



The
**Ehlers
Danlos**
Society

LOOSE CONNECTIONS



BRINGING TOGETHER
THE VOICES OF OUR COMMUNITY

AUG 2020 ISSUE

Table of Contents

AUGUST 2020

Liberation	4
Sarah Lauer	
I Want to Escape From My Body & Feel No More Pain	5
Deborah Capanna	
My Escape	6
Florence Howe	
On Rehearsal	7
Mary Crawford	
Moons	9
Jane Philipps	
You Keep Going	12
Christy Rohaly	
Linda	14
Ink & Watercolor Sketches	15
Kim McInerney	
A Sort-of Poem About My Sort-of Body	16
Amara George Parker	

The Night Sky	18
Paige Dettman	
Soul Good	19
Rae Tosh	
A Fictional Story About EDS	20
Cara Howe	
Untitled	23
C. Man	
I must sing	24
Myrna Sarrafian Onanian	
I struggle just to get through the day	25
Julianna Weninger	
Escape Station: Imagination	26
Aaliya Essack	
Tecidos conjuntivos, pedaços e linhas	29
Sarah Luise Kaminski	
Miles To Go	30
Caet Cash	
Steven B	31
Abilities!	32
Gafsa Bux Garson	
Beast & Passing Tears	32
Magdalena Tywoniuk	
A Compendium of Virtual Museums: Escape to Brighter Worlds	33
Mark C. Martino	
Publisher's Information	54

Liberation

SARAH LAUER

Our shackles are hidden,
invisible to the outside world
Heavy,
solid,
unbreakable to each who
toils beneath their
iron grasp

Secret burdens
oft borne in silence,
in solitude,
Fetters holding us back from
the possibility
that freedom brings

Our chains,
binding our lofty hopes,
bear witness to our pain
bring cause to our sorrows
and weight to our joys

Shamed,
we hide our bonds,
no two of us
weighted by manacles the same

Our tortures we carry
close to our chests
protected,
shielded from discovery,
Macabre infants
ours to defend

If our sufferings,
unique
yet shared
tether us to earth,
to self,
to each other,
then, truly, is
Unity the key to our liberation

I WANT TO ESCAPE FROM MY BODY & FEEL NO MORE PAIN ■ DEBORAH CAPANNA



My Escape

FLORENCE HOWE

When I was a teenager and wanted to escape
I'd row the boat quickly up the river
It was a grand way to clear my head.
Today I escape by writing down my thoughts.
Sometimes they're poetic, sometimes not.
Some people escape in a bottle.
Some have torrid affairs
While still others escape with drugs.
My kind of escape may not be glamorous or inviting to you
But I don't care.
So each time I need to get away I think of those calming
boat rides and then I grab a piece of paper
Begin writing,
Nothing exciting,
But it makes me feel better.

On Rehearsal

MARY CRAWFORD

AT THE END OF A LONG AFTERNOON, I drag my exhausted body across campus to the music building where I spend so much of my life. As my eyes and body adjust from the frigid, shining snow to the warm dark halls I know so well, I begin a familiar negotiation between the screaming pain in my body and the passion in my heart. Making my way into the band room, I greet the familiar faces, and begin the rituals of finding the most posture-friendly chair, and setting up my oboe and English horn as I chat with friends and our conductor.

A few minutes later, the once distinct sounds of conversations and practicing have grown to a roar before a sudden hush falls over the room as the conductor steps onto the podium. As we listen to the day's announcements, and the various corny jokes that accompany them, I feel the aches all over my body pulling my attention. The pain seems to press in from all sides, bringing its many companion symptoms along with it. I feel

almost like an intruder on the looming presence of my body's struggles.

But with a short glance from the conductor, the oboist beside me begins to play a concert A, a rich, glossy, and comforting sound that signals the true start of rehearsal. My lungs expand, and my arms bring the reed to my mouth almost as a reflex. As I join the tuning pitch, my mind begins to focus. My thoughts shift to finding unity with the rest of the band, and the pain and fatigue that normally seem to tie me to the ground become much lighter. The strange, life-affirming meditation of rehearsal begins.

Over the course of the next hour and a half, we explore complex harmonies, soaring melodies, and striking rhythms. My heart racing feels like bursting with joy rather than a desperate attempt to return blood to my brain. The electricity running down my spine feels like shivering in awe at the sound of 100 instruments building to form one sound, instead of shocks of

pain. For a few minutes I escape away from the reality of this disorder into a world made only of music, and the love of it.

In moments of pause, or when we drill the same passage over and over until we achieve perfection, the harsh reality of EDS comes rushing back in. My wrists ache from the strain of holding up my instrument, and my ribs cry out for rest. I am reminded of the reality of this body. But when we begin again, I'm amazed and grateful that such a fragile body can produce such a powerful sound. I can't help but feel like the luckiest person on the planet when I listen across the room to play a duet with someone I barely know, or when I hear an audience cheer after a triumphant encore. In those moments I briefly escape from the constant awareness of my body, and become part of a body of musicians instead.

At the end of the evening, my pain trickles back into focus as I pack my instruments, and listen to any remaining

announcements. I file out with the rest of the crowd of musicians to meet my friends also leaving their rehearsals. As we make our way towards dinner, I begin to feel like an EDS patient again. My head buzzes from tachycardia, and my joints shift unpredictably below me, but this time, there is fulfillment and peace as well. As with every rehearsal evening, I will be weighed down by a much heavier exhaustion than normal. I will spend the remainder of the day caring for my body and recovering, but I will also find myself sustained and refreshed by the experience of playing music with an ensemble I love. Music brings me joy, and allows other thoughts to briefly overtake my attention towards symptoms. They don't disappear entirely, but music allows me to interpret my symptoms differently and to better accept their place in my life. I truly consider music, and the opportunity to learn and perform it with people I love to be one of the greatest gifts I've been given. ■■■



MOONS2 ■ © Copyright 2013-2020 Jane Philipps

In my work, I marry my interest in paper, printmaking, and textiles by cutting apart pre-existing patterns, shapes, and colors and connecting them back together in different ways. I disrupt the existing order and create compositions with new rules, color combinations, and movement. Composed with found materials using precise techniques, my work explores the grid through woven structures and elements. My color systems and material juxtapositions create transparency, depth, and movement.



MOONS 3 ■ © Copyright 2013–2020 Jane Philipps

This series explores colored pencil as a backdrop for collage, with circles in small format pieces. I kept a rule where each piece needed to have three circles, drawn and filled in with colored pencil, each with a different diameter. I find the layering of the woven collage on top of the colored pencil to be a fun effect. In some pieces, the collage mostly obscures one or more of the circles, as if they are hiding, while in others, some circles remain completely visible to the viewer. The circles and their various juxtapositions remind me of moons and the woven collages give an impression of satellites in space.



MOONS 5 ■ © Copyright 2013-2020 Jane Philipps

Each collage measures 8" x 6" using colored pencil and mixed media on Somerset paper.

You Keep Going

CHRISTY ROHALY

YOU ARE 13. YOU DON'T PLAY MUCH sports, but somehow you got into basketball. Your knees start bothering you, and you think it might have something to do with your recent experiences with sports. You ask your doctor for an x-ray, which comes back normal. Your doctor says it's just growing pains, but you haven't had a growth spurt in quite some time. You dismiss the pain and it becomes a part of you. Sometimes you forget about it.

You are 14 and you start getting a queasy stomach every morning. You learn the difference between nausea and sickness. After almost a year of medical tests, you are finally diagnosed with chronic acid reflux. You have to learn by yourself what foods are safe and what makes you sick.

You are 14, and you started skiing with your school. You push yourself forward with your ski poles, and your wrists pop out of place. You start to think that maybe you pushed yourself too hard. You stop using your poles to push yourself

forward. Your wrists start clicking every time you move them. Again, you get an x-ray, and again, the results are normal.

You are 15, and you start swimming competitively. During a swim meet, you push yourself up out of the pool, and your shoulder pops out of place. Your first dislocation. You can't move your fingers. You push it back in with your other hand and ice it. You don't think much of it, pain has become so secondary, like an afterthought.

You are 16, and you're studying for exams, cross-legged on the floor. Your hip pops out of place. It hurts so much, but you can lean forward and pop it back in. That hurts too. This has happened dozens of times before, so you shrug it off. It must be normal, you think. Later, you find yourself sitting on your ankle. You can feel the joint separating. You make a note to not sit like that again.

You are 17, and you tell your doctor about back pain. You are referred to a physiotherapist, and start to go weekly. Seven years

later, and you are still going every week. He comments that your muscles are too tight, but he doesn't provide you with answers.

You are 21, and you have worked as a cashier for three years. You find that you can't stand for long periods of time anymore, but get yelled at by management for sitting between customers. You decide to get another x-ray, which comes back normal. You ask for an MRI.

While waiting for the appointment, you start using a cane for the bad days. Everyone asks you about it. You tell them your legs just hurt. Maybe it's arthritis, you say. There's no injury to blame. On a good day, you decide not to use your cane. Your friend tells you she's glad you were cured.

After waiting six months for an MRI, the results come back. You have a miniscule cyst that should not be causing any pain. You're faking. Your doctor tells you to exercise more. You stop using your cane. There's nothing wrong with your knee, so there's no reason to use it. You're still exhausted after standing for long periods of time.

You are 22 and still in pain every day. You ask your physiotherapist to write you a note for work, recommending a chair to sit on while working. Management lets you take a chair from the shelves to use, but it's not tall enough to see the register. Management knows. They're working on it. One year later, they're still working on

it. Every time you come in for your shift, you find that someone has put your chair back onto the shelves. You have to walk to the far end of the store to retrieve it.

You are 23 and you decide to take up boxing. The day after your class, your shoulder is so sore you can barely move it. Two weeks later and it's still painful. You ask for an x-ray, and they find a miniscule tear. Your physiotherapist recommends an MRI to determine the precise location, but the MRI finds nothing wrong with your shoulder. The x-ray was a false positive. You wait six months for an appointment with an orthopedic surgeon, who looks at your shoulders, then your wrists and fingers. He is able to pull your "good" shoulder out of socket. After the five minute appointment, you are finally diagnosed. Ligament laxity. You find this diagnosis to be accurate, but not enough. You spend the rest of the day endlessly researching hypermobility disorders.

You are 24 and having your first surgery. While in recovery, you find that your legs hurt more than your surgery scar. You continue researching hypermobility, and you come across a diagnosis that fits perfectly. You figure that the orthopedic surgeon would have gotten to the same conclusion if he assessed more of your joints. You wonder why your physiotherapist hasn't noticed this.

You are still 24. You wait six months to meet with a rheumatologist. He spends

an hour taking your medical history and doing a physical exam. He goes through a checklist to rule out hEDS. At the end of the appointment you have answers. Hypermobility spectrum disorder! Everything that happened in the past 12 years is finally explained. You have answers, and you know what to expect for the future.

You are 25. You still go to physiotherapy regularly. Every session, your physiotherapist works on your ankles, knees, hips, leg muscles, spine, ribs, clavicle, shoulders, and neck. Before diagnosis, you figured this was a normal experience of a young adult who didn't exercise as much as they should, but worked in a physically

demanding job. After diagnosis, you realize that your muscles work overtime to keep your joints in place, and become over-worked. You remember your body doesn't work like everyone else's. You remember to rest and have self-care days.

You find your community.

You find resources.

You find support.

You keep going.



LINDA



For me, to escape is to undertake a long journey to the clouds. To escape is to make my imagination fly and abandon pain, fatigue, and sad faces on earth. My escape is to make small clay keychains to give to the people I want to see happy, because they make me happy.



A Sort-of Poem About My Sort-of Body

AMARA GEORGE PARKER

Did you just crack your knuckles?
I can do mine too – watch...
I can do them twice on each finger,
and my wrists
and my knees
ankles
hips
toes
neck.

I can pop my shoulders too, see?
in, out
in...
they go out more than me.

I can slip my ribs and click my jaw
get it stuck if I'm not careful with a yawn.
don't misunderstand me
I'm not poor
I'm not a thing to be pitied
laughed at
isolated.

I just work a different way,
that's all.
like some are big,
some are small,
some are broken
but not defeated...

well, I am unique
so are you
but when you see us, you'd have no clue
that our legs are torture
perhaps one's gone numb
(sometimes relieved with a
 massage on the bum...)
or maybe the pressure of our
 blood's gone squiffy
and made us come over somewhat dizzy,

you'd never know,
not really,
how?
are we meant to limp around
 with furrowed brow?

and remind ourselves and
everyone we greet
of how much pain and agony we meet
with every step,
every morning?
I think I'd find that rather boring.

so just because the stick's not there
or we've hobbled in without wheelchair
it doesn't mean that we're OK
so please don't fuss and hinder
our way – we're trying to get
on with what's been dealt
no kings, no queens,
just bizarre genes

and we've all felt
that touch of death,
that hint, that trace
every so often seen on our face
when we wonder if peace is worth a sin
and if,
once our bodies are gone
the bliss sets in?

in an ideal world
we'd all have some understanding
that the things we do
are too demanding.
walking about
standing in a crowd
listening to you when our
pain is so loud...

most days we let it go
sympathise
empathise
when our bodies are low.
sometimes that isn't the case
and we get that crazy look on our face.

forgive us
forgive me –
this poem is a desperate plea
for love and acceptance
of something we can't accept yet
or ever?
but still
if you do,
it may just be
that we will too.



The colors of the sky in purple and blue and whites make me feel calm and good.

My EDS is like a shadow, like the trees are shadows. The trees against the sky help make the trees look pretty.

Soul Good

RAE TOSH

Times like these,
My soul soars,
Dancing among the stars.
My body may not keep up,
And I may be lying in my bed,
Eyes closed and headphones on,
But everything in me is singing.
Because music takes me back –
Back to who I was,
Before illness struck.
Back to who I was,
When I had the energy to sing
And the energy to dance,
Like no one was watching.
So while I may simply lie here in pain,
I find myself at peace,
Because everything in me
Is being who I was,
And it does my soul good.

A Fictional Story About EDS

CARA HOWIE

IT WAS IN SCOTLAND, A MORNING SO DRAB and uninspiring that every student sat at their desks, tapping their pen in an offbeat rhythm. Once that rhythm started, so did the endless cycle of never-ending uncertainty.

As misty skies brooded early in the cold October afternoon, the winds lashed at the trees and whipped the branches into a frenzy. The rush of drenched citizens outside became muffled from the harsh downpour of water that battered against the window. Typical Scotland, she thought. The girl always loved the sound of rain against a window but soon, the sound of rain would be changed for her, forever.

The piercing ring of the bell was enough to make half of the students jump out of fear, their eyes shot wide open as they threw their work into their bags and fought to get out of the door. However, one was daydreaming – creating her own perfect world whilst orchestrating the scenes in her head to “Le Rêve d'une note.” She never noticed the bell, she never noticed that he was standing in front of her. She only cared for the sombre

music and as the man reached to gently press his hand on her shoulder, she jerked, taking off her headphones and staring up at him.

“Don’t you want to go home, Miss McLaughlin?”

No, she thought. Just one more song, one more to keep me away from the reality that awaits me at home. The endless stream of medication, that hospital checkup at 4 pm. Let me be late for that, she prayed. She couldn’t bear to go through it all again, every day the same all because of the lack of knowledge by professionals. Crazy right? Professionals do not know a thing about her condition, sending her home constantly because there is “nothing wrong.” Bullshit, she thought. Utter bullshit.

She didn’t say a word to him, picking up her bag and giving that same smile she always does. That smile that hides so much pain. Pain that could never be described to anyone because she didn’t know anyone who would understand a single thing. She was alone, sure there were other people in the world with the same thing but did she know any of them?

No. Could she bear being alone anymore. She couldn't bear not having someone to talk to who would actually understand, she just wanted someone. Anyone.

She walked through the halls, they were near-enough empty now. Just the odd group of friends here and there, a kid shouting at someone on the phone – nothing new. Her mother was sitting in her car, playing a game of Candy Crush as she waited for her daughter to arrive, to take her to hospital, again. Her mother was just as sick of this whole ordeal; both of their lives were now consumed by the never-ending cycle, consumed by the girl's condition.

"Where've you been, love?"

"The halls were too busy."

"Ah."

Her mother's tone was almost angelic and that often meant her mother knew something that she didn't. It always annoyed the girl when people knew more than what she did. She had an obsessive need of always being right and "in the know." But don't we all?

"Where are we going today then?"

"Dr. Vangaard today."

"Check-up. Got it."

"Well, I think you're getting the plaster off today as well so you'll be able to see Michael, Mickey, and Ryan."

"Yes, but is it ever a good thing when we see them?"

"It is concerning that we are on a first name basis with them."

"Yeah."

It was always like this, for the past three years; ever since the first real incident happened, when the dreaded thumb popped out of socket. This may sound stupid and absurd to many but there's the select few who will understand. Those who are feeling that same pain now.

"How was school?"

"The usual."

"You've got to start giving me more than 'the usual,' Emily."

Emily didn't say anything. What was there to say? She sat on her own at lunch because everyone else was getting on with their lives whilst she was stuck in an endless cycle of hospitals. That she failed all of the tests she got back that morning. No, she wouldn't say any of that. There would only be more questions and more interrogations and she is already going to get it all from her doctor anyway. Instead of answering, she put in her headphones and drowned out the world.

Music. It was a godsend in her eyes, the way she can create a whole sequence to a song, imagining what it would be like to insert a song in a show or in any moment in time. Thinking about what the music video would be like, if there wasn't one out already. The possibilities were endless with her and music.

It was her escape. It was her everything. Emily turned to music at any given moment, when she is sad, happy, excited, calm, angry, or when she is just in need of some inspiration.

She listens to music before she goes into surgery and as soon as she wakes up from it. She turns to it at any point she needs to forget about something – which is almost all of the time. The rest of the time, she is finding another form of escape, whether it's writing, reading, or even watching TV. She can't ever be in her own mind for too long, it scares her to think about it too much.

Emily looked down at the hardened red cast. It was clean, no signatures, no dirt. Nobody really cared or jumped with excitement when she came in with a cast anymore, nobody cared to even ask what happened. It was the normality, it was weird to see her without one. She hated that. Emily traced her finger along the jagged edges of the cast, a feeling too familiar to her. She was thankful to get it off that day but she had to admit that the feeling would be weird. The cycle started over again.

Her mum was rambling on about an article she had read about Ehlers-Danlos syndrome somewhere on Google, Emily wasn't listening but she always appreciated the fact that her mum did her best to make sense of it all. At this point, her mum probably knew more

than what she did. However, that was down to Emily herself. She didn't want to know more, although she really should – it scared her. She didn't want to make sense of it. She ran away from it, escaped from it through books, music, whatever she could find.

The ride to the hospital felt long, it felt dreadful. She didn't want to be there and she could tell that neither did her mum. The only thing that kept her going was that promise of a meal deal from Tesco at the end. It was almost like a small reward for turning up to the dreaded appointment.

She knew as much about her condition as the doctors did, nothing. That's probably why she hated it so much. Emily knew that Ehlers-Danlos syndrome was a rare condition and she knew that many people in the world are affected by it, but nothing could have prepared her for the lack of knowledge anybody had about it. It terrified her, yet again.

As they turned into the car park, she had one thing on her mind – well, two: the lyrics coursing through her mind as they played from her curated Spotify playlist; and if today was going to be the same as last week.

And it was.





An acrylic painting of a hand posing in the ASL sign for "I love you." The bones of the pinky, middle, index finger, thumb, and wrist are exposed.

I must sing

MYRNA SARRAFIAN ONANIAN

I must sing
To quell the ding
Of the pain
Inside my brain

It is too much
Without a crutch
To ease the weight
Of this damn fate

Day by day
I strive to sway
The fiery dragons
In my way

In my heart
I strive to start
Songs to heal
Joy to feel

I struggle just to get through the day

JULIANNA WENINGER

I struggle just to get through the day,
I can't hear you when you say,
"I love you, I need you, you're beautiful."
I can't control the tears flowing down my face,
I begin to feel like I'm just wasted space,
I close my eyes and repeat in my head,
"Be strong. Be brave."
But this water feels too heavy to tread.
I wake in the middle of the night,
Panic. Fear. I think I'm losing this fight.
This pain feels impossible to bear,
I try to throw up a prayer,
"Help, God, I need you right now."
But I'm still struggling and wondering how,
How can I get through this?
One step at a time, day by day,
I promise, I'm trying to find my way.
My world just doesn't make sense at the moment,
Constant pain and fear are my biggest opponents.
I'm crying for help to get through this time.
Please don't forget that you'll always be mine.

Escape Station: Imagination

AALIYA ESSACK

ESCAPISM IS OFTEN A MEANS OF survival to those of us getting through chronic illnesses. It's not simply mindless or even an indulgent self-care tool, no, I firmly believe escapism is survival. We all use different means, music, daydreaming, books, traveling when we can, exercising when we can, spending time with people we love, binge watching our favourite shows or even passionately arguing politics, but it takes you out of the moment, out of your body. To me it doesn't mean the pain fades or my circumstances magically improve but escapism means I can survive. For as long as anybody can remember, you'd find me with a book in my hand, now it's sometimes a Kindle to give my wrists a break! Reading was everything: a generational love passed down in my family, the wisdom passed down of the power and promise that books hold, and the knowledge that the pen will always be mightier than the sword.

My Ehlers-Danlos journey began when I was too young to remember. My dislocations and other symptoms were

there from as early as a few months old but it took 18 years to get a name to pull all the symptoms together and finally feel like I wasn't totally losing my mind. In the meantime, there were plenty of hospital stays, surgeries, tests, severe infections it would take an age to get over.

But through all of it, I had my books. In the last few weeks I've had occasion to share this story a few times but one of my first memories of being in hospital is being in isolation, very sick, with my mother stuck to my bedside reading my books to me. I can still remember the books, the young sleuths solving crime over the Internet, one of them a boy that was disabled and very easy to relate to. I might have missed out on so many social norms of growing up, so many rites of passage I missed out on, being unable to ever truly immerse myself in school and the world around me; but my books could take me anywhere.

The power of reading flew me out of my hospital beds or out of my bedroom, it took me on expeditions to the Hundred

Acre Woods and with great anticipation to the top of the Magic Faraway Tree, I solved crimes with the Famous Five and Secret Seven and got in on midnight feasts and pranks at boarding school with the girls of Mallory Towers. I was transported to new worlds with Narnia, and don't get me started on my daydreams of how in an imaginary world I could probably get away with playing Quidditch and not break myself in half!

As I grew, my books grew with me, taking me to places even further away, back in time to learn more about wars and understand suffering is not singular or limited to me. My reading choices reached into the nuanced places of mundane life to help me understand just how different the human experience can be, how deeply our choices define us and how not speaking up and using our voices when we have an opportunity to do so is cheating ourselves. It has expanded my mind and constantly taught me more about the world, about people and about myself. Not that I only stick to the serious stuff! There's plenty of light-hearted humour and romance, fantasy and easy sunny day reading too. If I can get my hands on it, chances are I'll read it.

I crave that excitement of cracking open a new book, getting dug into a new story and shutting out the world. Books have indeed become a way to escape my body and take my mind off to different places and times. There are times I feel as though I relate to the characters so deeply they

feel like friends and family to me, but like I said at the beginning of this, escapism like this is survival. There are the days when I can't get out of bed because the weight of everything is too much and the pain is too much and in general, everything is too much. So I hide under my covers and read until I feel my mind going off and once it's travelled far enough for long enough, it's usually ready to come back and face what comes next. Books and reading have also opened up my imagination and creativity in ways I couldn't dream would have existed. They've been my guide to writing and writing has been my biggest coping skill. Realising that with my body, unlike in life, in writing I'm only limited by my own imagination; it's liberating beyond belief and healing even when what I'm writing has nothing to do with my illness.

But I'm able to communicate my experiences better because of what books have taught me and that's also important in advocacy and education. Books shaped my writing and my writing has allowed my family and friends to understand my circumstances in a better light, they may never fully understand what I feel or how deeply it affects me but my writing has definitely brought a deeper understanding that has greatly improved my relationships with people and also allowed them to see chronic disease in a different light.

This is why I'm so excited to be working on my dream passion project right now, a time when more than ever, the world is under the worst kinds of stresses and

escapism has never been more important. A year ago, after a long time of wanting to be involved in advocacy and wanting to help educate people but never feeling like it was the right time, or feeling brave enough to dive in, I took the leap and signed up to be a Patient Voices Ambassador for Rare Diseases South Africa.

One year in and I've just gotten to start digging into a project I'm completely in love with. People like you and I, children, teenagers and adults, across my country are stuck in hospitals, suffering from genetic and congenital diseases that require long term care or treatment. Oftentimes people don't have access to care where they live so they've travelled far and are stuck in underfunded, overwhelmed government hospitals that are trying their best, but most of these people are all alone with nobody from home to pop by and cheer them up or any kind of escapism at all. I can't imagine it, I think I'd lose my mind before anything constructive could be done to help me and yet it is completely necessary.

But we know, I know and you know, escapism is survival, it's how we cope, it's how we get through the pain and everything that gets thrown at us. The project is to hopefully build mini libraries, bookshelves called "Imagination Stations," filled with new and pre-loved books in good condition, that these patients, adults and children alike, can use to escape their circumstances and enjoy being temporarily transported to a different reality. People shouldn't be limited in their escapism and children have their imaginations curbed because they're sick and stuck in hospitals that have to prioritise medicine over providing something as simple as books.

Unfortunately with COVID-19, people don't have a lot to spare which is completely understandable but we're trying to get word of our project out there as much as we can. I'm hoping everybody reading this will give my Instagram page a visit [@liyae3](#) or visit Rare Diseases South Africa [@rarediseasesa](#) to find out more information and help us spread the word. Let's help get these kids reading and dreaming! ■■■

TECIDOS CONJUNTIVOS, PEDAÇOS E LINHAS ■ SARAH LUISE KAMINSKI

CONNECTIVE TISSUES, PIECES & LINES



Patchwork e arte têxtil. Todas as composições são feitas qd o corpo está "extreme pain". A capacidade de voar em pensamento. Sensorial catarse. *Patchwork and textile art. All compositions are made when the body is in "extreme pain." The ability to fly in thought. Sensory catharsis.*



Miles To Go

CAET CASH

((WE'VE TWENTY MILES IN AND I'VE only seen you pee once." Jimmy wipes the sweat from his eyes as I reluctantly take a swig from one of the water bottles in my pack. We've been hiking at a good pace for the past twenty miles but we've still got fourteen more miles until we make it back to our cars at the trailhead. Try as I might, I simply cannot get my legs to go as fast as I want them to go. I'm dehydrated from the prior twenty miles under the blazing North Carolina sun, but we can't stop for long. We need to complete this 34 mile route in under 20 hours to break the fastest known time.

At first my escape was music, but even in my teens my double jointed fingers had to be splinted to play. I tried track in high school, but my flat feet kept me out for most of the season. In grad school I discovered running, but after my first marathon my knee pain never went away. When doctors and PTs told me I couldn't run anymore, I walked. I walked 2,000 miles from Maine to

Georgia on the Appalachian Trail, and hiking and camping became my escape.

The next few hours pass in a daze as calories and water find their way back into my body. We pass marathon mileage for the day, and we take a break to share our last few snacks before getting ready for a steady hike into the night. The exposed rock face is cool against my back as I draw my knees up to my chest and try to press my flapping Kinesio tape back into place.

I hiked 10,000 miles before being diagnosed with hypermobile Ehlers-Danlos syndrome. I went to seven physicians. I saw eight physical therapists. I kept seeking answers because I knew something was wrong. I kept hiking because it was my escape from whatever that thing was.

"How are your hips feeling?" I smash my last few gummy bears into my mouth and wash them down with a tepid swig of water. I look up at Jimmy with a wry smile under a quickly fading sunset.

"They're still attached!"

The familiar bands of pain in my knees, hips, and back mix with the soft ache of exertion as I grab Jimmy's hand and haul myself onto my feet. This pain has been with me for thousands of miles. It is as natural as the moon rising above us and the trees that surround us. As natural as this body and all that comes with it. This pain is the vestige of a woman who gave me the unknown genetic variant(s) for hEDS and gave me every ounce of tenacity I possess. It is a complicated inheritance.

I am surprised when the thickets of rhododendron part, revealing the terminus of our hike. In 14 hours 43 minutes and

19 seconds we cover 39 miles and sixteen thousand feet of elevation change, becoming the fastest hikers to complete the route. Giddy and delirious, I sit on the floor of my van and begin the long process of rolling out my legs to help ease the pain of my overworked muscles.

I don't know how many more of these hikes I'll get. I don't know when my pain will get worse. I don't know what I will have to give up in the coming years. But I know that my Grandmother's genes are alive and well within me, bringing me pain and the perseverance to keep going one step at a time. ■■■

STEVEN B

During these hard times in America, I find it hard to see the response or lack thereof to the pandemic, the social and racial unrest, and the way our world is – as well as dealing with my own hEDS – and some days are better than other days. I find myself listening to sci-fi music, classical music, anything that sounds distant from this world, trying to escape for my own mental health, dealing with a pandemic people don't understand while just a year ago I was diagnosed with hEDS. It seems so unreal these days, so my mind is trying to escape reality even if just for a moment, like a child hides in their innocence and world of make-believe when times weren't so messed up. I believe it's okay to have escapism and to want to live in a world where you don't hurt, or a world where people aren't so cruel to one another. These are troubling times but we must band together, lift one another up and share our light. We are strong, and if you must, find an escape through movies, books, music, or video games. It's okay to not be okay. You are not alone. You are strong and you are loved. Escape is okay but we must all come back to the reality from time to time.

Abilities!

GAFSA BUX GARSON

Abilities!

There are human beings in this world!

That live with disabilities and some you can see are
disabled and some have invisible disabilities!

Show love, compassion and support disabled human beings!

It takes a lot of courage and strength to live with pain and disabilities!

So never underestimate human beings that suffer silently with their abilities!

BEAST & PASSING TEARS ■ MAGDALENA TYWONIUK



Beast – Beautiful girl's face with face of roaring lioness exploding from inside representing her strength and fight.



Passing Tears – Falling leaf with face of girl reflected in leaf, tears flow down leaf and land in puddles of rain.

A Compendium of Virtual Museums: Escape to Brighter Worlds

MARK C. MARTINO

Art represents the heritage, texture, creative problem solving, and expression of human experience. The museum collects, presents, researches, and supports the arts in order to create conversations across place and time and opens up new ways for all people to see and understand each other.

THE CLEVELAND MUSEUM

MUSEUMS AROUND THE WORLD have been digitizing their collections, and many are providing for visits in virtual space. Neither is quite the same experience as in person, of course, but there are decided advantages too. For instance, it is possible to view Van Gogh paintings far more closely than one would be allowed with the painting itself; the photograph on this issue's cover is an extreme closeup of a self-portrait. Some galleries have gone an extra step, providing VR-headset versions of their galleries.

There are quite a few links to Google's Arts & Culture non-profit initiative, which partners with cultural and arts institutions around the world in a mission to "preserve

and bring the world's art and culture online so it's accessible to anyone, anywhere."

Google Arts & Culture is an online platform through which anyone can view high-resolution images and videos of artworks and cultural artifacts. It can provide perspectives and information not available to physical visitors. While the links included here access [Arts & Culture through a browser](#), I have found the free Arts & Culture apps provide a richer experience.



A bit of "fine print" first: available online does not necessarily equate to free for

use. You might not be able to legally download or copy certain works in your country. It is your responsibility to ensure that your local law permits you to do this.

Some galleries and art works are protected by copyright. Please note the intellectual property rights for the site being visited, and that any content may be protected by the institution or other parties.

This is by no means an exhaustive list; there are many others. I hope you will enjoy these sites as much as I did while researching them; art is one way to run away without leaving home. Getting lost in masterworks and history has been a welcome distraction.

BRAZIL

Museu Nacional (Rio de Janeiro)

The National Museum in Rio de Janeiro is Brazil's oldest natural history institution, founded in June 1818 by King João VI of Portugal, Brazil, and the Algarves. Originally it was called the Royal Museum, because when the Royal family migrated to Brazil, their whole empire was transferred there, making Portugal and Algarves part of the Kingdom of Brazil.

Over the centuries the museum became home to more than 20 million scientific and historical items. On September 2, 2018 –three months after celebrating its bicentennial – a huge fire spread throughout the National Museum.

The 200-year-old museum lost an estimated 92.5 percent of its 20-million-item archive, one of the largest collections of natural history and anthropological artifacts in the world – but not before Google Arts and Culture digitized enough to recreate the experience of visiting the Museu Nacional virtually: <https://artsandculture.google.com/project/museu-nacional-brasil>

You can take a virtual tour of the highlights of the Museu Nacional as it was here: https://artsandculture.google.com/exhibit/5gJywQA_-ABfjw

Museu de Arte de São Paulo Assis Chateaubriand



The Museu de Arte de São Paulo is a private, nonprofit museum founded by Brazilian businessman Assis Chateaubriand, in 1947, as Brazil's first modern museum.

Google Arts and Culture:

- <https://artsandculture.google.com/partner/masp>

CHINA

The Palace Museum (Beijing)



Established in 1925, the Palace Museum is located in the imperial palace of the consecutive Ming (1368-1644) and Qing (1644-1911) dynasties. The magnificent architectural complex, also known as the Forbidden City, and the vast holdings of paintings, calligraphy, ceramics, and antiquities of the imperial collections make it one of the most prestigious museums in China and the world.

Virtual tours:

- <https://en.dpm.org.cn/multimedia/virtual/>

View the collection:

- <https://en.dpm.org.cn/cd/action/ListInfo/?classid=19>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/the-palace-museum>
- <https://artsandculture.google.com/project/treasures-of-the-palace-museum>

FRANCE

Louvre (Paris)



Formerly a royal palace, the Louvre has embraced the history of France for eight centuries. Intended as a universal museum since its inception in 1793, its collections—among the finest in the world—span several thousands of years and a territory that extends from America to the confines of Asia. Divided among eight departments, these collections feature works admired throughout the globe, including the *Mona Lisa*, the *Winged Victory of Samothrace*, and the *Venus de Milo*.

Virtual Tour in 4K high-resolution video:

- Part 1: <https://youtu.be/6vuFh6NNa70>
- Part 2: <https://youtu.be/FRmvCQM-XGU>
- Part 3: <https://youtu.be/i3-BauvSWHy>

Online tours

- <https://www.louvre.fr/en/visites-en-ligne>

Selected works by category

(Masterpieces, Travel, Landscapes, etc.)

- <https://www.louvre.fr/en/selections>

Musée d'Orsay (Paris)



The Musée d'Orsay, like the Musée de l'Orangerie and the Musée Hébert, is a national museum under the authority of the Ministry of Culture. These three museums are managed by the Musée d'Orsay and Musée de l'Orangerie public establishment.

- <https://www.musee-orsay.fr/en/collections/overview.html>

Video gallery:

- <https://www.musee-orsay.fr/en/tools/video-gallery/video-gallery.html>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/musee-dorsay-paris>

GERMANY**Pergamonmuseum (Berlin)**

The Pergamonmuseum was built as a three-wing complex. The museum now houses three of the Staatliche Museen zu Berlin's collections: the Antikensammlung, Vorderasiatisches Museum, and the Museum für Islamische Kunst. The impressive reconstructions of massive archaeological structures – the Pergamon Altar, Market Gate of Miletus, the Ishtar Gate and Processional Way from Babylon, and the Mshatta Facade – have made the Pergamonmuseum famous throughout the world.

- <https://www.smb.museum/en/museums-institutions/pergamonmuseum/home/>

3D Model of the Pergamon Altar:

- <http://3d.smb.museum/pergamonaltar/>

Virtual online offerings:

- <https://www.smb.museum/en/about-us/online-offers/>

Google Arts and Culture:

- <https://artsandculture.google.com/project/museum-island-berlin?hl=en>

GREECE**Benaki Museum of Greek Culture (Athens)**

- https://www.benaki.org/virtual/kentriko/ground_floor/index_en.html

Museum of Islamic Art (Athens)

- https://www.benaki.org/virtual/islamikis/entrance_and_room_1/index_en.html

The Ghika Gallery (Athens)

- https://www.benaki.org/virtual/gkikas/ground_floor/index_en.html

The Yannis Pappas Studio

- https://www.benaki.org/virtual/pappas/index_en.html

Google Arts and Culture:

- <https://artsandculture.google.com/partner/benaki-museum-of-greek-civilization>

ITALY

Uffizi Gallery (Florence)



Since 2014, the Uffizi Galleries have brought together three extraordinary museum complexes of art and precious crafts, books and botany of the Medici, Habsburg Lorraine, and Savoy families: a collection of treasures from antiquity to the twentieth century.

- <http://www.uffizi.com/>
- <https://www.uffizi.it/en/video-stories>
- <https://www.uffizi.it/en/artworks>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/uffizi-gallery>

Google Maps:

- <https://www.google.com/maps/@43.7688991,11.2559357,2a,64.6y,7.81h,86.71t/data=!3m6!1e1!3m4!1sp2-XPbV21o dNxehMTyFVbQ!2e0!7i13312!8i6656>

Museo Galileo (Florence)



The Museo Galileo is one of the foremost international institutions dedicated to the history of science. The museum, specialized library, archives, multimedia, and photographic and restoration laboratories serve scientific culture and technical/scientific heritage.

- <https://www.museogalileo.it/en/>

Virtual exhibitions:

- <https://www.museogalileo.it/en/library-and-research-institute/projects/virtual-exhibitions.html>

The library houses about 170,000 works concerning the history of science.

- <https://www.museogalileo.it/en/library-and-research-institute/library/information-library/571-collections.html>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/museo-galileo>
- <https://artsandculture.google.com/exhibit/le-collezioni-della-biblioteca-del-museo-galileo/wQkJUK5c?hl=it>

JAPAN

Ghibli Museum (Mitaka)



The Ghibli Museum showcases the work of the Japanese animation studio Studio Ghibli and is dedicated to the art and technique of animation.

- <http://www.ghibli-museum.jp/en/>

Hayao Miyazaki's studio:

- <https://youtu.be/FNEVhGy9HzM>
- <https://youtu.be/C4f3DAQU6ok>
- <https://youtu.be/BaX15taUGFY>
- <https://youtu.be/sTPDcLBVfSY>

KOREA

National Museum of Modern and Contemporary Art (Seoul)



The National Museum of Modern and Contemporary Art, Korea (MMCA) is a contemporary art museum with the main museum in Gwacheon and three branches each in Deoksugung, Seoul and Cheongju. It was first established in 1969 as the only national art museum in the country accommodating modern and contemporary art of Korea. Through its various locations, MMCA intends to function as a cultural platform that encourages communication and cross-pollination of contemporary art with other various disciplines of art, science, and humanities.

- <https://www.mmca.go.kr/eng/>

Online museum:

- <https://www.mmca.go.kr/eng/pr/movList.do?mbMovCd=01>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/national-museum-of-modern-and-contemporary-art-korea>

MEXICO

Frida Kahlo Museum (Mexico City)



The Frida Kahlo Museum (Spanish: Museo Frida Kahlo), also known as the Blue House (La Casa Azul) for the structure's cobalt-blue walls, is a historic house museum and art museum dedicated to the life and work of Mexican artist Frida Kahlo. The museum contains a collection of artwork by Frida Kahlo, Diego Rivera, and other artists along with the couple's Mexican folk art, pre-Hispanic artifacts, photographs, memorabilia, personal items, and more.

- <https://www.museofridakahlo.org.mx/en/the-blue-house/>

Virtual tour:

- <https://www.museofridakahlo.org.mx/en/the-blue-house/virtual-tour/>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/museo-frida-kahlo>

Museo Nacional de Antropología (Mexico City)



The National Museum of Anthropology is a national museum of Mexico. It is the largest and most visited museum in Mexico. The museum contains significant archaeological and anthropological artifacts from Mexico's pre-Columbian heritage, such as the Stone of the Sun (or the Aztec calendar stone) and the Aztec Xochipilli statue.

- <https://www.mna.inah.gob.mx/>

Virtual tour:

- <https://www.inah.gob.mx/paseos/mna/>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/museo-nacional-de-antropologia-mexico>

NETHERLANDS

Van Gogh Museum (Amsterdam)



The Van Gogh Museum in Amsterdam houses the largest collection of artworks by Vincent van Gogh (1853-1890) in the world. The permanent collection includes over 200 paintings by Vincent van Gogh, 500 drawings and more than 750 letters. The museum also presents exhibitions on various subjects from 19th-century art history.

- <https://www.vangoghmuseum.nl/en>

Collection (very high level of detail as shown on the cover closeup of a self portrait):

- <https://www.vangoghmuseum.nl/en/collection>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/van-gogh-museum>

Walk-through tour in 4K resolution:

- Part 1/7 https://youtu.be/SRDEmb5Eo_Y
- Part 2/7 https://youtu.be/j3kfiH_dacw
- Part 3/7 <https://youtu.be/wmq2yQAEHZY>
- Part 4/7 <https://youtu.be/ASXYtcl54Pk>
- Part 5/7 <https://youtu.be/wwIRO1nzJlw>
- Part 6/7 https://youtu.be/yKba_4M0kp8
- Part 7/7 https://youtu.be/9F_qqWd_RZs

Rijksmuseum (Amsterdam)



The Rijksmuseum is the museum of the Netherlands. Its world-famous masterworks from the Dutch Golden Age include the Milkmaid by Vermeer and Rembrandt's Night Watch. The Rijksmuseum itself is also a masterpiece. The collection is presented in a stunning building with amazing interior design. In 80 galleries 8,000 objects tell the story of 800 years of Dutch art and history, from the Middle Ages to Mondrian.

- <https://www.rijksmuseum.nl/en/>

App: <https://www.rijksmuseum.nl/en/tours>

- iOS <https://apps.apple.com/us/app/rijksmuseum/id621307961>
- Android <https://play.google.com/store/apps/details?id=nl.rijksmuseum.mmt&hl=en>

Collection catalog:

- <https://www.rijksmuseum.nl/en/rijksstudio>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/rijksmuseum>

Anne Frank House (Amsterdam)



The Anne Frank House was established on 3 May 1957 in cooperation with Otto Frank, Anne Frank's father. We are an independent non-profit organisation that runs a museum in the house where Anne Frank went into hiding and we try to increase awareness of Anne's life story all over the world.

- <https://www.annefrank.org/en/>
- <https://www.annefrank.org/en/museum/web-and-digital/>
- <https://www.annefrank.org/en/anne-frank/secret-annex/>

The Secret Annex VR app: Explore the hiding place of Anne Frank and her family in virtual reality:

- <https://www.annefrank.org/en/about-us/what-we-do/publications/anne-frank-house-virtual-reality/>

The Frank family home in 360 degrees: Look around the house where Anne Frank and her family lived before they went into hiding. The interior was photographed in 360 degrees and can now be seen in Google Arts and Culture:

- <https://artsandculture.google.com/exhibit/2AJCtLmxVrkeKA>

RUSSIA

State Hermitage Museum (St. Petersburg)



The State Hermitage Museum is the second-largest art museum in the world; it was founded in 1764 by Empress Catherine the Great. Its collections, of which only a small part is on permanent display, comprise over three million items (the numismatic collection accounts for about one-third of them), including the largest collection of paintings in the world.

A one-take journey of more than five hours through the Hermitage museum:

- <https://youtu.be/49YeFsx1rlw>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/the-state-hermitage-museum>

SPAIN

Picasso Museum (Barcelona, Spain)



The Picasso museum Barcelona is a key reference for understanding the formative years of Pablo Picasso. The genius of the young artist is revealed through the 4,251 works that make up the permanent collection. Furthermore, the Picasso museum, opened in 1963, also reveals his deep relationship with Barcelona: an intimate, solid relationship that was shaped in his adolescence and youth, and continued until his death.

- <http://www.museupicasso.bcn.cat/en>

Virtual tour:

- <http://www.bcn.cat/museupicasso/en/visiting/virtual-tours.html>

Collection:

- <https://cataleg.museupicasso.bcn.cat/?lang=en>

Museo Nacional Centro de Arte Reina Sofía (Madrid)



The conversion of the Centro de Arte Reina Sofía into a national museum in 1988 was based around the objective of bringing the various state collections of modern and contemporary art together in one place. The collection has recently expanded in format (film and video are pivotal areas in the Museum's development), historical context and geographical framework (Latin America has become a fundamental line of work), and the creation of present-based pluralistic takes on modernity, its precedents, and its repercussions.

- <https://www.museoreinasofia.es/en>

High-resolution works from the Museo Reina Sofía Collection in different views (visible light, ultraviolet light, digital infrared photography, x-ray imaging) and macro photography:

- <https://gigapixel.museoreinasofia.es/en/>
- <https://www.museoreinasofia.es/en/multimedia>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/museo-reina-sofia>

TAIWAN

National Palace Museum (Taipei City)



The National Palace Museum has a permanent collection of nearly 700,000 pieces of ancient Chinese imperial artifacts and artworks, making it one of the largest of its type in the world. The collection encompasses 8,000 years of history of Chinese art from the Neolithic age to the modern. Most of the collection are high quality pieces collected by China's emperors.

- <https://www.npm.gov.tw/en/>

In this virtual reality space, you can visit the National Palace Museum and its permanent exhibitions anytime, anywhere; observe and/or listen to in-depth descriptions of selected artifacts; and/or select featured tour routes to quickly browse through various exhibition items.

- <https://tech2.npm.edu.tw/720vr/enHome.html>

UNITED KINGDOM

The British Museum (London)



The British Museum's remarkable collection spans over two million years of human history and culture. Over six million visitors every year experience the collection, including world-famous objects such as the Rosetta Stone, the Parthenon sculptures, and Egyptian mummies.

- <https://www.britishmuseum.org/>

More than 1.9 million works of art in the collection are viewable online:

- <https://www.britishmuseum.org/collection>

There are virtual tours of galleries, including:

- <https://www.britishmuseum.org/collection/galleries/north-america>
- <https://artsandculture.google.com/streetview/british-museum/>

The National Gallery (London)



The National Gallery, London houses one of the greatest collections of paintings in the world, including many famous works, such as van Eyck's *Arnolfini Portrait*, Velázquez's *Rokeby Venus*, Turner's *Fighting Temeraire* and Van Gogh's *Sunflowers*. All major traditions of Western European painting are represented from the artists of late medieval and Renaissance Italy to the French Impressionists.

- <https://www.nationalgallery.org.uk/>

Experience the Gallery in virtual reality through your desktop, phone, or VR headset:

- <https://www.nationalgallery.org.uk/visiting/virtual-tours>

Search the collection:

- <https://www.nationalgallery.org.uk/paintings/search-the-collection>

Google Arts & Culture:

- <https://artsandculture.google.com/partner/the-national-gallery-london>

Science Museum (London)



Striving to be the best place in the world for people to enjoy science, the Science Museum's world-class collection forms an enduring record of scientific, technological and medical achievements from across the globe. We aim to inspire visitors with award-winning exhibitions, iconic objects and stories of incredible scientific achievement.

- <https://www.sciencemuseum.org.uk/>

Virtual tour:

- <https://www.sciencemuseum.org.uk/virtual-tour-science-museum>

Google Arts & Culture:

- <https://artsandculture.google.com/partner/science-museum>

Explore over 325,000 objects and archives from the Science Museum, Science and Industry Museum, National Science and Media Museum, National Railway Museum and Locomotion:

- <https://collection.sciencemuseumgroup.org.uk/>

The National Museum of Computing (Bletchley Park)



The National Museum of Computing (TNMOC), located at Bletchley Park, is an independent charity housing the largest collection of functional historic computers in Europe, including a rebuilt Colossus, the world's first electronic computer and the Harwell Dekatron / WITCH, the world's oldest working digital computer.

- <https://www.tnmoc.org/>

3D virtual tour of the museum:

- <https://www.tnmoc.org/news-releases/2017/6/6/3d-virtual-tour-now-online>

Galleries:

- <https://www.tnmoc.org/galleries>

Google Arts & Culture:

- <https://artsandculture.google.com/partner/the-national-museum-of-computing>

History of Science Museum (Oxford)



Approximately 20,000 objects cover almost all aspects of the history of science, from antiquity to the early 1900s. Particular strengths include the collections of astrolabes, sundials and early mathematical instruments, together with apparatus associated with chemistry, medicine, and communications. In addition, the Museum possesses a unique reference library for the study of the history of scientific instruments that includes manuscripts, prints and early photographic material.

- <https://www.hsm.ox.ac.uk/>

Explore the museum interactive tour:

- <https://www.hsm.ox.ac.uk/explore-galleries>

Collections:

- <https://www.hsm.ox.ac.uk/collections-areas>

Library and Archives:

- <https://www.hsm.ox.ac.uk/library-and-archives>

UNITED STATES

Smithsonian Institution (Washington, DC)



The Smithsonian Institution is the world's largest museum, education, and research complex. We are a community of learning and the opener of doors. Join us on a voyage of discovery and explore and learn online.

- <https://www.si.edu/>

Virtual exhibitions:

- <https://www.si.edu/exhibitions/online>

How to virtually explore the Smithsonian from your living room:

- <https://www.smithsonianmag.com/smithsonian-institution/how-virtually-explore-smithsonian-your-living-room-180974436/>

Google Arts and Culture:

- [American Art Museum](#)
- [Archives of American Art](#)
- [Cooper Hewitt](#)

Smithsonian National Museum of Natural History (Washington, DC)



The Smithsonian National Museum of Natural History virtual tours allow visitors to take self-guided, room-by-room tours of select exhibits and areas within the museum from their desktop or mobile device. Visitors can also access select collections and research areas at our satellite support and research stations as well as past exhibits no longer on display.

- <https://naturalhistory.si.edu/visit/virtual-tour#>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/smithsonian-national-museum-of-natural-history>

National Gallery of Art (Washington, DC)



The National Gallery of Art, founded as a gift to the nation, serves as a center of visual art, education, and culture. Our collection of more than 150,000 paintings, sculpture, decorative arts, photographs, prints, and drawings spans the history of Western art and showcases some of the triumphs of human creativity.

- <https://www.nga.gov/index.html>

Degas at the Opéra Virtual Tour:

- <https://www.nga.gov/features/degas-virtual-tour.html>

Marking the 500th anniversary of Raphael's death:

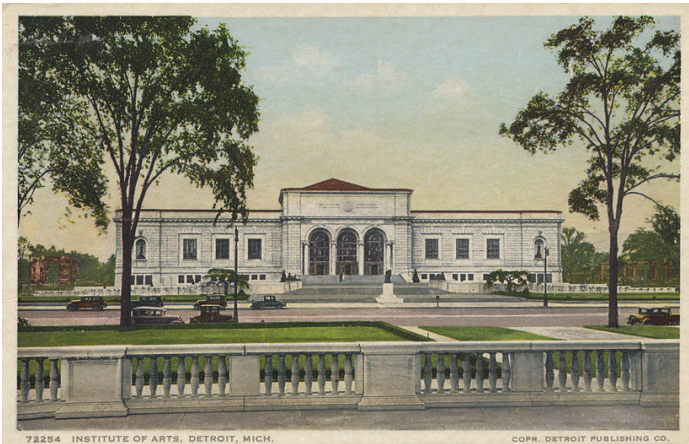
- <https://www.nga.gov/features/raphael-virtual-tour.html>

NGA Online Editions presents the most current, in-depth information on the Gallery's collections:

- <https://www.nga.gov/research/online-editions.html>

Google Arts and Culture

- <https://artsandculture.google.com/partner/national-gallery-of-art-washington-dc>

Detroit Institute of Arts (Detroit, MI)

Founded in 1885, the museum was originally located on Jefferson Avenue, but, due to its rapidly expanding collection, moved to the current site on Woodward Avenue in 1927. The Beaux-Arts building, designed by Paul Cret, was immediately referred to as the “temple of art.” Two wings were added in the 1960s and 1970s, and a major renovation and expansion that began in 1999 was completed in 2007.

- <https://www.dia.org/>
- <https://www.dia.org/art/collection>

Detroit Institute of Arts Virtual Field Trip

- <https://youtu.be/8NTOkwhjdEg>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/detroit-institute-of-arts>

Georgie O’Keeffe Museum (Santa Fe, NM)

O’Keeffe’s home in Abiquiú, New Mexico reveals her commitment to design and the aesthetics of her surroundings. Traditional adobe structures are found throughout the region, but O’Keeffe made her home distinctly modern, with abundant natural light, updated amenities, and midcentury modern furniture.

- <https://www.okeeffemuseum.org/home-and-studio/video-tour-homes/>
- https://youtu.be/nuzWJfUf4Cg?list=PLg1_ZP4Bzx7mvPIUNImxSvPYw3W5W4ABO

Google Arts and Culture:

- <https://artsandculture.google.com/partner/georgia-o-keeffe-museum>

J. Paul Getty Museum (Los Angeles)



The J. Paul Getty Museum seeks to inspire curiosity about, and enjoyment and understanding of, the visual arts by collecting, conserving, exhibiting and interpreting works of art of outstanding quality and historical importance.

- <https://www.getty.edu/museum/>

How to Use Your Phone to Virtually Display Art:

- <https://blogs.getty.edu/iris/how-to-use-your-phone-to-virtually-display-art/>

How to Explore Art While the Getty Galleries Are Closed:

- <https://blogs.getty.edu/iris/explore-getty-art-resources-closed-coronavirus/>

Works of art dating from the eighth through the twenty-first century, the collection includes European paintings, drawings, sculpture, illuminated manuscripts, decorative arts, and European, Asian, and American photographs. The J. Paul Getty Museum at the Getty Villa in Malibu features

Greek, Roman, and Etruscan antiquities presented in a setting modeled after a first-century Roman country house, the Villa dei Papiri in Herculaneum, Italy.

- <https://artsandculture.google.com/partner/the-j-paul-getty-museum>
- <https://artsandculture.google.com/streetview/the-j-paul-getty-museum/>



The collection of the J. Paul Getty Museum comprises Greek, Roman, and Etruscan art from the Neolithic to Late Antiquity; European art—including illuminated manuscripts, paintings, drawings, sculpture, and decorative arts—from the Middle Ages to the early twentieth century; and international photography from its inception to the present day.

- <https://www.getty.edu/art/collection/>



National Museum of the US Air Force (Riverside, OH)



The National Museum of the United States Air Force collects, researches, conserves, interprets and presents the Air Force's history, heritage and traditions, as well as today's mission to fly, fight and win in air, space, and cyberspace. These statutory duties delegated by the Secretary of the Air Force are accomplished on behalf of the American people. We are the keepers of their stories.

- <https://www.nationalmuseum.af.mil/Visit/Virtual-Tour/>

National Women's History Museum (Alexandria, VA)



The National Women's History Museum (NWHM) researches, collects, and exhibits women's social, cultural, economic, and political history in a context of world history. The Museum uses innovative and engaging means including physical and online exhibits, educational programs, and outreach efforts to communicate the breadth of women's experiences and accomplishments to the widest possible audience. Sharing this knowledge encourages women and men, people of all classes, races and cultures to move into the future with respect, equal confidence, greater partnership, and opportunity.

- <https://www.womenshistory.org/womens-history/online-exhibits>

Google Arts and Culture:

- <https://artsandculture.google.com/partner/national-women%E2%80%99s-history-museum>

Mütter Museum (Philadelphia)



America's finest museum of medical history, the Mütter Museum displays its beautifully preserved collections of anatomical specimens, models, and medical instruments in a 19th-century "cabinet museum" setting. The museum helps the public understand the mysteries and beauty of the human body and to appreciate the history of diagnosis and treatment of disease.

- <http://muttermuseum.org/collections/>

Virtual Tour:

- <https://youtu.be/dqj2fk29NZA>

Playlist:

- <https://www.youtube.com/playlist?list=PLE5U9L06rB7MSVglzy3jD-moDIIdteHBHO>

Petersen Automotive Museum (Los Angeles)



Enjoy the first ever full Vault Tour of the Petersen Automotive Museum vault. Over 60 minutes and 250 of the rarest and most expensive cars in the world. See everything from celebrity cars, Ferraris, Bugattis, and race cars.

- <https://www.petersen.org/on-display>

Full Vault Tour, over 60 minutes and 250 of the rarest and most expensive cars in the world.

- <https://youtu.be/e0IzyESwcTw>

Petersen Automotive Museum Tour:

- (Part 1) <https://youtu.be/7qaHlml1XWs>
- (Part 2) <https://youtu.be/72EGVQgAMC4>

A visit to the Petersen Automotive Museum in Los Angeles California . An expansive collection of cars and vehicles spanning thru history as well as a lot used in tv and movies.

- <https://youtu.be/f4MQfPhuFAA>

VATICAN

Vatican Museums



- <http://www.museivaticani.va/content/museivaticani/en/collezioni/musei/tour-virtuali-elenco.html>

Sistine Chapel:

- <http://www.museivaticani.va/content/museivaticani/en/collezioni/musei/cappella-sistina/tour-virtuale.html>

The Online catalogue of the Vatican Museums presents essential information regarding the mobile works of art (that is, excluding the spaces, buildings or their decorations) on display along the tour itinerary. The database is periodically updated, revised and expanded.

- <http://www.museivaticani.va/content/museivaticani/en/collezioni/catalogo-online.html>



Publisher Information



The **Ehlers-Danlos** Society™

FOUNDER

Nancy Hanna Rogowski (1957–1995)

STAFF

Lara Bloom, President and CEO

Alan Hakim, MA, FRCP, Chief Operations Officer

Fransiska Malfait, MD, PhD, Chief Scientific and Medical Officer

Staff members <https://bit.ly/EDSstaff>

BOARD OF DIRECTORS

Susan Hawkins, Chair

John Zonarich, Esq., Secretary

Board members <https://bit.ly/EDSboard>

MEDICAL & SCIENTIFIC BOARD

Clair Francomano, MD, Chair

Fransiska Malfait, MD, PhD, Vice Chair

Board members <https://bit.ly/EDSmedical>

WWW.EHLERS-DANLOS.COM

General Email: info@ehlers-danlos.com

Submissions: ehlers-danlos.com/submit-to-loose-connections

The Ehlers-Danlos Society

1732 1st Ave. #20373

New York, NY 10128 USA

Phone: +1 410-670-7577

The Ehlers-Danlos Society – Europe

Office 7, 35-37 Ludgate Hill,

London EC4M 7JN UK

Phone: +44 203 887 6132

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 are proudly working to provide global learning conferences, collaborative research and education 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.

Loose Connections is published by The Ehlers-Danlos Society. The opinions expressed in *Loose Connections* are those of the contributors, authors, or advertisers, and do not necessarily reflect the views of The Ehlers-Danlos Society, the editorial staff, the Medical and Scientific Board, or the Board of Directors. The Ehlers-Danlos Society does not endorse any products.

Loose Connections is published under Creative Commons protections: Attribution-NonCommercial-NoDerivatives 4.0 International (CC BY-NC-ND 4.0) unless otherwise noted. For more information, visit <https://creativecommons.org/licenses/by-nc-nd/4.0/>