ROCK ON
(left to right) The Band From TV on stage in L.A., August 2008; Grunberg with son Jake at the Gibson guitar "Paint For Pep" charity event for pediatric epilepsy.

LEFT: COURTESY GREG GRUNBERG; RIGHT: LISA O'CONNOR/ZUMA/CORBIS

From Hero to Advocate

Actor Greg Grunberg has become a passionate advocate for people with epilepsy, thanks to his own hero: his son Jake.

BY LINDA CHILDERS

On the hit NBC television show *Heroes*, Greg Grunberg plays telepathic detective Matt Parkman. But Grunberg's real hero is his 12-year-old son Jake, who was diagnosed with epilepsy five years ago.

"All three of my sons are heroes, but I'm continually in awe of Jake," Grunberg says. "He's a great student and athlete, and he doesn't let epilepsy slow him down or define him."

Since Jake's diagnosis, Grunberg, 42, has used his celebrity status to raise awareness of epilepsy, a neurological condition that affects over 50 million people worldwide. Epilepsy is characterized by seizures—temporary loss of consciousness or muscular control—that are precipitated by abnormal electrical overload on neurons within the brain. Approximately 45,000 children under the age of 15 develop epilepsy each year.

"The single most common cause of epilepsy in children is probably a genetic predisposition," says Donald Olson, M.D., chief of pediatric neurology at Lucile Packard Children's Hospital at Stanford in Palo Alto, CA. "Other causes include pre-existing brain injuries: for example, prior infections, head injury, or brain malformations. When otherwise normal children develop epilepsy and we don't find a cause, we call it 'idiopathic.'"

FINDING A SPECIALIST

Grunberg was starring on the television show *Alias* when he and his wife, Elizabeth, noticed that Jake was having frequent staring spells.

"Our pediatrician referred us to a neurologist who diagnosed Jake with epilepsy," Grunberg says. "No one in my family knew anything about the condition, but we were hopeful Jake could find relief from his symptoms."

Instead Grunberg and his family found that epilepsy can be hard to treat. Medications that work for one person can cause problematic side effects in another.

ACTING HEROICALLY
Grunberg with director J.J. Abrams at the "Hollywood's Helping Hands" fundraiser to benefit pediatric epilepsy; Grunberg (as Eric Weiss) and Jennifer Garner (as Sydney A. Bristow) on season 3 of *Alias*; Grunberg as Matt Parkman in a psychic trance on season 3 of *Heroes*.

"Jake has 'absence' seizures," Grunberg says, "and we learned that a medication that might work for one child might not work for him. Finding an effective course of treatment takes persistence and patience."

Grunberg and his wife met with staff at the Epilepsy Foundation (**efa.org**) and began learning all they could about their son's medical condition. Since Jake's neurologist didn't specialize in epilepsy, they found a physician with expertise in that area.

"I encourage families to consult with a specialist in epilepsy, not just a pediatric neurologist," Grunberg says. "Families need to be proactive about their child's treatment and not believe that medication side effects are just something they have to live with," Grunberg says.

Dr. Olson says parents should look for a board-certified pediatric neurologist who has extensive training diagnosing and treating children with epilepsy.

"In Northern California we are fortunate to have centers such as UCSF and ours here at Lucile Packard that can provide greater expertise and look at other treatment options—such as the ketogenic diet and epilepsy surgery—when initial treatments are not sufficient to control seizures," Dr. Olson says.

Grunberg says that Jake began having problems with his medications; sometimes they would work, then he would build up a tolerance to them and have more seizures.

"The pattern of getting initial relief with some epilepsy medications and then seeing the return of seizures is not common, but it is well recognized," Dr. Olson says. "It is frustrating for the family and the physicians."

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Dr. Olson says experts are not certain why this happens, but that our cells somehow learn to exclude foreign chemicals.

"This is probably a good thing under most circumstances, but it can be a disadvantage when a needed medication is being diverted," he says. "Some medications are known for inducing 'tolerance,' where the effect of the medication diminishes over time. The benzodiazepine class of medications, for example, is well known for this."

Jake's new doctor found a medication that worked to reduce the severity of his seizures.

"Jake is still growing and his metabolism is changing, which made finding the right medication combination challenging," Grunberg says.

"When children grow, their metabolism may speed up or slow down and medications may need to be adjusted for that reason," says Dr. Olson. "An infant's body size increases proportionately much more in a year than does the size of, say, a 10-year-old child, so dosages of medications in little kids may need to be adjusted more often to keep up with their growth."

Then, in the summer of 2008, Jake underwent brain surgery at Rush Medical Center in Chicago, IL. "He's doing really well and is no longer having seizures," Grunberg says.

TALK ABOUT IT

One of the things that helped Jake and his family was being able to connect with others who have a loved one with epilepsy. Grunberg helps to promote **epilepsyadvocate.com**, an online community of people living with epilepsy and their families. Members participate in live community events all over the country, where they speak about their experiences with epilepsy. The Web site also provides a resource where people can learn about living with epilepsy.

The **epilepsy.com** bookstore offers a number of children's books that provide children, their families, and friends with a better understanding of the condition (**epilepsy.com/info/family_kids_books**). Another good resource is the Epilepsy Foundation's magazine *Epilepsy-USA* (**efa.org**).

"There have been so many times I've wondered why this happened to Jake," Grunberg says. "It helps to learn you're not alone and there are other families out there facing the same challenges."

AP/WIDEWORLD; PHOTOFEST NYC; HEROES: COURTESY NBC UNIVERSAL

DAD'S HERO Jake Grunberg.

At the American Epilepsy Society's annual meeting in December 2007, Grunberg met Phil Gattone, 21, a college senior majoring in computer engineering. Gattone was diagnosed with epilepsy at the age of four.

"Here was this amazing young man who reminded me of Jake in many ways," Grunberg says. "He likes sports and computers and knows what it's like to grow up with epilepsy."

Grunberg asked Gattone if he could talk with Jake and share his own experiences. After one phone call, the two young men were fast friends.

"When I was young many of my classmates didn't understand what it meant to have epilepsy," Gattone says. "If Jake has a seizure at school, he knows he can talk to me about it, and that I'll understand because I've been through it."

Grunberg hopes to erase the stigma of epilepsy and help the public understand more about the condition that affects both his son and Gattone. He devotes much of his time off-camera to raising awareness of epilepsy and educating others about what it's like to have seizures.

"Most people don't know much about epilepsy, so the condition scares them," he says. "If people could talk about it and have more access to information about epilepsy, than I think the stigma would go away."

To further his efforts, Grunberg is launching **talkaboutit.org** in March 2009. The Web site will feature many of his celebrity friends talking openly about epilepsy and people they know who have the condition. Grunberg hopes the site will not only fight the stigma of epilepsy but also dispel many of the myths about it. (See "Myths About Epilepsy.")

HOPE FOR THE FUTURE

Grunberg also believes it's imperative to raise money for epilepsy research.

"There are a lot of cutting-edge research studies being conducted to help prevent or stop seizures," Grunberg says. "Doctors claim that we have never been so close to developing a cure for epilepsy."

"We can often control epilepsy with medication, or surgery, or certain diet therapies," says Dr. Olson. "Epilepsy researchers and pharmaceutical companies are always working to find better ways to provide long term control of seizures without side effects."

Improved epilepsy surgical techniques, as well as more sensitive MRI scanning, PET scanning, and magnetoencephalography, also hold promise.

Myths About Epilepsy

Myth Epilepsy patient can swallow their tongues during a seizure.
Fact It's physically impossible to swallow your tongue.

Myth You should force something into the mouth of someone having a seizure.
Fact When someone is having a seizure, gently roll them onto their side and put something soft under their head. Forcing objects into the mouth can cause a chipped tooth or broken jaw.

Myth People with epilepsy are disabled and can't work.
Fact People with this condition have the same range of abilities and intelligence as the rest of us.

Myth With today's medications, epilepsy is no longer a health concern.
Fact Epilepsy is a chronic medical problem that can be successfully treated in many cases, but treatments don't work for everyone and there is still a critical need for more research.

Myth Epilepsy is a mental illness.
Fact Epilepsy is a neurological condition. If your child has epilepsy and you would like to obtain materials to help teachers learn how to talk about epilepsy with your child's classmates, visit the Epilepsy Classroom at **epilepsyadvocate.com** under "Programs and Resources."

"There is also hope that ongoing investigational trials of direct brain stimulation in adults will prove effective and that children may benefit as well," Dr. Olson adds.

The Grunberg family regularly participates in the annual National Walk for Epilepsy. Recently, Grunberg has recruited his acting colleagues to join the Band From TV (**bandfromtv.org**). Grunberg, who plays drums, started the band after playing at the House of Blues in Chicago, IL, with other celebrities. Actors such as Teri Hatcher and James Denton from *Desperate Housewives* and Hugh Laurie from *House* come together to play music and raise money for non-profit organizations. Grunberg donates all of his proceeds from the band to The Epilepsy Foundation.

Grunberg is cautiously optimistic that a cure for epilepsy will be found in Jake's lifetime. Until then, he's content to watch his son enjoy childhood: playing baseball, swimming, biking, and doing Taekwando.

"I hope and believe that Jake won't live with epilepsy for the majority of his life," he says. "With stem cell research and the many other strides the medical community is making, the chances of finding a cure are getting better, but they still need our support."

Spoken like a true hero. NN

For more information on seizures, see RESOURCE CENTRAL on page 36.

COURTESY GREG GRUNBERG;