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## DaVita's 2007 Kidney Idol: Jenna Smith

When you look at Jenna Smith, you see a beautiful, energetic, athletic 21-year-old who loves life and lives it to the fullest. A student at University of Iowa College of Engineering, Jenna spends her free time painting, hiking, biking, fishing, listening to old favorites including the Beatles and Van Morrison and hanging out with her friends.



However, what you may not know from looking at Jenna is that she was born with a disease called membranoproliferative glomerulonephritis type II (MPGNII) or dense deposit disease. Because the disease destroyed her kidneys at a young age, Jenna began dialysis when she was only seven years old. Since then, she has been on [peritoneal dialysis](#) (PD), [in-center hemodialysis](#), and [home hemodialysis](#) (HHD). She also had a transplant in 2000 that lasted a year and a half. These days, she is doing short daily home hemodialysis for three hours each day.

### Living with dense deposit disease

Dense deposit disease attacks the tissues of the internal kidney structures or [glomeruli](#). The immune system of a person with dense deposit disease does not work as it should, and deposits build up in the kidneys. These deposits scar the kidneys so they are unable to function properly. The cause of the disease is largely unknown, and most current treatments for it are ineffective. Dense deposit disease occurs primarily in children, and it is inflamed and activated each time a [transplant](#) is done. Research suggests that half of transplants in people with dense deposit disease fail due to recurrence of the disease.

Membranoproliferative glomerulonephritis type II (MPGNII) is diagnosed by a kidney biopsy. A doctor examines a piece of tissue from the kidneys for dense deposits. Symptoms of dense deposit disease include:

- dark colored urine
- blood in the urine
- cloudy urine
- decrease in urine volume
- swelling of the body

Studies show that 50 percent of people diagnosed with dense deposit disease will go into [kidney failure](#) within 8 to 12 years.

While it's hard for Jenna to remember back to when she was seven years old and had to begin dialysis, she does recall how badly she felt and how much she wanted something to make her feel better.

"I know I was scared and confused, but I also know I felt so bad and I was so puffy that I figured if something could be done to change that, I would feel better," she said. "Plus, my parents have always done everything they can for me so I knew I was in good hands and would be taken very good care of."

Jenna said that living with MPGNII and being on dialysis is easier now that she's older because she knows all the kinks and can make sure her treatments go smoothly. She dialyzes at her parents' house everyday whenever she has time, which is usually in the evening. She has also learned to do the entire process herself so she doesn't have to rely on anyone for help.

"I do everything myself, from setting up and inserting my own needles to hooking up and getting off," she said. "If I need help, my mom and dad are there."

Throughout everything, Jenna has made sure to keep a positive attitude and be grateful for all that she has.

"I know people complain and highlight the negatives because, quite frankly, there are a lot due to all the inconveniences," she said. "But I also know that you are the only one who creates that mentality. I figure it's better to look at the situation in a positive light so I can avoid a frustrated, stressful life."

### **Volunteering for kidney disease research**

Inspired by their daughter's positive attitude and resiliency, Jenna's parents created Kidneeds in 1997. A nonprofit corporation, Kidneeds is dedicated to funding medical research initiatives in the hopes of finding a cure for dense deposit disease. All money donated to Kidneeds is used for research.

Over the years, Jenna has raised nearly \$50,000 for Kidneeds through everything from staffing neighborhood lemonade stands to starting two businesses, Twinkardink and Jensica Jewels.

Twinkardink, which Jenna started with her mom and twin sister, Jessica, began as a greeting card business and has now expanded to sell quilts, jewelry, Kidneeds bracelets and T-shirts.

Jensica Jewels (a name created by combining the twins' names) is a glass bead jewelry line that Jenna started after she got her transplant in 2000. Jenna makes each individual glass bead using a gas torch. She and Jessica then wire the beads together with sterling silver.

In addition to raising money for Kidneeds, Jenna also volunteers for the Kidney Heartland Network where she is a patient advocate and Vice Chair of the Patient Advisory Board. As a volunteer, she attends conferences, talks with other dense deposit disease patients who need support and brainstorms ways to make patient's lives easier.

"I like talking about and discussing what I have first-hand experience in and knowing that my input is valid," Jenna said. "Also, I like knowing I am speaking on behalf of numerous kidney patients in our region and doing my best to better all of our lives."

Jenna thinks it's important to volunteer her time and energy to organizations such as Kidneeds and the Kidney Heartland Network in order to get things moving.

"It always seems to take so long for any kind of visible result to appear," she said. "The faster progress is made, the sooner I will be able to have a working kidney."

### **The Kidney Idol contest**

Jenna was nominated for DaVita's Kidney Idol contest by her mother.

"I didn't know she was going to nominate me for the DaVita Kidney Idol," Jenna said. "I heard about it at the American Association of Kidney Patients conference in St. Louis and told my mom about this 'Kidney Idol' contest. She told me she had found something like that online and had written something about me."

Jenna said she was shocked to win the contest because she didn't think she'd be chosen out of all the entries.

"I think it's pretty safe to say anyone would be blown away if they were awarded a seven-day cruise for being viewed as a role model," she said.

Since winning, Jenna has decided to take an Alaskan cruise because she's always wanted to visit Alaska. Once she sets sail, she hopes to find some hiking trails or a place to do a little fly fishing. She's also looking forward to meeting new people on the ship.

### **Dialysis doesn't stop Jenna**

Right now, Jenna's main goal is to finish college where she's majoring in environmental engineering and studio art. After graduation, she plans to attend architecture graduate school, focusing on green architecture. She also wants to continue challenging herself to try new things and experience all that life has to offer, despite her daily dialysis schedule. One thing she has been able to enjoy as a result of challenging herself is going on road trips with her friends.

"Traveling is possible," she said. "It's so easy for me now that if I plan on a weekend only days before, it happens. I have been road-tripping much more now that I know I can. When I break down those boundaries and see that I really can live with this, it gives me more peace of mind."

When she hits the road with friends, Jenna simply loads up everything she needs and takes off. She has a check list of all her supplies to make sure she doesn't forget anything, and she usually has her sister around for help if she needs it.

"I take the dialysis machine to hotels, friends' apartments, friends' houses, aunts' and uncles' houses—basically anywhere. It's even been on a cruise before," she said. "Last year, I went hiking in the Smokey Mountains. We stopped at a friend's house before where I dialyzed. Then, after the hiking trek, we stayed in a hotel for the night, and I dialyzed there."

This past summer, Jenna volunteered for a week in South Dakota with her church where the group did construction work to repair buildings on an Indian reservation. She also hiked the Appalachian Trail, worked and took an engineering class. Determined not to let dialysis get her down, Jenna said the only thing that makes her life different from other young women her age is that she is always busy running around to get things done.

"With three hours of my day devoted to doing dialysis, I am always cramming a lot in," she said.

When asked if she had any advice for other dialysis patients on how to remain positive and enjoy life, Jenna said she thinks each person has to find what works for them.

"Everyone goes about reaching that feeling of self confidence and having a positive outlook on life differently," she said. "The way I am able to have that fulfillment requires a lot from me. I know I need to be involved in activities outside of school and dialysis. My interests change all the time, but right now I am involved in the American Society of Civil Engineers and Ultimate Frisbee. When I'm around friends, I am having a good time and enjoying life. When I am enjoying life, I feel upbeat and positive."

### **To learn more about Jenna's activities**

If you would like to find out more about Kidneeds or make a donation, you can visit the [Kidneeds website](#). If you would like to make a purchase from Jensica Jewels or Twinkardink, email Jenna at [jennalhsmith@gmail.com](mailto:jennalhsmith@gmail.com).

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