Twelve Years and Counting

Reflections on Life with Early Onset Parkinson's Disease

Poetry by Adele Pfrimmer Hensley

Photography by Frank R. Hensley

Twelve Years and Counting: *Reflections on Life with Early Onset Parkinson's Disease*

Copyright © 2016 Adele Pfrimmer Hensley
Photography © 2016 Frank R. Hensley
All Rights Reserved

This book is licensed for the purchaser's own personal enjoyment only and may not be re-sold or given away to other people. Unauthorized redistribution or reprinting of this book is prohibited and doing so constitutes copyright infringement. This book may not be reproduced in whole or in part without written permission from the copyright holder. Thank you for respecting this author's work.

First edition 2016
Published in the USA by *thewordverve inc.* (www.thewordverve.com)

eBook ISBN: 978-1-941251-75-1
Hardback ISBN: 978-1-941251-76-8

Library of Congress Control Number: 2016953612

Twelve Years and Counting

A Book with Verve by *thewordverve inc.*

Photography by Frank R. Hensley

Cover and Interior design by Robin Krauss
www.bookformatters.com

Ebook formatting by Bob Houston
facebook.com/eBookFormatting

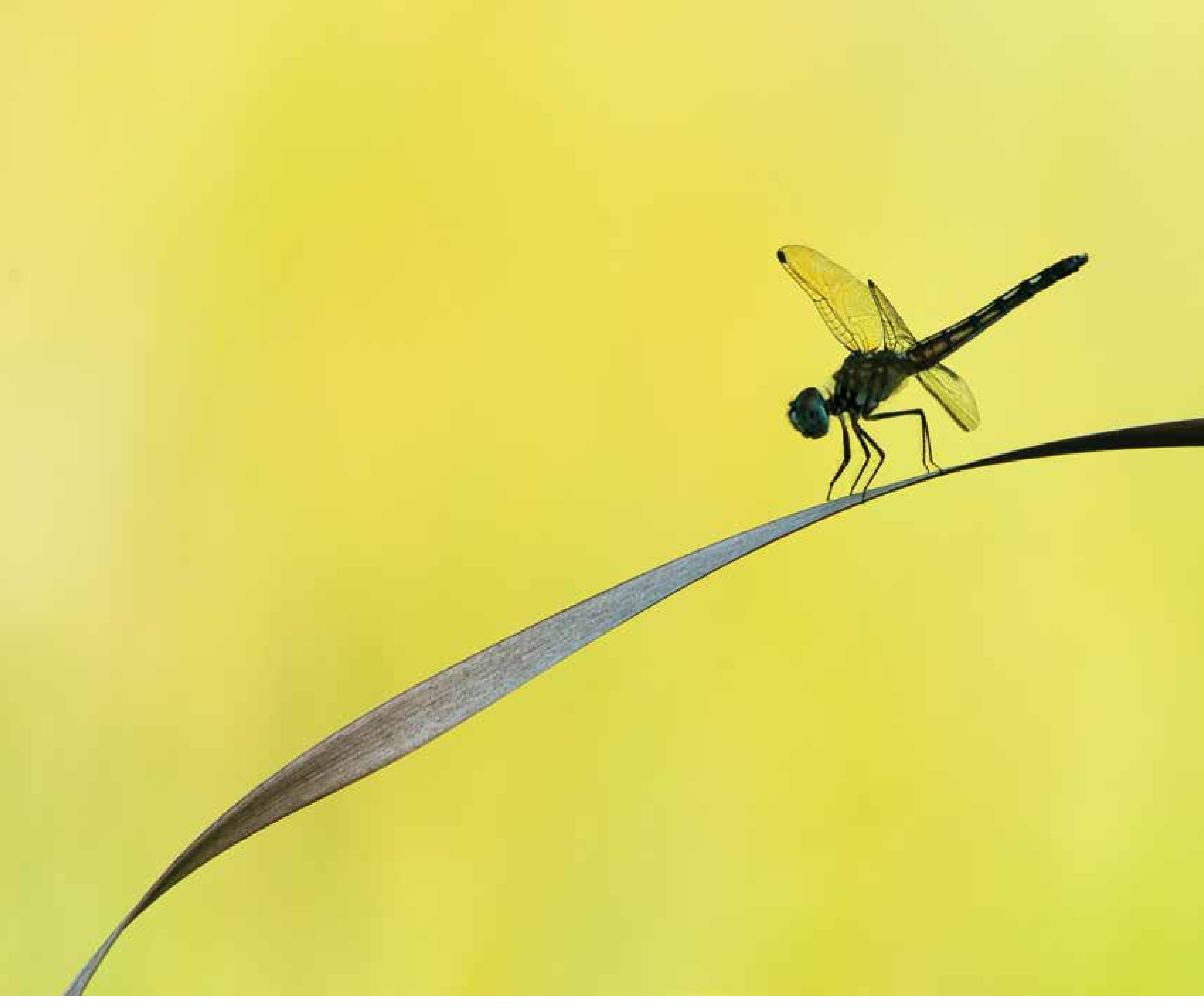
This book is dedicated to my parents, Bob and Faith Pfrimmer, to my brother, Andy Pfrimmer, and to Mrs. Dorothy Lamson, each of whom just began their own version of The Hardest Year, when they lost their homes of longstanding and most of their possessions in the Great Louisiana Flood of 2016. May you be sustained, as I have been, by the prayers of dear friends and family.

This book is also dedicated to my sister, Amy Pfrimmer, who when she was age two, used to chase me around our grandparents' house whenever she caught a green anole. I always ran away screaming. Always. I think of how much circumstances have changed. Amy, you are a real opera singer, impervious to lizards; I sat with that lizard until I had written an entire poem in my head.

Frank, I'm so glad we did this project together. Thank you for the pictures for my poems.

Last of all, this book is dedicated to Frank and to Clark with love always.

Table of Contents



The Secret Society

Finding out you have Parkinson's disease
is like getting a lifetime membership to a
secret society.
Actually, it is like finding out you must have
already been a member . . .
because, somehow, you already know the
secret handshake.

I don't mean that your hands shake,
although they may.
I mean that suddenly things about your
body are revealed
to be signs, or possibly billboards, of
Parkinson's.
You realize you have borne the marks of the
condition for a long time, even years.

You had thought they were quirks of your
own particular body,
but when you enter a room full of other
people in the club,
you see, over by the window, that man is
holding his left arm at a right angle
and tucking it tightly against his abdomen.
You've never seen it before, but you feel it
every time you take a walk.

Between the door and the table with the
pitchers of water, you see one . . . No, two.
No, three people whose right hands are
moving rhythmically back and forth in the
air at exactly the same frequency as yours.

The room is full of stooped shoulders,

A few bodies squirm dyskinetically in their
chairs.

A few faces have their chins marked red by
nighttime drooling. Just like yours.

You realize these weren't personal
peculiarities; they were symptoms.
Your brain completed the initiation long
before you got your membership card.
You already know the rituals.
You were just waiting for the name.

Enchanted Ham

It was just a little piece of ham.
Realistically, I'd say six bites.
Not enough for a sandwich,
But Powerful.

It took me down,
stripped me of my dopamine glamour,
and exposed the depths
of the damage
caused by this disease.

Hunched over,
shuffling steps,
I had traded my smile
for six bites of ham.

Enchantments are like that.

The sorcerer, the fairy,
the person with magical abilities
offers you the thing you want.
It might be a lover, or a long life,
or a little piece of ham.
And they seem to ask so little for this thing
you want.
You say yes.

You are so pleased with the result.
The lover is sweet. The life is long.
The ham tastes good.
I mean Really good.
When it is gone, though,
that's when you have to pay.

Forgetting that this was
the bargain YOU struck,
You look for reasons why.
What caused this disaster?

Oh, it was that ham.

I am lucky.
My enchantment fades
after a few hours.
The medicine regains its power.
My normal is restored.

Not everyone is so fortunate.
Some consequences are permanent.

Sometimes for less than six bites of
ham.

Anniversary

I. December 28, 2004

My doctor came around and sat lightly on the edge of his desk.
“I’m sorry. You have Parkinson’s disease.”
For almost four years, I had been trying to find out what was wrong, so I could fix it.
Sorry. Some things can’t be fixed.

I called my husband. I drove home.
A friend from church, a professor of nursing,
came over to answer questions and to tell us what to expect.
You can’t fix Parkinson’s but you can predict what is going to happen.

It is a strange to know what is going to happen to you but not to have a schedule.
All the pamphlets said that you could expect ten good years.
They also said most people were diagnosed with Parkinson’s around the age of 60.
I was 38. Did I have ten good years left or nearly thirty?

II. December 28, 2011

I could hardly function that day.
The whole week had been very hard.
I didn’t hug anyone after church on Christmas Eve. I had to scurry to get to a bathroom.
I couldn’t get in the bed without a struggle. Each time, I ended up in tears.
Despite almost never making it to the bathroom on time,
when I got there, it was taking forever just to empty my bladder.
I sent my mother and sister to shop the after-Christmas sales without me.
I love the after-Christmas sales.
I looked at my husband and said
I didn’t know why I was so much worse all of a sudden.

I was scared.
It hadn’t even been ten years.

For lunch that day I made sure to only eat vegetables and starches.

By three in the afternoon, I felt normal.

I realized I could be much better.

December 29, 2011

Dietary protein inhibits the uptake of my main medication from the small intestine to the bloodstream. I had known for years that I needed to eat two hours before my next dose of medicine or one hour after it. I knew that too much protein intensified my symptoms. What I didn’t know is that when I switched drugs this fall, I also switched my system’s tolerances. I couldn’t eat meat or cheese or eggs for breakfast and expect to feel good anytime before the midafternoon.

I figured this out in a burst. I wrote a poem called Enchanted Ham.

I feel great, probably as good as I felt three or four years ago.
I have some limitations,
but I feel like I have doubled the effectiveness of my medicines.

I can live on veggies, fruit, grains,
small bits of fish or poultry,
and the occasional spoonful of ground-up beans.
It’s not a cure,
but it feels pretty good

Adele Pfrimmer Hensley

Shift

A journey of a thousand miles
begins with a single step . . .
if the step begins with a good knee lift,
and a heel strike,
and is followed by
another and another.

If the step drags,
if the toes curl under,
if the knee isn't lifted,
or the hip enlisted,
the journey can end before it begins.

It seems like a lot of work to have to reteach
  your muscles how to walk correctly,
but it is definitely less work than dragging
  one leg when you walk
for the rest of your life

I thought I was having trouble because my
  right knee hurt,
but every time that I have caught my foot
  beginning to stumble,
it has been my left foot because I did not lift
  the hip and knee.

Every time I have lost my balance,
it has been because I have not
shifted my weight enough to keep
my center of gravity
centered.

I'm learning,
I'm practicing.
I'm hoping
that soon
I will have the muscular memory
to feel the shift before I need it
Instead of noticing what I should have done
afterwards.

I feel like, I think that, I wish, I pray
that I am approaching a shift in reality:
from awkward lurcher to smooth walker,
from fast stumbler to steady balancer,
from being afraid of falling to being safe and
mobile.

For When We Feel Alone

I never knew I would ever spend so much time alone.
I come from a big family, so when I was much younger,
there were always people in our home.
When I was still working, I was hardly even there.
Now that I'm retired, it seems I missed a memo or made an error,
because I do not know how to be alone so much.
I must learn to get through a day without another's touch.

Oh Lord, who has made the time to count my every hair,
teach me, when I cry, to pray; to turn from self and gladly share
the kind of love you've scattered there,
in my heart for me to see
when I rest in you, and meditate,
and listen, taking time to wait.

Lord, Jesus, I know you understand what it is to be alone.
You know when it made you stronger,
and when your heart felt as heavy as a stone.
I pray you will take my loneliness and use it to connect people,
those who know you or those who don't,
take the chain and make it longer.

A Theory

When my my voltage is too low and my dopamine is all but gone,
the way I walk resembles the walk of a chameleon.
I shift my weight from right to left and then from left to right,
and if I'm lucky, my feet might unclench from the floor sometime tonight.
When a true chameleon walks, it shakes just like a leaf.
And although I do not shake that much, it is my firm belief
though I cannot match my skin to my background, soil, or tree,
with respect to dopamine, the chameleon looks a lot like me.

Deep Brain Stimulation Begins Tomorrow

I used to be afraid.

When this was speculative.
When this was a last resort.
When this meant nothing else was left to try,
and I would submit to opening my skull
and wiring a battery pack to my brain in
hopes of some help.

Then it became a reality.
It was no longer the last resort.
It was the preferred treatment for people my
age.
I can make my future much more promising
by opening my skull and wiring a battery to
my brain.

Not only that. My present might be sunnier
too.
Less medicine. More flexibility.
Easier walking using both legs and both
arms.

This isn't a cure.
If the battery pack dies,
I go back to overwhelming symptoms.
But the batteries do not just die.
They last a few years.

The day this became the best thing to do is
the day my fear left.
It is funny to think but by
tying myself by a wire to a battery,
I am finding freedom.
Opening my skull will make my brain
work better than my pills ever could on their
own.
It is like they say:
If you want to make an omelet,
you have to break some eggs.

I won't be broken.
For a while
I will be repaired.
And then, watch out!

Life/Story

I was reading a piece in the New Yorker by Alice Munro.

I read a clever bit about a man with a funny name.

She wrote,

> "Roly Grain, his name was, and he does not have any further part in what I'm writing now, in spite of his troll's name, because this is not a story, only life."

I thought, "I love that! I'll put it on Facebook, or maybe on my blog."

But I decided to read the whole article first.

And then Alice Munro surprised me. Her memoir of her childhood ran right smack into my life.

She writes,

> "Sometimes on Saturday, I made a pie, and sometimes my mother did, though her baking was getting to be unreliable.
>
> Something had come upon us that was even more unexpected and would become even more devastating than the loss of income, though we didn't know it yet. It was the early onset of Parkinson's disease, which showed up when my mother was in her forties."

This would have been before L-dopa became available. Her mother would have only ever have gotten worse, never better.

I didn't expect this.

I think,

It isn't "only life," now.

It's a story.

Alice Munro's piece is called "Dear Life" and was published in the September 19, 2011, issue of the *New Yorker*.

Adele Pfrimmer Hensley

Change of Setting

I thought that day, straight through ’til two,
While I struggled for every breath I drew,
That before the day had reached its end,
I would know whether I gave in
or whether there was the slightest chance
of getting any better than I was right then.

At therapy, I talked to Matt.
He’s my physical therapist; did I tell you
    that?
We remembered how every evening last
    spring and summer
my labored breath was the biggest bummer,
because it never gave me the slightest ease
until I had taken my Requip. Please.
The one drug that I hate the most,
the drug that I’m trying to lower in dose.
Was I going to have to increase it instead?
I thought about going back to bed.

I left the clinic and went out in the light,
turned up my settings so that left matched
    right.
Then for the first time, I felt hope.
I wouldn’t have to take the slippery slope
that the Requip was offering me.
My breathing was better, clear, and free.
The settings on each side of my brain
were in agreement once again.
Was that what had been wrong with me last
    summer?
When one side was treated but not the
    other?

Then last night came a great big test.
I had to walk to Clark’s school. I was a mess.
But we made it, both my son and I.
And if anyone asks, give this reply,
A very small bit of that thing called hope
lifted my gaze from a downcast mope,
and then that hope began to expand
and helped me walk to hear my son’s band.

No disease is always easy.
Parkinson’s is never breezy.
But we each can teach ourselves to cope,
if we can find a kernel of hope.

Step/Wise

It isn't about balance this time.
It is more about patterning and muscle memory.
This is about 10,000 hours,
the time people—me, you, we—
must put into developing expertise,
mastering a skill.
No single step is that difficult.
At first they are literally baby steps.
Then, depending on the stepper's inclination, they may become
intricate fast steps of the flamenco or
the bounding steps of a runner or
the silent steps of a scout.
I wonder if my steps will find a specialty?
Or
if I will run out of time to specialize because I've
started over so many times?
But
for now
I will be content
with baby steps, because whatever my eventual choice,
I need a foundation I can count on, and I know how to build it: stepwise.

Control

When Parkinson’s moves
into your life, it starts to teach you
a lesson about control.
You don’t have as much as you used to,
or as much as you would like to have.

As time goes by and Parkinson’s
breaks you down bit by bit,
body and soul, it becomes
increasingly important to
exercise control where you can.

Sometimes that is an abstract concept,
like freedom or delicious or sincerity,
but this week reminded me
that sometimes control is concrete and practical.
Sometimes control is steadying your
balance on your right foot as you
set your left foot down gently and softly.
Sometimes control is slowing down
your hand enough as you write to
keep the loops of the letters open
and maintain your flow.
Every time you move with deliberate intent,
every time a movement is delicately precise,
is a moment that you push Parkinson’s back
and remind your brain who is in control.

I. Relative Timing

c

The speed of light and I, we have something in common now.
Neither of us is as fast as we had supposed.
Sure, the speed of light is unchanged,
it just isn't the fastest fast thing in the universe.

CERN

Scientists at CERN measured the speed of neutrinos,
and they were faster than the light.
They must have always been faster.
This is the first time anyone noticed.

slipping out of time

My Parkinson's disease is something like that,
except with a twist: I think my speed has not changed, but it has.
The first time I had to acknowledge my slow-down,
I was sitting with my sister in her house.

outside observer

I passed her a menu. It took about as long as such things take.
At least I thought it did,
until she looked at me solemnly and said,
"Did you see how long that took you?"

II. **Canine Perceptions of the Passage of Time**

My dog is 5 years old.
The kids say, “That’s 35 in dog years.”
Remember Dog Years?
I kind of feel like that’s how my life is measured now,
except instead of packing seven years into one,
I unpack ten seconds into one minute.

I can’t tell how long something really takes,
I just know how long it used to take before.
I only guess how much time has elapsed, but I have
an uncanny ability to tell specific time.

It is the same time super-sense you see in dogs.
They always know exactly when it is time to eat,
and when their people are coming home.
I know exactly when it is 10 or 2 or 6.

I know because that’s when
I get to take more medicine
And be myself.

Oops.

When researchers in the OPERA Collaboration
at CERN saw the results of their investigations
into the speed of the neutrino,
they were so excited that they
announced the surprising results
Quickly/Rapidimente/Schnell/Rapidement.

This called everything we thought we knew
about the speed of light into question.
Children and the fans of *Doctor Who*
dreamed of time travel.
We all wondered what it means
when there is a dramatic change
in our understanding of reality,
or whether physics really has
anything to do with life.
Life/La vida/Das Leben/La vie.

I don't know about your experiences in physics lab,
but at my college,
every time we did a new investigation,
we had to write a lab report that included
an ERROR ANALYSIS.
This was a three-point summary of reasons
why our results might not have been an identical match
with the predicted answer.
I hated the error analysis.
Mysterious/Misterioso/Geheimnisvoll/Mystérieux.

Physicists objected.
People from around the world double-checked the data.
Finally, the OPERA scientists made an announcement
about what I had learned in freshman physics.
They had correctly analyzed their data,
but they had neglected to include a complete
ERROR ANALYSIS.
Their GPS timers were not properly synched,
and they had a cord with a loose connection.
With this omission, they traded certainty for drama,
and triumph for apologies.
Oops/Oops/Hoppla/Oops.

The good news is they checked their work.
They told the truth,
and everyone pushed Albert Einstein
back onto his pedestal.
The problem for me is,
I wrote a poem about the
speed of light and Parkinson's.
They resolved their problem.
My problem is a little more complex.
Unsolvable/Insoluble/Unlösbar/Insoluble

Adele Pfrimmer Hensley

Inevitability

Parkinson's disease is not supposed to get
better.
When you receive the pronouncement, it is
always, always called
Chronic and Progressive.
Chronic means it lasts and lasts.
Progressive means it always gets a little
worse.

It isn't like it's going to kill you.

That's the consoling word you hear
when you get your diagnosis.

They tell you that, but they never say that
It's going to steal away your strength and
mobility bit by little bit,
or that you will find it nearly impossible to
smile when someone smiles at you first
or to ever make it to the bathroom in time.

You get medicine, and it makes you sick, but
you need it so badly
you take it anyway.

Eventually, the medicine stops working as
well,
and you add another, or maybe two.
And you start to talk about the inevitability
of brain surgery.

These last few weeks,
I have somehow gotten
an extension, or a reprieve, or even a reversal
of my sentence.

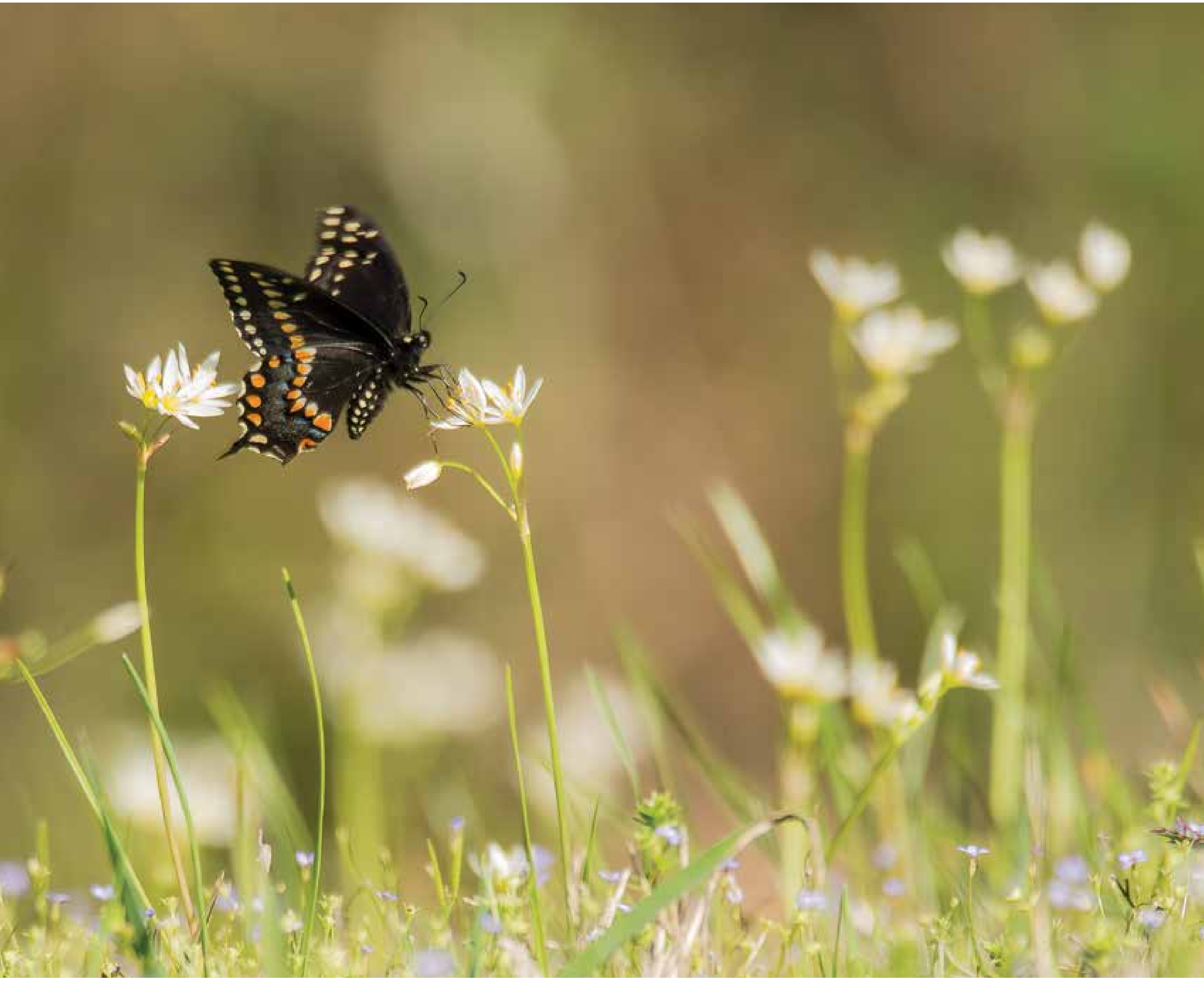
Several things have come together at once,
and I am doing better than I have been in a
long time.

The medicines I am taking are effective
almost the entire day.
I eliminated big pieces of protein from my
diet, so they no longer block the drugs
from working.
My physical therapist has figured out what
I needed to work on to gain balance and
strength.

It's not a magic formula. It's not a miracle.
It takes a lot of work, but it is a gift of time
and ability.

Last night, my son and my husband told me
they loved me when I was mom who sat in a
chair and couldn't do anything,
but they would be happy if she never came
back.

I don't know how long it will last
but I don't think anything has to be
inevitable
anymore.



The Metamorphosis Metaphor

I wanted a metamorphosis.

I wanted to go from crawling to flying and never really look back.

Only, no butterfly goes from the larval to the adult phase of its life, directly.
They spend at least a week, unless they spend an entire winter, in transition.
In that time of enforced immobility,
the butterfly is going through many changes.

All its legs and wings are present and,
though we might be surprised, it is still just as
much a butterfly as it ever was
or ever will be.

If you could peer inside, you might think the animal's body
was in a state of confused disintegration.

If you took the time to understand what you saw,
you would realize that the only
thing that had disintegrated was the butterfly's fat body.
It had come apart to
supply the developing insect's tissues with energy.

When the metamorphosis is complete,
the fat body will reform (although in a different shape)
and be useful to the adult butterfly when it is needed
for extra energy for reproduction or migration,
or whatever the major task the adult pursues.

Note: Many larvae such as caterpillars and tadpoles have large organs called “fat bodies,” where they store energy that fuels metamorphosis to the adult stage.

I am learning that when I readjust the voltage in my brain,
these neurostimulators are not able to operate at their peak efficiency right away.

This is not magic.
It is not a miracle.
It is a process not unlike metamorphosis.

When I push my buttons, the process begins.
When I can walk on my own with a sure gait and steady balance, it will be complete.
In between those two points,
many changes have to happen,
incremental adjustments must be accommodated.

I can be happy or sad, patient or impatient, relaxed or calm,
but I cannot speed the change.

I think my metamorphosis metaphor is more accurate and more powerful
than I expected it to be.

The Breath

"As the conductor," he told me,
"You really only need
to focus on two things."
(Now I loved to lead
children in singing, but I had never
ever been a CONDUCTOR and this
was my first and only lesson.)
He held up his hand, sort of in a fist
with the thumb and first two fingers closely
    appressed.
He gestured a downbeat,
and he said, "The initiation."
He inhaled,
flaring his nostrils,
opening his mouth,
lifting his palate,
and filling his lungs in an instant,
"And the breath."

Now. I cannot sing with children
because I never know
if my voice will speak.
My breath is unreliable.
When my medicine is effective, my breath is
    good,
but when it is not,
or when I am tired,
or, or, or . . .
My breathing sounds so ragged, loud and
    forced.
It is not discreet at all.
This labored breathing is so loud
it would give me away to
the first creeping foe
who wanted to find me.
When it ebbs,
my throat opens.
My chest feels free
of the constriction of my
rigid bands of muscle.
The breaths I have been taking
become breaths that I receive.

Regrets Only

We said we would and so we do
stay married. Oh but if we knew
the things this life would put us through,
would we still have said, “I do?”
You would have? Good. I would have, too.

Teaching a Muscle a Memory

Teaching a muscle a memory isn’t like
teaching multiplication facts to a third grader
who only has to see a flash card and
repeat the information on it a certain number of times
until it sticks.

To teach a muscle a memory,
you’re really teaching the subconscious part of the brain
to remember the feeling of an experience
you want it to replicate,
even if you have never done it correctly.

You want to
throw the ball/block the punch/play the sixteenth notes
exactly the same way every time.

You want to have the sequence
encoded in your hands/in your torso/in your mouth/in the deep recesses of your mind,
so that you can do this complicated thing without giving it a thought.
Automatically.

You need to learn each movement/balance point/measure
individually before you,
start repeating them in sequence.

If you are lucky
and your teacher/therapist/coach
is wise and clever,

the consequence of
your practice
may turn out to be
better than you imagined.

The movement you seek
may emerge from the training and
catch you by surprise.
Automatically.

This poem came from a week of walking training and karate testing. Both skills require the same kind of training I had undergone to learn to play the trombone.

Panic Cannot Listen

Yesterday was difficult.
It made me wonder, at times,
if I could make it through
to the side where hope and peace exist.
I have been alone most days while family is at school
So in a spiking panic, I cried out,
Ohnoohnoohno
Godpleasehelpmepleasehelpmepleasehelpme
It was something i wouldn't have done
but I knew that only the dog could hear me.
I do not know if this was an answer to my despair,
but I suddenly knew that when a person
gives in to distress and cries in panic,
he or she cannot hear any sort of response.
That calmed me down.
Today is better.

Forget. Press On.

. . . forgetting what lies behind and straining forward to what lies ahead,
I press on toward the goal . . .
~~ (From Philippians 3)

What lies behind?

Failure? Sin? Regret? No.
None of that keeps me from pressing on.
What lies behind me is a life of strength and spontaneity.
My past is good, but the future I had thought I'd have is gone.

Forgetting what lies behind . . .

Forget what was. What you wished.
What you had and what you had planned on.

Press on toward the goal . . .

The one you didn't know about.
The one that is part of what is coming.
Every day be more of who you will be and less of who you were.
There is a goal we are each called to reach. There is a way to reach it.

Press on . . .

Triumph*

My big toe kept hitting
the end of my shoe.
I looked down
and saw what I needed to do.

I tightened the laces
from bottom to top,
until my shoes fit me,
with no sign of slop.

My toe stayed in place
for the rest of the day.
When I saw my husband,
I had to display

this triumph I really can't
wait to repeat:
My tightly tied shoes
I'd tied on my own feet.

* Note: Before the day I wrote this poem, it had been several years since I had tied my sneakers tightly. Before I started physical therapy at the end of 2011, I had gotten to the point where I needed help with putting shoes on and tying them. A celebration was in order.

Dance for Parkinson’s

She said to me, “You are a dancer.”
How she knew, I have no answer.
She only saw a class one day,
where I danced sitting in a chair.

She never saw me move my feet.
I simply sat upon the seat,
but she perceived the joyful art
I sought to practice there.

It is true that when I dance,
if I trade a passing glance,
with another person whom
I recognize, our hearts are full.

From a smile the feeling grows,
like a moon which shines and glows
and exerts upon the earthly seas
a strongly tidal pull.

A moon makes seas go out and in.
A dance elicits grin with grin,
until everyone inside the room
feels joy in the dance.

Although it’s clear my strength and grace
and agile movement were replaced
with stiffening and slowness and a
loss of internal rhythm, there’s a chance

that there will be a happy beat,
a tune to make us tap our feet,
that lets us move each body part
and build up our endurance.

Released for that one precious hour
from Parkinson’s, all dancers flower.
We dance with smooth,
renewed assurance.

Rebuild the Balance

To rebuild your balance,
you have to start with the basics.

Stand up straight.
Plant your feet firmly on the ground.

Look straight ahead, or look at your feet.
(That part depends on what you are doing.)

Shifting your balance to one foot, lift the
 other.
Higher is better.

If you start to waver, go back to your own
 foundation.

Stretch your arms to the side like a dancing
 rabbi,
or a child-powered airplane,
or a belly dancer.
Use them as stabilizers.

When you balance on one foot,
place it solidly on the ground
before you move to the next step.

There is no reason to try
to go faster than you can go with balance.

When you walk heel to toe,
frontward and backward,
let yourself feel as elegant
as Olga Korbut on the beam.

The Hardest Year

This has been the hardest year.

Don’t get me wrong.
A person cannot commit
to experiencing two wide-awake
open-skull brain surgeries
and expect to emerge unscathed.

Only, I thought that would be the hardest
part.
I thought the surgery,
the hammering on my skull,
the drilling,
the risks of infection,
I thought these things would be
the most arduous bits.
I thought that if I got through these things
and I rehabbed my gait,
I’d be done,
finished,
well on my way to a complete recovery.
I never expected that it would be
so hard on my spirit.

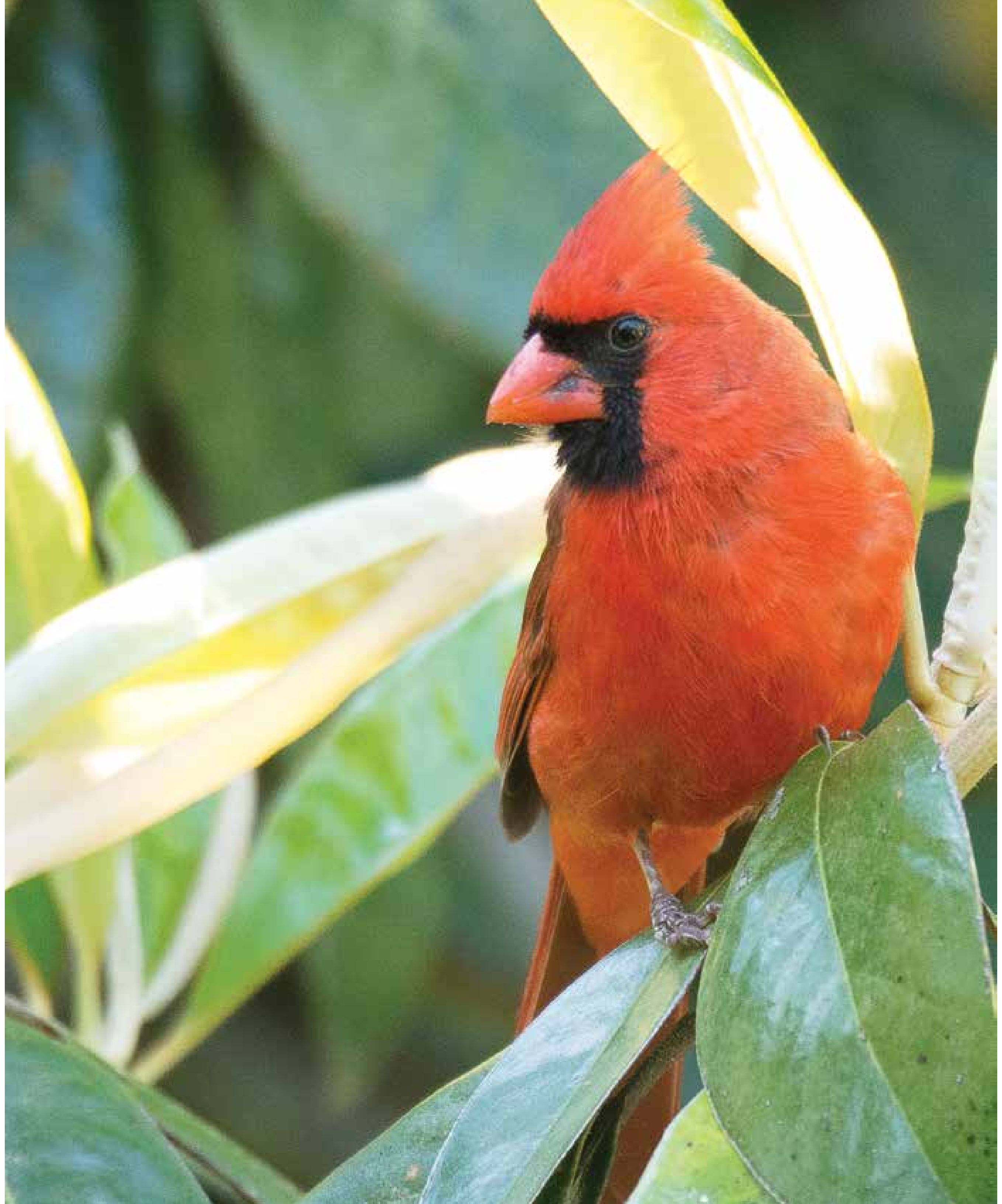
I never would have predicted
that ten months after I began,
I would still be afraid.
I would still have to call my husband
in the middle of the day
so I could ask for help focusing,
so I could move through the anxiety
caused by leaving the house on my own.
I did not think I would not be able to focus
long enough to read a Rick Riordan novel,

Or even to pray to the God who made me.

Some of my friends told me
they pray for me every day.
Perhaps this year is teaching me
that not only do I not need to be perfect
(I cannot),
I am part of a community committed
to the well-being of each of its members.
If I cannot pray, I know someone who can.

If I have no courage, friends will share theirs.
Just when I feel completely defeated,
someone shares a story
To tell me of a time
I was brave
or made a difference to them.

The weight of the world
can be borne by all of us,
even though it would
crush each of us.



Adele Pfrimmer Hensley

PATIENCE may be more like a cochineal insect . . .

Patience has no feathers.
Oh, it may look that way,
but the more closely you look,
you realize that what looks like feathers
is really tiny flakes of wax.

Patience has no real ability to move.
It sits on a leaf
and shelters in place,
surviving,
still.
It doesn’t seem possible that it could thrive, but if you don’t try to force anything,
if you leave its protective covering in place,
if you can just let it be,

when you return,
it may have multiplied a thousand-fold.
It may cover the plant that grew from the seed of hurry or worry in your heart,
draining its power,
halting its progress,
stopping it cold.

And when the trouble is done, the patience you have cultivated is no longer needed.
All you need for what lies ahead
is a deep knowledge
of the cultivation of patience.
The excess patience can be used to mark your soul the deep, rich red that will speak forever of your perseverance and the indomitable spirit that is in you.

** Note: A female cochineal insect spends her life patiently sucking sap from a cactus much like her distant relative called an aphid does on a rose. She sits in place, covered in a white wax to protect her from the hot sun. As she grows she produces a bright red pigment in her body that can be used as a cloth dye or natural food coloring.*

Adele Pfrimmer Hensley

Dependent Variables

The air is cool
The sun is bright
The sun warms the chairs and deck.

The Green Anole with the bronze colored
spine is on the umbrella stand.
Her blood is cool as the air.
Her muscles are rigid.
Until the sun can warm her
she is

I look up. I see the lizard’s appraising glance.
My muscles are rigid.
The sun is warming them, and my
medicine is traveling to my brain.
Until it gets there
I am

Slow and quite still.

Our eyes lock.

Too cool to skitter,
she creeps toward my foot.
Her gaze never wavers.

Too stiff to snatch her,
I watch wondering
how close she will come.

Our toes nearly touch.

Running like mad
she scrambles past my foot,
my chair, my shadow.
Warm and released from her stillness,
she is

Turning my head slowly,
I see her race from
danger to safety.
I feel the medicine unlock my stillness,
I am

free.

Strange Origami *

I can't fold the clothes. At least,
I haven't for the last few years,
since my cells got into a
protein-folding muddle.

Proteins are assembled from
DNA instructions,
but at that step, they are
merely polypeptides.

To become real proteins,
they have to fold themselves.
It isn't hard. In fact, it
should be automatic.

Proteins naturally fold up
into the exact shape
needed by the cell. At least,
that is usually
the story. Sometimes, though, things
don't go naturally.
Sometimes the conditions are
off and something goes wrong.

Is all this due to a change
in enzyme kinetics?

Slower folding gives proteins
freedom of assembly.
They form incorrect shapes – strong,
wholly unbreakable –
like origami cranes that
are permanently glued.

Aggregating into dark
implacable tangles,
this protein is like a piece
of origami that
fell into a toilet, by
permanent accident.

Origami's not for flushing;
strengthened paper clogs pipes.
Protein clumps clog brain cells
exactly that same way.
A research team thinks that
by changing the first step,
they could divert the folding.

I hope. I hope. I hope.

** The diseases of misfolded proteins include Parkinson's, Alzheimer's, and ALS.*

Doubt is like a Guinea Worm

There's a feeling I kept having. It started way down deep inside.
Now it's burrowed to the surface and it hurts.
When my body freezes and I just can't move my feet,
inside I start to panic. Then I hear two little words:
"I can't."
These words would devastate me,
if I heard them from a friend.
They would leave a stain in my ear like a curse.
If they were muttered by a stranger,
I would not stick around: in case they would contaminate me worse.
But this guinea worm-like parasite has popped out behind my ear.
The words it whispers fill my soul with dread.
The words that I would not accept from anybody else,
seem like they originate from right inside my head.
When I hear my voice speak the words, I'm sad, so blown apart.
The words, "I can't" keep welling up. They rip into my heart.
"I can't"
is just two little words, but their venom's very strong.
I have to find a way to stop the parasite and its song.
It takes all my abilities and throws them in the dust.
I can hold my own against the self-doubt but I know that I must
extricate the guinea worm
that whispers in my ear.
Replace its quiet voice with another speaking clear.
Gentle affirmations help.
I'll spread a few around.
I'll put them near the ceiling. I will put them near the ground.
They will need to say words that reverse the ones I've banned.
They only need two small words each. The two words are:
"I can."

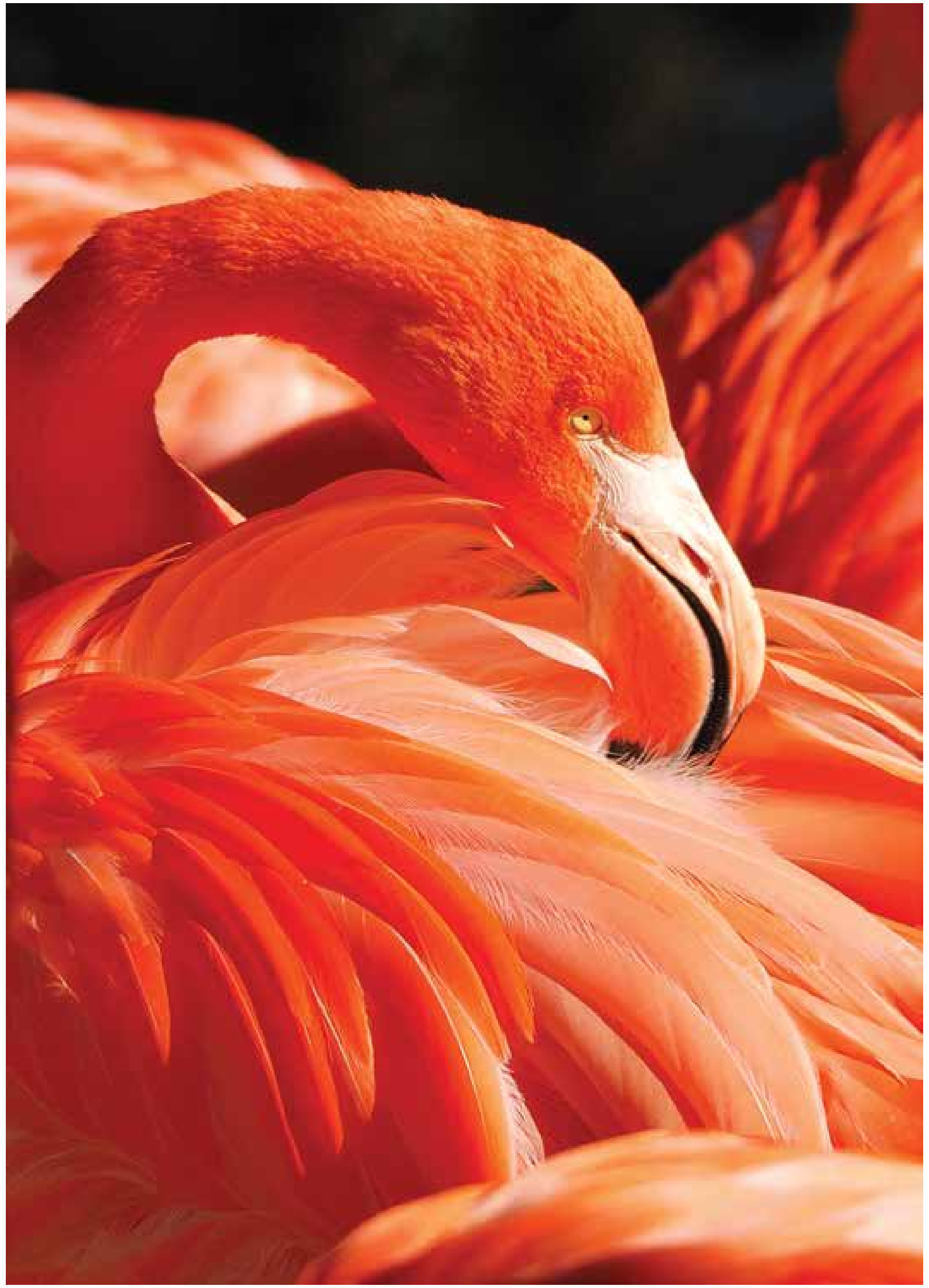
A New Calling

This summer there was a man who died.
So kind and so funny that everyone cried.

Then the news traveled over the air –
the man had perished because of despair.
The whole country was saddened when this was made known.
We had felt like we'd known him. Yet he died all alone.

Later we heard some more shocking news
from the famous man's wife, and it made me quite blue.
He had Parkinson's, she shared.
Maybe he felt that nobody cared.
Each case is different. It doesn't cause death,
but Parkinson's makes you feel like a terrible mess
The adjustment to the disease and its drugs takes some time.
They take hope-filled support and enough strength to climb out of a self-pitying state of your mind.

We can't help the man; he is already gone.
But we can share hope with others and a way to move on.
Upon diagnosis, you may feel quite alone.
If I can help it, you won't be on your own.



Auroras

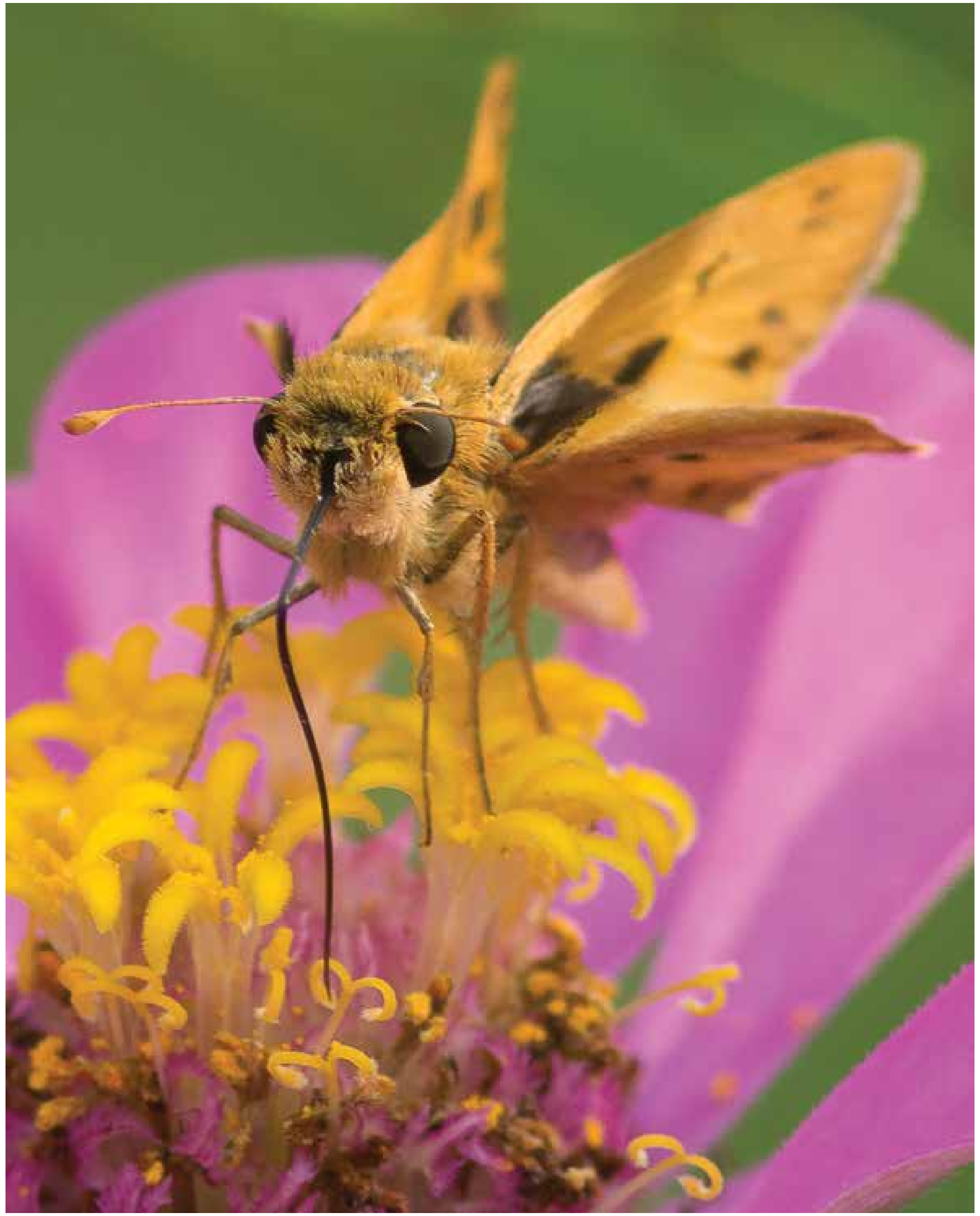
Red light and green,
  shone across the surfaces of Lake McDonald and Priest Lake.
A sight rarely seen,
  in any of the lower forty-eight states.
But on Thursday this week,
  in both Idaho and Montana, that same electromagnetic energy swirled
Peeking down from Denali's peak
  and skated merrily at the top of our world.

The lights are unseen,
  that signify the electrical fields within my brain,
where Stimulation has been
  applied for more than a year. Until now, there had been little gain.
On Tuesday my doctor adjusted my settings once more,
  and I glimpsed the health I hoped to find.
So on Thursday when I saw the pictures of the northern aurora,
  the electrons flowing from one pole to another in my head came to mind.
And I wondered: was last week's rare appearance by the aurora borealis reflected in my brain
  by an internal aurora?
I imagine a dawn of new ability is mirrored by green lights and red, shooting off in football
  shapes deep inside my head.

My Shoes

He walked along the windswept ground.
No living thing was there to be found,
so that when he saw the canvas shoes
that were just his size and such a bright blue.
He calmly slipped them on his feet,
and he proceeded down the street
toward the lights of the nearest town.
As he went, he heard a sound.
“You’ve got to walk, walk a mile, before you understand.
Walk, walk in my shoes on the roads throughout the land.”
“Who is that talking?” he wondered aloud.
“I’m the spirit of the shoe. I used to be proud
of my quick step and flashy blue color,
but my life changed from one day to another
when I became the shoes of a sick man.
It was much less fun and few people understand
how it is that a man who is young and strong
can just fall apart when a disease comes along.
It’s not going to kill him. It’ll only break him down.
It’ll take away his strength, and smile, and leave behind a frown.
Now you get to walk for just one mile.
You put me on freely, and it’s for a short while,
You’re going to live like you have Parkinson’s disease.
If you’re ready to start, then walk on please.”
Right then the spirit of the shoes stopped talking.
The man’s shoulders rounded, and he began walking.
His arm tucked up, and he shuffled his feet.
He almost fell when his gait froze on the street.

Though he was used to a faster pace,
he very soon realized it wasn't a race.
He kept going until his mile was done.
He felt so much better he was sure he could run.
That's just what he did as soon as he could
slip off those shoes at the edge of a wood.



Questionable Commemoration

Every year I observe several anniversaries. Usually these have a certificate or a license,
or some sort of official documentation.

I remember when I was a girl, someone made a point of telling all us kids that we should always know and remember the date of the day we were saved.

I could not. This fact troubled me for years. I remember kneeling and asking Jesus to live in my heart, but I suspect this was really some sort of formality;

A dotting of an i or a crossing of a t that was written long, long ago and seared into my being without a date or a certificate because I think in this way I am actually a real Presbyterian.

God is a God of Process. God is a Creator who is able to take what has been created and what has been broken and re-create.

God is a God of Relationship who is able to maintain the bond God has shared with us no matter how restless our wandering hearts are.

God does not need a certificate to remember you. Or me.

This is that sort of anniversary.
It is a day when I remember a formal declaration of a fact that had been true for quite some time.

Nine years ago today, my neurologist told me I have Parkinson's.
I was 38.

By the time most people living with Parkinson's are diagnosed, more than half the dopamine-producing cells of the substantia nigra are gone, dead or at least disabled.

The diagnosis is a formal recognition of something that has been going on a long time.
There is no certificate.

I wish there was no specific date, but it is just a memory of a formality.
I will spend this day with my family, my son, my mom, my dad, my sisters, and my brother, and
I will remember

being young,
silliness,
family stories,

and when I taste the salty deliciousness
of a chargrilled oyster, I will also remember the Gulf of Mexico and the way it is renewing
itself.

and I will feel
peace
and
love
and
hope.

Night and Day

Every day

I approach normal like a curve approaches an asymptote,
never reaching it but always drawing nearer.

Every day

I feel I might be living in the middle of a miracle
where physical therapy has stopped the progress
of this progressive neurological disorder cold.

Every night

I step off the curb of optimism
and become snarled in a traffic jam of tension, dread, and insecurity.
They sneak out, a little at a time, and taunt me as I try to fall asleep.

Every night

they put my optimism in a chokehold
and wait to see if I will tap.

Every night

I may cry but I'm not tapping, because I know

Optimism will return with the morning.

Hope lives, despite the fear.

Miracles happen.

Every day.

Comeback

A comeback is the hardest kind of victory.
You know what you used to feel like, to be able to do, to be.
You were so full of your life
but now you aren’t.
Now everything has been a struggle,
even things that used to be easy.
Deep concentration.
Talking.
Being in relationships.
Your training, your physical training that you depend on
to keep you grounded, to get you well, to restore your sense of your self
and your identity as a healthy person, is SO HARD.
It takes every last shred of your attention.
What you know is, if you give it your focus,
it could pay you back by letting you do your very best,
and THAT would represent Coming Back
from your troubles

to a life you want to live.
to health.
to Yourself.

So you take that challenge.
There aren’t many miracles in this life but
there is hard work,
there is sacrifice,
there is forgiveness,
there is the passage of time.

The dawn is just ahead.
You have come so far already.
This battle is worth the effort,
because you know that when it is over,
you'll be whole.
It's like a black-belt test.
You have to be a black belt to earn one.
The test is the way you let yourself know what is already true.
You are worth every good thing.
You are ready.
Your comeback is your test.
Your victory is certain.
You've got this.

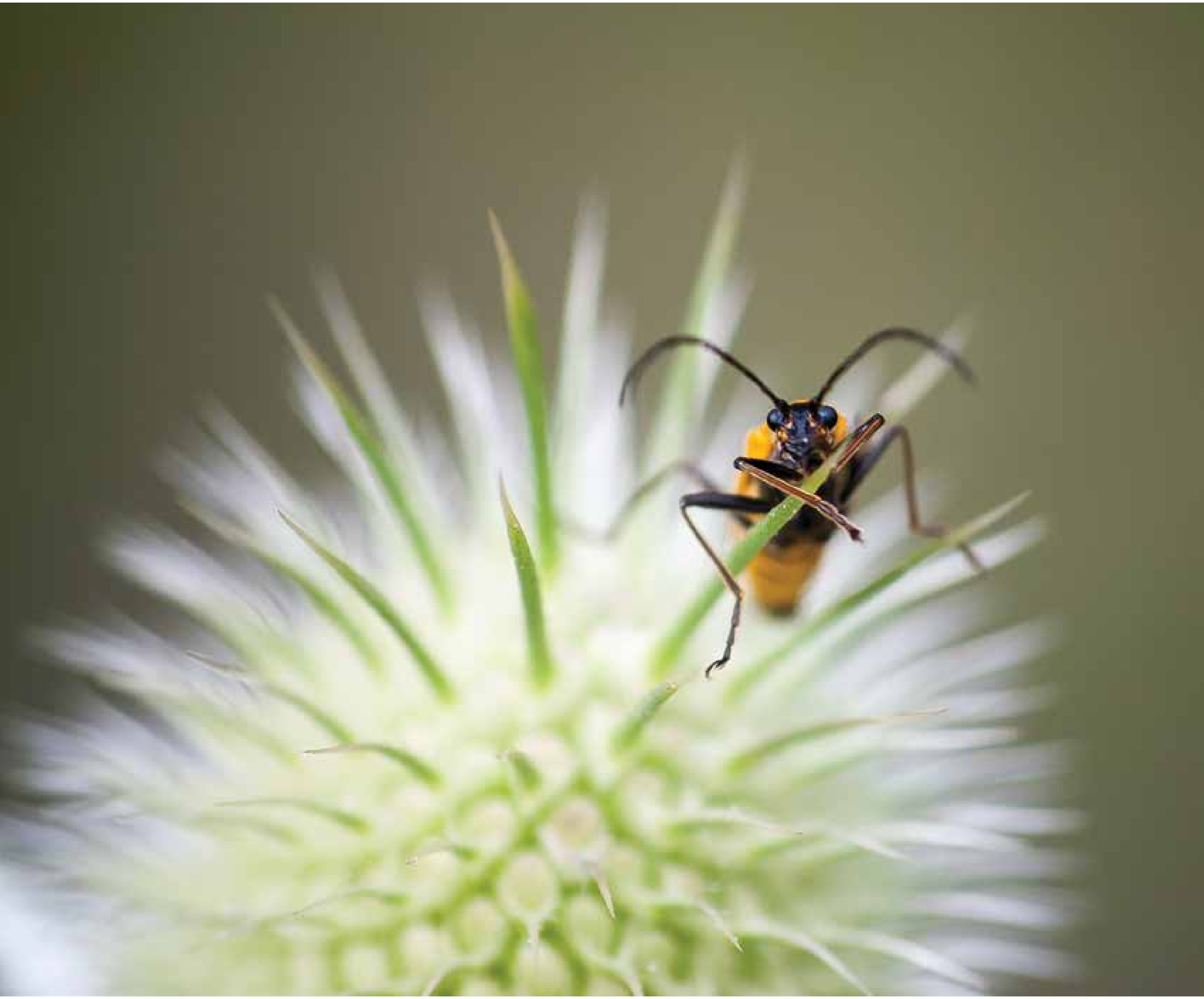
Hoping For Hope

The truth is that usually
I am able to ignore the pain in my knee.
I mean, you can't ignore the sound when
bone rubs on bone.
That sound is viscerally disturbing.
But once I realized that just
because it sounds painful doesn't mean it is,
I developed the ability to compartmentalize it.

Not yesterday.

Yesterday my knee hurt. My toe hurt.
I couldn't shift my weight to the right.
I couldn't swing my right foot through during
a step.
I couldn't do it.
I couldn't ignore it.
My mouth was full of "I can't."
My eyes were full of tears, that, of course,
spilled over.
When I cry like that,
I really don't know if they are
tears
of sorrow
or of anger or
of utter defeat.

All that is certain is that
I'm going back tomorrow, and
I hope things are
back to normal.



Don't Let It Get Ahead of You

"Don't let it get ahead of you"
usually refers to pain.
and the medicines we take
so we can keep going
or moving
or forgetting the pain
or never acknowledging the way it affects us;
we think it might make us feel weak
or damaged.
Sometimes, though,
we realize those medicines really do help to keep us functional.
Take today, for example.
I knew something was wrong, but I could not figure out what it was.
I know arthritis has taken over one of my knees,
but today I could not stand as easily as usual.
My knees and hips would not stack into a stable column.
Everything was collapsing.
I never fell, but I felt like the next time
I might collapse completely.
In the afternoon I opened my blue plastic box of pills for the day.
When I looked inside, I saw all my daily pain medicine.
I had forgotten to take my Aleve and my Tylenol,
and now the pain was ahead of me.
What a relief to have an explanation.
I took one of each and got on my bike.
I did not catch up to the pain yesterday,
but I made it look back.
I worried this would mean no more bike rides.

Then my friend reminded me that all I need to do on my rides
is change my attention from miles completed or miles per hour
to the cadence of my pedaling.
The faster my feet go,
the less force I apply to my knee.
I know this. I just need to embrace it.
I will be the slowest person on the road.
People will walk faster than I can pedal.
If I want to join their ranks, I will be content with
slow speeds but
fast cadences and
the absence of lingering pain.
It’s a matter of perspective and priorities.
My biggest goal has nothing to do with riding a bike
and everything to do with walking.

Priorities

After each of the last
two adjustments on my deep brain
stimulators,
the change in my ability
to stand up
and in my
ability to walk
has been
so astonishing,
so dramatic
so not the result of my labor,
that I really wondered if "I" had any role to
play
besides getting to New Orleans
once a month.

If the transformation were instantaneous,
it would seem magical or miraculous.
But it is a process,
just like it has been the last year.

And my bad therapy session showed me that
I do have a part.
I need to be ready to step off
anywhere, any time.
I also need to keep my pain
and my fear of it under control.

Walking toward a hopeful future.
Walking with a sense of peace and
competence.
Walking to the rhythm of "Holy Manna" and
"Ebenezer,"
sure of my footing,
my balance,
and my place in the world.

Would You Rather Be Doing Anything Else?

This is not the comeback you were hoping
for,
but this is the comeback you have.
It reminds me of New Orleans.
Parts of the city remain in ruins. Still.
Other parts are vibrant and thriving.

Hoping to find and feel a kind of strength
that you used to wear like body armor is
worthwhile,
but expecting it is not.
You have always been a person who fits most
people's definition of strong.
That was then, though. This is now.

Now your chance to rebuild is real.
Now it is time to let the wound heal.
The infection has raged and ravaged,
and now it is finally being exposed and
expressed.

This time the healing can be
from the inside to the outside,
and you can speak the truth; you can sleep
and rest.
You don't have to avoid or escape.
As you realize your identity, possibility,
and your basic human worth, you won't have
to wear your strength like armor. Instead
of going on you, it will come from within
you,
from seeds you had planted in your heart.

When the armor wears thin, as it always has,
you enter a cycle of stress, fear, and worry
that is hard to stop.
Those times will be further and further apart
until the day they disappear.
Until they do,
you'd rather be cycling.

This is not the comeback I was hoping for,
either,
but this is the comeback I have.
It reminds me of New Orleans.
A visit to the city shows remarkable
improvements.
But problems still exist.

Hoping to recover a sort of mobility that was
mine just a month or two ago is worthwhile,
but expecting it is not.
Every time my brain gets a new pattern of
electrical stimulation is a whole new
scenario. I know what I used to do.
That was then, though. This is now.

Now is the time to let the brain heal.
Now is the time to be patient
with my physical and emotional
slowness and imperfections.

This time, as I lay down the patterns
that will be the foundation for
my new muscle memory, as I find the
balance between working and being,
between stimulation and training,
between adjusting my settings and letting
    them be,
I am building my gait from the beginning.

When I am not patient with myself, when I
    am hurried or unkind,
I enter a cycle of stress, fear, and worry
that is hard to stop.
Walking is coming. It will just be the
last accomplishment on my list.
Until it comes, I’d rather be cycling.

Adele Pfrimmer Hensley

Two faces. One heart.

My smile slipped back today.

Both cheeks took part.
So did my lips.
The best part, though,
was that it reached my eyes.
I think they even sparkled.
Where had it gone?
I do not know.
I only realized how gone it had been
after it came back tonight.

Now
I want to go along
sharing sympathetic smiles
with every child I pass,
giving generous grins
to aggravated parents,
showing the feelings
that have been locked
inside my heart
and my face
by a duplicitous sobriety
for much too long.

Fledging

New pencils, as sharp as Vermont cheddar,
New computer charged up,
Nerves,
Smiles,
Seventh grade begins.
Ready to go.
Kiss Mom goodbye.
Hug Dad.
Off and away.

New pencils, as sharp as
Our boy,
New project all fired up,
Steady,
Smiles,
Fall semester begins.
Tired but ready.
Hug your boy.
Kiss your wife.
Flying free.

Neurostimulated brain as sharp
As it ever was,
Generator all charged up.
Nerves,
Smiles,
Independent life begins.
I feel
Anything but ready.
Kiss my son.
Kiss my husband.

I thought the seventh grader was fledging.
Maybe so. But on Monday, I realized I was,
too, when my husband kissed me goodbye.

Retrospective Analysis

It’s been twelve years
since I took my fears
and assigned one to every empty worry slot.

So that every worry,
anything that might make me hurry,
was assessed in light of the disease I’ve got.

At my diagnosis,
I got an unclear prognosis.
Most patients lived ten years but they were a much older lot.

I am not yet fifty.
And if I need to be thrifty
so I do not outlive my income, what other choice have I got?

I’ll live it day by day.
I’ll love, write, hope, and pray
that we’ll have a cure. A vaccine? I’d line up to get my child a shot at that shot.

About the Author

While Parkinson's disease is a part of her life, it is not her life. She is a mother, wife, sister, and daughter. Adele Hensley earned her BS in biology from Baylor University in 1987. She graduated in 1991 with an MS in zoology from the University of Florida. It was a few years later, as a graduate student at Duke University, that she realized the traditional academic life was not going to be for her. She saw that public education would best use her gifts and skills. She was very grateful to find herself on the right way, but she had to start on a new path when she was diagnosed with Parkinson's at the age of thirty-eight. It hit her voice early and made public speaking difficult. She funneled her efforts into explaining Parkinson's disease through writing. In addition to *Twelve Years and Counting*, Adele has authored three books for children about different aspects of Parkinson's disease. The children's books are *Monica, Mama, and the Ocotillo's Leaves*, about the process of diagnosis, *How Marty's Mom Became a Cyborg*, about Deep Brain Stimulation (DBS) therapy, and *Face It: Making Peace With Fear*, about the anxiety associated with Parkinson's. Adele lives in Clinton, Mississippi, with her husband Frank, who is a biology professor, their sixteen-year-old son Clark, and their Labrador retriever, Gryff.

About the Photographer

Frank Hensley is a wanderer of woods and meadows and a denizen of swamps and bogs. Sometimes he accidentally meanders to the front of a biology classroom, where he's surprised to find people who pay money to listen to him, but he is quickly drawn back out to habitats full of creeping and flying things. He fell in love with nature as a young boy in Nebraska. He fell in love with Adele when she agreed to help collect snails for his genetics project on a rainy night in Texas, even though she was wearing a dress. He loves sharing the beauty of nature with their son, with his students, and with anyone who can see that even scaly, slimy, or spiny critters are absolutely gorgeous.