

# Resolution to Share

## Hunter Syndrome Awareness Week Third Week of October

### RESOLUTION

#### Expressing support for the designation of the third week of October as National Hunter Syndrome Awareness Week.

**Whereas** Hunter syndrome, also known as Mucopolysaccharidosis Type II (MPS II), is a rare genetic disorder affecting approximately 1 in 100,000 to 170,000 live male births worldwide;

**Whereas** Hunter syndrome is caused by a deficiency of the enzyme iduronate-2-sulfatase (I2S), resulting in the harmful accumulation of complex sugars in the body's cells and leading to progressive damage to organs and systems, including the brain;

**Whereas** symptoms often appear in early childhood and may include developmental delays, physical impairments, and a significantly shortened lifespan;

**Whereas** early diagnosis and intervention are critical to improving quality of life and outcomes for individuals affected by Hunter syndrome;

**Whereas** increased public and medical awareness can lead to earlier diagnoses, better treatment options, and expanded research efforts toward potential therapies and a cure;

**Whereas** families affected by Hunter syndrome face extraordinary emotional, financial, and medical challenges, and deserve greater support, understanding, and advocacy;

**Whereas** recognizing the third week of October as National Hunter Syndrome Awareness Week will help honor the strength and resilience of individuals and families living with the disease, promote public education, and advance critical research efforts;

#### Now, therefore, be it resolved,

1. **Supports** the designation of the third week of October as *National Hunter Syndrome Awareness Week*;
2. **Encourages** federal agencies, research institutions, and advocacy organizations to expand efforts in education, research, and the development of treatments for Hunter syndrome;
3. **Urges** continued congressional support for funding rare disease research and initiatives that directly benefit individuals and families in the Hunter syndrome community; and
4. **Calls upon** the people of the United States to observe the week with appropriate awareness campaigns, advocacy efforts, and educational activities.

**[End of Resolution]**

## Sample Letter from Parent/Caregiver

Dear Supervisor Rowe,

I hope this message finds you well. I'm writing to respectfully request your support in formally recognizing the third week of October as Hunter Syndrome Awareness Week through a local resolution.

Hunter syndrome (Mucopolysaccharidosis Type II or MPS II) is a rare and life-limiting genetic disorder that affects approximately 1 in 100,000 to 170,000 live male births. Families like mine, who live with the reality of this diagnosis every day, are fighting not only for our children's lives, but for increased awareness, earlier diagnoses, and access to research and treatment options.

Attached, you'll find a proposed resolution that outlines the importance of this designation. By formally recognizing Hunter Syndrome Awareness Week, your office would help shine a light on the critical needs of this often-overlooked community, while honoring the strength and resilience of those affected. We would be honored to work with your team on this effort and would love the opportunity to discuss this further if you're open to it.

Thank you so much for your consideration and continued service.

Pictured below: My son Charlie, a 6 year old with Hunter syndrome living in Crestline.

Sample Letter from Friend/Community Member

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

## Adult Friendly Speech (if attending proclamation meeting)

Good morning,

Thank you for giving us the opportunity to speak today – and more importantly, thank you for officially recognizing the third week of October as Hunter Syndrome Awareness Week here in our community. This resolution may seem like a small step, but to the families affected by Hunter Syndrome, it means the world. Your support shines a light on a rare and often overlooked condition – one that profoundly impacts the lives of children and families across the country.

What is Hunter Syndrome?

Hunter Syndrome, or MPS II, is a rare and progressive genetic disorder that primarily affects young boys. Caused by a missing or malfunctioning enzyme, it leads to the buildup of harmful substances in the body. This buildup causes damage to organs, bones, and the brain, often resulting in a shortened life expectancy and a steady decline in health and abilities. There is no cure – but there is hope, and that hope begins with awareness.

Why This Week Matters – Even to Those Not Directly Affected:

By recognizing this awareness week, you're helping families who are too often forced to walk this journey alone. You're helping ensure earlier diagnosis, better access to care, and greater attention to the urgent need for treatments and research. And you're also sending a powerful message: that rare diseases deserve visibility, compassion, and action. Though this resolution is local, it serves as a foundation for something greater – a step toward broader recognition at the state level, where awareness and advocacy can reach even more families and decision-makers.

Closing:

Thank you again for standing with the rare disease community – for listening, for acknowledging, and for acting. This resolution may mark a single week in October, but its impact lasts far longer. Let this be the beginning of continued momentum – toward understanding, equity in healthcare, and ultimately, a future where no child's condition is too rare to matter.

Thank you.

Youth Friendly Speech (if attending proclamation meeting)

Good morning,

Thank you for giving me the opportunity to speak today but more importantly, thank you for recognizing the third week of October as Hunter Syndrome Awareness Week here in Worcester. This resolution may seem like a small step, but to the families affected by Hunter Syndrome, it means the world. The support of the community is really important to me and my family.

My brothers, Zion and Ezra, have Hunter syndrome and even though they are super brave, their bodies have to work extra hard everyday. It is hard seeing them go through painful infusions, and even more frustrating when they get upset because they cannot express themselves. It reminds me of how much they are dealing with everyday and it is challenging to see them go through that. But the extra support from the community gives me the strength to keep fighting for them. Hunter syndrome changes the dynamics of our family. It has changed my perspective, helped me become more understanding, and inclusive. It is something I wish more people understood.

This week matters to me because it gives us a chance to share Zion and Ezra's journey with Hunter syndrome, the hardships they face, and resilience they show. My hope is that through recognizing Hunter Syndrome Awareness Week here in Worcester we will spread awareness and inspire other communities to do the same.

Thank you again for choosing to support families like mine and I am extremely grateful for your recognition of this important week. It might seem small, but it means the world to us.