April Newsletter 2024

**Remembering Dr. Brooke Ellison
Written by Judy Wieber**

Dr. Brooke Ellison was an unyielding advocate for the rights of the disabled. “Enthusiastic and encouraged” by the partnership between SILO and Stony Brook University Medical Center. Brooke had brought both entities together in a grant project: Long Island Network for Clinical Translational Sciences. This was not the only venture she had intended to collaborate on.  Brooke had stated in a meeting with SILO’s Dignified Health Care Committee she wanted to see SILO participants more involved with the Hospital’s Community Advisory Board.

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Her life mission was to reach the “severely underserved” community of disabled persons living on Long Island, making medicine and health care more accessible.

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She was a native Long Islander.  After graduating from high school in 1996, despite her life-threatening injuries, Brooke became the first woman quadriplegic to graduate Harvard University in 2000 with an Undergraduate Degree in Cognitive Neuroscience. In 2004, she received a Master’s Degree in public policy; standing on the platform of stem cell research, she ran for Senate in 2006. In 2012, she obtained her Doctoral Degree in Sociology from Stony Brook University, where she joined the staff later that year.

The Harvard Crimson noted her as a “Leader and friend.”

Able Newspaper quoted Brooke’s Dad as stating how his daughter worked relentlessly, from the time she woke up to the time she went to bed, wanting to change the narrative for those with disabilities.  She appreciated the time she was given, squeezing the most out of every day, never knowing when her time with us would end.

**Suffolk Challenger Program**



## All of your Disability Travel Needs Made EasierWritten by Gina Kranz

There's a wonderful travel website that is geared towards helping people with disabilities. They have access to everything you need to travel and all at a discount. Roll-in showers, ADA tubs, flights, rental cars with hand controls, in-room refrigerator for medications, wheelchair van

rentals, hotels that welcome service animals, hearing accessible rooms, accessible swimming pools, equipment rentals, cruises, rides, etc.....

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It's so very stressful traveling without a disability already. There's double or more concerns when also traveling with a disability.

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Check out this video:
<https://youtu.be/YMWclUW5_EM?si=e2ljJe9BGX_PdqpA>

I haven't had the opportunity to travel much but I know that a lot of places say that they are accessible and have everything you need but really don't. It's not like promising extra pillows and not having them. Some of these things are crucial for many reasons. That's why, out of all

the services they offer, my favorite thing is that they call ahead to verify that they have everything that you need and they advocate for you! Services are great but there's nothing quite like someone advocating for you! It's like an invisible hug. I contacted them, and the co-founder replied. She was such a nice person! Anyone who thinks of providing a service like this is awesome, in my opinion.

She had this to say:

“accessibleGO is the first-ever travel booking site built exclusively for people with accessibility needs offering hotels, car rentals with hand controls, wheelchair van rentals, accessible rides and mobility rentals. With over 120,000 signups on our platform to date, we are quickly

becoming the go-to site for accessible travel needs. Every booking comes with our free accessibility confirmation service. With proprietary accessibility information for thousands of hotels across America, special discounted disability rates, an unparalleled customer service

experience, and access to a dynamic community of like-minded travelers, people know when you book with us— we’ve got your back.”

-Miriam Eljas - Co-Founder & CEO accessibleGO.com

They also have a community forum where many people ask for tips, recommendations, information, etc... on their upcoming trips, which eases many different concerns. All of these things allow you to actually enjoy your vacation instead of dreading all the worry. It makes traveling so much easier. I definitely recommend checking them out!

Please use this link so if you book a vacation, they'll know that I recommended you.

<https://accessiblego.refr.cc/ginakranz?t=em>

I often tell one person at a time when they ask. I would love to tell as many people as possible because I feel this service is so valuable. I’m always shocked that more people don’t know about it. Please check them out!

**Meet Kathryn, Dylan’s Sister
Written by Judy Wieber**

Kathryn, one of SILO’S Peer Integration Specialists; recently joined the PIP Team in January of 2024. Previously she served in the NY Connects department and came to us as a University of New England Intern in Social Work.

I learned that Kathryn has a brother, Dylan, with Autism and Seizure Disorder. With April being Autism Awareness Month, I wanted to do an interview from the perspective of a family member. I once heard it said, no one really knows you better than your sibling. Even if you do not get along all the time with your sibling, you have shared things together and have gone through things together that you haven’t shared with others.  From growing up in the same generation, to sharing the same parents. So who better to conduct an interview with, than a sister who bears witness to your existence and childhood life experiences.

**The following conversation is based on an interview, Kathryn and I had via zoom:**

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Kathryn spoke about her brother Dylan and shared how Autism presented the whole family with challenges as well as it’s pleasures.  While in school, from time to time it was hard explaining to other kids: “The reason my brother doesn’t go to school with us is, he goes to a school for kids with Autism. The term Autism at that time wasn’t really understood, and it set me apart from my peers who didn’t have a sibling with a developmental disability.”  “In my brother’s situation, Dylan is nonverbal. He can make sounds but relies on pointing and gesturing to convey what he wants to say.”  In fact, he has some words that are Dylan originals. Words he uses that only those close to him understand their meaning. It is like a new language.

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Ipad training is used more today as a means of helping kids with speaking difficulties. Dylan was older when this technology came about and prefers to use a communication book, a book filled with pictures and phrases used to communicate.

“Because of our family’s experience, I have gotten to hang out with some of the people my brother knows with Autism. I have found them each to have their own talents and skills.”

“My brother loves golf, we like to take him to pitch and putt, or to the driving range where he will practice his swing.”  He is also incredibly good at putting a huge jigsaw puzzle together. Kathryn is amazed at his ability to figure out where all the pieces go.

“His understanding and comprehension of what is happening is right on. The difficulties lie in his ability to speak.” He cannot always let us know when he may not be feeling well. In some cases, people with Autism may also have seizures. Kathryn has come to learn the safety procedures, what to do when a person has a seizure. Some of the medicines Dylan takes may cause side effects which are not always easy to figure out what may be bothering him.

Kathryn understanding the important need for more whole family supports is motivated by her relationship with her brother to advocate and educate others on the resources available to families. In fact, it is a major reason she decided to study social work. “One area we could do better with is providing support for siblings. There seems to be supports for parents, but not so much for siblings.”.  She wishes for others to understand that people with Autism are people like you and me having hopes, dreams, feelings too. A “person with a developmental disability is a person deserving of respect and not to be stared at, or judged as less than a person. “

Something Kathryn is grateful for, that Autism has taught her, is the way her mother and father were able to supply total family experiences despite the challenges. Her parents decided to work together not letting the stresses of Autism tear them all apart. Kathryn points out how the percentage of divorce amongst couples with children who have Autism is higher than the national average of divorce amongst couples in general. She commends them for working through obstacles instead of giving up and calling it quits, not only for Dylan’s sake, but being there for her as well.

Kathryn reflected on a time when she and her brother went on a family trip to Universal Studios and Dylan got to meet Shrek. “He was so happy. Everyone could see his joy. He was doing his ‘happy dance’.  It was so great, I felt happy knowing how happy he felt.



**The Following are insights from the Brain Injury Awareness Day sponsored by The Social Brain & The Town of Brookhaven on 3/15/2024.
Written by Dawn McCoy and Samea Husein**

It was our absolute pleasure to stand for SILO on this day of support and inspiration for those who have survived Brain Injuries and are still coping with the effects, along with their caregivers. Ira Dunne from The Social Brain put this event together in a beautiful way. There was food, giveaways and warmth everywhere. It was a welcoming and inclusive atmosphere that was inviting for all.

SILO was grateful to have a table, representing our organization. Many participants, their caregivers and service coordinators stopped by. Most notable were the participants. They were happy and grateful to share their stories with us, as they have worked hard and come far in their journey of recovery. It was heartwarming.

Our one participant, stopped by and shared his story. He was a first-year student at a local college on a sports scholarship, when two weeks in, he developed double vision and his symptoms only got worse from there. He learned he had a brain tumor and he could no longer play sports or attend college. He proudly told us how, after many years on the TBI Waiver, and at the program at Head Injury Association, he no longer needs the program. He is now holding two part time jobs and is more efficient at these jobs than the employees that have been there longer than him. The look of accomplishment and pride in his eyes is what makes the TBI Waiver Program everything we work so hard for here at SILO.

There were many speakers on this day. Ira Dunne received a well-deserved proclamation as well!



## The HillWritten by Judy Wieber

## \*Can be found on Netflix\*

If you like true life stories of inspiration, determination, and faith, The Hill is a movie you will want to see.

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Released in August of 2023, awarded Best Family Film, Denis Quaid plays Pastor James Hill, and Colin Ford plays his son, Rickie. Rickie overcomes a degenerative spinal disease to pursue his lifelong passion for baseball. Wanting to protect his son from the pain of rejection and heartache, Pastor James, realizes his son’s gift of ministry and strongly recommends that he follow in his own footsteps.

Pastor James is a fire and brimstone Baptist minister, strongly devoted to God and His word. The movie opens with a scene where Pastor James sternly stands up to those chewing tobacco and smoking in the Lord’s place of worship. As a result, the parishioners are not happy with him, and force the family to move.

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One even starts to question his compassion and empathy when Pastor James is found chastising his sons for looking at baseball cards. Robert, Rickie’s older brother bought the cards, knowing how Rickie loves baseball, and how he wishes to play in the major leagues. Pastor James overhearing the boys, dashes any hopes and dreams, making it clear to only encourage him to pursue his talent for ministry. Even his own mother-in-law is discouraged by her son-in-law, continuing to remain faithful to the Lord, when his ministry barely brings enough food for the family, let alone to pay for the medical care Rickie needs.

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Rickie does seem to have a calling for God and a strong wish to obey his father. He struggles with what to do. His talent to hit a ball over 220 feet is recognized, but his journey to play in the major leagues is filled with strife; from putting up with bullies, to dealing with the physical pain he feels, to combating financial strains. Having to convince “the powers that be” he is meant to play the game, despite his disability.

I do not want to give too much away, but the ending is a resilient, and triumphant one. Rickie in true life does play a brief time in the minor leagues, gets married, teaches golf, and coaches little league. Forbes’s magazine has noted that Rickie today has a career as a financial advisor, and a strong faith in God and the human spirit.

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The movie in my opinion should be entitled: “The Mountain” instead of “The Hill” For the bible says: “If you have the faith as small as a mustard seed, you can say to this mountain, ‘to move from here to there’ and the mountain will move.  Nothing will be impossible for you.” (Matthew 17,20-21)

## UPDATE on the Advocacy and Empowerment Team(from our February 2024 Newsletter)Written by Judy Wieber

Marilyn Tucci and Tiffany Luciano are happy to report that they are making some headway with bills:  S4242, and A8277. “An Act to amend the public health law, in relation to requiring telephones capable of making local and long-distance phone calls in every nursing home patients’ room, or bedside, dependent on the patients’ mobility. . .”

The bills have picked up more co-sponsors.

Marilyn would like to mention that now Senator Anthony Palumbo was the first supporter of the bill in the Assembly.  Marilyn remembers reaching out to him requesting his support two years ago. It is definitely a process, and it takes the work of everyone. Reaching out to your representatives is so important.