**April 2022 Newsletter**

## Roger Smith – “A Guy You Want On Your Team” Article by Judy Wieber



​Roger Smith is a retired police detective from the Port Authority of New York and New Jersey Police department.  
Decorated for actions of bravery taken during 9/11, as well as other events.  
He was 31 years in law enforcement. Four years as a police officer and then promoted to the rank of detective. He attended several training academies, approximately 25 academies in total over the years. He received training in: FBI investigations, hostage negotiations, homicide, white collar crimes, sexual abuse crimes, robbery, interrogations, just to name a few. He enjoyed his training and applying what he had learned to the field.     
He found it to be an enjoyable career. He had spent most of his career assigned to Times Square, where things were always very busy and fast paced. “Every day there was something different to be involved with. It was very intense and it made the 31 years go by very quickly.” He found fulfillment in challenging himself and really putting his skills and training to the test, which he enjoyed. The commute from Holbrook would sometimes end up being two to three hours long, but that did not matter because he loved his work the community he served and protected.  
 “I had a lot of fun.”  
   
Q:  
What was the hardest thing you may have done in the field of law enforcement?  
What was the most fulfilling, rewarding?  
   
A: Times Square was my assignment for 25 out of my 31 years. Sometimes Times Square could go from a pretty bad situation to a pleasant situation. In regard to me and my career, there were a couple of situations that were really painful to do. One was - death notifications. When you had to tell a family member that they had just lost someone very special. Also, dealing with child sexual predators. Working those cases were very disturbing. These two types of scenarios were definitely the hardest. On the other side, the happier stories dealt with sitting down and interviewing someone, as a composite artist. Part of my training, I was able to construct a drawing to recover a female child that had been kidnapped in Far Rockaway. That was something I took great pride in doing.It was a very lengthy interview with the witnesses. It took about six hours putting together a sketch.  The sketch was very accurate and we were able to apprehend the individual in Far Rockaway with the child.The other thing I am proudest about was Community Relations within our department. I started a department basketball team. It was a combination of police officers with athletic ability, coupled with kids in our precinctI formed a kids and cop’s basketball program. We played benefit games, raising money for: burn victims, school sports programs, disabled veterans returning home from service, and struggling communities that were looking for fund raisers. So, these are some of the prouder moments that I am truly proud of and enjoyed doing for several years; we raised a lot of money and we helped many communities both in New York and New Jersey.  
   
Q: What inspired you to go into the field of law enforcement?  
  
A: It is really comical. I went to visit a friend of mine, an old school buddy, who had relocated from East Elmhurst to the Bronx. When I went to visit him that day, he had plans to go and take the police exam in downtown Manhattan. I told him I might as well tag along with you, since I had come all this way to visit you for the day. So I went down there with him and waited for him outside. Just before they were going to shut and lock the door the test proctor asked me, if I wanted to take the test. Me? I am just waiting for my friend. The proctor asked: “So what about you?” I said ok and went inside and took the exam. The funny part is, I ended up passing and my friend did not. My whole life was changed. I was married with a baby on the way, moving into a better career with benefits and stability was a better choice. And that is how I ended up in law enforcement. A chance encounter for sure.  
  
And to tell you the truth Roger, I am sure there are many people out there that are very grateful you did!  
  
Retiring in 2003, after serving on the 9/11 Task Force, where he virtually non-stop conducted investigations of suspicious persons, working 7 days a week, 12 to 15 hours a day.  
He then developed a three prong approach to retirement. First, he expanded his real estate business, buying and selling properties. Second, was to become a better Salsa dancer, taking dance lessons for three years at a local dance school here in Holbrook, and then thirdly, to become more involved with his son’s softball program.  
Roger’s son Roderick has been playing softball for forty years. His dad initially went from sitting in the stands, to assisting on the field, to team parent, to an assistant coach, to a coach, to an assistant manager, to manager, and in 2003 he became the Director of the program; a division of the Sachem Little League. Roger did this for several years. They had as many as 150 boys and girls, men and women with a variety of abilities and ages, ranging in age from four years old, to players in their fifties.  
   
In 2017, the Sachem Little League folded. This came as a big shock. What would our kids and young people do? Roger sat down with his fellow coaches and no one wanted to see the program fall through. He then contacted Little League International, to ask how they could become their own stand-a-lone Independent program. In 2017, that is exactly what happened. Central Suffolk Challenger – Little League and Senior League was born.  
The League practices in Smithtown and Brookhaven and Henrietta Acampora Recreation Center, 39 Montauk Highway, Blue point, New York.   
They play Sunday afternoons from 2pm to 5pm. Presently they have about 100 kids and looking to expand the program much further. The program offers lots in terms of skill. They have a Tee Ball division. Players bat, run, hit, they throw the ball and they run the bases. There is an intra murals - and two travel teams. One travel team plays about 6 to 8 tournaments a year, the second travel team, which is the more competitive team, plays about 8 to 12 tournaments a year.  
   
This second travel team has also been invited to play in the New York State Special Olympics, where they competed against 3,000 athletes. There are only two teams chosen from Long Island to participate in this competition, and the Central Suffolk Challenger team was asked to participate six times. Out of the six times they were invited, they opted to play four, and each time they took home the silver medal!  
Roger is very proud of his athletes. “Those at the travel team level are pushed a little harder in terms of skill. “We let them know there are no shortcuts to doing good work; and that hard work does pay off.  Our athletes train all year long, watching their diet, exercising. They have developed very good sportsmanship values, learning to trust and depend on each other, dealing with high pressure situations, working as a team. It has been an amazing thing to watch. A lot of these skills are not things that can be taught from a book, but rather lived and practiced. What we have noticed on and off the field is supportive long term friendships. Many players will lift and support their fellow teammates. They see themselves as athletes because they are athletes with a natural love for the game of softball. For example, our spring season starts April 24th and then runs until July. We then break in August due to the weather, and then we continue in September through October. Then in January through March, my son hits the gym getting ready for the upcoming spring season."  
   
“I am just so happy that Little League International has provide a venue for these guys to play where they would normally age out of a program. Little League International created an opportunity with this Challenger Program to play as long as they want to play.”   
The program helps to build some of the social skills that some our players may have found to be an Obstacle or hurdle to overcome. Roderick has been able to give presentations to SEPTA Boards, and schools, despite his own special needs as a person with a learning disability and speech impairments.  He is being our number one fund raiser. The program gave him the opportunity to excel and overcome, and contribute more to the community. It helped to build confidence and self-esteem.  
  
Roger is a very proud dad, he is very proud of his son and the things he has seen develop over the years with the softball team. He would like for it to continue and thrive for a very long time, so other generations might be able and benefit for years to come.

[**CENTRAL SUFFOLK CHALLENGER SOFTBALL PROGRAM**](https://www.siloinc.org/uploads/1/2/6/1/126143408/softball_flyers.pdf)

*as referenced in article, Roger Smith – “A Guy You Want On Your Team”*

<https://www.siloinc.org/uploads/1/2/6/1/126143408/softball_flyers.pdf>

## Interview with Nancy Speller Article by Judy Wieber



​I would like to start by thanking SILO for the opportunity to interview Nancy Speller, one of SILO’S new team members. I have enjoyed hearing and telling some of her personal story.  
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Nancy Speller is a registered nurse with over 30 years’ experience in Community and Public Health. She has held leadership positions at St Mary's Healthcare System for Children, American Cancer Society and Long Island Jewish Medical Center. Nancy’s area of expertise and passion is focused on meeting the needs of children and adults with medical complexity and disabilities.   
Her professional accomplishments include, establishing and directing a NYS Health Home Care Coordination program serving 600 plus Medically Fragile children and young adults, the first NYS Patient Navigation program for the Pediatric Medically Complex population and a NYS Pilot Group Home for Medically Fragile Young Adults.  
  
Q:  What inspired you to go into the field of nursing?  
A:  My love for nursing and healthcare advocacy stemmed from my mother who, through her work as a Health Care Administrator, helped many patients and became a strong advocate for the needs of veterans and individuals struggling with substance abuse.   
   
Nancy’s passion for the medically complex and disabled population comes from her journey with her son John James (JJ), who was born with a rare neurological disease. JJ was not expected to live past a year, and Nancy believes it was due to the NYS Children’s Waiver and the critical services provided that JJ was able to have an extraordinary quality of life and live at home for 16 years.  
In addition to her professional work, Nancy is the Co-Founder of Project DOCC, Delivery of Chronic Care and Founder/ President of the Pediatric Neurotransmitter Disease Association. The following are the links to her nonprofit organizations: [*www.pndassoc.org*](http://www.pndassoc.org/) and [*https://www.unmc.edu/mmi/training/programs/devmed/project-docc.html*](https://www.unmc.edu/mmi/training/programs/devmed/project-docc.html)  
Nancy has been published several times, and her volunteer advocacy efforts led to a FDA approved gene therapy clinical trial for children with Aromatic- L- Amino Acid Decarboxylase Deficiency a rare life threatening neurological disease.  
Q:  If you could tell me a little about your advocacy efforts,  
A: I have had the honor of advocating at the national and state level and have spent many days advocating for rare diseases, waiver programs, services and legislation on behalf of the medically complex disabled population.  
   
Q: Has the clinical trial found success?   
A:  It took 12 long years to initiate and fund the clinical trial. I had learned through advocacy with the Parkinson’s disease groups (our children’s diseases were similar) that they were doing gene therapy on one of our diseases as it replicated Parkinson’s disease. As a desperate mother, I boldly reached out to the pharma company and told them about our kids, 5 years of back and forth I finally made contact with Dr. Krystof Bankiewicz, a world renown Parkinson’s researcher, who on the 5th anniversary of my son’s death wrote me and shared that he “just wants to help our kids” Dr. Bankiewicz utilized the initial NIH funding and then started the trial on his own. The trial has had successful outcomes and I have had the privilege of meeting one child who is now walking and talking.​  
Nancy holds degrees in Nursing, Public Health Administration and Health Education. When not advocating, Nancy loves spending time with her husband John and twins Katie and Alec. She also enjoys lots of girls' nights out or in, hiking with her dogs and traveling.

**Chocolate Avocado Pudding Recipe**  
  
The following recipe was submitted by Denise Lavery.  
The recipe came from All Recipes.com  
  
[https://www.allrecipes.com/recipe/234324/chocolate-avocado-pudding/?did=247862-20220330&hid=#main-content  
​](https://www.allrecipes.com/recipe/234324/chocolate-avocado-pudding/?did=247862-20220330&hid=#main-content)  
It is quick, easy, and 100% vegan and dairy free. Enjoy!  
  
​Chocolate Avocado Pudding Recipe  
Serves 4  
Total time 40 minutes  
   
Ingredients:  
Two large avocadoes- peeled, pitted and cubed.  
1/2 cup unsweetened cocoa powder  
1/2 cup brown sugar  
1/3 cup coconut milk  
2 teaspoons vanilla extract  
1 pinch ground cinnamon  
   
Directions:  
Blend all ingredients in a blender until smooth. Refrigerate pudding until chilled, about 30 minutes.

***Communication is so Important***  
**Article by Judy Wieber**  
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I have come to realize, as I travel down the road of life, how good communication plays such an important role in the life of people with disabilities.  
Let me share with you a story.   
This took place quite some time ago when my husband was alive, and we were living in Babylon Village.   
As some of you may know, Babylon Village is a very quaint town, filled with little shops and restaurants.  It is very easy to stroll along Deer Park Avenue and Main Street, to go shopping, get a bite to eat, take care of your banking, grab a bus or train, go to the theater, etc. We were very lucky to be living in such an area where we had access to so much, all within walking distance from our home. When you cannot drive, having so much close to walk to was truly a godsend.  
   
We had decided to go to a place, at the time, called the Armadillo Grill.  In order to get to the restaurant, we needed to cross over Deer Park Avenue.  We approached the corner, using our white canes, and listening skills.  We lined ourselves up and waited for the traffic light to change.  
A passerby spotted us. They sized up the situation, and must have thought, "Hmm? It looks like two blind people trying to cross a very busy intersection. I will try and give some assistance." They probably tried to put themselves in our shoes, thinking, "How in the world are these two people ever going to get across this very busy intersection in one piece? I will lend them a helping hand." Having had the life experience as a person with vision, I would have probably felt the same way. Two people, who cannot see, they will get killed trying to cross this street. I too probably, as a sighted person, would have felt the same way and would have offered some kind of assistance. The kind person approached and took my arm, leading me across the street. Words were not exchanged. I felt as though I was moving diagonally, but wasn’t too sure. I could feel, under my feet, the dip of the road. It felt not quite what I remembered it to be, but really didn’t think too much of it.  The route seemed a little different, taking a little longer than usual, but again, I really didn’t think too much about it. I finally got to the other side of the street, only to find the restaurant we were looking for was not there. Hmm? Feeling very puzzled. I thought a moment. Where were we? I normally like to take the elbow of a sighted guide, but I thought, "Wow, that was easy and so nice of that person to lend a helping hand."   
So now I figure my husband and I are now in front of the Armadillo Grill. I approach the door, again using my white cane, I navigate the sidewalk. However, I do not find the door. Harold doesn't find it either. We both stand scratching our heads thinking, what happened to the restaurant? We hear a person walking by. I ask," Excuse me, we are looking for the Armadillo Grill. Is it near here? The person answered, "Yes, it is on the other side of the street. You will need to cross over both Deer Park Avenue and Main Street to get there."  
  
"Holy cow," I think I should have said something, like, "May I take your elbow?" and, "My husband and I are looking to cross Deer Park Avenue. We are going to the Armadillo Grill." Then too perhaps it would have been nice if the helping person may have asked, “Do you need assistance?” and, "In what way may I assist?”  
Sighted guide is a great way to offer assistance to a person who cannot see. A sighted person would offer an elbow to the person who is blind. By holding the elbow, a person can let go if they do not feel safe, or can sense the body motions of the person leading them. For example, if a guide ducks down due to a low lying branch, a blind person can sense this. If the elbow is held close to the body, this will also help a person who is visually impaired get a better sense of balance.  It will put a guide in the lead position. Often a person may not know how to help, and without using dialogue, will try and steer a person from behind. A person may actually feel off balance or unsafe by this, making the situation uncomfortable. The last thing anyone would want is to make this type of situation unpleasant, because it may cause a person offering help to not offer assistance in the future.   
If a person would like to assist, keep in mind these few things:   
Ask if a person would like assistance. The blind person may feel very comfortable in their cane travel skills.   
If a person does agree to being assisted, ask how you may be of assistance.  
When offering sighted guide, offer an elbow and keep it close to your body.   
   
It is also a good idea when accepting assistance from someone you do not know, to be very specific with your directions and let them know what it is you are looking for. Communication is a two way street.

***American Idol Winner or Not, Christian Guardino is a Star in our Eyes!  
​***Article by Judy Wieber  
  
​Patchogue's hometown kid, Christian Guardino, makes it to the top eleven on American Idol  
If you haven't already seen him on America's Got Talent, maybe you have heard his beautiful falsetto crescendos, and bluesy jazzy tones on American Idol? Singing his rendition of “Take me to Church," he once again, wow-ed judges Lionel Richie, Katie Perry, and Luke Bryan, as well as the American audience, to earn him a position amongst the top eleven.

Aside from Christian's amazing singing voice, he was born with a rare progressive retinal eye condition, leading many to a life of very low vision, and in some cases, total blindness, of which until recently, had no cure. However, in 2013, Christian underwent an FDA controlled genetic therapy, resulting in Christian regaining a considerable amount of vision.

Christian regards his participation in American Idol as a crazy, unbelievable adventure. He has been quoted as saying, "I have been singing since I can remember and I know this is what I want to do with my life." Aside from sharing his talent with the world, Christian can also be seen as a brave young person, taking a leap of faith, as being one of the first candidates to undergo this sight restoring procedure which will undoubtingly open up the doors for others struggling with this same eye condition in the future.

As a person who has lost her sight to glaucoma secondary to Juvenile rheumatoid Arthritis, though not the same condition as Christian, I can certainly appreciate everything he and his family have gone through to get to this point in his medical journey. Listening to an interview conducted with Christian and his Mom, they had expressed their overwhelming joy for the gene therapy (produced by Penn and Spark Therapeutics) and how they wanted for others to know about it. 

I for one, would like to know more about the trials and advocacy involved with finding out and pursuing these medical break throughs. What kind of funding is available for this type of research? What types of things stop or slow up the research? Does our medical system, as it is presently, help or hinder patients from finding out about such discoveries?

As an employee of Suffolk Independent Living Organization, I am sure SILO and it's participants would love to hear Christian's journey in person at our at our October 2022 Conference, to be held mid month at the Holiday Inn in Holtsville.  
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So hey Christian, if you are hearing us, what do you say?