



NO TURNING BACK

My Journey from PD Diagnosis to DBS Surgery

By John Foley • Art by Mary GrandPré

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Foreword

Kendall H. Lee, M.D., Ph.D., Neurosurgeon, Mayo Clinic

Having successfully completed over 1,400 deep brain stimulation surgeries, I have seen firsthand the miracle of DBS. I have also witnessed the devastation and heartbreak that Parkinson's disease inflicts on patients and their families. I have experienced this disease on a personal level within my family. There is no cure. But there is hope.

Deciding to have DBS as early as your doctor and care team recommend could mean more years of quality time. It's a big decision to move forward, but considering the side effects of ongoing drug treatments makes DBS a powerful tool for managing PD. With DBS surgery, it's possible to significantly reduce medications needed to treat PD symptoms. We will continue to work hard to make DBS surgery faster and safer so more people can take advantage of this life-changing option.

Having read John's poetry, there's no doubt he's captured the essence of what it feels like to be a patient dealing with PD. That's why I asked him to help me flip the script on old attitudes related to DBS — to start a movement to help thousands of people take advantage of exploring DBS earlier in the course of their disease.

No Turning Back

John Foley

My journey began at age 65 with the diagnosis of Parkinson's disease (PD). This chapter of my PD journey concluded with deep brain stimulation (DBS) surgery followed by programming and meeting with my neurosurgeon. Doctors believe I had PD for about four years prior to diagnosis. My goal is to continue to enjoy adventure travel, cycling, photography and playing music with friends for as long as possible. There's no doubt that DBS will add years of quality time to my life.

I began writing poetry as a catharsis for dealing with the disease and treatments. Up until my diagnosis, I had never written or even been particularly interested in poetry. Looking back, my brain's response to the stress and adversity emerged in the form of poems that created an emotional vocabulary to express the disease at a visceral level. I never intended to share these poems with anyone except my wife and a few trusted friends. Having come through the other side of the process, and at the request of Dr. Lee, I felt it was important to share my work to give others a real understanding of the process of treating PD with DBS. I had the good fortune of working with Mary GrandPré whose talent and artistry interpreted my words and infused a level of visual emotion beyond my imagination. I hope you will find this writing to be honest, raw, vulnerable and accessible. This is one patient's experience.

At the time of diagnosis...



The Verdict

At first tremors are declared essential.
Nothing to worry about. Nothing to do.
Trembling arm betrays me, too late to hide the spectacle.
Mortified as others pretend not to notice.
Maybe there's a remedy. Maybe I can tame it. Maybe it's not essential.

Neurologist asked about sleep, "Sometimes I shout, sometimes I thrash."
More interrogations, medical history, finally, a fateful "evaluation walk."
A verdict is reached — Parkinson's disease.
My sentence is degenerative and incurable.
At first, it's as if we're discussing someone else, certainly not me.

And then, the enormity of it all comes crashing in.
The verdict produces a seismic shift. I experience total vertigo.
As my brain slowly catches up, it explodes.
Without warning a "Care Team" appears — one I'm not ready to join.
After "cheerful" introductions, like a new business meeting —
I stagger out.

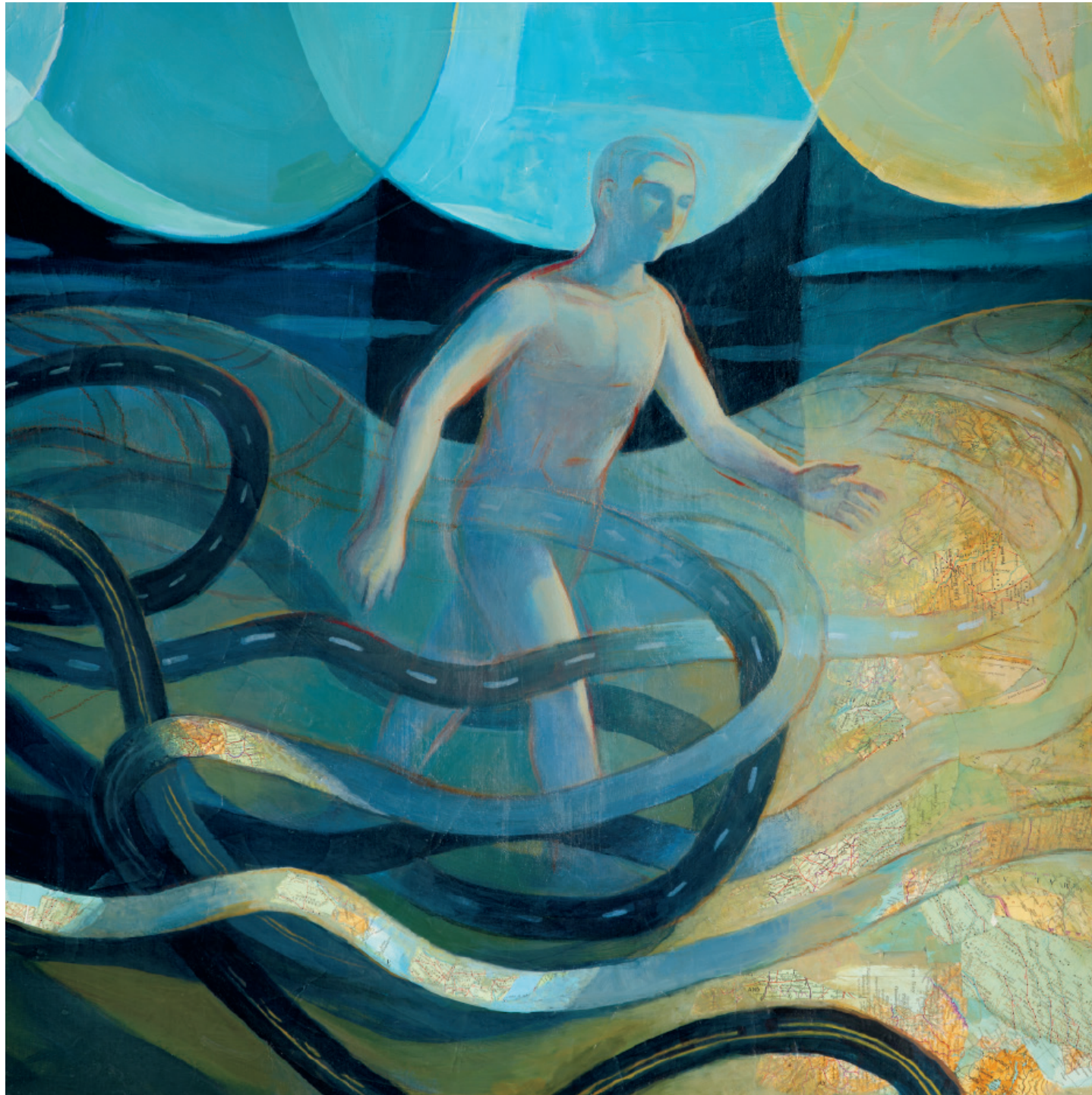
I'm drowning in a pool of unanswered questions.

*Terrified by what lies ahead. Humiliated by my plight —
my immediate reaction was, "I'm not going to tell anyone."*

I'm not going to be a label...

As a result of my diagnosis, I decided to retire and sell my business in order to dedicate my time and energy to educate myself about PD. My research became a full-time job for over a year. I also decided to share my diagnosis with friends and family.

Through my research, I began to recognize some of my new realities...



Aftermath

The verdict is clear, the future is not.

I imagine an epic battle waged on two fronts, physical and social.
It's neither epic nor battle, it's a slog.
A slow insidious march measured in months and years.
Trips to the doctor chronicle emerging maladies.

The search is on, options are few.
The goal is to mitigate and manage.
Resist limits, create workarounds.
Friends are unwittingly solicitous — I wish they'd stop.

Behind the tremors, behind the verdict, it's still me.
I'm not lost, just working on a new map.

*This poem represents the stages of PD (the Ghost of Christmas Future).
It was a very dark time for me. Coming to grips with the potential loss of
things most important to me and my identity.*

This poem reveals the abyss I stared into...



What Will I Do?

What will I do when my hands are no longer mine?
My camera trembles, images stop telling their stories.
What will I do when my guitar goes silent?

How will I cope when my legs refuse to support me?
My bike stowed away forever, confined to a world pushed by others.
How will I cope when life gets too small?

Who will I be when my mind has gone elsewhere?
Trapped without words behind a frozen mask, lost to those I love.
Who will I be then?

Is there dignity without control?
Perhaps the hidden gift is an early exit.
Shadows haunt me.

*My doctor was taken aback about my considering an “early exit.”
No one chooses to be a burden on their loved ones or family.
My journey led me to another option for control. I discovered deep
brain stimulation surgery.*

*In discovering DBS, I learned how incredibly difficult it was to
qualify for the procedure. The workup was arduous (as it should
be) to ensure the procedure will truly help the patient. Experts in
multiple disciplines assessed my speech and language, physical
movements, psychological health and cognitive abilities.*

*An MRI assessed my brain structure and function. Following these
protocols, the team met to discuss my case and determine if DBS
would be beneficial. The process was humbling — one of the most
difficult segments of the journey.*



The Gauntlet

Wanted to impress, wanted to be worthy — the perfect candidate.

Word Fluency

First up...

“Name all the words you can think of starting with the letter ‘S’ in sixty seconds.”

Slip-sliding through my “S’s” at a show-stopping, scintillating speed.

Stressing, squeezing every single syllable.

At thirty seconds, I smacked into a stone structure, suddenly, sadly, stumped.

Five hours to go.

Motor Control

Off meds, circle drawings looked like I had my eyes closed while operating a jack hammer.

On meds, drawings looked like circles.

Drawing hands on the clock — nailed it.

Four hours to go.

Memory

Asked “Who’s President of the United States?”

Answered “Depends on who you ask.”

Three shots at remembering twelve words — got eight right.

Couldn’t remember complex, in-depth story details.

Who cares what Mr. Stephen J. Strutz was wearing, on what day, at what time, at what address, while doing what to whom.

I’d make a lousy witness.

Three hours to go.

Depression Evaluation

Psychologist and I really connected, not depressed.

One hour to go.

MRI

Usually takes twenty minutes.

Kept having neck spasms and uncontrollable tremors as meds wore off.

Forty minutes later, I was done.

*Driving home, I prayed they would give me another chance.
Scared to death that I wouldn't qualify for DBS.*

Word came back, I passed — YES!

*While I was “preliminarily approved” for DBS, I kept hearing,
“You should wait.” Even though recent studies by Oxford and
Vanderbilt universities showed DBS to be as safe as and more
effective than optimal drug therapies over a five-year period
“if done early” within the FDA approved therapeutic window.
This is when I realized that the current treatment protocol for
PD was based on antiquated assumptions when DBS was the
treatment of last resort. To my dismay, these assumptions had
not been seriously challenged.*

Here's my rant about my intense frustration with the system...



In a Box

The tremors are light, my body is fine.
They say I'm the lucky one.
They say it's too early — the future is set.
We all follow the same worn path.
What I take is prescribed by others.
Side effects are expected.
The more I take, the worse it gets.
Whirling, shaking, loss of control.

The goal is to wait until things get bad.
That's when it's safe to drill.
If all goes well, not all is lost.
Minor gains feel like miracles.
Turning the clock back is not beating the clock.
The damage is done.
The few who've gone early are doing the best.
More stimulation means fewer drugs.

It's not a cure, the end is the same.
I'm playing for time.
Rules are inflexible, there's only one way.
Increase the dose, add another pill.
There is no choice, I'm in a box.
Waiting for things to get bad.

One of the worst aspects of PD is a condition called REM sleep behavior disorder (RBD). RBD is characterized by the dreamer acting out their dreams. The actions in an episode can result in injuries to oneself or one's bedmate. Approximately two-thirds of PD patients who also have RBD will develop Parkinson's dementia. Unfortunately, DBS does not treat RBD.



Nightmares

Nightmares, frightening bouts of shouting, thrashing, laughing, swearing.
Even when she wakes me, there's nowhere to hide — sleep escapes me.
An unsettling feeling of being out of control.
Each night is different, unpredictable, possibly dangerous.
What if I hurt her?
Each night, as the fog's rolling in, I'm scrambling for a way out.

While waiting for final approval for surgery, the disease continued its insidious march. I vacillated from periods of high anxiety, to fantasies of beating PD, to acceptance.

This is my attempt to capture those states of mind...



Waterfall

It's about the other shoe.
Waiting waiting looking for signs.
Body failing. Mind slowing.
An unsettling feeling of slipping.

A waterfall running dry.

It's about an unyielding spirit.
Pushing pushing away from the rocks below.
Ignoring the odds. Taking control.
Resisting nature's course.

A waterfall defying gravity.

It's about embracing fear.
Knowing knowing there will be setbacks.
Giving everything. Expecting nothing.
Moving with the stream.

A waterfall returning to the river.
A river becoming a waterfall.

Once I was finally approved for DBS, preparing for the actual surgery was exhilarating and terrifying.

I kept thinking:

“Be careful what you wish for.”

“Will there be complications?”

“Will I be strong enough?”

Getting my personal affairs in order. Subtly making sure I connected with family and friends before the auspicious day.

I think of the refrain in this poem as almost a prayer...



No Turning Back

It started unlike any other day.
It started with trepidation and hope.
Trusting my very essence to others.
Committing to whatever the outcome.
No turning back.

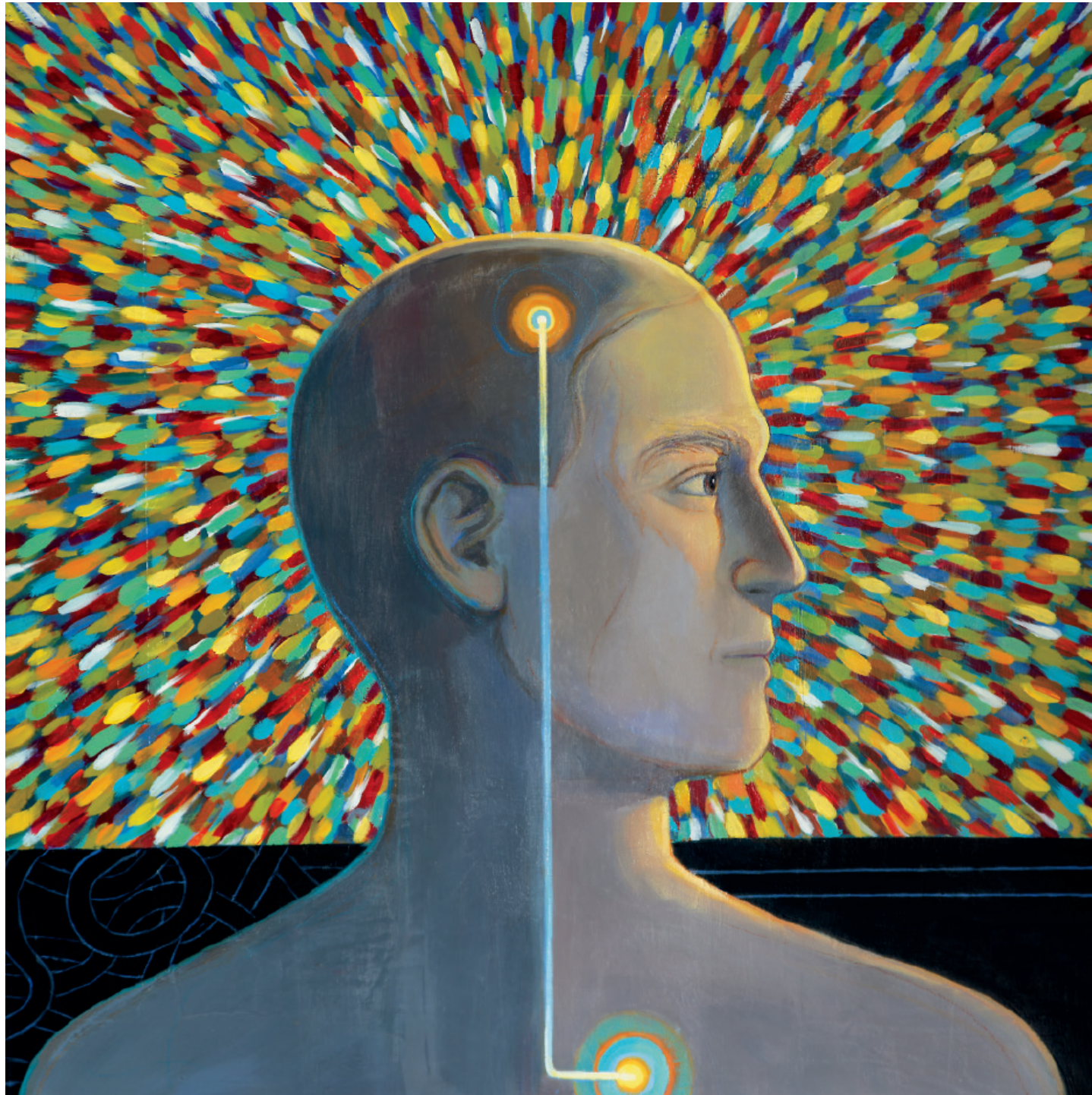
Awake and present, I'm part of the team — yet apart.
Awake and drifting, mild anesthesia to quell my anxiety.
I want to remind them that *I'm* here, under the surgical draping.
A living, breathing human, risking everything for more, quality time.
No turning back.

They said the risks were low, no guarantees.
They said very little pain — oh, but the smells, sounds and vibrations.
A cacophony of cutting, drilling, burning, stitching.
Burr holes in my skull. Perfectly placed probes, relying on finely honed skills.
No turning back.

And then the surgeon said, "Listen, that's the tremor we're hearing."
And then the room got quiet — my brain was telling them, that's the spot.
Turning on the probes, suddenly the tremors stopped. My toe stopped curling.
As they tested the parameters of the stimulation, I knew we made it.
No turning back.

The big payoff. I was truly fortunate to have access to one of the finest surgical teams in the world doing this procedure in record time of 22 months from diagnosis. Dr. Kendall Lee and Dr. Bryan Klassen at Mayo Clinic helped me navigate the health system. I was ready for the next chapter. The difference between recovering and healing is, after six short weeks, I was fully recovered. Healing continues to be the restoration of spirit.

Because PD is progressive and incurable, I will be working on healing for the rest of my life...



Turning On

The moment of truth.

The moment of completing an arduous journey.

Euphoric by the outcome, emotionally drained by the process.

Challenging the status quo, without alienating the team.

They say, "You're early." I say, "Time's running out."

DBS is still considered the treatment of last resort.

Technology over pharmaceuticals is the right choice.

New data has not altered old attitudes.

Better to be safe.

My experience supports the data.

Better control. Fewer drugs. No side effects.

They say, programming would be tedious.

Be realistic about outcomes.

I'm not looking for miracles. I'm looking for control.

Programming is uneventful — no surprises. Subtle yet profound.

Tremors gone. Dystonia gone. Worries gone.

At first, it's hard to trust the feeling.

The next night something wakes me.

Something's different.

Thinking and movements more fluid.

I'm back! An evangelist is born.

DBS is the best tool we have.

Turning on — never turning back.

Without educating myself, I wouldn't have had the knowledge to advocate for DBS.

Now, I want to share my knowledge and experience with others...



Evangelist

A manifesto...

I'm the voice in the wilderness.
Shouting from the mountaintop.
Evangelizing — proselytizing.

It's time for change!

Technology over drugs.
DBS as an early option, for managing this disease.
Drugs for those, where DBS is not an option.

PD beats us down.
Forces harsh choices, elective brain surgery or living
with debilitating side effects.
DBS is not a miracle — but damn close.

It is invasive.
There are risks.
Compared to current drug side effects — no contest.

Time to take control.
Time to challenge the status quo.
Time to flip the script.
Time to demand more quality time.
Time to make DBS available for everyone.
Time to rise up with one voice.

My Creed

*I don't know how long I'll be around
but with the precious time I have left*

I will

fear not

love freely

live honestly

expect nothing

protect my dignity

control my destiny

Take Control. Start a Movement.

We must all take responsibility for managing our disease. That means staying current on PD news and changes in treatments. If you can't be your own advocate, ask for help.

We must challenge the medical system to change its view of DBS as a treatment of last resort. Unfortunately, DBS is not a solution for everyone.

Talk with your doctor. Find a center that specializes in DBS surgery.

The surgery is covered by most insurance and Medicare. The sooner you start the conversation, the more quality time you can enjoy.

Every day we accept the status quo is a lost day for a person with PD whose life could be transformed.

About the Artist:

Mary GrandPré began her career as an illustrator. The path that led her to that point started with her education at the Minneapolis College of Art and Design. Her passion for light, color, drawing and design came together in evocative paintings, using a variety of mediums.

Much of her focus was creating paintings for numerous picture books and book covers. While she has illustrated more than 20 picture books, she is perhaps best known for her illustrations on the *Harry Potter* books. She has also worked as the conceptual artist on Dreamwork's animated film "Antz" and on Blue Sky Studios' animated film "Ice Age." Mary's book illustrations possess highly personalized lyrical story interpretations, and now her fine art paintings carry on with a new sense of narrative that combine abstract painting with realism, creating a new kind of territory for her to travel through...and ultimately, for the viewer.

About the Author:

John Foley is the founder and former CEO of LEVEL, a Minneapolis brand and advertising firm. LEVEL helps companies build and protect world-class brands and reputations.

He has provided strategic brand planning since 1986, having worked with over 220 businesses including 3M Health Care, American Express, American Lung Association, Blue Cross and Blue Shield, Beckman Coulter, Cargill, FICO, Medica, Medtronic, North Memorial, Sanofi, Tiffany & Co., Travelers, University of Minnesota and Walmart.

Beyond consulting, Foley has written for numerous business and trade publications as well as served on boards, including Reputation Institute, University of Minnesota Design Center and Brand Council for Carlson School of Business. Additionally, he has been a keynote speaker for many other organizations.

He is the author of the groundbreaking book *BalancedBrand* published by Jossey-Bass in 2006. In it, Foley explores why organizations must align corporate values with stakeholder values to build and protect strong brands and reputations. He's currently living the dream with his wife Cynthia Case and their dog Marvin.

