Stevie Roper of Waynesville, North Carolina, age 11, can now ride a bike, play baseball, go to the zoo or help his father rake the leaves. So what’s exciting about that, you ask.

To Stevie, all of it. Not so long ago he couldn’t do any of those things, nor engage in any kind of activity that would cause his temperature to rise. He faced the constant threat of heat exhaustion or stroke because he suffers from what he calls “hypo-whatever.” It’s actually hypohidrotic ectodermal dysplasia, HED for short, and it means that Stevie was born without sweat glands, which allow body heat to escape and thus serve as a natural cooling system for normal people.

For the first nine years of his life, Stevie couldn’t even venture outdoors in summer. He had to spend hours daily bathing or getting “greased.” At school he frequently had to wet himself down fully clothed. He suffered from a variety of HED-related afflictions and was often hospitalized.

In 1987, Stevie had a close call, a severe heat stress situation of critical dimension—but in the long run that turned out to be the best thing that ever happened to him. It triggered a series of events that resulted in relief for Stevie and others, perhaps eventually for all of the estimated 400 to 1,000 HED people in the United States and many more elsewhere. Thanks to NASA space suit technology, the cooperative “can do” spirit of a cooling system manufacturer, and the relentless perseverance and dedication of Stevie’s aunt, Sara Ann “Tootsie” Moody of Hampton, Virginia.

The story begins on a summer eve in 1987 when Stevie, visiting Hampton, took a short drive with Sara Moody’s daughter. Because of Stevie’s HED problem, the trip had been cautiously scheduled for after sundown. Even so, Stevie began to pant in the non-airconditioned car and within minutes was overheated, close to collapse. Quick thinking by the daughter, who swerved to the curb, borrowed a lawn hose and wet him down, may have saved Stevie’s life.

That incident frightened Tootsie Moody and set her in action. She telephoned NASA’s Langley Research Center in Hampton and suggested that the organization that had sent men to the moon surely must have developed a technology that could help Stevie Roper. A NASA official listened to Sara’s story, did some research and
reported back that there was indeed a spinoff product that might alleviate Stevie's problem. He referred her to Life Support Systems Inc. (LSSI), Mountain View, California, manufacturer of Micro Climate personal cooling systems for people in occupations where elevated body temperatures threaten fatigue and collapse.

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LSSI is an aerospace spinoff company, one commercialized to promote Earth uses of technology originally developed for aerospace programs. The Micro Climate technology had its origin in a 1968 NASA development program at Ames Research Center that produced a spacesuit undergarment for cooling astronauts on the surface of the moon or during forays outside their spacecraft or space station; the system circulated a fluid, cooled by a heat exchanger and delivered by a battery-powered minipump, through a network of tubes in the garment.

In 1971, Ames awarded a contract to Acurex Corporation for an extension of the technology involving development of a heat stress alleviating liquid-cooled helmet liner for helicopter pilots. In the mid-1970s, NASA and the Bureau of Mines jointly sponsored an Acurex program for development of a self-contained cooling system for mine rescue work. In 1980, William Elkins, formerly with Acurex and long associated with cooling system research, founded LSSI to pursue commercial uses of the technology. LSSI has refined the technology and brought to the commercial marketplace three generations of improvements.

Gary Rodne, LSSI's director of commercial operations, took the call from Sara Ann Moody. Yes, he said, after some reflection, LSSI could adapt its cool suit technology to Stevie's needs; it would cost about $4,000. That was a big barrier; Stevie's parents couldn't afford it, nor could Tootsie Moody.

With the same dogged determination that had started her on her quest, Sara Ann Moody tackled the money problem. She got a local printer to supply—free—posters with Stevie's picture and his story. With the help of friend Roger Bear, district manager for Po Folks Restaurant Corporation, she placed posters and coin collection jars in several Po Folks restaurants. Another friend, Chesapeake (Virginia) businessman Tom E. Arney, started a separate fund raiser for Stevie. Within five weeks, Sara had raised $5,000. LSSI, meanwhile, had decided to charge only for the suit's materials—$2,600. The extra money was applied to Stevie's extensive medical bills.

In October 1987, Stevie Roper was presented his cool suit, a miniature version of LSSI's Mark VII Micro Climate System®, which uses a rechargeable battery and a small pump to circulate an ice-pack-chilled fluid through a tube-lined headcap and wraparound torso vest. The system is designed to eliminate 40-60 percent of Stevie's body heat and lower his heart rate by 50-80 beats a minute.

Stevie Roper improved rapidly after he started using the cooling garment. "He became a different person," says Aunt Sara, "no longer

*Mark VII Micro Climate System is a registered trademark of Life Support Systems Inc.
withdrawn, no longer frail but filling out—it’s as if he’d been in a
closet, afraid to come out, but now he’s very happy.”

Sara Moody was happy, too, for Stevie and his parents, and
because she felt she had spearheaded something important. LSSI
president William Elkins and marketer Gary Rodne were happy that
their company had been able to perform an outstanding service.
Presentation of the “Stevie Suit” could have been a happy ending to
the story. As things turned out, it was just a beginning.

When Stevie Roper received his cool suit, it was something of a
media event. The story was carried by newspapers and television
from coast to coast and a documentary film was shown on about 800
TV stations in the U.S. and abroad.

Then Tootsie Moody’s telephone began to ring. There were calls
from all over the country from families with the HED problem or
related diseases. And there were messages from abroad—from India,
New Zealand, Kuwait, Saudi Arabia, Argentina. There was a common
theme to the comments: How can I get a cool suit? Why don’t you
start a foundation to help all the children who need such suits?

“Well, why not a foundation?” said Sara Ann Moody, who
proceeded to attack this new assignment with characteristic vigor
and determination. Within a few months she had established the
HED Foundation, Hampton, Virginia 23670. Joining her on the
board were Po Folks’ Roger Bear and businessman Tom Arney who
had helped her launch the Stevie Suit campaign, Stevie’s mother,
NASA Langley official Keith Henry, Tootsie’s husband, a Hampton
doctor and lawyer, and the man at the other end of the lifeline, LSSI’s
Gary Rodne.

With Roger Bear’s help, Tootsie Moody extended her contribu-
tion base to embrace 166 Po Folks restaurants all over the country;
each displays a HED poster and a king size pickle jar for donations.
In mid-1989 the HED Foundation’s income was running about
$4,000 a month from the Po Folks jars alone and there were
occasional outside contributions. At publication time, the founda-
tion had raised well over $40,000.

The money was put to good use. Six months after Stevie Roper
pioneered the movement, five-year-old Scott Gibson of Trussville,
Alabama became the second recipient of a cool suit. July 29, 1988
was a big day, a double suit presentation to a pair of six-year-olds,
Nick Elmore of Knoxville, Tennessee and Ossama Abdulla of Kuwait,
the first foreign suit recipient. By the end of 1988, eight children
were wearing cool suits, including the second foreign youngster,
Tarunpreet Arora of Jalandhar, India.

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This year, with a greater pickle jar yield, the pace of suit deliveries has picked up; on one occasion there were four presentations in a single month. At publication time, about 20 suits were in use, but the word was spreading and new applicants were swelling the waiting list. The HED Foundation's backlog had not diminished appreciably; there were another two dozen in line.

LSSI was still providing the suits at near cost. Company officials were delighted with the success of the program and they had no trouble coping with the increasing HED workload because it represents a small part of LSSI's operation.

Since its founding in 1980, LSSI has grown into a thriving business that has expanded both horizontally—more and more applications—and vertically—increasing orders for some of the principal applications. Micro Climate cooling systems are in service with U.S. and foreign military forces for use by personnel who must perform arduous tasks while wearing hot and bulky protective gear, for airmen flying unpressurized aircraft, for armored vehicle crews, and for shipboard personnel engaged in heat stressful work, such as boiler room or steam catapult room operations.

The range of civil applications is even broader. It includes protection for public service and industrial firefighters and hazardous materials controllers, plus workers in such industries as nuclear power, primary metals reduction, glass manufacturing, chemical processing, petrochemical refining, paper production, steel mills and foundries, and agricultural crop dusting.

LSSI is meeting a special sports need by providing—through Carlson Technology Inc., Livonia, Michigan—cooling equipment for professional race car drivers. Engine heat and aerodynamic measures that detour cooling air away from the cockpit create cockpit temperatures of 130-140 degrees Fahrenheit and such heat, sustained for long periods, can cause fatigue, dehydration, even collapse. So more and more drivers are turning to cooling suits. LSSI's list of clients includes such well known names as Richard Petty, A.J. Foyt, Dale Earnhardt, Ayrton Senna, Bill Elliott and Al Unser Jr., plus about 250 others.

A new sports application made its appearance in 1988. The ThermoAire Splint™ provides pneumatic compression with integrated cooling to replace ice packs and elastic bandages for sports injuries. The compression reduces fluid swelling while the cooling reduces the level of injury. LSSI's ThermoAire Splint™ made news in 1988 when San Francisco 49er quarterback Joe Montana tried one on a knee injury and was able to play the following week.

Scott Gibson of Trussville, Alabama, five years old when he received his cool suit, was the second recipient and the first after the establishment of the HED Foundation.

™ ThermoAire Splint is a trademark of Life Support Systems, Inc.
LSSI, in conjunction with the Jimmy Heuga Center and the University of Utah Medical Center, recently completed a pilot research program that clearly demonstrated significant benefits to multiple sclerosis patients, who must exercise but often cannot tolerate heat build-up caused by exercise. In the same program very significant results were also observed for a patient with limb neuropathy, a very painful disorder. In a separate experiment, conducted by Dr. Arnold Malcom at St. Joseph's Medical Center, Burbank, California, LSSI's vest was used with positive results for heat therapy of extensive superficial cancer. Additionally, the NASA-sponsored Research Triangle Institute Applications Team, Research Triangle Park, North Carolina is working toward commercialization of a cooling garment specially designed for use by quadriplegics, who are often unable to tolerate heat stress because they are unable to perspire below the level of injury to the spinal cord. (Continued)
Tootsie Moody’s phone is still ringing. With some four dozen cooling suits already delivered to HED youngsters or on the agenda, she feels the HED Foundation’s work will continue for a long time because she is continually hearing from new clients who have just learned of the foundation’s existence.

And her horizons are broadening. Sara Moody, who not long ago couldn’t spell hypohidrotic ectodermal dysplasia, can tick off a list of related afflictions whose victims are prone to overheating—lamellar ichthyosis, Cursayer Syndrome, cystic fibrosis, multiple sclerosis, severe burns and many other disorders. She knows about them because the victims’ families, desperate for a shred of hope, have turned to her. She refers them to LSSI, but it pains her deeply that she can’t do more, because the HED Foundation hasn’t yet enough income to expand beyond its chartered purpose.

“Not yet,” says Tootsie Moody. “But it’s there in my mind. I want to help all the children. If we can increase the contributions . . .” She’s off on a new dream and when Sara Ann Moody gets to dreaming, things start to happen.

And what’s in it for Tootsie? She has a ready answer.

“A wonderful satisfaction. I’ve never enjoyed anything as much as the activity of the last two years. It’s so rewarding to see the faces of the kids and their parents when they first try the cool suit and know it works.

“And later they respond to questionnaires and send me notes. It’s so exciting to read them, it gets chills down the spine. It’s not just a suit we’re giving these kids—it’s new hope.”

The cool suit story is a classic example of the spinoff potential for both economic gain and public benefit. Spinoffs often produce product sales in the multimillions of dollars annually. In other instances, spinoffs offer only moderate economic gain but provide public benefit in other ways, ranging from simple conveniences to significant developments in medical and industrial technology.

LSSI represents one side of the spinoff coin; here a technology transfer resulted in establishment of a prospering company, with attendant benefit to the Gross National Product and job creation.

Tootsie Moody’s HED Foundation is the other side of the coin, a compassionate movement made possible by space technology, a program that is already helping many, providing new hope for many more, and offering great potential as inspiration and catalyst for further spread of the medical applications of body cooling.
For the past 27 years, under its Technology Utilization Program, NASA has been actively engaged in encouraging the secondary application of aerospace technology. During that time upwards of 30,000 aerospace originated innovations have found their way into everyday use. Collectively, these spinoffs represent a substantial return on the aerospace research investment in terms of economic gain, lifestyle enhancement and solutions to problems of public concern.

The Arora family of Jaladhur, India pose with HED representative Keith Henry (right), who presented a cool suit to four-year-old Tarunpreet Arora. In foreground is the suit's cooling pack and pump, which circulates a chilled fluid through the tube-lined headcap and vest.

Cropduster pilot Gary Owens (left) solved the problem of high cockpit temperatures with his LSSI cool suit. So did NASCAR Winston Cup champion Dale Earnhardt (right) one of more than 250 race car drivers who wear LSSI equipment.