



2021 ANNUAL REPORT

 Society for
Women's Health Research

The Society for Women's Health Research (SWHR)

is the national thought leader dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education.

Since our founding in 1990, SWHR has worked to address unmet needs and research gaps in women's health. Thanks to SWHR's efforts, women are now routinely included in most major medical research studies and scientists are considering sex as a biological variable (SABV) in their research.

Today, SWHR seeks to fulfill our vision of making women's health mainstream through our core pillars of science, policy, education, and organizational strength. Through this work, SWHR continues to encourage the appropriate inclusion of women, minorities, and subpopulations of women in medical research; promote research on biological sex differences in disease and ensure the implementation of sex as a biological variable policies in research studies; advocate for greater public and private funding for women's health research; promote a diverse research workforce; and educate women, health care providers, and policymakers about the issues affecting women's health across the lifespan.



Letter from the SWHR President and CEO

Despite the challenges the United States and globe continue to face due to the ongoing COVID-19 pandemic, SWHR—under the leadership of the SWHR Board of Directors, Board Chair Dr. Shontelle Dodson, and the dedicated SWHR staff team—has had a successful year working to fulfill our mission of promoting research on biological sex differences and improving women’s health through science, policy, and education.

Among the highlights of 2021, we began [implementing our strategic plan](#), have grown our organizational structure to reflect the increase in the quantity and quality of our programmatic work, and have, through the vital support of our sponsors, been able to expand the number of SWHR programs and outreach spanning issue areas from autoimmune diseases and women’s eye health to menopause and endometriosis. This growth has led to the creation of valuable materials that empower women in their health care; educate policymakers, clinicians, researchers, and the public; and bring us closer to seeing women’s health become mainstream.

Our goal is to ensure that there is no question of equity within research, that women are automatically integrated into scientific breakthroughs, and that research that considers sex as a biological variable is not an after thought.

This year we continued to expand our policy presence. Notably, we launched our inaugural [Women’s Health Policy Agenda](#) to outline policies we support across public health, research and clinical trials, lifespan issues, coverage and access, and the biomedical workforce. The Agenda is one part of our policy work to propel women’s health forward through policy action. We are eager to build upon this agenda and our efforts in 2022.

Looking ahead, I see great opportunity for this organization and am optimistic about the future of women’s health research in this country. While we have much to do to fill current research gaps and increase the knowledge base on women’s health issues, we have partners across the public health and scientific communities as well as the federal government who recognize the value of this work and serve as invaluable partners in this journey.

I am grateful for the hard work and commitment of the SWHR Board of Directors, Policy Advisory Council members, and importantly the hardworking SWHR staff team. I look forward to seeing what we can accomplish together over the next year.

Sincerely,

A handwritten signature in black ink that reads "Kathryn G. Schubert".

Kathryn G. Schubert, MPP

President and Chief Executive Officer
Society for Women’s Health Research



Letter from the Chair of the Board of Directors

It has been a privilege to serve as the chair of the Board of SWHR for the past two years. Despite a host of challenges and the inherent quirks of virtual gatherings resulting from the pandemic, I have been grateful to work alongside SWHR's dedicated and enthusiastic Board of Directors and its staff in support of the Society's mission to promote research on biological sex differences in disease and improve women's health through science, policy, and education. Our collective confidence in and commitment to this mission has helped ensure that SWHR's programs and resources will serve women, their families, and communities for years to come.

SWHR's work over the past year makes evident why this organization remains a leader in women's health after more than 30 years and, why we must remain steadfast in elevating women's health issues at the research, policy, clinical, and societal levels.

From a public health perspective—as science and research remained center stage—SWHR took impactful, proactive steps to make sure that women were represented in federal conversations related to COVID-19. For example, the Society provided testimony to the U.S. House of Representatives Energy & Commerce Subcommittee on the future of telehealth and the impact of the pandemic, advocated for women's health needs in response to the National Institutes of Health's release of its Strategic Plan for COVID-19 Research, and posted blogs highlighting relevant COVID-related news for women. Such actions were key elements of SWHR's work this past year, and will remain important for the Society moving forward.

Over the course of 2021, SWHR produced myriad educational resources, from its [Endometriosis Patient Empowerment Toolkit](#) to a [Maternal Immunization Quick Guide](#). The Society published articles on issues affecting women’s health in several esteemed journals, such as the *Biology of Sex Differences*, the *Journal of Environmental Research and Public Health*, and the *Journal of Women’s Health*, and held engaging public events, like the public forum, “[More than Skin Deep: Understanding the Impact of Autoimmune Skin Diseases on Women’s Health](#).” SWHR’s science programs continue to yield tremendous returns for a range of stakeholders, underscoring why science and evidence are at the heart of the organization’s work.

In a year when health policy dialogues grabbed headlines, SWHR’s policy work stood out. SWHR launched its inaugural [Women’s Health Policy Agenda](#) to identify key areas of need for women across the areas of public health, research and clinical trials, lifespan issues, coverage and access, and biomedical research workforce, and released [policy position statements](#) on core topics, such as inclusion of pregnant and lactating populations in research and improving women’s health equity. In addition, SWHR engaged with Congress and the Administration on issues to drive women’s health forward, including calling for increased federal research funding.

Each year—and this year is no exception—I am proud of the work we continue to do together to see our vision of making women’s health mainstream a reality. But our success also depends on sustained and aligned collaborations.

On behalf of the SWHR team and its Board of Directors, I would like to thank the many partners with whom the Society engaged throughout the year. Your support, willingness to collaborate, and partnership have helped bring this work to life and contributed to our success.

We look forward to working with you in 2022 and beyond.

Sincerely,



Shontelle Dodson, PharmD

Chair, SWHR Board of Directors

Science Programming and Activities

SWHR is elevating our collective understanding of the health disparities facing women across the nation and how biological sex, gender, and hormones affect health across the lifespan. We do this by convening interdisciplinary stakeholders to provide expert analyses on topics related to women's health; identifying research gaps and unmet needs in women's health care across the lifespan; and leveraging expert analyses to create deliverables that address these needs across science, policy, education, and outreach.

Bringing Together Thought Leaders to Identify Research, Policy, and Education Gaps and Opportunities

In 2021, SWHR hosted seven interdisciplinary roundtables covering diverse topic areas in women's health. During each of these roundtables, researchers, health care providers, patients and patient advocates, and policy leaders discussed how various issue areas affect women's health, current clinical and research gaps, and opportunities to advance the field. The scientific roundtables held in 2021 focused on [autoimmune skin diseases](#), [expanded carrier screening \(ECS\)](#), [eye health](#), [fertility](#), [immunization education](#), [menopause](#), and [noninvasive prenatal screening \(NIPS\)](#).

Creating Tools and Resources to Support Clinicians and Patients

SWHR's more than 30-year history in promoting biological sex differences research and our continued working relationships with science, policy, and public health experts uniquely position SWHR to create evidence-driven content that can benefit a wide range of stakeholders.

Over the course of 2021, through SWHR's science programming, SWHR produced a variety of tools and resources that can be used by women and their families to assist with navigating their health care journey and by health care providers to assist in the diagnosis and management of care for certain diseases and conditions.

2021 Science Resources by the Numbers

7

Interdisciplinary Roundtables

7

Webinars & Public Forums

6

Journal Articles

5

Patient Fact Sheets

3

Blog Series

3

Clinician Fact Sheets

2

Patient Empowerment Guides

2

Roadmaps

Psoriatic Arthritis
Diagnosis and Management in Primary Care



Psoriatic arthritis (PsA) is a type of arthritis that may occur in patients with psoriasis. Psoriasis is a chronic, immune-mediated systemic condition which manifests with areas of skin cells that often multiply 30 times faster than the normal rate. This causes skin to build into raised patches or plaques, which may be red or discolored with any or silvery scales depending on skin type. PsA, a comorbidity that often develops after psoriasis, is a chronic inflammatory condition affecting the joints and where the tendons and ligaments connect to bone.

Timely diagnosis and treatment of psoriatic arthritis is important to prevent irreversible joint damage.

Common symptoms of PsA

- Joint pain, tenderness, stiffness or swelling
- Swollen fingers or toes (dactylitis)
- Foot pain, often in the heel or sole
- Lower back pain (axial)
- Skin symptoms – red or discolored patches with silvery scales on arms, legs, and torso
- Nail changes – detached or lifting nails or pitting (small depressions) in nails
- Eye inflammation (uveitis), more common in children
- Fatigue
- Ankylosing

PsA Risk Factors

The greatest risk factor for developing PsA is having psoriasis. Other factors include:

- Age – PsA often appears between ages 30 to 50, but may occur earlier in life. There is no clinical test for PsA, however certain genetic tests exist to help identify signs and symptoms of the disease. For example, it is recommended that individuals with psoriasis complete the Psoriasis Epidemiology Screening Test (PEST) every 5 months.
- The internationally agreed-upon Classification of Psoriatic Arthritis (CASPAR) criteria use a point system to help in diagnosis. A patient must have at least 3 points for PsA, with at least 1 point for psoriasis. Psoriasis is defined as red, itchy, scaly or thickened skin between tendons and bony prominences, plus a score of 3 points from the following list:

Criteria	Points
Current psoriasis	2
Family history of current psoriasis	1
Family history of psoriasis 5 years or more ago	1
Current dactylitis	1
Current enthesitis	1
Current nail psoriasis	1
Negative blood test for rheumatoid factor	1

• Family history of psoriatic disease

Smoking is associated with a higher risk of developing psoriasis along with more severe symptoms. Alcohol can also increase risk of psoriasis, decrease the effectiveness of treatment, and therefore has effects from some medications, such as methotrexate.

Psoriatic Arthritis Symptoms

PsA occurs equally, but presents differently, in women and men. Studies suggest that women are more likely to experience:

- Polyarthritis – arthritis impacting five or more joints
- Symptoms in the peripheral joints (arms, wrists, hands, feet, ankles, and fingers)
- More pain reported pain, swollen joint counts, fatigue, and functional difficulties
- Worse patient-reported responses to treatment and remission

The biological cause for these differences is unknown.

■ **Clinician Education Fact Sheets**

SWHR produced three fact sheets to assist with the diagnosis and treatment of [alopecia areata](#), [atopic dermatitis](#), and [psoriatic arthritis](#) in primary care, all part of SWHR’s Autoimmune Skin programs. The fact sheets review common signs and symptoms for each of the diseases, risk factors and health impacts for women, and treatment options.

■ **Journal Articles**

A key component of SWHR’s science program is harnessing the knowledge gathered through SWHR’s network of interdisciplinary stakeholders to address research, education, and clinical care gaps and opportunities. In 2021, SWHR, often in collaboration with members of its scientific Working Groups, published six papers:

- [Gaps and Opportunities to Address Human Papillomavirus-Related Cancers](#), December 2021, *Journal of Women’s Health*
- [The Roles of Sex and Gender in Women’s Eye Health Disparities in the United States](#), October 2021, *Biology of Sex Differences*
- [Menopause Preparedness: Perspectives for Patient, Provider, and Policymaker Consideration](#), October 2021, *Menopause: Journal of the North American Menopause Society*
- [Uterine Fibroids: Assessing Unmet Needs from Bench to Bedside](#), August 2021, *Journal of Women’s Health*

Diagnosing Psoriatic Arthritis

While no single test can confirm psoriatic arthritis, a physical exam, imaging tests, and lab tests are used to diagnose the condition and/or rule out other conditions. Diagnosis is often made easier by the presence of psoriasis, although in about 10% of patients, PsA may occur before psoriasis. There is no clinical test for PsA, however certain genetic tests exist to help identify signs and symptoms of the disease. For example, it is recommended that individuals with psoriasis complete the Psoriasis Epidemiology Screening Test (PEST) every 5 months.

The internationally agreed-upon Classification of Psoriatic Arthritis (CASPAR) criteria use a point system to help in diagnosis. A patient must have at least 3 points for PsA, with at least 1 point for psoriasis. Psoriasis is defined as red, itchy, scaly or thickened skin between tendons and bony prominences, plus a score of 3 points from the following list:

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• Family history of psoriatic disease

Smoking is associated with a higher risk of developing psoriasis along with more severe symptoms. Alcohol can also increase risk of psoriasis, decrease the effectiveness of treatment, and therefore has effects from some medications, such as methotrexate.

Treating Psoriatic Arthritis

There is no cure for PsA, but there are several medical and lifestyle treatment approaches that can prevent progression of PsA and improve quality of life for patients. Treatment approaches can vary depending on the type and severity of disease.

Medications

Reduce inflammation

- Nonsteroidal anti-inflammatory drugs (NSAIDs)**: ibuprofen, naproxen
- Disease-modifying antirheumatic drugs (DMARDs)**: methotrexate, cyclosporine
- Biologic agents***: etanercept, certolizumab, ixekicimab, secukinumab, ustekinumab

Slow progression and joint damage

- Disease-modifying antirheumatic drugs (DMARDs): methotrexate, sulfasalazine
- Biologic agents***: etanercept, certolizumab, ixekicimab, secukinumab, ustekinumab

Lifestyle Approaches

- Moderate exercise can reduce stiffness or pain
- Healthy weight maintenance puts less strain on joints
- Heat and cold therapy can ease swelling and joint pain
- No smoking and reducing alcohol intake

Diagnosis and Treatment

PsA often goes undiagnosed or misdiagnosed in individuals of color. While people are more likely to be diagnosed with PsA than Black or Latin people, in part because the latter are more likely to present in red patches of skin with itchy white scales that are not necessarily what the presentation of the condition in darker skin. There is also evidence to suggest that PsA may be underdiagnosed in people of color who are diagnosed.

When to Refer to a Specialist

Patients should be referred to a specialist clinic when there is diagnosis of PsA in suspicion of PsA. If suspicion of psoriasis is low, the patient should be referred to a dermatologist. If suspicion of PsA is high, the patient should be referred to a rheumatologist.

References

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Clinician Education Fact Sheet on Psoriatic Arthritis (SWHR Autoimmune Skin Program)

▪ **Patient Empowerment Guides**

With stigma and misinformation surrounding so many women’s health issues, SWHR recognizes the need to create easy-to-understand, all-in-one resources for women—both as patients and caregivers—and their families to help them navigate their care. SWHR’s 2021 patient empowerment guides—a [Uterine Fibroids Toolkit](#) and an [Endometriosis Toolkit](#), which was also adapted into an [Endometriosis Toolkit Video Series](#) for YouTube—provide guidance on uterine fibroids and endometriosis treatment and diagnosis, advice on how to have productive conversations with health care providers, and offer tips for living well with these gynecologic health conditions.



▪ **Roadmaps**

New in 2021, SWHR’s roadmaps are intended to serve as educational tools for specific stakeholder groups. SWHR’s roadmap, [Crucial Vaccination Conversations: A Roadmap to Engage Women and their Communities](#), was designed for community program planners as they engage women and their families in conversations and initiatives to improve individual and public health through vaccinations, and the [Genetic Screening Roadmap: A Clinician’s Guide to Improving Quality Maternal Health Care](#) was created to assist maternal health care providers in framing and implementing genetic screening across the women’s health continuum.

▪ **Fact Sheets**

In addition to clinician-focused fact sheets, SWHR also produced several fact sheets to provide information on a range of women’s health issues, including menopause, eye health, and maternal immunization. In 2021, SWHR produced the following fact sheets:

- [A Look at Women’s Eye Health](#)
- [Focus on Fibroids](#)
- [Maternal Immunizations: Quick Guide](#)
- [Menopause Preparedness](#)
- [Migraine Matters](#)

▪ **Blog Series**

To allow deeper dives into various topic areas, SWHR produced three different [blog series](#) in 2021 covering maternal and infant health disparities, bone health, and liver health. These blogs complemented the additional blog articles SWHR published throughout the year.

SWHR 2021 Science Programs

SWHR's science programs bring together expert researchers, health care providers, patients, and other health care leaders to identify research gaps and address unmet needs in diseases and conditions that disproportionately, differently, or exclusively affect women. SWHR programs in 2021 focused on the following topics:

Alzheimer's Disease.

This program published a commentary that shared how better integration of sex as a biological variable could open new doors in treatment research and provided examples of best practices to account for sex as a biological variable within preclinical studies.

Autoimmune Skin Diseases (Alopecia Areata, Atopic Dermatitis, Psoriatic Arthritis).

This program highlighted the health, social, and economic impacts of the autoimmune skin diseases alopecia areata and atopic dermatitis, as well as the immune-mediated disease of psoriatic arthritis on women, both as patients and caregivers.

Bone Health.

This program examined bone health's relation to other women's health conditions, such as menopause, uterine fibroids, and endometriosis.

Endometriosis. This program raised awareness of the gaps in research, diagnosis, treatment, and care for endometriosis.

Expanded Carrier Screening.

This program addressed access and coverage issues for ECS innovations and improving health equity for all women, regardless of risk, age, or ethnic/racial background.

Eye Health.

This program aimed to identify unmet needs, knowledge gaps, and burden of disease specific to women's vision health and explore means to raise awareness and further treatment strategies.

Fertility Options.

This program supported education for women, clinicians, and other stakeholders on the spectrum of fertility options available to women, including minimally-invasive fertility options.

HPV-Related Diseases.

This program raised awareness of the gaps in research, clinical practice, and patient education that need to be addressed in order to improve health outcomes in women with HPV pre-cancers and cancers.

Immunization Education.

This program supported public education and community outreach to educate women from diverse communities on the importance of vaccines in preventive health care for adults and children.

Liver Health.

This blog series raised awareness about women's liver health issues, such as primary biliary cholangitis, a chronic and progressive autoimmune liver disease that overwhelmingly affects women.

Maternal and Infant Health Disparities.

This outreach campaign explores these disparities and related issues affecting underserved populations, including Black, Native American, and Hispanic mothers and babies.

Menopause.

This program raised awareness of knowledge gaps and unmet needs related to the menopausal transition across areas of education, clinical care, research, and policy.

Migraine.

This program engaged, educated, and empowered patients, health care professionals, and health care decision-makers about the burden of migraine on women.

Noninvasive Prenatal Screening.

This program explored how access to innovation in NIPS may benefit individuals and families who are pregnant or planning to become pregnant.

Uterine Fibroids.

This program raised awareness of the gaps in research, diagnosis, treatment, and care for uterine fibroids.

Advocacy and Government Affairs

Throughout the year, SWHR champions policies that promote women's health. We do this by translating the scientific evidence base into policies aimed at improving women's health and related health disparities; acting as a source of expert guidance to policymakers; and pushing for improved inclusion and representation of women from diverse backgrounds across all levels of science.

Publication of the Inaugural SWHR Women's Health Policy Agenda

SWHR's inaugural Women's Health Policy Agenda outlines policies that SWHR supports across five key areas: public health, research and clinical trials, lifespan issues, coverage and access, and biomedical workforce. The document is intended to serve as a roadmap to advance the health and well-being of all women in 2021 and beyond. [View the 2021 SWHR Women's Health Policy Agenda.](#)

Launch of the Friends of ORWH Coalition

SWHR this year [launched a new coalition](#) to support the important work of the National Institutes of Health's (NIH) Office of Research on Women's Health (ORWH). The [Friends of ORWH](#) coalition is composed of organizations representing researchers, clinicians, patients and patient advocacy organizations, and policy advocates that are committed to addressing sex and gender disparities in health and prioritizing research gaps and unmet needs to advance women's health. SWHR is proud to have engaged in advocating for the 1990 creation of the ORWH, and the launch of the FORWH coalition is a way to continue this legacy.

SWHR President and CEO Testifies Before Appropriations Committee

As part of SWHR's broader efforts to support NIH and advance women's health, SWHR President and CEO Kathryn Schubert [testified](#) on May 19, 2021 before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies to outline SWHR's NIH funding priorities for fiscal year 2022, including funding requests for ORWH and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD).

Raising Awareness of Women's Health Research Issues on Capitol Hill

In response to the changing health care landscape and the many opportunities to shape health and health care at the federal level, SWHR actively monitors and responds to federal legislation and regulations that have the potential to impact the research enterprise, including the research workforce, and public health—and specifically, the health of women. Additionally, SWHR proactively engages with Capitol Hill by meeting with legislators on a number of policy areas and hosts educational events on the Hill to

raise awareness of the myriad issues that exclusively, differently, or disproportionately affect women and to identify policy gaps and areas of opportunity. In 2021, SWHR:

- Encouraged policymakers to provide prioritized and sustained funding for the NIH, ORWH, NICHD, and other federal research agencies and programs at the highest possible levels in fiscal year 2022.
- Hosted four congressional briefings on the subjects of the [role of sex and gender in research](#), in partnership with the Endocrine Society; [uterine fibroids](#), in partnership with the Fibroid Foundation, the Black Women's Health Imperative, the White Dress Project, and the Society for Interventional Radiology; [menopause](#); and [thyroid eye disease](#), in partnership with the Alliance for Eye and Vision Research, Research to Prevent Blindness, Prevent Blindness, and the Association for Research in Vision and Ophthalmology.
- Joined peer organizations on statements and sign-on letters on topics ranging from federal appropriations to the Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act.
- Collaborated with a coalition of stakeholders advocating for the Stephanie Tubbs Jones Uterine Fibroid Research and Education Act (H.R. 2007, S. 2444).

SWHR Elevates Women's Health Research through Agency Requests for Information

Throughout the year, SWHR reviews federal agencies' requests for information and responds to those that could affect the federal research enterprise or present a unique opportunity to elevate or promote women's health needs. In 2021, SWHR provided comments on the following:

- [National Cancer Institute's Request for Information: Enhancing Diversity and Inclusion in the Cancer Research Workforce](#)
- [National Institutes of Health Request for Information: Comments to Advance and Strengthen Racial Equity, Diversity, and Inclusion in the Biomedical Research Workforce and Advance Health Disparities and Health Equity Research](#)
- [Office of Research on Women's Health Request for Information: Informing the Women's Health Consensus Conference](#)
- [U.S. Department of Health and Human Services Strategic Plan for Fiscal Years 2022-2026](#)
- [U.S. Preventive Services Task Force Draft Research Plan for Cervical Cancer Screenings](#)

Education

SWHR drives the national conversation on women's health and sex differences research. We do this by serving as a trusted source for information on women's health and sex differences research; raising awareness of disparities and unmet needs in women's health; and creating engaging, scientifically-driven content for diverse audiences on women's health and sex differences research.

Engaging and Raising Awareness Through SWHR Channels

SWHR's social media channels and its blog are outlets through which the organization connects with partners, including peers in the scientific, research, and public health communities, industry, and the public. Over the year, SWHR engaged on Facebook, LinkedIn, Twitter, and YouTube, and published blogs sharing information of relevance to women and their families. Blog posts highlighted new SWHR tools and resources, women's health issues, and relevant policy updates.

Blog post highlights in 2021 include the following:

- [COVID-19 Impedes Career Progress for Women in STEMM](#)
- [Disparities in Biomedical Research: A Women's Health Issue](#)
- [Exploring the Connection Between Psoriatic Arthritis and Bone Health](#)
- [It's Time for a Mood Change on Menopause](#)
- [Living with PBC: A Patient's Journey with a Rare Liver Disease](#)
- [Maternal Health Disparities: A Q&A with Dr. Jasmine Johnson](#)
- [The Complementary Nature of Federal Science Agencies in Advancing the Nation's Health](#)

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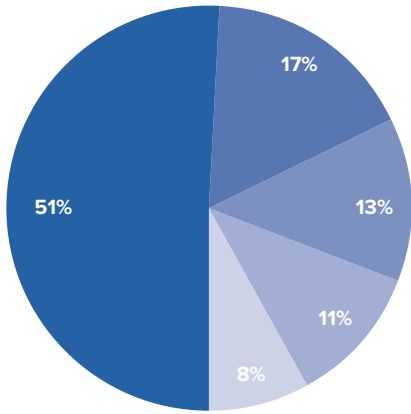
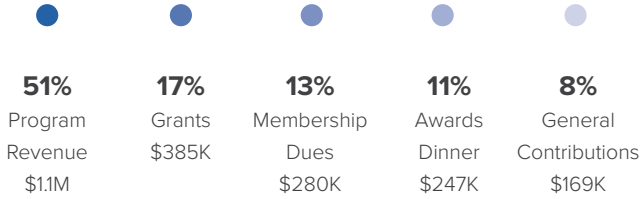
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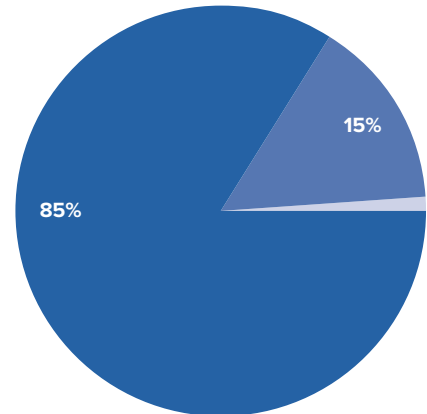
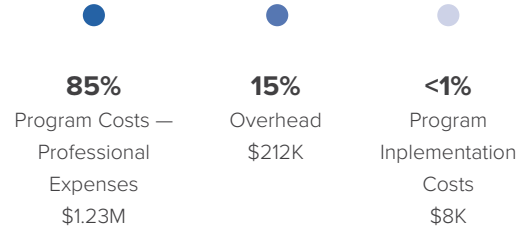
2021 Operational Highlights

Statement of Activities

2021 Revenue

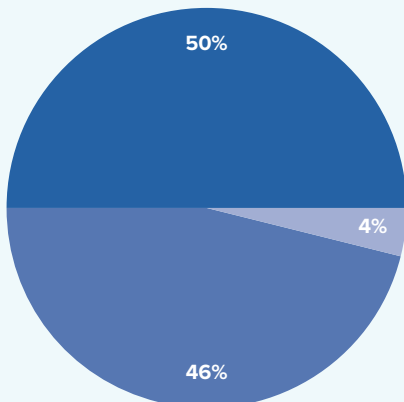


2021 Expenses



Statement of Financial Position

Balance Sheet



- 50% — Assets • \$2.4M
- 46% — Capital • \$2.2M
- 4% — Liabilities • \$167K

Executive Committee



Kathryn G. Schubert, MPP, CAE
SWHR President and CEO
Ex Officio



Shontelle Dodson, PharmD
Board Chair



Gretta Stone
Secretary/Treasurer



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