metabolic and mitochondrial diseases would be an excellent fit. For one thing, these illnesses are so little known that no opportunities like Camp exist for these youngsters. They can’t attend a conventional camp. The rarity of these illnesses is also a challenge. Imagine if you had an illness that was so unusual, you might never run into someone else who had it!

Few people are familiar with metabolic and mitochondrial disease. Just imagine if your body could not digest your food or turn it into energy for your body to use. Metabolism, the process by which food and drink are broken down and turned into energy, involves a complicated series of steps that makes use of chemical substances called enzymes. There are hundreds of enzymes. Any one can be missing or not work properly, resulting in metabolism getting stuck at that step. The intermediate substance builds up and can be deposited in various cells and organs throughout the body, leading to mental retardation, seizures, muscle weakness, pain, heart problems, blindness, deafness, diabetes and/or growth problems. Because there are so many enzymes involved in metabolism, there are many different diseases.

Mitochondrial disorders are related to metabolic disease. Mitochondria exist in every cell in the body except red blood cells. They process oxygen and convert food into energy for normal cell function. When the mitochondria don’t work normally, the cells can’t function properly. This can affect different parts of the body including the brain, heart, kidneys, liver, pancreas and so on. There is no cure. Treatment is aimed at decreasing symptoms and stopping or delaying disease progression. Treatment includes: special diets, enzyme and vitamin supplements and physical therapy.

Metabolic and mitochondrial disorders can be hidden diseases. Many children affected by them look normal and healthy much of the time. Their illness only comes out when they get into trouble — when they run instead of walk, spend an hour in the hot sun, or catch a common cold. A parent explained it to me best. Imagine a six-cylinder car that only has two cylinders that work. If you are going on a level road, the car can move along easily. However, as soon as you come to a hill, you’re in trouble. The car becomes stuck or slides backward. That is what life is like for these kids. If they follow the “rules” — get plenty of rest, eat what they should, stay hydrated, don’t overheat — they can participate in...
in our cover article, medical director Dr. Sharon Space talks about the new disease group we serve – metabolic illness – in which we see some of the most acutely ill children who have ever come to Camp. She shares the heartwarming experience of Camper Anna. Anna’s summer session was the first time since her birth that her parents were able to sleep through the night without getting up every four hours to feed their daughter through her G-tube. We take pride in knowing that providing our campers with a safe, outstanding Camp experience enables us to give a gift of respite to their parents and caregivers as well.

There is a beautiful addendum to Anna’s success story that Director of Nursing Patti Carlton recently told me. That same summer, Paul Newman stopped by Camp for a visit accompanied by Joanne Woodward, Board Chairman and longtime friend Ray Lamontagne and Ray’s wife Monica. Patti, along with Camper Recruiter Mike Hund, was reviewing medical charts on the infirmary porch. Paul asked how the summer was going. Patti shared Anna’s story and how much Camp had meant to Anna and her parents. She also thanked him for making it possible for campers like Anna to have the time of their lives at Camp.

Paul turned to Ray and said, “Twenty years ago, people told me it would never work, that parents would never leave their sick children at a camp to be taken care of by strangers. But we did it. And this is why.”

“The look so filled with happiness as he said it,” recalled Patti.

On June 9, 2010, our campers will arrive for the start of our 22nd summer season. Despite the severity of the economic challenges we face, Camp continues to reach ever more acutely ill youngsters both at Camp and in the many hospitals served by our Hospital Outreach Program. Your generosity will enable us to make a healing difference in the lives of thousands of children who need it the most.

The Spirit of Giving

The holidays are an important time for many companies to thank their clients for their business and demonstrate how their company gives back to the community – especially to children. Camp offers exciting ways for caring companies to thank their clients and showcase their corporate philanthropic goal of helping seriously ill youngsters.

One of Camp’s most valued corporate partners, Fusco Corporation, gave its clients holiday gift baskets with a card explaining that a contribution to The Hole in the Wall Gang Camp was associated with that gift and how it would benefit the youngsters who attend Camp. We at Camp worked closely with Fusco Corporation executives to develop the package that was sent, along with the language highlighting the company’s generous support. Each year, our own Kevin Rice, Hospital Outreach Supervisor/Specialist and artist extraordinaire, works with a child in the hospital who creates an original painting for our holiday card. Creating art can be therapeutic for seriously ill children, providing distraction from illness and giving them a sense of accomplishment, despite all the activities that may be off-limits to them while under treatment. We turn that artwork into a delightful holiday greeting card. Dedicated Camp friends and companies do the rest – purchasing a certain number of cards to give to clients and friends stating that a donation was made to Camp in their honor. Minimum donation per card is $10. Since 2002, MID-SHIP Group has made Camp’s holiday card a signature part of their customer care program, underscoring the company’s sincere wish to help families who struggle with a child’s serious illness. This past year alone, MID-SHIP Group donated $10,000 to Camp for holiday cards for 150 of their contacts. “We love sharing the work that Camp does with our clients who have all responded with great appreciation to the charitable holiday sentiment,” commented MID-SHIP Group Chairman Matthew Deluca.

RBS has also participated in our Corporate Holiday Gift Program. Most recently, the company made a generous gift to Camp of $251,340 to send custom gift boxes to their top clients. The goodie box prominently featured the company logo and included a Camp blanket, a tin full of Newman’s Own snacks, and a card printed with a message explaining the gift and the generous donation to Camp made in the client’s name.

In each of these instances, Camp worked closely with corporate officers to develop a package to promote the company’s look and focus, while highlighting its generosity to children. Gifts of $5,000 or more are requested for special initiatives. For more information about how you can create a unique holiday gift for your corporate clients, please contact Director of Annual Giving Maria Gomez at (203) 772-0522, maria.gomez@holeinthewallgang.org or visit our website for more Corporate Holiday Giving Opportunities.
Monika Goldschmidt attended The Hole in the Wall Gang Camp as a sibling camper at age eight. Later, as a student at Staples High School in Westport, Connecticut, Monika realized that, although her school had many clubs and service groups, there was no student organization with the goal of helping children with serious illnesses. Together with her friend Eliza Hamburger, Monika decided to change that.

"The idea of the Paper Hearts Club was to give back to kids with cancer. I thought that it would be best to support a charity that I knew really did help kids and cheer them up. I felt that Staples High School could benefit from having a service group like that," says Monika.

The Paper Hearts Club raises money through bake sales and other school-based activities to purchase card-making supplies: craft paper, glue, stickers, markers and more. During holidays like Christmas, Hanukkah and Valentines Day, club members sell the finished cards to friends and family. They also set up a table in downtown Westport for other community members to purchase the hand-decorated cards. The money made from card sales is given directly to the Camp. The paper greeting cards warm the hearts of their recipients and funds raised from their purchase promise the warmth of friendship at Camp for so many youngsters. The Paper Hearts Club offers a great model for students at other schools who are interested in giving back. Monika recalls her own experience at Camp, saying, "At such a young age, I didn’t fully understand what was going on with my brother, but going to Camp allowed the club to dissolve as if it had never been there, or work to ensure the club’s continuation. We have been busy passing on the positions to underclassmen and giving them the tools they will need to continue the club. We recently put the underclassmen into their new board member positions and have been allowing them to take over the club, as we advise and oversee their efforts.”

Upon graduation this year, Monika will attend Xavier University in Cincinnati where she will major in Marketing and Management. She hopes to identify a charity organization there where she can share her ideas and help out. We celebrate her giving spirit, great ideas and wonderful gifts to Camp.

The Paper Hearts Club: A Model for Giving

Monika Goldschmidt’s Paper Hearts Club offers a great model for youngsters who want to support Camp.

Barclays Capital: A Company that Cares

It was a sunny day in New York City last fall when a team of Barclays Capital employees rolled up their matching blue Barclays shirt sleeves and proceeded to make joyful memories for Hole in the Wall campers, their families and a host of invited guests at a special performance of the Big Apple Circus.

“The Barclays Capital crew came ready to work, setting up the event, preparing the goodie bags and greeting the families who were attending the show. Helping such a great cause and having fun doing it was very rewarding,” says Matt Senecal, longtime friend to Camp and a Director in Equities Electronic Trading Services for Barclays Capital.

Barclays Capital provided an outstanding summer experience Camp provides for the seriously ill children at the eleven camps in the Hole in the Wall family. This past year, the Barclays Capital Foundation generously supported Camp with a grant of $25,000 to support camperships and help make memories to last a lifetime for an entire cabin of seriously ill youngsters. Each summer, Camp provides an outstanding summer camp experience to approximately 200 New York City children who have been diagnosed with cancer, sickle cell anemia, HIV/AIDS, hemophilia and other serious illnesses. Thousands more are served each year through the Camp’s Hospital Outreach Program in New York City hospitals.

Those at Barclays Capital know firsthand what an outstanding experience Camp provides for the youngsters in its care, thanks in part, to former summer staff member Albi Skenderi, an Analyst in the Interest Rate Derivatives Operations group of Barclays Capital. But the generous connection of this company that cares doesn’t stop there. Last November’s ING New York City Marathon featured 22 runners from Barclays Capital who raised funds to help send seriously ill children to a Hole in the Wall Camp. Barclays Capital leveraged those gifts and matched $21,000 of the funds raised by the runners, with the grand total coming to more than $72,000 for seriously ill children at the eleven camps in the Hole in the Wall family.

It just goes to show what can be accomplished when generous corporate partners team up with Camp to help some of the most deserving youngsters on the planet.
A Camper’s Journey

One of the great strengths of Camp is the way in which our work is informed by the experiences of our campers. Last year, 25% of our summer counselors were former campers themselves who returned to Camp to make the magic happen for other children. In our New Haven development office, many of the staff members are former counselors or summer volunteers. In addition, we are pleased to announce that former camper Amanda Garbatini joined our full-time New Haven staff this past January as Associate Director, Special Events. Amanda took a few moments out of her busy day helping to organize some of our signature fundraising events and shared her thoughts about her Camp journey.

As a child, I had never been to a camp before attending The Hole in the Wall Gang Camp and had never spent more than a day away from my parents. The idea of spending a week in a strange new setting while on chemotherapy and radiation was absolutely terrifying, but something told me that I was supposed to be there. The minute I stepped out of my car, I was embraced by the loving arms of one of my future counselors. (We still keep in touch. She and her family are very important to me.) As scared as I was, this hug was very comforting.

At Camp, I didn’t feel like I was labeled as “the girl with cancer” or “sick.” Every kid I interacted with knew what it was like to feel like an outsider. Interacting with other children who have cancer has a healing power beyond words. You realize you’re not the only one with a serious illness and you feel safe and accepted.

When I arrived at Camp, I was sad, angry and scared. I left Camp with a renewed drive to continue fighting. Camp gave me back my childhood and a sense of normalcy. Looking back, I realize it is the people that made Camp so special. I’ve had the incredible opportunity to see Camp as a camper and a Leader-in-Training. More than anything, I want to help continue Mr. Newman’s legacy and vision.

Everyone works so hard to make Camp the best possible place it can be. The fact that I got to work for the Camp that changed my life is just an amazing experience for me!

Amanda continues to be part of that wonderful vision through her dedicated service as a Hole in the Wall Gang Camp staff member. And she can’t wait to volunteer this summer!

Travelers Championship Supports Camp

If you plan to be in Connecticut in June, you won’t want to miss the excitement of the Travelers Championship, the PGA TOUR Tournament held from June 21 to 27 at TPC River Highlands in Cromwell. The Hole in the Wall Gang Camp is pleased once again to be one of two primary beneficiaries of the proceeds from this premier golfing event that raised more than $1 million for charity last year and garnered a PGA TOUR “Best of” Award. Following last year’s tournament, the Travelers Championship generously donated $340,000 to The Hole in the Wall Gang Camp and the Greater Hartford Jaycees. Many additional Connecticut nonprofit organizations will also be supported through the tournament’s Bubbles for Charity program. “The sport of golf raises more money for charity than any other sport,” says Nathan Grube, Tournament Director at the Travelers Championship. “That’s what is so exciting about the Travelers Championship – how it promotes the great game of golf, the economic impact it has on the region each year and how it gives back to the community by bringing hope and healing to the seriously ill children of Connecticut’s own Hole in the Wall Gang Camp and their families.”

Over the past three years, the Travelers Championship has donated more than $877,000 to Camp. In 2008, its title sponsor, Travelers, made the visionary gift of a wheelchair-accessible, mini-golf course to Camp where all young patients can enjoy the great game of golf regardless of mobility or other challenges. This spring the Travelers Companies, Inc. announced a generous $500,000 grant to support The Hole in the Wall Gang Camp Hospital Outreach Program. To find out more about the Travelers Championship and how it helps Camp, visit our website at www.holeinthewallgang.org.
Keep an eye out! Those dedicated AngelRide cyclists may be coming to train on a road or bike path near you. This spring, The Hole in the Wall Gang Camp celebrates the more than 250 AngelRiders and their generous donors who support the 115-mile and 50-mile AngelRide routes across Connecticut taking place on May 28 & 29. The group’s goal is to raise $500,000 with all proceeds supporting The Hole in the Wall Gang Camp Hospital Outreach Program that brings the joy and healing of Camp to the bedside of seriously ill children in hospitals from New York to Boston. AngelRide has raised more than $1.6 million since its founding in 2004. Heartfelt thanks go out to AngelRide co-founders and 2009 “Most Wanted” Award winners Fred Brooke and Lynn McCarthy. Their inspiration and exhaustive leadership has turned a remarkable event into an outstanding cycling experience that is eagerly awaited by young and old alike. In addition, we wish especially to recognize the “behind the scenes” leaders and volunteers who make this incredible event and tradition so successful. It all happens year after year thanks to a core group of dedicated AngelRide volunteers. “What started as a modest group of us organizing a ride for Camp’s Hospital Outreach Program, has blossomed into a highly committed group managing every detail of Connecticut’s premier charity bike ride,” says Fred. AngelRide volunteers spend months in advance of the actual event preparing every detail of specific aspects of the Ride: the starting event in Norfolk, Connecticut; the finish event in Mystic; the Camp reception in Ashford; rider transportation from Mystic to Norfolk and Mystic to Ashford; rider safety, support and gear vehicles; motorcycle crew; marketing, website and finance. “Each aspect of the event’s excellence depends on our leaders and the Ride would not be the outstanding event that it is without the many hours they put in,” explains Lynn. “We are deeply grateful to all the leaders, the volunteers, and the leaders that make AngelRide so meaningful and for the impact of their gift on the thousands of children served throughout New England hospitals by Camp’s Hospital Outreach Team,” explains Mary Naumec, Director of Hospital Outreach. Members of the 2010 AngelRide volunteer leadership group include Paul Surprent, Dan Baruladli, Darrell Adler, Michelle Robinson, Jeff Routledge, Dave Grauendel, Cathy McAvoy, Deb Brown, Erny Momitho, Sarah Marvin, Michael Downing, Mary Stomboli, Ceci Iliff, Keith Knowels, Ed Dean, Amy O’Connor, Alison Harland and Michele Martinez. This year, a new group of Ambassadors joined the leadership group committing to regional training, recruiting, and broadening the reach of AngelRide’s mission. We’re grateful to them, too. They include Mike Tyler, Lenny Goldberg, Rich Stern, Dan Shapiro, Antu Keller, Leslie Mongillo, Chris Haddad, Dave Grauendel, Jim Carpenter, Keith Knowels, George Bussman, Tom Wood, Joanne Wilcox, Eddie Burke, Dan Gilbert, Brian Vaugh, Rick Schaller, John Waelik, Paul Welburn, Matt McKee and Bryan Cryder. It’s not too late to help. Check out the website at angelride.org to register to ride, support an AngelRider, or volunteer to help out at the event.

WHY THEY RIDE

AngelRider Dane Silcox is a well acquainted with The Hole in the Wall Gang Camp’s Hospital Outreach Program that AngelRide supports. His son was diagnosed with a serious illness in the summer of 2004. The protocol was a grueling three-and-a-half years of treatment. That first year, he spent a lot of time being hospitalized at Connecticut Children’s Medical Center. It was there that he came into contact with Camp’s Hospital Outreach Specialist Kevin Rice. Dane explains, “Kevin is a remarkable person who brightens a room just by entering it. He is a wonderful caring human being that has made a significant difference in the lives of young children that are sick and in the hospital fighting for their lives.” Dane started his adventure with AngelRide in the spring following the year of his son’s diagnosis. “I am very pleased that the funds from AngelRide go to help the Hospital Outreach Program that Kevin Rice and the other Outreach Specialists from the Camp are a part of. I cannot put into words how these people have impacted our lives,” he says. Today, Dane’s son is doing well. “He will be watched the rest of his life and the drugs he needed to take to make him well will have a life-long impact,” Dane explains. Dane looks forward to taking part in this year’s AngelRide.
Open House, Open Hearts

The kids arrive ready for fun. The parents arrive a little uncertain. Maybe even trepidacious. Leave my sick child in a place away from home to be taken care of by strangers? I don’t think so.

“They may not say it, but that is what many parents are thinking when they arrive at Open House,” says Cristina Sapovol, Director of Camper Admissions.

Each spring, Camp is pleased to host a special Open House primarily for potential first-time campers and their families. The Open House grew out of a feeling that families who had never experienced Camp might find the prospect a little daunting.

In a matter of a few hours, thanks to the infectious warmth and joy of our staff, Camp takes the concerns of these families and lays them to rest. “The children see what the inside of a cabin looks like,” says Cristina, “where they will play and eat. They meet some of the counselors who will take care of them and are usually caught right up in the fun-loving atmosphere and attention that our counselors are so good at providing. The parents meet with other parents, and visit with the medical team. They gain not only an understanding, but assurance that their kids will be cared for with the highest quality care. It changes everything.”

“It’s a really individual experience,” says Assistant Camp Director Hilary Gerson. “Sometimes the parents arrive, saying, ‘My child’s doctor recommended this, but I doubt that we’re interested in doing it.’ By the end of the day, all they can say is, ‘Where do I sign up?’ Meeting the program staff, seeing how friendly and open everyone is and observing their child making immediate connections with the staff makes all the difference,” she says.

“Camp isn’t just there for people who need it. Camp reaches out to people who need it, people who may not yet even realize all that Camp has to offer them,” says Karen Allen, Director of Community and Family Outreach.

“Long ago, Camp learned that when we support the families of the children we serve, we are supporting the children as well,” says Chief Executive Officer Jimmy Canan. “It’s all part of being proactive in how we serve the children at the heart of our mission.”

Open House is just one of Camp’s many programs and events throughout its fall-to-spring season that helps campers and their families network and establishes critical bonds with others who understand the challenge of serious illness.

Events Hosted by Camp

Each year, The Hole in the Wall Gang Camp hosts a series of fundraising events. These events are wonderful opportunities for Camp friends to connect with the magic and mission of Camp. For more information on tickets and sponsorship packages for Camp-hosted events, please contact Jennifer Weeks, Director of Special Events, at (203) 772-0522 or jennifer.weeks@holeinthewallgang.org.

**Boston Big Top Bash • Boston, MA • April 10, 2010**

Enjoy a private performance of The Big Apple Circus and reception at the Boston Children’s Museum.

**Polo for Children Benefit Luncheon • Greenwich, CT • June 6, 2010**

Now in its ninth year, Polo for Children takes place at the Greenwich Polo Club and features cocktails, a gourmet lunch, a silent and live auction hosted by a celebrity auctioneer, children’s activities and a high-goal polo match.

**Fore a Very Good Cause Golf Tournament • Fairfield, CT September 7, 2010**

Enjoy a round of golf that includes breakfast, lunch, evening cocktail reception and exciting live auction featuring celebrity auctioneer.

**The Big Apple Circus Halloween Bash • New York City, NY October 2010**

Join us for a fun-filled day featuring a private performance of The Big Apple Circus and reception complete with star-studded entertainment.

AND DON’T FORGET…

Consider supporting these events that raise funds for our campers.

**AngelRide • Norfolk to Mystic, CT May 29-30, 2010**

Join Connecticut’s premier cross-Connecticut cycling event organized by Angel Charitable Trust and Team Hole in the Wall, with all funds raised going to Camp’s Hospital Outreach Program. See angleride.org.

**Travelers Championship PGA Tournament Cromwell, CT • June 21-27, 2010**

The Hole in the Wall Gang Camp is delighted to be a co-charity of this wonderful, weekend golfing event sponsored by Travelers Championship. See travelerschampionship.com.

**Space and Aviation Day Windsor Locks, CT • August 14, 2010**

Support this free, fun-filled family event organized by Bradley Family Day at venues in and around Bradley International Airport. See spaceandaviationday.org.

**Camp Challenge for The Hole in the Wall Gang Camp Ashford, CT • September 12, 2010**

If you love cycling, join the Camp Challenge Ride with its choice of three routes through some of the most beautiful countryside in Connecticut. Sponsored by Team Hole in the Wall. See teamholeinthewall.org/cc2010.

**Gala New York City, NY October 2010**

Camp’s Annual Fandango Gala makes a special appearance this year in New York City. The “Celebration of Paul Newman’s Hole in the Wall Camps” will be sure to delight attendees, with proceeds benefiting both Camp and the Association of Hole in the Wall Camps.

**Not So Sneaky Wine and Cheese Tasting Windsor Locks, CT • November 19, 2010**

Guests enjoy the best of Connecticut’s locally produced wine, beer and cheese, all while supporting some of the most deserving kids on the planet. Sponsored by Bradley Family Day.
The Hole in the Wall Gang Camp, located in Ashford, Connecticut, was founded by Paul Newman in 1988. It is a non-profit, residential summer camp and year-round center designed to serve children and families coping with cancer and other serious illnesses and conditions. Each summer more than 1,000 children between the ages of seven and fifteen from across the country and abroad attend Camp. Through our Camp programs, year-round outreach to families, and ongoing services for children, families, and caregivers, the Camp serves more than 15,000 children annually. All of our services are provided free of charge.

Dr. Sharon Space is Camp’s Medical Director.

Camper Anna attended that first metabolic family weekend. Her mother, Teri, explains, “We had known about Camp for years but thought that Anna’s metabolic disease did not qualify her to attend. When we drove through the Camp gates for the first time, I got choked up. The weekend was everything and more I could have hoped for, a place of fun and freedom and acceptance for different medical conditions, and support and fellowship for us parents of kids with metabolic and rare diseases.” Anna joined our first summer program to include children with metabolic illness in 2008. Because of her illness, Anna has a G-tube—a tube into her stomach—through which she can be fed. She requires feedings every four hours, day and night, every day of her life. When her parents came to pick her up after a week at Camp, they found a new Anna, filled with confidence, smiles, and stories of swimming, arts & crafts projects, horseback riding, and new friends.

“Before Anna went to Camp,” says Teri, “she was not very social. She preferred to spend much of her time in her room, played alone, and new friends. As Anna’s Camp experience was a mature and more confident about talking to others, both children and adults. After going to Camp she now plays with others on the playground and is much more confident about talking to strangers and friends. Family members and teachers have all commented that she is more socially confident after attending Camp. We know her maturity is due to her experience at The Hole in the Wall Gang Camp.”

Anna’s Camp experience was a plus for her parents as well. For the first time since she was born, they were able to sleep through the night without waking up to feed her. Her brother attended sibling week and also had a great experience. Last summer, Camp hosted more than 30 children with metabolic and mitochondrial disorders. Because of the specific medical, nursing and daily care needs of these special kids, the numbers we serve are necessarily smaller than for some other disease groups at Camp. The Metabolic Family Weekend has become a staple in our spring schedule. We at Camp feel fortunate to be able to provide Anna and children like her a place where illness takes a backseat and childhood can truly take flight.

Dr. Sharon Space is Camp’s Medical Director.
Camper’s bask in the warmth and friendship of Camp, feelings of isolation and other challenges of serious illness forgotten.

― Counselor Bruce Ginsberg