Linda Texceira--SHARE-ing Her Success

There was happy laughter in the house that evening--and singing and presents and cake. But it was Linda Texceira who really gave her mother something special to celebrate that September night in 1981. Through her new computer system, Linda spoke the first independent message of her life: "Happy Birthday Mom. Love, Linda."

And with those simple words, the festivities suddenly marked more than another birthday. They became a joyous celebration of human triumph through technology.

But Linda's story has not always been a triumphant one. And for most of Linda's life, she could not have told you that story at all.

Born with cerebral palsy, the 28-year-old woman has never been physically able to speak, write, or gesture to express herself to others. In fact, Linda's only method of communication for many years was through her big brown eyes. By staring at individual letters of the alphabet on a clear plexiglass board designed by her father, Linda could slowly spell out messages. But without a partner to intercept those glances, Linda was still unable to reveal even her simplest wants and feelings.

"For 23 years I had to wait for someone to sit and communicate with me," recalls Linda.

That all changed in 1981, when the story of Linda's struggle appeared in a local newspaper and touched the heart of one of its readers, Professor Les Cory. Cory felt that something could be done to enable Linda to communicate independently. Recognizing the complexity of the task, he teamed up with Philip Viall to build a communications system tailored to Linda's unique needs and abilities. The system--a computer attached to a printer and a voice synthesizer--finally allowed Linda to compose, write, and speak her thoughts independently.

"I only dreamed about being able to talk," Linda says. "Les and Phil closed the door of silence and opened the door of communication."

That "door of communication" opens at the touch of a single switch which Linda operates by moving her head. To create a message, Linda sits before the computer and watches a cursor move across the screen displaying rows of letters, words, and commands. When the cursor reaches the item Linda wants, she presses her head against the switch and the item then appears at the top of the screen. Because the computer contains specialized menus with names, places, and phrases Linda uses in everyday conversation, it allows Linda to express whole units of thought, giving her a faster, more efficient means of communication than the previous letter-by-letter method.

Linda's new ability to express herself has given her a new lifestyle as well.

"My quality of life has changed," says Linda. "I'm more independent, have more confidence, and look for a brighter future now."

Today Linda is "using the computer to the fullest" in striving toward her personal and professional goals. She receives at-home instruction two days a week. Through her computer she is strengthening her language skills and vocabulary by writing short stories. Their next project will be the search for a fall day school program where Linda can earn her high school equivalency diploma.

Since she found a voice through her computer, Linda has become a spokesperson for the experiences and needs of the disabled. Her lectures often express her hopes for the lives of the many still waiting behind their own doors of silence.

"I wish that everyone in this world could have the same opportunity that I have had. It's been like a dream come true for me."
Meet SHARE's Founders

"CORY TAKES CHARGE." So proclaims the boldface, front-page headline taped above Professor Les Cory's office door. And although the clipping was hung there mischievously for a touch of humor, its message is nonetheless an appropriate slogan for the man whose initiative led to the founding of SHARE.

Cory was inspired to help the disabled by a newspaper story about Linda Texeira's struggle to communicate.

"I read the article and, frankly, I cried over it," recalls Cory. "I felt that something should be done for this girl."

First moved to tears, Cory soon moved into action. His dedication quickly spilled over from that initial project to full-time involvement in developing communications systems for the disabled.

Currently SHARE's president, Cory received the SMU Alumni Association Personal Achievement Award and the Salvation Army's OTHERS Award in 1984. He also was honored with a 1985 President's Volunteer Action Award from President Reagan for his instrumental role in creating the foundation. And for his professional accomplishments and contributions as a professor of electrical and computer engineering at S. M. U., Cory received the university's Leo M. Sullivan Teacher of the Year award for 1985.

Philip Viall kiddingly muses that his life might be very different now if only the janitor had erased that blackboard five years ago. One afternoon back in the late spring of 1981, Viall, now a visiting lecturer of electrical and computer engineering at S.M.U., found this chalk-scrubbed note from Cory: "Boy, have I got a project for you!"

Thus enlisted, Viall spent that summer with Cory developing Linda Texeira's communications system. He has been volunteering his energies and expertise ever since, designing and building electronics and computer systems for SHARE's ever-expanding clientele.

While Viall serves as vice-president and treasurer of the foundation, co-founder Richard Walder sees him as "the computer brains" behind SHARE's endeavors--"the magic that holds it all together." Cory credits Viall with possessing a "talent for doing the impossible."

For his dedicated application of those talents in benefiting others, Viall was awarded a Citizen of the Month citation by the New Bedford Standard-Times newspaper. This past March, Professor Viall took a moment from his duties to accept a Jefferson Award for his service to the community, as evidenced by his commitment to SHARE.

To hear Richard Walder tell it, he had to join Cory and Viall in their efforts to create SHARE. After all, someone had to "try to keep those guys from running crazy," he claims.

But in fact, Walder agreed to unite with his two S. M. U. colleagues after they requested his input and assistance in starting SHARE. Walder brought his ability for clear thinking to the task in an attempt "to give some sort of organization" to Cory and Viall's idea. Largely through his efforts, SHARE became a nonprofit foundation with tax exempt status. Walder says his role as vice-president and clerk for SHARE is "just a carryover" of his lifelong social commitment to "the highest ideals of engineering."

"A lot of people don't realize the important things engineers do," Walder reflects. "Our primary goal is to produce things for the benefit of people."

Last year, the S. M. U. professor of electrical and computer engineering was honored by Governor Dukakis with a Commonwealth of Massachusetts Citation for Outstanding Performance. The statewide recognition commends Walder's contributions to both his educational community and the SHARE Foundation.
Dedication behind SHARE's Doors

Vacation day? Not according to Ed DeSouza. You'll find him in his lab, tinkering with complex circuit systems, resistors, and capacitors as if they were his own toys. The trademarks of his handiwork are everywhere—in the computer terminals spreading across the room's neatly rowed desks, in the mathematical scribbles covering the dusty blackboards.

"I'll be here," said the technician with a smile as others left for the long weekend.

But Ed DeSouza’s dedication never takes a holiday. A behind-the-scenes volunteer for SHARE, DeSouza has devoted over four years in helping to create the inner workings of the many communications systems designed by the organization. Initially tackling projects as an undergraduate at Southeastern Massachusetts University, DeSouza, now a professional technician for the school, recalls his recruitment into SHARE.

"Les Cory was working on speech synthesis, and I was doing that for my work as a student," says DeSouza. "I found we had common interests, so I just managed to start doing projects for him."

For DeSouza, doing projects means planning, building, and implementing the complex circuitry within each of SHARE’s unique computer systems. Although DeSouza delegates some of the construction work to his volunteer students so that he himself is not "spending time just drilling holes," the technician admits to "getting involved in almost any project that comes along."

"You need somebody to go off and do the technical part," states DeSouza, "what resistors and capacitors to use—how to make a system happen."

Professor Phil Viall sees DeSouza as that somebody.

"I would describe him as a genius who can make things work when nobody else can," smiles Viall. "He certainly has enriched the lives of the disabled people he has touched."

Likewise, DeSouza has enhanced the educational experiences of S.M.U.'s students. Conducting laboratory seminars for electrical engineering seniors, DeSouza "intertwines" his teaching duties at the institution with his volunteer service to SHARE.

"The jobs fall together," he says. "We have students who are learning a lot and doing the projects—it's nice being involved with that."

Nonetheless, DeSouza admits that his hectic end-of-the-semester schedule cuts into his time usually devoted to SHARE. Juggling his volunteer hours among spare moments, open evenings, and slower weeks, DeSouza says his "positive feelings" for the organization underscore his dedication to its endeavors.

So, if you’re looking for Ed DeSouza, why not try his workshop near SHARE’s headquarters? You’ll probably find him there perched on a bright yellow swivel stool, working on complicated circuit systems, voicing his commitment to helping the disabled.

"If SHARE keeps on going, I'll keep on going too. I can't see any reason why I would ever stop."

SHARE: High Technology with a Heart

At first glance, Room 225 looks like the cluttered laboratory of a modern-day computer wizard. Strewed across congested table and counter tops, various terminals, keyboards, and printers emit a computerized chorus of beeps, clicks, and robot voices. Print-out sheets, books, tools, and lab equipment are crammed into every cupboard and drawer. The room is a haven for what seems to be the spare parts from every computer ever made.

But a closer look reveals another side to such technology. On the walls hang newspaper clippings of disabled clients—smiling proudly as they pose with their individualized communication systems designed and built in this very room. And amid the hum of electronic machinery, huddled volunteers discuss their latest projects while telephones ring with more requests for help.

Welcome to SHARE—a nonprofit foundation combining high technology with a heart for the world of the disabled. At Southeastern Massachusetts University, volunteers tailor communication systems to the unique needs of people unable to speak, write, or gesture.

So far, the organization's efforts have bettered the lives of many clients scattered throughout the country. In response to the physical problems associated with cerebral palsy, multiple sclerosis, Lou Gehrig's disease, and accident- or stroke-induced paralysis, SHARE's researchers have used state-of-the-art technology to free afflicted individuals, both young and old, from the prisons their bodies have become. Since its inception, SHARE has helped over 100 clients; more than 50 others still await its services.

"...Courage towers over pain and mortality... a sacred beacon to the world and to infinite worlds beyond time is your courage."

by the late Richard C. Jacobs, SHARE client

A Publication of the Society for Human Advancement through Rehabilitation Engineering Foundation, Inc.
New Board, Possibilities for SHARE

Challenges met—this is the hallmark of the SHARE foundation. Marked with smiling faces and many happy endings, SHARE's past is a bittersweet blend of trials and triumphs, of obstacles and open doors. Les Cory is the first to admit that it hasn't been easy. Recalling the foundation's early attempts to seek funding, Cory says it was difficult to generate financial support without the power of a full board behind him.

Enter Rich Warren, the driving force who transformed a need into a reality.

Once an appointee of the organization's Steering Committee, Warren now presides as the chairman of SHARE's Board of Directors, a 20-member panel officially instated in January 1986.

"In the past four months, some good things have happened," says Warren. A major development for the board has been the designation of four active committees to pursue SHARE's specific needs. At the core of the network, the Executive Board "deals with the business of the organization," says Warren. Comprised of SHARE's three founding officers, its committee chairpersons, and Warren himself, the board meets monthly to ensure that the organization continues to run smoothly.

"sets the short-term and the long-term goals" for SHARE, explains Warren. Serving as a resource to Cory, Viall, and Walder, the committee "helps establish direction for the foundation."

Members of the Public Relations Committee are responsible for introducing SHARE to the community. Producing the organization's newsletter, fulfilling speaking engagements, and developing a slide presentation are some of the committee's current projects.

But it is the Ways and Means Committee which plays the pivotal role in meeting SHARE's growing financial demands. "Their primary function is fundraising," Warren states.

Appealing to individuals as well as private and public corporations, committee members are now brainstorming and planning yearly events which would raise substantial funds for SHARE. Members are discussing a yearly concert featuring the Southeastern Massachusetts Pops Orchestra. Warren says the committee is eager to establish a continual flow of funds into the organization.

"As we look down the road, it's awfully hard to know what will happen," says Warren.

Nonetheless, he is determined to be there when it does. Initially learning of SHARE's endeavors through a neighbor (Les Cory), Warren immediately was interested in joining the group.

"I expressed a desire to help him in any way I could," recalls Warren. "It's nice to work with a group of creative, hard-working people." Once involved, Warren found himself steadily drawn into the organization as he accepted his leadership position.

"More and more time is being invested in SHARE," admits Warren, who is also the Assistant Superintendent of schools in Bourne. "But that's okay. I anticipate that's the way it will continue to grow."

"SHARE is meeting the needs of a lot of people," says Warren, "so I'm really hoping that it becomes a viable foundation."

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Would you like to join SHARE?

General members promote the organization by generating an awareness of SHARE's mission and its need for financial support. Committee members, on the other hand, partake in the specific tasks set by the group. Whatever your interests, we would like to hear more about you. Contact our Membership Committee at SHARE's headquarters!
Where the Money Goes

SHARE Foundation Breakdown of Income 1984–1985

- Donations–Cash
- Donations–Equip
- Inkind Contributions
- Special Events

SHARE Foundation Breakdown of Program Expenses 1984–1985

- Consultants
- Dues/Subscriptions
- Travel
- Office/Mail/Tel Tools
- Labor

While most non-profit agencies receive operating capital through full-scale contribution drives, a quick glance at the pie chart representing SHARE’s income sources for 1984 and 1985 shows that the foundation depends very little upon actual cash contributions. In terms of dollars, cash contributions make up about 25% of SHARE’s income.

More often than not, individual contributions of time and expertise help the foundation accomplish its goals. While laudable and welcome, these inkind contributions can only go so far.

For example, if there is not enough money to purchase the system components for a client, the technical volunteers cannot assemble those systems.

A look at SHARE’s expenditures, shown in the second pie chart, reveals that the lion’s share of income dollars goes to the purchase of equipment. Unlike other non-profit organizations, very little income is absorbed by management of the foundation’s operations. Every dollar accepted by SHARE is spent wisely, with the aim of helping more clients always as the uppermost priority.

Following circulation of this first newsletter, SHARE expects to receive even more requests from prospective clients. Committed to helping such individuals, SHARE intends to fulfill its promise to those without speech. But funding is terribly limited.

So, won’t you give us your financial support? Your donations, no matter how small, will help purchase the equipment, bring in the expertise, and further publicize our goals.

Lois Floyd--Waiting Her Turn

Just for a moment, imagine yourself stranded in the breakdown lane of a busy highway. There is no motorist call box, and the nearest city is miles away. Looking out the car window, you watch the stream of traffic speed by you. And you wait. As the minutes turn into an hour, you grow anxious, aggravated, angry. And you wait.

For you, the waiting is temporary—the emotions, fleeting. But for others, the waiting is indefinite, and the feelings never quite go away.

Lois Floyd is one of the "others." Afflicted with cerebral palsy, she lies in a reclining wheelchair, unable to move or speak. She has been waiting for the past 29 years to communicate effectively with the world around her.

Throughout her life, Lois’ world has been a changing one. Her childhood was spent with her family and remedial tutors. At 11, she was placed in Canton’s Massachusetts Hospital School. But for the past eight years, Lois has lived in a nursing home.

Her only contacts with the outside world are the posters and cassettes given to her. On the walls around her bed hang glossy reprints of Madonna and Michael Jackson. From her tape player, Cyndi Lauper giggles that “Girls Just Wanna Have Fun.” Lois spends most of her time in this room and by the nurses’ station, perhaps dreaming of joining in on the laughter and chatter around her.

On April 28, that dream moved a little closer to reality when SHARE installed the first of a series of computers designed to meet Lois’ communication needs. Connected to her new television, the system will allow her to build up her switch dexterity by moving blocks around on the screen. The next step is to develop software to teach Lois the letters of the alphabet. SHARE estimates that it may take as long as two years for her to develop the language skills needed to more easily communicate with those around her.

So, amid the posters and music, Lois continues to wait. Only this time, she’s smiling.

This is the first of a series of articles that will trace Lois’ progress throughout the coming months. We invite you to follow her successes along with us... watch for highlights in upcoming issues!
Tournament Suits Him to a Tee

Ron Kostyla sits at his kitchen table and his slice of linguica pizza sits before him, getting cold. Instead of enjoying a quiet supper with his family, the burly, bearded man talks incessantly and punctuates his stories with photos and newspaper clippings pulled from the cupboard nearby. The heightening color of his cheeks matches his growing excitement as he relishes favorite memories and reports every last detail of the event.

Kostyla has a lot to be excited about. For this year marks the third Annual Ben Boyle Golf Classic—a SHARE fundraiser organized by Kostyla, his golfing buddies, and the Pawtuxet Valley Rotary Club.

"It's really a nice, classy tournament," says Kostyla, the powerhouse behind the yearly, two-day event.

A weekend highlighted with food, fun, and friends, the competition took place June 21 and 22 on the rolling greens of Rhode Island's North Kingstown Municipal Golf Course. Tee-off time was from 12 noon to 2 P.M. each day. The $35 entrance fee included not only use of the course and a golf cart, but also a ticket to the tournament's banquet the following Sunday.

"There are always people who want to play in this [tournament]," says Kostyla, recalling last year's turnout of 126 players.

Noting that the greens can only accommodate 60 players per day, Kostyla explains that he and his partners tee off at 5:30 A.M. on Sunday so that they "can work the tournament at 12 o'clock and save room for more golfers" during the reserved afternoon hours.

"It's a long day," he says, "but it's worth it. It's really worth it."

The entire community agrees, and Kostyla finds widespread support for the event from churches to corporations to local baseball teams.

"Most of the businessmen in the town participate in this," says Kostyla.

Some, like the town's baseball players, support the event by participating as golfers. Local businesses have donated prizes such as a picnic table, a radio, and a liquor basket to be awarded during the banquet. Area merchants advertise by purchasing $35 tee signs—wooden triangular flags carrying their company's name—which decorate the golf course.

Whether through playing golf, providing prizes, or buying advertising space on the green, the community unites behind this cause much like Kostyla and his friends did three years ago. In honor of a former golfing buddy, Ben Boyle, who had become disabled as a result of an automobile accident, the group staged a benefit golf tournament in his name. The players, along with the Pawtuxet Valley Rotary Club, chose SHARE as their charity because it was providing services to disabled members of their community.

The first two tournaments raised $2200 and $2100, respectively, for SHARE, and Kostyla has high hopes for the 1986 figures.

"We want to raise more [money] this year," Kostyla states. "To take and turn over a check—it's really something."

But what's also "something" is the amount of time and preparation which the group devotes to each tournament. Kostyla, co-organizer Ron Jalbert, and interested friends work on the event throughout the winter and spring.

"It's a lot of fun," Kostyla says.

Especially rewarding is the sense of unity generated by the fundraiser. Kostyla takes pride in watching the community turn out in support of both Boyle and SHARE.

"It's really great," he smiles. "That day is really fantastic."
"He's involved in so many things...I don't know how he finds any time for SHARE," remarks Professor Phil Viall, "but he does."

Graduating this June, Ed Peck, an undergraduate in S.M.U.'s Electrical Engineering program, leaves behind a trail of accomplishments. Involved in student government and dormitory life throughout his four years at the school, Peck also has implemented the Council of Leaders, an organization which unites the leaders of the campus' many student groups. A member of various Electrical Engineering societies, Peck has received the Most Distinguished Student Service Award for his numerous achievements.

In the following interview, student volunteer Ed Peck explains what he has done for SHARE--and why.

Q. How did you first get involved in SHARE?

A. In my sophomore year, I had a teacher...Professor Walder. And I went up to him and asked if there was any way I could get involved in one of the labs--not knowing about SHARE--to get some hands-on experience. And he said, "Have I got something for you!" Then he brought me over to Phil and Les (Professors Viall and Cory), and we started to work together.

Q. So your motivation was to gain hands-on training through SHARE?

A. Partially my motivation was to look for something along the theory of my class work. What's kept me going is that I've worked with handicapped people. My neighbor had cerebral palsy...so that's been my motivation to continue.

Q. What kinds of projects have you worked on for SHARE?

A. I worked my way up from sorting diodes, to doing some soldering, to putting together communication systems.

Q. Specifically, how have you helped create these systems?

A. I've done a lot of software modification. Each client has a different vocabulary and different needs; therefore, the software has to be a little bit different, too. So, I've taken what clients send in--words and things they'd like in the computer system--modified it, and put the program together so that it can be put into a little chip that will permanently be in the system. I've also had the opportunity to design a switch.

Q. Could you explain a little more about that?

A. All these systems operate [by means of] a single switch. And each one has a different function. Sometimes people can move their fingers, so all they need is a little button. Other times, they can only move their eyes. I came up with an infrared light switch...it's no great invention...I mean, it's been done before. It's actually a simple design, but it allowed someone to use a system by passing his finger through a [beam of] light.

Q. Which project posed the biggest challenge for you?

A. Well, believe or not, that switch I talked about. It was not a technologically advanced thing--it's something someone with experience can do almost without thinking. But for me, it was the first time that I had actually taken an idea and [developed] it. When you conceive something, you kind of think of how you can make it work, put it down on paper, then actually build it. As simple as it was, that's quite a task if it's your first time. So that was the most difficult thing I've done.

Q. How do you feel about your SHARE experience?

A. I cherish it. I really enjoy it because I can picture four people who are professionals--Marty (Martha Gruer, Administrative Director), and Professors Walder, Viall, and Cory. They just give and give and give. That's a good role model for any engineer. Too often, engineers think money, money, money. They forget about one of the definitions of engineering--using modern technology to help mankind. SHARE is doing it for all the right reasons...and I think that's an excellent thing that people should see.

Q. Will your future plans involve SHARE?

A. I'm going to be an electrical engineer, working up near Boston. So that will pull me from SHARE, unfortunately. Although,...I'll visit quite often. I don't think it would be unlikely if I came in here on a Saturday and said to Viall or Cory, "What do you have for me--do you need help with something?" I'll always keep an interest in SHARE.
Think About It. . .

Communication. . .the power to touch the world around us. We express ourselves in the simplest of ways—a conversation, a love letter, a handshake. Often taken for granted, our ability to communicate releases the emotions, insights, and opinions found deep within each of us.

But not everyone can express these thoughts and feelings so easily. Severely affected by illness, disease, or accident, physically disabled people still think and feel, but may have little or no way of showing it.

SHARE, a non-endowed, nonprofit organization, is working to give these people a means of communication. But we need your support.

Because SHARE is totally dependent upon donations, we welcome your contributions of money, equipment, and/or supplies. Not only are all gifts tax-deductible, but they also allow individuals and industry alike to participate in our endeavors.

SHARE further invites people to lend their time and talents by joining our volunteer staff. Whether you are skilled in designing and building computer systems, working with the disabled, or fund-raising, your expertise can make an important difference in the lives of the disabled.

So help SHARE help others touch the world around them. . .because everyone has something to say!

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