from Oakland Mall was one for the record books. The \$154,000 raised by the '07 Radiothon pushed this annual event's grand total to the triple platinum level - 2.9 million dollars!

While the temperatures dipped outside, JJ & Lynne kept the air waves warm interviewing notables from the sports and entertainment world such as Bill Wyman of the Rolling Stones; Joe Dumars, President of Basketball Operations for the Detroit Pistons; Tom Wilson, President and CEO of Palace Sports and Entertainment; Brian May of Queen, Graham Nash, Paul Rodgers, Eddie Money and Roger Daltry of The Who, to name a few.

Once again, JJ & Lynne called out to guitarists young and old to meet at Oakland Mall's Center Court at 8:00

p.m. Thursday evening to perform in unison the immediately recognizable bass guitar riff of Cream's song, Sunshine of Your Love. Seventy-five guitarists of all ages and abilities joined JJ & Lynne's Guitar Jam, led by Jim Madaus.

New this year was the offering of "once in a lifetime" auction packages involving each of WCSX's on air staff. Packages included: Lunch with JJ, Lynne and Chris Chelios of the Detroit Red Wings; a cooking lesson and dinner with Tribute chef, Don Yamauchi and Karen Savelly; a Piston's game at the Rock Financial suite with 14 friends and Steve Kostan; Rock & Bowl with Uncle Buck; Pam Rossi's OverEasy broadcast, catered brunch and live concert; coney's with KC, and Mark Pasman's Motor City Blues Project concert and broadcast.

Diamonds in the Rough, aptly described the Diamond Dig held during

the Radiothon and for one lucky young woman, digging in the sand really paid off...she unearthed a diamond valued at \$1,600.

Special thanks to: JJ & Lynne for their tireless efforts and enthusiasm for CLF and the families we serve, the entire WCSX staff, Cavalier Telephone, Aesop's Catering, generous WCSX listeners, volunteers who manned the phones, Macy's Furniture, and countless others who made this year's Radiothon success possible.

Also, special thanks to our CLF families who were interviewed during Radiothon: Catherine and Cody Rowan, Laura Cesaro, Dana, Randy and Keegan Strnad, Nancy and Spencer Lisabeth, Kim and Jolee White, Scott, Karen and Kiley Sievers, Brent Berman, Catherine and Amanda Withrow, Alison Ealovega, and Jennifer Valinski. You are our heroes!



Clockwise from top left: JJ (Jim Johnson), Glenn Trevisan, Lynne Woodison, and Jim Madaus with a check from Radiothon proceeds; The Guitar Jam participants; JJ & Lynne with the Strnad family after their interview.

on the shots with the doll and devised a coping plan for him. He became quite receptive and did great. Some time later I was called to his room for a demonstration. And I was overjoyed to see him give himself the shot! He had successfully embraced his own power.”

The CCLS role requires seeing the treatment from a child’s perspective, clarifying the misconceptions and fears that accompany treatment. An I.V., for example, can conjure up images involving the “eye” in a child’s mind. And what would a small child imagine a CAT scan to include but cats!

The medical play box includes dolls complete with various catheters, ports, and lines, and felt bones that zip open to help children understand about bone marrow and where blood cells are made. The kit also includes toy comforts like magic wands, bubbles, and squeeze balls to help the child cope. Games like medical bingo can also help the child better deal with the medical environment.

Child Life Specialists also use deep breathing, guided imagery, and visualization to help lead children through difficult experiences. Images

children in a healthcare setting to help children understand their bodies and the procedures they must undergo.

“Medical play therapy helps increase their understanding of the medical procedures they must undergo,” explains Bethany, “and that understanding increases their ability to cope.”

The Child Life team at Children’s Hospital employs a mixture of guided and free play to inform children about their treatments and healthcare related topics. General topics include explanations of medical procedures like ports, catheters, shots, blood draws, and I.V.s. Specific topics might include dealing with adjustments to hair loss or loss of limbs.

“Our approach is very specific, depending on the child’s needs,” says Bethany. We provide dolls of every combination of physical traits and then allow the child to select one of the dolls to experience what the child will experience. Most of the time, children will select the doll most similar to themselves.

“To overcome fear, for example, we use needle play, allowing the child to

patient as well.

The biggest challenge, according to Bethany, is that there are so many variables case-to-case, including the wide age span, all of which require a highly specialized skill set.

“We really have to be able to carefully observe everything,” she says. “We need to be able to anticipate their questions and apprehensions and deal with them appropriately. For example, a common fear during transfusions is the possibility of ‘popping.’ In other words, you’re putting all that fluid in and it’s not coming out anywhere. Won’t I just ‘pop?’”

“Even the words healthcare professionals use can pose problems. I once heard a medical professional speak in front of a patient about ‘yanking’ out a catheter. To a child (or even an adult) that can be a terrifying prospect. Our job is to communicate with the patients on their level and to help them understand.

“Children can be incredibly honest, and we don’t lie to them. I don’t tell them it’s not going to hurt, but rather that I’m there to help them through the hurt. Our goal is to provide every child our special attention. Because that’s what every child deserves.”

**“Work consists of whatever a body is obligated to do.
Play consists of whatever a body is not obligated to do.”**

– Mark Twain

are the language that the mind uses to communicate with the body, and children as young as four or five are able to use this technique to eliminate stress. In younger children, distraction is a valuable tool, whether auditory, as in hearing bells ring; visual, as in watching someone blow bubbles; or tactile as in squeezing a ball or a lump of clay.

The requisite skills of the CCLS are comprehensive when one considers that pediatric patients can range from infancy to young adult, with each young person requiring age-appropriate and individualized techniques and approaches.

Bethany Russell, Certified Child Life Specialist at Children’s Hospital of Michigan, has utilized that scope of techniques many times as well. Her job, like that of her colleagues at the University of Michigan, is working with

actually give the doll a ‘shot’ of saline and food coloring to see how it’s done. By letting them use the needles themselves, we let the child take control and take the lead in a therapeutic manner. It’s a powerful tool.”

Bethany also uses medical teaching toys accompanied with descriptions that children can relate to, including the felt bones and red and white blood cells that are distinguished by “good guy/bad guy” labels.

And like CLF and the University of Michigan staff, Child Life Specialists at Children’s Hospital treat not just the patient but the entire family. Siblings are especially vulnerable in serious medical situations, and the goal of the CCLS is to make the medical environment a safe and comfortable one for the whole family. Additionally, when the family is able to cope, it is beneficial to the

According to C.S. Mott’s Sheila Morris, the ultimate goal is to make them open up enough to want to “take you along on their adventure” until eventually, the child and their siblings will actually look forward to coming in for medical visits.

“But first you must find that opening that allows you to gain their trust. Once you do that, you open the door to go forward together.”

These Child Life Specialists and other professionals are there to preserve the joys of childhood that every child indeed deserves, no matter how daunting the challenges. And the Child Life Specialist’s skills and compassion are an important component of the healing process.

Some might say the most important of all.

News from Patient Services

Toys, Toys, and More Toys

Our Holiday Toys room was filled with toys thanks to everyone who donated. With your help, CLF was able to provide toys and gifts to 1,100 children throughout the state – a record year. Even though we can't list each donor, please know that we value your support and that you have made an impact.



The Davis family at Holiday Open House with Santa.

"This was a very stressful year for us...my son was diagnosed with cancer. Nothing brought us joy, bills were falling behind because I had to quit work to take care of my sick child, transportation costs with gas, parking, etc...was another worry. Then we began to receive help from CLF, filled with caring staff and volunteers. Thank you so much not just for the Christmas gifts, but all that you do throughout the year."

- Parent of a child patient, Wayne County

Thanks also to Tonia Schneider, Manager at KB Toys, for arranging a Gift Card drive at her store in Westland Mall. The two-week drive raised \$1,300 in gift cards.

Holiday Open House

Decorating cookies, visiting with Santa, making crafts, and families visiting – these are some of the activities at CLF's Holiday Toys Open House on December 8 and 9, 2006. More than 170 people from ten area counties attended the open houses. The event offers families an opportunity to have fun, network, and meet with others facing similar situations. Both children and adults participated in the activities.

Thanks to Buffalo Wild Wings for providing the food, and to Grant Thornton and all the volunteers who helped during the Open House events.



Busy children at Holiday Open House.

Why I Support CLF: Mark Kahn

Mark Kahn was born, raised, and educated in Michigan. A University of Michigan graduate, he worked for 30 years in his family-owned area business. Mark's wife, Gayle, served on the CLF Halloween Gala Committee. When Gayle died in 2002, Mark established the Gayle Halperin Kahn Professorship in Integrative Medicine at the University of Michigan in her memory. "As a result of Gayle's involvement with CLF, I was invited to a local CLF meeting for prospective donors. And I was moved and inspired by the people who are involved in CLF. Their worthwhile efforts and their enthusiasm for helping were exciting. And the patient stories are so inspirational. I am amazed at how families cope despite their adversities, how they persevere with such courage and joy.

"I became involved in honor of my own two healthy grown children, and I knew I was doing the right thing. I've enjoyed such a blessed life and I feel obligated to share my good fortune. I don't have some dramatic life story. And I don't need accolades or tributes. I just try to help others. That's how I try to lead my life.

"There's a Jewish word – tzedekah – that means charity. But it's not optional, magnanimous, rich-to-the-poor kind of charity. It's more a duty and obligation that we all have for our space on this earth. It's about justice, fairness and righteousness. When Gayle died, I remember asking the rabbi whether it was OK to feel good about giving or whether I should try to remain more anonymous, more humble.

And she referred me to the Torah and the concept of tzedekah, that I should take pride in giving, because to be generous brings great joy to yourself and to others.

"It's a concept I try to instill in my own children because it's something that must be learned. It's a spirit that makes an impact on people. There are so many great causes out there and CLF is certainly one of them.

"CLF allows families and children to go on. What greater gift can there be?"

Thank you, Mark Kahn, for sharing your spirit of tzedekah with the world, and especially with CLF.

Heroes

Gordon Advisors Make the Holidays Merry & Bright

The folks at Gordon Advisors are long-standing supporters of Children's Leukemia Foundation. Over the years they have hosted a Walk for Charity, a Bowl-a-thon and a holiday drive, inviting both employees and clients to be a part of the tremendous support they give to CLF. Once again, their staff and clients raised more than \$7,500 for the Holiday Toys Program – helping to bring smiles to the faces of more than 1,100 children. Thank you for your continued support, totaling more than \$22,000 since 2000.

“Gone Casual for CLF”

Paychex may handle the checks but, when they decide to raise money they certainly know how to write a check. Paychex selected a week in December and offered their employees the opportunity to get comfortable at the office. Anyone who paid \$10 could come to work in casual clothes. When they totaled up their Casual Day receipts they raised \$1,075. Way to go Paychex.

These Ladies Really Know How to Wrap

Not only do the Ladies of Harley, Motor City Chapter really know how to ride, they really know how to make a difference. 2006 marked the sixth year that the Ladies of Harley held their Holiday Gift Wrapping at Motor City Harley Davidson in Farmington Hills. Beginning the weekend after Thanksgiving, the Ladies spent each weekend wrapping gifts for donations that support CLF. They also accept toy donations for the Holiday Toys Program. This year they raised \$1,109 and have raised more than \$14,000 since 2000. Thank you, Ladies of Harley, Motor City Chapter and Motor City Harley Davidson for your continued support.

Strike Three – It's a Turkey!

The Royal Oak High School Medical Skills class is learning what it takes to make a career in the medical field and how to make a difference. In November, the Medical Skills class, guided by teachers Mary Fry and Alicia Brown, held a Bowl-a-thon to “Strike Out Leukemia.” One of our patients, JP, attended the Bowl-a-thon with his dad and students had a chance to meet and talk with him. The Bowl-a-thon raised more than \$3,000 and students left the bowling alley with a better understanding of what a difference a day can make. Thank you to Thunderbird Lanes in Troy for your support of Royal Oak High School. Our heartfelt thanks to Mary Fry, Alicia Brown, and all the students in the Medical Skills class at Royal Oak High School.

General Electric Delivers

Preparing and packing toy boxes for more than 400 families definitely takes time and effort. Thanks to the volunteer group at General Electric, our job was a little easier. A group of current and retired employees and their family members volunteered at CLF over a three-day period and prepared holiday toy boxes for 100 families. Thanks for your help!

Organizing a fundraising event at your school or business is a great way to support Children's Leukemia Foundation. If you would like more information on how to conduct a Third Party Event, contact Betsy Bonnell at 248/353-8222 ext. 227 or by e-mail at bbonnell@leukemiamichian.org.



The Ladies of Harley collected toys and wrapped gifts for CLF at Motor City Harley in Farmington Hills.

Volunteer Profile: Dave Downs (a.k.a. Big Wave Dave)

Just who is David Downs? Well, his beginnings were fairly ordinary – that is, if you think being born in the front seat of a 1952 Ford station wagon is ordinary. His birth certificate prophetically indicates he was born “in transit.” And this guy hasn’t stopped since.

Dave is originally from Texas where from junior high school forward he excelled in the sport of spring board diving. His skills were such that he became a pro at a Texas aquatic park, performing clown-diving stunts in six 20-minute shows a day. From there he was promoted to perform in the dolphin show, climbing a 100-foot tower and diving from an 85-foot platform. During one weekend performance, he jumped feet first, hitting the water sitting down, and creating a tsunami-like wave. One of his drenched colleagues yelled, “Big wave, Dave!” and from that point forward he was “Big Wave Dave.”

Dave’s second profession is as a builder. Again, fairly ordinary, except that he builds sand castles, a skill that he perfected on South Padre Island in Texas under the tutelage of two world champions. His colleagues included Amazing Walter, Sandy Feet (yes, folks, that’s her name!) and her father Dad Feet. In fact, in 2000, Big Wave Dave and Dad Feet won the Sand Castle Days state championship in Texas.

Dave’s third profession was instigated by his wife, Phyllis, a retired elementary school counselor, when she “dragged him” (his words) to school to play the role of Santa Claus.

“The first room we visited was a group of mentally challenged children,” recalls Dave. “One little boy with very limited speech could not stop stroking my beard. Finally he ran off and brought me a magazine with a picture of a drum set. I told him I’d do my best. Then I signed, “I love you” and it set off a joyful emotional response from him that the teacher said was the most he’d ever shown. I didn’t need to be convinced to return after that.”

Soon Dave decided that, “fifteen years of spring breaks on Padre Island was enough,” and he and Phyllis moved to Michigan to be closer to her family. About four years ago, CLF contacted Dave about demonstrating his sand castle skills at the Kite Festival in Grand Haven that year. And thus a great friendship began.

Big Wave Dave then volunteered his Santa services to CLF for the annual Holiday Open House, a role he was thrilled to perform. He also delivered toys to two patient homes over the holidays.



Dave Downs created a giant sandcastle at the annual Great Lakes Kite Festival in Grand Haven, which benefits CLF patients.

“What’s amazing about CLF is that it’s not just for the patients but for the families of the patients,” he says. “I’m only in the house for a brief time, but to see the looks on the parents’ and grandparents’ faces is just tremendous.”

Big Wave Dave started out in a rented Santa suit and a fake beard. Today his suit is custom made, updated every year, and the white beard is really his. But his heart is the same big ole’ Texas heart that he was born with 53 years ago.

By the way, Big Wave Dave, also works as a property manager, but as he describes, he does it only “to earn money to feed the reindeer.”

Big Wave Dave is actually Big Hearted Dave. And CLF appreciates every smile he provides.

Thank you, Dave Downs.

CLF Scrapbook Workshop

CLF continues to offer a Scrapbook Workshop at the Southfield Office on the third Tuesday of each month. Veteran scrapbookers as well as beginners are welcome. This is a great way to meet others facing similar challenges and to get support. Upcoming dates: February 20, March 20, April 17, and May 15.

If you are interested in attending, call the Patient Services Department at 800/825-2536. We would love to see you there.



Mark Your Calendar:

March 3	The Happening, North Farmington High School, Farmington Hills
March 10-11	Walled Lake Western High School Volley Ball Marathon, Walled Lake Western High School
March 17	Liar's Club St. Paddy's Day Pub Crawl, Detroit
May 19-20	Great Lakes Kite Festival, Grand Haven State Park
June 9	First Children's Leukemia Foundation Walk, Kensington Metro Park
June 25	Gray's Reef Golf Classic, Indianwood Golf & Country Club
	Basic Rubber Memorial Golf Classic, Prestwick Village Golf Club, Highland, Michigan
July 21	John F. Aho Memorial Golf Outing, Links of Novi
July 22	Glitz Cut-a-thon, Glitz Salons, Orion Township
August 10-11	Hollywood Nights Movie Marathon, Imagine Theatre, Novi

New Event

Coming Soon, The First Annual CLF Walk

Get your walking shoes ready as Saturday, June 9, 2007 marks Children's Leukemia Foundation of Michigan's inaugural walk for "hope and support." Whether you walk as an individual or as part of a team you'll enjoy this scenic Spring walk beginning at 9:00 am at Kensington Metropark.

This walk for "hope and support" is a non-competitive, accessible, four-mile walk offering walkers of all ages a fun-filled and memorable day. The day's festivities include a picturesque route, special opening and closing ceremonies, entertainment, lunch, water stations with snacks and support all along the way.

Walkers are encouraged to raise a minimum of \$100. Those raising \$100 or more will receive a commemorative Walk T-shirt and are eligible for other great prizes. To assist with pledge recruitment and collection, walkers will have the opportunity to create their own personalized fund-raising page.

Visit www.leukemiamichigan.org soon to download a brochure or contact Kathy at 248/353-8222.

Join the Family Fun at May Kite Festival

The Grand Haven State Park shoreline is the beautiful backdrop for the annual Great Lakes Kite Festival, taking place on May 18-20, 2007.

The largest kites in the world will color the sky and families will share a fun-filled day at the beach watching world-class kite flyers and stunt kite routines choreographed to music.

Visit the Family Fun Tent, filled with interactive, make-and-take activities and games for children of all ages.

Outside the tent, children can test their skills on a giant inflatable obstacle course and a moonwalk or watch CLF volunteer, "Big Wave Dave" (see page 7) create giant sandcastles. Proceeds from Family Fun Tent activities support Children's Leukemia Foundation.

For more information, visit www.mackite.com, contact Kathy at 800/825-2536, or e-mail her at kmcgrath@leukemiamichigan.org.

Family Fun Tent sponsors:



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