

The NET Program

(Non-Emergency Transportation)



How one community came together to meet the transportation needs of its cancer patients

On Long Island, transportation is a critical concern for all healthcare organizations. As Suffolk County's only tertiary care facility, Stony Brook University Medical Center provides services to patients encompassing a geographical area of more than 900 square miles within Suffolk County alone. Additional referrals come from Nassau and Queens Counties.

Research consistently cites transportation as a major barrier to successful completion of cancer treatment. "Patients, particularly minorities, may opt to forgo needed care in the absence of available and affordable means of transportation to treatment facilities."¹

At Stony Brook Cancer Center, Stony Brook, N.Y., many of our patients consider English a second language and have difficulty navigating the state's complex transportation system. Traveling from the east end of the island to our facility by public transportation can take up to four hours and include several bus changes. Added to the physical burden of this commute to care is the cost of public transportation. Placing an immuno-compromised, fatigued cancer patient in this situation is an unconscionable burden on the physical, financial, and emotional resources of the patient and his or her family. Today—with a rising number of patients who are under- or uninsured being referred to our facility—the need for viable and cost-effective transportation is even more critical.

The Stony Brook Travel Experience

Long Island is composed of large suburban areas connected by major highways, which are arranged in a grid-like pattern. The Long Island Expressway, the Northern State Parkway, and the Southern State Parkway traverse the region in an east-west direction. In Suffolk County, the north-south routes encompass the Sagtikos Parkway, Route 111, Nicolls Road, and William Floyd Parkway. While this system of highways makes access by automobile fairly simple, the high cost of gas, health insurance, and auto repairs make personal vehicles a luxury for many of our patients. While public transportation exists, its limited location

and schedule make it an unreliable option. What's more, public transportation is sparse on the east end of the island.

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When possible, local agencies such as the American Cancer Society (ACS), Fighting Chance, the Leukemia & Lymphoma Society (LLS), Cancer Care, and the Suffolk County Department of Public Works Transportation Division, provide transportation or financial assistance for travel costs to cancer patients. For example, in 2013, Fighting Chance provided 24 trips to Stony Brook Cancer Center for cancer patients coming from the east end of the island. LLS offers a one-time, \$100 grant to blood cancer patients to spend on transportation as needed. Cancer Care provides \$175 per calendar year, per patient for transportation (specific restrictions apply). SCAT (Suffolk County Accessible Transportation) bus service costs \$4 each one-way trip. The ACS Road to Recovery program is a volunteer-driver ride service that is subject to the availability of volunteers and their location limitations.

In 2011 alone Stony Brook Cancer Center incurred a variety of transportation-related costs for its patients, including:

- Cab vouchers: \$40 per cab ride for a total of 35 rides or \$1,400.



- Bus vouchers: \$875 for 500 bus vouchers.
- Bus transfers: \$500 for 500 bus transfers.

Our oncology social workers say that they could easily triple the number of cab and bus vouchers they give to patients if Stony Brook Cancer Center had the funding to support these efforts. (Due to the increased cuts in state aid to the entire New York healthcare system, funds for patient transportation have been severely curtailed.)

Our cancer center helps patients apply for Suffolk County bus passes, including the SCAT program and the Brookhaven Jitney program. We also offer patients a list of financial resources that may be used to help pay for transportation, as well as assistance in filing Medicare, Medicaid, and Stony Brook Cancer Center financial aid forms.

Stony Brook Cancer Center treats more than 500 patients per week in medical oncology alone, currently averaging 550; more than 40 percent of these patients require some type of transportation or financial assistance.

The Dream—We Need A Bus!

Outpatient oncology social worker Darlene Kenny, LCSW, who assists surgical and medical oncology patients on a daily basis, dreams big. She was convinced that Stony Brook Cancer Center needed a bus to meet the growing transportation needs of its cancer patients. While cancer program leadership recognizes that patients are our number one priority, the cancer center simply did not have the financial resources to make such a purchase. Armed with only a “wish list,” Darlene and I began our campaign. For more than a year, our mantra was, “We need a bus!” And I am proud to say that we now have the 30-second elevator pitch down to an art form.

The donation of a bus would allow Stony Brook Cancer Center to offer transportation to patients in a variety of locations. We believed that the patient benefits would significantly outweigh the cost of hiring a driver. Further, extrapolating the patient volume and the cost of outside transportation services, staff anticipated that Stony Brook Cancer Center could spend well over \$20,000 per year in stopgap measures to help patients with transportation, such as bus vouchers.

Confident that we would find a donor to cover the cost of the bus purchase, we began the process of writing a proposal to hire a bus driver. This involved meeting with Long Island transportation experts, drafting policies, and mapping out bus routes.

Realizing the Dream

Sharing our dream with others would prove crucial to our efforts, and with the support of our community, our persistence paid off.

First to offer help was a member of the cancer center’s Advisory Board. Her family was committed to improving the patient





experience for individuals with cancer even as their own 28-year-old son battled against AML (acute myeloid leukemia). After she told her husband about our search for a bus, he contacted We Transport, a local bus service company based in Nassau County, which agreed to donate a wheel-chair accessible mini-school bus.

News of the donation spread through our community, culminating in local media coverage, and others soon stepped up to make our dream a reality:

- Penney's North Country Car Care, located in St. James, N.Y., offered to provide free repairs for the first year of bus service.
- The GIFT (Giving Hope, Fighting Together) Foundation, a local organization that supports our cancer patients, paid for upgrades to the bus and supplies, including a first-aid kit, new batteries, and a medical gas cylinder holder.
- Splashes of Hope, a non-profit organization that paints murals for hospitals, volunteered to "splash" the bus with the cancer center's signature sunflowers and cancer awareness ribbons.
- One of Stony Brook's medical photographers donated a GPS system.
- Stony Brook University's pre-med student club washed, scrubbed, and spruced up the inside of the bus.

Stony Brook Cancer Center had its bus, now we needed a driver and money for fuel.

Next Steps

Once the bus was secured, we turned our attention to finding a driver. Stony Brook's cancer program administrator agreed to let a staff member who worked part-time as a patient advocate take time away from her daily responsibilities to serve as the driver for the pilot bus shuttle program. (This employee had an R.V. so she had experience and was comfortable with driving a large vehicle.)

At about this same time, I saw an advertisement for the Citgo "Fueling Good" competition, a social media competition that awards \$5,000 in Citgo gas cards to regional winners. I completed the application, and in a few weeks we were told that Stony Brook Cancer Center had made it to the voting round. Approximately 50 applications in each of 8 geographic regions were selected to participate in the online voting campaign; one winner was selected from each region.

The entire university and medical campus participated in the online voting campaign. This social media effort drew attention to our cause and united staff, faculty, students, patients, families, and the surrounding communities with one common goal—to provide transportation help for our cancer patients. It also reinforced to Stony Brook Cancer Center the value of social media and the importance of partnering within the community. Cancer program staff shared the story of our bus campaign with their

children. Local high schools voted. Local sports teams participated. Local car clubs, dance studios, and restaurants—our entire community—helped spread the word about voting.

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An added benefit for the cancer center was the ability to involve students from kindergarten through college in our activities and to offer them a chance for community service. These future leaders learned about altruism and community involvement, and that we all can play a role to improve life for cancer patients and their families.

In November 2012 Stony Brook Cancer Center was awarded \$5,000 in Citgo gas cards. Citgo representatives came to the cancer center to present a plaque and T-shirts, and to allow staff the opportunity to meet local Citgo station owners who donate to the "Fueling Good" program. While many deserving charities win funding, Citgo said that Stony Brook Cancer Center was the first to use the gas cards for patient transportation.

Logistics: Rethinking the Process

Cancer program staff spoke to the community-based agencies that serve as resources for our cancer patients, and they were willing to coordinate efforts to make this shuttle service a viable option for our patients. Staff also met with the former director of the Suffolk County Department of Transportation to map out the shuttle bus runs that the cancer center would offer. The program started with shuttle service to patients within Brookhaven Township and then expanded to other townships outside of our core service area.

The logistics of scheduling shuttle service to coincide with treatment appointments were quite complicated. As the cancer patient advocacy and community outreach coordinator, I spent a significant part of my day working closely with the cancer center social workers and oncology medical staff to provide seamless service for our patients.

It soon became obvious that shuttle bus service was not the most expedient—nor appropriate—service. Due to limited driver availability and the large geographic area that needed to be



covered, cancer center staff determined that door-to-door service would be the best option.

Next, understanding that the need for transportation would be greater than the services available, we had to make decisions that would allow Stony Brook Cancer Center to serve those patients with the greatest need. Here is what was decided:

- Only patients with chemotherapy and/or radiation therapy appointments could request door-to-door bus service.
- Patients had to adhere to these guidelines: apply for SCAT bus service; work with their families and caregivers to provide at least some transportation; and apply for the ACS Road to Recovery program.
- Radiation oncology patients could receive bus transportation a maximum of three days a week.

- All patients using the service must be willing to adjust their travel and wait times to accommodate other patients on the bus.

Statistics: It's More Than Scheduling a Pick-Up

Stony Brook Cancer Center started its bus service in November 2012. Eighteen patient transports were made in November and December. The average roundtrip was 100 miles, and the average roundtrip time per patient was three hours. We learned quickly that you must factor the roundtrip at double the time and mileage. In other words, the driver must leave the cancer center to pick up the patient, drive to the cancer center, and then reverse the route.

In 2013 our driver logged 10,219 miles, providing 139 patient transports. Average round trip was 50 miles. Coordinating multiple

TRANSPORTATION & CANCER PATIENTS

Cancer is a life-altering experience. Patients, even those who are self-reliant, often find themselves lacking confidence, control, and the educational tools necessary to navigate the healthcare system. Costs related to cancer treatment can be significant.

Transportation to and from treatment services can have a negative effect on a patient's compliance with his or her cancer treatment regimen, which can lead to poor outcomes.

One study of 189 chemotherapy patients reinforced the impact of transportation on cancer treatment.² "The time spent travelling for treatment can be a potential barrier to patients' seeking treatment and keeping their medical appointments. Patients must have reliable transportation, which can be difficult if they have limited access to transportation or if long distances are involved. Transportation can be especially problematic if the patient cannot drive, does not have a car, or uses a wheelchair. Public transportation is often unreliable and time-consuming... The effects of travelling to the clinic can be so great that impaired access to transportation may cause patients to forgo treatment. In addition to the logistical inconveniences and economic hardships of travel, it [transportation] can be another source of stress and can have negative psychological effects on patients. This stress could even affect their will-

ingness to undergo further treatment."²

One study of more than 600 patients over age 65 in New Mexico included "impaired access to transportation" as one of the major reasons that older patients are less likely to receive definitive therapy.³

Another research study of 139 participants receiving outpatient chemotherapy required patients to keep a weekly diary of nonmedical expenses related to their disease.⁴ Although the study is dated, the results remain viable. The mean cost to patients for treatment weeks was almost double the cost of non-treatment weeks (\$72.81 vs. \$45.88).⁴ Transportation and food were the largest out-of-pocket expenses.

In an annual survey of its member programs, the Association of Community Cancer Centers (ACCC) found that transportation needs continue to present challenges and barriers to cancer care.⁵ Nearly 70 percent of respondents said that their cancer program has a foundation or philanthropic organization to help meet their patients' financial needs; 74 percent of those help its patients pay for transportation-related needs.⁵ Or, as one survey respondent put it: "Patient affordability continues to be an issue. Co-pays, co-insurance charges, and transportation are areas of continued need."⁵

patients on the same day increased the average time per patient to approximately 3.5 hours.

That same year, Stony Brook Cancer Center's bus service allowed two patients—based on their medical conditions and residence locations—to transition from inpatient to outpatient care. The cancer center was able to decrease both patients' hospital length of stay (LOS) by more than two weeks, significantly decreasing costs to the hospital, payer, and patients.

Because the impact on our driver's other work obligations at the cancer center was greater than anticipated, cancer program leadership decided to suspend transportation for new referrals and to keep the current list of clientele operational for the last 6 months of 2014. After this trial period, we hope to hire a bus driver on a per diem basis. This new position will allow the cancer center the flexibility of scheduling bus maintenance, staff vacations, downtime for weather, and more productive driving time. A new annual budget of approximately \$50,000 will pay for the driver's salary, bus repairs, fuel, and limited supplies. In the future, we hope to fund the program through an annual fundraising event and donors.

The "Pay It Forward" Effect

While the bus is a major "plus" for Stony Brook Cancer Center patients, a diesel bus consumes a greater amount of fuel and is more difficult to maneuver than a passenger vehicle. So staff soon adopted a new mantra: "We need a car!" Incredibly, the same generous family who was instrumental in obtaining the bus also donated a passenger car. (Their grandfather had recently passed away, and rather than sell his car, the family donated it to Stony Brook Cancer Center.) Their wonderful gift decreased fuel costs and allows the cancer center to use the bus more efficiently—for patients in wheelchairs or for multiple patients on the same trip.

Stony Brook Cancer Center staff and patients appreciate the bus service and what it entails: reduced travel time for patients, less fatigue for patients, a knowledgeable driver, and coordination with oncology services. In its two years of operation, our bus service has:

- Increased patient satisfaction.
- Improved patient adherence to treatment plans, vital for those at risk of recurrence or those whose stress does not allow them to complete treatment protocols. In turn, better patient compliance with treatment schedules will hopefully lead to better outcomes.
- Improved staff satisfaction based on our ability to meet the needs of the patients.
- Allowed East End patients to receive treatment at Stony Brook and forego travelling to Manhattan.
- Allowed oncology providers from the East End to offer transportation options to their patients.
- Strengthened community ties through ongoing efforts to obtain grants and community support of the bus service.



Stony Brook Cancer Center's signature sunflowers and cancer awareness ribbons.

- Improved utilization of chair time due to "on time" arrival that streamlined work flow and will likely have a positive impact on revenue flow.

Stony Brook Cancer Center's dream of a bus—and then a car—to help meet the needs of its cancer patients engaged our entire community. And together we were able to make the dream a reality and improve the lives of our cancer patients and their families. **OI**

Linda Bily, MA, is cancer patient advocacy and community outreach coordinator, Stony Brook Cancer Center, Stony Brook, N.Y.

References

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2. Fortner B, Tauer K, Zhu L, Okon T, et al. Medical visits for chemotherapy and chemotherapy-induced neutropenia: a survey of the impact on patient time and activities. *BMC Cancer.* 2004;4:22.
3. Goodwin JS, Hunt WC, Samet JM. Determinants of cancer therapy in elderly patients. *Cancer.* 1993;72:594-601.
4. Houts P, Lipton A, Harvey H, Martin B, et al. Nonmedical costs to patients and their families associated with outpatient chemotherapy. *Cancer.* 1984;53(11): 2388-2392.
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Non-Emergency Transportation (NET) Program

- Please note that completion of this application does not guarantee transportation.
- Application response may take up to 2 weeks.
- Transportation is primarily for patients in active treatment (chemotherapy and/or radiation therapy treatment). All other requests will be evaluated on an individual basis.
- In order to use the bus service, patients must have a pre-scheduled appointment.
- Transportation will not be provided “on demand.”
- It is the responsibility of the patient to be ready to depart 10 minutes ahead of scheduled pick-up time.
- To use this service, patients should try to make their appointments based on the bus schedule.
- Patients should allow at least 1 hour for travel time since the bus may make frequent stops.
- Due to limited space, patients may not be able to bring a companion on the bus.
- If patients fail to board the bus for the return trip, alternative transportation will not be provided.
- All passengers will receive a card indicating that they were transported on the Cancer Center shuttle. Please give this card to the clerk/nurse in your treatment area.
- Shuttle transportation may be provided from designated locations throughout Suffolk County.
- All patients are expected to complete a SCAT bus application, Road to Recovery referral, and (if applicable) a Brookhaven, Southampton, or Islip Jitney application.
- Note that approval for one visit does not guarantee approval for additional visits. All transportation is based on the number of patients in need, the severity of the need, location, and date/time of patient appointment(s).

Additional Resources

1. SCAT Bus: www.sct-bus.org/assets/SCAT%20APPLICATION_2012.PDF.
2. American Cancer Society Road to Recovery Program: www.cancer.org/treatment/supportprogramsservices/road-to-recovery. The ACS Road to Recovery program provides transportation to and from treatment for people who have cancer and who do not have a ride or are unable to drive themselves. Volunteer drivers donate their time and the use of their cars so that patients can receive the life-saving treatments they need.

Non-Emergency Transportation (NET) Program

Sheet to be Completed by Referring Source

Referral Name _____ **Referring Department** _____

Phone Number _____ **Email Address** _____

Last Name _____ First Name _____

Male Female

Age _____

Date of Birth _____

Height _____ Weight _____

Address _____

City _____ Zip _____

Home Phone _____

Other Phone _____

Emergency Contact _____

Phone _____

Stony Brook Physician _____

Primary Language _____

Insurance _____

Do you own a car?

Yes No

Do you have a N.Y. State driver's license?

Yes No

Do any household member(s) have a car?

Yes No

Could they drive you to your appointment?

Yes No

Do you have friends who could drive you?

Yes No

Do you live at a facility that has bus service?

Yes No

Have you completed a SCAT bus application?

Yes No

Are you disabled?

Yes No

Do you use Cane Crutches Walker

Leg Braces Wheelchair Oxygen

Can you sit independently?

Yes No

Can you get from your home to the curb alone?

Yes No

Type of appointment _____

Appointment date/time _____

MAIL TO:

FAX TO:

INFO:

EMAIL:

STONY BROOK USE ONLY

Date Received _____

Reviewed by _____

Approval for DATE _____ TIME _____ TO SB _____

FROM SB _____

SCAT application given

Road to Recovery application given

Jitney application given

Family to share transportation

Request Status _____