ANNOUNCING SHARE WALK-A-THON 1987

Dig out those running shoes you tossed into the closet and start limbering up because SHARE’s second annual Walk-A-Thon needs YOU!

Set for Sunday, October 25, 1987, the Walk-A-Thon will follow the same format as last year. Walkers register and begin the 10-kilometer route at Southeastern Massachusetts University’s Athletic Center. From there participants hike along the campus’ Ring Road, out to Old Westport Road, Lucy Little Road and back. SHARE volunteers will offer refreshments at route checkpoints and at the gymnasium, where walkers can relax after their trek through the countryside.

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TECH TALK: SHERI’S SYSTEM

The Challenge: To create a computer system for a severely visually impaired girl who also lacks fine motor control in her hands. Born with cerebral palsy, Sheri Keighley, 11, faces difficulties in learning because of her disabilities. For example, while Sheri is able to read, she must hold the printed material within 2 inches from her eyes in order to see the words. She also lacks the physical dexterity to hold a pencil and write legibly. Because Sheri can speak well enough to be understood by others, the system did not need to be a communication device, but rather an academic tool to lessen her struggle with school work.

The Analysis: At first, Sheri’s parents requested an oversized keyboard with characters large enough for Sheri to see and keys big enough for her to strike easily. But once Les Cory and Phil Viall assessed her abilities, they felt they could "open more doors for her in the long run" if she learned to master a regular keyboard. They concluded that although Sheri probably would not be able to see the actual markings on standard keys, her eventual proficiency at typing would allow her to use other computer systems in the future; an oversized keyboard would limit her skills to that one device.

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SHARE NEWSMAKER: DR. RICHARD WARREN

SHARE extends congratulations to Dr. Richard Warren on his recent appointment as Superintendent of Schools in Dartmouth, MA. Dr. Warren took over the position on July 1, 1987, thus adding yet another achievement to his outstanding career.

Dr. Warren comes to Dartmouth with the following credentials: classroom teacher in Tiverton, RI and Fall River, MA; Program Coordinator and Director of Community Services in Fall River; Associate Director of the Northeast Community Education Development Center in Storrs, CT; Supervising Principal of two schools in Scituate, RI; and most recently, Assistant Superintendent of Schools in Bourne, MA.

Photo by Rick Walder

Dr. Warren brings his administrative expertise beyond the school environment as well. A two-term chairman of SHARE's Board of Directors and a member of the S.M.U. Rehabilitation Engineering Center's Board of Governors, he has been a driving force behind SHARE's purpose and progress.

We at SHARE take this opportunity to thank Dr. Warren for his commitment to our endeavors. We also applaud the Dartmouth School Committee for choosing such a dedicated individual for Superintendent of Schools. Best wishes for the future, Dr. Warren!

* * *

Just a note... SHARE delivered a communications system to Dartmouth resident, Kim Sherman, this past June--look for her story in our next issue.

2 A Publication of the Society for Human Advancement Through Rehabilitation Engineering Foundation, Inc.
NEW REHABILITATION ENGINEERING CENTER JOINS FORCES WITH SHARE

On July 1, 1987, the Southeastern Massachusetts University Center for Rehabilitation Engineering officially took its place beside SHARE as a provider of services for the disabled. While SHARE still will supply funds and equipment to benefit its clients, the new rehabilitation center will take over the actual production of communications systems. Lester Cory, Director of the center, explains that although the sister organizations have separate roles, they nonetheless are working toward the same end.

"The bottom line is to enable us to provide better service to [disabled] people," says Cory of the new center's purpose.

In addition to creating computer software and hardware for clients, the center hopes to make technological advances in rehabilitation engineering through applied research. They also will conduct workshops for individuals involved in the field and provide hands-on learning experiences for engineering students.

Since the emergence of the rehabilitation engineering center, SHARE's role has changed. Primarily it will widen its fundraising activities and serve as a resource agency for the center. It also will lend the expertise of its board members to the new organization.

The center's Board of Governors includes eight representatives from SHARE's Board of Directors: Dr. Richard Warren, Prof. Philip Viall, Prof. Richard Walder, Ms. Barbara Bell, Mrs. Claire Carney, Dr. Thomas Curry, Ms. Paige Gibbs, and Mrs. Patricia Janiak.

Completing the board are Prof. Lester Cory, Director of the center; Dr. Donald Douglas, Vice President for Academic Affairs at S.M.U.; and Dr. L. Bryce Andersen, Dean of S.M.U.'s College of Engineering.

With the two organizations swapping board members and sharing headquarters at S.M.U., Cory says he sees no need for "sweeping changes" or a "revolution" in the day-to-day operations of the separate groups. But he does expect that their roles will become defined as each organization grows.

"Certainly there will be an evolution," says Cory, "and a quick one."

FUN PAR FOR THE COURSE AT BEN BOYLE GOLF CLASSIC

Someone shouted "Fore!" and the fun began as friends birdied and bogeyed for a good cause.

On June 20 and 21, 120 golfers teed up on the rolling greens of the North Kingstown (RI) Golf Course for the Fourth Annual Ben Boyle Golf Classic. Hosted by the Pawtuxet Valley Rotary Club and the "Sunday Morning Golfers," the two-day benefit raised over $2300 for SHARE.

"It was a real nice time," says Ron Kostyla, who, along with Bob Bjorklund, organized the event. "We had a good turnout."

Opening to blue skies and balmy weather, the tournament's first day welcomed 70 golfers to the 18-hole course in Quonset. Kostyla says that while "Saturday was beautiful," Sunday was a whole 'nother golf game. Gathering to play at 5:30 a.m. so that they could work during the tournament, Kostyla and his Sunday morning buddies could have used galoshes more than their golfing shoes.

"We got soaked," laughs Kostyla about their game in the pouring rain.

Ben Boyle with committee members (left to right) Patty Doyle, Susan Clark, and Carl Burnham

But rain or shine, the event was a success for SHARE. Kostyla already is setting his sights on a $3000 goal and an even grander splash for the fifth annual classic in June 1988.

"Next year's the biggie!" he says.

A Publication of the Society for Human Advancement Through Rehabilitation Engineering Foundation, Inc. 3
I sometimes dream a whole night through
Dream, dream, dream of all I’d do
If C.P. could be licked someday
To let me live a normal way.
I’ve known compassion all my years
Mixed in with joy as well as tears;
But always aware of problems too
That I must face each day anew;
So like a book with a missing text
Not knowing what might happen next.
I will just try to accept my lot
And not feel depressed at what I’m not.
But seek out the best in those I see
And make their good into a brighter me.

The message reflects the man. The words echo what it is like to want answers but know uncertainty, to face reality yet see beyond the limitations. The poetry comes from the heart and calls encouragement to the hearts of others. For poet Harold "Laddie" Holt, the art of writing is both an expression of his soul and a voice for change in the lives of the disabled.

"I’m trying through my writing to not only make a richer life for myself, but [for] others like me," says Holt, known to many as the Poet Laureate of Riverside, Rhode Island.

Building a richer life has not been easy though. Born with severe physical limitations due to cerebral palsy, Holt, 54, cannot speak or use his hands and is confined to a wheelchair. He does, however, have motor control over one foot and uses it as a communication tool. With a SHARE-designed computer system activated by foot controls, Holt is able to express himself through letters and stories and poetry.

But Holt’s literary creativity began long before he received his special system in 1984. Holt’s mother, Hilda, recalls her son’s first experiments with the poetic form. Lying awake at night, the seven year old boy would fabricate poems in his head and memorize them until the next morning. When his mother brought him breakfast, the child would struggle to recite the poems to her. By his bedside, Mrs. Holt would decipher the garbled sounds and transfer her son’s poems onto paper.

"He always had the ability to rhyme," says Mrs. Holt. "He thought in rhymes."

As Holt matured in talent and perspective, his work likewise grew from childlike verse to the introspective poems collected in his published book, As I Am. His subject range is wide, celebrating the beauty of the ocean, the antics of a teenage girl, the value of friendship. Holt says writing poetry is not only an aesthetic pursuit, but always has been his most eloquent form of self expression.

"I think [that] through poetry," says Holt, "I was more able to get what I felt across to others."

Many of Holt’s poems convey a special message of acceptance and perseverance to others like himself. A recurring poetic theme, his philosophy of life is simple.

... give me courage
That when the path I wheel gets soft
I don’t give up to sit and whine
And spread bitterness aloft.

Take what life has dealt and flourish--his credo rings for all the disabled people who have felt trapped by their bodies as well as for the able-bodied who have let their negative attitudes cripple their own lives.

(Continued on next page)
"Everything I do could be thought of as being hard if I thought it so," Holt says. "While others feel very unhappy about not being able to have never-ending vacations, I'm happy right now for a new deep-celled wheelchair battery to let me go a few miles further."

Perhaps it is just this attitude that has allowed Holt to get so much mileage from his own life. Mrs. Holt remembers her son's spirited outlook even as a boy. When his sister learned to read, he reacted to her new conquest with envious fervor.

"It got him so disgusted that she could do something that he couldn't," laughs Mrs. Holt.

From that point on, literature became one of his delights. Mrs. Holt says that because "he relaxed when he listened to stories," she read him childhood favorites like Black Beauty and Huckleberry Finn. Holt's home teacher, Mrs. Miranda Willoughby, also encouraged his literary appetite by assigning him works by Fitzgerald, Irving, and other great writers. After earning his high school diploma, Eleanor Dunfey Freiburger helped to foster Holt's own writing talents by teaching him the fundamentals of grammar and spelling.

Holt's enthusiasm for learning spilled over into his daily activities as well. Disregarding the confines of both his wheelchair and his backyard, he set off on explorations beyond his quiet world.

"At about the age of fifteen, he cut his apron strings," says Mrs. Holt. "He'd go everywhere without telling me."

She jokes that her son still keeps his whereabouts a mystery.

"The other day somebody called me up and said, 'Do you know Laddie's down at the shipyard? '" she says. "Everybody knows him."

And with Holt's latest endeavors, people like Rhode Island's Senator John Chafee and Governor Edward DiPrete have come to know him. Dissatisfied with the current educational, vocational, and housing programs available to the handicapped, Holt decided to utilize his writing skills to initiate a change. He embarked on a letter-writing campaign, voicing his concerns to state politicians. Currently, much of his time is spent corresponding with those people whose consciousness he has raised.

"He's been trying to write more things, but he's very busy writing letters," says Mrs. Holt.

Despite his hectic schedule, Holt has not abandoned his artistic pursuits altogether. He now is working on a story and preparing a new book for publication in the early fall. While he confesses that thinking about his future prompts him to wonder "what next," Holt can count on his thoughts to find the answers. They have had the power to spark friendships, inspire change, and weave mere words into poetry.

... Although I can't use my hands, talk to be understood, or get up and walk, I can think, and I've all the time in the world to do just that . . .

A SHARE SYSTEM EASES THE STRUGGLE TO WRITE

He's always loved to express himself through the written word—in letters, stories, and poetry. And like most writers, he struggles to capture the thoughts and feelings that bring a page to life. But for "Laddie" Holt, that struggle is not only an intellectual challenge, but a physical one as well.

Holt, who has cerebral palsy, cannot speak or use his hands to communicate what is on his mind. Instead he has found expression through some unconventional approaches and fostered his writing talents in the process.

Despite his physical limitations, Holt has learned to use one foot as adeptly as other writers use their hands. In Holt's younger years, his mother taped a fountain pen to his foot, and with difficulty he would form letters of the alphabet on large pieces of paper on the floor. As the years passed, he used a metal pointer attached to his shoe to strike the keys of an Underwriter typewriter. By his thirties, the old-fashioned Underwriter was replaced by an IBM electric typewriter, and the physical act of writing became easier for him.

But it wasn't until 1984, when SHARE designed a personalized computer system for him, that Holt discovered the freeing power of technology. Instead of maneuvering his foot across a keyboard to type words, Holt now could touch a single foot switch to activate his computer's program. Basically, the program displays on a computer monitor lists of words that Holt can select to build sentences. He also can choose individual letters to create words not stored in his system. An attached printer transfers his text to paper. The system even has a voice synthesizer to "speak" his words for him.

With his special system, Holt lets his intellect soar far beyond the confines of his physical self.

"SHARE has given me a whole new world," he says.
Editors' note: SHARE volunteer Robin Singer has designed Lois Floyd's computer programs and works with her regularly. This article reflects Robin's observations of Lois' progress.

She is a real favorite among both the staff and the residents in the nursing home. Smiles break out on the nurses' faces when they see her jokes and good-natured ribbing suddenly liven the halls. Residents make affectionate comments as they pass her, and aides bring her posters and small gifts.

Earning the love and interest of the people around you is not a simple task for the average person. It might be considered an especially large achievement for Lois Floyd since she is unable to communicate with anyone, except by rolling her eyes, wriggling around, and laughing. Yet with these limited tools, she communicates enthusiasm, friendliness, warmth, and a great sense of fun to all the people who come into her orbit.

For over a year, a measure of this enthusiasm has been directed at her SHARE switch-controlled computer system. She was fitted for a wheelchair-mounted head switch in February 1986, which controlled a microcomputer. The computer was programmed to supply brightly colored shapes to Lois' television screen, shapes which she could reproduce and position at will by touching her head to the switch at the appropriate time.

This program enabled Lois to master the art of pressing her head switch exactly when she wanted. Initially she found that difficult; a session with her computer left her tired and perspiring. As time went on, however, it became easier and easier for her to make selections, and she now seems very much in control of her switch.

Lois' SHARE volunteers thought she was thoroughly enjoying the shapes program, so they were amazed when she was even more thrilled with her second SHARE program, Tic Tac Toe. She played against the computer itself or against her friend and roommate, Lorraine. Lois loved putting X's and O's in the squares, and especially loved the musical refrain celebrating the end of the game and someone's win.

But these programs were merely the prelude to the real purpose of the SHARE system—to make it possible for Lois to communicate using a switch-controlled computer and a voice synthesizer. If Lois learns to recognize enough important words, she can learn to select them and send them to the voice synthesizer to be spoken aloud.

On Lois' third program, the voice synthesizer speaks words and then randomly selects one for Lois to identify. As the computer's cursor goes by each word, Lois presses her switch when the cursor reaches the printed word that she thinks matches the spoken one. A correct selection initiates a musical refrain and the spoken phrase, "very good, Lois." It is clear that she very much enjoys this reward.

Lois already recognizes many of the words on the lists. She has never missed identifying the words "T.V." or "music," two of her favorite activities. Once she masters them all, the software will be redesigned to let her put them together to communicate her thoughts and wishes.

Lois, her friends, and her SHARE volunteers are very much looking forward to the day when she can directly express her endearing enthusiasm, love of life, and sense of fun through the "spoken" word.

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WALK-A-THON
(Continued from page 1)

While the Walk-A-Thon officially kicks off at 9 A.M., walkers may begin the course as late as two o'clock in the afternoon. And hikers who enjoy a quiet morning walk may begin as early as 7 A.M.

Last year, 180 walkers raised over $14,000 for the benefit of SHARE's clients. This year we hope the event will match that success... or maybe even top it! SHARE needs and welcomes your support to make the day a special one. Anyone interested in walking or working as a volunteer may contact Linda Vandal at 999-8482. Pledge sheets are now available at SHARE headquarters.

SHARE Walk-A-Thon 1987 is being sponsored jointly by the student engineering societies of SMU.
SHARE Salute
SUPER SECRETARIES, TERRIFIC TEAM

SHARE secretaries (from left to right) Liz Moreau, Carol Novo, and Susan Fontaine

gal Friday n : a female assistant entrusted with a wide variety of tasks
syn 1 see SUSAN
FONTAINE 2 see LIZ
MOREAU 3 see CAROL
NOVO

The definition fits perfectly, but gals Monday-through-Friday-and-sometimes-Saturday better describes SHARE's three volunteer secretaries. By day Fontaine and Novo are secretaries for S.M.U.'s Electrical and Computer Engineering Department, while Moreau works just down the hall as secretary for the department of Civil Engineering. But come early morning, lunch time, or after hours, the three women tackle the volume of paperwork which flows in and out of SHARE headquarters.

"They go looking for work," says Philip Viall, one of SHARE's founders.

Aside from their full-time positions at S.M.U., Fontaine, Moreau, and Novo find the time to keep SHARE functioning from day to day. In addition to the usual office duties, the secretaries have tailored information packages to prospective clients around the country, composed correspondence for SHARE, and created an instruction manual for using a communication device.

"They also walked in the Walk-A-Thon," adds Viall.

Les Cory cites the dedication of the three women throughout SHARE's history. Fontaine and Moreau have worked with the organization since its inception in 1982; Novo joined them about a year ago. Cory attributes the secretaries' countless volunteer hours to their admiration for SHARE's endeavors. And he echoes his own respect for their contribution to SHARE.

"Basically ..." he says with a smile, "they make it possible for us to exist."

* * *

TECH TALK
(Continued from page 1)

The System: Designed by Phil Viall, Sheri's system consists of a keyboard (its keys are slightly larger than standard keys), a 21-inch television monitor, a voice synthesizer, and a computer line printer.

When Sheri types a letter—for example, the letter "Z"—it appears as a two-inch character in the upper left-hand corner of the T.V. screen. At the same time the "Z" is typed, the voice synthesizer speaks the letter. Once Sheri completes a word—such as "ZOO"—she can hit a button signaling the voice synthesizer to speak the whole word rather than its individual letters. Sheri can type eight letters across the screen; the screen can hold five lines of these characters.

If Sheri makes a mistake, she can hit the backspace key; the word "backspace" is voiced by the synthesizer and the letter disappears from the screen. When Sheri is satisfied with the text on the screen, she presses the "print" button to transfer her work to one line on the printer. Likewise enhanced in size and intensity, the print type is three times that of standard letters.

The Outlook: Sheri received her system on June 30, 1987. Sheri's progress will be checked periodically, and the system and its programs will be modified when necessary to meet Sheri's changing needs.

Readers—Do you know others who would enjoy reading a copy of SHARE Notes? If so, please send us their names and addresses to add to our mailing list!
WHAT IS SHARE ALL ABOUT?

SHARE is a non-endowed, nonprofit foundation combining high technology with a heart for the world of the disabled.

Founded by Professors Lester Cory, Philip Viall, and Richard Walder of Southeastern Massachusetts University, SHARE is a resource agency working with the new Southeastern Massachusetts University Center for Rehabilitation Engineering to provide communication systems to those who are physically disabled. SHARE's fundraising efforts support the work of Rehabilitation Engineering Center volunteers who tailor computer software and equipment so that the nonvocal can "speak" through voice synthesizers and "write" through special programs.

So far, over 150 clients have benefitted from SHARE's endeavors. But the waiting list grows each day. Please show your support by contributing to SHARE in whatever way you can--all gifts of money, equipment, supplies, or volunteer time can make an important difference in someone's life.

So, what is SHARE all about?

Simply...it's high tech with a heart for the disabled and all that they can become.