HIDDEN IN PLAIN SIGHT:

The Unseen Burden of Very High Triglycerides

> *"My acute pancreatitis was the alarm that made everyone pay attention.... I didn't even know what pancreatitis was or that it could happen until it was too late."*
>
> **—GAYLE K.**

Introduction

A routine blood test can identify very high triglycerides in minutes. For many patients, understanding their risk and getting the care they need can take years.

That simple reality reflects one of the greatest missed opportunities in cardiometabolic care today.

Every day, healthcare professionals identify people with severe hypertriglyceridemia, commonly known as very high triglycerides, through laboratory testing. Clinical guidelines clearly define severe hypertriglyceridemia and provide evidence-based recommendations for evaluation, treatment, and reducing the risk of one of its most serious complications: acute pancreatitis, a life-threatening medical emergency. For many people, a diagnosis of very high triglycerides becomes little more than an entry on their medical record.

The result is a care journey that patients often navigate on their own, with consequences that reach far beyond clinical care. Many never fully understand their diagnosis, what may be contributing to it, what it means for their health, or how the condition should be managed over time. They may never be referred to lipid specialists, registered dietitians, or other clinicians with expertise in managing very high triglycerides. Instead, they spend years searching for answers, coordinating care across disconnected providers with variable expertise in triglyceride management, and piecing together information that should have been provided at the time of diagnosis. Perhaps most concerning, many people may not understand that very high triglycerides can put them at risk for acute pancreatitis until they experience a medical emergency themselves.

This is what it means to be *Hidden in Plain Sight*.

Drawing on lived experience, clinical and advocacy perspectives, and published research, this advocacy-led white paper explores gaps in the recognition and care of very high triglycerides and what it will take to close them.

Understanding the Terminology

Healthcare professionals generally use the clinical term **severe hypertriglyceridemia**. Patients are more likely to hear **very high triglycerides**. Throughout this paper, we use both terms to describe triglyceride levels of **500 mg/dL or higher**.

What Are Triglycerides?

Triglycerides are a type of fat in the blood that the body uses for energy. Their levels can be measured through a blood test. Levels of 500 mg/dL or higher are considered very high and can increase the chance of acute pancreatitis, a serious inflammation of the pancreas. Knowing a person's triglyceride level matters, but so does understanding what it means for overall health. Regular follow-up and monitoring are important to manage triglyceride levels and help reduce the risk of serious complications.

Why Visibility Matters Now

The Care Pathway Is Clear. The Patient Experience Often Is Not.

Routine laboratory testing creates a unique opportunity to identify very high triglycerides early, while there is still time to evaluate underlying causes, reduce pancreatitis risk, provide educational resources and tools, and coordinate care. That opportunity is more important today than ever before. As our understanding of the genetic, metabolic, medication-related, and other causes of very high triglycerides has grown, so has our ability to identify people earlier, tailor treatment to individual needs, and reduce the risk of acute pancreatitis. In practice, those opportunities are not consistently realized. For many patients, the first meaningful conversation about very high triglycerides doesn't happen until a serious complication, such as acute pancreatitis, forces it.

> *"Severe hypertriglyceridemia is one of the few diseases where the healthcare system often knows exactly who is at high risk before disaster occurs, but oftentimes nothing is done about it. An opportunity to reduce that risk exists every time a laboratory reports triglycerides greater than 500 mg/dL."*
>
> **—DAVID SAXON,** MD

This disconnect cannot be explained by limited scientific understanding alone. Clinical guidelines clearly define severe hypertriglyceridemia and provide evidence-based recommendations to reduce pancreatitis risk and support long-term management, including evaluation for underlying causes, individualized nutrition support through medical nutrition therapy, pharmacologic treatment when appropriate, and ongoing follow-up.

The challenge lies in translating those recommendations into routine patient care. Patients do not consistently receive the education, referrals, integrated care, or long-term follow-up described in clinical guidance.[1-4]

What Patients Experience, and the Evidence Confirms

Patients experience the implementation gap, not the guidelines

For many patients, the challenge was not delayed diagnosis. It was delayed information and support. They were told they had very high triglycerides but often left their clinical conversations with more questions than answers. Discussions about genetics, pancreatitis risk, specialist care, medical nutrition therapy, and long-term management frequently occurred months (or even years) after very high triglycerides were first identified. Rather than moving through an integrated care pathway, many described navigating the healthcare system on their own, searching for information, requesting referrals, and piecing together their care as they went.

Sharon's experience illustrates this disconnect. Now 74, Sharon was diagnosed with very high triglycerides at age 55 but received very little explanation about the condition. Instead, she was advised to lose weight and take prescribed medication. She was never referred to a lipid specialist or registered dietitian. She did not learn about her risk of pancreatitis until recently through conversations with peers rather than healthcare professionals. Despite remaining highly engaged in her health, Sharon managed her condition independently because guidance was limited. Her diagnosis came many years before she received the information and support that could have changed the course of her care.

> *"Looking back, I'm shaken that no one ever explained my risk of acute pancreatitis. I would have been more proactive if I'd known it was a possibility. If I had developed it, I wouldn't have known to tell emergency doctors that my very high triglycerides could be the cause."*
>
> **—SHARON D.**

The care gap extends far beyond one patient

Recent estimates suggest that 3.29–3.98 million U.S. adults are living with severe hypertriglyceridemia, while only 2.43–2.88 million are estimated to have been diagnosed.[5-9] These findings suggest that hundreds of thousands of people may still be living with undiagnosed and untreated severe hypertriglyceridemia and its associated risks without appropriate management.

Severe hypertriglyceridemia rarely exists in isolation. Very high triglycerides may coexist with diabetes, obesity, insulin resistance, cardiovascular disease, chronic kidney disease, metabolic dysfunction-associated steatotic liver disease (MASLD), and inherited lipid disorders. This broader understanding is reflected in recently published cardiovascular-kidney-metabolic health guidelines, which recognize that these overlapping conditions create competing clinical priorities and emphasize the need for coordinated, team-based care.[1,10]

Recent dyslipidemia guidelines place greater emphasis on managing triglycerides alongside LDL cholesterol, reinforcing that very high triglycerides deserve clinical attention. Despite this growing recognition, many patients receive little information or support until they experience a serious complication or medical crisis.[11]

Professional guidance is consistent in describing what should happen after severe hypertriglyceridemia is identified. Patients should receive evaluation for secondary causes, consideration of inherited lipid disorders when appropriate, intensive lifestyle intervention, referral for medical nutrition therapy, potential pharmacologic treatment to reduce pancreatitis risk, and ongoing follow-up.[1-4]

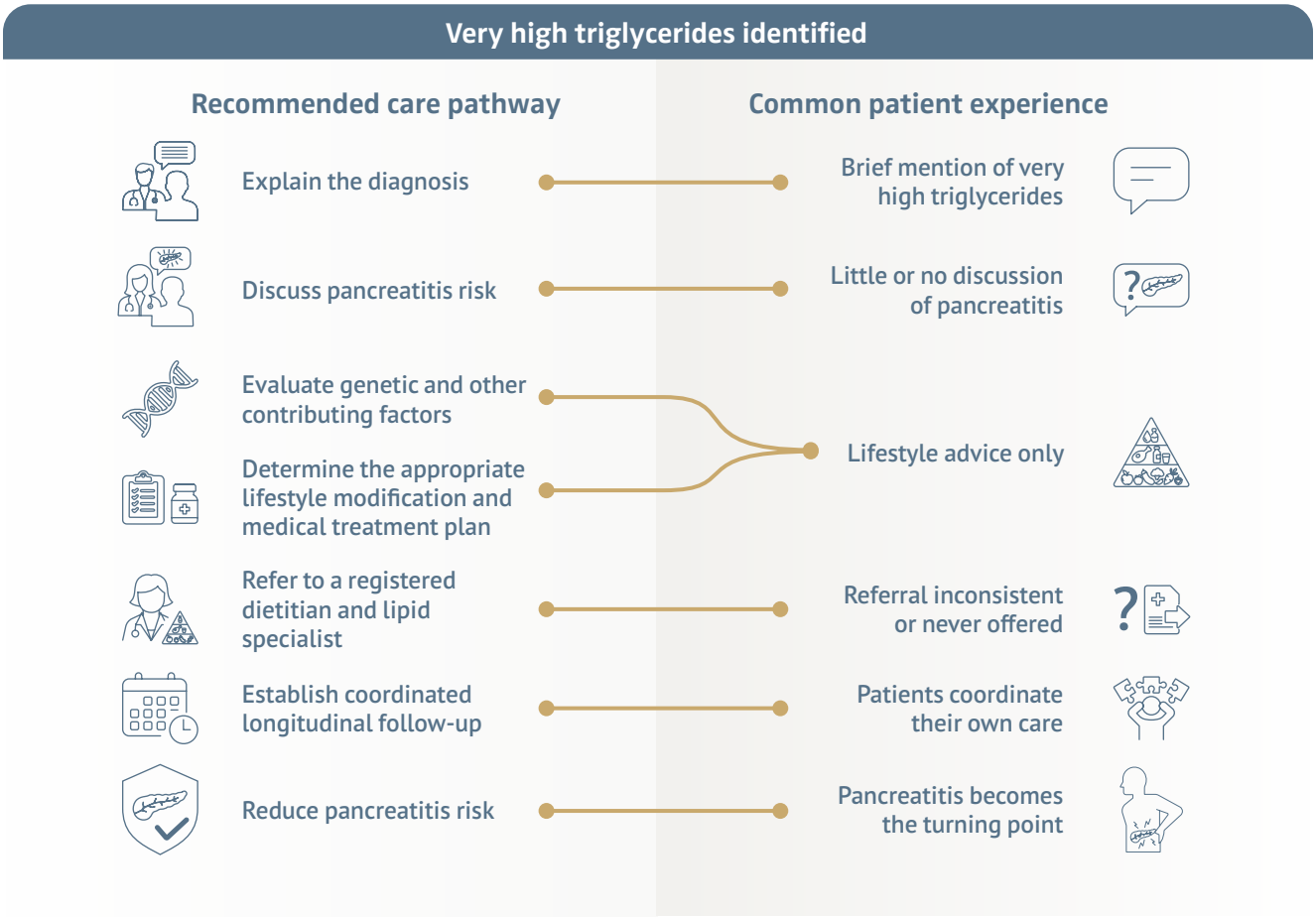
Although the risk of acute pancreatitis is well recognized clinically, many people living with very high triglycerides may not know it is a potential complication. In one study, up to 3 in 100 adults with severe hypertriglyceridemia experienced acute pancreatitis within three years, with the risk increasing sharply once triglyceride levels reached 500 mg/dL.[8] These findings underscore the importance of ensuring patients understand this serious complication.

> *"We need to raise awareness amongst our medical colleagues. We must all carry a sense of urgency in guiding people with severely elevated triglycerides toward help before they get to the point of pancreatitis or before they get recurrent pancreatitis."*
>
> **—ANN LIEBESKIND**

A Note on Person-Centered Language:

Throughout this paper, we use a combination of person-first and healthcare-specific terminology. When describing lived experience, we often refer to "people living with very high triglycerides" to recognize individuals beyond their diagnosis. In some contexts, we use the term "patient" because it is widely used in clinical practice, research literature, healthcare delivery, and advocacy, or because it reflects an individual's role when receiving medical care. Both terms are used intentionally throughout the paper based on context and readability.

After Identification: The Gap Between Recommended Care and Patient Experience



The laboratory result is not where care should end.
It is where coordinated care should begin.

Living With Very High Triglycerides: The Stories Behind the Numbers

When Pancreatitis Becomes the First Meaningful Conversation About Very High Triglycerides

For some people living with very high triglycerides, the journey to understanding their disease begins only after a medical emergency.

Despite maintaining a healthy lifestyle, Gayle K. was not feeling well. She sought medical advice repeatedly and was told to diet and exercise more, even though she was already fit. Everything changed when she developed severe abdominal pain and diarrhea. Determined to help emergency room clinicians understand her symptoms, she initially declined pain medication. She was then repeatedly questioned about alcohol use and lifestyle choices before laboratory testing revealed triglyceride levels of 6,200 mg/dL and confirmed acute pancreatitis. Within hours, what had begun as a stomachache escalated into a life-threatening medical emergency involving hospitalization due to organ failure.

Gayle's husband and care partner, Joseph H., remembers the uncertainty of that first pancreatitis emergency and every one that followed, and how fear quietly shaped everyday life. Their seventh wedding anniversary ended in the hospital instead of their home. Vacations, family celebrations, and even ordinary plans were overshadowed by the possibility of another attack, making uncertainty a constant companion rather than an occasional concern. "It was always in the back of your mind," Joseph recalls. "Every trip, every celebration, every plan came with the question of whether another attack might happen."

Gayle and Joseph's story is deeply personal. The burden they describe is not.

Across patient interviews, people living with very high triglycerides rarely defined their experience by a laboratory value. They talked about the constant fear of another pancreatitis attack. They described planning their lives around the possibility of another medical emergency. They shared the emotional exhaustion of never knowing when life might be interrupted again. Together, these experiences reveal a burden that extends far beyond a blood draw. It is measured in constant vigilance, disrupted routines, and the everyday decisions individuals and families make to avoid another crisis.

Now in her mid-50s, Gayle has lived with very high triglycerides for more than three decades, including nearly 15 years of uncertainty and recurrent pancreatitis. Long-term care and effective treatment restored not only her health, but her confidence.

> *"Finding the right team and treatment has made her life so much better because there's no fear factor anymore."*
>
> **—JOSEPH H.**

Acute Pancreatitis: A Risk Too Many Patients Learn About Too Late

It is a life-threatening medical emergency and one of the most serious consequences of severe hypertriglyceridemia.

A severe attack can result in:

- Permanent pancreatic damage
- Organ failure and other serious complications
- Diabetes caused by pancreatic injury
- Chronic pancreatitis
- Increased risk of pancreatic cancer
- Death

Reducing the risk of pancreatitis is one of the most important goals of identifying and managing very high triglycerides early.

What Patients Experience, and Research Reinforces

The burden extends far beyond triglyceride levels

Published qualitative studies and patient-reported outcome research consistently show that living with very high triglycerides affects far more than physical health. Common themes include:

- Persistent fear of acute pancreatitis and when another attack may occur.[15,17,19]
- Significant dietary restrictions that affect family life, travel, holidays, dining out, and social interactions.[15,16,17,19]
- Emotional burden, including anxiety, isolation, and constant vigilance.[15,16,19]
- Self-blame and stigma about their diagnosis.[16,18,19]
- Limited understanding of the disease and uncertainty about long-term management.[16,18]
- Difficulty accessing specialized care and nutrition support.[12-14,20,21]
- Feeling responsible for coordinating care across multiple providers.[12-14]
- Prolonged hospitalizations, including periods of intensive care, associated with acute pancreatitis attacks and recovery.[7,17,19,21]
- Financial strain and the challenges of managing a chronic condition.[15,16]

Taken together, the evidence suggests that improving quality of life for people with very high triglycerides requires addressing not only triglyceride levels, but also the emotional, practical, and day-to-day realities of living with the condition.

Registered dietitian Anna Doherty (Biggins), MPH, RDN, LD, observed that the constant attention required to manage food choices can become exhausting and lead to burnout. She also noted that people living with very high triglycerides often describe food-centered celebrations as sources of stress rather than joy, fearing that one wrong choice could trigger acute pancreatitis.

Anna further emphasized that generic heart-healthy nutrition advice may not always meet the needs of people living with very high triglycerides. Disease-specific nutrition counseling and individualized support are often critical to helping patients safely manage their condition, underscoring the importance of access to registered dietitians with expertise in lipid disorders.

The Everyday Burden of Very High Triglycerides

Beyond the physical symptoms, patients and care partners described the impact of very high triglycerides across **multiple dimensions of daily life**, including:

- Fear of another pancreatitis attack
- Food and nutrition
- Travel and celebrations
- Family and caregiving
- Emotional well-being
- Self-esteem
- Work and productivity
- Financial impact
- Hospitalizations and medical care
- Constant vigilance
- Future planning

Hidden in Plain Sight: Gaps in Awareness, Recognition, and Support

Looking Beyond Lifestyle

People living with very high triglycerides often face two challenges at once: managing a complex chronic condition and overcoming assumptions about what caused it.

Across interviews, people described being told to lose weight, improve their diet, or exercise more, even when they were already doing all those things. Before the broader clinical picture was considered, many felt their condition was viewed primarily through the lens of lifestyle or personal responsibility rather than genetics, metabolism, or other contributing factors. Some felt dismissed during medical appointments, while others found themselves explaining their condition to healthcare professionals unfamiliar with severe hypertriglyceridemia. Instead of finding answers, they often left feeling misunderstood, blamed, and uncertain about what should happen next.

When lifestyle change isn't enough: the genetic and metabolic realities of very high triglycerides

Diet, physical activity, weight management, and treatment of underlying health conditions are important parts of managing very high triglycerides. Yet even when people make recommended lifestyle changes and follow their treatment plan, triglyceride levels may remain very high. This is because triglyceride levels can be influenced by multiple factors, including diabetes and other metabolic conditions, medications, alcohol use, and genetics.

For some people, an underlying genetic condition could make it more difficult to control triglyceride levels. Genetics can play a role across a spectrum, from relatively common genetics that interact with metabolic and environmental factors to rare genetic disorders such as familial chylomicronemia syndrome (FCS). Understanding these contributors can help clinicians and patients decide the best plan to address the very high triglycerides.

For people living with very high triglycerides, this distinction matters. When very high triglycerides are framed primarily as the result of diet, weight, or other personal behaviors, people may feel blamed when their levels remain high despite significant effort. Recognizing the biological complexity of very high triglycerides can help shift the conversation from *"What are you doing wrong?" to "What else may be contributing, and what more can we do?"*

> *"Too often, patients are blamed because the condition is viewed as entirely lifestyle-related. The reality is that genetics play a substantial role in many cases."*
>
> **— DAVID SAXON**

Stigma shapes the patient experience

Lifestyle assumptions can have consequences well beyond clinical encounters. A growing body of qualitative research demonstrates that stigma, self-blame, and frustration remain common among people living with very high triglycerides and related disorders. When the condition is viewed primarily through the lens of lifestyle, opportunities to discuss genetic and secondary contributors, pancreatitis risk, and individualized management may be overlooked.[16,18,19]

Clinicians acknowledged these same challenges. Rather than viewing very high triglycerides primarily as a lifestyle-related condition, they emphasized the importance of recognizing its biological complexity and approaching conversations with greater curiosity, empathy, and individualized assessment. Moving beyond assumptions can reduce stigma, strengthen trust, and create opportunities for more informed, patient-centered care.

Patients repeatedly expressed that simply understanding why they had very high triglycerides, and knowing they were not solely responsible, changed how they viewed themselves and their future, strengthening their engagement and confidence in managing the disease.

> *"I'd like patients to know that there are options for them and that this is not just a lifestyle thing. They shouldn't blame themselves."*
>
> **— NISHANT SHAH**

Care should support patients, not depend on them

Although multidisciplinary care is consistently recommended, patients are often left without a clear point person to manage long-term follow-up. Guidelines identify important roles for primary care clinicians, endocrinologists, lipid specialists, cardiologists, gastroenterologists, registered dietitians, pharmacists, and diabetes educators. However, recommendations regarding who should coordinate care over time continue to evolve and vary across clinical contexts.[1,2,10]

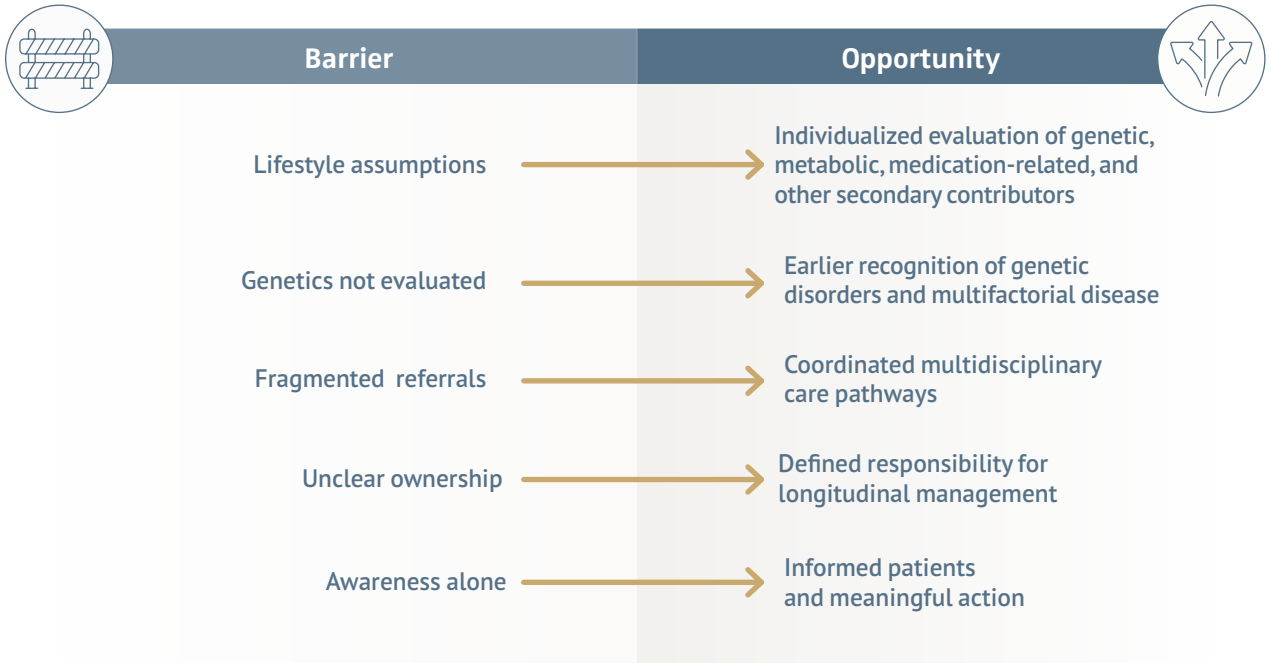
Patients described what happened when no one took the lead. Many researched their condition independently, identified specialists on their own, requested referrals, tracked laboratory values, and coordinated communication among providers who rarely connected with one another. Others received conflicting nutrition advice while trying to manage very high triglycerides alongside diabetes, obesity, chronic kidney disease, and other cardiometabolic conditions. Rather than benefiting from coordinated multidisciplinary care, patients often became coordinators themselves.

Published implementation studies describe similar challenges. Referral to specialists and registered dietitians remains inconsistent, follow-up after severe triglyceride elevations varies considerably, and structured multidisciplinary care models remain uncommon outside specialty centers.[8,12,13]

Encouragingly, standardized referral pathways, consult services, and clinical decision-support tools have been shown to improve the consistent delivery of evidence-based care, suggesting these gaps are not inevitable. They are modifiable.[14]

Patients should be partners in their care, not the people responsible for holding the care system together

From Recognition to Action



Patients need more than recognition. They need coordinated action.

> *"The fact of the matter is that triglycerides have been ignored for a very long time. Today, we know much more about very high triglycerides and how to support patients than we did in the past. People shouldn't have to experience pancreatitis before the condition is taken seriously. Greater awareness and earlier action can help ensure they get the care they need."*
>
> —CHRIS BRINE

Opportunities to Improve Care, Support, and Outcomes

Changing How We Recognize, Understand, and Manage Very High Triglycerides

Patient, care partner, clinical, and advocacy contributors consistently described the same need: helping people understand their condition earlier, connecting them to coordinated support, and designing solutions that reflect lived experience. The recommendations that follow reflect those shared priorities and are grounded in the experiences of people living with very high triglycerides and their care partners, alongside clinical expertise and published evidence.

Patients and care partners should help shape solutions

People living with very high triglycerides and their care partners bring perspectives that cannot be captured through clinical data alone.

Design solutions with patients and care partners, not just for them. Patients, care partners, and advocacy organizations should be engaged as partners in developing educational resources, support services, and care pathways. Involving lived experience from the beginning can help ensure that solutions are relevant, practical, and responsive to patient needs.

Partner with patient organizations to strengthen support and drive change. Patient organizations are more than a source of information and support for people living with very high triglycerides and their families. They are critical partners in advancing patient-centered care, bringing together lived experience, identifying unmet needs, informing education and service development, and advocating for meaningful improvements in research, care delivery, and policy. Working alongside these organizations can help ensure that efforts to address very high triglycerides reflect the priorities and real-world experiences of those most affected.

Supporting people means supporting everyday life

For people living with very high triglycerides, the impact of the disease extends far beyond medical appointments. Patients and care partners consistently described the need for practical guidance that helps them navigate daily life.

Help people navigate their condition with confidence. Expanding access to medical nutrition therapy, providing actionable educational and navigation tools, and strengthening peer and care partner support can help people make informed decisions and sustain long-term disease management in the real world. Success should be measured not only by clinical outcomes, but also by whether people feel able to live their lives with less fear and greater peace of mind.

Understanding should replace blame

Patients repeatedly expressed that understanding why they had very high triglycerides and knowing they were not solely responsible for causing the condition changed how they viewed themselves and their future.

Help people understand the whole story. Every conversation about very high triglycerides should create opportunities for education, not blame. Helping patients understand the genetic, metabolic, medication-related, and other contributors to the condition can support more informed discussions, greater engagement, and patient-centered care.

Every diagnosis should mark the beginning of coordinated care

> *"I don't want to be the only person that has this information on how to manage these patients. I'd like to make sure that cardiologists and providers feel confident that they also can care for this specific patient population."*
>
> **—SHANNON CHRISTEN**

Make the next step as clear as the diagnosis. Every identification of very high triglycerides should trigger a consistent care pathway that includes education, evaluation for genetic and other contributing factors, disease-specific nutrition counseling, appropriate specialist involvement, and a clear plan for follow-up. For some patients, that pathway may also include discussion of medication options to help reduce risk when lifestyle changes alone are not enough.

Make pancreatitis risk part of every conversation. Ensure people living with very high triglycerides understand that acute pancreatitis is a serious potential complication, can recognize symptoms requiring urgent medical attention, and know why managing their triglycerides matters, even when they feel well.

Multidisciplinary care should become the standard, not the exception

> *"Once the providers and the care team have the appropriate resources and an accurate perspective on the condition, we can all work together to provide the best care for these patients."*
>
> **— ANNA DOHERTY (BIGGINS)**

Build care teams around patients, not around healthcare silos. Expanding access to lipid specialists, registered dietitians, and other clinicians with expertise in managing very high triglycerides can improve diagnosis, accelerate appropriate referrals, strengthen patient understanding, and reduce unnecessary delays. Shared care plans and coordinated follow-up can help ensure that every member of the team is working toward the same goals and delivering consistent guidance.

Healthcare systems should make evidence-based care easier to deliver

Many of the barriers described throughout this paper stem from inconsistent implementation of what is already known. Health systems have a critical role to play in ensuring that evidence-based care is not dependent on where a patient enters the healthcare system or which provider they happen to see.

Design systems that make the right care the easy care. Incorporating very high triglycerides into care coordination programs, discharge planning, and quality improvement initiatives can help create more consistent patient experiences. The goal is simple: Every patient identified with very high triglycerides should receive the same opportunity for timely, coordinated, and evidence-based care.

What should happen after very high triglycerides are identified?

Every person identified with very high triglycerides should leave knowing:

- What their triglyceride level means and what may be contributing to it
- That acute pancreatitis is a serious potential complication
- Which symptoms require urgent medical attention
- What happens next in their care, including evaluation, nutrition counseling from a registered dietitian, specialist care that may include a lipidologist, discussion of treatment options when appropriate, and follow-up
- Where to find credible information, patient organizations, and community support

Making this possible requires:

- Clear, empathetic education tailored to the individual
- Evaluation for genetic, metabolic, medication-related, and other contributing factors
- Nutrition counseling from a registered dietitian experienced in very high triglycerides
- Timely access to coordinated specialist care, including a lipidologist when appropriate
- A clear plan for ongoing follow-up and long-term management
- Solutions shaped with patients, care partners, and advocacy organizations

Recognition should lead to informed, coordinated, whole-person care, not uncertainty.

From Hidden in Plain Sight to Seen, Understood, and Supported

Severe hypertriglyceridemia presents a rare opportunity in medicine. Unlike many chronic conditions, people living with very high triglycerides can often be identified before irreversible complications occur. The science has advanced. Clinical guidance is clear. The challenge is no longer determining what good care looks like. It is ensuring every person living with very high triglycerides experiences it.

Real progress begins when identification leads to action, but it should be measured by more than clinical outcomes. No one should have to experience acute pancreatitis before understanding that very high triglycerides put their health at risk. Success means that people understand their condition, know where to turn for help, feel supported rather than blamed, can access appropriate expert care, and can live with greater confidence and less fear. People living with very high triglycerides and their families should not have to navigate this journey alone.

Achieving this vision will require a shared commitment across the healthcare community. Healthcare professionals, researchers, advocacy organizations, health systems, policymakers, industry, patients, and care partners all have a role in advancing earlier action, access to coordinated care, and whole-person support. By working together and grounding solutions in lived experience, we can move from reacting to medical crises toward reducing their risk and burden while improving how people experience care and daily life.

Every identification of very high triglycerides is more than documenting a laboratory result.

It is an opportunity to change the course of a patient's life.

Whether that opportunity is realized is now up to all of us.

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Contributors

Clinical

- **ANN LIEBESKIND,** MD, FNLA, FAAP, FACC
- **ANNA DOHERTY (BIGGINS),** MPH, RDN, LD
- **DAVID SAXON,** MD
- **NISHANT P. SHAH,** MD
- **SHANNON CHRISTEN,** RD, CDCES

Community

- **CHRIS BRINE,** Advocate
- **GAYLE K.,** Person living with very high triglycerides
- **JOSEPH H.,** Care partner
- **SHARON D.,** Person living with very high triglycerides

Patient and care partner perspectives reflect individual lived experiences. Contributors include individuals with personal or professional relationships with Ionis Pharmaceuticals. Names and identifying details have been withheld for privacy.

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