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Brookville, NY Family Has Quite an *Entourage*

Rich and Colleen Genatt have always known that their daughter, Allison, was a star. Even when she was diagnosed with the incurable kidney disease FSGS on Mother's Day in 2001, the Brookville, NY, family has constantly been inspired by their daughter's courage and determination.

"Allison has been through the wringer and still has a wonderful, bubbly, fun, loving personality," said Colleen. "She has given us such hope by always staying positive, no matter what challenges were put in front of her. She is truly an inspiration to us."

Allie, now 15, has received a kidney transplant, and her family works closely with the national kidney disease nonprofit, The NephCure Foundation (www.nephcure.org), to raise awareness in the fight against FSGS in hopes of finding a cure.

Recently, another member of the Genatt family was able to showcase his star power as well, as older brother Alex taped a walk-on role for the hit HBO original series *Entourage*. The episode that Alex will appear in will air July 31.

Show creator Doug Ellin personally auctioned off the walk-on role at a NephCure event, which raised over $500,000 in the fight against kidney disease. The Genatts won the auction and made a week-long family vacation to Hollywood out of it, spending two days at the studio meeting the cast and crew of the show leading up to the taping on April 21.

"Allison is an inspiration to everyone she meets," said Ellin. "Nobody, especially a child, should have to go through what she has gone through because of this kidney disease. I'm just glad that I could help her family enjoy themselves in Hollywood. The NephCure Foundation is a great resource for families dealing with the diseases FSGS and Nephrotic Syndrome."

The family met and had pictures taken with almost all of the stars of the show including Adrian Grenier, Jeremy Piven, Kevin Connolly, Kevin Dillon and Jerry Ferrara.

"This was so exciting for us," said Rich Genatt. "It was very nice to do something as a family, and watch our kids light up at this opportunity, especially since they have been through so much. It's just great to be able to take a step back and relax and take part in something that benefitted a great cause like NephCure."

FSGS FACTS

- ✓ 5,400 people are diagnosed with FSGS per year

- ✓ It is the second-leading cause of kidney failure in children
- ✓ It is five-time more prevalent among African Americans
- ✓ The FSGS disease group (defined as Minimal Change Disease, FSGS and Membranous Nephropathy, among others) accounts for approximately 12% of prevalent ESRD cases at an annual cost in the United States of more than $4 billion.
- ✓ 50% of FSGS sufferers who do not respond to treatment will reach ESRD within 5 years.

Nephrotic Syndrome and FSGS are conditions that affect the tiny filtering mechanisms in the kidney. The result is that beneficial protein is spilled from the kidney into the urine and lost. Over time this condition can result in renal failure and the need for dialysis or a kidney transplant. The cause for Nephrotic Syndrome and FSGS is not known and there is no cure.

The NephCure Foundation is the only organization solely committed to seeking a cause and cure for Nephrotic Syndrome and Focal Segmental Glomerulosclerosis (FSGS), two potentially devastating kidney diseases. NephCure has committed over $7 million in recent years towards research into these diseases.

Because of privacy laws, The NephCure Foundation has a unique challenge in finding families affected by Nephrotic Syndrome and FSGS. Therefore, in addition to fundraising for research, The Nephcure Foundation devotes much of its efforts to identifying patient families. Further information for families or potential supporters can be obtained at www.nephcure.org or by contacting Miriam Long at mlong@nephcure.org.

www.nephcure.org