



Gaige



Rachel



David

■ “Just like a family”: One-stop clinic for patients with 22Q differences

Since 2013, the [Children's Mercy Super Q Express Clinic](#) — held at both [Children's Mercy Hospital Kansas](#) and the [Adele Hall Campus](#) — has helped patients with 22q11.2 deletion syndrome and 22q11.2 duplication. The multidisciplinary clinic coordinates care for patients and families affected by these complex and unpredictable genetic conditions. Instead of going to multiple appointments per month, patients see all their subspecialists in one day.

“We are really the premier site for 22Q patients in the Midwest, serving five states (Missouri, Kansas, Nebraska, Arkansas and Oklahoma) and are generally getting one to two new referrals a month,” [22Q Clinic founder Max Feldt, DO, Endocrinology](#), said. “We’ve been very fortunate to build the necessary resources and team members.”

Gaige, now a teenager, was diagnosed with 22Q11.2 deletion as a newborn at Children's Mercy. “With the clinic, they all get together, talk about him as a whole person and are able to coordinate his care,” said Heather, Gaige’s mom. “We appreciate the way Gaige is treated: as an individual. It’s an amazing group, and Gaige really enjoys seeing the doctors.”

As an infant, **Rachel** was diagnosed through Children's Mercy genetic testing and has traveled with her family from Wichita to attend the 22Q Clinic since it opened. “It has been incredible what the 22Q Clinic has done for our daughter’s care,” said Rachel’s mom, Katie. “We’re grateful for the staff and the support network and would encourage anybody who has a child with 22Q to get plugged into this clinic. It’s a different level of care. Honestly, it’s just like a family.”

David is one of the clinic’s many patients who make the trip up from Arkansas. “With multiple body systems affected, I believed we needed an interdisciplinary clinic where doctors can talk to each other,” said David’s dad, Ningning. “Children's Mercy has a clinic that coordinates everything. Without those doctors, we wouldn’t have guidance to move forward. The growth of the clinic will be very helpful for kids and allow doctors to provide a more holistic picture of the patient’s condition.”

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