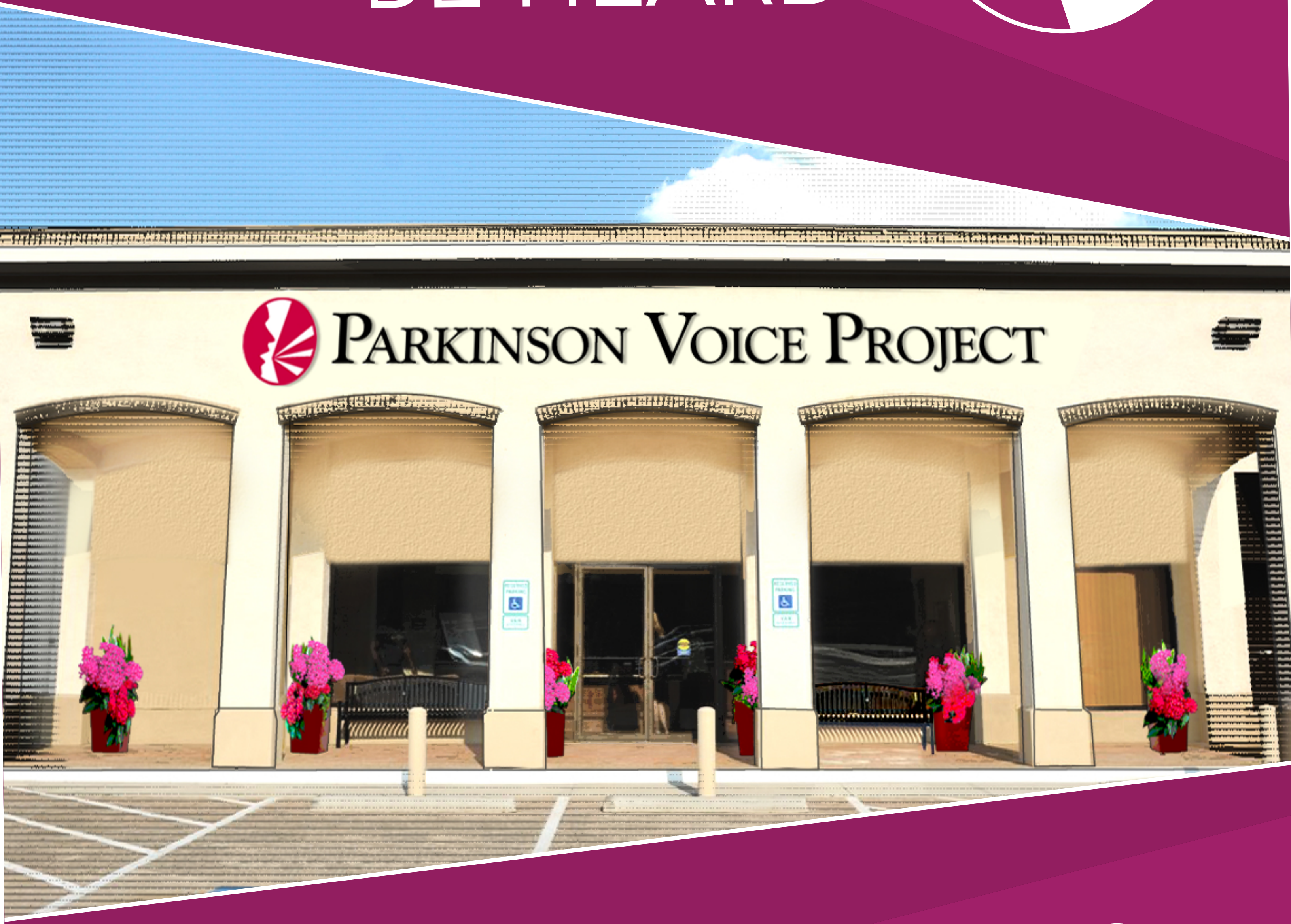
THEIR VOICES MUST BE HEARD



OUR CAMPAIGN TO REACH AMERICA

They Have Stories To Tell That Must Be Heard

There was a bright spot to the day Frank received his Parkinson's diagnosis. As he was leaving the neurologist's office, he saw a brochure from Parkinson Voice Project.

He picked it up and read the first paragraph, written by Project Founder Samantha Elandary:

> ***Nine out of ten people with Parkinson's are at risk of developing a weak voice that can lead to serious speech and swallowing issues.***

That was four years ago. Today, instead of diminished speech and swallowing abilities that 90 percent of those with Parkinson's face, Frank speaks with intent, volume, and clarity. He exercises muscles in his throat daily to fight the effects of the disease.

He concisely describes the impact of Parkinson Voice Project: "It changed my life."

* * *

Elinore's diagnosis came in 2005. By 2013, when she found Parkinson Voice Project, her voice sounded gravely. She spoke softly . . . when she spoke at all. Family and friends had a hard time understanding her. She found herself retreating from life.

Today, you don't notice the tremors affecting Elinore's hands – the result of degenerating control of the brain's motor function. You don't notice them because as she speaks clearly and succinctly, looking you straight in the eye, you are drawn to the considered points she makes in describing her experience.

"I felt alone," she says. "But belonging to this group has made such a difference in my life. You rediscover yourself here. It is wonderful."

* * *

Jay was diagnosed with Parkinson's in 2014. Just nine days later, he came to Parkinson Voice Project and received an assessment, speech therapy, a practice regimen, and a group of friends who understood his journey.

"If I hadn't come here, I couldn't be talking to you right now," he says.

I can tell my family

I love them

Jay's sense of humor certainly hasn't diminished. When he begins the story of a personal experience that proves how vital strengthening the throat muscles is, he says: "I was fighting a cat for a tuna fish sandwich."

In truth, Jay choked on a bite of that sandwich, was alone at his house, and easily could have died. He didn't. Now he practices his speech exercises daily online and meets with his SPEAK OUT! Therapy Group every Monday.

These are just three stories. At Parkinson Voice Project, we can tell thousands of them. Stories of thousands of men and women who come to us and receive life-changing – often life-saving – therapy to combat their Parkinson's symptoms and to connect with a cohort of friends walking the same road.

And it's all free to them.

"Parkinson Voice Project has changed the landscape for patients with the disease," Samantha says. "We're providing free speech therapy, practice, and camaraderie in our Texas clinic and replicating our program through grant sites across the U.S. and abroad."

But it's not enough. There are too many people with Parkinson's where our proprietary SPEAK OUT!® Therapy Program is not available, too far from the people who could benefit, or too expensive.

We Can and Must Do More

And so, we are embarking on a $20 million initiative to make our SPEAK OUT! Therapy Program accessible to ***every patient in America***, secure our "home base" in North Texas, ensure a sound financial future, and drive the publication of peer-reviewed research to further investigate the efficacy of our innovative treatment.

With your help, we will:

- Purchase our current home and endow the maintenance and upkeep;
- Fund five years of operating expenses for our clinic and our "SPEAK OUT! Therapy Grant Program;"
- Establish and fund for five years 50 *Therapy & Research Centers* housed within university speech clinics – one in every state in the U.S.;
- Financially secure our organization by depositing all donations received during these same five years into our Endowment Fund.

I sound like

my old self

Over one million people in the United States battle Parkinson's today. Most don't know about our treatment and the support available to them. And many who do, can't access it to gain the benefit.

The math is simple – ***90 percent of one million is 900,000 voices slowly fading away…*** on the verge of being lost forever. It's also 900,000 people whose swallowing is at risk.

These individuals – perhaps members of your family, neighbors, friends at church, and co-workers – desperately need what Parkinson Voice Project provides.

What we need . . . is your support.

Join with us in our groundbreaking
Campaign to Reach America.

Together, we will ensure men and women with Parkinson's disease will be able to tell their stories for generations to come.

Sound too good to be true?

We guarantee you… it is not. This is a problem Samantha and her team know <u>exactly</u> how to solve. And it won't take decades.

"We can have all 50 Therapy & Research Centers up and running by our 20th Anniversary in 2025," Samantha says confidently.

Real Need. Real Opportunity.

Is there truly a need to make Parkinson Voice Project programs available across the country?

The answer is an emphatic "yes."

Numbers Tell a Story

The one million people living with Parkinson's in the U.S. is more than the number of those with multiple sclerosis, muscular dystrophy, and Lou Gehrig's disease *combined*. It is the second-most prevalent brain disease after Alzheimer's.

"

I'm back

in charge

As mentioned, 90 percent of people with Parkinson's will struggle with voice, speech, and swallowing issues. **Seventy percent – that's 630,000 people in America –** will die from aspiration pneumonia related to these issues.

Swallowing safely is a vital act many take for granted. The ability to chew food, manage saliva, and swallow without coughing or choking is a gift our patients in Richardson are grateful for. Others across the nation are not so fortunate.

Parkinson Voice Project is uniquely equipped to make a difference as the only nonprofit organization in the U.S. addressing the speech and swallowing challenges related to Parkinson's.

But we are only licensed in *Texas*. Every state issues its own license for speech-language pathologists. So, we are restricted to only serving patients in Texas.

This is why ***each state must have its own Therapy & Research Center.*** It is also why we only need ONE center in each state. From just ONE university, any patient in their state can be treated, either in person or online.

Very Different, Yet the Same.

Parkinson's disease affects every individual differently.

Some deal with tremors; some don't. Some experience balance issues; some are steady. But nearly every person with Parkinson's **– 90 percent –** will experience speech and swallowing deficits.

Depression and apathy are also symptoms of Parkinson's. The will and motivation to complete speech and swallowing exercises every single day is compromised.

Parkinson Voice Project's unique combination of speech therapy, online practice, group support, and camaraderie of like-minded friends tips the balance in the patient's favor.

There is no program like ours in the world.


PARKINSON VOICE PROJECT
JOHN AND JANE DOE
THERAPY &
RESEARCH CENTER

We Must Have Research

Why aren't more doctors aware of our program? Why doesn't Medicare pay a reasonable rate for speech therapy? Why aren't more universities teaching the SPEAK OUT! Therapy protocol?

Almost all research conducted on Parkinson's is aimed at causes, medications, and a cure.

Very little research is conducted on programs that help those living with the disease right now… therapies that help patients with Parkinson's live longer and avoid feeding tubes and multiple hospitalizations.

Our nationwide network of Therapy & Research Centers will turn that around. They will treat patients AND conduct and publish peer-reviewed clinical research.

Just imagine . . . studies to evaluate how the SPEAK OUT! Therapy Program impacts lung capacity, vocal fold movement, saliva control, tongue strength, articulation, volume, stuttering, facial expression, swallowing, mood, overall well-being, and more.

The published research will ignite invaluable exposure for our program and will build awareness in the medical and insurance worlds about the speech and swallowing deficits plaguing this patient population.

We Must Have a Secure Home

Our investment in purchasing our current building in Richardson and endowing its maintenance protects us from the vagaries of the Dallas real estate market. We will always have a "home base" to put our work into practice.

I'm singing

in the choir again

People Behind the Numbers

Behind every number surrounding Parkinson's, there is a person and a family living with the disease. For the fortunate ones who have access to our program, we are making a proven, demonstrable difference.

"Just this month, we received the following email from one of our university grant sites, which could be a future Therapy & Research Center," Samantha says. "These graduate students – future speech-language pathologists – would never receive this clinical experience without the grants and free training provided by Parkinson Voice Project."

> ***"I am the clinical instructor for two first-year graduate students serving a Parkinson's patient receiving SPEAK OUT! Therapy in our university clinic. I went into the treatment room after his session. All three of us were in tears.***
>
> ***Mr. P came to our clinic three weeks ago as a man with Parkinson's who was defeated. His demeanor was one of sadness and resignation to his diagnosis. He sat slumped in his chair and was skeptical that there was anything left to look forward to.***
>
> ***Today, Mr. P is sitting tall, laughing, producing a voice he had considered long gone and looking forward to a trip to Nevada to 'reintroduce myself to my grandkids.'***
>
> ***Parkinson Voice Project changes lives.***
>
> ***Thank you for all you do for our patients, our students, AND our faculty who get to witness miracles every day!***
>
> ***We are forever grateful and changed by your program!"***

This is Parkinson Voice Project in action. Voices restored. Lives regained. No longer will speech pathology students graduate with their master's degree having never set eyes on someone with Parkinson's.

The need is real. And so are the solutions we offer.

My co-workers don’t ask me to repeat *anymore*

COVID-19 and Tech-Savvy Patients

Our Campaign to Reach America has been the *intent* of Parkinson Voice Project since its inception in 2005. Ironically, the plan became attainable because of COVID.

“Several years before the pandemic, we developed a 10-hour online training program for speech-language pathologists and an eLibrary for patients.” Samantha says. “We didn’t realize it at the time, but we were equipping ourselves to easily transition to a *telepractice*… providing our SPEAK OUT! Therapy Program online.”

But even though <u>we</u> were prepared for ***“teletherapy,”*** patients weren’t . . . not until the pandemic.

Initially, there was great uncertainty about using video conferencing software, such as Zoom. Then, the pandemic lasted over a year. Out of necessity, patients are now scheduling doctor’s appointments, attending church groups, and participating in family gatherings . . . all online.

The Parkinson’s population, especially, is recognizing the convenience of online therapy. Live too far from the clinic? ***No problem.*** Don’t drive or rely on others for transportation? ***No problem.*** Homebound or live in a nursing home? ***No problem.***

Karl Robb experienced his first Parkinson’s symptoms at age **17** and has stuttered most of his life. He finally gained access to our treatment during the pandemic. “The clinics offering SPEAK OUT! Therapy in my area were too far from my home,” Karl explained. “With D.C. traffic, it would have taken me over an hour each way on a good day, and I don’t drive anymore.” Karl is now making vast improvements in his communication skills.

Did you know 10 to 20 percent of people with Parkinson's are diagnosed <u>before age 50</u>?

Family Involvement and Support

People with Parkinson’s do better with family support and encouragement. Before COVID, adult children were burdened with taking several hours off work to attend therapy sessions with their parents. Patients whose family members lived out of town were out of luck. Not anymore…

Adult children, siblings, grandchildren, nieces, nephews, and friends – no matter where they live in the world – can hop on a Zoom call and participate in therapy sessions.

> *I order my own food*
>
> when dining out

Daily Online Practice Sessions

Since Parkinson’s is a progressive, degenerative condition, speech therapy is not enough. Patients *must* complete daily exercises or risk losing their speech and swallowing.

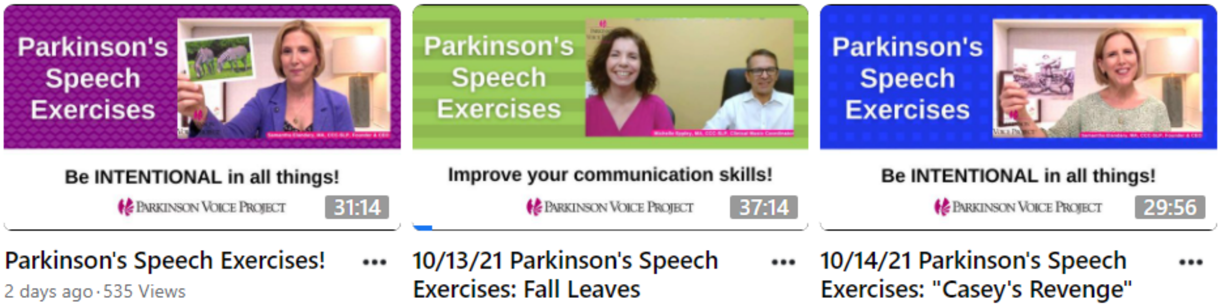
Barry has been in Parkinson Voice Project’s program since 2008. He’s learned the necessity of consistent home practice. *“If I go two or three days without doing my speech exercises,”* he explains, *“my voice starts to sound hoarse, my wife starts asking me to repeat again, and I start coughing while I’m eating.”*

***

George has been in our program since 2007. *“I can always tell when I haven’t done enough speech exercises because I suddenly can’t eat hamburgers anymore.”* George loves hamburgers. In fact, it was his inability to eat hamburgers that first brought him to our clinic 14 years ago. ***“As long as I do my exercises, hamburgers are no problem.”***

Maintenance has always been a challenge for the Parkinson’s population. Even though most patients make remarkable progress in therapy, they struggle to *maintain* the results because of the degenerative nature of Parkinson’s. Technology is changing this, too.

In March 2020, Parkinson Voice Project began offering *online speech practice sessions* – on ***Facebook, YouTube, and our website***. More than 1,000 patients participate each day. Technology provides a new means for motivating patients from all over the world and helping them MAINTAIN the strength of their voices. The pandemic has advanced Parkinson Voice Project’s progress by at least ten years… maybe more.



Parkinson's Speech Exercises!
2 days ago · 535 Views

10/13/21 Parkinson's Speech Exercises: Fall Leaves

10/14/21 Parkinson's Speech Exercises: "Casey's Revenge"

> *I can cheer*
>
> at my grandson’s
> soccer game

$20 Million Campaign

Here's the breakdown of our plan:

1. Purchase and Endow Our Building
$5 Million

Parkinson Voice Project's home on Coit Road is for sale. The price is $4 million, and we will dedicate an extra $1 million to endow the maintenance and upkeep.

It is financially advantageous to take this step, but there are additional benefits:

First, we are guaranteed a home, and the 10,000 square foot building is the perfect size for our operational needs. It is ideally located between – but not on – major thoroughfares and accessible from across the Metroplex.

Second, past donors have already invested $1.5 million to remodel, furnish, and outfit the clinic tailored to our patients' specific needs: private therapy rooms for both in-person and online therapy; wide hallways and doorways to accommodate walkers and wheelchairs; large family restrooms for those who need assistance; meeting spaces for speech and singing groups, educational conferences, volunteer activities, and board and staff meetings.

Third, if we were to move, we are severely limited in the number of properties suitable for our patient population. In 2019, our board contracted Jones Lang LaSalle to conduct a market survey to investigate other potential locations for our clinic. They were unable to find any suitable buildings our size that were centrally located. Mobility challenges require easy access in and out of the building. No stairs. No garage parking. No high traffic entrances and exits.

At 646 North Coit Road, we have 55 dedicated, street-level parking spaces. The path from our parking lot to our front door is short. And although we don't like to think about it . . . Richardson's emergency response time is less than four minutes.

2. Cover Operations for Five Years and Build Our Endowment
$12.5 M

For all we accomplish, our $2.5 million annual budget demonstrates we make efficient use of the support we receive: in-person and online therapy, online practice sessions, speech groups, singing groups, free distribution of SPEAK OUT! Workbooks to U.S. patients (4,554 last year), free training of speech-

> People
> *listen*
> to me now

language pathologists and graduate students (2,000 last year), and U.S. and international training grants for hospitals and clinics (303 in 2021).

Covering five years of operating expenses creates two benefits:

- We secure our services to <u>local patients</u> as we establish the 50 Therapy & Research Centers.

- We build our Endowment Fund to secure our programs for the future with all ***other donations*** received during this same five-year period.

3. Fund 50 Therapy & Research Centers for Five Years
$2.5 M

Through extensive consultations at the university level, we've determined that incorporating our Therapy & Research Centers into existing collegiate speech clinics is the best way to make our treatment accessible to patients across America.

University speech clinics already have the infrastructure in place. They have dedicated clinics. They are well-staffed with speech-language pathologists and eager graduate students to implement treatment and conduct research.

Each of our 50 Therapy & Research Centers will offer BOTH in-person and online treatment ***free of charge,*** just as we do in our Richardson clinic. This is possible in training institutions. No patient in America will be denied treatment due to insurance restrictions or financial limitations.

What these university clinics lack is specialized training in Parkinson's and funding for necessary therapy supplies and research equipment and expenses.

We already have our online training course. If we also provide each center with just ***$10,000 a year,*** they will make Parkinson's a priority in their clinics. A five-year commitment is necessary for these universities to design, conduct, and publish their research studies.

$10,000 x 50 Centers x 5 years = $2.5 million

It is hard to imagine a better return on investment. Hundreds of thousands of lives improved. Voices saved. Conversations continued. Swallowing preserved. More meals with family and friends. Future speech-language pathologists receiving quality education and training.

> I can
> *talk to*
> *my son*
> on the phone

Four Questions

As we explored our Campaign to Reach America with friends and supporters, four common questions arose.

Question One: Will there be a "Therapy & Research Center" in Texas besides Parkinson Voice Project's clinic in Richardson?

> ***Answer:*** Yes. Parkinson Voice Project does not have a cohort of graduate students and is not equipped to conduct the level of research possible in a university setting. There will be 50 centers PLUS Parkinson Voice Project's clinic.

Question Two: How can 50 centers treat all the people with Parkinson's in America?

> ***Answer:*** The Therapy & Research Centers are not expected to treat ALL the patients themselves. We will continue training speech-language pathologists and awarding grants to hospitals and clinics across the globe. Ideally, every patient will have access to our treatment in their city or town. But, for those who used up their Medicare benefits on physical therapy… for those younger patients whose insurance won't cover speech therapy… for those who don't drive… for those who live in rural areas or in cities without a trained speech-language pathologist… and for those who are homebound or living in nursing homes… ***they can all be treated through a Therapy & Research Center.***

Question Three: How is Parkinson Voice Project so confident it can establish 50 Therapy & Research Centers within a few years? What will happen after 5 years?

> ***Answer:*** Many of our current university grant sites operate as future Therapy & Research Centers. They only lack annual funding of $10,000 to make the commitment to offer ***free treatment,*** provide teletherapy, and conduct Parkinson's research. We have already identified more than one third of our future centers. After five years, we will continue supporting these centers and, possibly, expand the program internationally.

Question Four: Is the organization prepared for succession should Samantha Elandary no longer be here?

> ***Answer:*** Absolutely, "Yes." Samantha has no plans to retire any time soon. This is her passion and her life's work. However, she has *intentionally* planned for her successor all along.
>
> Parkinson Voice Project has written policies, procedures, and job descriptions for

I have

hope

now

all areas of the organization. Key employee insurance of $1.5 million was secured several years ago. And, if the unforeseen occurs, a plan is in place. A board member will serve as interim CEO as the search for the next leader is conducted.

A significant advantage to our Grant Sites (and future Therapy & Research Centers) is that we are already in contact with hundreds of experienced speech-language pathologists and clinical supervisors who understand our mission and vision. This will be the first place our board looks for our future CEO.

Finally, Samantha's son, Joseph Elandary, is also part of our succession plan. As our newest board member, he holds the key to preserving our organization's history and will mentor the future CEO. He was five years old when Samantha began treating patients in their home in 1999. He is a Certified Public Accountant, earned his MBA from Southern Methodist University, and currently works at FTI Consulting as a director in CFO Advisory.

Both our present and our future are in good hands.

People With Parkinson's Need Us

When is the time to help people with Parkinson's improve their speech and swallowing?

Yesterday.

Parkinson Voice Project receives cries for help every week from people with Parkinson's. The following message was received through Facebook on October 9th:

> *I live alone. I need to communicate to exist and survive. I can't imagine what will happen if my speech stops completely. I was only able to receive six speech therapy sessions with my plan, and I don't think the therapist was familiar with Parkinson's.*
>
> *-Monique*

Parkinson Voice Project has a long record of focused, efficient, and effective pursuit of this mission. ***The organization is financially sound and has never been in debt.***

There is no other organization in the world better equipped, more experienced, or more committed to improving – and extending – the quality of life for people with Parkinson's.

We have changed the trajectory of our *local patients' lives*. They are not losing their communication skills. They do not have feeding tubes.

> I feel like a *giant* again!

We have a viable way to help every person with Parkinson's in America preserve their speech and swallowing.

Will you partner with us in this noble effort?

Parkinson Voice Project's

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Samantha Elandary
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