# Primary Care Cures
# Episode 103: Brianna Greenspan

Ron Barshop:
You know most problems in health care are fixed already. Primary care is already cured on the fringes, reversing burnout, physician shortages, bad business models, forced buyouts, factory medicine, high deductible insurance squeezes the docs and is totally inaccessible to most of the employees. The big squeeze is always on for docs. It's the acceleration of cost, deceleration of reimbursements. I want you to meet those in this show that are making a difference. With us, Ron Barshop, CEO of Beacon Clinics, that's me.

Ron Barshop:

There are mega forces that are forcing change, probably in this presidential cycle. Number one, the US owes $27 trillion in these annual deficits, and more than six trillion a year are creating a Banana Republic financing structure that's going to force a bigger piece of the federal pie towards interest. It's clearly unsustainable, these ever-increasing payments.

Ron Barshop:

Number two, 48% of every federal dollar directly or indirectly is spent on healthcare, according to a John Hopkins study. By the way, Mr. Hopkins it turns out, was a slave owner. So I suspect that institution is going to have to change its name. What do you think? Anyway, that's also unsustainable, 48% of every federal dollar going directly or indirectly on healthcare. It doesn't work. Medicare and Medicaid are essentially broke in the next four years, that's this presidential cycle. And over half of all Americans, according to the Social Security Administration, make under $14 an hour. Most of these don't have the scratch to make their deductibles much less their premiums. So they're functionally uninsured. I think a lot of the anger on the streets is people that cannot get into this treehouse of care among other things. It's not an American dream anymore.

Ron Barshop:

Another structural change is that medicine simply has to change because a third of the workers that are functionally uninsured are not going to get to see a doctor, their health is going to decline. And docs are retiring due to this crisis, this pandemic, in record numbers due to the pandemic and is forcing 28 states to equalize mid-levels and digital first and virtual care are flourishing. And we are reliably getting less healthy and individually, as I said earlier, as a nation and feeding this big transaction care machine. The good news is that there are a few models that sidestep this well.

Ron Barshop:

And that's actually the function of this podcast is to present those to you and introduce those solutions. And it is changing, is the good news. There are millions in patient count that are embracing these new models. I'm estimating somewhere between 20 and 30 million, but it's hard to tell because there's no association for these digital first programs. And they sidestep the middles and I've been doing it for several years myself, and I'm estimating, as I said, 70 to 20 million because we've had Medici that's 13 million. Crossover Health is over a million, 98point6 is over a million with Walmart, One Medical. These are all examples of virtual care using mid-levels and onsite and digital care. And then every Silicon Valley is jumping in the game now. You know all the names, LinkedIn, Amazon, Google, Facebook, Apple into it, and value-based care may replace fee-for-service as deals go public like Oak Street and ChenMed thrives. VillageMD just cut a billion dollar deal with Walgreens.

Ron Barshop:

So the benefit advisors who can't disassemble these the plans and sidestep and reassemble direct contracts with the healthcare system are going to thrive in all this change, costs have to reverse, health has to improve and reverse too. With that, I am really excited to introduce you to today's guest, Brianna Greenspan is a genetics consultant and author who was born with a chronic illness that went undiagnosed until her mid twenties. She was in a wheelchair and today is not in wheelchair, for six years.

Ron Barshop:

Defying the logic of doctors and the temptation to be a victim, Bri has dedicated her life as healing herself from a wheelchair to a semblance of normalcy. And now is daily empowering others to take ownership over their own physical, mental, emotional, and spiritual health. Her health journey sparked her thirst for knowledge in neuroscience, mindfulness, permaculture, appreciative inquiry, facilitation, ancient healing methods, and habit stacking to increase vibrational frequencies. She was also a co author of multiple books, including one with Miracle Morning Series. Her life's work is centered around using her superpower as a master connector to facilitate all the good she can in collaborative settings to uplift global wellbeing, mainly focused in medical genetics, and education. So Bri, welcome to the show.

Brianna Greenspan:

Thank you so much, Ron. It's an honor to be here with you.

Ron Barshop:

Well, you were actually harder to get on than the former CEO of Apple. So I should be the one that's honored to have you.

Brianna Greenspan:

It's just that I'm shy and I've always been nervous to share my story and I'm grateful for you inspiring me to do so. So thank you so much for having the patience to wait until I was ready, and now I'm very excited to be here with you.

Ron Barshop:

All right. Well, so let's start with talking about Danlos syndrome and others like it. What percentage of, is it white females that have these rare diseases?

Brianna Greenspan:

So there's a huge percentage of the population that have undiagnosed or invisible illnesses. And within that, there's this realm of connective tissue disorders, and Ehlers-Danlos is one of them. And so I, and many, many others go undiagnosed or misdiagnosed for years and years and years before a genetic explanation for what we experience has been identified.

Ron Barshop:

Didn't we just have one of the finalists on The Voice come out with Ehlers-Danlos syndrome?

Brianna Greenspan:

I believe so. And that's actually a huge win for the EDS community. They call us medical zebras because we're basically hidden in plain sight. And for someone to be on a national stage sharing that they have this condition, it's really validating and exciting because it's not that we're rare actually, it's that we're rarely diagnosed. And so the more awareness that is possible, the better chances that someone's going to get diagnosed significantly younger than what happened to me, which was, I wasn't even diagnosed until my mid-twenties.

Ron Barshop:

So here's the wild thing is that there really aren't any specialists that specialize in diagnosing this type of disorder. You go to the EDS websites, they'll give you 16 different kinds of doctors you got to go to, to figure this thing out. There's not any specialty that knows how to do this.

Brianna Greenspan:

Yeah. And that's part of the challenge within healthcare. For Ehlers-Danlos specifically, it's a connective tissue disorder that affects the collagen in my body. And as a result, anything from dislocations to chronic pain, to gastrointestinal issues, to rheumatological issues, to everything in between is happening all at once. And so patients will go to the eye doctor, the ear doctor, to the general practitioner, to the urologist, to all these different specialists and talk about their challenges. But those specialists aren't really communicating and they're not really putting the pieces together. And so there isn't one subspecialty that deals with rare and chronic illnesses, and there isn't one that just takes on specific conditions. And so sometimes it would be a rheumatologist or a geneticist who might diagnose a patient, but there's no one type of subspecialty that we can go to, to get proper care, at this point.

Ron Barshop:

So you and Josh have developed a really nice friendship with me and Terry over the last, really since this pandemic. And what I've learned from you is some days that we plan to do things you have to cancel because you can't see that day. What are some of the symptoms that come up for you where your body's not cooperating?

Brianna Greenspan:

The eye inflammation is such a challenge. But when you say that, what really comes up for me is that there are so many spontaneous challenges that I'm basically fine until I'm not. And I might cough and dislocate a rib, I might cough and dislocate my neck. I might eat something and immediately feel very uncomfortable, whether I'm physically bloated or I start throwing up. There's just all kinds of challenges that I plan for the best, but also know that sometimes I'm just going to have to opt out when I'm really unwell. And so I'm really grateful for you for understanding that and being flexible to the times that I've had to cancel. And it just happens sometimes, but that's part of living with a chronic illness.

Ron Barshop:

You do some very unusual things that aren't reimbursed by healthcare, that they help you feel better. Some of it is frequency vibrations. Is that sound, or is that energy or what type of treatment is going on there?

Brianna Greenspan:

Yeah. Sometimes I use Rife technology and I do something called concussion treatment and it rebalances my body so to speak. But I also use a variety of different modalities, whether that's biofeedback or neurofeedback or craniosacral therapy, or neuro-linguistic programming, none of which are covered under insurance. Consistent physical therapy, which only a very, very small portion is covered under insurance, which is kind of the joke of all jokes, because if someone has Ehlers-Danlos syndrome, we actually need to be in physical therapy our entire lives. But insurance companies don't really understand that fundamentally. And so they might cover six sessions or 12 sessions or 20 sessions or 40 sessions, depending upon if you've just had surgery or not, but they don't fundamentally recognize the illness that I have and how I need to receive consistent treatment in order to be able to consistently walk.

Ron Barshop:

Now your morning consists of several hours of program things you have to do every day, just to build your foundation to operate that day. Tell us a little bit about what your morning looks like.

Brianna Greenspan:

Yeah. I actually do something called the miracle morning, which has six habits, something involving silence or meditation, affirmations, visualization, exercise, reading, and journaling, scribing. And within that, I take the exercise time and I do my physical therapy, which varies from day to day. If I have just dislocated my neck and I'm really struggling, I'll be doing a variety of neck exercises. If I have a lot of plans that day, I might do a very structured, basic physical therapy routine that I know is going to strengthen all of my joints.

Brianna Greenspan:

I basically pick and choose what habits to incorporate outside of the savers every day, based on how I wake up. If I wake up debilitated, sometimes I wake up and I have such eye inflammation that I'm not able to open my eyes, and that takes a very long time. I clean them with Cetaphil, I put something called Theramu in them. I have to be in a dark room until the inflammation calms down. And so every day is a little bit different, but I definitely spend a large amount of time grounding myself and getting as strong as possible to be able to take on the day.

Ron Barshop:

And then your diet is also super critical and functional to your day's success too, right? You know when you're slipping and you know when you're not.

Brianna Greenspan:

Yeah. And the awareness of how important my diet is really came for me, starting a symptoms journal. Years and years ago, somebody said to me, "Can you write down all the symptoms that you have for a week?" And with that, I started noticing how does food make me feel? Because when I was younger, I just thought, "Oh, I throw up every day. Every time I eat, I throw up," which was my normal. But when I realized that that shouldn't be anybody's normal, we should actually be using those moments to reflect on what are we consuming or what are we doing that we might want to eliminate or shift or rethink in order to have a different response.

Brianna Greenspan:

And so I had to cut out a lot of things that didn't serve me, especially fake food, anything that's in a package or anything that has chemicals or dyes or thickening agents. My body doesn't really enjoy those. So I might have an immediate reaction in my gut that you can literally see, or I might have a reaction that happens later on, that causes widespread inflammation and pain. And after I recognized how food is a huge trigger for me, I just decided, how could I eliminate the things that make me feel awful so that I could feel better more often?

Ron Barshop:

There's a simple blood test that can diagnose this isn't there?

Brianna Greenspan:

Unfortunately, there is not. That is part of the challenge. There's a bunch of different subtypes within Ehlers-Danlos syndrome and the most severe type, there is a genetic, which is called vascular Ehlers-Danlos syndrome. That is something that you can get a test for, a genetic test for, but hypermobile EDS, and a lot of the other variants of EDS are not diagnosable with a genetics at this point. And so it was a huge blessing because I'd heard that for many, many years. I was clinically diagnosed in my twenties. And everybody said, "There's no point in taking genetic testing because your type of condition isn't currently something that we can find in an exome test or in a point mutation test or in a panel." But actually, I eventually took a whole exome test and it did diagnose the classical EDS that I do have. And so that was a huge eye-opening moment for me. However, I know what you are thinking of, and we can get to that in a moment because that's really more my job versus the condition that I have.

Ron Barshop:

All right. Well, let's talk about that.

Brianna Greenspan:

Yeah. I work for a genetic testing company called Gene by Gene, and we are the collaborator of the National Institute for Allergy and Infectious Disease for a condition that they discovered called hereditary alpha tryptasemia, which is quite frankly totally fascinating to me on a personal level because hereditary alpha tryptasemia mimics the symptoms of Ehlers-Danlos syndrome, and of something else called mast cell activation syndrome and a type of dysautonomia.

Brianna Greenspan:

And as a result, the people that have hereditary alpha tryptasemia feel very similar to the way that I feel. So I have a lot of empathy and an instant connection with the patients that we work with. And there is a simple genetic test to be able to diagnose if you have extra copies of tryptase. And so I work with a lot of researchers and physicians, specifically immunologists and allergists, who are identifying patients that were previously completely misdiagnosed. Often, patients that need an EpiPen, they go into some kind of anaphylaxis and we're now properly diagnosing them. We're elevating their diagnosis to let them know the reason, that there's an interesting correlation between the symptoms that they have and them having extra copies of this thing called tryptase.

Ron Barshop:

So you had told me the numbers of, I think you said Caucasian females that have these mimic diseases. What are we talking about, the numbers?

Brianna Greenspan:

So with hereditary alpha tryptasemia specifically, they're claiming that between 4 and 6% of Caucasian people have an extra copy of tryptase or more, which is a huge amount of people, especially if they're all misdiagnosed and suffering in silence, most of which need EpiPens who find themselves in the emergency room and up against doctors who have no idea what to do to treat them.

Ron Barshop:

So can they work? Are they on disability? Are they able to get disability? Are they considered a minority that or a population that can get disability?

Brianna Greenspan:

Well, so a lot of these people are misdiagnosed with other conditions. And as a result, a lot of them are already on disability. However, getting disability for this specific condition is a complicated one right now because there's no official diagnostic code for hereditary alpha tryptasemia. It's a new condition that the NIH discovered six years ago. And since then, there have been nine supplemental papers published globally, which you can look up on PubMed. And now they have submitted to the CDC to get an ICD-10 code, but they're in public review. And so basically until there's an ICD-10 code that officially recognizes hereditary alpha tryptasemia, patients won't be able to get benefits for this condition specifically, even if they might be on disability for something like dysautonomia or Ehlers-Danlos, or mast cell activation syndrome.

Ron Barshop:

Right now, taking care of your fellow sufferers is almost like the underground railroad. You guys sort of have a network, they find you, you're able to give them some functional ways to get their day started like you're doing, things that have worked for you. Tell us a little bit about your daily journey with different patients that discover you.

Brianna Greenspan:

Yeah, that's absolutely correct. It's like the underground railroad. And a lot of the patients that find me, they come in either through a rheumatologist or an anesthesiologist that I work with that specifically refer me some of their most challenging cases. And they say, "Hey, can you please help this patient? It would be life changing." The other way that people find me is through the genetic testing company that I work with. If they've taken one of the hereditary alpha tryptasemia tests and they have questions, they end up finding me. And what's beautiful about that is the overwhelming response that I get is at the end of our call, people will either cry or they let out a sigh of relief and say, "I've never met anyone who made me feel seen or heard or had anything useful to say that gave me hope that I'm on a path that I can curb."

Brianna Greenspan:

And that's really what my aim is to provide people with the same resources, therapies, and tools that I know of that have helped me be able to walk, talk, see, hear and breathe more often than before, because the truth is there's tons of different things out there that can help us become stronger, most of which are not covered under insurance. But they're out there and if we could just share that wealth of information with those who are suffering, maybe we could ease the burden of suffering. So in the name of synchronicities, these people that really need me the most magically find me and I spend as much time as I can helping each one of them on their journey. And it's really a blessing each day because I never know who's going to call or who's going to reach out. And it's my honor to help them in the ways that I had wished someone could have helped me when I was a kid.

Ron Barshop:

Are there any symposium or continuing education, continuing medical education, on this subject so that doctors can learn more about what are the symptoms and how to find, how to spot them and what doctors to send them to? Because I'm sure there's got to be a few functional medicine doctors, or maybe even homeopaths that can handle this well.

Brianna Greenspan:

So for hereditary alpha tryptasemia, at this point, there is not, although a continuing education class is in the works for 2021. I think that will be available with AAAAI, The American Academy of Allergy, Asthma & Immunology. Once it is out, it will be available to their swath of physicians. However, that's really my highest hope, is that there's more education for physicians on a global level so that we can really move the needle on best practices in healthcare. It's a slow process. As you know, there's a lot of red tape. But behind the scenes, that is part of what I'm working on.

Ron Barshop:

And by the way, I know personally from our friendship, that you don't get paid for doing these consults. This is something that's like you're one of these angels walking the earth that are just there to ease the pain and move on. You don't expect anything in return.

Brianna Greenspan:

That is correct. I do not take any payment. And quite frankly, I feel like it's my honor to be able to support these people. One day, I really thought to myself, what do I wish I would have gotten, as like my ten-year-old self who was in a back brace and walked with a limp. Not because I had a limp, but because they literally created a custom back brace that went the entire length of my back. And then there was a metal bar that went down my entire leg and then a brace that wrapped around it, because the orthopedic specialist was trying to fuse my spine, which eventually did not work. And I ended up having a surgery. But back then, that little girl inside of me wished that someone had said to my mom, "Here's 10 different things that you can do to help your daughter get stronger."

Brianna Greenspan:

And for me to be able to do that for someone else, there's no amount of money you could possibly pay me for that. It's a priceless service. And also, a lot of these patients spend an exorbitant amount of money searching. And these therapies, especially the ones that aren't covered under insurance, the things that I'm telling them that they might need, it's exorbitant amount of money that they're going to spend on their illness to wellness journey. And so for them to be able to use that money, instead of paying me, to be able to actually get the therapies that they need, that's my highest hope. And so I have a job, as I said. I work for a genetic testing company building out this hereditary alpha tryptasemia condition. And anything that I'm able to do to serve patients is really just a blessing.

Ron Barshop:

Happily ever after is that I know Brianna's fiance, and he looks just like Nick Jonas, I don't know if he could sing like him or act like him or dance like him, but he is certainly one of the nicest guys and smartest guys you'll meet. So there is a happy ever after for the little brace kid.

Brianna Greenspan:

Yeah. It's actually such a blessing that you mentioned that because when I was younger, my mom was always very worried, "Who's going to love her when she's so sick all the time?" In between no seizures and throwing up and crying myself to sleep in pain and waking up with crazy inflammation and waking up with crazy allergic reactions and hives, just all of these things happening all the time. She just was very worried. Is that going to be the deterrent from somebody actually deeply loving me and caring about me? And I'm so grateful that I found Josh and he's so sweet through my challenges. So yes, a happily ever after.

Ron Barshop:

Is there a association or a loose association of angels like you that are also helping others with their chronic diseases that are invisible?

Brianna Greenspan:

Yes. A loose association, yes. And I personally know of a few other people that, whether they're Facebook support group leaders, whether they have their own nonprofits, whether they are just the sidekick to really brilliant physicians, they might call themselves wellness consultants, they might have a book. But there's definitely people in many, many, many different chronic rare disease communities that have found things that work, that have made themselves stronger and that are currently actively working behind the scenes to support others with similar issues, just out of the goodness of their hearts. And so, I pray that everybody who has a challenge is able to find someone who's ahead of them on the journey who can guide them along.

Ron Barshop:

And yes, you name the condition, there's somebody out there and maybe you don't know all of them. I'm sure you get conditions that are similar, but you can't help them and maybe you know who to send them to, or at least the direction to point them.

Brianna Greenspan:

Yes. Actually on that note, if there's somebody who's really struggling, who has a rare condition that they've never met anybody that has it, there's a place called The Mighty, themighty.com, which it's like chicken soup for the soul, but for sick people. And so what's so beautiful about that is that they have representation of all 7,000 rare and chronic illnesses on The Mighty. And it's just a mommy blogger or someone like me, who's sharing a story. And at the bottom of the story, it normally links to their website or their company or their book or their nonprofit. And so not only do you find a lot of connection because the stories really resonate with people that have those issues, but also you can easily find those people and connect with them in other worlds.

Brianna Greenspan:

And there's another great resource, it's called PatientsLikeMe, And that's like Facebook for sick people. And you can literally go on there and you can put in all your data, like I was diagnosed with Ehlers-Danlos at 23 and mast cell activation at 27, and I took this medication and did this therapy. And you can find people all over the world that have the same or very similar diagnostic journey that might be taking the exact same medications. And it's really beautiful to see how, when you input so much data, you can find others going through similar things and really find a lot of comradery there. So I recommend those two.

Ron Barshop:

Okay. Those are great resources. Thank you. I'm not going to say healthcare failed you, but American healthcare by itself would have failed you. You've had to rely on other inspirations and other types of medicine to get you through your day. Can you talk a little bit about that?

Brianna Greenspan:

I will say that healthcare failed me, honestly. I was a medical guinea pig. My parents knew from a very early age that there was something wrong with me. I never stopped crying until I could talk. The moment I started talking, I said, "Ouch, there's a problem. There's a booboo." And it was very clear to my parents that something was wrong, but also there was no one to turn to. And it didn't matter how many specialists I saw, they each just had another pill or a shot or a surgery or an assistive device. You had mentioned a wheelchair before. And I will clarify and say that it wasn't just a wheelchair. There were neck braces and back braces and wheelchairs and walkers and assistive devices of all kinds that I've had to use during challenging times. And none of the doctors that I saw really had any clue.

Brianna Greenspan:

And finally, when I did go to an east-west medicine doctor, she was the first person that ever put it together. And she said, "I think you have Ehlers-Danlos syndrome. Now I want you to go to a molecular geneticists to confirm that." And from there, even, we got one of the puzzle pieces and I was so grateful. But nobody said, "You need to change your diet. You need to start doing craniosacral therapy. You need consistent physical therapy." Nobody was saying the tools to success. And so I feel like there's a huge gap between patients getting diagnosed properly and then patients getting proper guidance on how they can effectively manage their challenges.

Ron Barshop:

I want to know, if people want to be able to find you Brianna, how do they find you? Can they find you on Facebook or LinkedIn or what's the best way?

Brianna Greenspan:

Yeah. They can find me on Facebook or LinkedIn. I'm very low key. But if you have a chronic illness, I'm pretty open and available on both of those platforms.

Ron Barshop:

Okay. So you have to tell the story before we sign off on how you and Josh got engaged, because I've witnessed you handing out these cute little pop outs to everybody at a restaurant when we go there, all the waiters or waitresses, all the cooks. You have this unique ability to sort of light up a place when you go somewhere. How did Josh propose to you with these little?

Brianna Greenspan:

Oh my gosh, this is such a good story. So for the last 10 years, literally before my EDS diagnosis, I made a decision, right after I learned to walk again, that I was going to spread as much joy as I could, to as many people as I could. And with that, I started finding these cute little things, which are now known as pop-open cards from a company called Compendium, which is live-inspired.com, and they have inspirational messages in them. And they've got smile cards and hope cards and believe and love and dream and all these different cards with messages in them. And so I was just the cute girl that gave out these happy cards to waiters and waitresses and all these people that I would meet on my journey. I called them the people along my path, and I just want to spark joy wherever I go.

Brianna Greenspan:

So this was just a little something that I did for probably eight years consistently. And then at one point I got into sustainability and I thought these cards are are actually killing trees. I can spark joy in other ways. And that was the end of that, and I never really thought about the cards again. And then I met Josh at a business meeting and he asked me for my address. And a few days later, a box from Compendium showed up and I opened it. I knew the brand. I knew this company very well. I had these beautiful memories flooding to me of giving out these cards and I opened the box and it was a box of smile cards. And I immediately called him and said, "Oh my God, why did you send me these?"

Brianna Greenspan:

And he said, "I've been giving these cards out all over the world for the last year." And I said, "Really? I was giving out these cards for eight years and then I just stopped last year." So this is a sweet little thing between the two of us. And so from that moment, we together started giving out these cards. And eventually when he decided to propose, he reached out to the CEO of the company and he had them make a custom smile card. And we were at an event and he had this musician call me up on stage. And the musician said, so serendipitously, I had just given out cards to the musician and everybody around us, just not knowing what he was about to do. But this musician said, "Because you've just given me this card, I want to give you a card," and hands me the smile card. Calls me on stage, hands me this card.

Brianna Greenspan:

And I open it and it says, "Brianna, here's something to keep smiling about. Will you marry me?" And my jaw dropped and I was shocked and it was so beautiful. And he later on said that everybody at this company knew my story, that I'd been giving these cards out for years and that they were so excited to make a custom one to solidify our relationship because we were like the happiness facilitator couple. And yeah. So I still give them out, so does Josh, and it's such a sweet little thing that he went above and beyond to create this memory for us based on memories that we individually had and we have together, of spreading kindness.

Ron Barshop:

Well, I'm going to read your card as the banner. My trick question at the end of every visit is to ask people to fly a banner overhead and give a quote. And I'm going to give you this one. I'm going to give yours out, that you gave me. May life's greatest gifts always be yours, happiness, memories, and dreams. Can we close the show out better than that?

Brianna Greenspan:

So beautiful.

Ron Barshop:

Thank you. That's what you gave me. All right. Brianna Greenspan, we'll get you back on the show again soon. This has been great and I hope everybody learns something. I certainly did.

Brianna Greenspan:

Thank you.

Ron Barshop:

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