

Silent struggle

Soap actress helps battle hearing loss BY JOSHUA M. BERNSTEIN

"Can you hear OK?" Kassie DePaiva asks as actors bustle past her basement dressing room in ABC's Lincoln Center–area Studio 17, their chitchat drowning out conversation.

The blond actress, who for 13 years has starred as trouble-making Blair Cramer Manning on daytime drama "One Life to Live," stands up from her orange chair - beside a hospital gown she'll soon slip into to play a coma patient - and shuts the door. "There, now we can hear each other," she says in her honey-smooth, Kentucky-native drawl, straightening her leather jacket and plopping back down.

DePaiva's concern for hearing is hardly a common courtesy. For the last decade, this married, Morningside Heights mom of two has toiled endlessly to shed light on childhood hearing loss.

The problem is simple: "If you can't hear language, you won't be able to understand language and experience normal development," says the actress and singer, 45. "Every minute spent without hearing is a minute a child is not getting back."

This sense of urgency drives DePaiva long after cameras stop rolling. She's a board member and fund-raiser for the League for the Hard of Hearing, a nonprofit dedicated to aiding deaf people and their families.



Mendez for NEWS

Inspired by her son's deafness, Kassie DePaiva of One Life to Live has devoted herself to raising awareness on childhood hearing loss.

She spends her sparse down time crocheting and selling colorful wool Happy Hats - "They make both you and the people looking at you happy," she says - and donates their proceeds to deaf charities. And she even agitates congressmen for legislation mandating hearing tests for newborns in all 50 states.

"Doing so is just plain common sense. It's a quick, cheap, noninvasive test," DePaiva says angrily. "How can a mother walk out of the hospital not sure if her child has the ability to hear? I find that to be criminal."

New York's newborn-testing law more than three years ago. But that was years too late for DePaiva.

When her son, James Quentin, was delivered via C-section in 1997, Mom and Dad (ex–OLTL actor James DePaiva, who was also Kassie's onscreen husband) were "overjoyed. We thought we brought home a healthy, perfect baby," DePaiva says, joining James' daughter, Dreama, now 14.

At least, that's what the doctors said. As months stacked up, however, the proud parents noticed that James Quentin, who they nicknamed him JQ, was unresponsive when they called his name. Was their son just stubborn, or was there a far more serious problem?

"If you think your 12-month-old son is deaf, there's nothing in the yellow pages to help you out. We were naïve, scared parents," DePaiva says as she rocks her chair back and forth. "We brought JQ in for testing, hoping it was just wax in his ears."

It wasn't. He had an enlarged vestibular aqueduct, an inner-ear abnormality destroying hearing. This was life imitating art in the worst imaginable way.

"It was so bizarre and ironic," DePaiva says, shaking her head. Several years before JQ's birth, hubby James' OLTL character had a son suffering from a hearing impairment.

"He experienced all these emotions of having a deaf son in this pretend world," DePaiva says. Acting couldn't prepare their emotions in the real world.

"We mourned for a week, not for his lost hopes and dreams, but because of our hopes and dreams for him."

But hope was not lost. Gander at DePaiva's dressing room walls and mirrors, which are lined with pics of a grinning, bowl-haircut JQ, and you'll comprehend the life-changing ability of his cochlear implant (tiny, internal microphones that enhance hearing). Thanks to grueling weekly therapy sessions teaching him how to interpret noises, JQ was soon awash with sounds like honking cars, chirping birds and, most importantly, his mother's voice.

"Every day I tell him how proud of him, and how he inspires me," DePaiva says.

The success of JQ's cochlear implants - he received a second one at age 8, and is now a fourth-grader at a mainstream elementary school - has inspired DePaiva to fight for other kids' rights to the same operation.

"Now, cochlear implants are not the solution for everyone, and some families only opt for one. But I stand on a huge soapbox when it comes to inconsistent insurance coverage: Some states won't insure cochlear implants, while some states, like ours, will allow you to have two. God gave us two ears, so we should be able to hear with both," DePaiva says, tugging on her earlobes.

Four years ago, at the urging of the Deafness Research Foundation, DePaiva and JQ traveled to Washington, D.C., to plead their case to congressmen. "What better poster child is there than JQ?" she says.

Additionally, DePaiva's soap-opera celebrity is instrumental in spreading the word about hearing loss to her fans. "One out of four e-mails I receive is from people who are frightened and confused. They ask, 'What should I do? Where can I go?' Now, most of my fans come from the heartland - my people - and they may not have the resources we have in New York. "I know that feeling of not knowing where to turn, and it's not pleasant. So I try to help anyway I can. I provide an open ear, I give them Web sites and I make sure they call the League for the Hard of Hearing," she says, her rocking chair coming to a stop. "If I can help one person, my day has been made."

Dr. Laurie Hanin is witness to the actress' positive impact. "She's taken on the cause of heightening people's awareness of hearing loss, and is making sure parents are informed of their options," says Hanin, an audiologist and executive director of the League for the Hard of Hearing.

Its fund-raising has skyrocketed due to DePaiva's involvement with events like last month's Feast With

Famous Faces, for which she helped corral oodles of soap stars. "People listen to her."

DePaiva blushes at the thought that she's going above and beyond the call of duty.

"I'm not doing anything out of the ordinary," she says, gazing at the pictures of her son while the loudspeaker crackles, calling actors to the stage. "This is a part of who I am."

For more information on Kassie DePaiva, visit <u>www.kassiedepaiva.com</u>. To find out more about hearing loss, visit <u>www.lhh.org</u>.

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