

My



Journey

No fair. No fair. It's not fair.

Butterfly needles. IVs. Bedpans. Noisy medical machines. Gauze. Alcohol. Frigid stethoscopes. There's no rest, there's no privacy and there's no promises. There is however worry, uncertainty, anger, and fear.

This. This is how it feels to be a perpetual, continual, regularized chronically ill patient. You sit and lie in the hospital bed or emergency room for hours and hours on end waiting to get your vitals taken, your labs taken, keeping conversations with hospital staff at surface level, seeing other patients suffering.

You wait for hours to talk to your doctor for 2 minutes reporting how well or inadequate your condition is and the limited options there are to fix it. Most of them being painful where you're poked and prodded like a science experiment then wrapped in gauze and tape like a Christmas present. Thus, leading to self-doubt and self-questioning of if you were able to prevent this or what you did to deserve this.

Your phone keeps lighting up from the messages and calls you receive from your loved ones asking about the most recent status and you may or may not have an answer. You get to lie there in the uncomfortable rigid bed staring at the ceiling as your loved ones continue looking for cures, they can't provide. You continue to observe them helplessly fumbling around the room performing services to comfort you and occupy themselves knowing their head is filled with worries.

You wish you could ease their pain too as you notice all the exasperating feelings, they're trying to hide that you can't comfort cause your body is too busy being in pain.

Test after test after test. Next are scans, then pre op, then you finally get to go into surgery. Where instead of a nice beach view or even the comfort of your own living room once was, you get to be in an incredibly freezing room, placed onto a stiff board, arms secured down and busybodies filling the room speaking medical jargon that just confuses you even more.

Being a human is not easy, surviving daily tasks can be demanding, but when your own body is failing, and you can't do anything about it but be trapped in it is probably in the top ten worst betrayals to be in. We already have no say in what bodies we are born into and there aren't days that you can just choose to not deal with it and do whatever you want. You're never sure if today or the next day is going to be a good symptom free day. Every single day is a battle and every single day you're just wishing that you can survive and stay alive.

My name is Joana Mari Narvarte. A name derived from my loving parents. I am their first daughter, I am the oldest sibling, I am the first granddaughter and the first niece. I am the first chronically ill individual in my immediate family. And we don't know why. I can write about how unfair it is that my family and I are in this situation. I can write about how hurtful it is to constantly question why me. But instead, I choose to embrace this experience as an opportunity to show myself and others that life may not always be fair, no one said it was going to be. It is what we choose to do with it, who we spend it with and how we leave this earth that matters.

I have been sick since I was fourteen years old. Fourteen. A time where I should be developing my identity, beliefs, forming social connections and emotional growth. Instead, I'm gaining different diagnoses, seeing endless doctors, and suffering painfully lasting symptoms. I had my first seizure. A seizure of all things! I went from only having a cold once a year to a whole seizure. And this was only the beginning.

Over the next few years, I would become very familiar with emergency rooms, hospital stays and doctor visits. I experienced fainting spells, joints swelling, high fevers and gastrointestinal problems that led to meeting with 5 different specialists that consisted of a Nephrologist, Hematologist, Gastroenterologist, Neurologist, and a Rheumatologist each with their own prescriptions, treatment plans and many appointments. It was exhausting for my family and I. By sixteen years old I was experiencing my first surgery for my hemodialysis catheter to be placed as I was finally diagnosed with End Stage Renal Failure and Crohn's disease. Ahh finally an answer and concrete solution to why I was feeling the way I was. Although it provided some relief to be given a condition, it just solidified how ill I truly was.

I remember my first dialysis treatment session. My nurse showed me the machines, walked me through the process and explained every step of the procedure. But I couldn't focus on her words and felt my eyes wandering such unfamiliar territory. There were other patients there, patients younger than I, in worst conditions than I and I couldn't help but feel guilt and shame all over my body. It was painful and heartbreaking seeing us kids in such a predicament.

These were other people's daughters and sons connected to machines in hopes they too would find a kidney soon to help them live. Once I was finally in the chair, and my catheter and machine became one, I didn't move a single inch for the next three hours. My hands stayed folded, feet together and eyes hyper focused on the spinning machine.

I sat there scared, I sat there with my thoughts, I sat there hoping this wasn't going to last for too long. Oh how I didn't know the loud beeping machine, the color of red in tubes and view of other suffering patients would become familiar territory for the next three years.

Moving time, oh how I loved moving. Moving meant new opportunities, new people, and new environments. My family and I were moving to California from Las Vegas as I had just finished high school and was now entering college. I was filled with excitement because college was a brand-new start, and I could be a brand-new Joana.

I always had a strong interest in academics and enjoyed the challenge that courses brought. Even when I was a young girl, I knew my academic career was going to go far because I was going to put the effort needed to become successful no matter what.

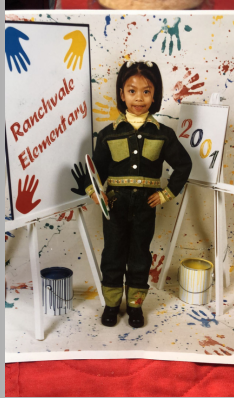
I began my first year and found myself unable to walk between classes efficiently. I was experiencing dizzy spells, my limbs feeling numb and my dialysis treatments not getting any better. I knew this meant another dreaded doctor's visit.

We were informed that my kidney function was now at 5% and a kidney transplant was vital or else I would have to insert a fistula into my frail arm. My family and I were devastated. It felt like we were backed into a corner but three years of 9-12 hours of treatment every week was finally enough.

My kids, I meant siblings and cousins :)



Love stickers, don't you?



Don't mess with me...



@ 18 I'm such a big girl



My baby sister Jada May



Don't Dad and I look cool

My son Jax Milo



Continued

On August 28, 2013, my mother graciously and selflessly donated her kidney to me at Stanford Medical Center. I was so grateful; my parents and family were so relieved, and we could finally breathe.

No longer did painful symptoms consume my days, no longer did I anticipate the next sick day that would prevent me from completing my goals and no longer did I have to sit in that rigid chair to complete my dialysis treatments. This moment allowed me to live life again for the next 9 years. 9 years of not being ill, 9 years I put into my education and earned myself an associate degree, a bachelor's degree, and a master's degree.

9 years I was able to travel around the world, spend time with friends and family, and experience life outside the hospital room. This all came to an end in March 2022 when I entered the emergency room doors for yet another symptom. It was there I was informed that my donated kidney, the piece of my mother that I carried, was now failing. I couldn't believe it, I felt like a failure for not being able to carry my mother's kidney longer. Now there's no promise that a donated living kidney would last forever, all doctors ensure to tell their patients that and on average it could last 20-25 years from a living donor.

I surely thought it would've lasted longer than 9 years. Next thing I knew I was immediately in surgery for a different type of dialysis called peritoneal dialysis where the catheter is placed in the abdominal cavity. My days turned from being able to participate in many fun activities to 8-9 hours of treatment every single day, still working full time as a Marriage and Family Therapist and a Professional Clinical Counselor at a job that had me commuting 1.5 hours back and forth.

At first it was doable. I was able to juggle this demanding schedule and still try to be the bubbly upbeat Joana that everyone knew. Only my immediate family and close friends knew that I was chronically ill again while

I continued to hide my illness at work. I always had an issue with others knowing I was sick because of the pity that I received and that wasn't anything I wanted from others.

Even when I was sick the first time around it was never a good feeling to be on the receiving end of sorrowful eyes and distressed change of tone once they found out. So, it was no better this time around. The peritoneal dialysis couldn't keep up with how fast my illness was progressing and my condition became worse. I experienced fluid retention that would swell up my legs, it made it hard for me to breathe and my blood levels were so low that it left me depleted. Instead of completing healing work with my clients I became a patient again.

I would be at the hospital weekly, getting weaker and weaker requiring blood transfusions, a variety of medications and a repeat of testing. Every single day it was a gamble to see whether I was going to experience a handful of symptoms or few enough that I could experience a decent day. All I knew was that I was not getting better.

It's hard to believe that I'm here for a second time. As if the first time was not enough to teach me lessons, to help me mature, to see life as challenging. Nope, here I was faced with End Stage Renal Failure, heart failure because my heart was overworked dealing with the ESRD and back on hemodialysis.

This time I'm an adult, an adult with responsibilities and in a space where I am building a life, a career, and my future. I didn't have time for all this illness, but who does? In order to keep moving on, I had to complete open heart surgery to fix my mitral valves and tricuspid, I had to insert a hemodialysis catheter in addition to my already placed peritoneal catheter and continue to take daily medications. Now I complete three-hour dialysis treatments 3-4 times a week.

It is no easy feat to try and look at this part of my life through a positive lens, but this time is different. Yes, my illnesses are more severe but now I don't carry that same shame and guilt I did the first time around with those diagnoses. Now I welcome the love and support from others in asking questions and wanting to know what life is like as a kidney and heart patient. And now I try to face every day as it is and have a positive outlook because I know that I still have an amazing life despite this setback and that things could be much worse. This time around I'm not scared and want to use this experience to bring awareness and help to those who may be in the same predicament.

I choose to believe that this happened for a reason. Not everyone could deal or survive with this illness and yet I am still standing strong. There is purpose in the suffering because it'll help me appreciate the joys of life that much more. I am eternally grateful that my mother was able to donate her kidney the first time around, and I'll be just as appreciative when the second kidney comes. Whether the donated kidney comes from a living or deceased donor I would be lucky to even be considered for it.

People always ask me how I do it, deal with the sickness, deal with the demands of it and continue day to day and my answer is this:

Life may not always be what you planned it to be or be easy. We may not always be faced with what's desired, or even born into what we imagined for ourselves. There is so much out of our control and as humans, we naturally do not like uncertainty. But we figure it out as we go, pushing through the fear, learning from our mistakes.

It is not easy and it's not always fun. But I choose to try and make progress where possible and find peace in the way I deal with each problem. I value all the things that bring me joy and try to not be so hard on myself because life is hard enough. Happiness is something you create. I must believe better for myself and not overthink the situation I've been placed in. My peace is more important than understanding why something happened the way it did, so I accept it for what it is. It's better to be a good person with a good heart that can spread joy with others than to sulk in sadness for the situation I've been put in.

I always carry an awareness that life could be a lot worse while still acknowledging that mine has its tribulations. I continue to fight my illness and carry all the faith that it will get better eventually.

I am spending time with my family as I recover and am slowly but surely returning to life with another new normal. My body is covered in scars, but I am proud of them as it reminds me of the strength it took to get here. I am honored to do my part in spreading awareness and educating those about these diseases and will continue to do so for the rest of my life.

My family and I continue to bring as much education and awareness to the community around us in hopes to help those who may be going through similar situations. If our story could even provide the smallest amount of optimism for an individual suffering from a chronic illness, then it would have made this journey worth it.

Thank you for spending a moment to hear from a patient and her journey.

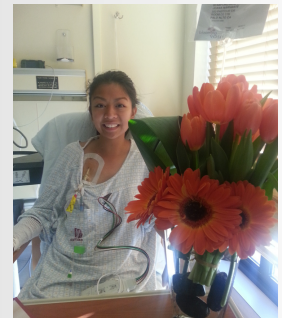
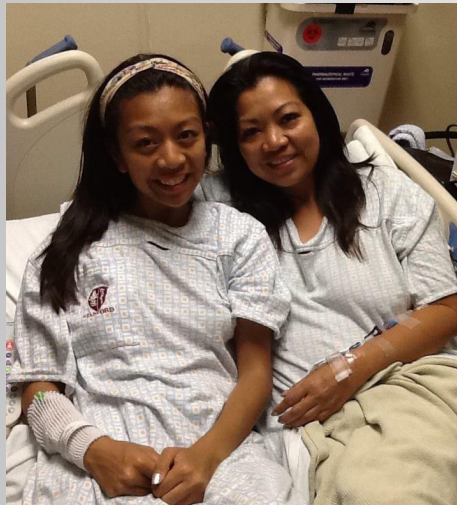
Joana Mari C. Narwarte

The Second Round



Dialysis Time at the hospital

10 Years Ago, the night before our transplant



One of the beautiful flowers I have in my room



Can't breathe, trying all kinds of machine to help me



Putting tube on my chest to remove more fluids, almost on code blue there.



A week after my open heart surgery

A Mother's Story behind the Pain

All the pain and suffering we went through all began with my daughter's health journey. A journey we have learned so much from in the past and the journey we continue to fight with to this very day.

I gave birth to my daughter on May 17, 1994, in my hometown of Manila, Philippines. I was scared, anxious, excited, and having my first child by myself as my husband was deployed overseas at the time as he was serving in the United States Air Force.

We were young first-time parents, having her at eighteen years old, still figuring out how to navigate life myself. She was tiny, being born at 6 pounds and 19 inches. But even then, in those first moments looking at her, I knew she was going to experience a life full of happiness, success, and adventure. I promised her at that very moment to try to give her everything that life had to offer and more.

At least, that's what every parent wishes for their child. I never imagined my child would have to go through what she did in years to come.

They always tell parents to enjoy the early years because they grow up right before your eyes and boy were they right. As she grew up through the years, I enjoyed watching her become this stubborn, self-confident, and determined young lady.

And these traits were consistently shown throughout her infant, toddler, and childhood years. She always impressed me with getting what she wanted because she would always figure out a way, just like her mama. She did well academically, was respectful and polite to all she crossed paths with, and the way she loved taking care of kids always made me proud.

She was able to adapt to all the relocations our family was assigned to, was able to help whenever possible and was my right hand once her siblings entered our lives.

Her goals and dreams were always big. She's wanted to become a pediatrician ever since she was young. There's this picture of her completing a "checkup" on her Elmo doll when she was four years old and ever since then she has been motivated to achieve that dream.

It wasn't until her first symptoms started to show up that halted that fantasy and had her face reality. She was like every other kid who only got sick once a year. So, you could only imagine how scared, surprised, and anxious we were as her parents when she experienced a seizure at 14 years old.

This was confusing as she never had anything of this sort prior to. Here we are now in the emergency room completing spinal taps, blood work and many other tests to figure out why this had happened. I can remember her tears, her screaming, and the overwhelmingness of helplessness I felt as the doctors tended to her.

Who knew that helplessness feeling would cling on for years to come.

Since her seizure she only became much sicker. By the age of 16 she would have seen 5 different specialists that consisted of a Nephrologist, Hematologist, Gastroenterologist, Neurologist, and a Rheumatologist each with their own prescriptions, treatment plans and many appointments.

Our family was stressed, confused as to why this was happening and trying our best to follow the medical advice being given.

Joana eventually was taking so many medications for her small body that she ended up suffering from side effects that resulted in her being under 90 pounds, she couldn't walk properly, experienced daily fainting spells, swollen joints, and high fevers whenever she got too cold.

We were living in Las Vegas, NV at the time and even though we would have triple digit weather, there she was with a jacket because her body could not sustain enough heat. This was all happening during her high school years where she should've been hanging out with friends and being a teenager and instead, she was completing millions and millions of medical tests spending her time in the hospital and doctor's offices.

After seeing so many specialists and trying different treatment plans, she was finally diagnosed with End Stage Renal Failure and Crohn's disease at sixteen. She was promptly started on hemodialysis where she received three-hour treatments three times a week. It was rough at first as she had to learn a new normal with a catheter in her chest but eventually began to show promise.

Accomplishment

Hey, I graduated!

Meet my grandparents



Seastar



Beautiful mommy
and aunties

Ring a Bell for a good
cause



Fall Season, Love it!

Continued

She started to gain more energy, her blood labs results were improving, and her other symptoms were decreasing. We were gaining hope that this would help her feel better both physically and emotionally. And it did, until it didn't.

She suffered an infection in her catheter causing her to need a replacement that required another surgery.

She would be on hemodialysis for three years from age 16 through 19. We had just moved to California where she began her college, and everything was going well until we received news that her kidney function was now at 5%. Now we were only faced with two options, to put a fistula in her arm or find a kidney for a transplant and fast.

And after her being on the transplant list for three years and hoping for a deceased or living donor I knew it was time for me to help our baby girl.

On August 28, 2013, I donated my kidney to Joana at Stanford Medical Center. It was so successful in helping her heal that on that day she came to visit me on the donor's floor, something that hasn't been done according to our nurses! I remember being so happy and being at such peace because she immediately had a big appetite, walked better and was not reporting any more pain.

Our recovery didn't take too long, and we were both so grateful that life was back to normal. It was a blissful moment for all of us that would last for 9 years.

9 years of her returning to achieving her dreams, finishing both her bachelor's and master's degrees and just experiencing life without any more medical issues, or so we thought.

Come March 2022 my donated kidney is fighting to hold on. She went to the emergency room for an entirely different reason and was informed that her kidney was failing. We were all devastated as we knew this meant another road of challenges for her.

She was immediately in surgery for peritoneal dialysis as she required treatment fast if they were going to preserve the little function the kidney did have. She was on peritoneal dialysis for 8-9 hours every single day, still working full time as a Marriage and Family Therapist and a Professional Clinical Counselor at a job that had her commuting 1.5 hours back and forth.

As much as she tried to hold her head high and continue to live life with her new normal it began to become too much for her. She only ended up more ill as the stress, commute, and treatment overwhelmed her body. She had fluid retention that would swell up her legs, make it hard for her to breathe and difficulty with her blood levels that would leave her depleted.

Watching her get weaker and weaker requiring weekly hospitalizations, blood transfusions, and medication after medication was difficult to endure. Every single day, every month there are new symptoms that she suffers from, and the same feelings of helplessness are ever so present.

Now at 29 years old, she faces End Stage Renal Failure for a second time, Heart Failure from her heart overworking itself to fight the ESRD and is back on hemodialysis. She has completed open heart surgery and is recovering to the best of her ability. Every day we hope that she'll get lucky enough to get a donated kidney soon but until then we will do all in our power to keep her comfortable and live the best life we can provide.

When I ask her what she thinks about what she's gone through she says:

"This time is different. Yes, my illnesses are more severe but now I don't carry that same shame and guilt I did the first time around with those diagnoses. Now I welcome the love and support from others in asking questions and wanting to know what life is like as a kidney and heart patient.

And now I try to face every day as it is and have a positive outlook because I know that I still have an amazing life despite this small setback and that things could be much worse. I hold myself a lucky one with all things considered because I gained so much from this entire 9-year journey. It has helped me mature, be grateful for everything I have and solidified the reasonings behind why I am so keen to finish my goals. This time around I'm not scared and want to use this experience to bring awareness and help to those who may be in the same predicament."

All of that positive attitude coming from such suffering is the reason why we continue to push forward. We continue to want to bring the best out in others because we know we have been blessed with this journey. This is the reason why we created this organization because we believe that we can bring forth the community to help those suffering chronic illnesses. Whether it's testing themselves to become organ donors, helping financially, spreading awareness of how to help, or educating those who may not know of these diseases. We are glad to do our part.

Joana continues to fight to this day to stay as healthy as possible until she does receive her kidney transplant. She completes 9-12 hours of hemodialysis treatment weekly and still has many visits to the hospital. We continue to hold hope and faith for her healing and will continue to do what we can to bring awareness to the community.

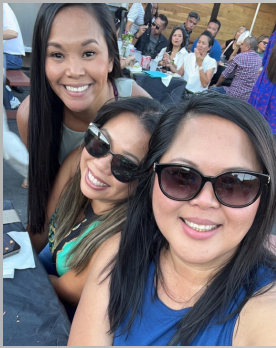
Thank you for spending a moment to read about my family's journey and how we got here.

The Narwate Family

Thank you for Joining Us



Our Friends and Family



Maraming Salamat

August 28th, 2023, was our 10th year kidney anniversary and this year we celebrated it in a special way. My gracious mother has been working so hard over the past couple weeks to create this fundraiser dinner in my honor and I couldn't be more grateful. Because of her, family and friends in the community we were able to meet our fundraiser goals!

Thanks to everyone that has supported us, donated or sent prayers. We have been instilled with hope that everything is going to be okay. These donations have provided a relief for my family and I to deal with the medical expenses and beyond while we continue to fight these illnesses. We thank you from the bottom of our hearts for taking the time out of your busy lives to support us and share our story.



To my one and only mother Marina, words cannot express the gratitude I have for you. I can't imagine how painful it is to have a sick child nonetheless having to do this a second time around. I know there are times where we both feel helpless but know that your presence is appreciated more than I can say. I thank you for always being there by my side when I'm in pain, when I'm hearing bad news from the doctor, and being there through my worst days. You've given me life twice already and now you're making it possible to receive another one. I could not have gotten this far in life without you. I know there's times where I can be real bratty but please believe that you're the person that's helped me heal in more ways than one. It is your hospitality, your genuineness, and the ability to make those shine around you that pulled this event off and your community and family love you so so much. There aren't enough thank yous to say to begin to express how thankful I am. You're nothing short of amazing and I hope you were also able to feel how much you're appreciated.

Love, your first princess 🎂🤍❤️

THANK YOU "doesn't suffice to convey the depth of our gratitude for your presence at Joana Mari Narvarte's Fundraising Dinner. The outpouring of love, blessings and support our family received was truly inspiring and overwhelming, and it's all thanks to all of you. Not only did we achieve our goal, but surpassed it.

That evening marked a profoundly special moment for us. As I often say we may not be blood related but our connection forms a tight-knit family bound by our hearts.

As always, no matter what challenges we face, we set aside our difference and unite as one. 'Let's live for this second not for tomorrow and each moment we shared will bring us closer together '

Love you all, The Narvarte Family! 🙌❤️🥰



Special Thanks

FIVE WINDOW BEER CO
NORIEGA'S CHICKEN GRILL
ARTEAGA FOOD CENTER
INCLUSION FILMS
And to our
WONDERFUL FAMILY
whose always been behind us!

