



# LOOSE CONNECTIONS

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# EDNF Becomes The Ehlers-Danlos Society

## Strength begins with hope: Ehlers-Danlos National Foundation Forms The Ehlers-Danlos Society As Next Step In The Global Fight Against Under-Diagnosed Genetic Disorder

**I**N AN INTENSIFYING BATTLE TO BETTER understand one of medicine's most vexing, misunderstood, and potentially dangerous and debilitating genetic disorders, the Ehlers-Danlos National Foundation (EDNF) announced today its evolution into The Ehlers-Danlos Society, a new global nonprofit umbrella organization devoted to worldwide advancement of Ehlers-Danlos research, patient care, advocacy, and social support.

### Ehlers-Danlos syndrome, medical mysteries for more than a century

Ehlers-Danlos syndromes (EDS) are a collection of heritable connective tissue disorders. Either directly or indirectly, EDS are known or thought to alter the biology of collagen in the body (the most abundant protein), which can lead to multi-systemic symptoms. Each type has certain physical traits and with notable exception to the most common form, the hypermobile type of EDS, most types have a known disease-causing gene.

There are physical characteristics that are common to all types of EDS, including hypermobile joints (joints that move in greater amounts than expected) and skin involvement, such as any of

the following: soft, stretchy, saggy, too thin, easy bruising, easy wounding, poor wound healing and/or atrophic scarring.

Each type is a distinct entity and may have very specific and unique features. It is highly improbable to have more than one type of Ehlers-Danlos syndrome, but as they have features and 'biology' in common, each type may appear to have variable features of other types.

### From one woman's journey to a global catalyst for discovery, community, and hope

Founded by Nancy Rogowski in 1985, the Ehlers-Danlos National Foundation (EDNF) filled a deep void for patients living with one of the most misunderstood and underdiagnosed syndromes in history. EDNF grew from one woman's tireless efforts to find others with whom to share emotional support, into a vital information link to and from the medical community. Often existing on a shoestring, the impacts of EDNF's contributions to the advancement of Ehlers-Danlos research, patient support, and public advocacy, have been felt around the world.

### Global impact from the start

As co-sponsor of the 1997 international Ehlers-Danlos conference in Villefranche, France, EDNF helped bring together the world's top medical experts to clarify the wide ranging types of Ehlers-Danlos syndrome, developing diagnostic criteria for each type. The subsequent report from this meeting was published in the American Journal of Medical Genetics, leading to the to a simpler and more uniform diagnoses of EDS.



A challenging fifteen years later, EDNF co-sponsored the 2012 Ehlers-Danlos conference in Ghent, Belgium to advance and update the work completed in Villefranche.

At a June 2015 follow-up conference in Glasgow, Scotland, EDS experts articulated the need for a global organization to coordinate Ehlers-Danlos research, medical education, advocacy, and patient care.

To further advance these efforts, EDNF, in partnership with Ehlers-Danlos Support UK (EDS-UK), committed to sponsoring the 2016 international Ehlers-Danlos symposium in New York to update the diagnostic criteria of EDS—and to develop standards of care which had never existed before EDNF.

Experts from the Glasgow conference joined forces with our initiative, and began assisting with the planning of the symposium, forming the initial structure that would lead to the creation of The Ehlers-Danlos Society.

## A brand new international organization—thirty years in the making

EDNF's final evolution began in late 2015, with the expansion of its board of directors to include international leaders in Ehlers-Danlos research, nonprofit management, fundraising, and communications, and the formation of a comprehensive international medical board comprised of the leading experts involved with the 2016 NYC symposium.

On May 1, 2016—to coincide with Ehlers-Danlos Awareness Month and the Ehlers-Danlos International Symposium 2016—the Ehlers-Danlos National Foundation, in partnership with EDS experts from around the globe, officially becomes The Ehlers-Danlos Society.

# Ehlers-Danlos Society Global Learning Conference

July 14-16, 2016



The  
**Ehlers  
Danlos**  
Society

Hilton Baltimore Hotel, Baltimore, MD

Join the EDS community for a three day event that will empower those living with EDS. Learn about the newest research—as presented at the EDS International Symposium for medical professionals—as well as how to become an advocate in your community. This event will feature an all new program of events, new speakers, new timing and more! Don't miss this opportunity to be a part of something great! [Click here to register.](#)

SPRING  
**2016**





# No longer invisible.

**F**OR TOO MANY YEARS, PEOPLE affected by Ehlers-Danlos syndrome have suffered quietly, fighting through each day with little hope, and even less visibility to the medical world.

As of May 2016, Ehlers-Danlos syndrome will no longer be invisible to the world.

Together, the people of the Ehlers-Danlos National Foundation have joined with an internationally renowned group of physicians, scientists, advocates, and health professionals to launch a global symposium to redefine the standards for diagnosis, testing, and clinical care – The Ehlers-Danlos Society International Symposium 2016.

To further advance our cause, our global medical advisory board will team up with some of the world's top patient advocates to launch The Ehlers-Danlos Society, an international non-profit organization united in our cause to strengthen the connections between Ehlers-Danlos patients, physicians, families, and caregivers in an effort to improve patient care – worldwide.

The Ehlers-Danlos Society will help those patients who wonder why their hips or joints were dislocated multiple times, why their skin tears and scars so easily or why they're often too weak to move. We will help those facing the long-term psychological impacts of Ehlers-Danlos: heightened depression from years of lacking validation, frustration that doctors think they're hypochondriacs, and social maladjustment from being held back a grade for excessive school absenteeism. It is for these people that the Ehlers-Danlos National Foundation (EDNF) was founded in 1985 and now thirty years later, we seek to extend our position as the leading organization for EDS information and resources in the United States to the entire world.

Together we can accomplish even more. Your donation enables us to:

- **EDUCATE** by providing educational materials in an effort to build awareness and understanding.
- **CONNECT** patients, physicians, and caregivers to share ideas and knowledge. With over 26,000 Facebook likes and more than 4,000 Twitter followers, we are poised to reach thousands and thousands more.
- **INNOVATE** through our partnership with the Greater Baltimore Medical Center (GBMC). We helped to establish the EDNF Center for Research & Clinical Care at GBMC's Harvey Institute for Human Genetics to care for patients, conduct professional education, and provide cutting-edge research for physicians throughout the world.
- **ADVOCATE** as the voice for EDS on the local, regional, and global stage, as we advance the need for government investment in Ehlers-Danlos research, awareness, and patient care, demonstrating through data and our personal EDS stories how policy changes can improve the lives of patients and their loved ones.

We're excited that 2016 has the potential to transform the EDS community. But it will take hard work, and your support, to turn that potential into reality.

Please join this effort by making a financial gift today! We promise that every one of your hard-earned dollars will be greatly valued and carefully used. Every gift counts.

Thank you for your support.

**Shane Robinson & Lara Bloom**  
Co-Executive Directors



# My Story

**W**HEN I WAS 25 I BEGAN TO HAVE debilitating pain that left me bedridden and reliant on my family for care. After leaving an abusive relationship, I decided to reclaim my life and find myself once again.

During this transition period, I worked very hard on my physical and mental health. With diet and exercise, I had gone from 240 pounds to 180 pounds in about five months. I thought losing weight would make me feel better but not only was it painful, I couldn't move my leg. On the days I thought I felt OK I would be going along just fine when out of nowhere it would feel like a knife was stabbing into my leg, twisting around and ripping out my insides. The pain would bring me to the ground, screaming and crying, unable to communicate with the concerned onlookers.

Was I OK? I was 25. There was no way I could be having pain. Was I just being a baby? I had a very high pain tolerance in everything that came before. I began to focus on where the pain was coming from. The majority of the pain was in my hips, traveling down my legs into my feet. My primary care physician had no idea what to make of this so she sent me to a specialist.

I waited months for the referral. Finally my prayers would be answered, I thought: The specialist would be able to help me! Instead he gathered all of his colleagues into the room and ordered me to perform "my tricks" while they laughed and told me I should join the circus because I was so flexible; I am double-jointed in every part of my body. Was this really the treatment I should be getting from a specialist? I should have known then that this was just the beginning and it was going to be a long ride.

Four doctors, two physical therapists, and \$8,000 of useless therapies later, I finally found a specialist who diagnosed me with congenital hip dysplasia. They told me I had a torn labrum, severe tendonitis of the hip, and a shallow socket that permitted my hips to dislocate with even the slightest of movements. They would do a surgery called a peri-acetabular osteotomy (PAO). At the time, this surgeon was one of only two in the US that performed PAOs. It was fairly new but had promising results, and it had been three years since the onset of my symptoms so I was desperate to try anything that would relieve this around-the-clock pain.

An incision was made into the skin, through the muscle, through the nerve, and into the bone. The pelvic bone was then cut in four spots, making it freely mobile and the head of the femur bone was reshaped. Lastly, the pelvic bone was tilted forward, and the femur is fit into the head of the joint. Three huge screws held everything together. A PAO is one of the biggest major orthopedic surgeries in existence. The recovery was supposed to be three months and then I would have my right side done, but it took three months for me to even move my leg on my own. I needed help with all of my self care, even to go to the bathroom. I was completely shocked at my state and although it was extremely discouraging, I hoofed on (a little zebra joke). It took six months to learn to move my legs and walk again. After a year of recovery, I would continue on with my new normal: constant pain.

I have had complication after complication with my original hip surgery. Two years went by as I told my doctors I was continuing to have excruciating pain. They ignored me and told me it would go away. I ended up going to a chiropractor when I herniated a disc in my back and after having taken the x-rays



he came racing into the room. Did I know my pelvic bone was broken—in three different spots? He told me no wonder I was in hideous pain; my bones had broken around each of the screws that were holding my hip together.

In 2013 I had my second surgery to remove the original hardware. I was told the recovery would be three weeks. Two more years went on with horrible constant pain before they finally agreed to do an MRI. The results showed the screws holding my hip together were now completely loose. I had my third surgery in 2015 to take the hardware out. Complications arose during surgery and one of the screws had to be left behind, still loose, still turning, still causing pain. My hip will never be the same. I will never get better.

I became a prisoner in my own body, a hostage on the roller coaster ride to hell. In 2011 they told me I would be better in three months. But I am now fighting for my life.

ER visits became a usual thing for me, whether it was a dislocation, costochondritis and slipping rib syndrome, blood clots, hematomas. All of my joints began to fail. I can no longer walk without a cane, and some days I have to use a wheelchair to get around because the multiple dislocations in my knees, hips, shoulders, and wrists are so bad, I am unable to move my arms or grip anything with my hands. At this point, I needed help with almost all aspects of my self-care.

I was finally sent to a geneticist, and in 2015 I was diagnosed with Ehlers-Danlos syndrome—my saving grace. I was so happy I wasn't crazy. There was something wrong with me, and it connected every weird problem since I was born.

But being diagnosed with an incurable chronic illness is an entire grieving process in its own. It is important to be responsible about recognizing signs and symptoms, but you also can't let it consume you. You can't let the fact that you will almost always know more than your specialist upset you. You have to stay positive even though there is no light at the end of the tunnel.

I began to find different ways of dealing with the pain like deep breathing, meditation, listening to music. It was tough but I was getting by.

In January 2015 I started becoming very ill. I was constantly sick to my stomach and couldn't keep anything down. I spent most of my days throwing up and didn't know why. By April I had lost 70 pounds, and I began to fear something was very wrong. My situation was becoming dangerous.

I set out on another search for yet another specialist. In June, I met with a gastrointestinal doctor. After taking my history and doing testing, I was diagnosed with gastroparesis\*. Ordinarily, muscles propel food through your digestive tract but in gastroparesis, your stomach's motility works poorly or not at all; my digestive tract was almost 100% paralyzed. I had to do something quick or a feeding tube would be in my near future. I had always been overweight my whole life and never thought for a second I would literally be starving to death. On top of everything my illness had already taken from me, it was now taking my body, my curves, my breasts. I stopped getting my period and couldn't stop the weight from coming off, and went from a size 14 to a size 0 in a matter of months. Friends would tell me I was lucky I was thin. *LUCKY?! I feared for my life! They couldn't possibly know what that felt like.* I spent most of my days with my head in the toilet, praying I wouldn't aspirate and die, holding my head up by my hair with the tightest grip I could muster.

I would give up anything to be able to eat again, to be able to look in the mirror and see my vivacious frame, instead of the sunken skeletal figure that was there now, but this is a distant reality for me. Like Ehlers-Danlos syndrome, there is no cure for gastroparesis and it can only be treated as symptoms arise. With medication, a new eating plan, and a daily shot to the stomach, I have been able to get somewhat of a handle on my illness.

In the beginning of this story I was a happy, healthy, outspoken young woman with a great job,

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\*Functional gastrointestinal disorders like gastroparesis are frequently a result of EDS — Ed.



my life's savings of \$25,000, and the world on my shoulders. I had infinite possibilities ahead of me!

I am writing to you now as a 29-year-old female with the body of an 80-year-old. I completely exhausted my savings accounts after the numerous surgeries, office visits, and medication. I had to quit my dream job that I loved; I am no longer able to work, and filed for disability at the age of 28.

I was let go from my most recent job after two years because they thought I needed to "focus on my health." I was told I could go home and not worry about anything – what a laugh. I had tried to keep my job for as long as I could. It was the last thing that kept me connected to the real world, and provided my full dental health and vision insurance, *essential* to my life. My parents have been helping me financially, but as time goes on, they are pretty much tapped out. I have thousands of dollars of medical debt, I am months behind on my rent and utilities, and I have no groceries or gas.

My illness has taken everything from me: my body, money, job, my positive outlook, independence, and friendships. I am lucky to have a family that loves me, and I have been blessed with an amazing boyfriend that does everything in the world for me, but they are overwhelmed. Loving someone with a chronic illness is not always easy and definitely not fair.

I don't write to get sympathy. Sympathy won't help me, it won't cure me or make me better, but I write I want people to know that this horrible illness exists and what it does to our lives. I want people to know that there are millions of fellow human beings who are suffering from this under-diagnosed illness.

Most of all, I want doctors to know EDS is more than just being flexible. If I have to, I will single-handedly wipe out all of the ignorance surrounding Ehlers-Danlos syndrome. It has now become my goal to create and spread awareness.

I don't spend a lot of time these days wishing for my old life back. I do take time to think about the future. With medical technology advancing every day, and with the help of others, there is no reason we should not be able to find a cure!

I know this has been a long story to read. It hasn't been the happiest story or the most positive story, but it is my story. It is my story and I will do whatever it takes to spread awareness. I only ask that you can join me in fighting for this cause!

**Sarah Daniels**





# The Zebra Revealed

**WHEN YOU HEAR HOOFBEATS, MAYBE** you *should* think zebras.

I was the little girl who couldn't catch a ball because it hurt her hands, who could never run fast enough, who was clumsy, and who was never picked for a sports team. The girl who was good at ballet, but whose mother made her stop, because, as she told my father, "It takes too much out of her." I always thought that was just an excuse; my mother really didn't want to be bothered taking me back and forth to the ballet lessons I loved. Now I realize my mother saw something in me for which she had no explanation; she acted on her instincts to protect me, and most likely saved me from injury.

I was the child who could never fall asleep: The TV was too loud, the bed was uncomfortable, I was too hot, too cold. My mother's response was, "At least you're resting," though I never felt rested. I was a whining complainer with constant stomachaches and many days of missed school, constantly skinned knees, dark circles under my five-year-old eyes, bruises, and a ceaseless dreaminess and lack of concentration. My mother admonished me daily: Stand up straight! I thought I was.

Once after another fall on the playground, I became so bored of explaining my skinned knees to my mother that I made up a story about being bitten by a dog. I must have been six or seven. I had never heard of rabies. Imagine my horror when my mother began frantically calling the school and the neighbors to find the dog that bit me. She wanted to kill it! Weeping hysterically, I interrupted her phone call to tell her the truth. I think then she must have wanted to kill me, but honestly I was so distraught at almost condemning an innocent dog to death that I can't remember my actual punishment.

I was the child who retreated into books. I became the teenager who smoked pot and slept instead of playing sports and going on dates. I never learned how to ride a bike or swim like my older brother did. I never had his energy, but then, he looked like my mother. I was the spitting image of my father—and my father was a sickly man. He died when I was ten. Complications of ulcerative colitis, they said. A hemorrhage. He bled to death. So my life didn't seem much different than his. I thought most people hurt, had trouble sleeping, and felt tired all the time.

As a teenager, I didn't think about it much at all. Oh, maybe I realized I wasn't as athletic as most people my age (I wasn't even good at Frisbee), but I took it in stride. I tried to fit in. I couldn't sustain a large group of friends, but I had a best friend and I went out on the weekends. I did well in school. But I slept a lot. I was depressed, but I was a teenager with no father and a working mother long before working mothers were the norm, so who wouldn't be depressed? I wrote a lot of angst-ridden poetry. I was artsy. I was unhappy. I thought all my problems were in my head.

I met the love of my life when I was eighteen. He was twenty-two. Our relationship was difficult because of the age difference. None of his "adult" friends wanted to hang out with a teenager. He wasn't especially thrilled to hang out with my high school friends. But we couldn't stay away from each other. He was my soul mate—not that I was the type to believe in such things. Maybe he was simply my perfect genetic match. Chemistry. We had it.

When we met I had just committed to attend an out-of-state college. He had just earned his bachelor's degree and was beginning a management-training



program at a local bank. We had been together less than a year when I left for college. We were young and resilient. We thought we could manage a long-distance relationship, even back in the days before the Internet, cell phones and Skype, back when long distance phone calls cost dollars per minute and I had to take his calls on the payphone in the dorm hallway. We wrote letters. We talked once a week. Neither of us wanted to see other people.

I couldn't do it. I fell apart. It wasn't just that I missed him. It took so much energy to make all new friends. I was exhausted all the time. I wanted to climb into bed and pull the covers over my head and never come out. It was so bad that the college refunded my tuition and sent me home after six weeks: depression, they said.

I was embarrassed and felt like a failure. At the time I thought I was just heartsick, but looking back I know that the stress of moving and being in a new environment triggered something. This was just the first incident in what would become a pattern throughout my life, times when my body refused to adjust to some new condition – or turned on me without warning.

I married my soul mate, and we had two children and a lovely life together. His strength provided the perfect counterpoint to my physical weaknesses. Even though I never had a name for everything I went through – migraines, colitis, fibromyalgia, chronic fatigue, chronic UTIs, allergies, and more) – he was there to support and encourage me. I had a good life: two kids with a few unexplained illnesses; a career as a homemaker because I couldn't juggle job and kids; and a master in yoga class!

I had two C-sections, so I never faced what my grandmother had, bleeding out giving birth to my father. I had a bowel resection that removed the stretched-out section of colon that failed in my father.

Sometimes I struggled to keep up with my family, and because I was often sick, deep inside I assumed I'd be the one to die first. It didn't happen that way. He died of cancer two months before our twenty-fifth wedding anniversary.

And my body reacted.

Everything got worse, a long downward slope. I'd spent years seeing various specialists and having tests and taking lots of medications, often in odd combinations (those doctors loved to prescribe medications). At times I didn't know what was a symptom and what was a drug side effect or a drug interaction. I was alone, sick, and scared. Doctors kept telling me I was depressed. I'm sure I was: you can't feel terrible all the time and not get depressed. But mainly, I was angry.

Doctors were all too eager to dismiss depression in a woman, particularly a widow, with a wide range of symptoms that amounted to being in pain and tired all the time. But I knew something else was wrong. I was mad at them for not hearing me, I needed a voice.

I was granted disability on my first application. I went back to college and earned an MFA in creative writing and publishing, thinking that I could write from home and have some sort of a career, not something someone with severe depression does. But I still had the fatigue and the pain was getting worse. The drug list was getting longer. I often spent days at a time in bed, avoiding any movement that would trigger my joint pain. I felt like I was an unsolvable medical mystery.

The pain got so bad that one of my doctors sent me to a physical therapist to ease my painful joints and muscles. The diagnosis was fibromyalgia syndrome and pelvic floor dysfunction. During the intake visit when the physical therapist was filling out her standard questionnaire, she looked me over and said, "You don't look like you have fibromyalgia. Has a doctor ever mentioned Ehlers-Danlos syndrome to you?" She had worked with Dr. Howard Levy's EDS patients from Johns Hopkins. I came to her as a horse; she saw a zebra.

That was when everything changed.

I began my journey to diagnosis at age fifty-seven. I moved from Maryland to California because I was so sick that I needed to be near family in case I was unable to care for myself. I waited six months



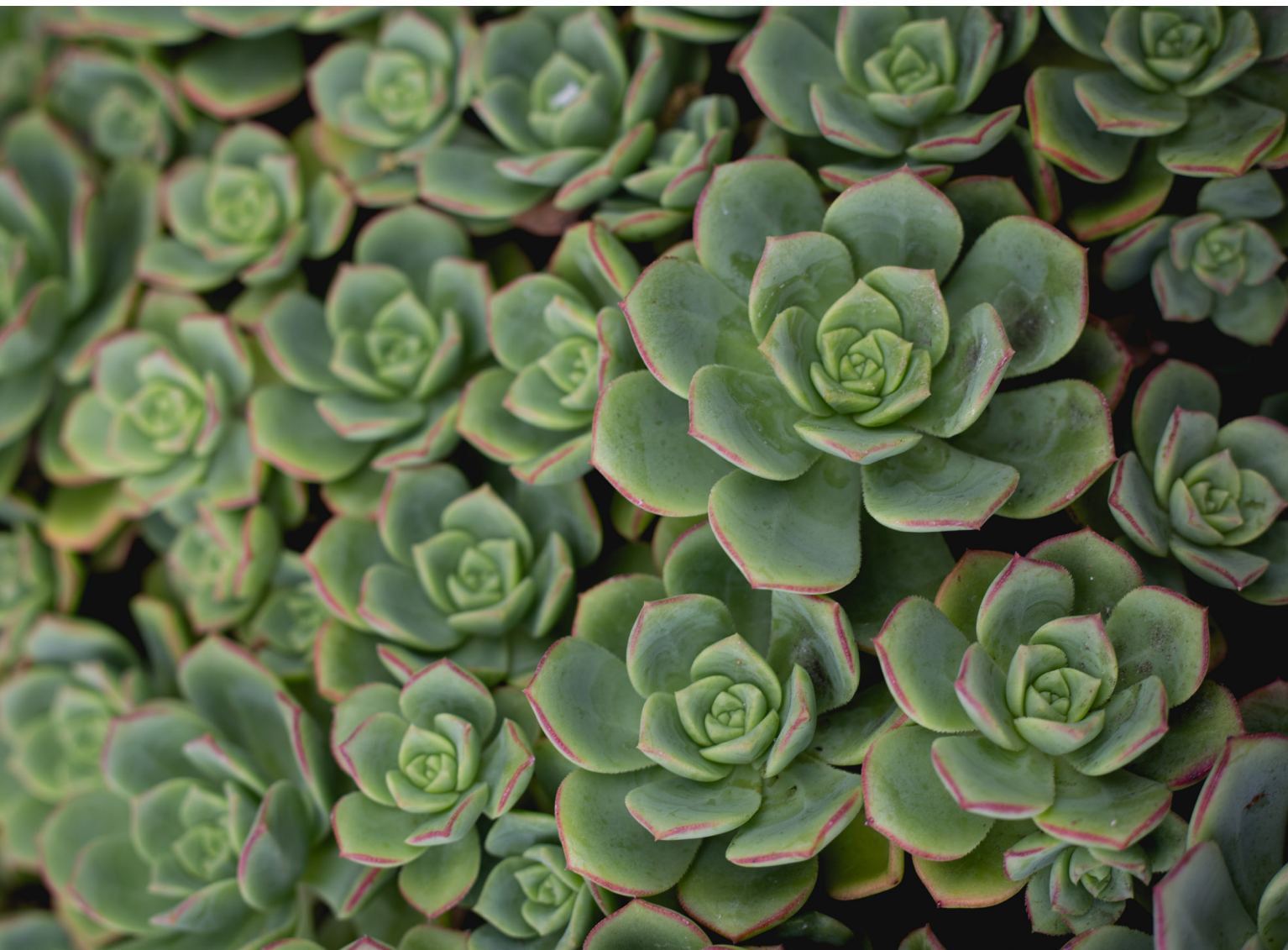
to see Dr. Robert Nussbaum at UCSF. I received a diagnosis of Hypermobile Type Ehlers-Danlos syndrome (HEDS). That simple act of reporting a diagnosis in my medical record has changed the way doctors treat me.

I am a zebra, not a horse. Now every seemingly unrelated symptom is viewed through the lens of Ehlers-Danlos. Before my diagnosis I had one primary care doctor tell me that their practice wasn't equipped to handle patients "like me." After diagnosis, doctors no longer throw prescriptions at me in futile attempts to cure my depression or stop my complaining. I receive appropriate pain management and physical therapy. I've learned to pace my life and live with my condition, instead of struggling to be like everyone else. I have a rheumatologist who has Classical EDS and, though treatments are scarce, she listens to me and searches for ways to improve my quality of life.

Throughout my life, I struggled to fit in. When I received disability, I told no one but my children; I didn't want people to think about me "that way." I lost friends because I never offered an explanation for my last minute cancellations, or declined too many invitations because I knew the activity would be too physically taxing to bear. I hid who I truly was.

This year I'm coming out as a disabled person, someone who is different. I'm coming out and coming to terms with the way my body is made, the way it functions, the pain I deal with every day, even though I look perfectly normal on the outside. I'm coming out at this late age because I didn't know that my struggles in life were due to a debilitating genetic condition. I have HEDS. This is who I am and this is who I have always been. I am a zebra who is no longer pretending to be a horse. Hear my hoofbeats.

**Catherine Maire**





# The Patient

**“A**LISON, CAN YOU TELL ME WHAT happened yesterday?” questions the psychiatrist. Reluctantly, I begin to reveal the events that lead up to this moment, me sitting in this oval shaped chair, talking to this old lady, who expects me to just pour out my emotions to her. Besides the fact that I don’t want to talk to her, I also don’t think she can handle it. Because honestly, I can barely handle it.

“The day started like any other day,” I begin. “The IV pump had woken me up. I laid in bed for a couple of minutes, with my eyes still shut, hoping that I could fall back to sleep. It didn’t happen.” The psychiatrist nods to show understanding. “Once I opened my eyes, I was suddenly sitting down in what I believed to be a classroom. The next thing I knew a teacher called on me, I was frozen.”

The psychiatrist interrupts me, “What was going through your mind at this point?”

“Well what would you be thinking about if this happened to you?” I answer sharply.

She says calmly, “This didn’t happen to me, it happened to you.”

She was right. I said, “I was asking myself where am I? What am I doing here? How did I get here?”

“What happened next?”

Without thinking I blurt out, “You ask too many questions! I’ll continue anyways. Then it hit me, I was sitting in my grade four classroom.”

“But how could you have gone back in time seven years?” the psychiatrist rudely interrupts.

“Whatever the reason was it didn’t matter because I was finally free. I could move without pain, breathe with such ease, and stand up without falling back down. Once my teacher called on someone else I asked to go for a walk. I had to figure out what I was going to do with this time.

“While walking in the hall I concluded that today was a gift and that I had to take full advantage of it. The first thing I did was enjoy the time I had with my school friends. Later that day, I had dance class. I was so excited to see everyone and to be able to dance again. When I got to the dance studio, I ran up to my closest friend and hugged her. She looked at me, confused. Then I remembered I would’ve just seen her two days ago. After that it was time to go into class. A part of me was scared because I hadn’t danced in so long, but the excitement took over and I began dancing. It all came back; the joy it brought to me, the outlet it gave me, the encouragement that I got from my teachers, and the fun I had with my friends. I wanted to cry, I hadn’t felt this way in so long. But I managed to hold the tears back and just soak in this night because I wasn’t sure how long I would be there.

“Once I got home my family was already asleep, so I didn’t bother waking them up, I figured I would see them tomorrow.

“The next morning I woke up back in the same bed, in the same hospital, with the same beeping from the IV pump waking me up. I was devastated. The tomorrow I had dreamed about didn’t happen. I tried to fall back to sleep hoping to wake up back in time, but that never occurred. I called the nurse in tears. I could barely get a word out. Then she made me come to see you.”

**Holdyn Bly**



# From the Editor's Desk:

## Reinvention

**REINVENTION: THE ACTION OR PROCESS** through which something is changed so much that it appears to be entirely new. To adapt into a different form; to give a new style or image to: "He had the ability to reinvent himself as needed."

Endings of any sort are hard to manage, and reinvention can be a scary thing to face, jumping into the future without a safety line. In these days, almost everyone reinvents themselves at some point in life; but reinvention is particularly difficult when one is diagnosed with a chronic problem like Ehlers-Danlos syndrome. What shape will my life be, how will my day-to-day change? Everyone, everything, changes. Everything becomes something else.

It's not a failure to accommodate the body you were born with. It's not surrendering to find activities and passions that you can also manage physically. I've reinvented myself several times. Normal people have to do it, too; we who live with EDS are just inherently forced to be more flexible about, well, everything. As Michael J. Fox has said, "Acceptance doesn't really mean you're resigned to it. It just means acknowledging that that's what it is."

In my early teens I was on a path to become a concert pianist; when faced with the offer of a tour in Europe, I realized that path, even if I could manage to be one of the successful one percent of pianists, would lead to its own early ending because of arthritis in my hands. For university, I reinvented myself first as an architecture student,

but I found I was having trouble standing at drafting tables for twelve hours a day, and anyway, theater seemed to call me. So I reimagined a future as a communications major before there was such a thing: a writer, an artist and designer, a performer, and a music director. The US Army ROTC scholarship program decided that didn't really fit for them anymore, which was fine—I was growing into understanding myself as a gay man, reinventing my social space. Somewhere in there I met the first person outside my family who had what I'd always been told were the "family joints"

but I had no idea what that meant or what the effects on us would be. I started discovering how outside the norm I was.

I found nonprofit theaters needed things other than art to survive, and people to do them. So I learned public relations and publicity for nonprofits, and over the next decade, more than I ever wanted to know about development and fundraising, and how to come through the struggle to exist. My first

reinvention was complete: I was no longer on the path to, well, anything I had expected. I was working during the days mostly for the business side of nonprofits, working nights and some of the days for the artistic side.

This held together for a while — until one rehearsal I suddenly found my left arm couldn't play. Once past that immediate crisis, I found in general my body, particularly my back, wasn't as reliable as it had been. So I moved away from playing music and took on a business in graphic design. And that

**The only way to  
make sense out of  
change is to plunge  
into it, move with it,  
and join the dance.**

**Alan Watts**



worked for a while. Until EDS presented me with a crisis one day, and I soon realized I could no longer be relied on, that I couldn't serve my customers who expected one day turnarounds because I couldn't guarantee deadlines. I kept acting for a while, but found I wasn't reliable on stage, either, walking into walls and unable to be precise physically any longer—which can be a danger to other actors, much less my own health.

This was probably my greatest self-reinvention, finding how to live in a way that accommodated my new status as a mutant. EDNF had been the reason I finally got diagnosed, and volunteering for EDNF meant I could manage expectations and create my own deadlines.

Here I am at the second, primary focus of this editorial. Everyone reinvents life as needed, and so do institutions. EDNF started as a membership organization from the dedication of Nancy Hanna Rogowski. After being told “no one else has this condition,” something she refused to accept, and saw the need for those of us with EDS, like her, to talk to each other and have a national voice in the US. Nancy formed the nonprofit in 1985, serving

as executive director. Local branches and support groups were chartered around the country, bringing together EDSers who had struggled in isolation. *Loose Connections* was there from the beginning of the foundation, as a printed newsletter sent to members of the foundation.

The first national EDS conference was in Chicago, 1988. The first conferences were small—by the third in 1991, the group gathered in Seattle had grown to a small crowd of 50 people.

THE OFFICIAL COMMUNICATIONS LINK OF THE EHLERS-DANLOS NATIONAL FOUNDATION



P. O. BOX 1212 \* SOUTHGATE, MICHIGAN 48195 \* (313) 282-0180

## PERSPECTIVES ON PAIN HISTORY AND CURRENT STATUS

**Introduction:** During the past year, we have asked for your input on what issues, relating to Ehlers-Danlos syndrome, you would like to see covered in *Loose Connections*. The single most requested topic is that of pain control and management. In an effort to publish timely and accurate information for you on this subject, we approached several pain management experts for advice, and have decided that this complex subject can not be covered in one or two issues of *Loose Connections*. Therefore, it is our plan to have a regular column on pain management. We will ask different experts to discuss assessment and management of acute and chronic pain. As always, we invite your input, because you are considered the best experts of all.

To start this column off, we approached Margo McCaffery, who, along with Alexandra Beebe, co-authored a nursing manual entitled “*Pain - Clinical Manual for Nursing Practice*”. The information contained within this manual is excellent, and though it was written for the nursing profession, the information is very timely and easily understood. Contact your local bookstore if you are interested in ordering a copy.

The Foundation would like to thank Margo McCaffery, R.N., M.S., F.A.A.N., Consultant in the Nursing Care of Patients with Pain in Santa Monica, California for her immediate response to

our request to copy portions of this manual for this article; co-author Alexandra Beebe, R.N., M.S., O.C.N., Founder and Director of InControl: Cancer Pain Care Associates in Washington, D.C., and the C.V. Mosby Company for their permission to use this manual in our first installment on pain.

### Historical Perspective on Pain Control

Traditionally, pain has been viewed as a symptom for which a cause is diagnosed, and pain is then eliminated by cure or control of the cause. However, during the last 15 to 20 years in North America, health professionals have looked beyond this approach to what can be done in the meantime to help the patient with pain. That is, how do we help the patient whose pain cannot be cured or controlled? Such a patient might have an end-stage illness, but the person might live for months with pain. The patient might have a normal life expectancy with a non-life threatening cause for pain, such as arthritis or peripheral neuropathy. How do we help people with these various sorts of pain? The palliative (therapy designed to relieve or reduce pain), as well as the curative (treatment designed to cure pain), approach is now seen as important.”

“Relief from pain has probably been a concern of mankind since the beginning of time, but health

## Loose Connections

THE OFFICIAL NEWSLETTER OF EHLERS DANLOS NATIONAL FOUNDATION

NANCY HANNA  
Executive Director  
SUSAN STEPHENSON  
Vice President

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West Point, Indiana 47992  
Phone (317) 572-2610

VOLUME 1  
NUMBER 2  
1986

PATRICIA HONEY  
Editor  
CHRISTINE TOPIC  
Assistant Editor

### NANCY'S NOTES Nancy Hanna Executive Director

Well, it has been about four months since I released the first edition of our newsletter. Look how far we have come. I am pleased to announce the appointment of Patricia Honey as *LOOSE CONNECTIONS* Editor, and Christine Topic as the Assistant Editor. Pat and Chris have done a terrific job. Chris is the person who came up with the newsletter's new name.

I am pleased to report that the Ehlers Danlos National Foundation is really on the move. On March 27th, a brief article about the Foundation appeared in a nationally syndicated newspaper medical column. This article kept me busy answering over 150 letters. Also, many State Medical Associations are beginning to print articles about our Foundation, and we are beginning to reach doctors who treat EDS patients. Susan Stephenson, our Vice-President, was subject of a very well written newspaper article in Richmond, Virginia. If you are interested in receiving a copy, please send me a stamped, self-addressed business size envelope.

Very soon, we will have pamphlets written by our Medical Advisors that contain information about Ehlers Danlos Syndrome. I will let you know when they are available.

Our first fund-raiser is already a success in Virginia, where Susan Stephenson is handling the details. A flyer about the VERNA CHAIR is included in this newsletter. Your tax deductible purchase will assist the Foundation's current educational programs.

In order to develop a stable relationship with the press, we need members to step forward and request interviews with their local papers. It is extremely beneficial to have press releases in our files when we are trying to establish our presence with the public. If you are interested in helping the Foundation in this manner, please contact me first for additional information about the Foundation and the disorder. It is imperative that you follow specific guidelines so that our non-profit status is not jeopardized.

If you have other skills that might be of use to the Foundation, please contact me. We are trying to establish separate and functioning committees in order to divide the responsibilities that a few good people are shouldering alone. If you can serve on, or chair a Fund-raising, Public Relations or Education Committee, please let me know. I believe that unity is the key to our successful growth. You each have specific talents that we can put to good use.

Last, but not least, I would like to take this opportunity to thank you for your support and encouragement. Our goals are being realized each time we are able to help someone. Soon Ehlers Danlos Syndrome will be a household word! Hope that you enjoy the newsletter. Please give Pat and Chris your support. They will do a fine job, but they need your ideas. Contact Pat for guidelines.

Thank you,  
Nancy

Ten years after the start in 1995, Nancy passed away. The foundation underwent its first reinvention. Nancy Regas, RN, MS, MFCC became executive director. “I have been part of EDNF since its conception; I have experienced its birth, its growing spurts and pains and now its rebirth. I am grateful to all those who have stood by the foundation and believed in its mission and its people. The foundation is bigger than all of us and only together will we tell our story. Giving heart brings hope for ‘A Brighter Day’ will be our motto and will carry us through good times and bad.”





Nancy Regas shepherded the foundation through surviving the loss of its founder, including the move of our office from Michigan to Los Angeles. As Board member Karen Czerpak said in the December, 1996 *Loose Connections*, "In 1995, after the death of our founder, Nancy Rogowski, the Board found themselves in dire straits. Nancy had pretty much run the entire organization on her own, with the help of her husband and her parents. We had no one in Michigan that could just pick up and smoothly transition EDNF into someone else's hands. Through a deep sense of devotion to the organization that had provided her with comfort, information, and new friends, Linda Neumann-Potash took a leap of faith and decided to quit her job as a pediatric nurse and take on the duties of running the Foundation."

Linda Neumann-Potash (now an Ehlers-Danlos Society Board member) took on the new Los Angeles office by herself, volunteering four days a week. There were no employees or payroll, just a determined will that Nancy Rogowski's dream wouldn't die. The first EDS bulletin board grew up, bringing EDSers together in the electronic realm for the first time. EDNF had its first tag line: "Together...We Will Find a Brighter Day."

Twenty years ago in France, EDNF sponsored the first international symposium on diagnosis, to revise the 1980s Berlin criteria; the Villefranche nosology was published in 1997 by *The American Journal of Medical Genetics*.

The intervening years have seen an outburst of information about EDS, as the field of genetics has expanded; more research into EDS has happened in the past 20 years than in the century between Chernogubov (who first presented in 1892 a case report of what would be named EDS) and the Villefranche Conference.

**To improve is  
to change;  
to be perfect is  
to change often.**

**Winston Churchill**

From *Loose Connections*, Summer 2002:

"The EDNF consists of a nationally and internationally distributed membership and it is growing. ...The EDNF provides emotional support and updated information to those affected by EDS and to their family members. It also provides educational programs and literature to the medical community.

"These desires can be reduced to the following Mission Statements:

1. To disseminate accurate information
2. To provide a network of support and communication
3. To foster and support research for those affected by EDS and other related disorders."

Those mission points remained EDNF's core values for more than a decade.



Vol. XIII, Number 3 The Official Communications Link Of The Ehlers-Danlos National Foundation August 1998  
6399 Wilshire Blvd, Suite 510 Los Angeles, California 90048 (323) 651-3038

## **Ehlers-Danlos Syndromes: Revised Nosology, Villefranche, 1997.**

The American Journal of Medical Genetics, 77: 31-37, © 1998, Wiley & Sons, Inc.  
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**Running title:**  
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**Key Words:** Ehlers-Danlos syndromes,  
diagnosis, joint hypermobility, skin  
extensibility, tissue fragility, arterial rupture,  
heritable disorders of connective tissue.

### **Introduction**

The Ehlers-Danlos syndromes (EDS) are a  
heterogeneous group of heritable connective  
tissue disorders characterized by articular  
hypermobility, skin extensibility and tissue  
fragility.

### **Abstract**

The categorization of the Ehlers-Danlos  
syndromes began in the late 1960's and was  
formalized in the Berlin nosology. Over time,  
it became apparent that the diagnostic  
criteria established and published in 1988 did  
not discriminate adequately between the  
different types of the Ehlers-Danlos  
syndrome or between the Ehlers-Danlos  
syndrome and other phenotypically related  
conditions. In addition, the elucidation of the  
molecular basis of several Ehlers-Danlos  
syndromes has added a new dimension to the  
characterization of this group of disorders.  
We propose a revision of the classification of  
the Ehlers-Danlos syndromes based  
primarily on the cause of each type. Major  
and minor diagnostic criteria have been  
defined for each type and complemented  
whenever possible with laboratory findings.  
This simplified classification will facilitate  
an accurate diagnosis of the Ehlers-Danlos  
syndromes and contribute to the delineation  
of phenotypically related disorders.

Classification of the EDS began in the late  
1960's (Beighton, 1970; McKusick, 1972)  
and in 1986 a nosology was proposed at a  
meeting in Berlin which formalized the  
nomenclature of the various types (Beighton  
et al., 1988). Recent developments in the  
elucidation of the biochemical and molecular  
basis of the EDS, together with increasing  
clinical experience, now permit refinement  
of the existing nosology. We met in June  
1997 at Villefranche-sur-Mer, France, in  
order to discuss the revision of the  
classification. Our proposals, which form the  
subject of this communication, have the aim  
of facilitating development and improvement  
in the following aspects of the EDS: 1)  
diagnostic uniformity for clinical and  
research purposes, 2) natural history, 3)  
management, 4) genetic counseling, 5)  
identification of potential areas of research.

We propose a new simplified classification of  
the EDS into 6 major types. Our guiding  
principle in formulating the proposed

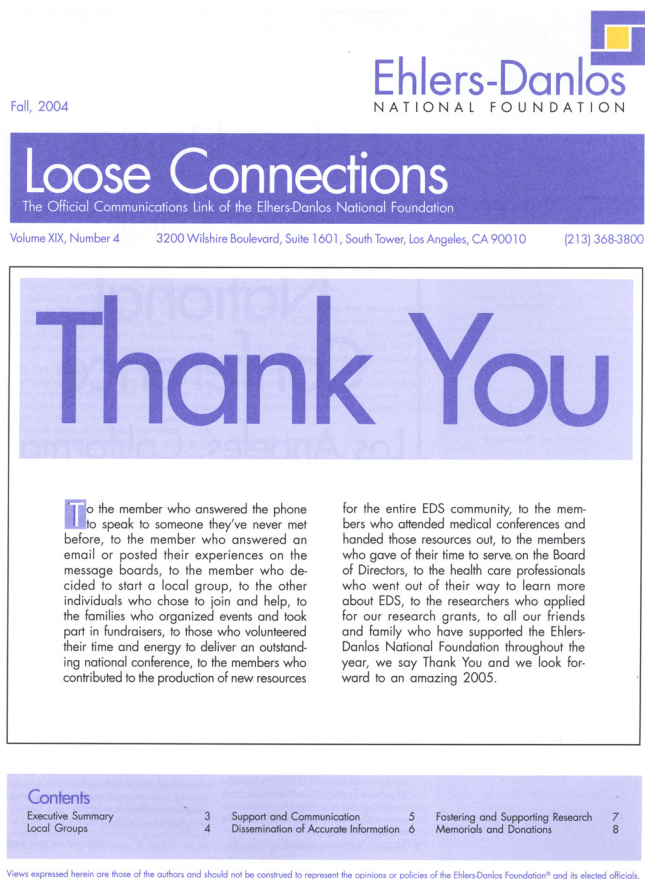
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In 2004, EDNF had a new logo and graphic identity, and a new executive director in Andrew McCluskey. *Loose Connections* was remade to match.



Change came again in 2005 when Cindy Lauren was promoted to President & CEO and Barb Goldenhersh became Communications Director and editor of *Loose Connections*; Barb remained editor until her death in June, 2011. Through these times we saw the ER CD-ROM released, the *Parents & Teachers Guide*, the various *Medical Resource Guides* and the *Vascular Clinical Reference Manual*, the wallet card.

*Loose Connections* went full color in 2009, leveraging the possibilities of turning into an electronic magazine during the worst of the recession when printing and mailing became prohibitive. Conferences started to include a second program for children and teens and kept increasing in size and content. These days, conferences are attended by well over 600 people of all ages.

The next reinvention of EDNF came in the autumn of 2010, when the office was moved from Los

Angeles to McLean, Virginia and Lesa Faris took over as executive director, followed by Shane Robinson a year later.

The foundation's biggest reinvention is underway, as we expand into an international organization with the EDS International Symposium 2016. The board added Lara Bloom as Co-Executive Director, and the professional advisory network has been turned into an international medical and scientific board.

Our new vision statement is: "We are striving toward a time when all those with Ehlers-Danlos syndrome can expect an early diagnosis, good management, respect, and recognition for their condition. A time when geography does not determine your quality of life and when you tell someone you have Ehlers-Danlos syndrome, you are not asked what that is."

We have come a long way since 1985, as a community and as a foundation. The growth over these past ten years has been phenomenal despite the hiccup of the economy, and the past year has been particularly interesting and intense. But here we are. The EDS International Symposium 2016 is completed now and the work continues, around the world from now on – as it will until the day EDS can be cured.

Change is certain. Whether we grow is not; growth is a choice. Change is opportunity, to find something new in ourselves and reinvent the way we approach the world. It's waiting for us.

**Mark C. Martino**

**If we don't change,  
we don't grow. If  
we don't grow, we  
aren't really living.**

**Gail Sheehy**



# #ItsOurTime

**P**ATIENTS BORN WITH EHLERS-DANLOS syndrome often fight many for years for proper diagnosis, recognition, and treatment.

Most patients wait more than a decade to obtain diagnosis.

Their fight can be a difficult, tortuous road. Because of the multisystemic nature of many forms of Ehlers-Danlos, too many patients struggle for over a decade to obtain comprehensive diagnosis and treatment for their overall condition. As a result, many are not diagnosed until much later in life when damage to joints can be irreversible.

We asked the Ehlers-Danlos community how many years it took to be diagnosed from the onset of their symptoms. Their answers are shocking. This needs to change.

#ItsOurTime for educating the medical world, to ensure symptoms will be recognized sooner and diagnosis is no longer not such a battle to receive.

The Ehlers-Danlos Society is dedicated to nothing less than a total transformation of our understanding of Ehlers-Danlos and the mechanisms by which it causes so much pain. Show your support and download the charity single 'It's Our Time' now by STINA on iTunes:



<http://apple.co/1TEqFLo>

YouTube



My type, type III, was obvious from the time I was a child, yet I wasn't diagnosed until I was nearly 40. (N.D.)

I have been seeking answers since I was a teen for other symptoms that after looking at EDS related conditions make sense now. It's like a light at the end of the tunnel! (D.P.)

I sought answers for ten to fifteen years. Yet when two different MDs told me I had EDS, I didn't believe them. It was at an EDNF conference where I met others, saw several docs and had a genetic evaluation that I finally accepted the diagnosis. (B.R.)

I'm 43. I was officially diagnosed last week although it was mentioned a few years ago. I knew myself for years I have every symptom and more. (J.S.)

I had my first dislocation at one year old and had various issues throughout childhood. During my second pregnancy symptoms got a lot worse. Two years ago I was diagnosed with EDS by physio, all doctors agreed. (L.S.)

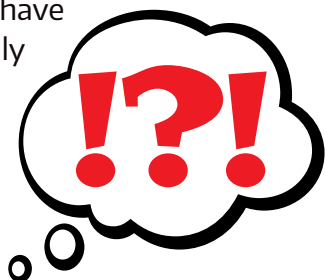
Growing up, my mother told me I was clumsy and lazy. I was in my 50s when pain overtook my life, but was not diagnosed until I was 60 years old. (N.E.)





First symptom at 4, diagnosed at 58. (D.L.)

I had problems since being a baby and 19 operations in total from my eyes to my toes . I've seen more than 60 doctors and no one could explain my multiple signs and symptoms so I had various diagnosis. When I got pregnant at age 27 my OBGYNs realized I must have EDS but could not officially diagnose me. Since then other doctors didn't think I have it or they just became silent. I am in South Africa. So I may never get an official diagnosis. (Y.S.)



43 years, it took almost three and half years for the genetics to see me after my rheumatologist referred me, it was hard answering questions about pain and fatigue because it was the norm to me. (R.A.)

Approximately 34 years of symptoms and misdiagnosis before my EDS diagnosis...now another ten plus years of most docs never listening or paying attention to why I am different. (R.S.)

42 years...or about how long it takes me to explain it to somebody. Took about 16 years from the date I was told I my ankle was inoperable because of "benign" hypermobility. The orthopedic surgeon who told me that my shoulder was also inoperable suggested I might have EDS...thus began a three-month chain that led to my eventual diagnosis. (A.S.)

Well, I am 33 now and my mother states that I first started complaining of pain in my legs at around the age of two. Documented Hypermobility from Shriners Children's Hospital at 13. And now I am waiting for my genetic testing in October of this year. (M.D.)

Thirty-four years from onset of symptoms as an infant. Twenty years of going to docs on my own looking for answers. Convincing my mom there was something wrong didn't work since she had many of the same symptoms, so I had to take control of my health care at a fairly young age. (M.H.)

How long we were activity looking for help for my son? He has always struggled. However, at age six

he woke one day and couldn't bear weight. From that morning until diagnosis was three years. (L.J.)

I was diagnosed as being "loose as a goose" when I was three, but it took until I was 30 before I got the EDS hypermobility diagnosis. (L.N.)

Definitely looking back the functionally impacting symptoms were there traceable from before seven, but we didn't start actively seeking diagnosis beyond my back injury at 11 until I was 15. Eighteen years later I got it. I am still amazed, as it was pure luck I had my kids at the same hospital as Dr. Francomano's practice! (H.B.)

Birth or maybe two years of age is when it started—that was when I took my first steps and the delayed gross and fine motor skills were all along with that. I'm 32 and was finally given a preliminary diagnosis a few months before my birthday so, 31 years, I guess. (B.G.)

Got diagnosed in 2008, problems all my life. Sought help and diagnosis from 16 years old. So 18 years to get diagnosed. (M.K.)

I was diagnosed at 1971 at four years old with hypermobility EDS. (P.J.)

Saw my first orthopedist around my 8th birthday with dislocating patellas and severe pain in my knees. My ligaments were so lax he could move them himself around to the side of me leg and said the ligaments were just growing faster than my bones and I would grow into them. I had joint pain the rest of my life and never "grew into" any of it. That was 22 years ago. It was this year I was diagnosed and still waiting for the geneticist to type it. (H.R.)

My baby sister was just diagnosed after over 10 years of being physically disabled. She walks with a cane sometimes and sometimes for long distances has to be in a wheelchair. She was born with clubfoot and has had health problems all her life. She's 58 now. Our Dad died of an abdominal aortic aneurysm when he was 67. I am almost 62. I was just found to have a thoracic aortic aneurysm. (R.Z.)

It took 15 years from the point where I began actively searching for a diagnosis. I was 30 when finally diagnosed. (D.R.)



27 years for me. Seven and eight years for both of my girls. 42 years for my mother. I was the first diagnosed and helped so many in my family find their answers since. (D.S.)

36 years and it took five years of arguing constantly with my doctors, that this wasn't an easy quick fix problem or that it was all in my head. (A.T.)

42 and a half years. Birth, third generation—luckily an EDS lifestyle was already in place. But it is important to know the true range of diagnosis. (K.T.)

My daughter is 21. She had every possible sign of hypermobility since she was two. They finally paid attention when she was 19 when she was diagnosed. I was just diagnosed two months ago. I've had symptoms all my life. Since birth. I'm 43. I've been lied to, called mental, drug seeker, faker. The list goes on. They also said the same about my daughter. Because according to those doctors she was dislocating her shoulder for attention. (D.W.)

Showed symptoms since birth; born pigeon-toed and it all started there. Multiple injuries later and no idea why, symptoms that didn't make sense, a work injury that sent me a PT who told me I was hypermobile and the search began. It was a two year search but I diagnosed myself before I got the official diagnosis. I was 38. (D.P.)

What if you've only been diagnosed with JHS because the doctor is too scared to diagnose you with EDS-HT? (L.R.)

For me, THIRTY YEARS. That's kind of mind blowing, considering it's something I was born with and it affects other family members. (M.M.)

I was lucky and diagnosed at five. (L.M.)

Six years for a preliminary diagnosis, still waiting for a geneticist. (M.D.)

My seven-year-old was diagnosed in-utero, my ten-year-old diagnosed at eight months old, with the kyphoscoliotic type. (C.D.)

Twenty-three since I started asking for a diagnosis. (A.C.)

I'm still waiting! (A.S.)

35 years for me and 21 months for my 23-month-old daughter. (G.L.)

Getting diagnosed was the easiest part. Finding a doctor that understands...a different story. (J.T.)

Five years...I have done lots of research. (F.F.)

Problems at three, diagnosed at 12. Took two years from initial genetics consult. (M.J.)

35 lat zajęło im zdiagnozowanie mojej choroby. Ja mam typ IV naczyniowy. [It took them 35 years to diagnose my illness. I have type IV vascular.] (I.K.)

22 years for myself, three years for my first son. (J.S.)

42 years! (S.F.)

11 years for my son (J.M.)

8 years, 7 months, 12 days. (B.H.)

59 years just referred from doctor to doctor. (R.W.)

40 years, my son eight years. (S.L.)

47 years! (S.I.)

20 years for me! (J.L.)

I got lucky—two weeks after my first serious complication. Hematologist saw my scars and recognized it immediately. (M.M.)

11 years. (J.P.)

60 years. (L.V.)

It took 54 years! (M.B.)

Wow, 19 years. 19 years that I'll never get back but here's on to better things. (L.M.)



I am almost 70 and it's only after my daughter and grand daughter were diagnosed and 14 surgeries that my doctor said, gee maybe that's your problem too. 60 years! Thankfully my grandchildren will have better care. (L.D.)

31 years...a really long time. Hope for new generations that it will go quicker! (C.I.)

38 years. Wow. Never thought of it like that. (B.R.)





May 3-6, 2016

TKP New York Conference Center  
109 West 39th Street, New York, NY 10018

## Introduction / Welcome



Lara Bloom

## Diagnosis & Management of Classical EDS



"Diagnostic Criteria &  
Approach to Diagnosis"  
Glenda Sobey



"Genetic & Allelic Heterogeneity"  
Marina Colombi



"Natural History & Organ  
System Review"  
Nigel Burrows





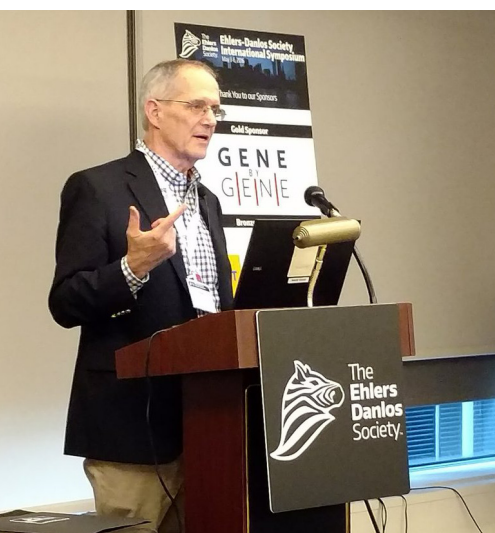
"Treatment of Classical EDS"  
Jessica Bowen



Question Session  
Howard Levy



## Diagnosis & Management of Vascular EDS



"Diagnostic Criteria & Approach to Diagnosis"  
Peter Byers



"Allelic Heterogeneity," "Natural History," & "Pregnancy in VEDS"  
Melanie Pepin



"Medical Management"  
Julie De Backer



"Surgical Management"  
James Black



Discussion & Questions with the Vascular Committee





"Allelic Heterogeneity"  
Tim Van Damme

## Reception • Social Hall at Union Theological Seminary



Top left: Brad Tinkle  
Community Choice Award

Above: Rodney Grahame  
Lifetime Achievement Award

Top right: Fransiska Malfait  
Pioneer in EDS Research

Left: Clair Francomano  
Pioneer in EDS Clinical Care

Right: Peter Byers  
Pioneer in EDS Research





# Diagnosis & Management of EDS Associated with N-Peptide Processing: Arthrochalasis and Dermatosparaxis

22



Tomiko Kosho, Francis Pope, and Fransiska Malfait

## Diagnosis & Management of Rare & Rarer EDS Subtypes



"TNX-Deficient EDS"  
Eelco Dulfer



"Spondylocheirodysplastic EDS"  
Cecilia Giunta



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## Hypermobile EDS: Definition, Diagnosis, Controversies



"Diagnostic Criteria & Approach to Diagnosis"  
Brad Tinkle (seated, Birgit Juul Kristensen and Howard Levy)



"Natural History & Organ Systems"  
Rodney Grahame

SPRING  
2016











"Gastrointestinal Involvement"  
Qasim Aziz



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Alan Hakim



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Question Sessions  
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Patient Perspective: ["Strength Begins with Hope"](#) • Lara Bloom



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(as of April 27)

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Germany  
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Italy  
Japan  
Mexico  
The Netherlands

New Zealand  
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Poland  
Spain  
Sweden  
Switzerland  
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Lara Bloom and Shane Robinson

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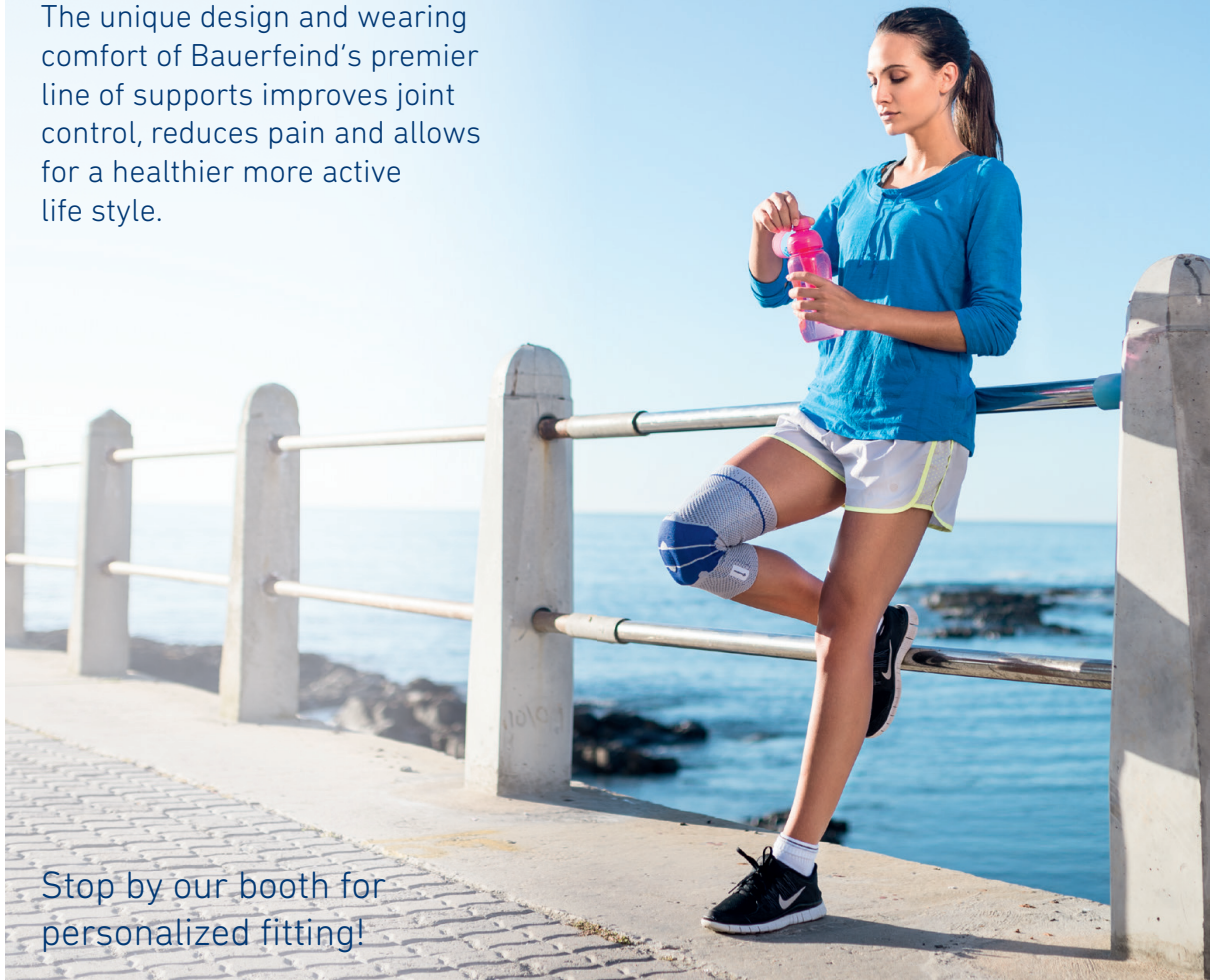


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