

## Transcription for: "Undiagnosed: The Businessman"

What does it mean to live with primary immunodeficiency? What does it truly mean to compromise? Throughout the spring of twenty twenty five, the immune deficiency foundation will be hosting select online screenings of our new documentary, Compromise, life without immunity. You can join us on January thirty first, February twenty eighth, March fourteenth, or April twenty fifth at seven thirty PM eastern. Compromise is an intimate look into the lives of six individuals facing this rare condition with incredible strength and determination.

The film reaches beyond medical definitions to reveal the real human experiences of those living with PI. Through their stories, we see how love, support, and proper medical care make it possible to face life's daily challenges. Again, those dates are January thirty first, February twenty eighth, March fourteenth, and April twenty fifth twenty twenty five at seven thirty PM Eastern. To register for free, visit [primaryimmune.org/slash/compromised](http://primaryimmune.org/slash/compromised). On average, it takes nine to fifteen years of untreated illness to be diagnosed with and treated for a primary immunodeficiency.

Recent studies estimate that seventy to ninety percent of those with PI do not yet have a diagnosis. You're listening to undiagnosed, an immune deficiency foundation podcast. These are the true stories of the harrowing journey to diagnosis. For those without rare diseases, like primary immunodeficiency. It's easy to assume that a harrowing diagnosis is the single complication that defines the struggle of their life.

This is almost never the case. Life persists, the financial, familial, and professional problems that almost everyone has experienced don't just disappear when you're diagnosed. They are substantially amplified. The story of Matt Lesser is one that's marked, of course, by persistence, but also by vulnerability, self reflection, and hard earned humility.

**Matt Lesser:** So I grew up in a small lake community just north of Fort Wayne, Indiana. It was actually my it's about the first year. It was my life in in the Chicago suburbs and then up in Wisconsin. Family here when I was four. So growing up for me, I guess, a fairly typical childhood other than I was sick a lot.

And then in my teenage years, when I was fifteen, I was diagnosed with ITP. And I was originally admitted to the hospital with a platelet count of less than a thousand. And so spent the better part of a year basically in a hospital confined to a bed with very little activities. I was in and out of the hospital, but I was my very restricted activities. That's where I think my a lot of things happened that year.

So I was going into my freshman year of high school. And prior to that, I would say that I was a kid that was basically just living a kid's life with very little thought to the future. That year, I was homeschooled because I did not I wasn't allowed to go to school because there was

too many risks of fall or illness or whatever. And so really taught me to really think differently, I guess, about life. And I I I view that year as the end of my childhood. And so from there forward, I I had difficulty fitting in with my peers and and and so forth. And I don't and so I I I'm grateful for that year in many ways because it taught me a lot about life, and it taught me a lot about perseverance and resilience, the importance of fighting. And so from there, so I I had treatments every year, actually the same treatments that I have now, believe it or not. And so, but for a different reason. And so after that, about a year later, it went away as mysteriously as it came. I still have a my platelet count is still low compared to normal. I'm always below normal, but I can live life fairly normally.

**Narrator:** ITP or immune thrombocytopenia is an autoimmune disorder characterized by low platelet counts. Matt's subsequent year of trauma left him with a trait all too familiar to anyone who suffers from mysterious medical symptoms. An acutely heightened awareness of the fragility of life. For Matt, such insight came with growing pains.

**Matt Lesser:** I would say, as I look back on on my life, I look at it, there are, you know, there are definitely these mile markers events in my life where I can see, I can tell you that there was it was life altering. In some way, shape, or formals, life altering. So when I had ITP as a teenager, going into that, you know, I was all about fitness and all about sports. Growing up, I was the overweight kid that was always picked last for gym class or whatever it was. And so I didn't wanna be that way.

And so in seventh grade, I found soccer, started to get in shape. And by the time I was going to my freshman year, I was bound determined to be a starter on the Varsity squad, my freshman year, and I was good enough that I would have been. And so I went in my freshman year in best shape I'd ever been in, and then I got sick. And so so the first six months of so I literally admitted the hospital two weeks before school is supposed to start. It was an August of, I think, eighty seven.

And so here I was now in a hospital, I can't play sports and I'm pissed. I'm just I'm just woolly pissed off at the world, right, at everybody. Because I had worked so hard for this thing. Right? And so going through that at about the six month mark, I was in and out of the hospital for the better part of a year.

At about the six month mark, I had I called an epiphany type moment where literally it was a middle of the night... the treatments I was getting gamma globulin, which is what I'm getting now, but I was getting through IV. Yeah. So I was getting these const and doses every week, and it would make me terribly sick. So terrible headache and vomiting almost every time. Now what I did learn is over time, as I've had drank two gallons of water during treatment, I didn't get sick.

So I've learned to drink two gallons of water a day. But anyway, this was so about six

months into it. I had a treatment. I was really ill getting back into bed in my hospital room. My parent I was all alone.

My parents had gone home. And as I'm crawling to bed, I had this this thought. And the thought was this. And it's like and I had this conversation with God, and I just said God, here I am. I'm ticked at you.

I'm ticked at my parents. I'm ticked at my body. I'm ticked at everybody. And you're the one person that could actually heal me from this. And so guess what?

I I I'm done in fighting. I'm done being angry. And I'm just gonna turn it over to you and just see what happens. And and so people ask me, were you healed that night? The answer is I was not healed physically, but my perspective changed immediately.

And from there for that from that point forward, I began to have a different view of my illness. I'd be having a different view of, you know, my reason and purpose for being here. I began to realize, you know what? I almost died multiple times as a fifteen year old kid. And here I am worried about playing soccer.

And and so from that point forward, sure, I still played soccer in basketball. I love sports, but it didn't have the same it it just they they became an appendage to my life. They weren't the focus of my life. And so my focus changed. My focus changed on, okay, why am I here? What is my purpose? What am I what am I supposed to be doing here? Okay. And all for all intents and purposes, and I heard those from multiple doctors, they couldn't understand why I was still alive. They'd never seen a platelet count that low.

And they said, you should have spontaneously hemorrhaged out and died. So they couldn't understand it. And so but it took me six months to get over myself, to get past my own self pity, if you will, and wallowing in the net before I began to realize, okay, wait a minute. There may be something more for me to do. In my life.

And so that's what changed for me during that year. But when I went back to school finally, I had a terrible time fitting in because I didn't think like my classmates thought anymore. And so in And it was just a yeah. It was a difficult time. So the next two years of high school, I graduated my junior year just because I just had a terrible time fitting in.

And so I took extra classes to, like, get out of there. I love college. I fit in there, but that was a different mindset, I think. So I don't know.

**Narrator:** After earning his degree in business, Matt married the longtime girlfriend he'd known since elementary school and went to work at his family's company, a Midwestern oil distributorship ran by his father. Soon, however, he began to feel as though his place was elsewhere. When he tried to quit the family business to follow his own path, his plans were soon shattered by a trauma that would come to shape how he would see the world for the rest of his life.

**Matt Lesser:** I studied business in college, grew up in a family business. And a year after college, I needed a job, but I didn't necessarily wanna work in the family business. My dad and I just didn't see eye eye on many things, but I needed a job. So a year later, I went into resign and he flipped the table on me and he left. And so here I was a twenty five year old kid with a business and a father that just left.

And so I felt responsible for the business, for my mom, whom he divorced, and then my youngest brother. And so the business was in shambles, and I didn't know that. And so it it failed after after about a hundred twenty days in the saddle, it failed, and I got super sick. And I spiraled into a very deep and clinical depression, became suicidal. I literally, I got to the point where I wasn't getting out of bed.

So I the first thing that happened is I began to period. The more that I uncovered in the business and, you know, was it was like each discovery was bigger than the last. And I finally got the point of realizing, guess what? The ship's going down and I am the captain. And so it started with panic attacks.

It started with just anxiety. Then not sleeping, then panic attacks, then then I didn't get out of bed. And and if I did get out of bed, I mean, literally, it was one of those things too. At this point, I had been married for a year. And, you know, I didn't know what it was to be a husband.

And so, you know, I thought I had to be this much guy that was protecting my wife from all the bad things going around. And so what I would do is I would get out of bed in the morning and then I would leave the home and I'd either go I'd either wait until I knew she went to work, then I'd come back and get back in bed, or I would just go sit in the park. And sit in my vehicle all day and just kind of stare. You know, I didn't really do anything because I didn't know what to do. Life was so overwhelming.

You know, I didn't wanna be around the phone because I was afraid there was on the phone. Literally, when I was still in my office, the phone would ring and it was usually a a a debt collector. And luckily, I had a I had a bathroom just off my office, and so I got the point the phone would ring. I go throw up. And that was my reality.

And so so I just stopped going to the office. And and and then I got then I got I just I just continued to spiral down darker, darker, darker, deeper, Until finally, about six months of that, I got the point of I didn't see any way out other than any of my life. And so that was what I was going to do. And so I actually got up. So this all started in July, of of nineteen ninety seven.

And so by February of ninety eight, I was suicidal. And so I actually went to my office and I was gonna write three letters, one to my mom, one to one to my wife, one to my one, one to my brother. My mom I had hired my mom to work for me, actually. And so and so she was actually trying to keep things together while I was sick. And but I had this thought before I wrote not one letter on those letters ever got written by the way.

I had this heightened thought before I wrote it, and I thought was, you know what? I know my parents took out a life insurance policy on me when I was a kid. And so so it was probably one of the first logical thoughts I'd had in months. And but rather than calling my life insurance agent, and I and I wanna make sure that that money was gonna go to my my wife and not my dad. And so luckily, I I checked because it would have actually gone to him. And so I drove to my life insurance agent's office he happened to be in.

He was a lifelong friend of my mom's. I changed the beneficiary to my wife. And and I was also trying to fish around for a suicide exclusion clause, but I don't remember ever using the word. And so but whatever happened, I left. In the time I drove back to my office three blocks away, he called my mom. And I didn't know this till years later.

He called my mom, and he said her name was Jean. It's a Jean. I was like, I know things are tough. I know that you're trying to figure everything out. Because he knew my dad had left. And he's like, but none of that matters because I just saw your son and if you don't do something today, he will not be here tomorrow. And so she hung up the phone and she called the only other person that she knew of that went through something very similar, actually a decade or so before when I was going through it then. And he was in his office and he said bring him right over. And so I got back to my office. My mom literally met me at the door and said, hey, let's go out for tea, which we would do that.

And we hadn't been out for tea in a long time. It's okay, fine. And she's like, I'll drive. Which was odd. I always drove, but I didn't wanna fight.

So I said, okay, fun, you drive. And so I got in the car and we started to drive. And rather, going straight on the road to get t, she turned left. And I said, where are we going? And she said to see a friend.

And I said, what friend? And so she's like, you'll see when we get there. So got there, we pulled in this guy's office. And I had grown up with this guy's kids. He's a very, very successful businessman in our community.

I grew up with this kid's. And the only idea about this guy was that he was tall, deep voice, very successful on his therapy. And so I said, yeah, I'm not going in there. And she said, well, he said you might say that. So he said he'd come sit in the car with us.

And so I went in and we spent basically, I think, six hours with him or four hours, whatever it was, the rest of the day. First thing he did is he got me help. And so I was removed from everything for about three months. And then while I was out, he said it's made people in to see what we had. And luckily, we had enough because of the way everything went down.

We had enough to start over and that's how a new company was formed in about six months later. When I finished meeting with what who became wanted between my business mentor. Right? The guy who walked with me through my from that point forward of my depression, I was taken away not taken away. I volunteered I went away, split that way.

And then he called my wife and he met with her and told her basically the story that I wasn't

telling her. She only knew she knew that things were tough. She had no idea how mess, how how big of a mess and how how ektop this was. And he he unpacked that for her. And and obviously, that threw her it threw her big time.

And she didn't you know, and that that created a huge breach of trust in our relationship because, you know, I I hear I thought I was protecting her and she felt like I was pushing her away. And so and that was one of the first things that came out, and then as I began to heal through it. So I went for there was a period of time where I had very little I didn't have any contact with anybody. Right? I just had to get actually just had to get medicated.

And and try to get my chemicals in my brain, the serotonin. I was just in a constant fire mode. Right? My my my my receptors were all fried. And so but as I started, that started to be a little healthier than I started to engage with my wife.

And primarily just hurt for a while. And so and so at first, it was just, I think, weird. We just kind of existed together. And then, basically, then there was this breaking point. And I think it was about the six month bark.

I I was beginning to wean off the meds because I was getting healthier and healthier. I came home from work when my my wife's on the couch and and and she she got home earlier than me that day for whatever reason. We didn't have kids yet. And she's on the couch and she's crying. And so, you know, my initial and it was like a sobbing and crying.

It wasn't like the, you know, little little and so I'm thinking, okay, who died? Or what happened? Or who had an accident or whatever. And and so, literally, when she composed herself enough, she looked at me and she's like, I don't know who you are anymore. And what that meant after we talked about it and now reflecting back on it, what that what she really meant was I knew this person that I married.

I married this cocky arrogant prick. Basically. And she probably used different terminology, but I know it's that's what she means. So but I was known. Right?

She knew I loved her. She knew I cared about her, but she also knew I was just cocky arrogant prick. And and she's like and now she's like, the cockiness is gone. She's like, sure, I see glimpses of it. She's like, the arrogance is gone.

She's like, and you're no longer a prick. And she's like, and you actually care for people. And she's like, I don't know what to do with any of this. And she's like, the bigger issue is, I don't know where I fit in it. And so from that point forward, we started going to counseling together and we went for five years together.

It was the honestly, it was probably the it was it was not probably it was the best investment in our marriage because we had five years together to build a new foundation for that. So it it just began a different conversation. And it began a different level of trust in our in our relationship. And one of the things that I think that we both agreed to is that when we don't know the answer, we we don't pretend to have the answer. We ask for help.

**Narrator:** By the age of thirty, Matt had been diagnosed with ITP, left alone with a failing business and given institutional help with depression that nearly killed him, all while managing bizarre and recurrent symptoms due to his undiagnosed primary immunodeficiency. By forty, the symptoms were far too severe and persistent to ignore. As is often the case in the story of Matt's life, help soon came from a friend.

**Matt Lesser:** And now we're talking about it was in my probably my mid my my my lower forties. My my mid thirties to lower forties. I started to routinely get sick, primarily sinus infections. And and they were nasty ones, almost always required antibiotics. And so I would go on antibiotics for seven to ten days, and I would be fine for maybe two weeks, and then I was right back on them during time during certain times of the year. And there was just no there was just no relief for that. And over time then, they began to get more severe and more frequent. And then into my mid forties, I actually applied my early, I'm sorry, my early forties, they began to then progress into my lungs, and I started to get bronchitis and then pneumonia. And literally by the time I was my mid forties, anytime I give a science infection, it would turn to pneumonia. And then COVID hit and I had COVID six times in one year.

One of my best friends is a family doctor. And he was the one that was treating me all these years with antibiotics. And, you know, literally, we had to get the point where he was layering in up to three antibiotics at the same time just to fight off the infection that I was facing. And and he finally got to the point, and I think it was December of twenty one, where he said, I'm tired of seeing my friends suffer. And so I'm referring you to a hematologist. Now we had been looking for answers. I started going to a holistic doctor five years ago or, actually, seven years ago, went to a holistic doctor to try to find answers for all these science infections and being ill all the time and being sick. I just felt like crap all the time. Even when I wasn't sick, I didn't feel well. Had no energy.

My wife would tell you that, you know, literally, I get home from work and I I I maybe have dinner before I'd fall asleep on the couch. And and that was my life. And I was I was healthy, I was fit, I exercise. But I just felt like junk all the time. And so I went to holistic doctors, I went to specialists, you know, I I can't tell how many times I've been poked and prodded and had samples and tests, and scopes, multiple scopes, and I've had liver liver biopsies, I've had my lung scan.

I don't know how many times. I'm probably a walk in radiation machine. And so because just trying to find answers to what's going on, I've had my sinuses exam, MRIs, CAT scans, you name it. I've had it done. No answers.

And and so blood work was usually fine except for platelets, but my blood work was always normal except for that. So December of two thousand twenty one, my friend says, I'm my my doctor friend says, I'm tired of it. I'm gonna I've sent you a hematologist. And I said, do

you think I have cancer? And he said, I don't, but I don't wanna rule anything out at this point.

But he says, you're just getting sicker and sicker and you're getting more severe, more frequent, And he's like, and, you know, we're at the point that I'm afraid you're gonna be resistant to all antibiotics. And so he said, we gotta we gotta figure something out. So, we're to a hematologist, and he did a whole series of blood work. Well, one of the things that he tested was IgG. Now interestingly enough, my holistic doctor, I sort of seen, like, five years prior to that, tested me for IGA.

I had none. It kept consistently coming back to zero or less than five or whatever the writing was. And so so that was always a red flag. It's like, okay. Well, I explains maybe some stomach issues.

So, you know, I've always had issues with my stomach and bowels on the chest. Anyway, so this hematologist studies, takes a whole bunch of tests and tests for IgG. It comes back at zero. And so at that point, he said, okay. He's like, I don't think he's like, you don't have cancer, but he said, this is this is not in my wheelhouse.

I'm referring you to an immunologist. And he said, there's something wrong with your blood. And he said, I he said, but I don't know what it is. And so I had already been seen this asthma allergy, a doctor as well. Again, trying to figure out answers.

One one more doctor in my list. And so I called him up and I said, hey, are you are you also an immunologist? And he said, actually, he says, I am. He said, I just don't amortize so much because I can't make money at that. But he says, yes, I'm actually an immunologist and I prefer that.

And so I said, okay. I got one for you. And he said, I don't know what's going on. And so first thing he did is he tested all the IG's. It came back to zeros across the board.

And he's like, oh, that's interesting. And so so he said, I think you have something called CVID. And he said now, he said interestingly enough, he said the replacement therapy is IgG Infusions. But he So then he explained to me, he tried to explain to me. He said, what happens is, he said, you base actually have only half of an immune system.

He said, the Igs are your body's army. He's like, you don't have an army. He's like, you have the special forces with the t cells. And so he says, so when the body doesn't have the army and they have the special forces, then the special forces then are called in to do with the army, is supposed to do. And he's like, but they do it.

They don't do it efficiently, and so you get sick all the time. And unfortunately, then what happens is your t cells are distracted, and that opens the door to cancers and other things that will eventually take you out. And so he said, so you there's no wonder you're getting sicker and sicker and sicker and he's like, unfortunately, if we don't start something, he says your lifespan is gonna be very short. And so so we immediately started to do the research answer the application process with the insurance, which they denied it denied it

denied it. It took us six it took us almost six months fighting with the insurance. Before they finally approved it, I can't tell you how many appeals that my doc made. Actually had two different doctors making appeals. They were interviewing. They were demanding the review process. And finally, it got approved. And so in July of twenty two, I had my first treatment. And and it wasn't pleasant. I had pretty severe reactions for the first, I'd say, six to eight weeks, a lot of dizziness, a lot of nausea, and I had the, I had the subcutaneous treatment through IgG. And my initial dosing was seventeen grams a week. And that's which is now it's twenty grams a week. We upped it after a year. So twenty grams a week, every week for the last two and a half years, two two years and three months. And here's the thing. I have not been sick since.

**Narrator:** Following his diagnosis of CVID, Matt's immunologist referred him to doctor Charlotte Cunningham Bundles of Mount Sinai in New York in order to confirm the diagnosis and treatment plan. Today, Matt is healthier than he's ever been. He has written two books on leadership called unsatisfied and unengaged with a focus on the importance of valuing relationships and vulnerability over unsustainable growth. He is also understandably a passionate advocate for the inclusion of immunoglobulin testing during routine blood panels.

**Matt Lesser:** I'm grateful. I wasn't grateful at first obviously, but I am grateful that I'm grateful that I had ITP. I'm grateful that I went through this depression. You know, you asked me earlier what these what these have taught me. Going through the depression, you know, in in addition to teaching me that I need to rely on people and trust other people, it also taught me a level of so humility there, you know.

And by nature, I'm not a humble person. So, you know, literally, it was if so when God wants to get my attention to history, I said that I've said that I have the two by four. As I get older, I'm trying to say, teach me before you hit me. Will you please? But anyway, it's but humility and empathy.

K? I believe that we're all humans on a human journey. And the more that we can be real with each other and, you know, open up our lives and be authentic and transparent. I think the better we can help each other. It doesn't do any good for me to sit here and say that my life's all grand and wonderful and everything is coming up roses when it's not true and it's not true for anything.

Right? We all have stuff. All of us do. And the more that we can share our stuff, I think the better we're all as humans.

**Narrator:** Your support of the immune deficiency foundation helps ensure that people like Matt have the diagnosis treatment, and quality of life they deserve. To donate, volunteer, or learn more, visit [primaryimmune.org](http://primaryimmune.org).

