

Siproena Johnson  
May 19, 2013  
As Poetry Recycles Neurons  
Spring Term Paper  
Patience for Life with Lupus

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Siproena Johnson  
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**Abstract:**

*There are similarities I find with others who are teachers such as the desire to construct and share the arts passionately. The artists who have influenced me with their application of patience in the art of origami include Tomoko Fuse, Robert J. Lang, Vincent Palacio, Kunihiro Kasahara, and John Montroll. Where does their patience come from? There tends to be an application of resourcefulness throughout the constructive process. Ultimately, a mixed media artist is envisioned when seeing and hearing Howe's work and this vision is what my work will strive to provide. Her work titled "The Midnight" will be my guide as this essay develops. The media I will use shall include pictures, collage-like poetry pieces, and narratives to describe the sections much like introductions of myself through the work. Although usually designated for pictorial sketches, bound lineless paper becomes a space to share for visual arts of the imagination in with words. Rules are guidelines to follow for ease of communicating ideas and can be amended just as basic art techniques create a template with room for variations by the project designer. Diseases have their own rules for me to follow in order to stay in the best of health. Systemic Lupus Erythematosus, or Lupus for short, has been the primary disease and rules I, from childhood have tried to defy. Sometimes these trials were in my favor, reducing the intense levels of medication while others have brought multiple near death experiences. How these experiences with the disease evoked my own sensations to write this narrative will be through a compilation of prose and poetry. "Literary sketchbooks" emerge with Howe's use of the paper. My various uses of paper are my means of an outlet in response to Lupus; my Midnight. She continues drawing and printing mediums to convey her transition of thoughts to words and words to images with her audience. As I draw from my consciousness, I will try to trace with words, along with images, the practice of intertextually writing. Allusions will primarily be about the positive aspects of patience which has brought me this far and is the premise for this paper.*

Patience can be both a positive and negative quality for us as human beings. Personalities with high, medium, or low levels of patience can differ slightly with any given situation while anyone tends to revert to their default nature. As social beings, there are times we may recognize our default personality emerging. Other times, it may be necessary that someone else give you a nudge toward strengthening your desired characteristics for more positive outcomes. The focus here will primarily be the positive aspects of having patience for life's inevitable conflicts while also noting that conflict is not necessarily a bad experience.

Although patience has been noted as one of my positive attributes, it too has been my downfall. I wish to understand and present how anyone like me can overcome years of adversity and yet, become so enduring to what could lie ahead. I understand there are obstacles others face, much like my fight and embrace of Systemic Lupus Erythematosus. It is simply known as Lupus for short. It is the chronic

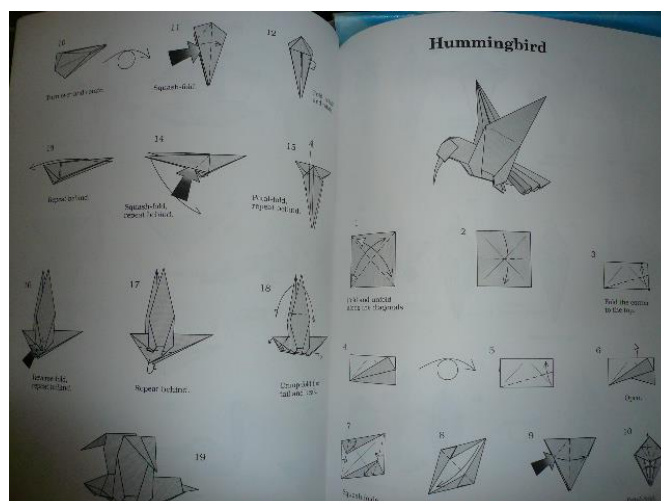
autoimmune disease that creates an over-reactive immune system within the person. Consequently, the body overproduces antibodies, the white blood cells, which in turn attack both invasive illnesses such as a cold and the body's healthy cells. One immediate thought is that anyone like me may feel suppression and avoidance are the best coping mechanisms to apply in order to hold our head up and face each day. At the same time this facade becomes a downfall to being a patient, tolerant, enduring person. Anyone like me who habitually answers obstacles with too much patience can unintentionally become a pushover for others to feast upon. This is the patient person I have been and the patient personality I would not wish upon anyone. I felt like control over my body as a patient was lost to Lupus; the wolf feasting upon my body and mind. Control would be reclaimed in 1993 with paper.

Paper is used for many occasions as it is a versatile element to manipulate. For many, it is bringing forth chances for happiness and sorrow perhaps even irritation growing steadily into anger. Paper would bring all of these with my manipulation. Origami developments still emerge from my strife with the Lupus disease. For more information, you can check out Systemic **lupus** erythematosus: MedlinePlus Medical Encyclopedia.

[www.nlm.nih.gov](http://www.nlm.nih.gov)

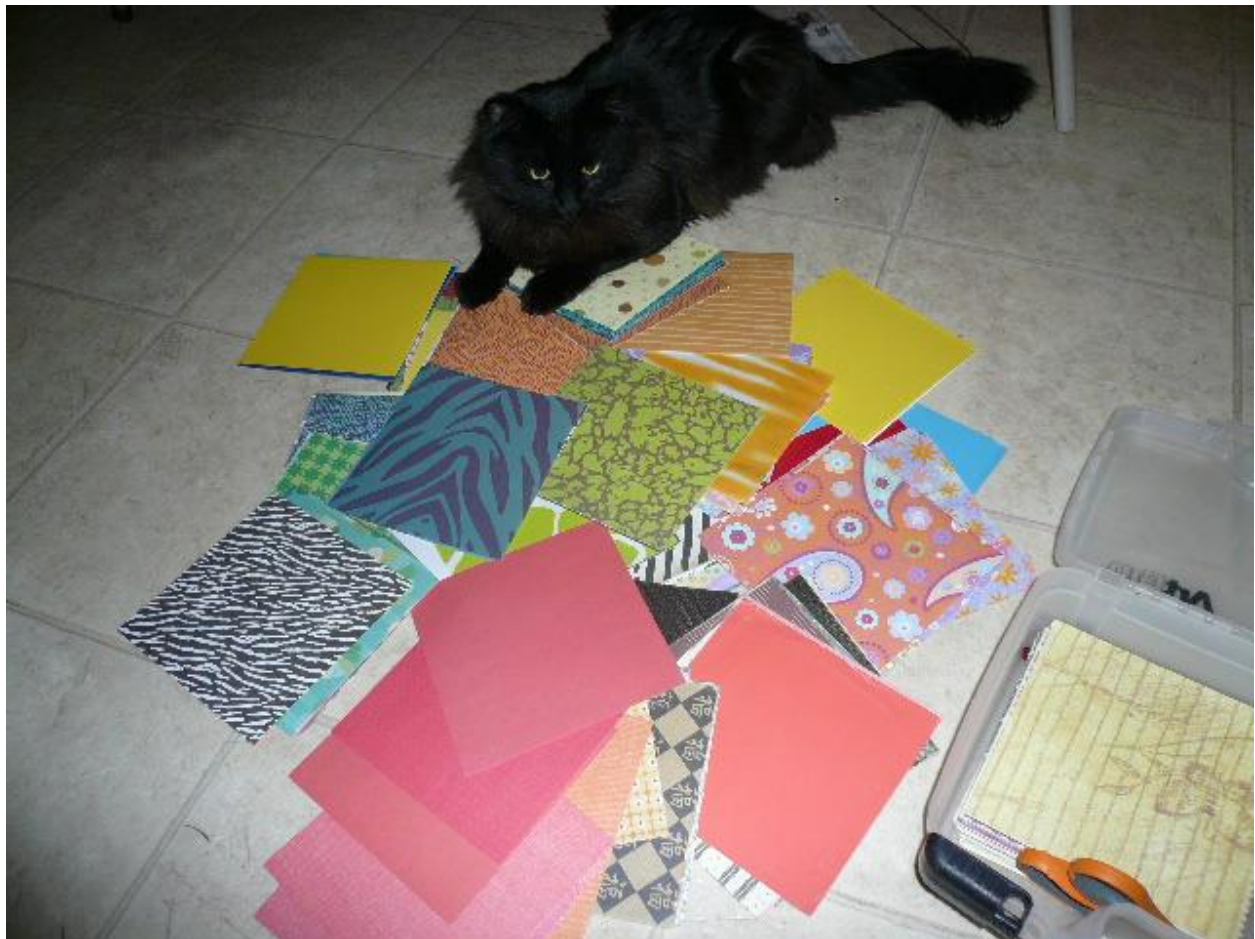
I wanted to share the knowledge and pursue greater challenges within the craft. My practice of origami in elementary school while approximately 7 years of age was then a sculptural platform that would develop into the flapping crane. Construction toys were a staple at home and strengthened my desire to initially become an architect. As 3 more years past and I found myself in the hospital again, a new book by Tomoko Fuse presented by my grandmother would again begin to sway the architectural

ambitions  
designs in  
much like the  
children, my



toward something more. The Fuse's book, Unit Origami were construction toys. Others, age and younger spent our less

ill periods of hospitalizations in a place called Child Life in The Texas Scottish Rite Hospital for Children. The small papers and diagram filled pamphlets included when purchased became a starting point. Small simple animals, hats, and more intricate airplanes could be found in the pamphlets. The desire for detailed figurines would branch into using books providing lengthy instructions to be read with pictorial diagrams as well. Origami books, paper, and more intricate figurine creations live in my shelves, still demanding my return to the more challenging practices. These more challenging works require so much more attention to detail. While my patience is good, it is not ready for such strenuous focus to varying fine details. Modular origami forms; requiring simple folds repeatedly upon 30 to thousands of pieces of paper often entice my mind's retreat. Sitting here with paper now brings a period of serenity as the sequence of repetitive folds simply flow.



## Daydreams as Poetry:

Hands were and still are the essential part of my body as the movements are orchestrated with my mind. Juvenile Rheumatoid Arthritis would become a slight hindrance when I was diagnosed at the age of 7. *"I'm too young for this!"* was my thought back then while I was researching the disease further and found it too is considered an autoimmune disease. The first formal meeting with the thin 5 and 7 8ths size of graceful paper was during the second grade. I still remember the teacher's name. She was delightful and patient with care beyond her instruction of the elementary aged. With her introduction of origami art, the formation of teaching aspirations became larger.

### *Teachers as Advocates*

Teachers take time and give time a way.

Remain open to perspectives, giving their student a say.

Careful planning becomes necessary with so many factors to keep in mind.

Rely on the pursuit of happiness to keep the mind alive.

Alive is not simply a heartbeat but an opportunity to which we find our drive.

Success can come with patient practice, careful thoughts and movements planned.

Think of this like a chess game or card game where strategy is in demand.

Patience helps the mind and body pursue goals with a calm and steady hand.

1"Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish."

It is with some experience that this statement can show true.

Good craftsmanship requires patient steps to see projects through.

Arts and crafts are activities requiring participation.

Movements are what you do.

There is not necessarily a single instructor who can orchestrate the movements with considerable passion.

2 “The function of education is to teach one to think intensively and to think critically... Intelligence plus character – that is the goal of true education.”

Relying on each other; minds and bodies unified but with different ideas,  
They can complete a task with strength in numbers.

### *Second Home*

Texas, home, ward

A state, place, bind

Anger, frustration... miscommunication lack of age into consideration

Stares here are alone, a home full of machines

Würzburg, Germany; a part of Europe and my place of birth,

A new life beginning with military exposures as a child,

At times there is wonder if there lays the origin of my poor health record.

Nuclear projects then and to this day stir my suspicions

What exposures, if any could have occurred in 1990?

Could they have been a key to causing my predisposition?

This box with a keypad draws more of my attention

The social here are workers, nurses, counselors and sometimes another patient or two.

The room sits it confines so many times

Hospitality expected, release; far distant hope within this collective

Sun streams at an irrefutable 45 degree angle



Stares continue until darkness covers the window now pitch black



The *Human Genome Project* is in progress 1986, the year of my birth.

The Chernobyl Nuclear Power Station Explodes causing the release of radioactive material across much of Europe.

Two years progress since 1991's overwhelming news.

Lupus is the catalyst for more chronic illnesses to come.

The first full year of living with **Lupus** goes by.

The disease sets my own body against me.

White blood cells breach their contract with the disease's subliminal messaging.

Turns out the list have only begun and to this day in 2013 there is still uncertainty in whether or not it is done.

Next at the plate 1993, this year juvenile rheumatoid arthritis hits me.

Slowing but not stopping this heart and mind's ambition although at times wonder would take over to think this life must be fiction.

Questions build regarding the knowledge I've been force fed and depression begins to set in with wonder if I would have been better off dead.

Uncertainty is answered with another disposition all because some doctors wanted immediate results from drug treatment.



Back to present day, 2013, seizure disorder is determined to be the most recent ailment I am coping with.

### *Patient*

Enduring at length, perseverance, strong willed



Looking, on forward, until goals are fulfilled

Too kind at times, too patient with the wrong few

Hold close this key virtue during trials and afterward too

Patience, a prerequisite for facing ourselves

Ourselves, a piece, part of the whole

Stimulating the other, each of us in some way, consciously or not, plays a role

## **Distortions:**

### *Emergency Room*

Fevers fail to dissipate with fever reduction trials

The sudden manifestation is a conundrum all its own

Discoloration and bruise-like patches begin to cover the skin

The hospital is now the destination and the place many trials would continue to be in

I am told I have an illness for which there is no known cure

I am a 4 year old child in 1991 approaching my fifth year in two months

The origins of the disease is unknown and no family history can be found to pinpoint the culprit to be genes

Diabetes has been linked to family history, yet has not fallen upon me.

I do not quite understand the level of caution that comes with this news

Hypertension, anemia, nephritis-these words, what do they mean?

Information comes in piles of what is unknown about the illness and provides very few clues

The language of the doctors would carry on in years and in some time, overwhelm my own.

Thrombocytopenia; low blood platelets leading to anemia

This is causing my lack of energy and the condition may manifest itself with complications related to protein loss, including edema, or retention of fluid, and ascites, or retention of fluid in the abdomen

Parents sit alongside me absorbing what the doctors have to share

The looks in their eyes tell me they are uncertain of what to do

These are the people, elders, caretakers interacting throughout and with this life

Mixed feelings with mixed teachings of hope from these people tangle inside.

Here now with all, but from myself, I cannot and will not hide.

### *Fragments of Perception*

Kusudama origami often relies on thread for the units to be bound. Sometimes layers of paper are used for a single unit and the finished product is a paper folded bouquet.

Skein; a grouping layering of collected frays,

Finely textured throughout the length of the plane,

Threads found exposed show abrasion has given way,

The now separated binding rely on patches for repair,

The patches themselves rely on the threads for their design,  
Vibrant colors begin to fade with the increase of time,  
In order to refurbish the patches, the fabric of thought through the plane of the mind,  
Minds need one another to grow and create a stronger bind,  
Stubbornness to the necessity of social interaction, can lead to abrasions from community in a harsh  
fashion.

Additional threads can be created if given the time.

Patience is needed to sift through the materials like silk, wool, or cotton.



Searching for these resources can take varying amounts of time,  
Whatever the duration the threads created are worth and with you for more than a dime.  
Minds found together can create a great frame,  
For better or worse intentions, their desire for greater power remains the same.  
Perceptions from mixed origins are placed strategically and put to the test,



The playing field of perceptions can now be  
manipulated until the time is best.  
Revealing, slow and steadily a powerfully  
functional idea designed from many fractals,

The end creations can become great spectacles.

"He appeared to be proceeding in the direction of the water, but at each line of transition between pavement slabs, he halted in a frenzy of anxiety." (Howe, 115)

"A ghostly skeptic." (Howe, 115)

"Collectively, these studies highlight the weaknesses of attempts to generate a 'unified theory' of depression." (Rose, 134)

## *A Sinkhole*

Left or Right

Indecisiveness of the mind

*Is there no way out of this maze?*

*Do we take the first answer for immediate gratification?*

Many more questions for my caregivers

begin to arise.

*How often in our history has this been the lead into self-destruction?*

*Suicide attempts weave throughout my childhood.*

Now, to this day, we weave our own demise.

Often I'm told to follow blindly, without question, I must obey. *Apathy overruns me and my sense of self is lost.*

It may be the winners we follow, for their tales are the accepted history written.

*What then of the losers, were they then and are they now still the true enemy?*

Impulses and assumptions leading into later possibly regretted transgressions.

The mistaken, the misunderstood

4 "Children need models rather than critics."

Study, research, inquiry

Deeper thought, searching too hard

*How do we use theory accurately to prescribe what we need?*

What is the remedy if not a thing?

Penetrate the mind and journey to the heart

Connect these organs beyond the physical blood streams only to return to the beginning...

Or what is thought to be

What is thought to be if not a thing?

A machine like the body is never perfect

Every system has its flaws

Fear...Control...Lost

Paint a picture to document the  
journey

Large scale, microscopic, literally  
invisible by any measuring tool

Not that the presence is a problem,  
It is simply in need of a name.

Inconceivable by onlookers to grant  
legitimacy



Disregard for feeling by the people as a whole or the person in their self?

How much farther? What distance will be scoped for the answers desired?

Artists continue moving with uncertainty but somehow create the remarkable without any thought.

Meditative movements now break through barriers.

Now null and void are these barbed wires.

Mere paper tape these artists' blocks seem!

Threshold now met!

Defiance in lieu of the terms!

This diagnosis cannot and will not conquer me!



### *A Product of the Environment*

Meaning as sense or meaning as art,

Intellectual growth within music,

Continuum of a child-like mind for  
optimal growth,

When writing thoughts sense how they  
are felt rather than written,

Perceptions similar and rarely same,

Skein; a grouping, a collective, an opportunity for growth... family

Frays develop, mutual cause eventually lost overseas. *The long and short military separations were creating more quarrels between parents and children. My brother and I needed to depend on each other for stable comfort as our parents focused on custody and money.*

Unlike the kusudama with its nearly eternal construction of floral blooms, our sense of the family bond was withering.

Threads exposed; diffusion makes a way,

Divorce statistics in the military increases

Varying aggressions over time merciless to defiance,

**Trust** no longer has a meaning,

Incidents of 2007 bring forth the word's long felt demeaning

A simple assembly of letters brushed off like sand

*My brother and I were taken so quickly by our mother's impatience with the court system, her lies and her car.*

The bomb since childhood between parents was bound to go off

Truth of its definition diminish with the turbulent waves

Solidarity breached once and for all when Tumwater is reached

Why here? Why now? What cowardice is this? Abducting one's children for refuge from one's own lies!

Passing this Washington milepost sometimes disturbs these traumatic memories slumber.

### *My Patient Friend*

Waldo looks up lovingly as he lies on my stomach.

Day break is coming and he motions for me to wake.

This dog can be quite patient with his long gentle stare.

I turn to sleep a bit longer but his persistent nudging is beginning its wear.

Slowly rising from his "pillow" and stretching on bed's side,

He bends his neck back snakelike and his tail whips my behind!



"Okay Waldo." I tell him. "I'll take a walk with you, but first of all I'd like it if you'd move off my house shoes. His heavy sigh pressures me to move but I carry on telling him we will be out soon.

Finally I finish getting dressed for a long walk while

at the same time he wiggles on the bed watching me happily like a hawk.

I open the door and bolts past me to the stairs.



His paws sound like thunder as he tramples down alongside the cat making quite a pair.

I watch my footing as I follow them down.

Waldo turns his head occasionally to see I'm still around.

From the cabinet in the kitchen, I grab this boy's leash.

He promptly knows his cue and is seated ready to receive the leashed collar.

I find it nice that I don't need to holler.

I grab my hat, ready as well.

We walk out together for a time that's sure to be swell.

## ***Patient***

It's hard not to see the hospital as a second home.

Hours would turn to days, days to weeks, weeks move to months and so on....

Times would require endurance, resilience, even cooperation- for the sake of better health.

Although the childhood mind was resistant, patience would mature my wealth.



While hospitalized, origami practices would continue and this swan would be the first creation done with stacking units. The grand total was 520 folded and assembled units. Ultimately, this was raffled off for a church fundraising venue.

Medications would be a mouthful, sometimes fluctuations from more to few.

Hours hooked up to an intravenous treatment learning to do what one need's

to.

Guidelines and strict rules would be more difficult to adhere, when later; a normal life would be birthed.

The lack of food restriction my new sibling received would increase the deemed forbidden foods worth.

Speculations of normalcy accrue over and over again.

Who makes the rules regarding normalcy to begin with?

#### Language to Live By

1“Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish.” ~John Quincy Adams

2“The function of education is to teach one to think intensively and to think critically... Intelligence plus character – that is the goal of true education.”

— Martin Luther King Jr., American civil rights leader (1929-1968)

3“How can a society that exists on instant mashed potatoes, packaged cake mixes, frozen dinners, and instant cameras teach patience to its young?” ~Paul Sweeney

4“Children need models rather than critics.”

— Joseph Joubert, French essayist (1752-1824)

5“The best way to teach morality is to make it a habit with children.”

— Aristotle, Greek philosopher (384-322 B.C.)

6“It takes a long time to grow young.”

— Pablo Picasso, Spanish artist (1881-1973)

7“Everybody gets so much information all day long that they lose their common sense.”

— Gertrude Stein, American writer (1874-1946)

#### Afterthoughts

Practice the art of attention. The slightest detour can fray the focus but this can keep the mind open and less critical. The small things can be the most wondrous when allowed the time to take them in. Peace can be found with the art of attention. Our minds are like waters filled with a collective of emotion, logic, and turbulence. The art of attention is focus without strain and something very much like trivial mind games. Take the time in for attention gradually, in your own steady pace, I understand life can sometimes feel like a tortoise and hare race.

## References:

Gardner, H. (1994). *The Arts and Human Development*. New York: Basic Books.

Lawrence, J. (1999). *Argument for Action: Ethics and Professional Conduct*. Brookfield: Ashgate Publishing Company.

Jacobs, J.S. & D.T. (2001). *Teaching Virtues: Building Character Across the Curriculum*. Lanham: Scarecrow Press.

Howe, S. (2003). *The Midnight*. New York: New Directions.

Scarre, G. (2010). *On Courage*. New York: Routledge.

Thubten, A. (2012). *The Magic of Awareness*. Boston: Snow Lion.

Montroll, J. (1995). *Birds in Origami*. New York: Dover Publications.

(2010). *Intravenous Pump Photo*. Retrieved from

<http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/GeneralHospitalDevicesandSupplies/InfusionPumps/ucm205424.htm>