Celebrating Progress and Demanding More: the National MPS Society Celebrates Newborn Screening Month

National MPS Society celebrates NC's milestone in newborn screening for MPS II and calls for nationwide access to early diagnosis and care.

DURHAM, NC, UNITED STATES, September 10, 2025 /EINPresswire.com/ -- September is National Newborn Screening Awareness Month—a time to honor the life-saving power of early diagnosis and to advocate for expanded screening for rare diseases. This year, the National MPS Society celebrates a milestone: as of August 30, 2025, North Carolina began screening all newborns for Mucopolysaccharidosis II (MPS II, or Hunter syndrome).

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>
> *Terri Klein*

This achievement places North Carolina among more than a dozen states advancing newborn screening for MPS. For many children with MPS or mucolipidosis (ML), symptoms are invisible at birth. Without screening, diagnosis often comes too late. Early detection allows treatment to begin sooner, improving health, extending life, and offering brighter futures.

"The launch of newborn screening for MPS II in North Carolina is a significant achievement for our state Newborn Screening Program and for the babies and families we serve," said Dr. Scott Shone, Director of the State Laboratory of Public Health at NCDHHS.

The advancement follows years of advocacy and a pilot study that proved the feasibility of screening for MPS II. Families like the Selsers experienced its impact firsthand.

"Our son Benjamin was diagnosed with Hunter Syndrome at only seven weeks old," said Megan and Edward Selser. "His diagnosis was caught through a pilot study that was being conducted in the state of North Carolina. Since then, all newborns in the state will now be screened for our son's condition."

"Screening for this condition at birth improves not only the quality of life for children, but for

their families as well," they continued. "While we will always grieve the seven week period of 'ignorant bliss' that we had with our son, we are forever grateful for early detection and early treatment. Knowing this information early has connected us to all of the people we never knew we would need to navigate this journey."

Benjamin, like many children with MPS or ML, had no visible symptoms at birth.

Stories like Benjamin's show why the Society works with policymakers, researchers, and industry to advance newborn screening. Without it, families endure a "diagnostic odyssey"—months or years of uncertainty and lost time. For diseases as aggressive as MPS and ML, every lost day matters.

Yet many states still do not screen for MPS disorders, leaving families unprotected in a system that varies by geography. The Society continues to push for all MPS disorders to be added to the federal Recommended Uniform Screening Panel (RUSP) and for equal access to care.

The Society has already spearheaded the successful nominations of MPS I and MPS II to the RUSP—landmark achievements that created a pathway for state adoption. But progress is now complicated by national setbacks. In April, the federal Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)—which evaluated RUSP nominations—was dissolved.

"The addition of MPS I and MPS II to the federal RUSP demonstrates what is possible when science, advocacy, and policy converge for the benefit of children," said Terri Klein, President and CEO of the National MPS Society. "But these victories mean little without timely and consistent implementation at the state level. Every day of delay in newborn screening is a day that families risk losing precious opportunities for intervention. We must ensure that the promise of screening becomes a reality for every newborn, in every state, without exception."

Families also face delays in accessing therapies. Promising treatments like UX111 for Sanfilippo Syndrome and RGX-121 for Hunter Syndrome remain stalled at the FDA.

"Our community has fought too hard to see progress delayed by systemic barriers," said Klein. "Children with MPS and ML deserve timely access to treatments as they become available. It is deeply concerning to see trends that slow or block these pathways to care, when we know early intervention can mean everything."

To confront these challenges, the Society is redoubling advocacy efforts, including in-person visits to Capitol Hill this October.

“Our commitment is unwavering,” said Sharon King, COO at the National MPS Society, and a rare disease advocate of nearly twenty years. “We will continue advocating for clarity, stronger systems, and a future where every newborn with MPS or ML is identified early and has access to the treatments and support they need.”

North Carolina’s milestone proves advocacy works. Every newborn screened for MPS or ML gains more time, earlier access to resources, and renewed hope.
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