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\$5M gift from Barton G. Weiss to UM will help families affected by kids' hearing loss

The University of Miami will boast a new national information clearinghouse on child deafness -- thanks to a \$5 million gift from Barton G. Weiss.

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Events impresario, restaurateur and hotelier Barton G. Weiss makes his living creating moments that are exquisitely perfect, and meticulously planned -- "a multisensory experience" is his official corporate catchphrase.

The birth of Weiss' daughter, Jadin, three years ago, however, brought a challenge he hadn't anticipated. Jadin was missing one of life's most joyous senses: the ability to hear.

"At that point you live in fear and horror," Weiss said. "You don't know where to run, you don't know what to do."

Through cochlear-implant surgery, Jadin's hearing was restored, but Weiss never forgot the difficulty of navigating through those initial moments of uncertainty. He vowed to make the journey easier for other families, a pledge that on Thursday culminated in a \$5 million gift to the University of Miami Miller School of Medicine.

ROAD MAP

The money, donated by Weiss' Kids Hear Now Foundation, will create a comprehensive resource center for families affected by child's hearing loss -- a road map, essentially, to treatment options, support groups and healthcare providers. Though based at UM, it will serve families from across the country.

"Families will no longer have to struggle alone as they decide the right course of treatment for their child," University of Miami President Donna Shalala said during a ceremony announcing the gift. Even the announcement had Weiss' elegant touch, Shalala joked.

"I love getting a gift from Barton G," she said. "He classes the place up -- we get designer water."

Two years ago, during a dinner with the UM doctor who performed his daughter's surgery, Weiss made clear his intention to help.

"What do you need?" Weiss asked back then.

In the time since, details were hammered out, leading to the new Barton G. Kids Hear Now Cochlear Implant Family Resource Center at the University of Miami Ear Institute.

The doctor who broke bread with Weiss, Thomas Balkany, on Thursday said there's roughly four million people nationally who could benefit from cochlear-implant surgery -- yet only about 100,000 have undergone the procedure in the past 20 years.

“So we're just not making it easy for people to get the help that they need,” Balkany said, though he's optimistic Weiss' gift will improve those numbers.

“Now we have the part that allows us to treat families the way they should be treated,” Balkany said.

Under the current healthcare landscape, Balkany said parents usually find out very early, through hospital screenings, that their child might be deaf. But from there the road becomes a confusing labyrinth. Parents are often referred to pediatricians who know little about how to combat hearing loss, or about the intricacies of cochlear implants -- small, complex electronic devices that can help provide a sense of sound.

While these overwhelmed families are shuttled between doctors, the window of opportunity for a cochlear implant is rapidly closing, Balkany said. The surgery is most effective before age 1, and by age 5 a child's brain can become so hard-wired into deafness that cochlear implants won't help.

Even when performed early, the surgery doesn't instantly correct hearing problems. The children involved must spend years undergoing intensive therapies that teach them how to speak, and how to listen.

SUCCESS STORY

But at the end of that arduous road, there are tremendous rewards.

Miami's Michael Lefkowitz is a former UM cochlear-implant patient who was on hand for Thursday's announcement. Now 14 years old, Michael is taking honors classes, playing sports like golf and ultimate Frisbee, and adores his iPod.

By all appearances, he is a normal teen. Michael hasn't needed specialized therapy for 10 years.

“Now it's basically just a matter of keeping on top of things, and changing batteries,” Michael said.

Weiss' 3-year-old daughter isn't quite that far along, but the toddler has gone beyond mere speaking to becoming a “chatterbox,” according to her dad. Weiss savors those hard-fought words.

“When you hear your daughter say ‘I love you,’ you just melt,” he said.