



Impact Report

April 2019 - August 2021

stroke onward

Leadership Letter

Friends, Supporters, and Collaborators,

As *Identity Theft: Rediscovering Ourselves after Stroke* was approaching publication in early 2019, we believed strongly in the impact it could have on improving the recovery process for millions of stroke survivors and their families. Researching and writing the book reinforced our personal experience of a huge gap in the recovery system -- little or no focus on the critically important emotional journey to rebuild rewarding lives in the face of the devastating disruption and disabilities caused by a stroke. We believed *Identity Theft* would help, but more needed to be done. We created **Stroke Onward** to do more, and began our work in earnest in late 2019.



Initially we thought Stroke Onward would simply be the structure through which we volunteered our time personally to address this problem. But we quickly saw that the need -- and the opportunity -- were even greater than we thought. Our ambitions grew and we've now built a fantastic small team.

Stroke Onward could not be where it is today without the generous support we have received from many of you -- longtime friends, colleagues, and others who learned of our work and believed in it. Your critical contributions got us off the ground and keep us going. Equally important are the incredible allies we have developed through our work, and with whom we have had the privilege to collaborate -- you all are simply amazing.

We hope you will agree that we have already created some real and significant impact in our short life as an organization. And even more important, that we have laid a foundation on which we can effectively build toward making significant and important changes in the stroke system of care. Our vision is that future survivors and their families will have all the guidance and resources they need to rebuild their identities and truly rewarding lives after stroke.

With gratitude and admiration,

Debra Meyerson and Steve Zuckerman
Co-Founders and Co-Chairs of the Board

Leadership Letter

Stroke Onward is Born

Impact Model

Raising Awareness

Creating + Sharing

Resources

Changing the System

Organizational Update

Leadership Letter



At the age of 34, I experienced a stroke, leaving me with aphasia, physical issues, and lots of questions about my future. Fortunately, I regained most of my capabilities, but the emotional journey to heal from this trauma and reimagine my life, was one that I had to walk virtually alone. I wasn't offered resources to help; I only had myself, my family, friends, and a therapist I found on my own to support me. When I learned about Stroke Onward and *Identity Theft* late last year, I immediately knew that I had to be involved in this mission to change the stroke system of care. I am humbled to be a part of this team, proud of what has been accomplished so far, inspired by the colleagues and allies we have developed, and eager to help Stroke Onward contribute to a movement that can improve the lives of millions of stroke survivors in the years ahead.

Warmly,
Flannery O'Neil
Executive Director



Debra + Steve presenting at Aphasia Access Teach in. Pictured with (L-R): Todd Von Deak and Elizabeth Hoover June 2020.



Debra + Steve with American Heart Association CEO Nancy Brown - February 2020.



Stroke Onward team presenting to Adler Aphasia Center during a staff inservice - April 2021.

Leadership Letter

Stroke Onward is Born
Impact Model

Raising Awareness

Creating + Sharing

Resources

Changing the System

Organizational Update

Stroke Onward is Born

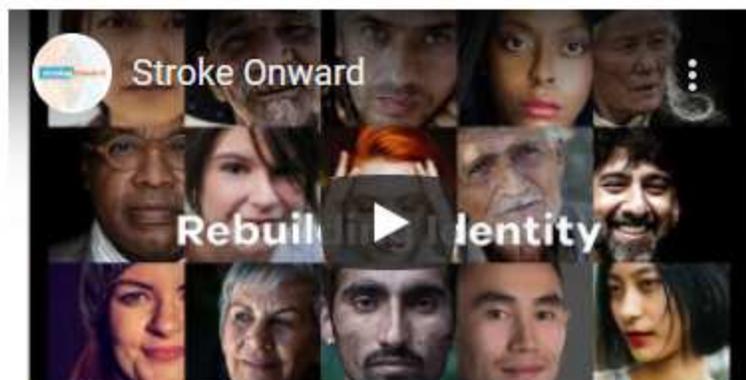
Stroke Onward was founded in April 2019 by Debra Meyerson and Steve Zuckerman, to help survivors and their families get support with the critical, but often overlooked, emotional journey in recovery. Debra, a Stanford University professor who taught and wrote about gender, diversity and identity, survived a severe stroke in 2010. She spent three years working to regain her capabilities, expecting to return to her job and other aspects of her life “as it was”. Ongoing aphasia forced her to relinquish her Stanford position; that and other physical disabilities meant much of her life was changed forever.

OUR MISSION:

To ensure stroke survivors, families, and caregivers have the resources they need to successfully navigate the emotional journey critical to rebuilding their identities and rewarding lives.

Debra spent the next five years, with help from her husband Steve, son Danny, Sally Collings and others, writing *Identity Theft: Rediscovering Ourselves after Stroke*. The writing process became her journey to rebuild her identities as a survivor and to begin building a new and different life -- not one that was a lesser version of the old. This process led Debra and Steve to recognize the crushing need for more resources to support others in this critical part of the recovery process, and Stroke Onward was born.

Stroke Onward Video Introduction



The Emotional Journey to Rewarding Lives

Leadership Letter

Stroke Onward is Born

Impact Model

Raising Awareness

Creating + Sharing

Resources

Changing the System

Organizational Update

Impact Model + Strategy

We want to change the system. The healthcare system is one of the largest, most entrenched, and many would say broken, systems in America. Nonetheless, we believe we can change how it treats and serves stroke survivors and their supporters. It's a tall order, and will take time, but we can do it. The journey to system change will enable us to help stroke survivors and their families real-time -- both directly and by supporting healthcare professionals, researchers, educators, non-profits, and others in the stroke system of care.

Stroke Onward Impact

Direct: can help thousands or tens of thousands

Distributed (others using our work): can help hundreds of thousands

Systemic: can help millions

We are committed to measuring our impact. Today, that is mostly through measuring activities and outcomes, supported by anecdotal data about how our work is improving people's lives. We have begun to collaborate on more rigorous analysis of impact, and will grow that work in the years ahead.

Our work is organized around three core strategies, each of which reinforces the others, and contributes to building toward all three levels of impact described above.

Raising Awareness

We are filling a void -- little or no focus on the emotional journey in recovery, and few resources to support that journey. We have to make people more aware of the problem. For some, heightened awareness is already proving to change the recovery experience in very profound ways.

Creating + Sharing Resources

When people do see the need for emotional support in their journey, they rarely can find resources, materials or people, to provide it. We're creating and organizing materials that support survivors and families on their emotional journey in recovery, making them available directly and through collaborations that substantially increase their reach.

Changing the System

Everyone in the stroke system of care should experience a **whole-person approach to recovery**. It will take years, even decades, and effective collaboration with others. Big change starts with small wins and Stroke Onward has launched projects that will help take concrete steps forward.

Leadership Letter

Stroke Onward is Born

Impact Model

Raising Awareness

Creating + Sharing

Resources

Changing the System

Organizational Update

Raising Awareness

Stroke Onward focuses significant effort on speaking and writing about the importance of the emotional journey in recovery, and sharing ideas and tactics that can help. We are reaching our ultimate beneficiaries -- survivors, carepartners, and families -- as well as key influencers in the stroke system of care. These activities have raised awareness, built important relationships critical to both current and future work, and have created impact on their own.

Speaking Engagements

Due to Covid, this strategy required a major pivot right from the start. After giving just a few talks in late 2019 and early 2020, we had other large convention speaking engagements cancelled or converted to virtual events. We've presented at several big events, but quickly realized the work to secure and prepare for them, in a virtual world at least, was no longer our best strategy. We embraced Zoom fully, and began speaking by video much more frequently to small audiences as well as large.

We have been particularly active speaking to and working with organizations supporting people with aphasia (PWA), the communication disorder that impacts roughly one third of all stroke survivors. Stroke Onward has led or presented to more than 30 survivor and carepartner groups, and has worked closely with Aphasia Access, an incredible association of aphasia professionals. These early contacts were instrumental to the collaborative work we have done (and continue to do) with teams from Boston University and Cal State East Bay, including the development of our aphasia friendly book group discussion guides for stroke survivors.

Total Speaking Events
57



● 2020 ● 2021

Total Attendance
1,288*



Data collection for attendance began in 2021.

Audience Composition

63%
Survivor/
Carepartner



37%
Professional /
Academic

Leadership Letter

Stroke Onward is Born

Impact Model

Raising Awareness

Creating + Sharing

Resources

Changing the System

Organizational Update

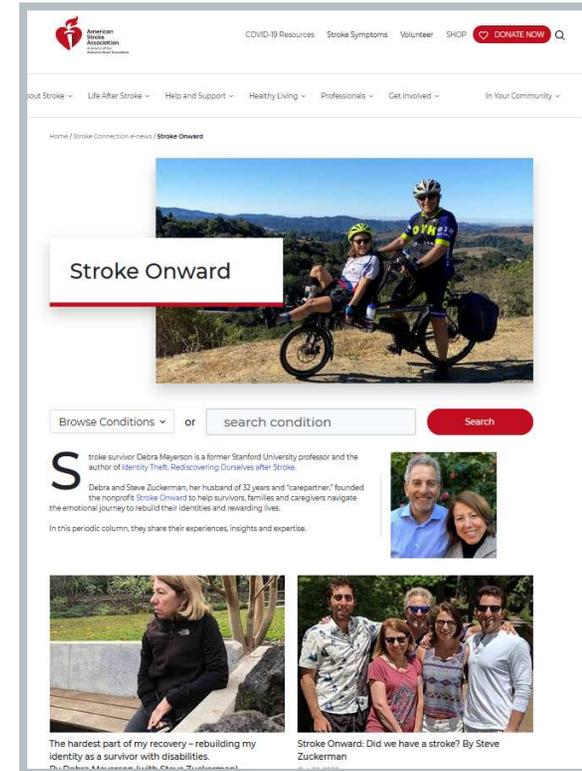
Raising Awareness

Writing

When *Identity Theft* was released, several impactful articles were written about the book and we continue to use interviews and articles written by us and others as a key strategy. The last in-person event before the Covid-19 lockdown was a presentation to American Stroke Association's (ASA) Advisory Committee. The ASA is by far and away the largest organization in our field, driving a great deal of research, education, stroke programming, and advocacy. That presentation led to a formal collaboration with ASA including our bi-monthly Stroke Onward column for their Stroke Connection newsletter and website, with other collaborative projects in development.

We did significant early writing to the blog on our website and continue to use this as a major strategy for raising awareness, primarily through articles or posts with organizations including:

- American Brain Foundation
- Anxiety and Depression Association of America
- Constant Therapy
- Psychology Today
- Thrive Global



128,165

views of our articles in the
Stroke Connection newsletter

Creating + Sharing Resources

Stroke Onward is working hard to fill the immediate need to create resources to support the emotional journey in recovery. This assistance is critical for survivors, carepartners, families, and most importantly, the healthcare professionals who can point hundreds of client families to them.

Identity Theft

We hear frequently how the book at the foundation of Stroke Onward has impacted people's lives. We have continued to use our work to spread the word, more than tripling the number of books in use since shortly after the original launch, with a focus on getting the book to “key influencers” as word of mouth has been our most powerful accelerator for distribution.

Book Group Discussion Guides

We learned that many survivors find it extremely valuable to discuss the book in a group format with peers. A facilitator guide and aphasia friendly materials were developed in partnership with faculty and students at Cal State East Bay and Boston University. The materials were tested and refined at seven sites (six in the US and one in Canada) before the public launch in July. We have also released book group prompts for the general public and healthcare professionals. As of August 31st, 50 healthcare professionals have accessed these resources and additional materials customized for carepartners are in development.

100%

of pilot book group member survey respondents indicated that their experience was **extremely valuable or valuable.**

“

There has been a great response to the book. Many of the members stated they've never discussed their stroke in this way before, even after years of recovery.

- Julie Rowlett, MS CCC-SLP
Neuro Rehab Network

”

Curated Resource Guide

Being careful not to duplicate work done by others, we want to curate the best material we can find that is specifically relevant to the emotional journey in recovery. Our goal is to provide a “go to” place for support materials related to our mission. These materials are drawn from hundreds of sites we've reviewed, and often from those not specifically focused on stroke. These resources will be launched later this fall and we will continually improve them through further research and additional input from the survivor and stroke care community.

Leadership Letter

Stroke Onward is Born

Impact Model

Raising Awareness

Creating + Sharing

Resources

Changing the System

Organizational Update

Changing the System

This is Stroke Onward's long-term strategy. We are already hearing key influencers and healthcare professionals citing our work and voicing our message about the importance of emotional recovery.

“

I think that in the medical field we often gloss over the emotional effects of conditions in favor of discussing the physiological (or physical in particular) effects that they have on the real people who experience them... Some days you will need to address their emotional needs before you can think about rehabilitating physical or cognitive abilities.

-Student Clinician

”

Our first initiative to influence the stroke system of care is exploring interventions in healthcare professional education. Initial pilots at Boston University and MGH Institute for Health Professions confirmed multidisciplinary faculty interest in utilizing *Identity Theft* as a training vehicle for students in degree granting programs. Now there are more than **12** other schools with student classroom/clinical activity, impacting more than **300** students.

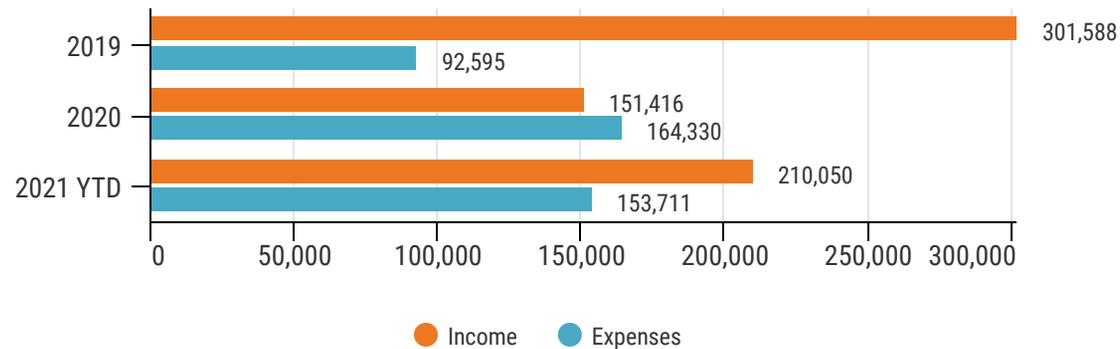
We are now working actively with faculty at several locations to explore ways to build the book, material from the book, and related Stroke Onward material into their course curriculum. Our faculty partners are incredibly creative, and we expect this effort will create innovative ways to shape the caregiving approach of the next generation of stroke system clinicians.

Leadership Letter
Stroke Onward is Born
Impact Model
Raising Awareness
Creating + Sharing
Resources
Changing the System
Organizational Update

Organizational + Financial Update

Stroke Onward was formed in April 2019 as Stroke Forward, a fiscal project of Social Good Fund. In 2020, after the publication of a book titled Stroke Forward, we chose to differentiate and rebrand our work as Stroke Onward. As we grew, we saw the increased benefit in being fully independent; we incorporated Stroke Onward, Inc. in February 2021, received our 501(c)(3) charitable tax determination mid-summer, and officially began independent operations on September 20, 2021. Special thanks to Cooley LLP for their pro bono legal services to support this key step. We also want to thank Patrick Brannelly, Karen Jordan, and Tony Stayner who join Debra and Steve as the founding board members for Stroke Onward, Inc.

Our activities in 2021, and much of the impact described above, was driven by our first formal planning process. We will be deepening this work with the pro bono help from the Stanford Business School Alumni Consulting Teams (ACT) program. That project will run from October through March 2022. We continue to operate as a “fully virtual” organization, with a team of paid staff and volunteers across the country, with no plans to change.



Financially, we remain strong as we head into the year-end fundraising season. We especially want to thank our Founder’s Circle, composed of roughly 50 donors who made two year commitments to help launch the organization. We have done the planning this year to develop a fundraising strategy to include a broad based year-end campaign, event-based fundraising to begin in 2022, and foundation support. Strategies for recurring revenue are in our longer term roadmap.

We have consistently underspent our budget, largely due to the lack of travel and conference expenses during Covid. We chose not to accelerate other forms of programmatic spending, including staffing, choosing to preserve deeper reserves as we transition to independent operation, and get the benefit of the strategic planning work mentioned above to guide our growth.

- Leadership Letter
- Stroke Onward is Born
- Impact Model
- Raising Awareness
- Creating + Sharing Resources
- Changing the System
- Organizational Update

Thank You

Once again, thank you to all of the friends, colleagues, supporters, collaborators and allies who have been instrumental to our launch, and the first two years of making impact on a problem that so desperately needs it. We look forward to the hard work it will take to make our vision a reality, a stroke system of care that truly embraces whole-person healthcare, providing ample support for the emotional journey of survivors and their families in the recovery process.

The Stroke Onward Team



@strokeonward



info@strokeonward.org



www.strokeonward.org