



Schizophrenia<sup>®</sup>  
& Psychosis  
Action Alliance

Shattering the barriers to  
treatment, survival and  
recovery for people with  
schizophrenia and  
psychosis.



2025 Annual Report

# Who We Are

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The Schizophrenia & Psychosis Action Alliance (S&PAA) is a national nonprofit organization dedicated to improving the lives of people affected by schizophrenia and psychosis. Founded in 2008 by a steering committee of individuals, family members and care providers from across the United States, S&PAA was created to address the urgent need for stronger support. Today, we work to break down barriers to treatment, survival, and recovery through research, education and care, and advocacy and public policy.

**Our Vision:** A cure for schizophrenia and psychosis spectrum disorders.

**Our Mission:** To advance systemic change and promote recovery through Research, Education & Care and Advocacy & Public Policy.

## Key Barriers Facing our Community

**Illness Self-Awareness & Anosognosia:** A relatively unstudied and complex symptom that can result in untreated or undertreated psychosis and increase burden on caregivers.

...

**Emotional Burden & Social Isolation:** These challenges cause stress, health issues and reduce quality of life and productivity for people with schizophrenia and their care partners.

...

**Inadequate Healthcare Systems** that lack early detection tools, deliver poor-quality treatment, failure to coordinate care across all treatment and medical needs; and limited access to care.

...

**Excessive Caregiver Burden:** Caregivers provide critical and extensive care but are often isolated and unsupported.

...

**Lack of Housing & Independent Living Support:** Inadequate housing options and other services to help people live as independently as possible.

...

**Discrimination & Stigma:** People with schizophrenia are dehumanized, maltreated and rejected by nearly every segment of society.

# A Year of Impact

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2025 was a year of impact.

Time and time again, S&PAA showed that when research, education, advocacy, and community converge around a shared purpose, real change is possible. **The barriers standing between people and the care they need are not permanent obstacles.** For the millions of individuals and families navigating schizophrenia and psychosis spectrum disorders, that impact matters.

Schizophrenia is hard enough as it is. There shouldn't be added barriers layered on top of it; fragmented systems, persistent stigma, limited access to treatment, excessive caregiver burden, and the devastating isolation that comes with this illness. These are the barriers S&PAA intends to shatter. In 2025, we made good progress, but there is always more to do.

We made significant additions to our professional staff and expanded the capabilities of our leadership team, strengthening our capacity across research, communications, development, and clinical expertise. **2025 was also our strongest financial year to date**, with growth in both revenue and net assets reflecting the increasing scale and strength of our organization. Together, these gains positioned us to do more than ever before. What followed was our most productive year yet. We helped **drive FDA REMS reform**, expanding access to one of the most effective treatments available for schizophrenia. **We put tools into the hands of families navigating housing**, one of the most overwhelming hurdles they face. We **expanded our support groups** more than fivefold, reaching nearly 2,000 new attendees. And we **laid the groundwork for a national standard of care** that will fundamentally transform how this illness is treated across the country.

The work ahead is as ambitious as the boldly growing organization we've become. Fragmented care still leaves too many people without a path forward. The justice system remains a de facto substitute for treatment for far too many. And social isolation continues to rob people of connection, dignity, and a sense that they matter. These are serious problems, but they are resolvable ones, and for the first time, we have the team, the tools, and the reach to do so. In 2025, we moved forward on our vision for a **Schizophrenia Center of Excellence** while also outlining a multi-phased approach for two additional long-term initiatives: a **Schizophrenia Justice Center** focused on improving navigation and outcomes at the intersection of serious mental illness and the justice system, and a **National Center for Social Inclusion and Mattering** focused on reducing isolation and advancing connection, belonging, and quality of life. More details on both efforts will take shape in 2026.

We know what works: early intervention, coordinated care, peer support, and the relentless belief that every person living with schizophrenia and psychosis spectrum disorders deserves the chance to recover. That belief drives everything we do, and the voices of our community power every step we take.

**We are grateful for your partnership. Together, we are shattering the barriers to treatment, survival, and recovery, one family, one barrier, one life at a time.**



Angela Babaev, D.N.P., C.N.S., M.S.N.  
Chair, Board of Directors



Gordon Lavigne, M.Ed.  
Chief Executive Officer

# Our Top 5

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We are proud to share five highlights from a year in which we made meaningful progress against the barriers standing between our community and treatment, survival, and recovery.



## Bringing Excessive Caregiver Burden Into Focus

Caregivers provide critical and extensive care, yet their needs and sacrifices have remained largely invisible to the systems that should be supporting them. When we fail caregivers, we fail the people they care for. In 2025, S&PAA shed light on this crisis by leading the study ***Quantifying the Societal Impacts of Schizophrenia: A Survey of Caregivers*** in partnership with Blue Persimmon Group and Precision AQ, bringing new visibility to the hidden costs families bear.

The findings reinforced what we have long known: schizophrenia reshapes not only the life of the person diagnosed, but also the lives and livelihoods of their loved ones. By quantifying this overlooked burden, this research **gives advocates, policymakers and families stronger evidence to push for policy reform, better support, and recognition of the role caregivers play.** This is how S&PAA uses research to fuel the advocacy needed to drive real, system-level change.

***“As a caregiver, so much of what we do can feel invisible. My hope is that this study will shed light on the realities we face every day.”***

- Community Member

**\$1,810 average monthly out-of-pocket cost**

**36 hours of unpaid care per week**

**58% of caregivers reported lost wages**



## Launching a Community Resource for Housing Stability

For people living with schizophrenia and psychosis, the path to recovery cannot begin without a safe place to call home. Yet for many individuals and families, finding and maintaining stable housing can feel overwhelming and out of reach. What settings are appropriate? Where do I even start?

Our community told us this was one of the most overwhelming barriers they face, and our own data confirmed it. Schizophrenia-related housing instability carries a societal cost of **\$35.2 billion annually**. In response, S&PAA launched **I Need Housing, Now What?**, a free comprehensive toolkit that walks users through their housing options. When individuals and families are navigating one of the hardest moments of their lives, they should not have to search a dozen different places for answers. Now they don't have to. By translating a fragmented and confusing landscape into **one clear, trusted resource**, we are actively removing one of the largest practical barriers standing between our community and recovery.

*"I only wish this kind of reference was available when we were struggling to find my son a place to live. This is exactly the kind of resource families like ours need to help our loved ones.*

- Community Member

### I Need Housing, Now What? Modules





## Building Community to Combat Isolation

The needs of individuals and families affected by schizophrenia and psychosis spectrum disorders are unique, and too often, people are left to carry that weight alone. **Emotional burden and social isolation compound every other challenge our community faces.** S&PAA is committed to creating spaces where people can find connection, guidance, and support from others who truly understand what they are facing.

In 2025, our Peer and Caregiver Support Groups **reached more people than ever before**, with expanded offerings and **near-perfect satisfaction scores** across the board. Our Resource Line was there every weekday for individuals and families who had nowhere else to turn, providing reliable guidance by phone and email. The message is clear: when people find community, it changes everything. In 2026, we will expand our offerings even further and lay the groundwork for a first-of-its-kind initiative dedicated to tackling the epidemic of social isolation and loneliness in schizophrenia. **Because belonging is not a luxury. It's part of recovery.**

**1,961**

new attendees, up  
from 483 in 2024

**11**

caregiver support groups, up  
from 2

**95%**

of attendees gave a 5/5  
rating

**3,000+**

resource line cases handled  
in 2025

**85%**

of callers gave a 5/5 rating

***"I finally entered a safe place, around smart, caring, gracious, strong, helpful people who understand me more than anyone has before."***

- Caregiver Support Group Attendee

# 4

## Breaking Down Barriers to Treatment

For people with treatment-resistant schizophrenia, clozapine has long represented hope, yet for years federal restrictions made it nearly impossible to access. People who could have been helped were shut out, not because the treatment did not exist, but because the system stood in the way. In 2025, S&PAA played a key role in driving **FDA REMS reform**, a landmark change that eliminated the **Clozapine Risk Evaluation and Mitigation Strategy program** and significantly expanded access to this lifesaving treatment for people who had long been unable to reach it.

Recognizing that regulatory change alone would not remove every barrier, S&PAA partnered with the American Association of Psychiatric Pharmacists (AAPP) to develop and launch **A New Era in Clozapine Management**, a set of clinical, evidence-based courses designed to provide rapid education and appropriate dispensing guidance for clozapine. Together, these efforts helped **expand access to clozapine and reduce barriers to one of the most effective treatments available for schizophrenia**, and pushed back against a system that has failed our community for too long.

*“One of the hardest parts of this illness is knowing that effective treatment exists, but that too many people still cannot access it. What S&PAA did this year to help reduce barriers to clozapine access matters deeply to families like mine.”*

- Community Member

MODULE 1  
Clozapine Through the Patient Lens

MODULE 2  
The Untapped Potential of Clozapine

MODULE 3  
From First Dose to Full Effect

MODULE 4  
Navigating Clozapine Monitoring in a REMS-Free Era

MODULE 5  
From Drooling to Drowsiness

MODULE 6  
Clozapine Across the Spectrum

MODULE 7  
The Clozapine Rechallenge Dilemma



## Solving Foundational Problems

Every barrier we have fought this year tells the same story: a system that was never built to support people living with schizophrenia and psychosis. Up to 40% of people with schizophrenia receive no treatment at all, not because help does not exist, but because the system is too fragmented, too inconsistent, and too disconnected to deliver it. There is no national standard for coordinated, lifelong care for schizophrenia and psychosis. That is what S&PAA is building.

In 2025, S&PAA convened an eighteen-member Planning Committee of multidisciplinary experts to assess the feasibility of a national **Schizophrenia Center of Excellence**. Drawing from successful models in cancer and rare disorders, the Center will span the entire care ecosystem, from academic medical centers and coordinated specialty care programs to community providers, peer networks, families, and caregivers. It will establish a certification pathway that aligns training, reimbursement, and whole-person treatment across the full course of illness.

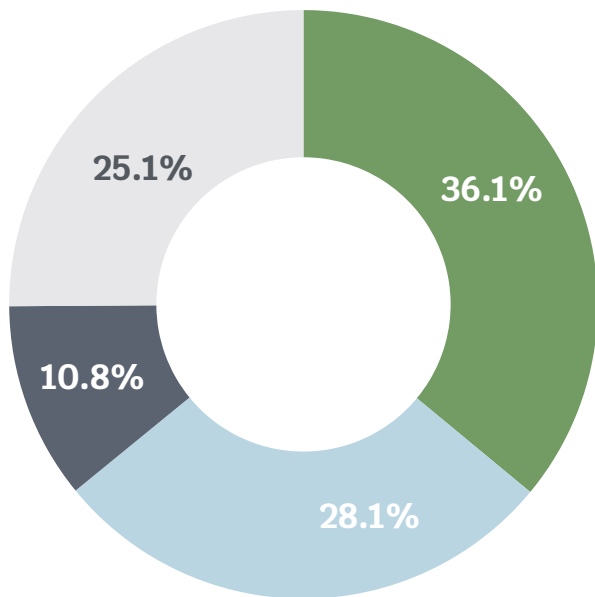
In 2026, the official Steering Committee launches to begin designing the Center, including the voices of those with lived experience, because people living with schizophrenia and psychosis deserve a system that was built with them in mind.

***“For families like mine, quality care can depend too much on where you live or who you happen to find. S&PAA’s Center of Excellence gives me hope that families will have a clearer path to the care they need.”***

– Community Member



# 2025 Financials\*



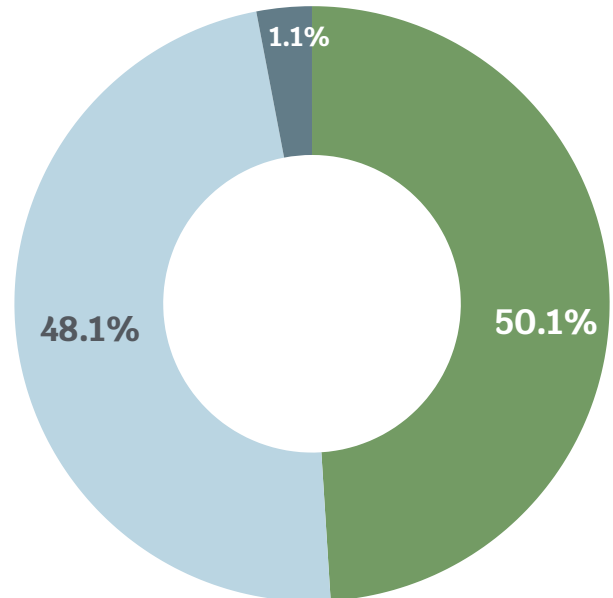
## EXPENSES

Research	\$748,000
Education & Care	\$584,000
Advocacy & Public Policy	\$224,000
General & Fundraising	\$520,000
<b>TOTAL</b>	<b>\$2,076,000</b>

75% of funds go directly to S&PAA programs.

## REVENUE

Corporate Sponsorships	\$1,203,000
Individuals & Foundations	\$1,142,000
Other	\$25,000
<b>TOTAL</b>	<b>\$2,370,000</b>



**TOTAL 2025 ENDING NET ASSETS: 1,722,000**

\*Financials are unaudited.  
Audited financial statements and 990s can be found on the S&PAA website.

# The People Behind This Work

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Behind every resource, every advocacy effort, and every step forward is a community of people committed to improving the lives of individuals and families affected by schizophrenia and psychosis.

## S&PAA Staff

Gordon Lavigne, M.Ed., CEO  
Priya Chirayil, Research Assistant  
Anne DeGeorge, Director of Development  
Krissa Rouse, MA, LCPC, Program Manager  
Marissa Shepherd, Director of Operations  
Erica Tingler, Director of Communications

## S&PAA 2025 Board of Directors

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Angela Smith  
Paulie VonEdWaerd-Benjamin

## Family Advisory Committee

Tracy Ganser  
Gus Granger  
Marjorie Greenberg  
Matt Peterson  
Randy Rodriguez  
Ariel Snowden  
Karen Steingart, MD, MPH  
Christen White

# Thank You!

To learn more about how you can support S&PAA, visit [www.sczaction.org](http://www.sczaction.org) or email us at [info@sczaction.org](mailto:info@sczaction.org).

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