Overheard

Learning to Heal: Mothers' Voices, Miracle House and other confront the pain head on

June 1, 1994 By Christopher Petrikin

When Nita Pippins uprooted herself from her peaceful life in Pensacola, Florida to come to New York City to care for her son Nick, she didn't know what she was getting into. Nick was sick with AIDS and she was not prepared for the harsh realities of the city nor the overwhelmin responsibilities of acting as supporter and caretaker for her dying son. "But I learned to overcome my fear, at times driven only by the knowledge that my son was critically ill and needed me more than ever," says Pippins. After his death in 1991, Pippins couldn't shake the feeling that her help was desperately needed. She chose to remain in her son's adopted city to help care for people with AIDS as a volunteer peer counselor at Miracle House.

Pippins' panhandle drawl and undeniable charm have a soothing effect on a young woman from upstate New York who is visiting her husband at a local hospital. Nervous and lacking sleep, the woman has just arrived at Miracle House for the first time this morning.

"I practically have to sneak out of my town to come see my husband, since even my parents don't know he has AIDS," she says, holding back tears. "Even though we have known he has had AIDS since 1989, and my four-year-old daughter and I are both HIV negative, we live in such a small community that my daughter would be subjected to teasing and rejection if anybody knew. The first few times I came to visit him, I either had to go back home that same day or try to find a safe hotel room. But that became too expensive."

Modeled after the successful Ronald McDonald houses throughout the country which provide temporary housing for out-of-town families of hospitalized children, Miracle House -- actually located in a high-rise on Manhattan's West Side -- is a temporary sanctuary for families of PWAs.

Pippins is just one of the angels that have descended upon Miracle House, says co-foundes Nancy Sweetser, an elegant, genteel woman who, in 1990, along with Wayne Davis, decided the best way to directly serve the AIDS community was to bridge the geographical and emotional gap between PWAs and their families. "On its own, New York City is very stressful; but compound that with the stress of having someone you love dying of AIDS, and it's almost unbearable," says Sweetser.

"Although we are privately funded and our financial resources are limited, we offer whatever emotional, psychological and even legal assistance is within our means for those who are not

prepared for what they're facing," says Eric Menkes, board president.

Miracle House Executive Director Gilles Mesrobian says that Miracle House was formed to "help ease the emotional pain and educate these families to what they can do. Many of these people don't realize that they really can touch, bathe and kiss their loved ones. Our peer counselors validate that."

On occasional Monday nights on New York City's Upper East Side, Eileen Mitzman and her husband Neil, host what, at first glance, could be mistaken for a bridge party but is, in point of fact, a support group of five couples who have lost children to AIDS. The group, along with their facilitator, a psychiatrist, has been together for more than a year. Many were friends before joining the group but have become closer through the trials of having children die before them.

"Children are not supposed to die before their parents. It isn't right," they all seem to be saying.

"AIDS does not just strike down the infected child," says a mother who lost her daughter a few years ago. "It also strikes their families, leaving us devastated and feeling helpless."

After a small, lighthearted digression -- to recent vacations and minor traffic collisions -- from the highly charged sharing, the therapist refocuses the group by tapping his watch and saying incredulously, "Do you realize what you've been doing for the last 20 minutes?"

"Avoiding the issues," they say, almost in unison.

Back on track, the couples begin discussing the pros and cons of antidepressants and antianxietals. The psychiatrist leans over to me and says, "This doesn't look like a bereavement group, does it? But it's this sense of family that has enabled them to support each other and carry on with their lives."

Conversation shifts to the inability of some of the couples to associate with friends outside of the group because as a mother says, "They almost always end up saying something insensitive, patronizing or clumsily try to avoid the subject of children and AIDS altogether."

"This group allows us to gather support from people who will not judge us because they have gone through the same thing -- with the politics of this disease and the accompanying issues," says one of the fathers.

"But sometimes when my husband and I are together, we finally have that quiet time together -- away from the AIDS advocacy groups and other organizations we're involved in -- and we just sit there, let out a deep sigh and do nothing," says another woman who has lost two children, one to AIDS. "We often don't have anything to talk about if it's not AIDS-related."

Eileen Mitzman is a sparkplug of a woman with a voice that envelops you like your favorite old coat. She has lost two children, one to an automobile accident 12 years ago, and more recently, a

daughter, to AIDS. She has endured the bedside vigils and pain of burying her own children. While she still grieves for her children, she and the well-heeled women who make up Mothers' Voices are as angry as they are bereaved.

These women have gathered since 1991 to channel their grief and anger into a forum for AIDS research and public policy advocacy. As Mitzman, or the "Energizer Bunny" as she is called by the other mothers (so named for her seemingly limitless supply of energy and activis fervor), says, "We like to say that Mothers' Voices is ACT UP in sheep's clothing."

Fresh from protesting at New York City Hall against Mayor Rudolph Giuliani's proposed closing of the Division of AIDS Services, Suzanne Benzer, whose son has AIDS, attempts to explain the need for this seemingly homogeneous group of "ladies who lunch" in the already crowded arena of AIDS activism. "Even in tragedy, people gravitate towards those they would normally be friends with. And because of our backgrounds and common bonds we might not feel at home at an organization that was in the vein of, say, ACT UP. Our strength lies in the fact that mothers are natural networkers and caregivers. From the time our children were young and we gathered at the playground, we would network."

This tendency to network allows Mothers' Voices to harness their anger and use it -- particularly through their annual Mother's Day Card Campaign in which they organize hundreds of thousands of families to send greeting cards with an AIDS message to Congress and to the President -- to persuade the government to increase funding for AIDS research.

"We will settle for *nothing* less than a cure," Mitzman flatly asserts.

So how do they keep the activist furor alive?

"It's easy because they are mothers," says Executive Director Marian Soroge. "It's their natural inclination to give support. They're the ones who were always able to kiss the pain away."

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