



THE POWER OF CONNECTION AND COMMUNITY
Annual Report 2021



AMY ACTON, RN, BSN
Burn Survivor
CEO,
Phoenix Society for Burn Survivors

Dear Friends,

We've all had to learn to navigate new and unpredictable challenges in the past two years - similarly to the beginning of a burn survivor's journey. Over the past year, we spent substantial time getting a deeper understanding of the survivor journey and determining critical milestones along the way.

One of the most critical milestones during a burn survivor's journey is the transition from the hospital to home. Many survivors felt a sense of loneliness and confusion during this time as they weren't sure what came next or where to turn for help. To ease the transition from the hospital and to introduce our community to survivors sooner, we are launching the Journey Forward pilot project, the centerpiece of which is a kit that provides tangible connections to resources and community, burn aftercare products, and more. We are excited to work with six hospital partners on the pilot program before launching on a larger, nationwide scale over the next few years.

Our learnings also solidified our view and commitment to continue building platforms to expand programs virtually for greater reach and impact. We are dedicated to advancing and reimagining our services to elevate survivors' quality of life no matter where they are in their journey and geographically. In addition to the Journey Forward pilot, in 2022, we will expand Phoenix: Engage from a one-day event to a seven-event series as well as launch community-led affinity groups. As we continue to emerge from the pandemic and push our work forward, we will spend time deepening our relationships with survivors, hospitals, partners, and more to scale our impact, grow our community, and increase access to networks of resources and support.

I am filled with gratitude for our Board of Directors, staff, donors, and community for partnering alongside Phoenix Society as we strive to reach more survivors and welcome them to our community sooner. Frankly, the past two years have not been easy - but the work and advancements that have come from these challenging times are exciting and filled with hope. Our unique understanding of the survivor journey allows us to focus our work on areas with the most significant impact, and the power of our community for burn survivors is unmatched. 2022 will be a big year, and I'm glad you've joined along on the ride.

Gratefully,

A handwritten signature in black ink that reads "Amy Acton".

Amy Acton

JOURNEY MAP

In 2021, we conducted extensive research to better understand the burn survivor journey from injury and acute care through long-term recovery and life after a burn.

Fundamental Objectives

- Document what's most important to burn survivors along their healing journey.
- Identify significant pain points and needs across the journey.
- Determine areas of opportunity along the journey for Phoenix Society to engage and serve.

Research by the Numbers

- 306 Surveys Completed
- 17 In-Depth Interviews
- 594 Ideas Generated

Key Takeaways

- A critical milestone for survivors is the transition from hospital to home. While the majority of those interviewed continued to have support once they went home, 66% still didn't know what to expect about their recovery and what that journey would include. Additionally, 73% of survivors were unsure how to find and access the information they needed.
- Over half of caregivers and family members interviewed did not have anyone to relate to, and only 34% were made aware of Phoenix Society while their loved one was in the hospital.

JOURNEY FORWARD PROJECT

As a result of our research, we are launching the Journey Forward Project, the centerpiece of which is the Journey Forward Kit! This first-of-its-kind kit will provide tangible connections to resources and community through technology, burn aftercare products, and more during the critical stage of transitioning home.

The pilot program will be available to survivors in the following six locations around the country beginning in early May:

- Massachusetts General Hospital (Boston, MA)
- Orlando Regional Medical Center (Orlando, FL)
- Spectrum Health Hospital (Grand Rapids, MI)
- UC Irvine Regional Burn Center (Orange, CA)
- University Medical Center New Orleans (New Orleans, LA)
- University Medical Center of Southern Nevada (Las Vegas, NV)

We are excited to work with our hospital partners as we learn through this pilot together! After the pilot is complete, we will take our learnings and advance the project further for a larger, nationwide rollout over the next two to three years.



CALLED TO CONNECT

If there is one thing Sandra Cramolini is not, it's a token. She doesn't lend her name to a cause without pouring her soul into it. She's an advocate. A champion. A changemaker.

For Phoenix Society, she is a self-described cheerleader. But you won't find her simply shouting encouragement from the sidelines. Whether she's organizing fundraisers, sponsoring survivors to attend Phoenix Society virtual events, training survivors as Phoenix SOAR Peer Supporters, donating her own money, adapting programming for virtual formats, or juggling decisions in a leadership role—she's always hustling.



SANDRA CRAMOLINI

Sandra is an activist and giver by nature. But her passion for Phoenix Society was born out of her early experiences as a burn nurse when she cared for survivors who had no support system after leaving the hospital.

In the early 1990s, Sandra joined the burn team at a county health system in California. A pivotal time in medical advancements for burn injuries, new treatments were improving survival rates and care. It was exciting, but something important was still missing in burn care—something Sandra couldn't ignore.

"I saw very early on in my career the struggles that survivors faced after their hospital stay. They would be comfortable recovering in the hospital, but when they would go home, they would find life was not what it was prior to their injury."

Sandra saw survivors without aftercare or community, overwhelmed by what life had become. She witnessed them grappling with depression, suicide, and emotional disabilities that left them isolated, unfulfilled, not returning to work or having personal lives. Nothing was the same for them, and they didn't know where to turn.

Hospitals were providing the medical care more patients needed to survive. But many of those same survivors were left to struggle on their own, as they tried to cope and learn how to live again.

More had to be done. So, Sandra set out to do it.

Through the American Burn Association, Sandra met burn survivors and advocates like Cindy Rutter, James Bosch, and Jill Sproul, who introduced her to Phoenix Society and exposed her to the power of peer support.

In 2008, Sandra attended her first Phoenix World Burn Congress. She was hooked.

"It was there that I found the connection that survivors had been missing—those critical opportunities for psychosocial support after they left the hospital. I immediately felt like we, as healthcare professionals, were doing survivors a disservice if we did not provide them with these opportunities to network."



Cover of the updated Peer Supporter digital manual.

Sandra was energized. She started a burn foundation within her hospital foundation to connect survivors with Phoenix Society and support resources. She organized a walk-a-thon, formed a team, and recruited donors. For years, her grassroots efforts raised burn awareness, trained Phoenix SOAR Peer Supporters, and sponsored survivors to attend Phoenix WBC...one year, raising enough funds to send 22 survivors.

“There is nothing more powerful than peer support. It changes lives.”

The burn community captured Sandra’s heart and talent decades ago. Through the years, she has worked tirelessly, connecting countless survivors to Phoenix.

In 2017, she retired from her role in healthcare. But she has no plans to slow her role in the burn community. In fact, she’s ramping up her engagement. Most recently, she expanded her involvement by joining Phoenix Society’s Board of Directors.

“I hope that by being on the board, I can make an impact in educating more healthcare leaders about the importance of survivor support.”

In her experience, hospitals face many hurdles in providing support to burn survivors. Most don’t have money or resources dedicated to aftercare. And many hospital caregivers don’t realize the need for or benefit of connecting survivors to a community of support.

Sandra sees it as her responsibility and her mission to change that.

“It is up to us—professionals like me, at the end of our career—to model and recruit burn leadership within healthcare that understands the impact they can make on a survivor’s life. It is up to us to champion the medical directors and get our doctors engaged. That is my role going forward.”

Doctors and nurses are uniquely positioned as the first point of contact for survivors. Sandra’s goal is to empower more of them to connect survivors with community and support early in their recovery.

It’s her calling. And it’s how she’s changing lives.



The most recent virtual Phoenix SOAR training with MUSC Burn Center (Charleston, SC).

2021 BY THE NUMBERS

921

Active volunteer peer supporters

9,605

Facebook followers

8,980

Journey Magazine subscribers

1,998

New members joined the Phoenix Society community

11,021

Newsletter subscribers

482

Phoenix SOAR Coordinators

71

Phoenix SOAR hospitals and burn centers

304,998

Resource Center visits

636,895

Website visits



CONNECTION — THE UNEXPECTED ANSWER

“Everybody is different.” It seemed to be the only answer Jane ever got. It felt like a nonanswer when answers were what she longed for most.

Jane Fayer’s search for answers began on October 29, 2020. Her father had just died. She was preparing to leave for his funeral the next day. Her heart was aching as she prepared her morning coffee. And then her electric kettle tipped. Boiling water cascaded down her leg.

Her memories of that day are a tangle of grief, pain, heartache, and shock. But one memory stands out—the feeling of being alone.

Coronavirus restrictions left the hospital feeling strangely hollow. While her care was excellent, the empty halls seemed to multiply the questions swirling through her mind. Questions about pain, healing, and her future spilled over to the only resource she had...the burn professionals at the hospital.

But when every answer seemed to echo the ambiguous phrase she grew to hate—“everybody is different”—her frustration deepened. Her loneliness intensified. Her uncertainty grew.

Until one day in a treatment room, she spotted the Phoenix Society’s Journey Magazine (formally known as Burn Support Magazine). From the magazine, she found the website, explored articles, dug into research, and realized... there were others. There’s a whole community of survivors like her.

Less than three months after her injury, Jane logged into her first Phoenix Society Virtual Support Group. As survivors introduced themselves and shared their stories, relief flooded over Jane:

“All I remember saying is, ‘You are the first people I’ve ever met that have been burned, and I don’t feel so alone anymore!’ It triggered waves of tears of emotional release and of joy that these people knew and understood what was happening to me.”

It was a turning point for Jane. In her search for answers, she found more. She found connection to community, resources, and support that helped her journey toward healing. And she discovered the phrase “everybody is different” is an answer that all survivors live with. A truth that, with peer support, she learned to embrace.

While every individual and every recovery are unique, the need for connection is universal. There is strength and hope in having other survivors journeying the unpredictable with you.

For Jane, it wasn’t actually clear-cut answers that she needed most. It was people.

“I am here today because of peer support I found early in my recovery through Phoenix Society. I am in a very, very different place now than I was.” - Jane Fayer

To our Phoenix Society community,

The past couple of years have created and accelerated many changes in our world. This period has challenged many of our norms and assumptions on how we live and work. Significant changes like these, even when accompanied by stress, are natural and can be generally positive over the longer term – if we continue to learn and adapt, we can become more effective and more resilient.

Our beloved Phoenix Society is no exception to this – we’ve been continuing to examine ourselves, how we operate, and are now moving to adapt to a new future. We don’t see a need to adjust the essence of our work: To provide support for burn survivors and their families throughout their journey – from initial injury through ongoing healing to living and thriving with a burn.

But, in the past year, we’ve been doing a lot of listening about those ‘journeys.’ They are all unique, but we’ve now generally mapped them through time for both our survivor and supporter communities. We’ve identified the most critical areas and where and how we can better serve our community.

In 2022, we are now acting on what we learned. We know we can effectively help many more people than we currently serve, so first we want to scale and expand our community in a very significant way. We will do that by effectively introducing Phoenix Society at the time of the initial injury and by leveraging our information platforms and data to reach and better serve our community throughout their journey.

To help accomplish this, we are now piloting the Journey Forward kit and reforming our relationships with hospitals to improve the timeliness of our introduction to survivors. We are also moving to leverage our current information and data better by creating a more personal experience and a resource marketplace our community can all use, including our own programs and other helpful resources.

We see our future as being the connector and guide of choice for survivors and their families, in addition to our role of providing direct support. No other organization has the unique ability to provide resources and support we can and the experience and informed personal touch that we can.

We are all committed to evolving the organization to effectively help so many who need our support. We are very proud of all we’ve done, but as our future becomes clearer, we are even more excited about where we are going!

THANKS to our entire community!



Jeff Gallinat

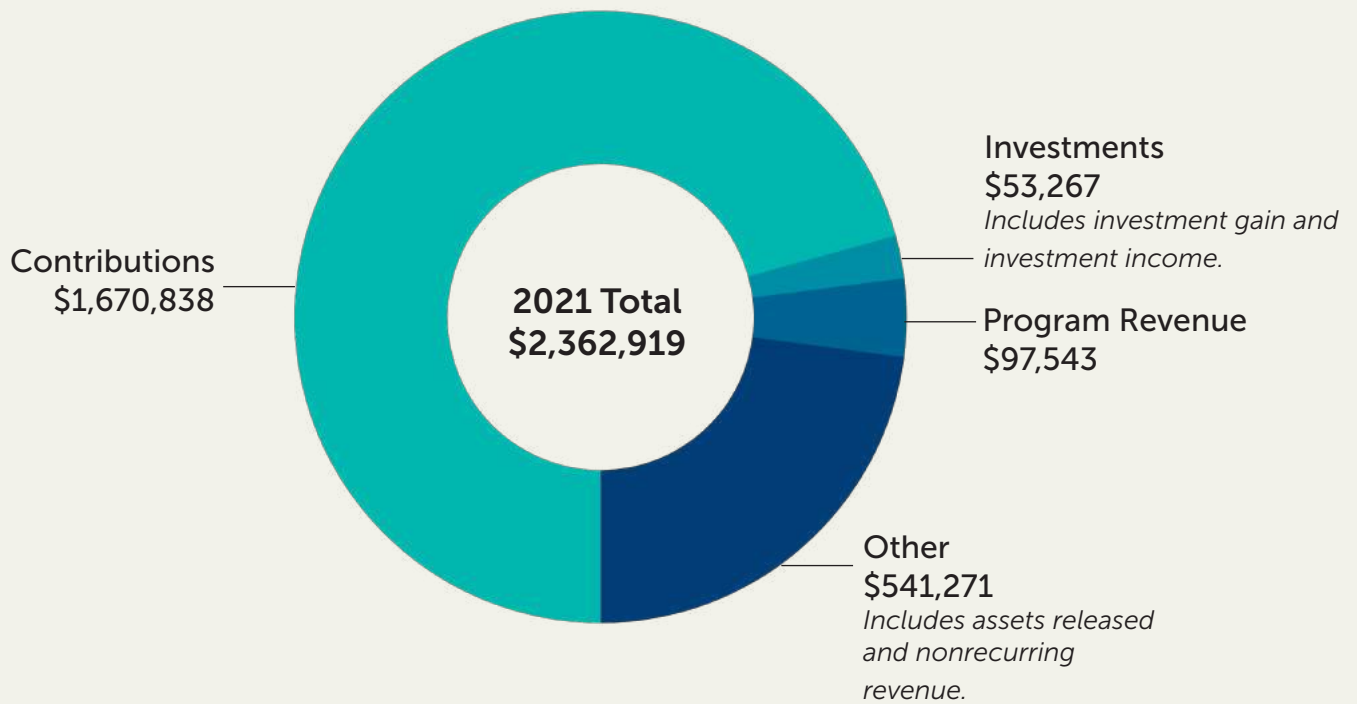


JEFF GALLINAT

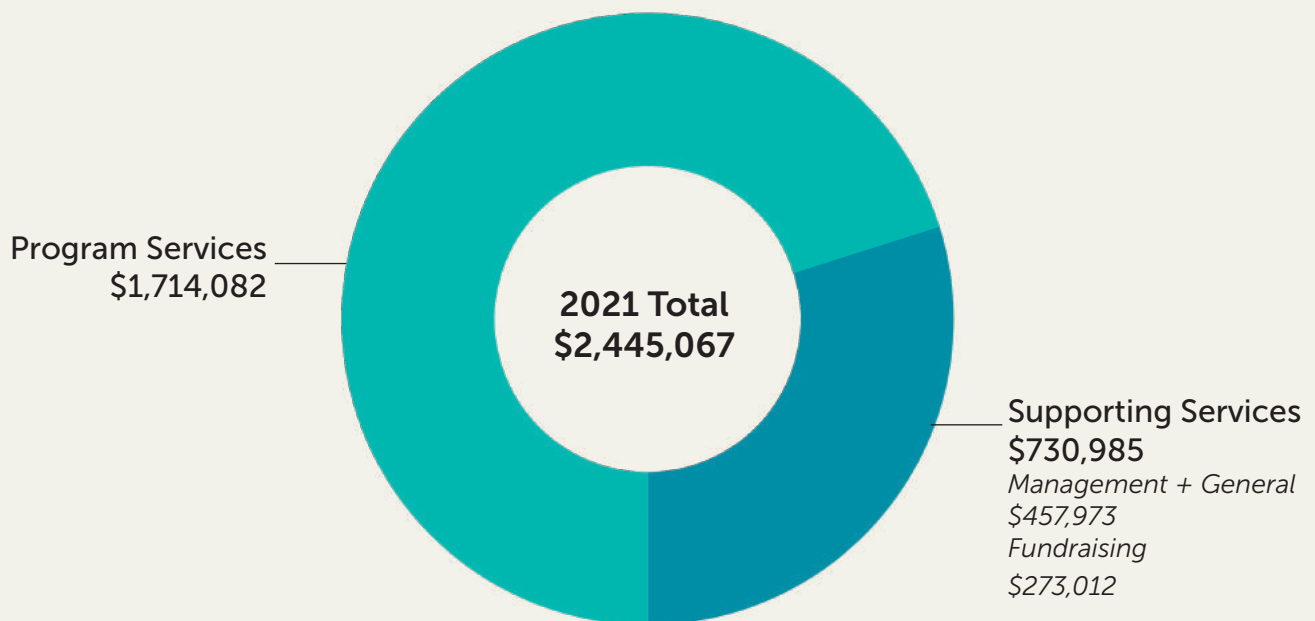
Burn Survivor
Board President,
Phoenix Society for Burn Survivors
Retired Senior Vice President -
Manufacturing,
Cisco Systems

FINANCIAL REPORT 2021

REVENUES + SUPPORT



OPERATING EXPENSES



NET ASSETS

Change in Net Assets	-\$42,138
Net Assets - Beginning of the Year	\$3,435,571
Net Assets - End of the Year	\$3,393,433

BOARD OF DIRECTORS

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Burn Survivor

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Prashant Kulkarni (PK)

Vice President of Engineering, Johnson Controls - Fire Suppression

Sandra Cramolini

Former Nursing Administrator, Leon S. Peters Burn Center
Cramolini Consulting

Tony Gonzalez

Burn Survivor

OUR MISSION

Building a Community for Transformational Healing

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