

2024 Annual Report

Message from Debra Meyerson and Steve Zuckerman, Co-Founders

Each year, more than 800,000 strokes occur in the U.S., leaving millions to navigate recovery. While physical survival is the immediate priority, and rehabilitating lost capabilities is essential, the emotional journey of rebuilding one's identity is often the most challenging. Yet there is virtually no support for that process, and that's where Stroke Onward steps in.

2024 was a year of deepening impact, affirmation, and transition. Seeds that we and our small team had been sowing since 2019 continued to sprout. Importantly, feedback has consistently reinforced that we have, in fact, identified a critical gap in the stroke system of care. Many people and



organizations are joining us to create better support for the emotional journey in recovery, as we actively support survivors and their families, and drive toward real systems change.

Response to our programs in 2024 was fantastic – and reinforced what we concluded after our 4,500 mile Stroke Across America journey in 2022 – we need to do more. And for that, we needed the right kind of experienced, entrepreneurial, full-time leadership. It took us all of 2023 to find Liz Wolfson, and we are thrilled that she joined Stroke Onward as our first CEO in early 2024. Liz is a great leader who has, with eager support from us and our board, set a bigger, bolder, more strategic path for growing our organization and our impact.

As we reflect on our life journeys – together since we met in 1985 – our identities have constantly evolved. We became a married couple, and then parents. We changed jobs and careers. And the most wonderful change in 2024 – we became grandparents! Since Deb's stroke in 2010 we have also navigated new aspects of our identities that we'd rather not have– stroke survivor and carepartner. That change led to our writing *Identity Theft*, published in 2019, and we're pleased to share that a second edition will be released in Fall 2025. It includes a new preface and two additional chapters that reflect our continuing journey to improve stroke recovery for millions of people and their families.

Thank you for your interest and support. Together, we will build a lasting legacy of hope, healing, and transformation.

Warmly,

Deb & Steve

Co-Founders and Co-Chairs

Message from Liz Wolfson, CEO



Message from Liz Wolfson, CEO

In her 1999 book *All About Love*, bell hooks wrote, "Rarely, if ever, are any of us healed in isolation. Healing is an act of communion."

Reflecting on my first year leading Stroke Onward, I have witnessed the strength of this community— those with lived experience and those working daily to support recovery. This community is united by a common drive: to ensure that stroke recovery is holistic, supporting not only physical recovery but the rebuilding of identity in support of living meaningful well-lived lives.



CEO Message

As well, the resilience, strength, and determination of this community to advocate for a just healthcare system is inspiring. At Stroke Onward, we are committed to recovery—not just individually, but collectively.

I am deeply grateful to our Co-Founders who remain at the center of all that we do, our Board of Directors, the professional staff, and a growing list of over 200 collaborators. This is my year one in leading the organization, and navigating this challenge with such dedicated individuals is a gift.

In 2024, our focus was on fostering an inclusive, engaged network of stakeholders—survivors, carepartners, healthcare professionals, researchers, and innovators. Stroke Onward has become a convener and a safe space for everyone involved in this shared mission.

We made significant strides, expanding the work of the organization in order to scale programs and our audience. This growth includes launching the Regional Collective Impact Gatherings, which featured the powerful debut performance of The Stroke Monologues in Denver, CO in November. Additionally, we launched the development of the *Stroke Onward Community Circle* (SOCC), an online platform designed to connect all stakeholders in our ecosystem and amplify partners. We have now shared the platform infrastructure with individuals, allied organizations and emerging tech and pharma companies, working with superusers and content providers, and there is great excitement for its public launch in 2025.

To our generous supporters—your unwavering commitment strengthens our bonds and brings greater joy to our work and those we serve.

As we continue to grow in numbers and influence, I am excited about the impact we can make together in 2025 and beyond.

Sincerely,

Liz Wolfson CEO, Stroke Onward



Expanding our Voice...

Raising awareness continues to be at the forefront of Stroke Onward's mission. Highlights from 2024 include:

2024 American Congress of Rehabilitation Medicine (ACRM) Plenary



Debra and Steve were honored with an invitation to deliver a keynote address at the 2024 American Congress of Rehabilitation Medicine (ACRM) conference, the world's largest interdisciplinary rehabilitation research event. Their plenary session, *Journey of Rebuilding Identity Following Stroke*, showcased Debra's use of an innovative AI voice cloning platform, ElevenLabs. As they shared in their remarks, "Disabilities may limit choices, but they don't have to dictate who we are." On the heels of the 2024 ACRM

conference, Stroke Onward and ElevenLabs began a partnership that will allow us to offer free licenses to all people with aphasia who sign up to participate on the Stroke Onward Community Circle (SOCC), an online platform described more fully below.

American Stroke Association Partnership

This year we celebrated our 4th year collaborating with the American Stroke Association to create and share an online column focused on rebuilding identity after stroke. In addition to sharing insights from Debra and Steve, in 2024 our columns highlighted Rory Polera, a young survivor who shared how wearable technologies and smartphone applications helped him rebuild his strength, confidence and identity. We also





welcomed a guest column from Lucia Valdez, LCSW and founder of <u>Colorado Brain Injury</u> <u>Therapy</u>, in which she explored the complexities and challenges of loneliness after stroke. We are committed to utilizing these columns to inform and learn with our community.

Gearing up...

Stroke Across America, Debra and Steve's 2022 cross-country bike ride, continues to be a source for content creation and impact. Stroke Onward was thrilled to begin work in 2024 with WCNY, Central New York's public communications organization, to develop a documentary film that would, "capture the will, spirit, and small wins" achieved during Stroke Across America. WCNY's vision is to, "inspire the curious of all ages through educational programs and transformative experiences that open minds and spark change." Stay tuned.



Learn



... and Amplifying Other Voices

At Stroke Onward, we believe in the power and importance of amplifying diverse voices so that every survivor knows they are not alone. Here are a few of the individuals and partner organizations that inspired us in 2024:

Beyond Stillness: Stories After Stroke





Stroke survivors often face the daunting task of rebuilding a sense of community while facing acute and lifelong impacts. After experiencing a stroke in rural Colorado at age 34, Flannery O'Neil initially relied on her therapeutic team for support. As she began to recover and sought peer support, she realized that the closest survivor support group was more than an hour's drive away— so she co-founded a new one. In 2020, Flannery joined the Stroke Onward team and expanded her community and contributions, sharing her many talents and lived experience to spark the organization's vision and growth. She has shared her personal story countless times to encourage others, as she did in this 2024 podcast and partnership with Beyond Stillness: Stories After Stroke.

Active Peace Yoga

Reggie Hubbard, an internationally recognized yoga and meditation teacher and the founder of <u>Active Peace Yoga</u>, became an invaluable thought partner to Stroke Onward in 2024. Reggie's practice served as a sanctuary while navigating the stresses of being a man of color in the world. Following his own stroke in April 2023, Reggie transformed his work and now shares his inspiring stroke recovery journey, offering powerful lessons on vulnerability, compassion, and nuanced thinking.



Listen

Maddi Stroke of Luck



In 2024, Stroke Onward was honored to partner with Maddi Niebanck, a rehabilitation advocate and founder of Maddi Stroke of Luck. Just ten days after graduating from Georgetown University, Maddi experienced a stroke that drastically altered her life's trajectory. Despite facing grim odds and emergency brain surgery, Maddi has not only recovered but has thrived, becoming an accomplished author, passionate disability advocate, and content creator. Her belief that "obstacles are opportunities" resonates deeply with Stroke Onward's mission. In 2025, Maddi will be performing at

The Stroke Monologues, sharing her inspiring story and furthering Stroke Onward's commitment to empowering stroke survivors. Her organization, Maddi Stroke of Luck, will also collaborate with Stroke Onward to bring support and rehabilitation resources to stroke survivors. This developing relationship is a testament to our mutual commitment to ensuring all survivors and care partners have the resources needed to rebuild identities and rewarding lives.

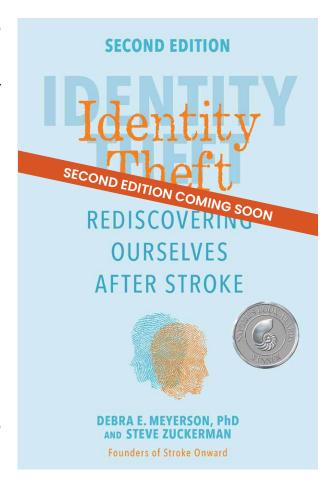


Identity Theft: Rediscovering Ourselves After Stroke

Identity Theft: Rediscovering Ourselves After Stroke conceived by Debra Meyerson and influenced by her expertise in identity scholarship, remains a foundational resource for the work of Stroke Onward. More than a memoir, it conveys the varied stories and experiences of people and families post stroke, all in the context of the critical need to rebuild identity on a path to find new purpose, meaning, and joy.

Stroke Onward has created audience-specific book group discussion guides that we have developed in collaboration with academic and community partners. Our goal is to make it as easy as possible for people to create dialogue that can help deepen and personalize the reading of the book. Through 2024, these guides have been downloaded more than 570 times by facilitators supporting survivor, carepartner, and healthcare professional groups, as well as other individuals, impacting thousands of readers.

Stroke Onward is delighted that Debra and her husband Steve, our co-founders, authored a second edition of the book in 2024, with an expected release in fall 2025. We plan to update the book guides to reflect this updated version post release.





Academic Collaborations: Influencing Next Generation Professionals

Aphasia Curriculum

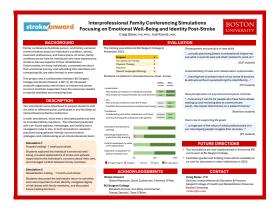
Incorporating *Identity Theft* and related activities into curriculum has been a cornerstone of our work to develop a pipeline of future stroke care professionals sensitized to our mission and the communities we serve. Six faculty members from across the country completed an IRB-approved research study that featured *Identity Theft*, "The Effect of In-Depth Exposure to the Lived Experience of Aphasia on Student Learning." Their manuscript has now been accepted for publication in the journal, Teaching and Learning in Communication Sciences & Disorders (TLCSD).

We congratulate and thank the following faculty innovators for inspiring us and their peers:

- Brianne Roos, EdD, CCC-SLP, Loyola University Maryland
- Chaleece Sandberg, PhD, CCC-SLP, Penn State College of Health and Human Development
- Elizabeth (Liz) Hoover, PhD, CCC-SLP, BC-ANCDS, Boston University
- Gretchen Szabo, MS, CCC-SLP, Montclair State University
- Tami Brancamp, PhD, CCC-SLP, University of Nevada-Reno School of Medicine
- Tom Sather, PhD, CCC-SLP, University of Wisconsin-Eau Claire

Interprofessional Simulations

We were honored to have Craig Slater, PhD, MPH, OT and the Director of Interprofessional Education and Practice at Boston University's Sargent College of Health and Rehabilitation Sciences, present co-created materials at the 2024 Nexus Summit: Navigating Complexity to Advance Outcomes. Together we've developed two interprofessional simulations to introduce students to family conference scenarios that highlight person- and family-centered communication about an individual's condition, values, treatment preferences, and future plans in a way that normalizes the need for survivors to rebuild identities and a rewarding life post-stroke. After a successful 2024 pilot, upcoming plans include incorporating additional disciplines and making these co-developed materials freely available to other faculty.





Aphasia and Mental Health Support

In support of mental health skill building in professionals who serve those impacted by stroke, Debra and Steve have been honored to serve on the Aphasia Community Advisory Board associated with the innovative Acceptance and Commitment (ACT) for Aphasia project led by William (Will) S. Evans, PhD, CCC-SLP, School of Health and Rehabilitation Sciences, University of Pittsburgh. This important project seeks to expand the availability of mental health support for people with aphasia by training Speech-Language Pathologists to deliver interventions for both evidence-based compensatory language and counseling treatment components in partnership with supervising psychologists.



Industry Collaborations: Influencing the Ecosystem

Emerging Technology

In 2024, Stroke Onward expanded its impact by partnering with Stroke Onward board member Mukul Pandya and Swarna Kuruganti, an accomplished business-oriented technologist, to author a series of articles focused on emerging technologies and innovative approaches in stroke rehabilitation and recovery. With the prevalence of stroke rising globally, these articles address the urgent need for effective and forward-looking solutions. They completed three collaborative articles in 2024, "Rewiring the Brain: New Frontiers in Aphasia Treatment", " 'I





Read

am What I Choose to Become': How Ingrid Clarfield Reinvented Her Musical Life After Stroke" and "Technology as Enabler: Constant Therapy". Additional articles are planned for 2025.

Engaging Stakeholders

Stroke Onward recognizes the critical importance of industry collaboration in achieving its mission. As such, we are proud to announce that Bayer AG, a leader in stroke prevention and a national sponsor of the American Stroke Association's "Together to End Stroke" initiative, has become a national sponsor of the Stroke Onward Community Circle (SOCC) and our Regional Collective Impact Gatherings. This 2024 partnership laid the foundation for impact through upcoming events in major cities where we will work together to spread awareness and empower stroke survivors and their care partners with the resources they need to rebuild their lives.

Sharpening Our Strategic Focus



Since launching Stroke Onward we have been very clear about our vision – helping to create a stroke system of care that supports every survivor and their families in the emotional journey in recovery. We believe our programs to date have been working successfully toward that vision. But we have built them somewhat opportunistically, and we have seen far more opportunities than we have the resources to pursue. So a key priority for 2024, under Liz Wolfson's leadership, was to sharpen our strategic focus around programs that would:

- Help survivors and their families to navigate the emotional journey in recovery;
- Enable us to build greater scale with a sustainable revenue model; and
- Create an effective foundation for systems change in the years ahead.

Community as Strategy

Over and over we have heard how isolating the stroke experience can be for too many survivors and their supporters. Researchers, clinicians and people with lived experience tell us about the devastating impacts of isolation on recovery. Through many of our programs, and those of our allies, we have seen the healing power of engaging in community.

We also know that long-term solutions require the collective expertise, resources, and influence of strong, diverse coalitions. And we believe that any successful movement for systems change must be centered on those directly impacted by that system.

Late in 2024, Stroke Onward leadership and board agreed to focus our efforts on "Community as Strategy" and the team developed and began implementing two clear programmatic priorities: Regional Collective Impact Gatherings and the Stroke Onward Community Circle (SOCC).

Regional Collective Impact Gatherings

This is our in-person strategy. Our goal is to build our community through a series of meetings –in several distinct formats – one city or region at a time. We talk of "collective impact" because complex social problems require solutions developed in collaboration by people with diverse viewpoints and expertise — including those with lived experience. Our goal is to hold events in four or more regions each year, enabling us to build coalitions throughout the US over time. Each regional gathering may include any or all of the following events, with other formats under development:

The Stroke Care Onward Gatherings

For healthcare professionals from all backgrounds, these interactive panel discussions foster dialogue among thought leaders in stroke care – academics, administrators, and practitioners from a multidisciplinary perspective – who are eager for the system to more effectively support post-traumatic growth after stroke.

The Stroke Monologues

A collection of powerful and poignant performances given by survivors, carepartners and people who support them. They highlight the difficult and complex emotional journey in recovery, including efforts to rebuild identities and rewarding lives.

Sharpening Our Strategic Focus



Author Talks

An opportunity to share and discuss writings that involve stroke and issues important to the recovery process. These talks will often involve *Identity Theft*, but will also feature relevant local authors.

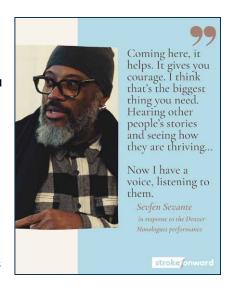
A Toast To Excellence

Gatherings that recognize and celebrate outstanding contributions by individuals, teams, or organizations toward improving the lives of stroke survivors, their families and other supporters, as well as the systems that support emotional wellbeing in recovery.

Denver Launch

In November, the Stroke Onward team travelled to Denver, CO and launched this program with two successful events. The inaugural Stroke Monologues showcased stroke survivors Thomas (TC) Dantzler, Jr. and Maggie Whittum, Denver neurologist Dr. Michelle Leppert, Lucia Valdez LCSW, a counselor with expertise in stroke and brain injury, and Stroke Onward co-founders Debra Meyerson and Steve Zuckerman. The diversity of the performers and their content was noted by many attendees. An audience of almost 100 was deeply moved by the raw honesty and vulnerability of the Monologues. As one stroke survivor in attendance said: "I feel like I just came out of the stroke closet!"

Stroke Onward also hosted its first Stroke Care Onward gathering in Denver. Sitting in a large circle, doctors, counselors, hospital administrators, stroke survivors and carepartners shared their experiences and perspectives on stroke recovery, including strategies for bringing more emotional support into the stroke care system. Our network grew and seeds were planted for future collaborations.



Stroke Onward Community Circle

Personal gatherings are powerful, but they are difficult to scale. In today's increasingly digital world, online communities are another critical avenue for connection and collaboration – one that can reach far more people and locations. During 2024 Stroke Onward began developing the Stroke Onward Community Circle (SOCC), with its launch expected in mid-late 2025.



SOCC will bring together survivors, carepartners, healthcare professionals, allied organizations, and others committed to building more emotional support into the stroke recovery process. It will be a place for survivors and families to find community and resources that can help them live well after stroke. It will be a platform for those who provide care and support for survivors to connect, learn, and collaborate. And it will be a strategy through which Stroke Onward can build a broad and diverse community that is critical to power future systems change initiatives.

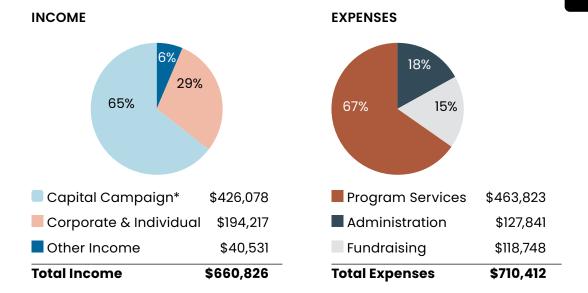
Financials and Support



Stroke Onward's financial position remains strong as of the close of 2024, bolstered by careful financial management and the continued generosity of donors. We utilized a small portion of the reserves built in our early years to continue our investment for growth. The information below provides an overview of our financial position for 2024:

Gold Transparency 2024 Candid.

Learn



^{*} Capital Campaign represents contributions from individual donors who made threeyear commitments of \$1,000 or more per year beginning in either 2022 or 2023 to support organizational growth.

View Form 990, Including Detailed Financial Statements

Thank You



Thank You for your Support

2024 DONORS

We are deeply grateful to all of our donors for partnering with us to support stroke survivors on their emotional journey through recovery and create meaningful change in stroke systems of care.

Donor notes:

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.

- * Indicates participation in our 2022-25 Capital Campaign and reflects a three year commitment of at least \$1,000/year beginning in either 2022 or 2023.
- Indicates Founders Circle.

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Accessibility Statement

Stroke Onward is committed to providing a website and resources that are accessible to the widest possible audience regardless of technology or ability. We are actively working to increase the accessibility and usability of our website and this report. This report works well with screen readers but if you have any issues accessing it please contact us at connect@strokeonward.org and we will do what we can to improve your experience.

Note: We incorporated the use of artificial intelligence tools to create this report, and Change Agent AI and <u>Perplexity.ai</u> were particularly helpful. We continue to explore and share ways to use assistive AI for good in our work.



Stroke Onward is a 501(c)(3) charitable organization, tax ID 86-2595994.