

Dear Councilman Roberto,

My name is Sarah Napier, and I am a Knoxville resident and Community Programs Manager at Project Alive, a national nonprofit advocating for families impacted by Hunter syndrome (MPS 2). Hunter syndrome is a progressive and life-limiting genetic disorder caused by the absence of a critical enzyme. This leads to the buildup of toxic substances in the body, resulting in severe physical and neurological decline. Children with the severe form of Hunter syndrome often do not live beyond their teenage years. There is currently no cure. Families face significant hardships, from managing complex care plans and traveling long distances for treatment to experiencing profound emotional and financial strain. Despite all of this, we remain hopeful—because we know that awareness, early diagnosis, and support make a difference.

I'm writing today to respectfully ask for your support in officially proclaiming the 3rd week of October as Hunter Syndrome Awareness Week in Knoxville. I have attached a draft resolution for your consideration and signature. Designating this week for awareness would mean so much to our local families and would help shine a light on the importance of early detection, including the urgent need to add Hunter syndrome to Tennessee's newborn screening panel. Early diagnosis can change the trajectory of a child's life by giving them timely access to therapies, support services, and clinical trials.

Thank you for your time, your leadership, and for considering this opportunity to support the rare disease community here in Knoxville. I would be honored to speak with you further about this initiative and share more about the incredible children and families who inspire our work.

Warm regards,
Sarah Napier