

Rachel Cowan Karch – August 4, 1986 – May 21, 2023



Rachel Cowan Karch died May 21, 2023 in Madison, following a brief serious illness. Born August 4, 1986, to Anne and Paul Karch in San Diego, California, Rachel had Duplication 15q (Dup15q) syndrome, a rare and disabling condition caused by extra copies of part of chromosome 15. As a result of Dup15q, Rachel had severe cognitive impairment, epilepsy, low muscle tone, and autism, and processed the world around her as a typical one-year-old child would. Later in life Rachel experienced difficulty swallowing, aspirating food and liquids, and low muscle tone, resulting in periodic and increasingly severe lung infections over the past 6 years. During hospitalization for the last lung infection, her weakened breathing muscles could no longer keep her alive. Dup15q made life for Rachel quite challenging and frightening as she

moved through a world she did not understand. In spite of this, she was able to persevere and be an important member of her family, her job site, her neighborhood, and her church.

Rachel and her family moved to Appleton, Wisconsin, when she was eight in a successful search for schools able to include her more fully in classrooms and school life. She attended Janet Berry Elementary School, Madison Middle School, and East High School, and spent many weekends at Easter Seals Respite Camp in the Wisconsin Dells. She swam regularly at the Appleton Y, attended church at First Congregational United Church of Christ, visited the Appleton Public Library, and went for frequent walks around town and at High Cliff State Park. She attended her siblings' soccer games and cross country meets, but usually paid little attention to the athletic competition and spent her time walking around at or near the events. Rachel was always in motion, and her favorite activities included hiking and walking, jumping on the trampoline, pushing shopping carts around the grocery store (and sometimes down the street), and singing her favorite songs while doing all of the above. Rachel's memory and love for her favorite songs often amazed people meeting her for the first time, as she chimed in on favorite words and punctuations in the chorus, including her own inventions or additions.

Shortly after Rachel finished high school when she was 21 her family moved to Madison, where she began both a community-based job at the Wisconsin DNR and life in her own house at Arboretum Cohousing. Rachel received 24-hour care from personal caregivers, most of whom were UW undergraduates in nursing, Rehab Psychology, pre-medical, or social work. These young women worked creatively and devotedly to provide Rachel with a healthy and stimulating life. She attended Sunday Worship most weeks at First Congregational United Church of Christ where the congregation welcomed her with love and accepted with grace her occasional disruptions. On weekends she enjoyed going to the Saturday Farmers Market to walk with the crowds and eat pastries, swimming at the West Side Y, and taking walks at Dane County Dog Parks. Outside of Madison she frequently went to Devil's Lake to hike and swim, and visit with her Baraboo grandparents who were always sure to supply her with bottomless popcorn. Rachel and her dad often rode a recumbent side-by-side tandem bicycle in the

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summer, including around Lake Wingra and along the shores of Lakes Monona and Mendota, and in the Vilas neighborhood 4<sup>th</sup> of July parade.

It took a large village to provide a life for Rachel. Rachel's family would like to thank all of the people, places and organizations that helped Rachel live a life full of love, friendship, and meaningful activity: first and foremost, her sister Lydia and brother Chas, sister-in-law Sally, and her nieces Willa and Lena. Others important to Rachel's life are those listed above and her San Diego doctors and special education early intervention teachers and therapists; Pacific Beach Presbyterian Church members, Sunday school teachers and pastors; San Diego Parks and Recreation; Canine Companions for Independence; Appleton Parks and Pool; LOV Inc.; her grandparents, aunts, uncles and cousins; many loving and energetic personal caregivers in San Diego, Appleton, and Madison; UW Health primary care, neurology and gastroenterology doctors, nurses, nurse practitioners, therapists and hospital staff; her Wellness Inclusion Nursing (WIN) nurse; classroom, physical education and special education teachers; teacher's aides; occupational, speech and physical therapists; school principals; neighbors and friends.

Rachel was loved fiercely by her family who survive her: her parents, sister Lydia (Chicago), brother Chas & sister-in-law Sally and nieces Willa and Lena (Madison), uncles, aunts and cousins, and at least 70 caregivers now scattered across the country. Rachel attracted love and brought joy with her perseverance, intensity, and enthusiasm in the face of daunting life challenges.

A service to celebrate Rachel's life will take place at 3:00 PM on Sunday, June 25, 2023, at First Congregational United Church of Christ, 1609 University Avenue, Madison.

We invite you to help us make Rachel's legacy be progress in the search to alleviate the symptoms of duplication 15q syndrome. If you would like to make a donation in Rachel's memory, please visit [www.dup15q.org/rachel](http://www.dup15q.org/rachel) or send a check to:

Dup15q Alliance, 250 N. Trade Street, Suite 205, PMB 155, Matthews, NC 28105.