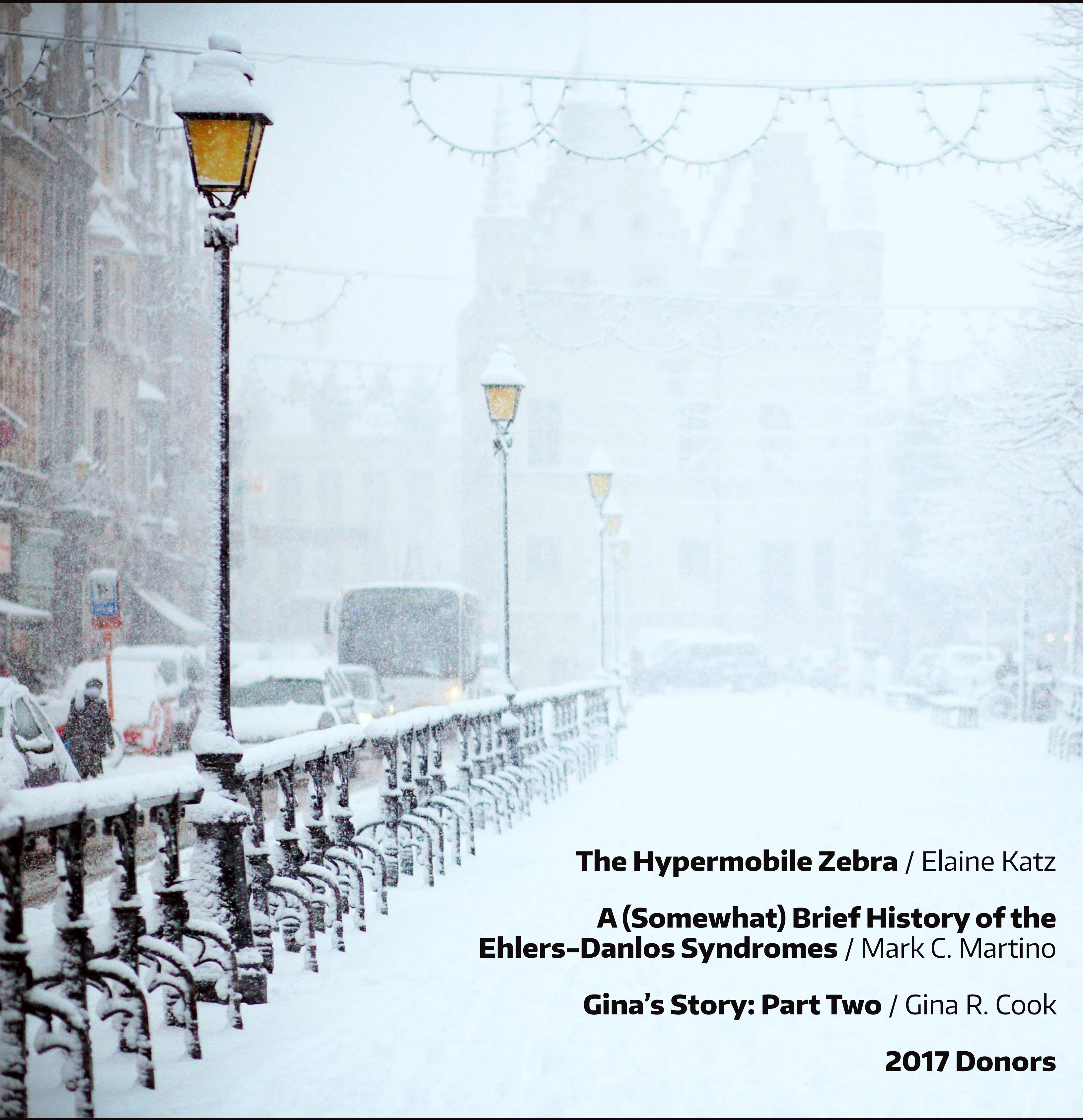
LOOSE CONNECTIONS



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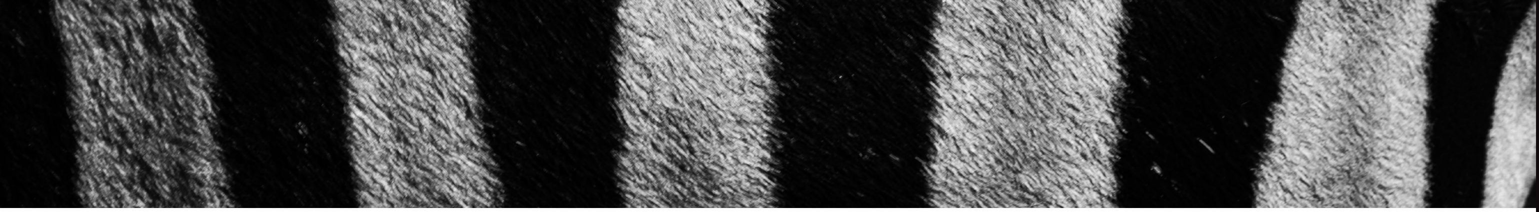
The Ehlers Danlos Society™

Your Magazine About Living With EDS and Related Disorders
Winter 2017



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THE EHLERS-DANLOS SOCIETY

The Ehlers-Danlos Society is a global community of patients, caregivers, medical professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes, hypermobility spectrum disorders, and related conditions.

We support collaborative research initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD population.

Our goals are worldwide awareness – and a better quality of life for all who suffer from these conditions. Research is at the center of what we do, so that one day we will have a cure.

Our strength begins with hope.

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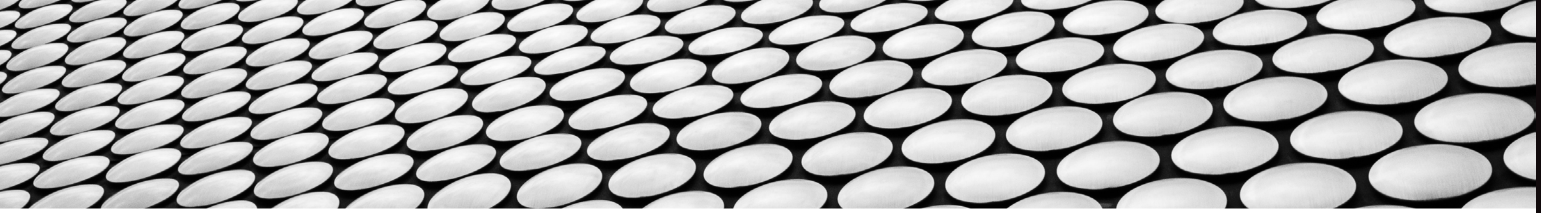


On the Schedule

The Ehlers-Danlos Society Learning Conference Australia

After years of demand and need The Ehlers-Danlos Society is very excited to bring together in Australia leading world experts to discuss the Ehlers-Danlos syndromes and related disorders, including the newly-described hypermobility spectrum disorders. Lead by Dr. Jane Simmonds, we will be holding workshops for professionals and lectures for patients over two days next December in Sydney and Perth. This is our first Australian conference and we look forward to meeting experts and those affected by these conditions from across the world. Please tell your fellow zebras and medical professionals to hold the dates and we will announce more information on registration, venue details, and agenda in 2018. We are proud to be fulfilling our mission of reaching zebras from all over world to ensure that one day geography will not determine your quality of life. As details become available, they will be found on the conference page here.

The Ehlers-Danlos Society
Learning Conference Australia
7-8 December 2018, Sydney
10–11 December 2018, Perth

International Symposium on the Ehlers-Danlos Syndromes 2018

We are delighted to announce that registration will open at the end of January for the next EDS Scientific Symposium, 26–29 September in Ghent, Belgium. Please keep an eye on our website and social media pages for the latest updates. Registration to the event is limited to medical professionals only and those representing patient organisations with legal status.

Registration for the patient day on Sunday, 30 September, will also open at the same time. The theme of the day will be 'Holistic approaches to living with Ehlers-Danlos Syndromes and Related Disorders'. Topics covered will include physiotherapy, cognitive behaviour therapy, mindfulness, Alexander technique, diet, supplements, marijuana, and more!

The European Ehlers–Danlos Syndromes Conference

Friday, 6 April 2018 for medical professionals
Saturday, 7 April 2018 for people with EDS
Crowne Plaza Maastricht
Ruiterij 1, 6221 EW Maastricht,The Netherlands

We are very excited to bring together leading world experts to discuss Ehlers-Danlos syndromes and related disorders, including the newly-described hypermobility spectrum disorders. This is our first European conference and we look forward to meeting experts and those affected by these conditions from across Europe.

Registration fees (limited to 350 participants)

Medical doctors, heath care organisations, insurance companies, policy makers	€ 375,00
Medical doctors in training, paramedics, policy makers	€ 175,00
Patients and relatives	€ 15,00

To register https://congresscare.com/congress/ehlers-danlos-syndrome-congress/
Information https://www.ehlers-danlos.com/2018-european-conference/

The local organizing committee of Henk Klooster, Debbie Hellenbrand, and Daniel Keszthelyi is supported by The Ehlers-Danlos Society and Congress Cares.

Qasim Aziz, MBBS, FRCP, PhD
Gastrointestinal complications in EDS and HSD

Lara Bloom
April 6 – The international work of The Ehlers-Danlos Society
April 7 – 2017 criteria: what do they mean for patients?

Antonio Bulbena, MD, PhD, MSc
April 6 – The therapeutic value of identifying psychopathology in the EDS
April 7 – Handling the subjective emotional dimensions in the EDS

Marco Castori, MD, PhD
HSD and hEDS (2017 criteria)

Alan Hakim, MA, FRCP
Autonomic dysfunction and fatigue

Fraser C. Henderson, Sr., MD
Headaches in the EDS population

Fransiska Malfait, MD, PhD
April 6 – The rarer types of EDS

Jane Simmonds, MCSP, MMACP, FHEA
Physiotherapy and rehabilitation within the context of the multidisciplinary team

The Hypermobile Zebra

A-stagnant, dynamic balance is the fulcrum on which my fragile world rests.
My feet instruct my body, cell by cell, mitochondria by mitochondria; trickle down economics in reverse; Newton's Laws capsized; Welcome to my world.
Where pieces are normally askew, off-kilter and out of place.
The chaos of my body, an adolescent gone haywire and dissident, makes music: a crack here, a pop there until the whole symphony of Rice Crispies incarnate is complete
My body defies anatomy, overlooks the aged medical textbooks and has a dialogue that rings true to this: Left knee cap to the rest of my joints: so I'm considering relocating but I want to keep it on "the down low" so don't say a word. I'm popping out right now and trying out the real-estate inside the leg.
And all of sudden I'm flummoxed, halted in my tracks as pain gushes in my left leg, which purples and bruises and goes numb.
Another day, another game of hellish musical chairs.
But I can usually retaliate, counter the popping out with a popping in, put the world's most insane jigsaw puzzle back together.
But here's the upside: when the entirety of one's self is out of whack, you expect nothing to go right. Every right, painless forward step counts and matters.
I am the conductor of my body's symphony, trying so hard to channel the allegro to a middle place, to balance that moves like the waves, with predictable dynamism.

Elaine Katz

A (Somewhat) Brief History of the Ehlers-Danlos Syndromes

400 BC: Hippocrates in *Airs, Waters and Places* notes that Nomads and Scythians had lax joints and multiple scars (thought to have been caused by cauterization, an attempt to stiffen the joints).[1]

1657: Job Janszoon van Meekeren, a Dutch surgeon, makes note of George Albes, a boy of Spanish origin. Albes was presented repeatedly at the Academy of Leiden, demonstrating how he could stretch the skin from his chin down to his chest or up over his eyes, and the skin over his knee out to the length of half a cubit. Oddly, this was limited only to the right half of his body.[2] EDS is also known as Van Meerketen's disorder.

Of a Soft-Skinned Spaniard

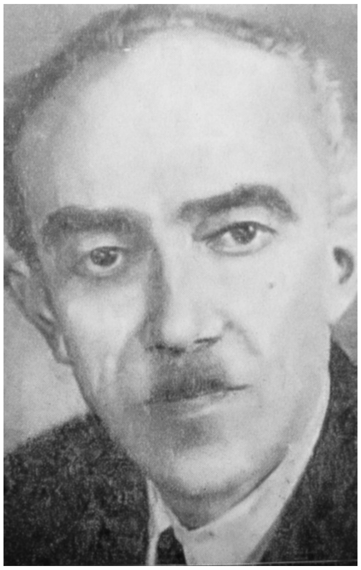
"Out of pressing needs and unforgettable sufferings our ancestors raised us, as it were, from the cradle with the belief that there is no wilder, more merciless and cruel people to be found in the world than the Spanish. As the history books, especially the chroniclers of the Dutch wars and the American barbarities to excess prove. *[Note: the Dutch had just endured an 80-year war with Spain.]* In spite of this we must confess that we have not seen a softer or more lithe Spaniard than Gregorius Albes, begotten by Spanish parents and on a Canary Island born. However, in his skin alone was he such. We saw him together with the famous professors, Johann von Horne, Francisco Sylvio, Guil. Pisone, and Francisco von der Schaagen in the year 1657 in the large hospice. He was a young fellow, twenty-three years of age, healthy in body and build. In our presence he took with his left hand the skin from his right shoulder and pulled it to his mouth, like an archer pulls the string on a cross-bow. The skin, however,from the chin he pulled with both his hands into a point like a beard, to his breast, from whence he then pulled the self same skin over his head, covering his eyes in a manner such that we could no longer see them. Even more of a wonder was how his skin, when he let go of it, fell back immediately into its proper place in such a manner as if it had never been touched. In just such a way he pulled the skin from his right knee up and down about half an arm's length. And once he let go of it, a man could not notice that it had once been pulled up. At the same time we were astonished to discover that the skin on his left shoulder and knee in no way let itself be pulled, as it was in these places so fixed and firm, it would have been impossible. What however the causes of the soft parts as well as the firm parts were remains to us till this very hour unknown."[3]

1782–1840: Niccolò Paganini was the most celebrated violin virtuoso of his generation and a popular idol. His reputation as the "Devil's Violinist" still lives because of the enormous legacy of his technique. He had hypermobile, lax joints, and a thoracic deformity, consistent with a connective tissue disorder—and possibly an EDS.[1]

Late 1800s: Some patients with probable EDS used hyperextensibility as performers at travelling shows, such as the "elastic lady" (1897) and the "India Rubber Man" (1883).[4,5]

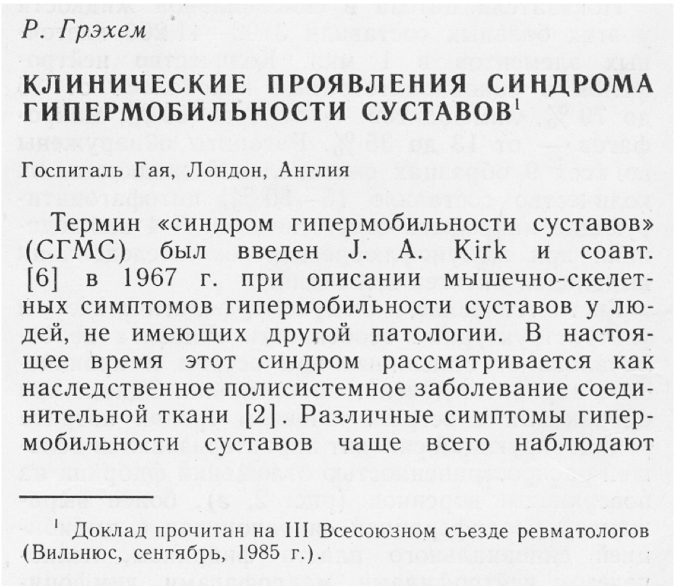
1880: First photograph of someone with most likely an EDS. Charles Eisenmann took this portrait of Felix Wehrle, the "Elastic Skin Man," who besides having extremely stretchy skin could also bend his fingers backward. Wehrle was exhibited in the dime museum circuit (a polite form of "freak show"); he was a contortionist as well.[6] His career was eclipsed by the more spectacular India Rubber Man, James Morris, who had a documentary short made about him in 1902.[7]

Felix Wehrle (photographer Charles Eisanmann, approximately 1880)



Alexandr Nicolaevich Chernogubov

1891: Russian dermatologist A.N. Chernogubov presents two patients at the Moscow Venereology and Dermatology Society, the first recognition of the disorder as having multisystemic features attributed to a defect in the way connective tissue fibers formed in embryo. One was described as an "intelligent 17-year-old peasant" with epilepsy who had "'fragility and hyperelasticity of the skin, and a failure to hold sutures. He also had hypermobility and luxation of joints, and molluscoid pseudo tumours of the knees, elbows, and other areas." European and American medicine failed to notice, but EDS is still most known in Russia as Chernogubov's syndrome. In his publication of the case, Chernogubov predicted, "There might be an opportunity to clarify the observed looseness of the connective tissue that impaired the generalized development of all connective tissue



Р. Грэхем

КЛИНИЧЕСКИЕ ПРОЯВЛЕНИЯ СИНДРОМА ГИПЕРМОБИЛЬНОСТИ СУСТАВОВ[1]

Госпиталь Гая, Лондон, Англия

Термин «синдром гипермобильности суставов» (СГМС) был введен J. A. Kirk и соавт. [6] в 1967 г. при описании мышечно-скелетных симптомов гипермобильности суставов у людей, не имеющих другой патологии. В настоящее время этот синдром рассматривается как наследственное полисистемное заболевание соединительной ткани [2]. Различные симптомы гипермобильности суставов чаще всего наблюдают

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[1] Доклад прочитан на III Всесоюзном съезде ревматологов (Вильнюс, сентябрь, 1985 г.).

components… It is possible that the development of this looseness is due in part to a deficiency in the supporting structures with a resulting diminution in the ability of the skin to resist deformation."[8]

Edvard Lauritz Ehlers

1899: Edvard Lauritz Ehlers, a dermatologist from Copenhagen, presents to the French Dermatological Society a 21-year-old law student from Bornholm, a Danish island in the Baltic Sea who had a history of late walking and frequent knee subluxations as well as lax joints and hyperextensible skin ("cutis laxa"). The student had a tendency to bruise from minor trauma, which had resulted in discolored lesions on his elbows, knees, and knuckles. Ehlers published the case history in 1901.[9]

1900: M. Morris describes in the *British Journal of Dermatology* [12:208–209] a similar case, of a boy with elastic skin and multiple cutaneous nodules.

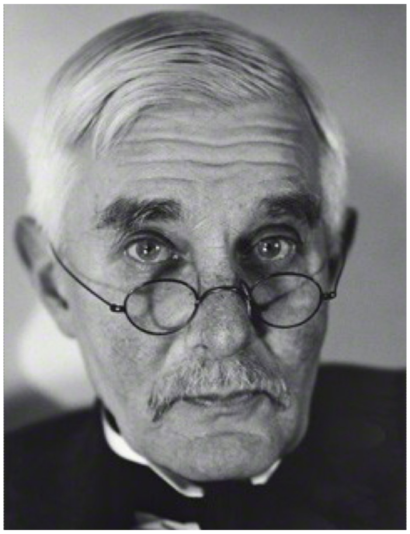
1908: Henri-Alexandre Danlos from Paris gives a presentation to the French Dermatological Society. This boy had lesions on his elbows and knees and had been presented to the same Society 18 months previously by colleagues but with the diagnosis of juvenile pseudodiabetic xanthomata. Danlos disagreed, pointing out the patient's thin, fragile, and hyperelastic skin. He explained the lesions as post-tramautic, the result of chronic bruising and inflammation.[10]

Henri-Alexandre Danlos

1934: The first case is reported in the United States by Tobias.[11]

1936: Georg Sack describes a patient with "excessive friability of the arteries."[12]

1936: Frederick Parkes-Weber proposes the name Ehlers-Danlos syndrome when he described a single disorder with joint laxity and skin hyperextensibility and fragility.[13]



Frederick Parkes-Weber

1936: A review of the literature by Ronchese finds 24 cases as well as three of his own.[14]

1949: EDS is found to be probably inherited in an autosomal dominant pattern.[15]

1955: A genetic defect of connective tissue collagen is suggested as the cause.[16]

1956: Victor McKusick writes about fewer than 100 reported cases.[17]

1960: McKusick's second edition reports EDS as genetically heterogenous (similar sets of symptoms that result from different genetic causes).

1962: Sestak supports Jansen's conclusion that EDS is caused by connective tissue collagen defect.[18]

1966: The third edition of McKusick's book lists the number of EDS cases as 300.

1967: A. P. Barabas publishes *Heterogeneity of the Ehlers-Danlos syndrome: Description of three clinical types and a hypothesis to explain the basic defect(s).*[19] His arterial-ecchymotic type is subsequently named Sack-Barabas syndrome, and later becomes known as vascular EDS.

1967: Hypermobility syndrome is coined by Kirk *et al.*[20] The split continues to evolve over the next decades with rheumatologists and hypermobility syndrome on one path, and geneticists and EDS on the other.

1970: Peter Beighton proposes five clinical forms.[21]

1972: McKusick lists seven types of EDS in the 4th edition of *Heritable Disorders of Connective Tissue*.

1985: Nancy Hannah Rogowski starts the Ehlers-Danlos National Foundation, the first national EDS support charity.[22] Ehlers-Danlos Support UK joined the field in 1987.[23]

1988: The International Nosology of Heritable Disorders of Connective Tissue, Berlin, 1986 is published in March 1988, and classifies nine types of EDS. This is the numbered system, using EDS I through EDS IX.[24]

1997: In June at Villefranche-sur-Mer, France, EDNF and Ehlers-Danlos Support Group UK co-sponsor a meeting to discuss revisions to the nosology. The numbering system was simplified and replaced by a named system, in which six main types of EDS were defined for diagnosis with major and minor diagnostic criteria. "The presence of one or more major criteria is either necessary for clinical diagnosis or highly indicative and warrants laboratory confirmation whenever possible." The revised nosology was peer reviewed and published in 1998, again by the *American Journal of Medical Genetics*; it was the result of a review of known clinical data, and the biochemical/molecular observations established since the 1988 Berlin nosology.[25]

1999: A meeting in Banbury Center, Cold Spring Harbor Laboratory, "The Clinical and Biological Basis of the Ehlers-Danlos Syndrome," brought together researchers and clinicians from around the world in an effort to better define EDS from the molecular basis through its natural history (the presentation of the disorder over a person's lifetime).

An explosion of new research and publications followed, too many to list individually. The collective discoveries in genetics, connective tissue disorders and EDS, and in how to treat EDS symptoms led to an international symposium in Ghent during 2012 and the formation of an international consortium of researchers, clinicians, and patient experts.

The Ehlers-Danlos Society (born out of EDNF) with the assistance of EDS UK aided the international consortium in putting together a complete, new examination of the EDS, joint hypermobility in general, and for the first time, those conditions associated with EDS as well as treatment options. Included is a new classification for the field of joint hypermobility attempts to join the paths of rheumatology/hypermobility syndrome and genetics/EDS that diverged in 1967. First results were presented at the New York International Symposium in 2016, followed in March 2017 by peer-reviewed publication of 245 pages as *American Journal of Medical Genetics Part C: Seminars in Medical Genetics Supplement to the American Journal of Genetics.*[26]

The 1998 nosology published as one paper focused on defining the EDS and the diagnostic criteria. It names five authors and 25 references covering almost 40 years. In 2017, the equivalent classification and diagnostic criteria article was but one paper of 17 that included individual papers on EDS types, a re-examination of the field of joint hypermobility, information of treatment and management, and articles on associated disorders. The 2017 nosology article lists 45 authors and 32 references – 27 of them written after the 1998 Villefranche criteria. We've come a very long way in a handful of generations.

MARK C. MARTINO

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Gina's Story: Part Two

ONCE I WENT TO THE DOCTOR, MY mom finally understood me fully. I had X-rays done and filled out a question sheet. I marked my daily pain on average before the knee and shoulder injuries as an 8 out of 10. My mom just stared at me. When asked what I felt now I said a 9.5; the doctor showed me I had broken my knee cap, and one half was back in place but jagged the other half was behind my leg joint cutting into me, making me unable to straighten my leg. I was also told my joints are all very loose, that they will need to all be tightened, and that I was deformed in some places. My shoulder was OK, but my knee needed surgery.

I had SoonerCare, the Oklahoma Medicaid system, so surgery needed preapproval. It took five months to get approved, which meant the half of my kneecap behind my leg was dead and could not be saved. My leg had to also be broken to fix my deformed joint. They reset it, and put a plate and two screws in my leg.

When I awoke, I found out my other leg needed the same treatment. The surgeon also said all my joints were quite bad and he felt one day they would all "fall apart." He also told me I had had a seizure.

Three months later when I had my other knee done, my body tried to reject the stitches and hardware. I got an infection, but month after recovering I had to have surgery to have my wisdom teeth out. I had a seizure yet again and took forever to heal. The pain medication gave me side effects, didn't stop the pain, but at least knocked me out so I could get rest.

My last year of high school was very much a blur. After healing from the surgeries I got a second concussion that still affects me. I know that year I showed my doe and won a lot, but I didn't retain a thing. I was on so many drugs and brain fog I was lost. I was lucky to graduate. I'm pretty sure my teachers felt bad for me and just gave me As, as that was my best report card ever!

College and working was not better. I was glad to be out of high school. I kept my goat because I wanted to have a herd one day. I hopped from job to job; I would get hurt or get laid off.

I saw my new main doctor to talk about my pain. He told me, "Not a thing wrong with you. Fibromyalgia most likely, it's just all in your head. You should stop babying your Illusions. Just grow up." He told me stop bracing everything when I hurt, the pain was just in my head – if I worked past it, it would stop. I and my mom really felt like he was not hearing me. We never stopped wondering what was happening.

School didn't help. Writing was just about impossible and after so many bad days, I could not even go up and down stairs. I did find my dream job at the OKC Zoo. I knew every animal's name and I loved getting up four days a week to go to work. 2015 was my last year of a "normal" life.

I had been saving up to move out. I always put aside 15% of my paycheck to savings. I worked hard. I just loved my job and I was saving money, I was making great grades. My job took very good care of me, they were always happy to see me. I felt like I belonged. It had been my dream since I was little to work at a zoo and help animals. I was in school to get a zoology degree and planned to work with the wolves.

This all came crashing down in the blink of a eye. I was working a ticket booth for Stingray Bay when I gave a ticket out and turned wrong. My left leg popped out of socket and jammed right back in and my back went out all at once. It was so bad they closed early. I didn't realize that was the last day I would walk without a limp. I was sent home early; my doctor told me it will take a few weeks to get better.

Three weeks later, I was getting my cash bad; my left hip had a sharp pain go right up my spine. I started hearing ringing. As my friend ran to get help, I put my head down and tried to keep from blacking out, but I hid my head on the counting counters and was out for a good amount of time. I could feel and hear everything but could not move talk or open my eyes. I heard my bosses come in, I heard them call 911, I heard them trying to call my mother, and I tried to wake up.

The paramedics wrenched my shoulder, and I started to recover, I could see the blinding flashlight. They told me that if I didn't sit up soon without help I was going to the ER. I got up and was taken into the ambulance. I was shaking but better, joking with the medics. I was just drained. I started crying because I felt like I let my work down. After two weeks of rest I felt better.

I was doing well until every once in a while from the waist down my legs would just go numb. I started not being able to work some of my favorite places in the zoo, but over time this was not working at all. At times I was unable to move for hours.

On day in August, they got me in a wheelchair and they told me to go to lunch. I came back and my register was closed and counted, even my cash bag was gone. My supervisor said I was being sent home. I later got a call from one of my bosses telling me to please not come back to work till I was better.

I wish I'd known that would be my last day, I wish I could have taken it all in more fully. It still makes me cry.

I never did get better. I saw doctor after doctor. My pain become worse and worse. Scan after scan, test after test, I felt helpless. The cane wasn't enough, and I got a service dog.

I had more black outs, my legs would go out (full paralysis), I would get worn out fast, my joints popped out more and more. I even began having seizures multiple times a week, or when stressed as a result of PTSD from being molested when I was 11-18 years old. I would still call my bosses with updates and would visit the zoo to see everyone.

The spring semester of 2016 at OCCC, I started taking my classes. I made it only four weeks before it was over. I was getting sores where my backpack straps where, the heavy books in my bag was hurting my back and hips, so I got a cart to pull ,but too little too late. I made it to my first class, a biology lab.

Not only did my legs go out, but I got a sharp pain in my lower back that was making me ears ring. All I could say was, "Professor, I'm going down!" Then I slammed my upper body on the hard lab table with test tubes and beakers. I had a seizure.

As usual, I could still hear everything, and I felt bad for my lab partner. She was a champ, and we did get an A for the day. It was a mess. The paramedics awakened me, got me in a wheelchair, and mom had to come get me yet again. I got slapped with a $900 bill stating I needed to pay for what I broke – with my face, mind you.

I went back to college four days later, thin and sickly looking. Everyone in first class was shocked because they thought I had died. I found out that rumor had hit all my classes. I always stuck out with my huge service dog "Grimm" that looked like a timber wolf.

A new doctor found I was not fit to go to school anymore. I would kill myself at this rate. I was doing damage to myself by pushing past the pain. I was not eating right and wasting away. I was told to stay out of school until further notice – which cam to be never again.

I started getting sick faster. I got strep, leading to my tonsillectomy. Same as usual: seizure, medication not working, long time healing. Then a spinal tap during which I felt everything despite the anesthetic. Instead of a week to heal, it took more than three, and I had another ER visit because I was getting worse; I had a leak. Oddly, I had Dr. Pain as my doctor that day.

Doctors kept telling me, "You look fine, I just don't know!" I developed TMJ problems, swollen joints, nose bleeds, fainting spells, on and on.

My dad asked me what I wanted for my 21st birthday, and I wanted a dairy goat. I had started not being able to eat the foods I always had, and I needed raw lactose-free dairy, lean red meats, only organic, gluten free, no GMOs, and that is pretty pricey. Growing, hunting, fishing, and raising my own was all I could do. Medical bills had eaten up every bit of my and my mother's savings. I wanted to cut down on money we had to spend and try to make some on my own; I wanted to make goat milk soap and sell goat kids.

For my birthday I got a papered American Nubian doe goat kid named Sequoia Gems Flower Buttermilk. She is brown red with a white belt, and frosted lopped ears. She was four moths old. I love her greatly. Sadly when my dad found out I was making a farm for my new life he wouldn't help anymore, because he thinks farming isn't good enough for a child of his. He hated I wouldn't work, and my mom is still trying to make him understand I can't.

Now I have a farm named "Made with Heart, Farm and Dairy." I'm part of the ADGA and ABGA. I keep my girls at a fellow goat friend's ranch where I go on weekends; it gets my mind off my life. I'm happy, something I haven't been in a while.

In the fall of 2016 I was sent to a rheumatologist. After looking over my tests and history and after a good exam, she asked, "You ever heard of EDS?" My mom and I said no at the same time. She printed out a sheet about it.

Mom looked it over and said, "This is all Gina, this is her all her life!" She handed it to me. I gripped it tightly, reading word after word.

After I finished the last page I looked up and said in a shattered voice, "So I will never get better?!"

I started to shake and almost cried, as it hit me that I would not walk right again or do sports I loved, hobbies I loved, or just be me. And my dream job!, how could I go back and work at the zoo?

I took it hard. My mom knew, she held my shaky hand as my doctor told us about treatment to try to stop it getting worse: PT, rest, don't push it at all, medication, and something to keep me happy and busy (my farm) .

As time passed, I felt good with PT and the rest of the plan. But I started going down again. First, with drilling, rotting pain in the bones of my legs; X-rays showed nothing. I started falling more and more, and it was hard for my mom to get me to a safe place in the house. My doctor ordered new drugs and custom braces for my lower back down to my toes and wanted me to use a wheelchair at home and when walking far or long. I just feel useless and warn out. Once I get a grip, I'm kicked right back down. It just keeps going down faster and faster.

I'm still waiting insurance approval of my new braces. I have an indoor and outdoor wheelchairs, but mostly I stay tucked in the house. Buttermilk didn't get bred and I have not been to the farm in over a month. The meds are not working. I may have a Chiari malformation and need a neck brace now. I'm thousands of dollars in debt and I just don't know what's going on. I normally look to the better side of things but it's moving so fast I can't keep up.

I felt I had to tell my story and get it out there. EDS and PTSD are trying to beating me, but I still have a smile on my face because it's hard to be down when you smile. I hope people read my story and become more aware of EDS, and for the ones who have it, I hope they feel they are not alone!

Gina R. Cook

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