



## Just Like Any Kid...Who Knows a Lot about PD!

Like most 11-year old New Yorkers, Nicole is a busy sixth grader—she has homework, school projects, and household chores. She likes to spend time with her family and play with her puppy, Daisy. But in addition to her usual activities, PD treatments and a quest for kidney disease knowledge also play a large part in Nicole's day-to-day life.

At the age of 9, after a 2-month hospital stay, Nicole was diagnosed with kidney failure due to a very rare disease called Wegener's Granulomatosis. Her doctors made the decision to start her on PD, and she began hemodialysis for two and a half months while waiting for her catheter to heal. "I didn't really know what was going on," Nicole recalls. "I was kind of out of it. Usually things like this happen to other people. When it happens to you, you think, 'Why me?'"

### ***On a Learning Quest***

Nicole's solution was to begin researching her diagnosis and PD. "I thought I should know what Wegener's was," she explains. "I wanted to find out more about it." So Nicole went to her dialysis center and wrote down some of the website addresses they gave her. She also took informational handouts from the center logbook.

Looking for information took time, but Nicole made sure to fit it into her busy schedule. "I would look for information on weekends, when I didn't have home-



work, after dinner, or after I did my homework," she says.

Nicole won't go so far as to call herself an expert, but does feel she knows a good amount. "If you know more about PD, you can tell your family and friends about it...then they won't ask you any more questions!" she declares. "Also, if you have information, then when doctors talk you can actually understand them."

Helping her teachers, school nurse, and classmates gain an understanding of PD was the next step in Nicole's quest—in a science fair project. "The title of my project was 'Kidneys and Dialysis,'" she explains. "I got my information from the computer and from other places. Merrienne (my Home Patient Service Representative) from Baxter, gave me materials to help build my exhibit, and my social worker Julie gave me websites to go to."

Nicole also drew a picture for a 'Kidney Calendar' contest, winning a trip for her family to Washington, D.C. "I'm happy to tell people about kidney disease and PD," she says. Her picture is included in the American Kidney Fund 2003 calendar.

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## **Looking Forward to the Future**

Nicole's mother, Sherri, says Nicole was lucky to make it out of that 2-month hospital stay. "Nicole has an idea of how lucky she is and doesn't feel sorry for herself," she says. "I don't know how she does it, but she's got a good attitude. She's handled it better than most of the adults in her life."

If Nicole's good health continues, she hopes to get a kidney transplant from her mother in 2003. What else does the future hold for Nicole? "I want to go to college," she explains. "Then I'm going to go for extra school so that I can become a teacher." Nicole has already taught us that learning all you can about PD can help you live a good life with kidney disease.

## **It's Your Turn...**

*Looking for information about PD can seem like a difficult task. Luckily, there are a wealth of resources available!*

*Start by talking to your healthcare team—write down your questions, ask them, and take notes. Internet resources like [www.kidneydirections.com](http://www.kidneydirections.com), [www.aakp.org](http://www.aakp.org), and [www.kidneyschool.org](http://www.kidneyschool.org), can help answer some of your questions, too.*

*Also, check for information at your local library and with national organizations such as the American Association of Kidney Patients (AAKP) and the National Kidney Foundation (NKF).*

*You can use the information you find to discuss your concerns or questions with your doctor, or other members of your healthcare team.*

## **Becoming an Expert Patient**

Having a wealth of information about kidney disease and PD is crucial to having a full and active life. Your healthcare team will give you many resources, but you are the one who lives with PD day-to-day. Becoming your own PD expert is something you can do for yourself!

Research suggests that having information and taking an active role in your care can help you maintain a good quality of life, and even live longer. By choosing PD, you've already demonstrated your desire to be in control of your treatment—and that's a big part of managing your disease.

So how else can you become an expert patient? You can:

-  Write down questions you have as soon as you think of them
-  Search for answers to your questions (see *It's Your Turn...* above)
-  Talk to other patients about their experiences, either in person or on an on-line support group

Learning as much as you can about kidney disease and PD may seem like another job, but the payoff is great—knowing more can help you make educated decisions, stay positive, and live better and longer.

**Baxter**

[www.kidneydirections.com](http://www.kidneydirections.com)