

What Happens When Your Disease Is an 'Orphan'

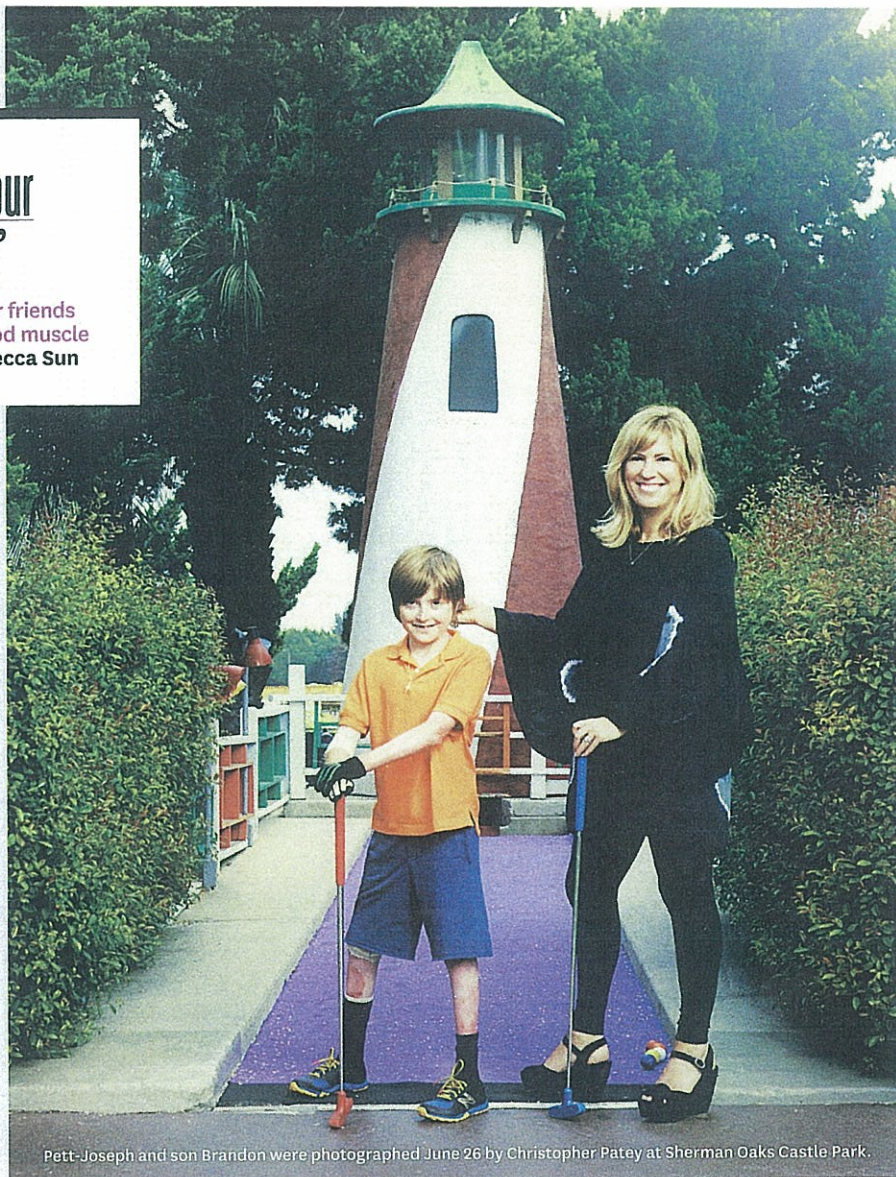
For industry leaders who've had family or friends touched by a rare illness, getting Hollywood muscle involved makes all the difference **By Rebecca Sun**

Rob Ashe's daughter was 4 days old when he first saw the word "arthrogryposis," written on her incubator in the NICU. Elliot, now 4, had been born with severe contraction in her major joints, resulting in extremely low muscle tone. Only one in 3,000 newborns has the condition. "There still isn't a ton of research," says Ashe, an Emmy-nominated editor on TBS' *Conan*. Disease expert and geneticist Judith G. Hall had one big piece of advice for Ashe: "You need to get celebrities involved."

For those touched by the 6,800-plus classified rare (or orphan) diseases, access to such powerful platforms is vital. Just ask Brillstein manager Andrea Pett-Joseph, whose son Brandon has epidermolysis bullosa (EB), which causes extreme skin fragility. She helped establish the EB Medical Research Foundation, enlisting the support of Courteney Cox, Zach Galifianakis and Nina Dobrev to raise more than \$5 million.

"The industry can be helpful in getting [rare diseases] the attention and funds they need," says UTA CEO Jeremy Zimmer, whose friend Wendy Landes died in 2013 of liposarcoma. The agency sponsors the rare-cancer support group Wendy Walk, founded by Landes' children in her honor. The group so far has raised \$2 million.

That money can go far because many rare diseases are caused by single-gene mutations that are relatively less complex to investigate, says Jill "W" Wood of her son Jonah's Sanfilippo Syndrome, a disease



Pett-Joseph and son Brandon were photographed June 26 by Christopher Patey at Sherman Oaks Castle Park.

that leads to central nervous system degeneration. "Scientists say we can have this done within five years if somebody threw \$20 million at it," she says. Wood and her husband, Jeremy Weishaar, founded the charity Jonah's Just Begun to raise money. Last year, Weishaar posted a few fundraising flyers on the set of CBS' *Elementary*, where he's a camera operator, catching the eye of series star Jonny Lee Miller. An avid runner, the actor completed his next race for JJB and since has raised \$250,000 toward a clinical trial.

Disney publicist Carrie Davis and her sister, screenwriter Hadley Davis (*Ice Princess*), are funding (with a matching gift from Disney) a study on

glioblastoma, the brain cancer that took their father's life in July. They're working with Baylor oncologist Dr. Melissa Bondy to examine evidence that Ashkenazi Jews are more likely to get the disease and to find families "who can help unravel the puzzle," says Hadley. The Jewish Glioma Project soon will publish its first paper.

But other rare diseases haven't reached that point. Ashe, the *Conan* editor, has the Rolodex but not the outlets for heeding Dr. Hall's advice. "I don't want to cash in those brownie points when there's nothing in place [for researching my daughter's disease]," he says. "But the second we find an opportunity to set up a foundation, we will."