

2022 ANNUAL REPORT



strokeonward

Rebuilding Identity +
Rewarding Lives

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LEADERSHIP LETTER

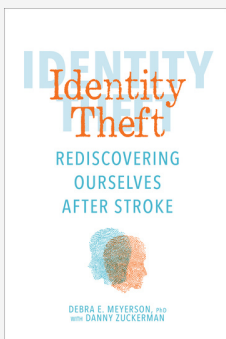
Dear Friends, Supporters, and Allies,

It has been just a few years since we launched Stroke Onward with the mission of ensuring that stroke survivors and their supporters have the resources needed to rebuild identities and rewarding lives. We're humbled by the incredible reception we've received from survivors, families, and healthcare professionals alike. And, of course, by the incredible support we have received from our donors, collaborators and countless volunteers, all of whom have been critical to our ability to do this work.



Needless to say, we are on a journey we never imagined... nor wanted. Like tens of millions of others in the United States, a stroke changed our lives and changed our futures. We don't pretend it was a "blessing in disguise" and, while we still have so much to be thankful for in our lives, we have trouble talking about "silver linings." In a word, stroke sucks.

But we are grateful beyond measure that Debra survived her stroke, and that we have been able to build something meaningful and constructive out of our experience. We sincerely believe that Stroke Onward will help to change our healthcare system so that all stroke survivors receive whole person care and get the help they need to rebuild truly rewarding lives.



2022 has been an extraordinary year for Stroke Onward. We gave more talks, wrote more articles, facilitated more groups, and tapped more avenues for distributing our work than ever before. Our book discussion guides have been used broadly to make Identity Theft more accessible and meaningful to thousands of stroke survivors and others nationwide. We have collaborated with incredible people who are teaching the next generation of professional caregivers, helping them build into their curricula the importance of the emotional journey in recovery. We partnered with wonderful academics to launch research projects that will help us discover new avenues to do more, and create a critical foundation for system change.

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And we led a 4,500 mile bicycle ride, from Oregon to Boston, to raise awareness – including 16 community events that could not have been more inspirational to nearly 2,000 participants – including us! We returned from Stroke Across America more convinced than ever that the gap in the system we identified is very real, that it is devastating to millions, and that there is a desperate need for significant change. So we made a commitment to build Stroke Onward to do more -- and do it faster.



Just before our cycling trip, our Board and staff had the privilege to work for six months with a pro-bono project team from Stanford Business School's Alumni Consulting Teams. Together we refined our strategic framework which has given us important clarity in the prioritization of our work. Inspired by interactions throughout our trip we raised our aspirations to more aggressively grow our impact and our organization. At the end of 2022, we did a soft launch for a \$1.5 million capital campaign to provide the funding security we need to invest in the staffing needed to do so. We're pleased to have reached 70% of our campaign goal by year end, and continue to make progress toward that goal in 2023.

Our progress in 2022 reaffirms the importance of our mission, and is a testament to the hard work and dedication of our team, our allies, and all of our supporters. We sincerely thank all of you for your interest, collaboration and support, and hope you enjoy reading – and seeing – some of our progress in the pages that follow.

With great appreciation, we go Onward...
Debra and Steve

WHO WE ARE + WHAT WE DO

WE WANT TO CHANGE THE SYSTEM

The US healthcare system is a complex and entrenched and is not meeting the needs of people impacted by stroke. We seek to change how the system cares for stroke survivors and their supporters to ensure that the focus is on whole person recovery. Today, the focus is primarily on acute care intervention and rehabilitation support. And these are, to be sure, critical.

But there is a need for more focus and resources to ensure survivors get the support needed to maintain and rebuild their emotional and mental health in recovery. For most survivors, stroke becomes a chronic condition they live with for years – or the rest of their lives. We believe they deserve the help they need to rebuild their identities and rewarding lives.



REFINING OUR STRATEGIC FRAMEWORK

From the beginning, we've had a pretty good sense of who we are as an organization – starting with our mission, our vision, our values, and our strategy. But like any good “lean startup”, we've been refining as we progress.

During late 2021 and early 2022, we had the privilege of working with a fantastic team of four Stanford Business School alumni who teamed up for a pro bono project with us through the Stanford Alumni Consulting Teams (ACT) program. Our goal for this six month project was to refine our strategic framework – based not only on our experience to date, but also the input of high quality research and an outside perspective.

Their work was fantastic – it reinforced with more rigor much of what we believed we knew, and it raised some interesting new perspectives that strengthened our thinking. We now have a refined articulation of our vision, mission, values, and strategy, and added some guideposts for critical success factors. Together, this represents a Strategic Framework that is proving tremendously helpful in keeping us focused on the right priorities.

STROKE ONWARD

STRATEGIC FRAMEWORK

Mission. To ensure stroke survivors and their supporters have the resources needed to rebuild identities and rewarding lives.

Vision. A stroke system of care that fully supports every survivor's emotional journey in recovery.

Values. We are guided in all that we do by our mission, vision, and shared commitment to:

- 1. Relevance and Respect:** We ground our work in the lived experience of survivors, their families, and other supporters.
- 2. Rigor and Innovation:** We use research and analysis to guide and evaluate our work, have a bias towards action, seek new approaches to create impact, and change course when experience and data suggest we should.
- 3. Collaboration and Accountability:** We leverage the experience and expertise of our team, actively seek to partner with others who share our goals, and always remain accountable for the quality of our work.
- 4. Diversity and Inclusion:** We cannot serve the diverse population we support without diverse input, and we strive to improve care for those who have more limited access to resources.
- 5. Survivor Support and Systems Change:** We work to help survivors and their supporters now while driving progress towards an improved stroke system of care.

Strategy. To fulfill our mission, achieve our vision, and honor our commitments, we will prioritize efforts to **catalyze system change** through initiatives that create impact in one or more of the following areas:

Increase Awareness	Create + Share resources	Build Communities	Drive Institutional Change
Continue knowledge building efforts that promote broad awareness that stroke recovery is more than physical rehabilitation – it also involves rebuilding identities and the broader emotional journey to rebuild rewarding lives.	Create, cultivate, and curate resources to aid survivor and supporter emotional wellness in recovery. Use these efforts to deepen our understanding of the needs and best opportunities to impact the system of care in both the short and longer term.	Build and engage with targeted communities in order to improve care for people affected by stroke and to build the networks that will be necessary to effectively catalyze change in the stroke system of care.	When appropriate, build on our other work to drive specific initiatives that will meaningfully improve institutions within and outside the formal healthcare system, so they can better support the emotional wellness of people impacted by stroke.

Critical Success Factors. To fulfill our mission, achieve our vision, and implement our strategy, we must:

Focus time and resources for greatest impact	Mobilize others and create partnerships to drive change	Ensure long-term financial sustainability of Stroke Onward
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EXPANDING OUR IMPACT

Our 2022 strategy continued to focus on the following three pillars of work: Increasing Awareness, Creating + Sharing Resources, and Driving Institutional Change. Each of these pillars is key to achieving an improved stroke care system and, not surprisingly, many of our initiatives impact two or three of these pillars. During the strategic planning work with the Stanford team, the fourth pillar of Building Community was added to our strategy but significant effort here was consciously deferred until 2023 and beyond.

Increasing Awareness

Increasing awareness has been a core Stroke Onward priority since the beginning, as few people understand the depth of the emotional impact that stroke can have on survivors and their supporters. Speaking engagements, written columns, blogs, and development of online tools like our website and social media formed the foundation of this work.

STROKE ACROSS AMERICA

In 2022, we took our message across the country. Stroke Across America was an ocean-to-ocean, 4,548 mile cycling trip designed to connect, inspire, and educate. Debra and Steve led the trip and were accompanied by two other people living with brain injuries: Michael Obel-Omia, a stroke survivor with aphasia, and Whitney Hardy, a survivor of a traumatic brain injury.

Central to the trip were 16 community events we developed in partnership with local organizations and volunteers. These events were a true connection point with communities across the country, and highlighted both our awareness messages and incredible stories of recovery and hope from local survivors and stroke support organizations.



58,000

Website
Pageviews



36

Articles +
Interviews

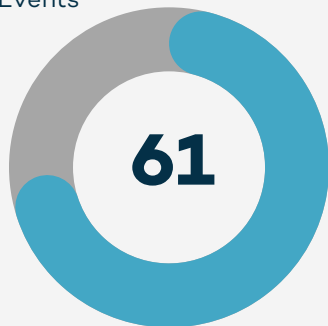
Clearly unable to visit every community across the nation, we designed campaigns to engage with people across the country, and the globe, through social media, email updates, and virtual event participation. Online engagement helped to amplify the awareness reach of this project.

Thanks to our [sponsors](#) and network of over [100 allies](#) from across the country, we were able to dramatically increase the number of individuals that have greater awareness and understanding of stroke recovery. To learn more about the project and see footage from the incredible journey, visit our [Stroke Across America page](#) on our website.

While Stroke Across America was our biggest awareness effort for the year, we also continued engaging with a variety of audiences and communities through presentations, support group facilitations, and community events. Connecting with survivors, professionals, academics, and others continues to be a critical avenue toward deepening our impact.

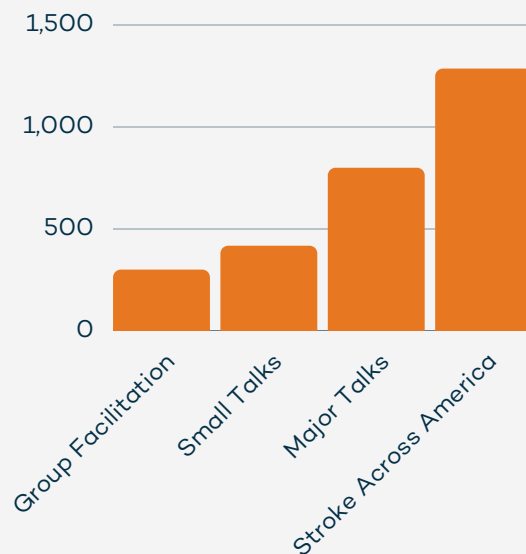
Total Speaking Events

Stroke Across America Events



Other Academic + Community Events

Event Participation



212,000

Social Media Impressions (unique views)

on our channels alone with many multiples of that through ally sharing.



Scenes from Stroke Across America

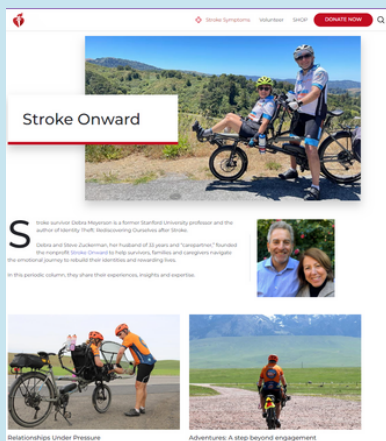
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Creating + Sharing Resources

There is a distinct lack of resources to support the emotional wellness journey after a stroke. And the resources that do exist are difficult to access. Our work in 2022 continued to address these problems.

WRITTEN MATERIALS

In 2022, we completed the Identity Theft Book Group Discussion Guides with the release of carepartner specific materials. Debra and Steve also continued their column for the American Stroke Association's Stroke Connection. Four columns were penned and covered topics like life engagement, adventure, and living with conflicting emotions.



4

Columns for American Stroke Association

Hosted on American Stroke Association's website, featured in their newsletter, and on our blog.

87,500 Column Views

Guides

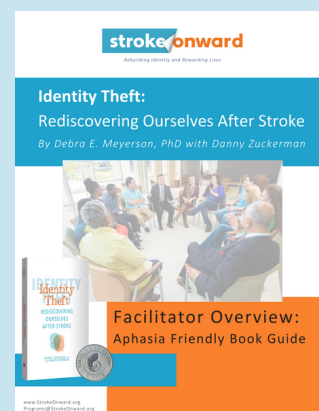
Stroke Survivors, Carepartners, Healthcare Professionals, and General Readers.

Material Downloads

Each download impacts many individuals as materials were designed for use in support groups, typically containing 5-10 people per session.

4

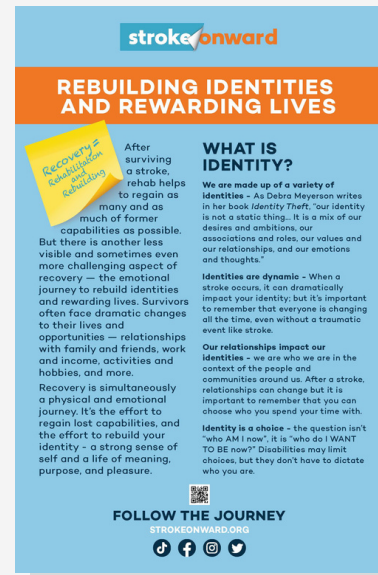
300



VISUAL MATERIALS

During 2022, we developed new educational materials shared at in-person events.

These materials provide an effective introduction of core messages about the emotional journey, the importance of rebuilding identity, and stroke and aphasia awareness more broadly. Initially used at Stroke Across America community events, these materials now deepen our impact at in-person and remote events alike.



Video is a powerful medium to inspire, share stories, and impart resources. In 2022, we launched a professionally edited version of Debra and Steve's foundational presentation "Rebuilding Identity in Recovery."

This video expands the reach of their highly impactful story and is now being used by a growing number of classes, support groups and other facilitated meetings across the country. If interested, the video is available on [YouTube](#) or [Vimeo](#) (ad-free).



This is an invaluable resource for students, clinicians, and researchers working with individuals with acquired neurogenic disorders. The client and family perspective that it provides is so useful for enriching our knowledge and approach to rehabilitation practice.

- Chaleece Sandberg, Ph.D., CCC-SLP, Penn State, discussing *Identity Theft: Rediscovering Ourselves After Stroke*, our foundational resource.

Driving Institutional Change

We want every survivor, and their families and supporters, to enter a system of care in which emotional health gets the attention it needs. Systemic change is hard and it will take years, if not decades. But we are already doing work that is chipping away at institutional norms.

Curriculum Development



One way to change the healthcare system is to influence the knowledge and perspective of the next generation of healthcare professionals. To that end, we successfully worked to get Identity Theft and related themes incorporated into courses at speech therapy and other graduate and undergraduate programs at more than a dozen schools across the country. We can't thank our faculty partners enough for their collaboration in this work. Debra and Steve are frequently asked to share their story and engage in conversation with students, and do so when they can. In 2022, they delivered 10 "live" presentations, both in person and virtual. As these requests continue to grow, the recorded version of their presentation has become an increasingly accepted alternative in support of this important work. If you're a faculty member using our work in your course and we don't know it, please do let us know!

Contributing to Research

Significant aspects of the healthcare system won't change without an evidence base indicating that it should. We are thrilled to be collaborating with an experienced group of Communications/Speech-Language faculty across six universities who have pioneered the use of Identity Theft in



the classroom. They have designed a survey-based research initiative to examine the effect of in-depth exposure to the lived experience of aphasia on student learning. Preliminary results are very promising and initial findings will be presented at an international conference in 2023.

Another research project advanced in 2022 is led by the faculty team that spearheaded the development of Stroke Onward's aphasia friendly [book discussion guides](#). They completed a qualitative impact study "Using bibliotherapy to rebuild identity for people with aphasia: A book group experience" and presented their work at the November 2022 American Speech-Language-Hearing Association (ASHA) Conference, the premiere convening for speech and hearing professionals. The related academic paper was just accepted for publication in the Journal of Communication Disorders, a peer reviewed journal.

Engaging with Mental Health Providers

The systemic lack of mental health support available to survivors and their families, especially those living with aphasia, is a huge barrier to an optimal recovery after stroke. In 2022, we took concrete steps to begin our work to address this problem.



With colleagues from the Adler Aphasia Center and the University of North Carolina-Chapel Hill's School of Medicine, we developed and delivered a six-hour training for 16 mental health professionals. This was a pilot project (repeated again in early 2023) designed to explore effective ways to increase available and trained professionals in the stroke recovery system able to support people with aphasia with their mental health. Feedback from participants was extremely positive, and we are working with our collaborators to build on that success.

We are thoroughly convinced that there is an opportunity to improve stroke care by better engaging trained mental health professionals in the stroke system of care. But we don't know what we don't know! Late in 2022 we began a Mental Health "learning tour". Leveraging relationships built through our work, we are talking with thought leaders across the spectrum of mental health disciplines to better understand the current landscape, including barriers and opportunities, to improve their engagement in the stroke system of care. This work has been extremely enlightening and will help shape the development of more concrete programs in this area for 2023 and beyond.

The rebuilding of one's identity is a key factor to supporting a healthy quality of life. Despite my training as a psychotherapist, I don't think that I valued the role of identity as much in the aphasia context until this meeting.



- Neuropsychologist and participant in our
Mental Health Professional Training

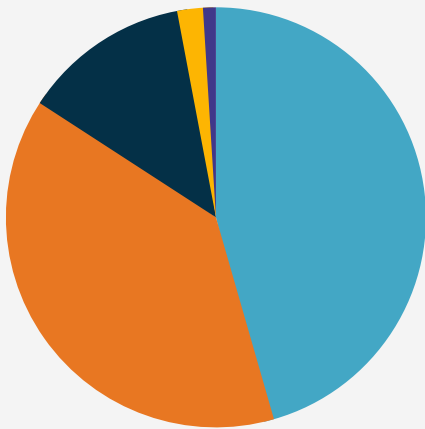
2022 FINANCIALS

2022 was a strong financial year for Stroke Onward. Individual donors who have been with us since the beginning continued to provide strong support. Many new donors invested in our work. Successful fundraising for Stroke Across America enabled us to invest a bit more in our communications efforts to more fully capitalize on this unique awareness-raising opportunity.

Late in 2022, we did a pre-launch for a 2023-2025 capital campaign that will give us the ability to grow our team - and our impact - in 2023 and beyond. We had commitments for about 70% of our goal by year end. Given this early success, early in 2023 we formally launched the campaign, as well as a search (ongoing) for a Chief Executive Officer with the skills and experience to lead us in our next phase.

If you are interested in supporting our capital campaign to support our growth, please [click here to learn more](#).

Income



Capital Campaign	\$282,500
Individual Donations	\$239,559
Corporate Donations	\$80,439
In-Kind Contributions	\$10,757
Grants + Program Service Fees	\$6,778
TOTAL	\$620,033

Expenses



Program Service Expenses	\$412,568
Management and General Expenses	\$34,350
Fundraising Expenses	\$12,795
TOTAL	\$459,713

THANK YOU TO OUR DONORS

2022 DONORS

Sincere thanks to all our donors, without whom we could not do the work we do.

SPECIAL THANKS

Two funding efforts have been particularly important to our success thus far, and we can't thank you enough.

Founder's Circle donors made two year commitments of at least \$500/year beginning in either 2019 or 2020. These donors provided critical support to the launch of Stroke Onward. (indicated with ^)

Capital Campaign donors have made three year commitments of at least \$1,000/year beginning in either 2022 or 2023. This campaign is providing critical support to add staff and accelerate our impact toward system change. (Indicated with *) As of June 2023, we've secured 80% of our \$1.5 million capital campaign goal. If you are interested in learning more, [please click here](#).

\$100,000+

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\$50,000 - \$99,999

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Jack Little and Nancy Wittenberg^^
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For this report, donations are recognized in the year intended by the donor which may be different from the year in which the donation was received and recognized for accounting purposes.

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Charles Zuckerman

Debra and Steve with Gabby Giffords, Senator Mark Kelly, and Team Friends of Aphasia at El Tour de Tucson, November 2022.



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(cumulative giving)

As this 2022 Annual Report is our first, we want to look back to our beginnings and thank all of those who helped get us started. We could not be here without the generous support of the following donors who, like us, believed there was important work to be done.

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Celebrating the successful completion of Stroke Across America on August 26, 2022 by dipping their front tires in the Atlantic Ocean near Boston, Massachusetts.

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