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## Day-by-Day: Averie's Story

*By Rebecca Rengo MA, MSW, LCSW, ACSW*

In the middle of a busy classroom she sits alone. Kids are talking, laughing, and sharing food and notes. It's a party in kindergarten, then 6th grade, and now, high school. She remains silent. No one seems to notice or care, and she likes it that way.

### Neurofibromatosis

Averie has Neurofibromatosis (NF) Type I. Although this condition is characterized by changes in skin coloring and the growth of tumors along nerves in the skin, brain and other body parts, Averie looks normal. NF occurs in one of every 4,000 births, affecting an estimated 100,000 people in the United States. Between 30 and 50 percent of new cases arise spontaneously through mutation (change) in an individual's genes; many inherit the disorder as Averie did from her father. If either parent has NF1, each child has a 50 percent chance of having the disease. Genetic counseling is recommended for anyone with a family history as the mutant gene can be passed on to future generations. Because of this condition, Averie feels different— like the ugly duckling trying to hide in a room full of people.

### The First Signs

When she was two months old, Averie started having spots appear on her skin. Called café-au-lait spots, these are flat patches on the skin that are darker than the surrounding area. Her mother and family doctor noticed them, but didn't think they were significant. Many healthy people have one or two café-au-lait spots. Doctors familiar with NF 1 look for six or more café-au-lait spots on the skin that are larger than five millimeters (mm) across in children, or 15 mm across in adolescents/ adults. In most people with NF 1, these spots may be the only symptom. Some of the other signs or symptoms may include:

- Blindness
- Convulsions
- Freckling under the arms or in the groin area
- Large, soft tumors (plexiform neurofibroma)
- Small, rubbery tumors of the skin (nodular neurofibroma)
- Pain from affected peripheral nerves
- Colored, raised spots called Lisch nodules on the colored part (iris) of the eye
- Mild cognitive impairment

Children with NF 1 often have learning disorders. Diagnosis is usually based on the unique symptoms and signs of NF 1.

### NF's Impact on Daily Life

At six, Averie fell off her bike and broke her arm. Her doctor did a work-up and referred her to a specialist. She had a tumor on the nerve of the bone in her arm. That's when her parents learned she had NF Type 1, also known as von Recklinghausen disease. Doctors told Averie she couldn't play sports and had to be very careful because she could easily break her arm again. She has worn a sling ever since.

Instead of childhood memories of sleepovers and sports, she remembers watching other girls giggle and play softball. Now 16, she overhears classmates at school discussing boys and getting their drivers' license. Meanwhile, Averie immerses herself in complementary and alternative (CAM) techniques for pain management. Aromatherapy, biofeedback, acupuncture... the list goes on and on. Her mother devotes her life to helping Averie manage her pain; she has taken training in Reiko, Emotional Freedom Technique and Cranio-Sacral therapies as most CAM techniques aren't covered under insurance. They all help. Using CAM as an adjunct to her pain medications keeps the pain at a "7 or 8;" she can function.

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