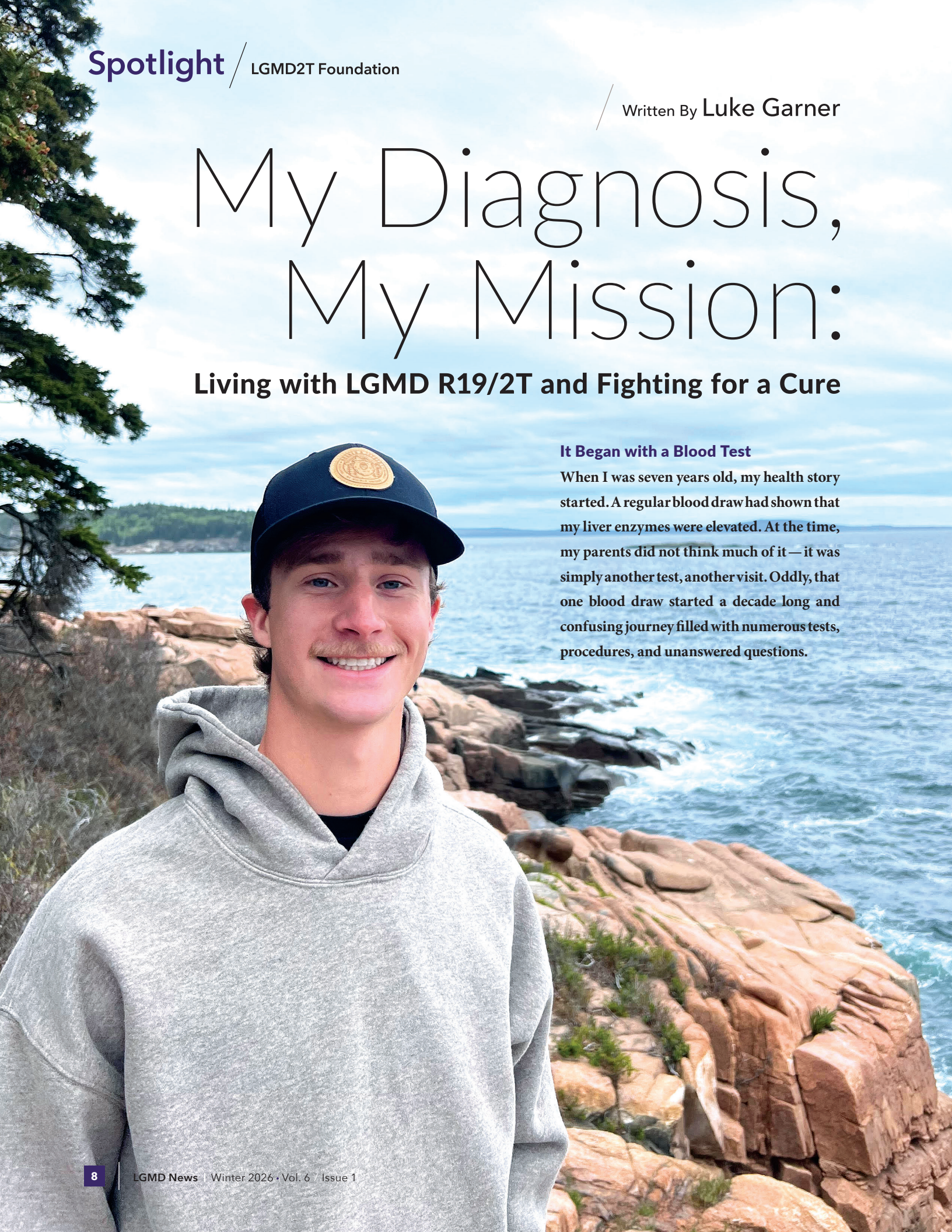
Written By Luke Garner

My Diagnosis, My Mission:

Living with LGMD R19/2T and Fighting for a Cure



It Began with a Blood Test

When I was seven years old, my health story started. A regular blood draw had shown that my liver enzymes were elevated. At the time, my parents did not think much of it — it was simply another test, another visit. Oddly, that one blood draw started a decade long and confusing journey filled with numerous tests, procedures, and unanswered questions.

Eventually, doctors discovered I had an elevated CK (creatine kinase) level, a sign that something might be affecting my muscles. A muscle biopsy was ordered — but the results were normal. We went through genetic testing for Duchenne and Becker muscular dystrophies, but those tests were negative, too.

Without a clear answer, I was eventually given a diagnosis of *idiopathic hyperCKemia*, which basically meant, "Your CK levels are high, and we don't know why."

Living with the Unknown

For the next ten years, my family and I continued with life as best we could. But in the back of our minds, the uncertainty lingered. We didn't know what was really going on with my body or what my future might look like.

When I turned 17, we decided it was time for a second opinion. That decision changed everything.

A new round of genetic testing finally gave us the answer we'd been searching for: I was diagnosed with limb-girdle muscular dystrophy type 2T (LGMD R19/2T), caused by mutations in a gene called GMPPB. The diagnosis was later confirmed by Dr. Steven Moore, a renowned expert in neuromuscular pathology.

It was overwhelming. After ten years of questions, we finally had a name for what I was living with — but it wasn't the answer we had hoped for. There is no cure, no treatment. Just a name and a new reality.

Turning Diagnosis into Purpose

Once we knew what we were facing, my dad and I knew we couldn't sit still. He immediately began learning everything he could about LGMD R19/2T. He attended rare disease conferences and even participated in LGMD Day on the Hill in Washington, D.C., advocating for increased awareness and research.

Those experiences lit a fire in both of us.

Above: Luke Garner and his father James together founded CureLGMD2T, a nonprofit dedicated to supporting patients and families affected by LGMD R19/2T and GMPPB-related congenital myopathy.

Together, we founded CureLGMD2T, a 501(c)(3) nonprofit dedicated to supporting patients and families affected by LGMD R19/2T and GMPPB-related congenital myopathy. Our mission is to raise awareness, build community, develop a patient registry, and push forward the research that could someday lead to a treatment — or even a cure.

We want to give this rare condition a voice, because too often, people with LGMDs are overlooked or misunderstood.

"Our mission is to raise awareness, build community, develop a patient registry, and push forward the research that could someday lead to a treatment — or even a cure."

Above: Friends Isaac Redman (Left) and Luke Garner (Right), both living with LGMD R19/2T, working together at the recent 2025 International Limb Girdle Muscular Dystrophy Conference.

Finding Community and Connection (Start of the 2T Team)

One of the most meaningful parts of this journey has been meeting others who are living with the same diagnosis. That's how I met Isaac Redman. He's my age and was also diagnosed with LGMD R19/2T. We connected instantly — not just because of the shared condition, but because each of us really understood what the other was going through.

I'm currently a fourth-year nursing student, and Isaac is in his fourth year studying marketing communications. With Isaac and his mom Becky joining our team, we were able to expand our outreach, build a social media presence, and strengthen our community connections.

It's been amazing to see how much stronger we are when we work together.

The Power of the Patient Registry

A major focus of CureLGMD2T is developing our patient registry. It's one of the most powerful tools we have — not just to connect with others who have LGMD R19/2T, but to help researchers better understand this condition.

If you or someone you know has LGMD R19/2T or GMPPB-related congenital myopathy, I strongly encourage you to register. Every entry helps:

- **Raise awareness**
- **Strengthen the LGMD R19/2T community**
- **Provide valuable data for future research and clinical trials**

The registry gives us a collective voice — the more people who participate, the louder and more impactful that voice becomes.

How You Can Help

Starting CureLGMD2T has been a journey of hope, determination, and resilience. But we can't do it alone. We rely on donations, grants, and community support to fund research, support clinical studies, connect patients, and keep moving forward. Every contribution — big or small — brings us closer to answers and helps shine a light on this rare condition.

If you're able to donate, spread the word, or get involved, please visit our website at **CureLGMD2T.org**. Together, we can build something bigger than ourselves. Something powerful. Something that matters.

> **"Getting diagnosed with LGMD R19/2T wasn't the end of my story — it was the beginning of a new chapter. One filled with challenges, yes, but also filled with community, compassion, and purpose."**

Moving Forward with Purpose

Getting diagnosed with LGMD R19/2T wasn't the end of my story — it was the beginning of a new chapter. One filled with challenges, yes, but also filled with community, compassion, and purpose.

Through CureLGMD2T, I've learned that rare doesn't have to mean invisible. Even in the face of uncertainty, we can choose action. Sometimes, the best way to cope with a diagnosis is to fight for the people who share it.

We're not giving up. Not now. Not ever. ▪

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