

PicnicHealth and Wylder Nation Foundation Announce ASMD Accelerate to Contribute to Acid Sphingomyelinase Deficiency Research

A Real-World, ASMD Dataset Will Be Developed and Used to Advance Research in Acid Sphingomyelinase Deficiency (ASMD)

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SAN FRANCISCO & SCOTTSDALE, Ariz.--(BUSINESS WIRE)--PicnicHealth, the venture-backed startup giving patients unprecedented access to their medical records and the ability to contribute to scientific research, and Wylder Nation Foundation, an organization committed to advancing research for Acid Sphingomyelinase Deficiency (ASMD), are announcing a partnership to generate a real-world ASMD dataset to contribute to medical research.

“This partnership with PicnicHealth will not only help families overcome this barrier but will also lay the groundwork for real-world evidence-based data to help us better understand the true burden of this complex disease, and ultimately help accelerate future treatment options.”

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Together, PicnicHealth and Wylder Nation Foundation are forming “ASMD Accelerate,” to understand patient journeys documented in medical record data and translate them into an actionable, de-identified dataset to advance ASMD research. ASMD Accelerate is initially focused on chronic neurovisceral forms of ASMD, commonly referred to as Niemann-Pick Disease Type A (NPA) and Type A/B (NPA/B).

ASMD Accelerate centralizes medical records for those living with ASMD or those who have passed away from ASMD. Data from these records will be de-identified and analyzed by Wylder Nation and other researchers to better understand how ASMD progresses over time and how it is managed.

Ultimately, the goal is that this data will lead to better care, a better understanding of ASMD, and new treatments.

PicnicHealth has helped tens of thousands of patients with chronic or complex illnesses navigate the healthcare system via their patient product. Through the PicnicHealth Research Platform, the company is working with top life sciences, academic institutions, and advocacy organizations to structure anonymized and aggregated medical records, giving researchers access to longitudinal real-world datasets.

“Unlocking patient control of medical data is especially important for rare diseases where the data can be incredibly powerful for both clinical care and powering research when too often little is known about the disease,” said Noga Leviner, CEO PicnicHealth. “We couldn’t be more excited to partner with Wylder Nation Foundation, patients, and their families.”

“Adequately caring for a child with ASMD typically requires the ongoing involvement of multiple physicians associated with different hospitals and academic institutions, creating challenges for families to access and organize their complete medical history,” said Steven Laffoon, Co-founder and President of Wylder Nation Foundation. “This partnership with PicnicHealth will not only help families overcome this barrier but will also lay the groundwork for real-world evidence-based data to help us better understand the true burden of this complex disease, and ultimately help accelerate future treatment options.”

Wylder Nation Partnership Leverages Data to Benefit Patients, Their Families, and ASMD Researchers

This partnership centralizes medical records for patients and their families. Additionally, it allows Wylder Nation and ASMD researchers to access valuable, anonymized information from medical records that was previously inaccessible.

PicnicHealth uses a patient-centered approach and believes keeping patients and their families at the center of research is critical to ensuring patients control their data. In the future, ASMD researchers will be able to apply to access the anonymized dataset for various research projects.

Advancing Medical Research with Machine Learning

PicnicHealth uses advanced human-in-the-loop machine learning (HITL ML) to digitize and structure complete medical records, including unique details like notes, imaging, and lab records directly from patient providers. PicnicHealth can get records from any facility in the US, in any format, regardless of hospital system or what electronic medical record system they use. Their proprietary algorithm “reads” the records and a nurse validates each abstraction. This approach allows the company to process records at scale while ensuring regulatory-grade accuracy and improving the algorithm with each record.

About PicnicHealth

PicnicHealth is a healthcare technology company that partners with patients, porting their complete medical records into an easy-to-use online application. The platform gives patients unprecedented access to and control over their medical records and, with their consent, the opportunity to contribute this valuable data to further scientific research. Founded in 2014 by Noga Leviner and Troy Astorino, the company partners with several of the world’s largest biopharma companies and academic research institutions. Learn more at [PicnicHealth.com](#).

About Wylder Nation Foundation

Wylder Nation Foundation is committed to improving the lives of children and families living with Acid Sphingomyelinase Deficiency (ASMD). Founded in 2013, the organization is focused on fostering collaboration among academic researchers, industry, and other stakeholders to accelerate the discovery and development of treatment options for ASMD and other similar Lysosomal Storage Diseases.

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