"Today, our five-year-old runs after daddy, asks tons of questions, teases his sisters, and talks about going to school in the future."

December 2023

Dear Friend,

After the loss of their first two children, Miranda and Jeremy, to spinal muscular atrophy (SMA), the Sensenig family **never lost hope that one day a treatment may become available.** When their son Kirklyn was born in 2018, he was quickly diagnosed with SMA by the Clinic for Special Children's laboratory team. His birth came 15 years after his siblings had passed from SMA and the family knew that his journey would be very different.

Shortly before Kirklyn was born, a new SMA gene therapy entered the clinical trial stage. Given the Clinic's long history of caring for patients with SMA, our practice was set up as a clinical trial site for the new gene therapy.

At just one week old, Kirklyn was dosed with SMA gene therapy at Penn



One-year-old Kirklyn at the Clinic in 2019

Medicine Lancaster General Hospital with his family and Clinic physicians
and researchers at his side. He was able to get this groundbreaking
treatment quickly thanks to the Clinic's rapid and low-cost genetic testing and the Clinic's
involvement in the clinical trial study. The Sensenig family's story demonstrates how the
Clinic has remained on the cutting edge of genomic research and continues to identify and
develop innovative therapies for children who need it most.

If you would see Kirklyn today, you would never guess the journey that he has been on. The fact that he is walking, talking, and enjoying life as an active five-year-old feels like nothing short of a miracle, made possible by the creative and persistent work of our dedicated staff.

We are grateful for your interest in the Clinic for Special Children! Donations, fundraisers, auctions, and grants provide over 60% of the Clinic's annual budget and **no family is turned away based on their ability to pay.** Your support means everything to nearly 1,500 active patients who rely on the Clinic's care and many more who receive testing through the Clinic's on-site laboratory.

Will you consider a gift to the Clinic's 2023 year-end appeal so children, like Kirklyn, with SMA and other genetic diseases can receive high-quality and accessible care?

Thank you for your consideration and your support.

Sincerely,

**Herman Bontrager** Chair, Board of Directors

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