



Camp Talk

Fall 2011

Camp John Marc Transformations

During the summer of 2011, 1,165 campers with chronic illnesses and physical disabilities experienced the power of Camp John Marc. Many camper stories can be told that substantiate the power of Camp, but two from this summer have been chosen to illustrate the transformations that occur at Camp John Marc. Life experiences at Camp really do affect the campers' well-being.



Joe is a ten-year-old boy with spina bifida who attended Camp TLC this summer. He enjoys reading and is a Dallas Cowboys fan. While at Camp this year, Joe chose "Word of the Day" as his special project. Being a part of the "Word of the Day" involves getting in front of the group every day, participating in silly skits and announcing the accomplishments of the campers. There were 96 campers at Camp TLC, a sizeable group for anyone to speak in front of. In Joe's case this endeavor was extra challenging because he stutters. The first time Joe spoke from the microphone, many adult eyes revealed to each other unspoken concern: "How is this going to go over?" "Are the other campers going to laugh or get impatient?" The first thing that occurred was rather remarkable. Joe began reading the camper accomplishments with much stuttering. That is not what was remarkable. It was the fact that not one camper laughed, nor did any campers nudge the person next to them; they collectively gave Joe their attention. Each day during "Word of the Day," the same attitude prevailed whenever Joe stood in front of the group with microphone in hand. But each time at the microphone, Joe became more confident. He stuttered less and less. By the time the final "Word of the Day" rolled around, there was a significant transformation in Joe. His stuttering had nearly vanished.



Allison was an eleven-year-old camper who had Brainstem Glioma. The summer of 2011 was Allison's first time at summer camp, but she and her family had previously attended Camp NOW (Neuro-Oncology Weekend). Her mom said, "The decision to let Allison (and her brother Travis) attend Camp Sanguinity was one of the toughest decisions that my husband and I had to make since Allison's diagnosis in early 2010. Allison was on hospice care when we received the paperwork to sign up for camp, and she required a lot of care. For me, personally, camp was the same week as my birthday, and there was a part of me that wanted Allison with me on my birthday. Allison knew that camp would be hard on her physically. But she never brought that up; all she ever said was that she was going to camp."



Allison's parents drove her and Travis to Camp since they thought it would be difficult for her to ride on the bus. Additionally, in the previous week she had started using an electric wheelchair that her parents wanted her to have at Camp. Allison was somewhat uncertain about being at Camp as her parents drove off. As the day progressed, she said that the heat was bothering her, and she was concerned about her dressings. By Monday Allison was doing okay but was wondering if community living was for her. On Tuesday Allison conquered the Challenge Course through the efforts of the ropes course staff. When Allison was asked about the view from the top of the ropes course she replied, "It is all right." It was not the highlight of her week.



But the transformations had also begun. Allison was making friends. She was telling jokes in the cabin, she was working on the camp yearbook, and she was becoming more independent. Katie Campbell, Allison's Child Life Specialist, said, "Camp life was an adjustment for Allison. She slowly found her place and loved all of the experiences she encountered." Allison's mom said, "That week was hard. It was the longest that my husband and I had ever been away from the kids. We knew Allison was getting the absolute best care, but I was not in control, someone else was. We did not hear much from Camp that week and trusted that no news was good news."

Allison had a wonderful week at Camp. When Thursday rolled around, she announced that she wanted to ride the bus home like everyone else. She wanted to walk on that bus like everyone else. On Friday morning after breakfast and after being honored as Camper of the Year, Allison (with help) walked onto the bus. Her mom said, "When the buses rolled into Cook Children's parking lot that Friday and I saw Allison sitting on the first bus right behind the driver, and I saw the look on her face, I knew it had all been worth it. She had a look of total joy, and peace and serenity radiated from her. Camp had been the best thing we could have done for her, to let her go and be a kid for a while, and forget about treatments, and cancer and all the rest. I would give anything to be able to go back to that moment in time, just to see that look on her face. We will always cherish the wonderful memories we were able to create, thanks to Camp John Marc."

Allison died on September 10. Allison's adventures at Camp and their effect on her life journey were shared by Katie Campbell and Allison's mother during her memorial service.

Allison experienced a transformation at Camp. She felt independence; she got on that bus; and she enjoyed being a kid again, not so much a patient. Katie Campbell said, "Allison found herself in a place where she was accepted and loved and could just focus on experiencing it all, and she delighted in that."





Ley at Camp Esperanza with his Fort Graham campers

Volunteer Counselor

One of the joys of being involved with Camp John Marc is the opportunity for folks to volunteer as Camp counselors. Some 800+ did so this past summer. Most come from the DFW area. But I have worked with some who have come from as far as the Bahamas, California and places between. So why do they do this? Of course there are many reasons but most center around a desire to help others and in so doing, hopefully, be ‘transformed’ themselves. And many have a friend or a relative who has experienced childhood illnesses or major physical disabilities. Many (a growing number each year) have been campers at CJM themselves. It is again transformative to watch these now-volunteers share their experiences with the campers. There is nothing quite like “been there, done that” in this setting. These former campers have become some of the best adult counselors imaginable.

At Camp Esperanza (for cancer patients from Children’s Medical Center) I have had the chance to participate with many adult volunteers. It’s remarkable to see this group of 70 or so people come together each year. Typically most of these folks don’t see each other much, if at all, during the rest of the year. But with careful planning, excellent guidance from the CJM staff and a whole lot of care about kids, a transformation occurs. This group focuses its entire effort on the kids coming to Camp. No other motives.

Twenty plus years ago something serendipitous happened. A friend, Linda Vorhies (who, along with her husband John, had lost a daughter to cancer), called to talk to our son about possibly being a volunteer at Camp Esperanza. Camp was to start very soon and they needed male counselors. I knew Easley could not help because of a summer job. I was aware of Camp Esperanza but had never given any consideration to volunteering. Without any further thought I simply said, “I’ll do it.” That turned out to be a good thing. At Camp I have learned a great deal about shared experiences and how important it is to let the kids participate fully in all activities, to let them lead when possible, to let them learn about boundaries, including physical, mental and those brought on by the common sense application of Camp rules.

An example from a few years back . . . It was fascinating to watch and listen as the kids settled into their cabin upon arrival. One camper had had to have a leg amputated above the knee. During reconstructive surgery that would allow him to use a prosthesis, his ankle/ foot had been reattached, backwards, at the place where his knee had been. He was not wearing his prosthesis. The kids noticed. With the usual curiosity of youth they did the simple thing. They asked what/how/why his leg looked the way it did. He gave a brief, very clear explanation to them all. Their curiosity satisfied, they were on to more pressing issues like what was the schedule for the evening activity, etc. Transforming moment for me. This young man, as well as his fellow cabin mates, taught a valuable lesson. Unusual things happen in life. It’s OK to be curious, to question them, to learn and to move on.

Ley Waggoner
Board Chairman

MEMORIALS/HONORARIUMS

MEMORIALS

Payton Agnew (Esperanza camper)
John Christopher Aldridge (Moss camper)
Damarea Allen (Feliz camper)
Luke Altobelli
Kathryn Baird
John Bass
Burnie Battles
Louis A. Beecherl, Jr.
Priscilla Bell
AnaLaura Benitez (Esperanza camper)
Phillip Bilnoski
Mildred Boes
Camille Bromwell
Elizabeth Callender
Leonard Carr
William Chrismas
Cody Colley (CMC Family camper)
Virginia Cotton
Les Crawley
Caroline Curnes
Ginger Daniel
Van Davis (Sanguinity camper)
Melva Deakins
David Delatour
Harrison Joseph Devlin
Duane Eberhardt
Mary Lou Ficke
Mickey Geron
Gabriel Khris Hall (Tecumseh camper)
Becky Harper
Shiann Henson (Sanguinity camper)
Edna Herrin
Geanette “Tommy-Jo” Holland
Joshua Cole Houston (MDA camper)
Evalyn Huff
Dr. Henry Jaehne
H.W. “Buzz” Jordan
Kegan (a Cocker Spaniel)
Rachelle Kolby
Charlie Langell (Sanguinity camper)

Richard Latty (MDA camper)
Hudson Lockett, Jr.
Allison Long (Sanguinity/NOW camper)
Logan Lyckman
Tony Madkins (MDA camper)
Maggie (a King Charles Cavalier Spaniel)
Adam Main (MDA camper)
Mariah Mann (Sanguinity camper)
Robert P. Montague
Adrian Munoz (CMC Family camper)
Shelley Musselman
Geraldine Marie Campbell Naschke
Marilyn Oates
Ida Papert
Emily Parsons (Sanguinity camper)
Carmen Patterson (Esperanza/CMC Family camper)
Austin “A.P.” Pruitt (Moss camper)
Ramiro Ramirez (Esperanza camper)
Joe Roach
Veronica Rodriguez (Sanguinity camper)
Dr. Peggy Sartain
Donna Scott
Ernestine Smith
Jesus Romero Smith (Reynal camper)
Gregory Solis (DBMAT camper)
Lila Spoor
Starr (a Cocker Spaniel)
Bradley Stoner (SOAR camper)
Herb Sutton
Veida Marie Thoben
Maureen Travis
Carol Alice Tyler
Daniel Tyler
Paul Wallace
Randall Wallace
Jacyia Whitfield (Tecumseh camper)
Branta Wingate (Sanguinity camper)
Charles Wood
Diana Pratt Wyatt
JoAnn Youngman

HONORARIUMS

Maggie Chisholm & James Abbott
Monica Baca
Dr. Jim Bentley
Greg Biggs
Alisha & Kris Bunn
Amber & Austin Burk
Mr. & Mrs. Randy Cooper
James A. Cox
Noland Fulks
Harry “Buddy” Gilmore
Joanne & Tom Hurtekant
Marsha & Craig Innes
Martin “Jake” Jacobson
Emily Brown Larkin
Michelle & Chris Lindsay
Donna Tanner & Al Lubren

Molly Macatee
Maggie Mathis
Holland McQuaid
Ellen & John McStay
Loyd Powell Family
Jan & Trevor Rees-Jones
Rachel Renfro
Scott Sams
Lynn & John Sears
Annie & Josh Stewart
Carol & Gifford Touchstone
Hunter Vela
Ley Waggoner Family
Monica & Leland White
Louise “Sweetie Pie” Willoughby (100th Birthday)
Lisa Wilson

Life Directors’ Highlight



Jan & Marc

resources to support the mission of Camp John Marc for more than twenty years. Their support knows no boundaries. If any task, large or small, is for the benefit of Camp John Marc, Jan and Marc take it on.

Fall 2011 has brought Jan and Marc some well-deserved community recognition for their leadership and commitment to Camp John Marc. Together they received the “Each Moment Matters” award from Faith Presbyterian Hospice. Jan was also presented the Equest Award for Community Service.

Seldom in life can parents build from the unbearable loss of a child a legacy that not only honors the memory of that child but also blesses the lives of countless other children and their own families. Jan and Marc have certainly done so through their dedication to Camp John Marc.

Native Texans Jan & Marc Myers met as college students at the University of Texas and married after graduating. They had four much-loved children, John Marc, Russell, Joanne, and Molly.

Jan and Marc’s second child, John Marc, died in 1987 at age nine of osteogenic sarcoma, a rare form of bone cancer. In John Marc’s memory, Jan and Marc donated the beautiful ranchland on which Camp John Marc was built. Because of their love for John Marc and a commitment to every child who comes to Camp John Marc, Jan and Marc have given of their time, energy, and



Marc sidewalking at Camp Moss

Wish Links

Last summer a simple activity using construction paper and staples to make paper chains became more than a simple decoration. Each camper was given the option of making a paper chain that was renamed a “wish link.” The arts and crafts director asked the campers, “What is your wish?” The campers were instructed to roll their wish either on the outside of the link or, if they wanted their wish to be private, on the inside.

At the end of the summer the rafters in the Arts and Crafts room were full of colorful wish links. Here is a sample of the wish links that were turned out for others to see:



Wish Links in the rafters

“I wish I could go into remission”
Camp Esperanza Camper

“I wish my eyes would work again”
Camp I-Thonka-Chi Camper

“I wish I could be cancer-free forever”
Camp Sanguinity Camper

“I wish I could get a kidney transplant”
Camp Reynal Camper

“I wish I could live even longer with my sick heart”
Camp Moss Camper

“I wish my hair was back”
Camp Esperanza Camper

“My wish to attend West Point”
Camp Ailihpomeh Camper

“I wish everything could be perfect”
Camp MDA Camper

“My wish to come to camp every year”
Camp TLC Camper



Chalisa, Camp Sanguinity camper, with her Wish Link

Although not all of these wishes can be granted, a lot of magic happens at Camp each week.

Job Well Done, Dr. P.!



Pat & Claude Prestidge

In 1973, pediatrician Claude Prestidge was in private practice in Dallas, but a significant part of his work was at Children’s Medical Center of Dallas, treating patients in the Cystic Fibrosis Care and Teaching Center. Cystic Fibrosis (CF) is a life-threatening, hereditary disorder that causes thick, sticky mucus to build up in the lungs, digestive tract, and other areas of the body, and at that time the life expectancy of a child with Cystic Fibrosis was just twelve years. Dr. P., who had worked as a camp counselor during college at Camp La Junta in the Texas Hill Country, saw a need for children with Cystic Fibrosis to go to camp. There they could meet other children living with Cystic Fibrosis and have the opportunity to play, laugh, and enjoy life at summer camp. They could be, for a week at least, just like other children.

So in 1979 Dr. P., along with Susan Williams, RN, founded a camp for children with cystic fibrosis.

At the time, this was a radical concept. How could a child go to camp with a serious disease that required “percussion” treatments (pounding on the chest and back of the patient to loosen the mucus) and inhalation treatments for up to four times each day? Only by their doctors, nurses, and respiratory therapists, along with volunteer activity leaders, giving of their time to make it happen, and so, Dr. P. and his staff offered CF treatments at camp in between fun activities like fishing and swimming and games. He also pioneered the role for future Camp Docs at camps for children with all kinds of chronic illnesses. In the wildly successful “Dr. P.” model, the Camp Docs and the medical team were to be out and involved in camp activities, interacting with the campers. This was a LOT more fun than clinic for the children, and helped the campers see their medical caregivers as real people, approachable and caring.



Dr. P. showing off his best dance moves at skit night

Dr. P. helped change the public’s understanding of who could go to camp, and he led the way by showing that active

treatments could actually take place at camp. When Dr. P. created CF Camp, he knew that children dealing with Cystic Fibrosis had few opportunities to develop independence because much of their life was regimented and directed by others. He wanted the campers to experience a measure of independence at camp, and he wanted to improve their quality of life.

CF Camp, “Camp Koinonia,” operated under Dr. P.’s direction for one week each summer at Camp Sweeney for more than a decade, until Camp John Marc opened in 1991. CF Camp then made the move to Camp John Marc, with its wonderful new facilities perfectly suited to children with chronic diseases following the model that Dr. P. had helped pioneer. But in 1993 the National Cystic Fibrous Foundation, along with the Centers for Disease Control, ruled that children with cystic fibrosis could not attend camp anywhere in the U.S. because of a bacterial organism, B. cepacia, that could spread among children with Cystic Fibrosis and shorten their already short lifespan. Camp Koinonia, after two happy years at its new location, had to be cancelled. This was a terrible blow to CF Camp, its campers, and Dr. P.

Yet despite this setback, Dr. P., who continues to be involved with Camp John Marc to this day, can count Camp Koinonia and Camp John Marc as perhaps his greatest legacy to sick children in Texas and far beyond. Dr. P. made an impact on the camping industry, showing that children with almost any diagnosis could attend camp. He showed that the Camp Docs needed to be part of the play and fun at camp. Today many different treatments, including hemodialysis, take place at Camp John Marc, scheduled in between horseback riding and swimming, just as Dr. P. initiated with percussion treatments all those years ago. The Camp Docs play in the water wars, climb the challenge course, and dance with campers at Party Night, just as Dr. P. did.



Dr. P. & Friends, along with Susan Williams (left), co-founder of CF Camp

On September 1, 2011, Dr. P. retired as the director of the Cystic Fibrosis Care and Teaching Center at Children’s Medical Center of Dallas after thirty-eight years of serving children with CF. Children’s Medical Center has honored Dr. P. by renaming their clinic the Claude B. Prestidge, M.D., Cystic Fibrosis Center.

Dr. P. is beloved by his patients and their families. He is not hanging up his heart along with his “Children’s” white coat. The expert treatment, kind care, corny jokes, and opportunity for so many children with chronic health issues to have a week of real childhood each summer will endure.

Dr. Claude Prestidge lit a light that will always shine.

One Family. Three Bricks. Sixteen Years Apart.



Camp John Marc does not plan for second generation campers the way many camps do. But, for the first time, last summer, children of a former camper cooked fajitas on a campfire, tried to catch Netter, and played poker at Party Night, just as their father did sixteen years ago.

In 1995, Marcus Onvani was a camper at Camp I-Thonka-Chi, for campers who are burn survivors. Today, Marcus is Operations Manager with Boeing Defense, Space & Security. Marcus and his wife, Tiffani, are the parents of Maverick and Farrah, first time Camp Sanguinity campers.

Recently Marcus shared that before he attended Camp he would turn his head when he entered a room to hide his burns. But after Camp, because of the perspective and self-assurance he gained from meeting others like him, Marcus would enter a room with confidence.

This summer, Maverick and Farrah also got to experience what it is like to share the Camp experience with others just like them, campers who have cancer and their siblings. Farrah is an oncology patient at Cook Children's, and because Camp Sanguinity also serves siblings, Maverick came with Farrah to Camp.

When Marcus learned his children would be attending Camp Sanguinity, he also learned about the family Getaway program and last spring the whole Onvani family spent a weekend at Camp. Marcus couldn't wait to show his family the brick with his name on the Live Oak Path. Now that Farrah and Maverick have also been Camp John Marc campers, their names will join their Dad's on the Live Oak Path.

This Thanksgiving season you will have an opportunity to honor Farrah, Maverick, and all the other campers who came to Camp John Marc for the first time in 2011. Watch your mail and email to learn how you can purchase a brick for the Live Oak Path that will be engraved with the name of a first-time Camp John Marc camper. Or visit www.campjohnmarc.org to purchase a brick today.

Camp Talk Photos by Karen Gilmore

Inside

	Page
Volunteer Counselor by Ley	2
Memorials/Honorariums	2
Life Directors' Highlight	2
Wish Links	3
Job Well Done, Dr. P.!	3

If you would like to be removed from our mailing list, please let us know: mail@campjohnmarc.org



An official publication of
Special Camps for Special Kids, Inc.
Camp John Marc
2824 Swiss Avenue
Dallas, Texas 75204
214-360-0056
www.campjohnmarc.org

Non-Profit Org.
U.S. Postage
PAID
Dallas, TX
Permit No. 755