

H.A.L.O. Reports

A Publication from the Help A Little One Foundation



**A Foundation
for Children
with Neurological
Impairment**

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Founder's message

Crisis Strikes Home, Nation

Dear Friends,

The tragic events of New York City and Washington, D.C and the continuing threat to the health of the nation have taken an enormous toll. As hundreds of family stories have unfolded, and thousands have attended fundraisers and memorial services, we have seen and felt the impact.

Crisis occurs on a personal level for individual families when birth, illness or injury results in devastating neurological impairment, but the consequences ripple through our lives in similar fashion.

It is ten years since our daughter Sarah became ill. The child we knew was replaced by a severely-challenged shell of a girl. On the one hand we are grateful for her survival; on the other, this personal tragedy has brought continued stress and profound loss to our home.

The Help A Little One (H.A.L.O.) Foundation continues to dispense funds to meet the physical comforts of children with neurological impairment, but more and more our focus is on the families who care for and about the children. H.A.L.O.'s Family Circle support and information programs seem to be addressing a void in family services. In this second year of a three-year pilot program, it is becoming apparent there is much more we can do.

Families never discharge their responsibilities and their love for their children. If we can help their families to stand strong beside them, children with neurological impairment can better achieve their potential.

As always, we thank you for your continued support in this endeavor.

Sincerely yours,

Alan Pinshaw

A Foundation for Children with Neurological Impairment

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Snapshot of a Man Who Follows His Heart: Jack Doyle

Jack Doyle says he's just a regular guy, nobody special, he just likes to feel good about the man he sees in the mirror every morning.

In his day job as administrator for medical liability insurance at New England Medical Center, Jack is witness to the challenges and tragedies of modern life: illness, birth defects and disabilities faced by the tiniest and most vulnerable patients — children. In the other half of his life, Jack has his family and his hobbies, but he devotes many, many hours to fundraising for charities that serve children with special needs.

This past summer Jack donated the proceeds from what friends affectionately dub the "Doyle Classic" golf tournament to the Help a Little One (H.A.L.O.) Foundation. Each year Jack invites 50 or 60 friends to the usual smorgasbord, raffle and golf game at a local course, and includes a small charitable donation in the price of the ticket. "This is just my small, personal effort," Jack said in an interview. "It's not hundreds of thousands of dollars, but it's something."

Jack believes in helping others. His efforts are not directly rooted in any personal tragedy. He and his wife Patricia are the proud parents of two healthy, grown-up daughters, Shannon and Allyson, and two grandchildren.

His charitable bent was fired up about 25 years ago when a fellow congregant at Our Lady of Lourdes Church in Jamaica Plain (Boston MA) urged Jack to visit Camp Fatima in New Hampshire. It took Jack a while, but he finally dropped in when he was

vacationing nearby. "I was just so impressed with what they were doing, I signed on as a volunteer dishwasher and remained a dishwasher for the next 20 or so years," he said.

Doctors, nurses, therapists and counselors volunteer their time at absolutely no cost to Camp Fatima so that 125 seriously-challenged children can enjoy outdoor

pics. Jack refereed high school and college basketball games for 30 years. He now coordinates the referees for the Massachusetts Special Olympics and has worked at the last two International Special Olympics.

Why does Jack Doyle donate his time and effort to charity?

"I was moved by the needs of the families," he said. "We have two wonderful daughters. If we needed to go shopping, we buckled them up in the back seat and off we went. If they acted up, they got a little pat or a talking to and we sent them to the back yard to think."

"Families who have children with special needs don't have this luxury. We don't even think of it as a luxury, but they can never send their child out to play. They can't run a quick errand. Everything is a production — the wheelchair, the oxygen tank, and so forth. I became committed to Camp Fatima for those parents. They get a worry-free week while their children have fun."

Jack said he's too old to work at the camp any more, but he continues creative fundraising. "There are lots of generous people out there, you just have to open their eyes," he said. He makes it sound easy, for instance he ran a Silver & Gold campaign, where Silver was a \$1,000 commitment, Gold was \$2,000, to be paid over four years. Jack also makes people aware of employer matching gift programs, that add to the value of their gift.

When asked how to encourage potential volunteers or donors, Jack Doyle says to appreciate what you've got, and think about giving a small slice of that to someone less fortunate.



Jack Doyle enjoys helping families.

activities in a safe environment. A total of 375 volunteers, including college students, lawyers, accountants, small business owners and even a judge now and then, donate their time in various roles, he said.

However, Jack's work didn't end with his summer stint at Camp Fatima. When it became apparent that the camp needed an endowment, Jack rolled up his sleeves and personally helped create the Camp Fatima trust fund. Today he continues to network with donors, and does the 'grunt work' of organizing fund drives for other charities, including the Special Olym-

Nurse Says Alternative Therapies Improve Quality of Life

Desperation brought Deborah J. Risotti, R.N., to alternative medicine.

Success led her to integrate non-traditional techniques with traditional medicine to improve quality of life for her daughter Sarah, 19.

Sarah has severe neurological impairment and is medically fragile.

Deb described Sarah's positive response to acupuncture, magnets, acupressure and moxibustion to parents at a recent Family Circle support group meeting. She also shared her own parent's guide to alternative medicine.

A graduate of St. Elizabeth's School of Nursing in the Boston area, and an experienced recovery room, critical care and emergency room nurse, Deb is also certified as an early education specialist. She was skeptical of alternative medicine, but

investigated treatments as a last resort.

"Sarah was failing to thrive with traditional medicine alone. Seizures, pneumonias, and bowel dysmotility caused frequent, lengthy hospitalizations. I had to do something."

Initially Deb rejected alternative recommendations because some were counter to the medical interventions she had performed successfully over the years. Then, after a five-week hospitalization to resolve a post-operative paralytic ileus, doctors decided to discharge her home on Intravenous feedings to meet her nutritional needs. Deb called Dr. Agatha Colbert M.D./acupuncturist at this point, and after one acupuncture treatment, bowel sounds returned and Sarah was able to tolerate a feeding. The IV was removed and Sarah was discharged home on her regular feeding regime.



Debbie, Sarah and Pebbles the dog, share a laugh.

"Since that day Deb has explored a myriad of alternative treatments. Therapies that were effective for Sarah decreased spasticity

boosted her immune system and improved Sarah's vision.

Once Deb demonstrated
(Continued on the back page)

What are Non-Traditional Treatments?

The following definitions were condensed from Deb Risotti's handbook for parents.

Acupuncture: The Chinese explanation is that channels of energy run in regular patterns (meridians) through the body and over its surface. These meridians nourish body tissues and can be unblocked or stimulated by needling specific acupuncture points.

The modern scientific explanation is that needling the acupuncture points stimulates the nervous system to release chemicals in the muscles, spinal cord and brain. These chemicals can change the experience of pain or trigger the release of other chemicals and hormones, which influence the body's own internal regulating system. Needles are sterile and

disposable.

Chinese and Japanese acupuncture differ in the size of the needle and technique; French Energetics acupuncture is usually taught to medical doctors.

Magnets and ion pumping cords: The theory of using magnets connected by a cord with an electrical wire inside is complicated. In a nutshell, needle phobic people can get a very good acupuncture treatment by having magnets placed on specific acupuncture points, then connecting a cord with a wire in it to a metal clip on one end and a diode on the other. The cord facilitates a one way flow of the body's electrical current and helps balance the meridians mentioned above. 10,000 gauss (measure of strength) magnets are used during treatment, which

is painless and lasts 20 to 30 minutes. Tiny 800 gauss magnets (smaller than a pencil eraser) with the strength of a refrigerator magnet) can be taped to pressure points and massaged during the course of a day to stimulate the meridians. Placement and polarity are important aspects of instruction and placement.

Moxibustion: This method involves the application of heat produced by burning the herb moxa (also known as mugwort) in an acupressure instrument called a tiger warmer. It looks somewhat like a fountain pen. The theory is that the heated pressure on specific points will relax, tonify and stimulate the body. In herbal medicine mugwort is anti-spasmodic, recommended for digestive and menstrual complaints.

Mayflower Residents Enjoy Visit to Spooky Salem MA



Mayflower Pediatric Center residents toured Salem, Massachusetts, as part of their Halloween activities this year. Community interaction is an important component of Mayflower's recreation program, according to Pam Bailey, A.C.C., Director of Activities. The Center is located in Plymouth, Massachusetts, and has been a recipient of H.A.L.O.'s holiday gift program for several years.

Outside the Peabody Essex Museum are, from left to right, residents Raymond, Mike, Amber and Timmy with Nurse Marilyn Bowen, Activities Assistant Betty MacDuffee and Activities Assistant Rebecca Hanelt.

RN Says Acupuncture Therapy 'Can't Hurt, Might Help'

(Continued from previous page)

results, she said Sarah's doctors gave their support to her program, along with Sarah's teachers, therapists and nurses.

Can she prove any of this? Sarah has not been hospitalized at all in the past ten years. Deb said a child with such involvement would typically require several hospitalizations per year. Physician visits have decreased by 75%, and the number and strength of medications have been reduced significantly. Deb was invited to present these findings on pediatric grand rounds at Massachusetts General Hospital in March 2000, and received high marks from the medical staff, she said.

"Nothing has changed with Sarah's diagnosis. She still has severe brain damage and

serious medical issues, but by supplementing medical treatment with alternative treatment we have dramatically improved her quality of life" Deb said.

"If I can keep Sarah out of the hospital, and more comfortable in a relaxed body, it brings normality to her life, and to our (family) life." Deb said she now has had more time for her son Daniel, 16, since Sarah doesn't have as many doctor appointments, tests and hospitalizations.

The therapies she utilizes for her daughter "can't hurt, and might help" others, Deb said. "If I can achieve the same or a better outcome using acupressure on a point on her upper lip (GV 26) instead of more medication to halt a seizure in its tracks, what harm is there?" she asked.

The medical community's primary objection to alternative medicine is that there is no research, Deb said. She collects and distributes reports that may not have received mainstream attention. For instance, she quotes the National Institute of Health on the efficacy of acupuncture for treating a variety of ailments. She notes FDA approval of acupuncture needles as a controlled medical device. She spotlights insurance companies reimbursement for legitimizing acupuncture treatments.

One such report utilized functional Magnetic Resonance Imaging (MRI) to prove that acupuncture increases blood flow to the brain. Another study documented that acupuncture increases neurotransmitters such as endor-

phins, serotonin and dopamine in the spinal fluid, and decreases in the stress hormone cortisol, she said.

Deb said she thoroughly studied acupuncture therapies to satisfy questions raised by her medical training, but lay people can benefit without the scientific background. Parents can develop a home program in partnership with certified practitioners to supplement and enhance their child's medical program, she said.

Traditional and often necessary medical and surgical interventions should not be cast aside, she emphasized.

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NOTE: Presentation of this information does not constitute an endorsement or recommendation by The H.A.L.O. Foundation.