



**Schizophrenia
& Psychosis**
Action Alliance

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

2024 Annual Report

A groundbreaking year

2024 has been a groundbreaking year for the Schizophrenia & Psychosis Action Alliance and for the schizophrenia and psychosis community. We've never been more confident that we are on a meaningful path forward, and that recovery is a real and achievable goal for people with this brain disease. Key 2024 milestones for our organization included:



Hosting our first SPRING Summit in Washington, D.C., bringing together 125 people with schizophrenia, caregivers, clinicians, community leaders and law enforcement to identify major barriers to recovery and identify solutions.



Expanding our peer support groups and Resource Line, developing interactive toolkits for people with schizophrenia and their caregivers and launching a popular webinar series that explores innovations in treatment for schizophrenia.



Sharing the priorities and perspectives of our community with clinicians, drug developers and policymakers, from scientific conferences to meetings on Capitol Hill. The more our voices are heard by these influencers, the more treatment will be tailored to our needs, and policies created to support us.

The schizophrenia and psychosis community experienced a momentous step forward with the launch of the first novel schizophrenia treatment in decades. We expect more to come, with a schizophrenia treatment pipeline that is more robust than ever. And thanks in large part to efforts by S&PAA and our partner organizations in the mental health community, the U.S. Food and Drug Administration eliminated the burdensome restrictions on clozapine, which have blocked access to the drug for many people with treatment-resistant schizophrenia.

At S&PAA, we have never believed more strongly that recovery from this disease is achievable. Whether it's returning to work or school, having a family or enjoying friendships, we all deserve to live a meaning-driven life. We are working every day to help clear the roadblocks to recovery, and we are so grateful for the partnership of our community.

Angela Babaev

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

Gordon Lavigne

Gordon Lavigne, M.Ed.
Chief Executive Officer

Shattering the barriers so we all can thrive

Schizophrenia is a treatable brain disease, and people with this disease deserve urgent treatment, respect and recognition so they can live and thrive. Many people do not realize that schizophrenia and related psychosis disorders affect at least 1 in 100 people in the United States – more than two million adults. Yet navigating the schizophrenia journey can be nearly impossible in the face of our broken healthcare system, treatments with devastating side effects and the deep-seated stigma caused by society’s misunderstanding of this disease.

The S&PAA exists to transform how we treat this disease, by shattering the barriers to treatment, survival and recovery. S&PAA is the only organization that focuses solely on schizophrenia and removing the enormous foundational barriers to recovery from this disease by:

- Advancing best-practice treatment.
- Empowering the community with knowledge, skills and support.
- Fighting discrimination and stigma.
- Advocating for equal access to care.

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I learned through S&PAA support groups that there's hope out there. You don't have to feel alone or isolated, because there's always hope.”

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.



Our Guiding Principles

We are a catalyst for change.

We empower individuals to navigate schizophrenia with evidenced-based knowledge and skills.

We fight to end the discrimination and stigma that hurts our community.

We pursue equitable access to high-quality care for all members of our community.

We advance and advocate for best-practice treatment and prevention methods.

The voices of our community inform all aspects of our work.

S&PAA is leading the charge to transform the treatment and care landscape.

Our work is organized into three strategic areas, each of which plays a critical role in supporting S&PAA strategies. Our programs in these three areas build on one another and interconnect to achieve maximum impact for our community.



Our **Research** programs focus on accelerating earlier diagnosis and breakthrough treatments and uncovering the societal, caregiver and patient costs of schizophrenia to improve resources for care and recovery.

Our **Education & Care** efforts provide resources for people living with schizophrenia, caregivers and clinicians to fill knowledge gaps and empower all stakeholders to help improve patient and caregiver outcomes.

Our **Advocacy & Public Policy** work drives systemic change to fix our broken healthcare system and create equitable access to high-quality care for people with schizophrenia and psychosis.

Working with schizophrenia community stakeholders, including those diagnosed with schizophrenia, caregivers, clinicians and community advocates, we have identified key barriers to treatment, survival and recovery and are activating solutions to these barriers. These solutions will inform and drive S&PAA's operating plan over the next three years.



2024 Accomplishments

Our work is laser focused on shattering the foundational barriers to schizophrenia recovery, and our efforts in 2024 had substantial impact:

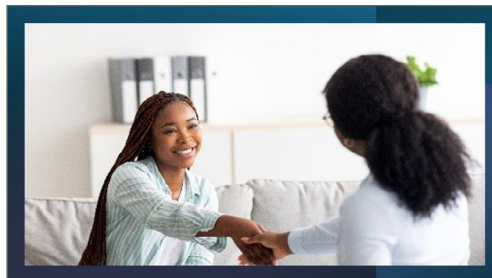


Education & Care

- We expanded and enhanced our national peer and caregiver support group meetings, which served thousands of people through more than 400 meetings.
- Our free telephone and email Resource Line helped thousands of people, directing our community to educational resources and tools to support their recovery journey.
- We published free toolkits for diagnosed individuals and their caregivers to help them navigate this complex disease and chart a path toward recovery:
 - **“I’m Diagnosed. Now What?”** supports people through the early stages of a schizophrenia diagnosis and guides them on the important steps to recovery.
 - **Our Caregiver Toolkit** helps caregivers navigate the difficult journey of caring for a loved one with schizophrenia.
- We launched a webinar series to explore how innovations in schizophrenia treatment can help people manage their disease – and how clinicians can work with their patients to achieve meaningful treatment outcomes.

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Thank you for your tireless efforts on behalf of people with schizophrenia and their families!”



Innovations in Treatment: Understanding the Cognitive Impact of Schizophrenia

Shattering barriers to treatment, survival & recovery

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Research

- Our first annual Schizophrenia Policy and Research Institute Next Gen (SPRING) Summit convened the full spectrum of schizophrenia community stakeholders to align on solutions to the key barriers to recovery. Our resulting Roadmap to Recovery maps a plan to transform the fragmented system of care for people with schizophrenia into a path toward recovery.
- We shared insights from our community with researchers and clinicians through presentations at 10 scientific conferences and events, on topics such as:
 - The impact of negative and cognitive symptoms on those with schizophrenia.
 - The unmet needs of caregivers.
 - The daily lived experience of people with schizophrenia.



- We infused the perspective of diagnosed individuals and their caregivers into drug-development research, including patient insights on clinical trial design, patient preferences and expectations.
- Our participation on the National Institutes of Health’s Accelerating Medicines Partnership-Schizophrenia (AMP-SCZ) Steering Committee supports improvement of schizophrenia treatments and outcomes by identifying early indicators of the disease.
- Our work with the Biomarkers Consortium, led by the Foundation for the National Institutes of Health, helps drive cross-sector efforts to validate and qualify biomarkers and other drug development tools to support new treatments and technologies.

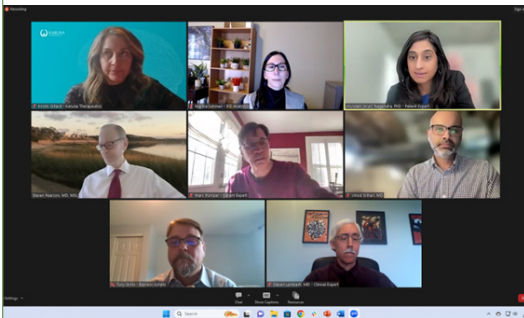
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I'm so thankful for S&PAA. What you do for our loved ones is why our family continues to support your efforts for better lives for those who live with schizophrenia.”



Advocacy & Public Policy

- We created the **Schizophrenia Policy Action Network (SPAN)** to advocate for laws and policies that connect our community with the care they need – and the respect they deserve. Our Roadmap for Change Advocacy Workshop convened 75 advocates to discuss policy issues that impact our community and how to advocate for solutions to key barriers.
- We developed and released nine **position statements** that formally articulate our advocacy priorities and call on policymakers and other influencers to address barriers to schizophrenia treatment, care and support.
- We successfully advocated for **removal of the burdensome FDA REMS requirements for clozapine**. These restrictions prevented access to clozapine for people with treatment-resistant schizophrenia and resulted in dangerous treatment interruptions. Our efforts (in partnership with other organizations in the mental health community) led an FDA Advisory Committee in November to recommend removal of the requirements, and FDA officially eliminated the REMS in March 2025.
- We deeply engaged with the Institute for Clinical and Economic Review (ICER)'s evaluation of the cost effectiveness of Cobenfy/KarXT, underscoring the importance of innovation in treatments for schizophrenia.



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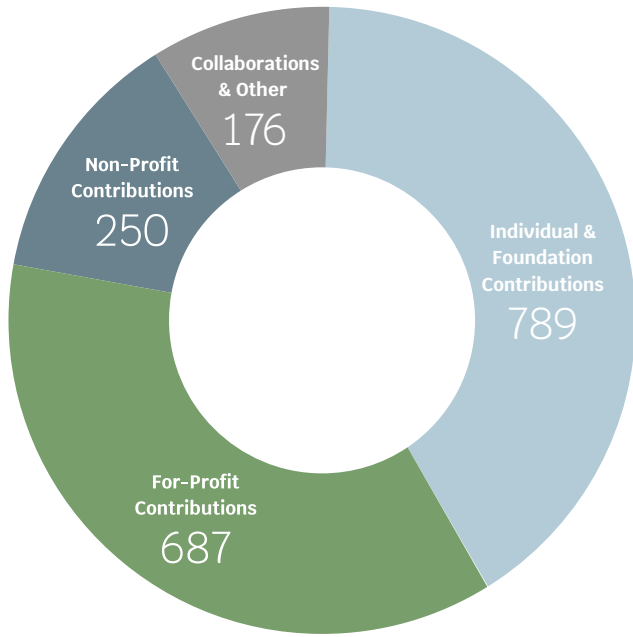
Thank you for all your hard work and commitment to this cause!”



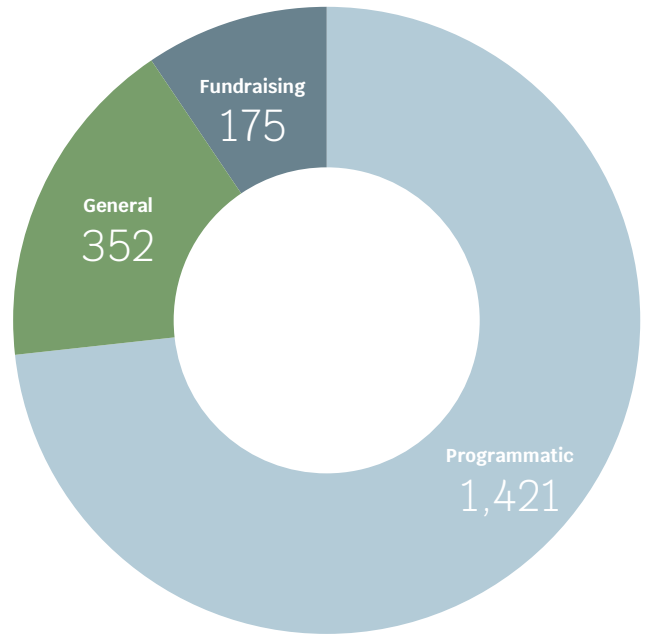
Just before year's end, we were honored to be named Advocate of the Year by the STARR Coalition, a collaborative network focused on advancing mental health research. As part of the award, they noted: "Not only has S&PAA been a driving force behind initiatives aimed at improving access to equitable, high-quality mental health care by addressing systemic barriers and advocating for legislative change, but the organization has created a wide range of resources...ensuring that individuals with schizophrenia and psychosis, as well as their families, feel understood, supported and equipped to navigate the challenges they face." We were humbled and grateful to be recognized for our efforts – which are fueled each day by passion, determination and hope.

2024 Financials*

2024 Revenue | \$ in thousands

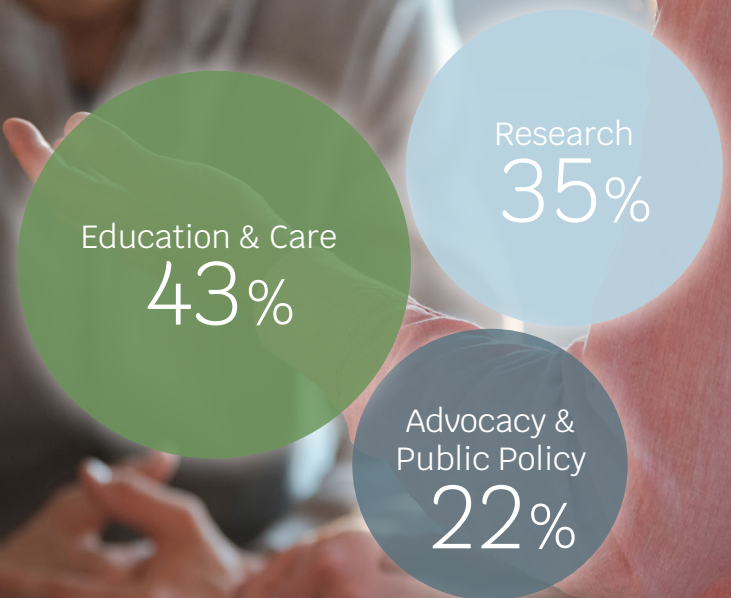


2024 Expenses | \$ in thousands



TOTAL 2024 ENDING NET ASSETS: \$1,005,046

2024 Programs



* Financials are unaudited.

Audited financial statements and 990s can be found on the S&PAA website.

S&PAA Staff

Gordon Lavigne, M.Ed., CEO

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Marissa Shepherd, Director of Operations

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Ariel Snowden

Karen Steingart, M.D., M.P.H.

Christen White

**Advancing system change and
promoting recovery through
Research, Advocacy, Education & Care
for the millions of people who live with
schizophrenia and other psychosis
spectrum disorders.**

Schizophrenia & Psychosis Action Alliance
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