

Rare Sounds

Poetry by people
living with rare diseases



Workshops directed by
Roopa Ramamoorthi

UCSF Innovation
Ventures



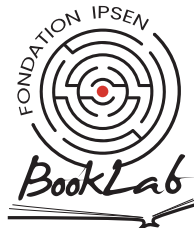
Front cover:

artwork by Janelle La Chaux

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The voices of millions of people, many children, living with rare diseases are often unheard. People living with rare diseases are silenced through stigma and discrimination. Poetry gives its writers power through self-expression. In this magnificent project, Dr Ramamoorthi teaches people who would otherwise be silenced to express themselves through poetry. By teaching poetry as a method of self-expression, the teacher gives voices to the silent. Not only are the poems eye-opening and heartrending, but this book includes a teaching guide so that the method is scalable. I wish for a world where people are valued for who they are and not for what they appear; this beautiful collection of poetry takes us one step closer.

James A. Levine, MD, PhD, Professor
President, Fondation Ipsen

This collection of poetry was written by people impacted by rare diseases and is a testament to their resilience. The collection also serves as a work of support and inspiration for the rare disease community. Poetry captures the deepest feelings: despair and hope, uncertainty and understanding, as well as loss and love. The healing words of poetry can have a positive impact on both the reader and the poet. These poems serve as a vision for a future with better diagnostics, better treatments and even cures. On behalf of the organizers of the UCSF Rare Disease Symposium, I want to thank all of the contributors to this thoughtful and heart-felt collection. Additional thanks to the Foundation Ipsen for their generous support.

Charles Hart, PhD,
Executive Director, Catalyst Program, UCSF

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Introduction •

It was my pleasure and honor to work with these remarkable individuals who have demonstrated their amazing strength, resilience and grace in dealing with their rare diseases and how they are navigating life. When I embarked on this project, initially to get poems from people at Benioff Children's Hospital in Oakland so their voices could be heard during the lunch hour of the Rare Disease Symposium, I had this naïve notion of just conducting a poetry workshop and pulling the poems out and the patients voices heard. I focused on developing a good lesson plan. However after that initial workshop and in subsequent workshops after Dr. Levine suggested I develop an entire collection I went on a journey with amazing individuals I had the pleasure to get to interact with. I realized they had serious medical issues, were in pain a lot of the time and had to make the workshops available when it was convenient for them and so I conducted these on zoom often one on one or sometime with two of them together. Also it was important for me to be vulnerable and share my own life challenges e.g my divorce and read some of my own poems exposing my wounds for them to feel a safe space to be vulnerable to share their precious work.

I was even invited to and attended a creative writing event with them through the Stanford Patient Advisory Committee where I too was vulnerable writing and creating my own poem and sharing to build trust. I write this so when this workshop is replicated on zoom or in person I encourage other workshop facilitators to be vulnerable and open about your own challenges and also to tailor the workshops more individualized or suiting the people's availability and needs.

And I want to thank them for showing me how strong and courageous and vulnerable they are, it has been my privilege to work with them and I hope these poems reach and pierce your heart as they have mine. I also wanted the voices to be powerful in their beauty and vulnerability and so these are not edited and I believe have more power just as they stand.

Roopa Ramamoorthi
Poetry Workshop Leader

Rare Disease Poetry Workshops
Lesson Plan ●

The lesson plan can be used to conduct workshops for people with rare diseases and beyond for those suffering other ailments or life challenges too.

Poetic Devices

Metaphors: e.g. Their cheeks were roses

Similes: e.g. Their cheeks were like roses

Internal rhymes: when you have rhymes within a line, e.g. the red robin was fed, where red and fed are rhyming words within a line.

Alliteration: when words on a line start with the same letter, e.g. the red robin reached around, here the r sound is repeated

Anaphora: when the same phrase is used at the beginning of each line

When you write a poem you want to create vivid imagery, use all your senses as you write, the visual, the sense of touch, taste, smell and hearing.

Use some of these poetic devices when you write.

First read these two poems for inspiration:

<https://www.henshaws.org.uk/news/poem-rare-disease-day/>

<https://medium.com/illumination/perseverance-972377008857>

Now write for 10 to 15 minutes, and use it to write your own poem what you want others to understand about your struggle with a rare disease.

Do not overthink it and just write.

If the workshop is on zoom it helps for people to be off camera on zoom while writing.

For the next exercise,

First read this poem:

<https://patientworthy.com/2022/02/28/places-youll-go-rare-disease-edition-2/>

Now make a list of five things about your rare disease, five things that soothe, calm or inspire you. Use as many of these ten words to write a poem. Do not overthink, write the poem in 10 to 15 minutes.

After you have written your poem, in case of both poems, read them aloud to those around you and let the listeners say what they liked or what resonated with them around the poem. Look forward to your using the lesson plan to create your own workshops and your own poems.

Poems collection ●

Poem

by Michael D

Deficiency of red and white blood cells alike
caused me to panic
But music helped me calm my infinite manic
Although near impossible I could still do the minimum
But exercising was hard regardless of the curriculum
Videogames kept me sane when I was losing hope
I think that watching TV also helped me cope
I've always dreamed of hooping
Maybe one day I still can
Until that day comes, aplastic anemia made me a better man.

Aplastic Anemia

by Michael D

*Blood is so accessible and yet I lack its cells
If only people knew the struggles
That the disease entails
I've been laughed at, called names
And even called a liar
But nothing is worse than when you lose your fire
That beautiful fan that blows gently on your flame
Was taken away from me
But do not dismay
I plan to come back brighter*

Who Am I?

by Sparsh Shah

I get around in a powerchair,
My bones break, here, there, everywhere;
I'm shorter than most of my pals,
My body's not shaped in the "normal" style.
I may not have good eyes to see,
But I can bend my thumbs with ease;
I cannot walk, but I can fly —
Now you tell me: who am I?

My head's in Heaven, wheels in Earth,
I'm Curious George in human birth;
I love to stroll on Nature's roads,
And sing and write, and play with notes.
I hold my friends and family dear,
And always chase my vision clear:
I cannot walk, but I can fly —
Now you tell me: who am I?

No matter what aspect you see,
My looks or personality;
They are two sides of the same coin,
In my identity, they join.
No matter how you define me,
I know who I am exactly;
I cannot walk, but I can fly —
Now you tell me, who am I?

Doors and Windows

by Sparsh Shah

Whenever I'd talk about my condition to people,

I used to tell them something like this:

"When, in life, one door starts closing,

One more door will start to open;

But on closed doors, when we focus,

We can't see the ones that open!"

Then, I'd tell them how this proverb applies to me:

"See, God may have closed the door,

On my ability to walk;

But He gave a mind to speak,

And then a voice to sing and talk!"

And by the end of the conversation, they would say things l

like:

"Oh, what wretched men we are!

We don't have so many woes;

But look! Life beat him black and blue,

Yet still, he strolls, onward he goes!"

But then, I learned about neuroplasticity.
Here's how I've come to understand it:
"Our brains are wonders to behold,
So adaptable are they;
That when some senses can't be used,
The parts of our brains that convey ...
Messages to these dead senses,
These parts take on other roles —
Now you know why Stevie Wonder,
Could find a mouse at a few years old!"

So I submit to you today:
What if we were always wrong?
Just because we look the weakest,
Doesn't mean we aren't strong.
Everyone has strengths and flaws,
Good at some things, others not;
So why do we haste toward labels,
Like "Disabled" — why these thoughts?
What if "disability",
Means "dissing our abilities";
And acting not on our potential,
'Cause we're trapped in the circumstantial?
We're not underprivileged,

Even though we are underserved;
So let us put aside our bias,
And treat us as we're deserved!
So now, whenever I talk about my condition to people, I tell
them something like this:
“Sometimes, when we do compare,
Ourselves to others, we conclude;
That life for us is never fair,
'Cause what they can, we cannot do.
So, we think the doors are closed,
But what if we thought differently:
What if, really, these 'closed doors',
Are windows of opportunity?”

Allodynia

by Heather Dever

Why is a gentle breeze wafting across my skin
Unbearable?

Why is sunlight painful?

Why did I have to train my husband how to touch me?

Not too soft (too gentle, feather-touch, nauseating)

Not too firm (sandpaper, not nice)

Gentle rhythmic motion, hair-brushing, just right

So soothing

A hug after his death, so excruciating

Why can I never wear even my wedding ring?

Why can no one see?

Moonlight

by Heather Dever

Fragile steps and broken columns
The garden sat under the moon
In the distance the bay gleamed fitfully
Bitter pills rained down from the sky.

The girl sat in the garden.
When her eyes could open,
She was transfixed by the stars.
Burning glass shot through her body
She was transported with movement
Swirling and twirling within the garden.

Darkling plants glimmered below.
How could she walk, without crushing leaves?
How could she stand, existing?
Swirling and twirling, bitter pills rained down from the sky.
The garden of her body was broken.
Neither drowsing nor waking,
All she could do was exist.

That mournful struggle had no glamor, no sparkle of fame or
celebrity.

In the garden behind her eyes she existed,
Moving and unmoving, transfixed by the stars,
Shot through with indescribable pain.

What does burning mean?

These fragile steps and broken columns, were they on fire?
Flames licked the garden walls, the pergola, the folly, the ferns
and asphodel.

What does electric shock mean?

Lightning struck the garden, forever, relentless, over and
over again.

She was trapped in this world, relentless, unmoving, swirling
and twirling.

The bay gleamed in the distance, always in the distance. She
could never reach it.

She longed for the bay, longed for the stars, longed for death,
relief from the mournful struggle.

The bay was hope, life beyond pain so extreme she had to sit,
unmoving, eyes half closed, just to bear existence.

*Fragile steps and broken columns, ferns and asphodel,
The eternal, burning garden sat behind her eyes.
And bitter pills rained down from the sky.*

The Girl Who Cried Wolf

by Heather Dever

Once upon a time, a girl was walking in the woods when a
wolf bit her.

“Help, help!” she cried.

The doctors smiled gently, and told her to exercise.

The girl tried to walk, through molasses it seemed, but the
wolf continued to bite her.

“Help, help!” she cried.

The doctors tested and tested her, but the wolf only bit harder,
and she cried in pain. “There’s nothing wrong,” they
said, and rolled their eyes.

The wolf bit her so hard now that she could barely walk, “But
is this pain?” she said. “I must be weak, be a bad
person, it must be my fault.”

Years went by.

The wolf bit and bit until the girl, now a woman, could no
longer walk. “Why didn’t you tell us?” they
said. “Move, don’t move, rest, we don’t know what to do.”

The woman smiled gently, and cried.

Fire Within

by Janelle La Chaux

Life is a blessing day to day
I pray for no pain in my legs.
Though I smile, I know it will only be for a while,
that I feel no pain.
When the weather changes from hot to cold
I know hard days are coming.
I must be bold I have been told living with
Sickle Cell Anemia is Hard
I am scared internally, like people hurt me deliberately
thinking I am weak and sick
They couldn't even imagine the fire within,
burning like a furnace
I hurt yea, but could you take my pain and
have an unexpected sick day?
Imagine pain coming out of nowhere, and your stare and
glare with fear of not knowing.
Will you have to go to the hospital? The thought is mind
blowing.

*Life is precious and filled with lessons, don't think that
nothing will happen to you
because as soon as you turn your head, you will be dead or up
in old age.*

*With every acting pain and stain on your short, you will be
hurt just like me
the only difference is I will be burning within the fire that
burns within me.*

Poem

by Janelle La Chaux

Unexpected issues of pain caused from my sickle cell, that
can bring on Therapy sessions that need to be talked out loud
I shout out "NO MORE SICKLE CELL ANEMIA" at the sickle
cell walk

I thought about all my hospital admission, with hip pain and
the scaring of my veins from my damaged sickle cells things
I sleep from pills I need to comfort my pain not thinking
dreaming of what new sickle cell artwork to create

Breathing thinking at the Berkeley Marina, thinking seeing
what I can't dream of

A long drive to nowhere with good friends of mine I just love
the architecture of this brain of mine

I have a fine husband that kisses me at night that loves me
and brings me my oxygen at night

Poem 1

by Gael Muteba

I watch my father cope, my mother mourn.
I watch my sisters dote, my brother run.
But I am out of breath. Brittle bones breaking and aching.
But I cannot escape.
I am forever a slave to you. I cannot help but run from you,
 with this sickly body that always aches.
And I am out of breath before I can even take a step. I wheeze.
I cannot breathe.
I am out of breath.
And 'it's normal' for 'people like you, they say.
Just take it easy, it's how you'll always feel, they say.
Take two of these per day, preferably after a meal, they say.
Otherwise you'll hurt, and we'll have to see you again.
But I cannot escape, I am forever in a race with you.
Knowing you'll catch me, when I am out of breath.

Poem 11

by Gael Muteba

Beneath all the fatigue and pain,
The time I spent in hospitals, there was still love.
As I shrunk beneath your stares, I came to acceptance.
But my reliance on you, has brought me to a community.
As our outreach spreads with the sound of one unified voice,
we create hope.

I already Know

by Tamara Hattis

*I already know
I won't be understood
It's been 28 years of feeling bone fire pain
It hurts to talk, kiss, smile,
Sit, stand, type, write*

*People think me eccentric at best
I turn into a feral animal
At the doctor's office because
They hurt me beyond repair
They never believe me
They give me anti-depressants
They look at me with judgement
They try to disguise but
I am now wise
There is no treatment,
There is no cure*

My Secret

by Tamara Hattis

With trigeminal neuralgia
It hurts like crazy to wear a mask
For more than an hour

I don't want healthy people
To use my truth
As their excuse

I tell no one that
Masks start hitting a nerve
In the upper bone of my nose

If I don't take the mask off
The pain will become it's own
For weeks, even when
not wearing the mask

Therefore I have not left my house
For anything social indoors since
February 2020.

Graduate School for Communicative Disorders

by Tamara Hattis

Sudden spasms ruined me
I was sad when it
Hurt to kiss,
But then not to
Smile without
Severe repercussions, like
No chewing,
No talking
Cold compress on the jaw
I tried to get my graduate degree
Strained my tongue
Teaching sibilants and
Affricates: ch, sh, dʒ, ʒ, s
Helping the children
And I dropped out
No longer able to talk

I became a vertigo damsel
Dangling from my satellite television
Reality TV on loop
Unable to go out or socialize for months
Still looked normal physically

People thought I was trying to
Look sexy because I
Wasn't smiling
I was just
trying to
survive
without
spasms
that would wither
me away from
Food,
Sex
Living

Brain Storm

by Josiah Titan

As hard times and tribulations press me
I stop and think of the life that can be
To be free of this disease.

As my mind wonders through the sky
I see a foe claiming, "You will die!"
This foe has a familiar face like a black mirror.
As I pray and hope to be done
I know there is still a battle to be won
A battle of the body and the mind

Hope Is My Cure

by Josiah Titan

*I thought an orchiectomy would save me
Yet here comes stomping recurrent disease
Positive affirmation put me at ease*

*Good Risk is what classifies me
Hope fills the eyes of me and my family
The small kiwi of a mass is now becoming a distant tragedy*

Corrected Vision

by Van Duesterberg

*My eyes are mine and I cannot tell
Whether you understand my experience well
The challenges I endure like doing a simple task
And do it precisely the way you'd asked*

*Oh it's frustrating and demoralizing in and of itself
I don't need to hear your remarks on how I stacked these
books on the shelf.*

*It's your rigid, unwavering approach to life that needs
to be adjusted*

*Maybe it's your parents that taught you perfection always
to be conducted.*

*So it's your eyes, not mine that needs to be corrected,
As I am content even with these challenges,
is yours the way you expected?*

From One to Many

by Van Duesterberg

You may not know my vision loss unless I use my cane,
To navigate dimly lit places and detect an uneven plane.
During the day when there's plenty of light,
I navigate and socialize like those with normal sight.

When the sun slowly sets, I anxiously rush home
To prevent myself from getting injured, lost, or alone.
As I only have 10 percent of my vision intact,
I plan to use what's left of my vision to make an impact.

Trained as a PhD, an engineer, and an entrepreneur,
I hope to develop a streamlined process to find a cure
For every mutation and every gene, I'll model using
 patient-derived cells
Of their specific disease by growing millions to test dozens
 of drug cocktails.

I hope this path of N of 1 pave will be seen and heard
Throughout industry, academia, and regulatory even
though it seems absurd
To develop a cure for only a few but eventually
These few will change the landscape and then the few
become many.

Prose Poem

by Brittany Postle

Isolation is the true killer. Insidious, cold, uncaring. Some days, a slow, creeping liana. Other days, a torrent of viscous magma. Both pull you under. I wonder what changed? The gap between dis- and -abled? To make me so invisible to society and so easily passed over. A phantasm of my former self.

Prose Poem II

by Brittany Postle

Rendered flat, left in bed yet again with a cerebrospinal fluid leak. My brain is mired in fog. My head is encapsulated in pain. Pain comes in radiating waves. But waves have also brought relief, lapping at my legs. Better times, when the ocean danced on my toes, holding Ben's hand as Nola dog pranced in the sand. Balancing pain and gratitude is a tricky teeter-totter. How to evenly spread that weight, so one is not suspended in air? When I begin to leak anew, bulk is added to the side of Pain, diminishing the ability of Gratitude to touch toes to the ground. As Gratitude flails for purchase, I remind myself that I am continuing my education. I am blessed with the opportunity to explore that pathway. Toes to dirt- The balance is restored. I am still perpetually exhausted. My pain doesn't ever leave me. But this constant shifting of weights, between chronic pain and gratitude, this teeter-totter, it keeps me going.

From the Outside

by Michael Rabow, MD

You cannot see it from the outside.
I still look “normal.”
So there is no easy excuse
for my bad balance.

And all my old friends
say they are fatigued too.

When I walk,
you might think I’m drunk.
I wish I were.

Inside my head and heart,
suffering lives on.

And I keep getting angry
at my body,
until I remember that MS
has befallen it too.

Not Every Problem

by Michael Rabow, MD

*When I have double vision,
I can just close one eye.*

*When the heat becomes intolerable,
I can refrigerate.*

*When I worry about the next loss
I can often rejoice in an unchanged MRI.*

*When I fear being immunosuppressed
I can give thanks for masks.*

*MS is faulty wiring,
basically,
treated with medicine
proven in a randomized trial.*

But of course,
not every problem
has a solution.

Still, my neurologist assures me
I'll almost for sure
die of something else.

Poets' Biosketches •

Brittany Postle is a person with disabilities. She is also a student at UC Berkeley, an avid reader, a dog mom, a partner to Ben, and a daughter to Shelley and Chuck. She loves nature, reading, & research. She believes that human rights, such as healthcare, should be accessible to all.

Gael Muteba was born in Zaire, now the Democratic Republic of Congo (DRC). And he has always loved to read, write, and listen to the world around him. He is big on art and music, and most creative pursuits. Because he finds them to be the function of the soul.

Heather Dever is a collage artist living in Livermore, CA. She has suffered from severe chronic pain for most of her life, but actually had not thought of herself as having a rare disease before this collaboration. She is grateful for the poetry workshop and the Ipsen Foundation for having helped her find her poetic voice.

Janelle La Chaux-Dandy is a black and Mexican woman, who suffers from Sickle Cell Disease. An activist in her community

sitting on different boards, or creating artwork with oil paint. Art-therapy is her voice www.janellelachaux.com. On a board, or creating artwork is the voice we all need for change.

My name is **Josiah Saavedra-Flores**, I am attending UC Riverside during the fall of 2023 where I will be earning a degree in bioengineering. While I have a fascination for bioengineering I love to write poetry and play soccer in my free time.

Michael D: Once anemia hit I was unaware of it because of another medication that had similar effects but eventually it got to the point where it was blatantly obvious that something was wrong so they brought me to Dameron Hospital and there they said my white blood cell count was wacky so they started pumping me with blood until I felt better and from there a helicopter picked me up and brought me to Oakland children's hospital and there I spent the next six months in recovery before I was allowed into the recovery house and from there I slowly started to ween off the immunosuppressants and now in a month I will be able to completely enter society as a normal person and as

traumatized as I was I know that after this was all over I'd be a different person and here I am feeling great and a month away from what should be my final surgery and for that I appreciate Oakland's children's hospital and thank you for listening to my story.

Michael W. Rabow, MD, FAAHPM, the Helen Diller Family Chair in Palliative Care, is a Professor of Clinical Medicine and Urology at UCSF. He is the Associate Chief of Education & Mentoring in the Division of Palliative Medicine and the Medical Director of Palliative Care at UCSF's Helen Diller Family Comprehensive Cancer Center. He is the founding Director of the MERI Center for Education in Palliative Care at UCSF/Mount Zion.

Sparsh Shah, also known as Purhythm, is a singer, songwriter, inspirational speaker, philanthropist, and Guinness World Record holder. He has spoken and performed in 9 countries and appeared on numerous television shows. Sparsh has inspired millions worldwide and helped raise over \$2 million for non-profit organizations. He has received various prestigious awards and is followed by people from 150+

countries on social media. Despite never having walked and having over 150 fractures, he aims to “Sparsh” (means touch) everyone's hearts worldwide. Click here to know more: www.SparshShah.com

Tamara Hattis has been published in Ghost Town Literary Magazine, Incandescent Mind by Sadie Girl Press, Cholla Needles Magazine, Wordgathering, and Pile Press. She published Colors of My Pain in 2019. Her work is also featured on her website Tamilani.com and she can be followed on her Instagram page @tamarahattis

Van Duesterberg is a patient and scientist developing a treatment for her retinitis pigmentosa. She's spent more than 20 years in academia and industry navigating the healthcare space for patients with rare and undiagnosed diseases. She hopes that her journey inspires, helps, and paves the path for more cure odysseys.

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Have your say!

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Not for sale – free book



Roopa Ramamoorthi, is a scientist and published poet as well as Director for the Catalyst and InVent Fund at UCSF. Her essays, poetry and short stories have appeared in over 80 publications including various anthologies, perspectives on NPR and she has

been featured at former San Francisco poet laureate Kim Shuck's poetry events. She feels honored to have conducted the poetry workshops with people living with rare diseases and to help send their voices out into the world.



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