

From: BioMarin <MPSInfusionInsights@bmrn.com>

To: <Recipient's email>

Subject: CNEs to NCCs. New name, same partnership

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MPS INFUSION INSIGHTS

Supporting nurses through
the infusion process

An eNewsletter for nurses by nurses

A team of BioMarin Nurse Clinical Coordinators (NCCs) developed this quarterly eNewsletter as a way for nurses from around the country to share insights and best practices.

Have an insight to share?

[Email us.](#)

Clinical support has a new name

Clinical Nurse Educators (CNEs) will now be called Nurse Clinical Coordinators (NCCs) to better reflect all of the vital support services they provide. NCCs will continue to support:

- ✓ Patient education on MPS disease state and aspects of disease management
- ✓ Safe and effective use of enzyme replacement therapy (ERT)
- ✓ Therapy management issues related to infusion therapy

Educate about expectations.

Keep patients on therapy.

Educating patients and caregivers about what to expect from therapy is critical to helping them take charge of managing their MPS over the long term.



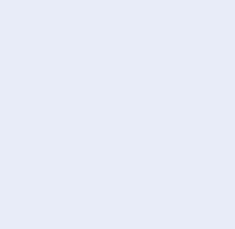
Personalized management plan

Since MPS is heterogeneous and will affect each patient differently, it is important to reinforce that patients and caregivers should work with their doctor to create a personalized management plan.¹⁻³



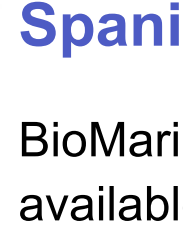
Regular assessments matter

Regular assessments of endurance and respiratory function are crucial for disease management. Encourage Morquio A (MPS IVA) patients to learn more at [Morquiosity.com](#).⁴



Managing MPS takes a team

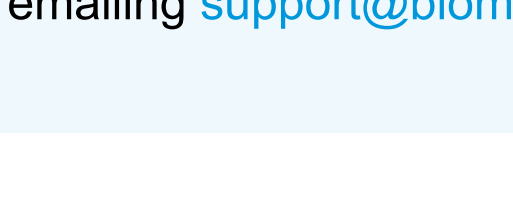
Close partnership and information sharing between a patient and their entire healthcare team can help ensure that the patient receives the specific care they need to manage the impact of their MPS.



Download an assessments overview chart at [Morquiosity.com](#)

Spanish resources

BioMarin has select patient/caregiver materials available in Spanish. Contact your BioMarin NCC for more information.



Direct your patients to find out more about support and available resources by calling **1-866-906-6100** or emailing support@biomarin-rareconnections.com.

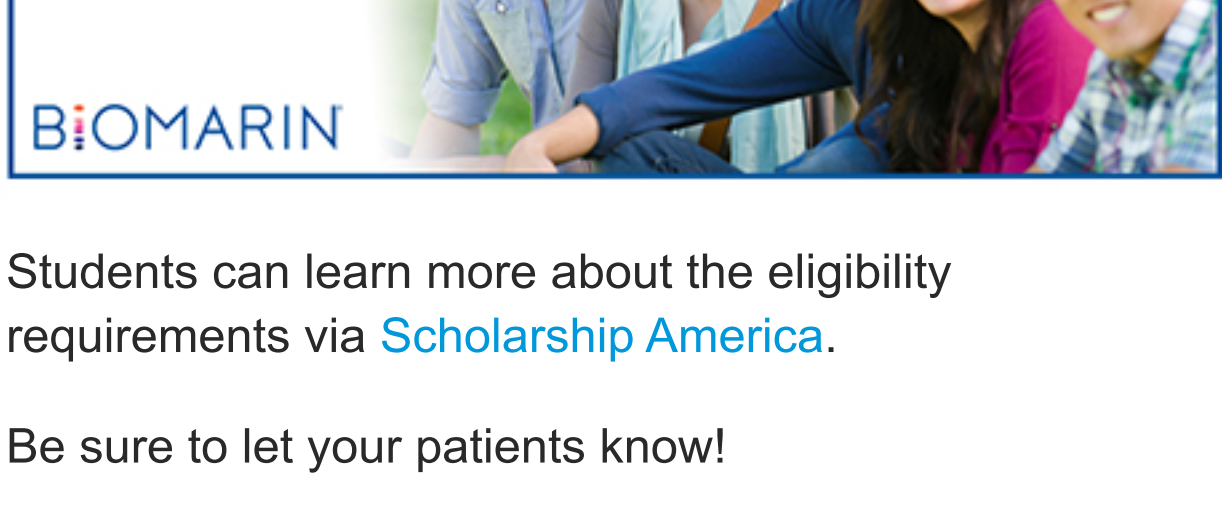
Communicating surgical risk

information with your patients

- People with MPS are at risk of anesthesia-related complications during surgery.⁵ Arming both patients and caregivers with information is critical. Treat every patient touchpoint as an opportunity to help both patients and NCCs prepare
- Help the patients you interact with be proactive. Urge them to contact their NCC before surgeries or after any major medical event

Did you know?

BioMarin has launched RARE Scholars, a new scholarship program for students living with rare disease who show leadership and participation in school and community activities.



Students can learn more about the eligibility requirements via [Scholarship America](#).

Be sure to let your patients know!

NURSE SPOTLIGHT

Lindsay Torrice is a Pediatric Nurse Practitioner at the University of North Carolina (UNC) at Chapel Hill.

After working in basic science research, Lindsay returned to school to earn her nursing degree from UNC in 2008. While practicing as an RN in the Neonatal Intensive Care Unit there, she continued her education, earning her Master's in Nursing in 2012.



In 2013, Lindsay began working as a Pediatric Nurse Practitioner with the UNC Pediatric Sedation Service, where she was introduced to patients with MPS disorders.

Hoping to work more with the MPS population in both clinical care and research, she joined UNC's Division of Pediatric Genetics and Metabolism in 2016. She has since worked with many patients with MPS, developing a strong bond with 4 amazing children who have Morquio A. She enjoys getting to know their families and is dedicated to helping them navigate the healthcare system to ensure they optimize every healthcare opportunity.

When Lindsay is not at work, she's often teaming up with her husband on building their new house. An active, creative person, she always finds time for trying new recipes, quilting, running, and yoga.

Do you know a nurse who goes above and beyond?

Want to see them featured in the next edition of MPS Infusion Insights? [Nominate a nurse here!](#)

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