

Caroline West

Name: Caroline West

Age: 18

Hometown: Tampa, FL

Hospital: St. Joseph's Children's Hospital



She loves music, enjoys school and has even been to prom, but Caroline is definitely not a typical teenager. That's because a rare genetic condition has left her with severe physical and mental disabilities that require constant supervision and more than a dozen medical professionals directly involved in helping her manage the disease.

Caroline was born five weeks early, then suffered a seizure and stopped breathing in the first 12 hours of her life. The doctors did not diagnose her for several years because she has an extremely rare neurological disorder, Alternating Hemiplegia of Childhood (AHC), which is only diagnosed in 800 people worldwide. Prior to her diagnosis, Caroline was tested and evaluated extensively at Johns Hopkins, Columbia Presbyterian and Boston Children's Hospitals.

Besides AHC, Caroline also has cerebral palsy and a seizure disorder. As a result, she cannot walk, has speech and motor delay, and is developmentally delayed. She attends school part-time in a specialized classroom and receives speech, physical, and occupational therapy weekly. She has a GI tube for nutrition, has had her spine fused and has extensive specialized equipment at home to meet her daily living needs.

Caroline's medical home is the Chronic-Complex Clinic at St. Joseph's Children's Hospital. The clinic coordinates Caroline's health care needs, which include daily nursing care, physical, speech and occupational therapy, medical supplies, durable medical equipment, medical care and communication between all of her specialists.

See Caroline's story and learn more about the clinic at <https://www.youtube.com/watch?v=nsVxL115jTk>.