

#### Message from Debra Meyerson and Steve Zuckerman, Co-Founders

#### Dear Friends:

We are filled with gratitude as we reflect on the influence, impact, and growth our organization continues to have.

When we started Stroke Onward, our goal was to create awareness, provide resources, and catalyze an improved care system for stroke survivors and their loved ones. We focused specifically on the emotional journey to rebuild identity and rewarding lives in the face of the chronic condition that persists after stroke. What began as our personal mission born from Debra's stroke and our family's life-changing experience has blossomed into an inspiring community dedicated to a growing movement driving positive systemic change.

This past year was transformative for Stroke Onward as we expanded our reach and resources and focused on recruiting a CEO to lead us into a more deliberate growth phase. The highlights you'll read about in this report represent important milestones - from the publication of research validating the impact of our Identity Theft book group discussion guides to local and national speaking and writing focused on the emotional journey of rebuilding identity in stroke recovery.

None of this would be possible without the tremendous support of our friends and community of donors, partners, and advocates. Your generosity propels us forward in our mission.

There is still so much work to be done and we remain fully energized. In the year ahead, we will continue forging new collaborations, developing innovative resources, and striving to gather together in person and virtually, to further serve the needs of stroke survivors, carepartners, practitioners and providers. We hope this annual report illustrates our steadfast dedication and inspires you to remain with us on this important journey to create a more supportive path for all those touched by this life-altering event.

With gratitude,



Steve



#### Message from Liz Wolfson, CEO



#### Dear Friends, Supporters, and Partners:

Having joined the organization as CEO in February 2024, I am wholly motivated by the vision and achievements of our co-founders, board of directors, our professional team, funders and partners. I am filled with immense gratitude for the dedication and passion that each of you has shown Stroke Onward this past year.

Stroke Onward amplifies the deep need for a holistic, inclusive approach to stroke recovery, acknowledging the psychological and interpersonal challenges in rebuilding identity post stroke. As a leader, I am driven to ensure that all perspectives are valued and integrated into our work - from survivors and carepartners to healthcare practitioners and providers, researchers and students. And that those perspectives come from people with diverse backgrounds and experiences in life.

#### Looking Back and Moving Forward

The work accomplished in 2023 provides a strong foundation for what comes next. We have solid proof of concept grounded in a growing body of evidence, and supported by a diverse professional community that aligns with our mission. As we move forward, we are focused on exerting our influence and impact by focusing on growing our community and boosting our voice. As well, we will work to diversify our revenue streams to ensure a sustainable – and growing – organization. All that we accomplish will continue to rely on powerful partnerships with key influencers and institutions.

I look forward to sharing a number of new initiatives with you in the coming months. It is a very exciting time for Stroke Onward.

#### A Call to Action

Now, more than ever, is the time to act. With 9.4 million people living in the US with the impact of stroke, about 600,000 more joining those ranks each year, and more than 10x that number globally, we must recognize that stroke creates a chronic condition, and we must push for systems change to provide the necessary support. Your ongoing support is crucial in helping us realize our mission.

Together, we can create a much brighter future for all those affected by stroke. Thank you for your unwavering devotion to Stroke Onward and for being part of this transformative journey.

With heartfelt gratitude,



#### Accessibility Statement

Stroke Onward is committed to providing a website and resources that is 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 report. The tool we used for this report, Visme, works with screen readers. If you have any issues accessing this Annual Report, contact us as 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 Perplexity.Al was particularly helpful. We are exploring and sharing ways to use assistive Al for good in our work in the coming weeks and months.



### 2023 Impact Highlights



**62K** 

Readers

Through our American Stroke Association Columns



195K+

**Impressions** of our social media



2,300+

People attended 56 Speaking events



1,740+

New Readers & Downloads Of *Identity Thef*t and our Book

Guides



2,000+

People read and/or downloaded "A Guide for the Emotional Journey Guide in Recovery"



### 2023 Impact Highlights



#### **Dedicated to Awareness**

Co-Founder Debra was honored with the American Stroke Association's (ASA) 2023 Stroke Survivor Hero Award. The ASA's annual award honors stroke survivors, health care professionals, and care partnerss who want to build more resilient communities. Debra was honored in recognition of her efforts to use her lived experience as an inspiration to others and to bring awareness about rebuilding identity and emotional recovery to people across the country. This award was not just a celebration of her individual experience and recovery, but a testament to the power of resilience and the unwavering spirit of those who turn adversity into action.

Stroke Onward is entering into its fourth year of collaboration with the American Stroke Association where they provide a platform for conversation and exploration of rebuilding identity after stroke. Our columns have reached more than 315,000 people. While most columns have been written by one or both of our co-founders, we had two columns in 2023 authored by other members of our team. Flannery O'Neil, our COO and Director of Partnerships, also a stroke survivor, wrote about the value of peer support in recovery. The final column of 2023 was penned by author and stroke survivor Mukul Pandya who detailed how utilizing artificial intelligence (AI) tools helped him to resume writing and working after his stroke. Read more about Mukul further in this report.





#### Click to Listen!



Media coverage plays a vital role in expanding our reach and impact. A highlight of 2023 was an interview featuring Debra and Flannery on CapRadio, the NPR affiliate in Sacramento. This powerful dialogue enabled us to connect with listeners, humanize our cause, and motivate communities to get involved.

Discover more podcasts centering around stroke and recovery!

# Seeding Systems of Change

#### Identity Theft Book Club Experience



Thank you, Elizabeth Hoover, PhD, CCC-SLP, BC-ANCDS (Boston University), and Ellen Bernstein-Ellis, M.A., CCC-SLP (California State University, East Bay) for their invaluable work on this research.

Analysis of semi-structured interviews from pilot book club sessions revealed themes and areas of positive impact; Mechanism for Reflection, Engaged Learning, Power of Community, and Therapeutic Environment.



The findings were presented at multiple professional gatherings before being published in the **Journal of Communication Disorders** in the article "<u>Using bibliotherapy to rebuild identity for people with aphasia: A book club experience</u>", authored by Hoover, Bernstein-Ellis and our Co-Founder, Debra Meyerson, PhD.

Image Sources: Boston University and Cal-State East Bay

#### Virtual Connections Book Club reads Identity Theft



The <u>book group discussion guides</u> were released in 2021 and have been downloaded more than 500 times by people from across the world. In 2023, the Virtual Connections Book Club read *Identity Theft*, and used the book guide materials over 12 weeks.

Thank you to the Virtual Connections team and Ellen Bernstein-Ellis, M.A., CCC-SLP for thoughtfully facilitating this group of people living with aphasia as they read the book and processed the impact that stroke and aphasia has had on their lives. This was our first opportunity since developing the materials to see in person the life-changing impact that the guides can have and it was incredibly moving.





#### Pioneering Research on the Impact of Identity Theft on SLP Student Learning

What began as an informal gathering to share experiences incorporating *Identity Theft* into graduate aphasia coursework evolved into a formal, IRB-approved research study. Utilizing a common survey instrument across six universities, the study titled "The Effect of In-Depth Exposure to the Lived Experience of Aphasia on Student Learning" yielded promising initial results. These findings were presented internationally at the 2023 Nordic conference and in greater depth at the 2023 American Speech-Language-Hearing Association (ASHA) convention in Boston.

We are grateful to those who spearheaded this work:

- 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

## "The "realness" of the simulation is so appreciated. I learned how to best communicate with my colleagues and conduct an empathetic session. We worked together to provide patient-centered care despite the barriers- such as that the patient had aphasia and a tension-filled family dynamic." BU Simulation Student

#### Innovative Simulations

Through a collaboration with Craig Slater, PhD, MPH, OT - Director of Interprofessional Education and Practice at Boston University, we co-developed new materials to support better conversations about the emotional journey and rebuilding identities after a life-altering event like stroke. The resulting tools are family conference simulation materials focused on two settings: acute care and a rehabilitation hospital. These innovative simulations engage students in interprofessional teamwork, facilitating collaborative interactions with individuals post-stroke, their care partnerss, and the healthcare team.

Our goal is to share these co-developed, simulation materials with the broader community, enhancing interprofessional education and patient-centered care.

#### Education and Research Highlighting Lived Experience

For the past several years we have had the privilege of collaborating with the Pioneer Valley Interprofessional Practice and Education Collaborative on an annual initiative that brings together students from occupational therapy, physician assistant studies, speech language pathology (SLP), nursing, social work, and other allied health disciplines at the University of Massachusetts Amherst and other local universities.

The events feature an introduction to stroke and aphasia by speech-language pathology students, followed by interprofessional student groups engaging in discussions. A keynote presentation by our founders allows students to gain invaluable first-hand perspectives from their lived experiences.

We are grateful for the leadership of this community-driven project by Jacquie Kurland, PhD, CCC-SLP, Lisa Sommers, MA, CCC-SLP, Peta-Gaye Johnson, MSW of the Hampden County Workforce Board, and Julie Berrete-Abebe, PhD, LICSW, faculty at Fairfield University.





#### Emotional Journey in Stroke Recovery Guide

In May, we introduced our newest resource,
"Emotional Journey in Stroke Recovery" (EMOJO).
This tool is designed as an introduction for stroke
survivors and their loved ones/care partners as
they begin to navigate the emotional aspects of
healing and recovery. Since its launch, it's been
read and downloaded by more than 2,000 people.

At Stroke Onward, we have long recognized the need for accessible materials that introduce and affirm the concept of identity disruption and rebuilding after stroke as a crucial component of whole-person healing.

View the Guide



#### Stroke Onward's Board of Directors Welcomes Mukul Pandya

Mukul experienced a stroke in 2021 and connected with Stroke Onward after being gifted with *Identity Theft* to read. Mukul is an Associate Fellow at Oxford University's Saïd Business School and a consulting editor of Oxford Business Review. He is the founder of Knowledge@Wharton (K@W), the web-based journal of research and business analysis published by the Wharton School of the University of Pennsylvania. He served as its first executive director and editor-in-chief until retiring in 2020 after 22 years.

Mukul has won four awards for investigative journalism and has more than 40 years of experience as a writer and editor.

#### Gathering-Melting Silos in Mental Health Care

Throughout the year we engaged with mental health professionals and survivors around the country to build a foundational understanding of mental health care in stroke recovery. These conversations culminated in hosting an event called "MELT", short for Mental Health and Emotional Wellness Learning Team.

This event brought together attendees from a wide range of disciplines, including rehabilitation psychologists, neuropsychologists, social workers, general psychologists, neurologists, stroke support coordinators, speech-language pathologists, and others. The intent was to begin "melting" disciplinary silos, build a professional community, explore shared interests, and identify potential collaboration opportunities.



## Financials

Gold Transparency 2024

Candid.

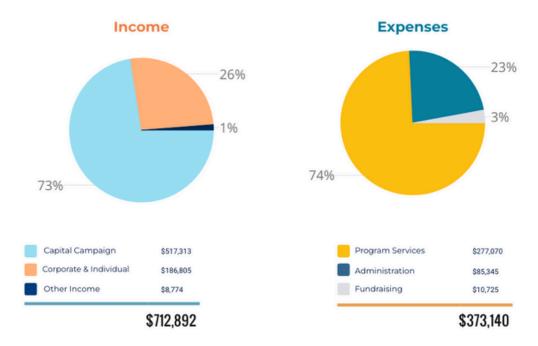
"Visit our Condid profile to witness our commitment to transparency and inclusivity.



Stroke Onward's financial standing is looking solid for one more year, thanks to the generous support from our donors. In particular, donors to our Capital Campaign made three-year commitments of support. With our new CEO in place, there is a stable foundation for the organization to launch expansion efforts.

In FY 2023, income was (20%) higher than expected thanks to securing a few new donors to the Capital Campaign and the year-end campaign, as well as a deposit issue from the end of FY 2022 which resulted in a large donation being posted in FY23. Expenses were about 30% lower than planned due to the timing of the CEO hire and related expenditures originally forecasted for late Q3 but did not occur until Q1 of 2024.

The information below provides an overview of our financial position for 2023. The Stroke Onward board of directors remain committed to prudent financial stewardship and transparency as we continue driving positive change for the stroke community.





#### THANK YOU

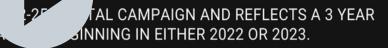
#### 2023 DONORS

WE EXTEND OUR DEEPEST GRATITUDE TO EVERY ONE OF OUR DONORS.

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 COMMITMENT OF AT LEAST \$1,000 A





HOSTED A VIRTUAL FUNDRAISER TO SUPPORT STROKE ONWARD.



INDICATES SUPPORT FOR OUR CEO RECRUITMENT EFFORTS.



INDICATES FOUNDERS CIRCLE.