

"The purpose of this study is to document the clinical course and outcomes of children with the genetic condition MPS IIIC also known as Sanfilippo syndrome type C. This data will act as the control arm in an interventional trial. The information gained from this study will also help create benchmarks to measure the effectiveness of future treatments for this disease and provide us with valuable insight into the course of the disease." -- Phoenix Nest Inc.

- If your child is/was diagnosed with MPS IIIC and you live in the United States or Canada, please consider participating in this vitally important study.
- Participation takes very little effort on your end, with maximal reward for generations.
- To learn more about the study and how you can help, please contact Dr. Souad Messahel at Souad.Messahel@utsouthwestern.edu.



"When my son Solomon was diagnosed with MPS IIIC last year, I was devastated. I felt helpless and hopeless. My doctors told me that there was no treatment yet available. I later learned that a treatment in the form of gene therapy was being developed and could reach my son in his lifetime. I'm thrilled to be participating in this retrospective study with UTSW. UTSW is now analyzing and charting Solo's medical records and school reports. I no longer feel helpless, and I am full of hope for the future." -- Cybill Aros-Pearson

Note: If you are part of the AllStripes Sanfilippo research program, you can download all your records in one step to share with UTSW. AllStripes is an independent, rare disease research platform that makes it easy for you to participate in multiple studies without leaving home.