

The Steven M. Perez Foundation

LETTER FROM THE FOUNDATION

In the year since our last newsletter was published, The Steven M. Perez Foundation has been hard at work organizing events and trying to assist those in need. The Foundation continues to focus on a broad array of charitable activities that will bring friends and family together with the opportunity to have fun and create new memories in Steven's name.

Our mission is to help people who have been directly or indirectly affected by leukemia and other related cancers. The Newsletter highlights ways The Foundation has raised funds in Steven's name and how your donations are making a difference. We want you, who have so generously donated, to know that these funds will continue to be invested in programs committed to helping people affected by these diseases, and to improve the quality of life for those suffering from these diseases.

We are proud of the work we've done over the past year. It is no small accomplishment to raise over \$100,000. To know that the money is going to help people who need it is truly inspiring. Events like the "El Rey Banana" Golf Outing and the Comedy Night keep Steven in our hearts and minds. Thanks to the Perez family, friends like the Goldrings, the Genatts and the Schiffs, and to Sal "The Stockbroker" Governale, these events were hugely successful. Helping the victims of Hurricane Katrina, sending six students to college and ten families to Camp Sunshine reminds us all of the most important thing Steven had to teach us – that life is precious and should always be celebrated.

The Foundation has participated in three Leukemia & Lymphoma Society events over the past twelve months. They are the Light the Night Walk in downtown New York City, the Spring Fling at the Latin Quarter, and, most recently, the NYC Triathlon through the participation of Scott

Redler and Michelle Marx. We are extremely proud to be affiliated with The Leukemia & Lymphoma Society and look forward to working with them again on future projects.

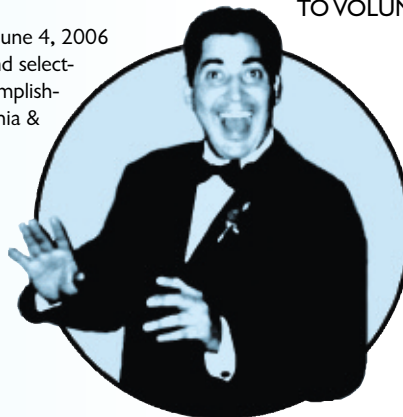
The NYC Triathlon was an especially heart-warming event given the tireless effort and dedication of Scott Redler. Scott not only finished the race in under 3 hours, but he did it on the bike Steven helped give him for his birthday. For the months leading up to the race, his life was devoted to raising awareness and money for The Leukemia & Lymphoma Society and The Steven M. Perez Foundation, successfully generating close to \$20,000 in donations. His hard work, for the Triathlon and for The Foundation, was featured in articles in three local newspapers. We are extremely proud of all that he has accomplished and genuinely appreciate his commitment to meeting his physical and financial goals.

The Foundation has great plans on the horizon and we all hope to continue to create positive momentum in helping those who are affected by leukemia and other related cancers. We have received formal approval as a 501(c)(3) status organization from the Internal Revenue Service. This entitles The Foundation to operate as a not-for-profit, and allows donors to deduct the value of their donation for tax purposes. We welcome your feedback and hope you enjoy reading about all of the wonderful activities we have been involved in over the past year.

In the future, The Steven M. Perez Foundation will continue to seek out worthwhile projects to participate in. It is the strong support of our donors that makes such contributions possible. We are always looking for ways to celebrate Steven's life, and his love of life. Please contact any of the board members or go to our website at www.smpfoundation.org for more information about upcoming events.

Upcoming Events & Sponsorship Opportunities

- Third Annual El Rey Banana Golf Outing will be held on Monday, July 17th for the first time at the Tam O'Shanter Country Club in Brookville, New York. We expect another terrific turnout and encourage you to get involved and make this the best outing yet!!! Sign up on-line to reserve your spot now, www.smpfoundation.org.
- Friday, April 21st at Gotham Comedy Club, a comedy event hosted by the Howard Stern Team, thanks to Sal "The Stockbroker" Governale. Tickets are \$75.00 and are available at www.smpfoundation.org
- Candidates for 2006 scholarships are being identified, evaluated and considered for the Steven M. Perez Scholarship. Please contact the Foundation with potential candidates or other worthwhile opportunities for the Foundation to participate in.
- Scott Redler continues to race for a greater goal on June 4, 2006 at the Escape from Alcatraz Triathlon. Scott was hand selected to participate, given his physical and financial accomplishments achieved at the NYC Triathlon For the Leukemia & Lymphoma Society.
- Evaluating an opportunity to help Camp Ronald McDonald "For Good Times" provide assistance to cancer / leukemia patients throughout the United States. The camp helps these special children enjoy being children, providing an opportunity for them to have fun and interact with other children in similar circumstances.



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The Steven M. Perez Foundation is a not-for-profit organization operating under Section 501 (c) 3 of the Internal Revenue Code. All donations are gratefully accepted.

Recent News

September 2004: Dana and her friends represented The Steven M. Perez Foundation in The Leukemia & Lymphoma Society Light the Night Walk across the Brooklyn Bridge. The event was a big success and the girls had a special night doing something positive for a great cause.

October 2004: Some of Steven's close friends put together a dodgeball team and Team "Los Reyes" won their 1st tournament at Chelsea Piers and dedicated their championship to the memory of Steven.

April 2005: The Foundation participated in The Leukemia & Lymphoma Society Spring Fling event at the Latin Quarter. On behalf of The Foundation, Lauren Jarvis and Alana Yavers arranged for a fabulous night in Manhattan and braved the auction process, donating their time to raise funds for The Leukemia & Lymphoma Society.



May 2005: Comedy Night at Stand-Up NY was a great night of fun and laughs, sponsored by Sal "The Stockbroker" Governale. Our special thanks go to Artie Lange, Reverend Bob Levy and the rest of the Howard Stern Show crew who donated their time to make May 13th a night to remember.

June 2005: Through the efforts of the Redler family, Enterprise Rent-A-Car Foundation notified the Foundation that we were the recipient of one of their employee sponsored awards. Enterprise Rent-A-Car Foundation donated funds to just ten organizations throughout the country in support of programs designed to enhance the lives of children. The Steven M. Perez Foundation is honored to be among them, and we deeply appreciate this substantial gift.

June 2005: Six students from the New York area were awarded college scholarships from The Steven M. Perez Scholarship Fund. Successful coordination with the respective guidance counselor offices and in coordination with North Shore Hospital helped to identify these deserving candidates.

June 2005: Scott Redler, on behalf of The Steven M. Perez Foundation, was honored for his leadership and fundraising abilities at the NYC Triathlon award ceremony. After many months of hard work and training, we are proud to say that Scott raised almost \$20,000 to benefit The Leukemia & Lymphoma Society and the Foundation.

June 2005: The Foundation raised over \$80,000 at the second annual "El Rey Banana" Golf Outing, held on June 20th. The event was attended by over 100 participants and would not have been possible without the help of our generous sponsors, volunteers and all the terrific silent auction and raffle items.

July 2005: Scott Redler and Michelle Marx successfully completed the NYC Triathlon with a combined time of just under six hours on Sunday, July 10th. It was a beautiful morning and over fifty people came out to cheer Scott and Michelle as they finished the race. Many stayed to enjoy the day in Central Park and celebrate with the athletes.

July 2005: The David Corey Challenge, a Foundation sponsored contest to guess the combined completion time for Scott and Michelle, was won by Max Hechler. Good guess, Glenn!!

July 2005: Ten families were sponsored by The Foundation to attend Camp Sunshine, a camp that supports children with life-threatening illnesses and their families. We are pleased to report that The Foundation donated over \$16,500 to provide opportunities for young cancer patients to enjoy a week away.

August 2005: Scott Redler raised almost \$20,000 in the New York City Triathlon. \$14,198 went directly to The Leukemia & Lymphoma Society, who generously donated half that amount to The Foundation. In addition to that sum, Scott raised approximately \$5,000 for The Foundation directly through raffle tickets and private donations from people who supported him through all his hard work in the months leading up to the Triathlon. We congratulate Scott on an incredible finish and express our deepest appreciation for his love and tireless effort.

August 2005: "Los Reyes" defended their dodgeball championship title, winning another tournament in honor of Steven. Their win was also dedicated to the speedy recovery of our friend David Schneider who is recovering from pancreatitis. We congratulate Co-MVP's Ryan, Rich, and Glenn along with Steve, Dave, Chris, Scott, Fredo, Mike, Lee, Dani and the rest of their team for another tremendous victory.

September 2005: Over fifty of Steven's friends joined us at Mo's Carribean to celebrate his birthday and enjoy a fun Thursday night out together in his name. Thanks to Glenn Hechler, Scott Redler, Steven Dixon and Anthony Iufredo for putting this together.

October 2005: The Foundation donated \$21,000 in support of the families of seven New Orleans children suffering from leukemia. These children were relocated from New Orleans area hospitals to Texas Children's Hospital in Houston because of Hurricane Katrina.

January 2006: A special thank you to the Goldring & Baron families for printing this newsletter and to Steve Dixon for the layout and design.





On June 20, The Steven M. Perez Foundation was proud to host our 2nd annual "El Rey Banana" Golf Outing at Inwood Country Club on Long Island. It was a beautiful day of bright sunshine, good golf, and the laughter of over one hundred participants and volunteers. The Foundation would like to thank Jessica and Peter Goldring, Mellen and Jack Genatt and Tara and Eric Schiff for working so hard to make this event successful.

Founded in 1901, Inwood Country Club is one of the oldest and most challenging courses in the New York area. The scramble format allowed for smoothness of play, team comradie and a positive mental attitude, even for those of us new to the game of golf. Having great food and drinks

available all day is surely something Steven would have appreciated. In addition, various games throughout the course gave participants a chance to win some great prizes, and certainly kept things interesting.

After finishing the round, it was exciting to come in and see the clubhouse bustling with still more activity. The raffle and silent auction prizes, generously donated by a variety of individuals and organizations, offered something for everybody. Tee times, hand made clothing items, designer gift baskets and even tickets to the Playboy Mansion were only some of what was available. We greatly appreciate all the hard work Mellen Genatt, Carole, Rachel and Dana Perez put in to organiz-

ing the raffle and silent auction.

This year's Golf Outing was one of The Foundation's most successful events to date, raising over \$80,000. But the best part was knowing that Steven was there with us. One of his favorite pastimes was golf, and nothing would have made him happier than a good reason to get his friends to take a day off to play. It seemed like Steven was smiling down on us with the beautiful June sun, laughing and cheering us on as we played. The "El Rey Banana" Golf Outing is a tradition The Foundation plans to continue for many years to come. Please join us at Tam O'Shanter Country Club on monday, July 17th for another great event.



Los Reyes Dodgeball?

Question: Why on earth would a group of thirty something friends get together to play in a ridiculous dodgeball tournament?

Answer: Steven would have loved it.

Los Reyes came together after Dave Schneider sent out an email with a website for "The Dodgeball Tournament of Champions". The Team was made up of Steven's friends who all recognized how funny and fun this tournament would be. Our team name was a play on Steven's nickname "el rey banana"

With the winning team getting a trophy, individual medals and all the beer they could drink, we instantly took dodgeball very seriously.

The result was an unprecedented 38-2 record and 3 champi-



onships. Los Reyes quickly became the bad boys of dodgeball, a reputation we enjoyed. Our jerseys, with a skull and cross-bones design, probably didnt help!

It was easy to picture Steven sitting with a cooler in the stands, laughing and heckling our opponents as we tore them apart. We decided, like all true champions, to retire on top of the New York City Dodgeball world. This came as a relief to our loved ones and the bartenders.

All the players that participated could agree that we laughed loud-er and played harder than anyone else.

I know that Steven was watching, and he was equally proud of both. Every player keeps his medal hanging proudly at home or the office. **By Steven Dixon**



The Steven M. Perez Scholarship Fund Scholarship Award Winners

The Foundation continues to seek out candidates who have been directly impacted by Leukemia or by the devastation of losing a family member to leukemia or other related cancers. In 2005, we awarded six college scholarships to graduating high school seniors. Each candidate was nominated by a high school counselor and several were referred to us through the Leukemia Unit at North Shore University Hospital.

Dean Bourazeris

On July 29, 2003, as Steven was a patient at North Shore Hospital, just down the hall, Dean's father succumbed to Acute Myelogenous Leukemia (AML). Our families passed in that hallway every day and shared a caring smile. Dean attended New Hyde Park High School and will be going on to college.

Maria Dente

Maria lost her young brother to a blood disease so rare that the only treatment available to him was the Leukemia Unit. With the support of her family and friends, Maria started a foundation linked to North Shore Hospital which provides non-medical support for leukemia patients, including special food and equipment required for care but beyond the scope of normal medical insurance coverage. In the fall, Maria will attend Mount St. Mary College in Newburgh, NY. She is also a graduate of New Hyde Park High School.

Kellie Giangregorio

Kellie's mother received a bone marrow transplant in early 2004 to treat her leukemia. The family was hopeful for her recovery. However, she suffered a setback, and Kellie lost her mother in June 2004. Kellie attended East Islip High School and will use her scholarship for college expenses this fall.

Alexandra Berger

In a story similar to Kellie's, Alexandra's mother went through a grueling bone marrow transplant after being diagnosed with Chronic Myelogenous Leukemia (CML). Her weakened body rejected the transplant and Alex lost her mother in April 2005. She graduated from Syosset High School.

Kenny Zawistowski

Kenny also attended Syosset High School. He will go on to SUNY Geneseo in the fall to continue his education. His father died of leukemia when Kenny was in 6th grade.

Kristin Smith

Kristin was the only candidate to apply from the Half Hollow Hills School District, where Steven was once a student. She graduated from Half Hollow Hills High School West. She will attend Penn State in the fall. In the last year, her family suffered two severe blows - the death of her mother to cancer and the loss of the family's chief source of income. We feel certain that Kristin will put her scholarship funds to good use.

As we read the referrals from each high school counselor, there was a single unifying theme: each candidate had drawn strength from his/her loss and grown into a stronger, more caring adult. Most candidates have directed their energies to supporting their surviving family unit and serving to improve the lives of others in need. They found success in their studies and direction in life.

A total of \$8,250 was awarded in scholarships in 2005. Each of these stories highlights the difficulty of a life-threatening disease, and we are pleased that our scholarships can help provide these students with an opportunity to attend college. The Foundation continues to search for new ways for your generous donations to reach families in need of assistance.

The Perez Family



Lou and Carole Perez



Rickey, Dana and Steven



The Perez Family

Racing for a Greater Goal

To begin, I would like to thank everyone for their tremendous support and contributions. I had no idea what to expect when I first decided to go down this path. When I attended my very first meeting at the Leukemia & Lymphoma Society, I sat in the back and learned what it was all about. I heard tragic stories from individuals sharing why they were involved and why others should help. At that time, I did not grasp the magnitude of this endeavor and how it would change me forever. As I listened to the team coaches lay out the plan for the next few months, I looked around the room and saw hundreds of unfamiliar faces. These faces were soon to become a major source of strength and support for me. We were all working together toward the same goal.

When I set my goal to raise \$20,000, I was not sure if it was attainable; but then again, Steven always taught me to think big! As soon as I sent out the very first e-mail blast (which I think hit more than once - sorry!), I received an overwhelming number of responses. After the first hour, I had already raised \$2,000. This completely energized me. I knew that if I continued to network and contact enough people who knew Steven, I would reach my goal. It was amazing to reconnect with so many old friends and acquaintances. Each and every individual who donated was personally touched by Steven and many of the things that he and I did together, dating all the way back to our high school years. I knew that this was the start of something very positive. All of the e-mails that I received were filled with old stories and memories of Steven. People who I haven't spoken to in as long as ten to fifteen years eagerly donated as they remembered how Steven affected their lives. Getting Steven's name out there again felt



awesome. It felt like the two of us were handing out passes, making phone calls, and networking to fill a New Year's Eve Party or a Hampton's house like we had done so many times in the past. Unfortunately, we weren't. We were networking together to try and gain awareness for a disease that tragically took his life and affects so many others.

By continuing to raise money and awareness through future triathlons, I know that I can create something positive from such a devastating situation. In a short time, The Steven M. Perez Foundation was in 3 newspapers and on the local cablevision station in northern New Jersey. The money that has been raised will help save lives and help to make the lives of those affected with leukemia better. I have witnessed it first hand and I know that the money and resources reach those in need. The survival rate of blood-related cancers is increasing each and every year because of the time and money donated to programs like this. I promise to continue to figure out ways to raise money and awareness through more grueling and bigger races. Steven wanted me to think bigger and do a "real" race. I will not stop until I ultimately cross the finish line of an Iron Man

on the bike that Steven presented to me on my 30th birthday! On my path to that finish line, however long it takes, I will get Steven's name and the Foundation as far on the map as I can take it. I will try and raise as much money as possible so I can help many more individuals in need. Hopefully, I will continue to receive all of your support. If anyone has contacts for corporate sponsors or ideas that can help please feel free to let me know. Steven touched so many people in his short life and he has many more to help. It is all of our jobs to make sure we do that for him, and more importantly, to make sure that no one forgets the legacy he left behind.

By Scott Redler

Millionaire in the Bleachers

When I think of a day that always makes me smile, one that always comes to mind is the day we all went to the Yankee game. It was a hot summer afternoon and Steven must've just gotten paid. About eight of us all went to the game. Of course Steven managed to drop over four hundred bucks that day, buying everything under the sun-jerseys, t-shirts; it's one hundred degrees outside and he buys a wool Yankee blanket-who the hell does that??? Obviously, the usual hooting and hollering goes on along with the tradi-

tional bleacher chants. All the while, I don't think I saw Steven without a beer or some type of food in his hand the whole game and we're having a blast.

Anyway, the 5th inning rolls around, it's last call, the beer man walks over and Steve asks him, "How many you got?". The guy says eighteen and Steve yells back, "We'll take them." Unfortunately I believe Paul O'Neill hit a home run an inning later and most of the beer got dumped amidst the cheering, which was probably for the best.

During the 7th inning stretch a few of us are in the bathroom and some little kid with his dad says to Steven, "hey you're the millionaire in the bleachers" and we all just laughed...He felt like such The Man that day and I will always remember him like that; just living life to the fullest and not caring about tomorrow because today you were hanging out with him. As long as you're having fun, he's happy. Whatever he had he'd share with you and that's the way it was.

By Rich Park



Supporting Children with Life Threatening Illnesses & their Families

Camp Sunshine is a unique setting supporting children with life-threatening diseases and their families. The camp has the distinction of being the only program in the nation to address the impact of a life-threatening illness on every member of the immediate family – the ill child, the parents and the siblings. Since its inception, it has provided a haven for nearly 16,000 families from diverse cultural backgrounds.

Families attend in groups according to the disease which affects their lives. A child with leukemia and his/her siblings and parents can get to know other families in similar situations. Camp Sunshine also offers programs for families dealing with other conditions, such as cancer, kidney disease, lupus, diabetes, and organ donor recipients, to name a few. In the summer of 2005, responding to the need of the community, Camp Sunshine designated one session to single parent families coping with life-

threatening illnesses. Each group attends a one-week session and many families return the following year to renew acquaintances and enjoy a respite from the reality and stress of everyday life.

The Steven M. Perez Foundation has received many letters of thanks from the children and their families who were sponsored in 2004 and 2005. They all express their tremendous gratitude to those who made it possible for them to enjoy the Camp Sunshine experience with their families. They describe the serenity of the environment, the competence of a caring staff, the medical support team and the fun of just enjoying normal life in a beautiful place. The parents are grateful to have discussion groups with other parents coping with similar problems, but most often, these letters stress the impact that a sick child has on the emotional stability of their siblings. At Camp Sunshine, the healthy siblings meet others in similar circumstances. For many, it is the first time they have a chance to express their feelings to someone in the same unique situation. Play dates, piano lessons and soccer practice often take a back seat to doctor's appointments, in-patient care and chemotherapy.

To sponsor each family, The Steven M. Perez Foundation donates \$1,500. In 2005, we were pleased to expand our donation to support ten families from the Long Island area. All the families chosen have a young child with leukemia.

In the coming months, Camp Sunshine will be upgrading its grounds to include a brick and stone walkway. Each brick and larger stone insert will be paid for with direct donations to the camp. The Steven M. Perez Foundation will have a stone with The Foundation's name and the message "Live Life to the Fullest". The \$1,500 donation will be added to their fund for capital improvements at their site in Maine.



Lots of Laughs at Stand-Up NY

On Friday, May 13th, The Steven M. Perez Foundation hosted our first Comedy Night at Stand-Up NY. With the help and support of Sal "The Stockbroker" Governale, a close friend of Steven's, the event was a huge success. Sal recruited Artie Lange, Reverend Bob Levy, Richard Christy, Mike Bochetti and Geno Bisconti to perform and donate their time. It was incredible how well the comedians responded to the audience and how quickly they got a sense of the kind of person Steven was. There were so many jokes Steven would have really enjoyed. Carole and Rickey recalled how Sal used to call them every day when he worked with Steven, and he always made them laugh.

It was really special to have so many friends come together for a night of laughs and good times celebrating Steven. Even the comics commented on how much they enjoyed themselves and how they would love to participate in this event again. Fortunately, the event was sold out and The



Foundation generated over \$11,000.

We want to thank Stand-Up NY and Ketel One for hosting and sponsoring the event. We sincerely appreciate all the efforts of Sal "The Stockbroker" Governale, all the comics, our organizers

Dana Perez, Glenn Hechler and Anthony Iufredo for making it such a fun-filled night for all. This Comedy Night was a special tribute to Steven because of the laughter he brought to all our lives. We look forward to this year's event at Gotham Comedy Club on Friday April 21st. Please visit our web-site for more information.

Hurricane Relief

Hurricane Katrina has been one of the largest natural disasters our nation has experienced. Our hearts ache for our neighbors in Louisiana, Mississippi and Alabama whose homes, businesses and lives were destroyed by Katrina. We at The Foundation felt it appropriate to identify a way we could help.

We chose Texas Children's Cancer Center based in Houston, Texas. A division of Texas Children's Hospital, it is one of the world's premier research and health care education centers focusing on childhood cancer. It is the largest pediatric cancer and blood disease treatment center in the United States. Young patients suffering from every type of children's cancer and blood disorder come to Texas Children's Cancer Center from all over the world to receive the most advanced care.

Texas Children's Hospital was caring for up to fifty-five children evacuated from New Orleans area hospitals by air ambulance or in private planes donated by friends of the hospital. About twenty of these children are critically ill. The Steven M. Perez Foundation has identified seven families devastated by Hurricane Katrina who, unfortunately, also have a child suffering from leukemia.

It is a tremendous honor to provide all the help that we can to these young victims and their families. We are proud to have been able to donate \$21,000 to Texas Children's Hospital. The Foundation has decided to allow the hospital's team of social workers the discretion to determine each family's needs on a case by case basis. It is our hope that the support provided by The Foundation will ease some burdens and help put these families back on track.



Spring Fling

On May 5th, twenty-five brave men and women took the stage at the Latin Quarter nightclub in New York City to be auctioned off for a date. Two of these women were Lauren Jarvis and Alana Yavers, friends of Dana.

The Leukemia & Lymphoma Society hosted The Spring Fling: Bachelor & Bachelorette Auction. The event includes an auction for dates with young singles in the New York area and with celebrities. Alana and Lauren were auctioned off as a double date, which was sponsored by The Steven M. Perez Foundation. The date included dinner at City Crab (compliments of Mitch Rosen) and drinks at Union Bar. One lucky guy won a date with the girls.

The event also included a silent auction and a raffle, as well as hors d'oeuvres and cocktails. About \$43,000 was raised by the Leukemia & Lymphoma Society and approximately 250 people attended. Gratitude for the generous contribution made by The Steven M. Perez Foundation was mentioned in the evening's program. All of the funds raised went to The Leukemia & Lymphoma Society.

Light the Night Walk

Last fall, Dana and her friends took part in the Light the Night Walk hosted nationwide by The Leukemia & Lymphoma Society. Light the Night Walk is a national fundraising campaign to commemorate and celebrate the lives of those touched by cancer. The mission of this evening Walk is to build awareness of blood cancers and to raise funds for those in need. This is a two-to-three mile non-competitive Walk; survivors carry white illuminated balloons while other participants carry red ones. The girls

started at South Street Seaport and walked over the Brooklyn Bridge. During the event, participants are also invited to share in food, live entertainment and fun. The three 2004 Light the Night Walks in New York City were the most successful in the nation, raising nearly \$1.6 million. The event hosted over 7,000 walkers.

We would like to offer a special thanks to Dana for hosting the event and to her friends, Jennifer Berk, Brooke Koster, Shera Lashin, Lauren Jarvis and Alana Yavers for participating on behalf of The Steven M. Perez Foundation.



Jacob's Cure

On Sunday, March 5, 2006, the Steven M. Perez Foundation was happy to be a sponsor of the Jacob's Cure Family Bowl "Strike-Out Canavan Disease" Event. The event was held at the Chelsea Piers Bowling Alley and was a huge success attended by over 300 participants and family members. The Foundation sponsored a bowling lane and we enjoyed a great day of bowling and socializing with old friends and acquaintances. Thank you to the Redler's, Schilling's, Kahn's and Steinwolf's for joining Rickey, Rachel, Dana and Jesse for a fun afternoon and supporting a very worthwhile cause.

Jacob's Cure, a non-profit foundation, was established in September 2000 to save the life of Jacob, who is afflicted with Canavan disease, a devastating genetic brain disorder. Because Canavan is so rare, federal funding has been scarce towards therapeutic research in Canavan disease, so it is through the help of friends, family and a philanthropic community that Jacob and children like him may be cured. Canavan disease is a fatal genetic neurological

disorder that deteriorates the white matter (myelin) in the brain. The white matter forms a protective coating around every nerve in the brain and spinal cord, to ensure that nerve impulses are properly transmitted from one part of the body to another.

It is the lack of white matter that leaves Canavan children incapable of performing the simplest functions. Even if they live to their full life expectancy - three to ten years - they become blind, paralyzed, prone to seizures, and increasingly lost to the world around them. Luckily, the Canavan gene has been identified, allowing at risk couples to carrier test for this deadly disease. Both parents must be carriers in order to have a child with Canavan (25% risk or 1 in 4). While prevalent in the Ashkenazi Jewish population, Canavan has recently been identified in people of other ethnic backgrounds as well. Jacob's Cure urges all expectant couples to seek genetic counseling.

Many of you may have seen NBC News a few weeks back feature Jacob and his interaction with his classmates in Purchase, NY.

Jacob recently celebrated his 10th birthday and the news story highlighted his great attitude and his ability to socialize with his class-



Courtesy LotusPhotographers.com

mates. Experiencing all of the love and support everyone has for Jacob is a testament of their generosity and tireless effort to find a cure. The Foundation is very pleased to help support this important cause.

Steven M Perez Foundation
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