



Lloyd Harbor *life*

An Exclusive Newsletter for the Residents of Lloyd Harbor

April 2015



*Huntington
Lighthouse.*

Photo courtesy of Pam Setchell.

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THE LIFE OF T.J. ARCATI

FRIENDS OF TJ FOUNDATION SUPPORTS PIONEERING CANCER RESEARCH AT CSH LAB

By Nancy Arcati



Looking back, they were the good old days. With the backdrop of the California mountains, a beautiful coastline and an endless amount of outdoor activities, a little boy named T.J. Arcati grew-up. That was the venue for ski trips to Lake Tahoe, tennis and soccer in Monterey and many sleepovers with his best friends, Andy and Matt. T.J. and his young buddies spent hours catching lizards, climbing trees and started to play baseball, soccer and tennis. He flourished in school and teachers would brag about him. He traveled all over the west coast with his parents from Oregon to Mexico, skiing, camping and exploring. This was also the setting where his brother, Matthew, would enter his life. A brother bond formed that would never be broken.

At 9 years of age and with a heavy heart, T.J. moved to New York with his family. For the first time, he felt true sadness saying goodbye to his friends and his home. The good news was that T.J.'s family settled in the beautiful coastal town of Lloyd Harbor. After adjusting, which he did well, life was good again. His Dad coached his baseball team and everyone was making friends quickly. A home was built that would be T.J.'s home base for the rest of his life and the place where many happy events would occur. With lifelong friendships underway, he was also learning to ice skate, play with go carts and excelled at Lloyd Harbor Elementary School.



TJ as lifeguard at Lloyd Harbor park.

Time passed quickly and before he knew it, he started 6 years at Cold Spring Harbor Jr./Sr. High School (CSHHS). T.J. played soccer and 4 years of varsity tennis, became a high honors student, volunteered, became a life guard at the Lloyd Harbor Park and taught children to sail and swim. Life was busy and good.



TJ sailfish fishing in Guatemala

Everyone loved family trips spent skiing, fishing or enjoying the beach. T.J. loved his life and took advantage of all the opportunities he had. He made good impressions along the way and many often said, "Everyone loves T.J." He was always considered to be mature, smart, kind, compassionate and had a great sense of humor too.



TJ at Notre Dame Graduation

As a senior at CSHHS, T.J. found himself heading to the University of Notre Dame. Just like leaving California, T.J. left with a heavy heart and had trouble saying goodbye to family and friends. However, he was happy right away and never looked back. Life was good! Now, living in Indiana, he was blessed with another great educational opportunity both in

and out of the classroom. He became one of the most devoted Fighting Irish fans and was forming lifelong relationships with a great group of new friends. College summers would find T.J. lifeguarding at the Lloyd Harbor Park and pursuing an internship at Cold Spring Harbor Laboratory (CSHL) assisting a scientist with a research project.

Post-college plans took T.J. to medical school at New York College of Osteopathic Medicine. He was accepted into a residency in anesthesia at Maimonides Hospital in Brooklyn and finished his education with a fellowship in Cardio-Thoracic Anesthesia at Mount Sinai Hospital in New York City.

During his residency, T.J. married his long-time girlfriend, Heidi, who also worked at the Lloyd Harbor Park. Heidi was a camp counselor and went on to teach at the Greenvale School. They had a beautiful wedding in Westhampton in 2006. A perfect match! When T.J. finished his fellowship, they both decided to move back home with their one-month old daughter, Hadley. T.J. said he loved his life here so much that he wanted his children to have the same gifted experiences he had. He was literally on top of the world. He was thrilled to accept an anesthesia position at Huntington Hospital after 9 years of post college education and training. He loved his job. Life was good!



Heidi, TJ and Hadley



Hunter and Hadley

With a son, Hunter, on the way and a move into their first home complete, something very disturbing was about to happen. T.J.'s wonderful life was shockingly interrupted with a cancer diagnosis at 31 years of age.



Matthew, TJ, Nancy and Tom Arcati

Illness

The world as T.J. knew it was gone. Faced with a gruesome chemo/radiation schedule, he had to leave his job for about a year. However, with much resolve, T.J. told his Doctor at Memorial Sloan Kettering Hospital that he would do everything he could to put this disease behind him. They, in return, promised a tough road but a 70 percent cure rate. T.J. stayed focused on surviving rhabdomyosarcoma, a formidable opponent. It strikes children, adolescents and young adults with no known cause. Everyone surrounding T.J. was in shock!

Finally, clear scans! T.J. didn't waste a minute. Hockey, a quick ski trip and fishing as well were all on the agenda. Most importantly, however he was thrilled to be with Heidi and the children minus the Sloan schedule and side effects. His parents and brother were always near and they all lived a new normal ... happy but scared of the unknown.

Unfortunately, T.J. was scared again when a local recurrence was discovered. This was a most difficult time but the team at Sloan said they had a plan to keep this in check and hoped to have new treatments coming down the pipe. After a year, this plan stopped working and they didn't have other treatment options available at Sloan. Perhaps at other institutions!

T.J. and his family traveled all over the country looking for other treatments in Boston, D.C., and Texas. They all had limited trials and limited data. He tried all of them including another approach at Sloan. T.J. felt forgotten by the medical field and felt that no one should have to go through this torturous ordeal. He was worried about himself, his family and could only get by hoping for the best.

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Heidi, T.J. and Matthew Arcati

T.J. died on January 7th, 2013 surrounded by his parents, his wife and his brother just three years after his diagnosis and just shy of his 35th birthday. He faced everything with such courage and dignity but struggled with this cruel twist of fate.



Foundation and Lab

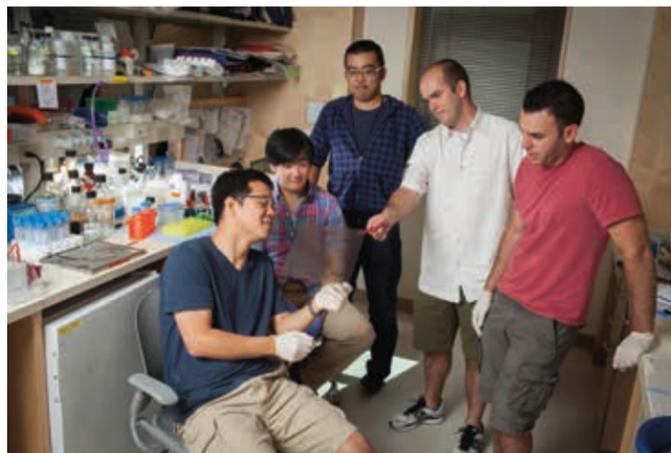
Along his journey, T.J. started a Foundation with two college friends. They called it: Friends of T.J. Foundation. He hoped to get well and then use his experience to fund research to help others with this disease. Now, his family and friends work tirelessly on the Foundation which is devoted to research. A lack of research translates into a lack of treatment options.

Eighteen months ago, the Foundation met with Dr. Bruce Stillman, President of the Cold Spring Harbor Laboratory. Shortly after, plans were underway for the first research project at CSHL on sarcomas ever to take place. Under Dr. Stillman's direction, the first stage was to host a Rhabdomyosarcoma Symposium which took place in May of 2014. The Lab brought together researchers and clinicians from around the world for a 3 day meeting of the minds. This meeting crystallized the most promising avenues for future research and outlined the path necessary to advance research and move into the clinic. This allowed the Lab to identify a clear direction and the meeting became the catalyst for a new Sarcoma Research Project.



Scientist Chris Vakoc working in T.J.'s lab. Photo courtesy of Connie Brukin.

This project is a directed effort to understand how sarcomas arise and to identify new therapeutic strategies. CSHL scientist, Chris Vakoc, M.D., Ph.D., is spearheading the initial research. He has developed a powerful approach that pin-points genetic weaknesses within a population of cancer cells. Dr. Vakoc is working in close collaboration with Dr. Charles Keller, a physician and professor at the Oregon Health and Science University, who is one of the world leaders in rhabdomyosarcoma research. Dr. Keller offers tremendous insight into the disease and has already created tools that will be instrumental in moving research forward. Dr. Keller visited CSHL in September, 2014, when he presented a seminar to summarize the current state of the research.



Scientist Chris Vakoc working in T.J.'s lab. Photo courtesy of Connie Brukin. Also funding the project are: CSHL, The Christina Renna Foundation, The Michelle Paternoster Foundation and The Clark Gillies Foundation.

To fund this work, share T.J.'s story and raise awareness, the Foundation held an inaugural outing at the Huntington Country Club in June of 2013 with the help of many friends and family. Plans are currently underway for the 2015 Outing to be held on June 22nd at both the Huntington Country Club and the Huntington Crescent Club.

To summarize, in just 18 months, the first sarcoma research project at CSHL is underway. CSHL is one of the world's premier cancer research centers. This cutting edge project hopes to have far reaching results for all types of cancers.

As you consider supporting any charity, please think about the cancers that are underfunded and deny children and young adults of their future. These diseases also deprive society of their many productive years lost. More importantly, the years lost to these young people are also magnified by the loss of crucial relationships between parents and children, spouses, siblings and friends. So many lives are changed forever!

We would love to see you at the Outing on June 22, 2015. The Outing offers golf, tennis, bridge and/or a cocktail/buffet reception at Huntington Country Club. Organize a group or sign-up solo.

For further information or to donate: Visit the website at: www.FriendsofTJ.org, follow us on Facebook (Friends of T.J.) or call us at 516-695-5870.

For so many, it's hard to live in this world without T.J. but we know the world is a better place because he lived in it.

With hope for tomorrow.