

## Advocacy Continues

It's been nearly 10 years since Peter Dankelson attended Speak Now for Kids Family Advocacy Day representing Children's Hospital of Michigan in Detroit, Mich. At the time, Peter was 8 and had been diagnosed with Goldenhar Spectrum, a disorder that causes abnormal development of the head and face. Born at 30 weeks gestation, Peter did not have a left ear or ear canal, and had an underdeveloped lower jaw and a cleft palate. Furthermore, he had a single pelvic kidney among several other serious health conditions. Despite his health challenges, Peter displayed an amazing sense of humor and often made his prosthetic ear a prop in pranks aimed at his classmates and even his doctors.

Peter and his family were advocates with the [Children's Craniofacial Association](#) (CCA) years before attending Family Advocacy Day. The family's first event was hosting a neighborhood golf outing to raise awareness for Goldenhar Syndrome, and in 2010 Peter's mother, Dede, joined the CCA Board of Directors. In addition, she has served as a parent advocate on the Family-Centered Care Advisory Council at Children's Hospital of Michigan and the Advisory Council for Children's Special Healthcare Services (Michigan's CHIP Program). Dede's gift for activism seems to be a family trait, with Peter sharing an affinity for advocacy work.

"I think that the [2008 Family Advocacy Day](#) was the first time Peter talked publicly about his condition. He was 8 years old the year we participated, and his willingness to share his story is what prompted me to include him in my own advocacy activities," recalls Dede. "Now at 17, he has matured from helping me with presentations to completely giving them on his own. One of his strongest messages is to embrace what makes you different."

In recent years, Peter and his family have become involved in the #ChooseKindness antibullying campaign inspired by the R.J. Palacio book, *Wonder*, about a boy with craniofacial abnormalities who enters a mainstream school for the first time at age 10 where he and his peers assimilate to one another.

"I read the book just after it was published in February, 2012. It is beautifully written and was a story our family deeply connected with," said Dede. "There were so many striking similarities between the fictional family and our own. I felt as if the author had a camera in our house."

"I saw an opportunity for this book to help CCA approach schools and educate kids about craniofacial differences. I reached out to the author and also asked everyone on the CCA board and staff to read the book," explained Dede. "We had no idea at the time how popular the story would become or how its message to "choose kind" would go viral on social media. I honestly can't thank R.J. Palacio enough for writing this book and for allowing both CCA and our own family to share it with the world."

In 2012, Random House recognized that teachers were sharing curriculum plans on Twitter using #WONDERSchools and organized a week-long "Blog Tour" where teachers could sign up for a day to share a post about using *Wonder* in their class. As part of the tour, Dede contributed a post about Peter,

[Every Kid Needs a Hero](#). In the post she compares the protagonist, Auggie, to Peter. The reaction to the blog post led CCA to develop [educational materials](#) for teachers in support of the book.

In 2013, the Santa Monica Public Library chose *Wonder* for their One Book, One Community reading program. The library hosted a [staged reading of scenes](#) from the book and Peter was selected to read the part of Auggie.

“The entire experience was amazing,” recounts Dede. “Seeing Peter receive a standing ovation for his performance brought tears of pride and joy. It was a defining moment, validating that he had much more to offer.”

During that trip to California, Peter and Dede were invited to speak at an elementary school with students who just read *Wonder*. After returning home to Michigan, other teachers asked the pair to address their students about the book and the family’s experience with Peter’s condition. By Dede’s count, Peter has shared his story with an estimated 20,000 students and is on track to connect with an additional 10,000 more during the current school year.

When it came time to film the movie version of *Wonder*, Peter was invited to be on set during filming and attend the movie premiere in Los Angeles. Seeing the book become adapted for screen was not just a dream come true for Dede, Peter and others in the craniofacial community, the creative team behind the film was also deeply passionate about the project. The director and the actors worked closely with families like the Dankelsons to ensure an authentic portrayal of the challenges and perseverance experienced by these families, making it a labor of love for all involved.

Peter’s work in raising awareness for craniofacial conditions has garnered him personal recognition. In 2016, Global Genes, a global non-profit advocacy organization for individuals and families fighting rare and genetic diseases, recognized Peter for his advocacy and honored him as their [Champion of Hope for Teen Advocacy](#). Peter was also named a [Rare Storyteller](#) for Harmony 4 Hope, an organization that uses music to raise awareness of rare diseases.

While Peter remains undecided on what type of college he will attend, he does want to study communications, combining his talent for public speaking with his developing skill as a guitarist — a recently discovered passion. Dede is extremely proud of Peter though she especially enjoys Peter’s ability to connect with his audience and peers, making his story accessible to them.

“My favorite thing is when students ask Peter to take a selfie with them. To go from worrying about your child being bullied in school to watching kids ask to have their picture taken with him always puts a smile in my heart,” reflects Dede. “Peter is changing our world one student at a time, and it’s the most beautiful thing I’ve ever watched.”