

# Greenwich Time, In the Community

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## Responding with courage

### Disorder turned health award winner into activist

By Cameron D. Martin  
Staff Writer

She just wanted to pick up a few groceries, so she didn't think it would be a big deal to leave her oxygen machine in the car. Besides, it attracts unwelcome attention, she thought.

No sooner had Bettina Irvine begun shopping, however, when she ran out of breath. She couldn't even summon enough energy to make it back to her car. Luckily, she spotted a friend who was also shopping. Admitting her foolishness, she asked the friend to fetch her oxygen machine.

"After that I said, 'You can't be vain, Bettina, you need your oxygen.'"

Irvine suffers from Alpha-1, a genetic disorder that has slowly destroyed her lungs. No longer embarrassed by the apparatus she needs to perform even routine chores, the Cos Cob resident has been on a mission to make people aware of the somewhat obscure illness.

In recognition of her awareness-raising efforts both locally and nationally, the former *Mademoiselle* magazine editor is the recipient of Greenwich Time's

Louise Crisafi Community Health Award.

She was nominated by friend and neighbor Pam Krueger, who in her nomination letter wrote: "Diagnosed with a life-threatening breathing disorder in 1996, Bettina chose to respond not with bitterness but with extraordinary courage. Refusing any temptation to engage in self-pity, she has used her diagnosis as an opportunity to make a difference for others."

Ten million Americans are carriers of the Alpha-1 gene, but one has to inherit it from both parents to be affected. According to a report published by National Geographic, it is a genetic variant that originated in Scandinavia and spread during the Viking exploration of northern and eastern Europe.

Irvine, who said she had never heard of Alpha-1 before she was diagnosed, was also not aware she was a descendant of the Vikings.

Now, raising awareness of Alpha-1 and the fact it is often misdiagnosed as asthma and other breathing ailments, is Irvine's major goal.

"Awareness, I think, is the first step," says Irvine, 57, who is waiting for a possible double lung transplant.

Among her awareness campaign undertakings was a fundraising walk at Greenwich Point last October, which several Greenwich High School groups organized.

Irvine has two sons, Billy and Jonathan, who attend the high school. Her oldest son, Andrew, is a GHS graduate and current Brown University student. Like their mother and father Ken, the Irvine boys are committed volunteers. Andrew was Greenwich Time's 1998 recipient of the Young Community Leader of the Year award.

Krueger marvels at her friend's steadfast resolve to spread awareness of Alpha-1 even as she deals with her own condition.

"She's just shown remarkable courage," Krueger says. "It's really a test of character when something difficult enters your life and a lot of people fold up under these circumstances."

"She was a good steward of the bad thing that happened to her."

To Irvine, the option of self-pity is eclipsed by the need to help herself and others.

"I have what I have what I have, and there's nothing I can do about it, because I was born with it ... and I have to live my life with what I have," she says'.

"When you're put in a predicament like this, what else you going to do? Lay down and die?"

Irvine keeps busy attending her son's sports games and a local Bible study group. She even plays golf, though never without her oxygen.

"Oxygen makes a big difference," she says. "(The first time I used it) was like drinking from a cold stream. It revitalized me, it energized me."

Like many sufferers of Alpha-1, Irvine was misdiagnosed several times before doctors pinpointed her illness. She has felt evidence of the affliction since she was young.

She recalls trying not to expend too much energy during sports practices in high school. otherwise she would be winded later on during choir.

"I sort of knew there was something wrong with me most of my life," the Washington D.C., native says.

That feeling is shared by millions of others, she says, many of whom still do not realize they have Alpha-1.

Westport resident Frank Deford, the well-known sportswriter has Alpha-1, she says and has joined her in helping to heighten awareness of the ailment.

"It is an insipid disease," Irvine says. "When your breathing gets in

the way of your living, it takes a while to figure out what's wrong with you."

Ironically, a simple blood test can now pinpoint the presence of a disease she has been grappling with her entire life, Irvine says.

If the general public is aware of it, (the blood test) is a really simple thing to do."

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**Bettina Irvine  
Louise Crisafi  
Community Health  
Award winner**

And early testing, coupled with lifestyle management and aggressive medical treatment, including pulmonary rehabilitation, can greatly enhance the quality of life of Alpha-1 sufferers, Irvine says.

"If you get it diagnosed early you can manage it really well," she says.

Irvine says there is also another simple, albeit somewhat taboo measure that can raise hope for the sufferers of Alpha-1 and many other diseases - organ donation.

Last year, during a chance encounter, Irvine met Art Caplan, the director of the Center for Bioethics at the University of Pennsylvania.

It was a lucky meeting for both parties: Caplan was looking for funding for a pilot study on organ donation. Irvine, who has been approved for a lung transplant, had an obvious interest in organ donation and was eager to help.

When a person dies, Caplan recently explained, if he or she has organs that are suitable for transplant, medical personnel ask the family if they are willing to donate them, often with the presumption that the families will say no.

Fewer than one in four families agree to donate a family member's organs, Caplan says.

Caplan's study is about semantics, not science. He believes that if medical personnel simply changed the way they asked for organ donations, it would yield better results.

Already the efforts of Caplan and Irvine are showing. In response to their exhortations, the Department of Health and Human Services recently granted more than \$1 million to Caplan's study.

Time will determine the success of the study, but "Other people don't have to lose as much lung capacity as me." Irvine says.

**Bettina Irvine, the President of the Alpha-1 Association, was the recipient of the Association's Newsmaker of the Year Award for 2001.**

**Bettina is dedicated to servicing the needs of the Alpha-1 community as one of the many hardworking members of the board and staff, and all the professionals, volunteers and passionate people in the Alpha-1 community.**