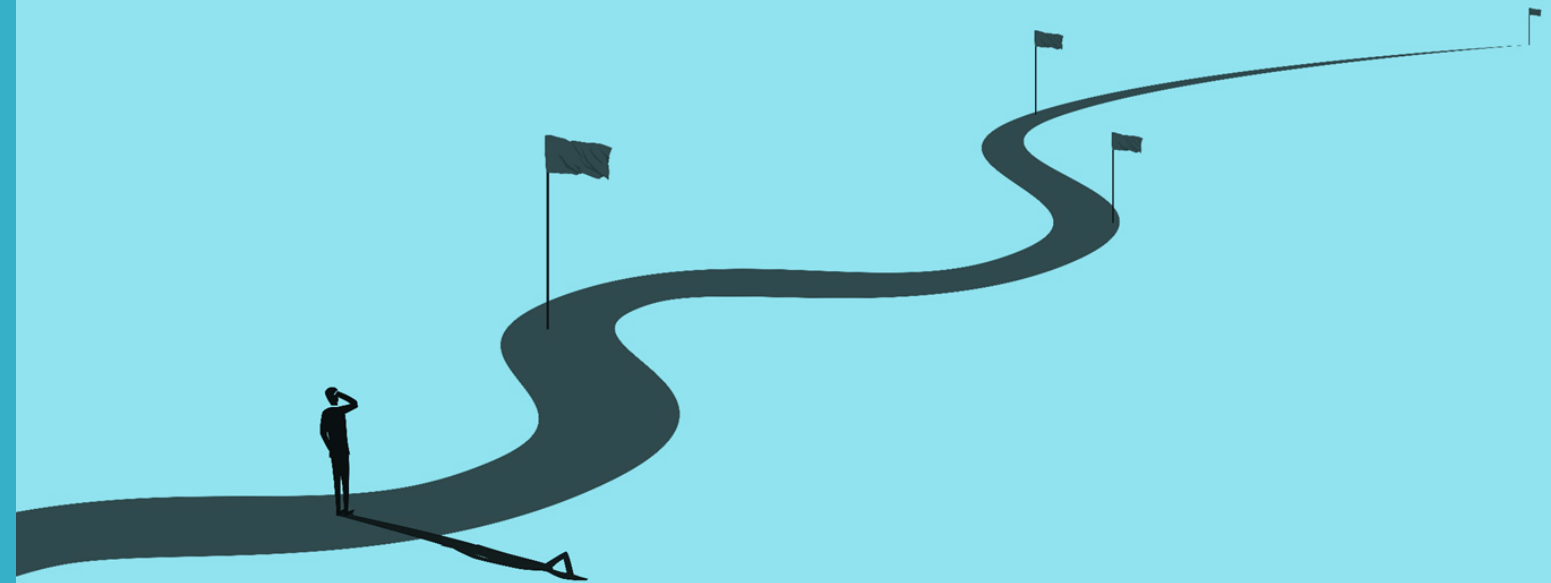
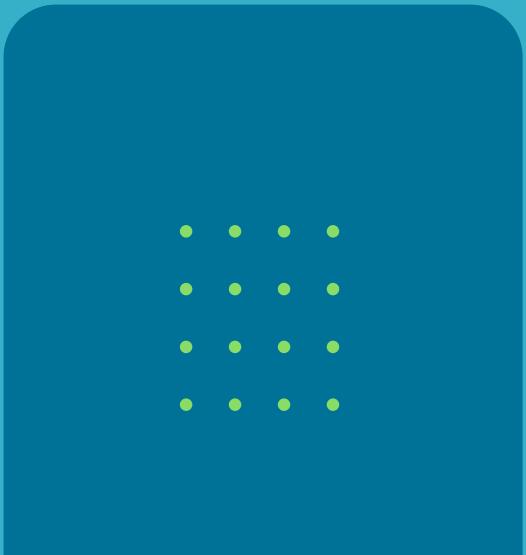


National  
Scleroderma  
Foundation

# Strategic Framework for 2024 and Beyond



# Introduction



I believe that a powerful sense of community is at the heart of solving some of the world's most challenging problems. As the leading patient advocacy organization serving people living with scleroderma in the United States, the National Scleroderma Foundation is positioned to play an important role in addressing the challenges of the future. This new strategic framework enables us to focus the Foundation's efforts toward maximizing the impact we can have on complex issues facing those living with scleroderma, their families and support networks as well as the medical and scientific communities.

This framework is meant to serve our organization in an ever-changing world and provide flexibility in scope and scale, while providing a clear vision of where we want to go, and where we need to be, in order to best serve the scleroderma community in the United States.

I am immensely proud of the new framework our leadership has co-created and believe that working together, we can ensure that the Foundation realizes its vision of being a relentless force in finding a cure for scleroderma.

A handwritten signature in black ink, appearing to read 'Mary J. Wheatley'. The signature is fluid and cursive, with a large loop at the end.

Mary J. Wheatley, IOM, CAE  
Chief Executive Officer



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# Methodology



**Initial Themes**

- Strategic Discussion at Board of Directors Meeting



**Leadership Input**

- Joint Board Meeting including:
  - Board of Directors
  - MSAB
  - PAB




**Community Input**

- 196 respondents
- Open to public
- Net Promoter Score
- Data shared at Leadership Weekend



**Stakeholder Interviews**

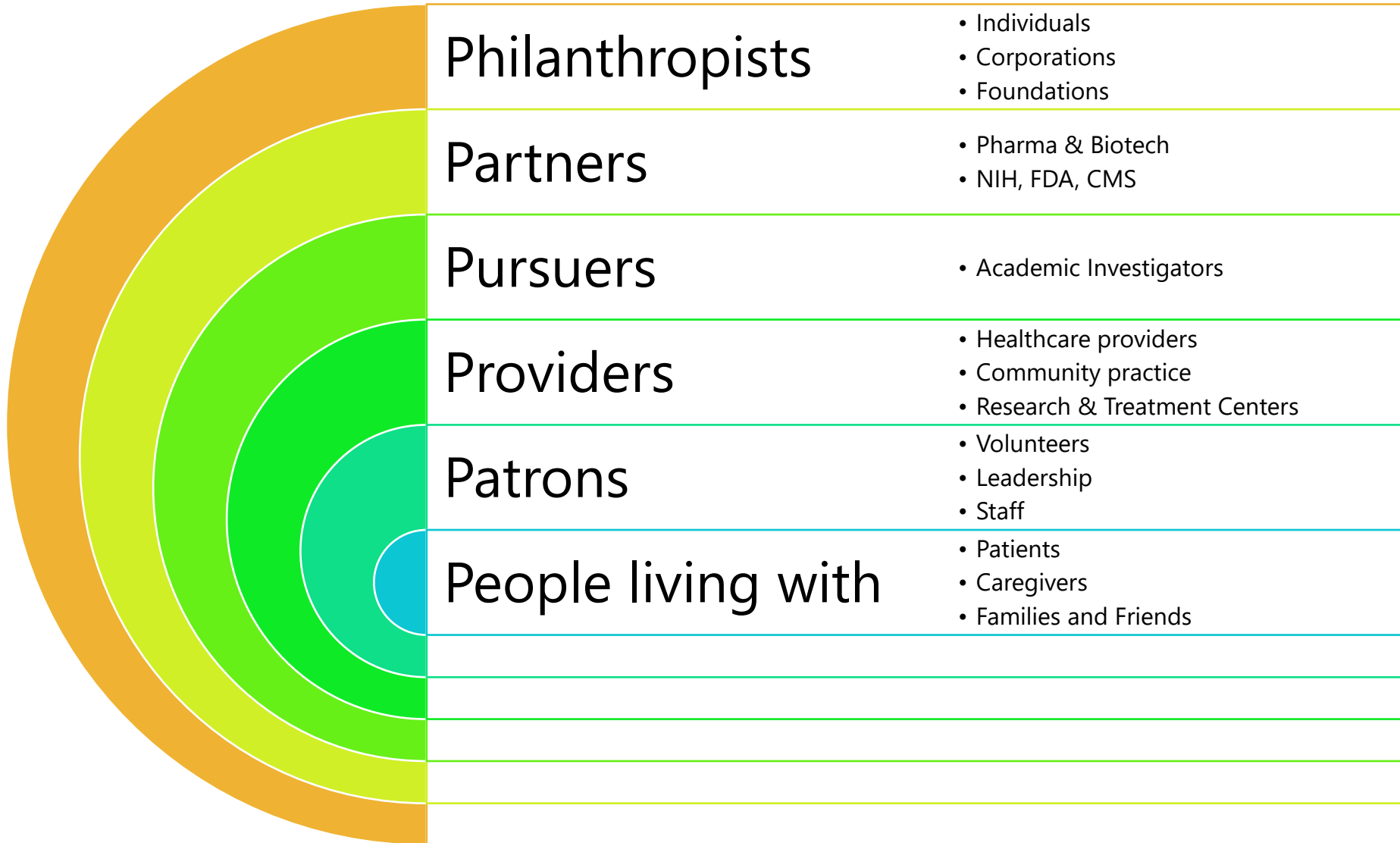
- Six stakeholder groups represented
- 20+ hours of interviews
- Data shared at Leadership Weekend



**Chapter Input**

- Chapter Advisory Committee Reps
- New Chapter Volunteers
- Executive Directors

# Stakeholders



# Vision for the future

- Increase Collaboration
- Facilitate Clear and Open Communications
- Build on our Reputation as a Trusted Source
- Create a Diverse and Unified Community
- Embody Innovation
- Build a Culture of Philanthropy



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## Goal A: Increase Collaboration

- Increase awareness of scleroderma across stakeholder groups
- Foster an environment that encourages partnerships across all stakeholder groups
- Forge alliances and cultivate synergies across stakeholder groups
- Pool expertise and resources to drive groundbreaking advancements in scleroderma research and care



## Goal B: Facilitate Clear and Open Communications

- Facilitate clear, accessible, and open channels of communication
- Employ transparent and effective communication practices
- Encourage open dialogue across all stakeholder groups
- Ensure interactions within our organization, with the community we serve, and among our diverse stakeholders foster trust and unity
- Build strong, enduring relationships built on trust and understanding



## Goal C: Build on Our Reputation as a Trusted Source

- Partner with the best and brightest in the scleroderma community
- Maintain our dedication to accuracy, reliability, and integrity
- Disseminate information that underscores our commitment to being a trusted source for scleroderma-related resources, guidance, and support
- Serve as the go-to authority, empowering individuals with credible information to make informed decisions regarding their health and well-being





## Goal D: Create a Diverse and Unified Community

- Celebrate diversity and embrace unity across all stakeholder groups
- Create an inclusive environment that values and respects the unique experiences, backgrounds, and perspectives of all individuals affected by scleroderma
- Foster a sense of belonging and solidarity
- Unite our community in a collective journey towards empowerment, support, and resilience



## Goal E: Embody Innovation

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- Embrace innovation across all facets of our endeavors, from research methodologies and treatment approaches to outreach strategies and advocacy efforts
- Foster a culture that encourages creativity, experimentation, and the adoption of cutting-edge technologies
- Drive transformative change in the fight against scleroderma



## Goal F: Build a Culture of Philanthropy

- Cultivate a culture of giving and generosity within the scleroderma community, across all stakeholder groups
- Inspire individuals, corporations, and philanthropies to support our cause
- Expand our reach, amplify our impact, and ensure sustainable initiatives that continue to advance research, provide support, and advocate for the needs of those affected by scleroderma





# Summary



The Foundation's new strategic framework is meant to be a three-to-five-year roadmap on how to succeed in the current environment and thrive in the coming years. It is intended to be a living document that is flexible and responsive to the emerging needs of our community, as well as anticipated shifts in the environment. Rather than being an endpoint, the plan is the first step in a process designed to ensure that the Foundation remains an effective and sustainable voice for people living with scleroderma, their families, support networks, and the medical and scientific communities that care for them.

The planning process was driven by the knowledge that, in order for the Foundation to effectively serve the community, the framework itself must be co-created by its leaders, volunteers, members, donors and staff, with input from the broader scleroderma community. To achieve this, the Foundation was intentional in seeking input from every member of the community and each of its six stakeholder groups.

This meant that every member of the Foundation's Board of Directors, Chapter Advisory Committees, Medical and Scientific Advisory Board, Patient Advisory Board, as well as chapter volunteers, staff, and individual and corporate supporters were asked to participate in planning meetings, strategic discussions, surveys and phone interviews to discuss the key issues and opportunities facing the organization.

The resulting framework is the culmination of 10 months of work, including more than 100 hours of strategic discussions, community input, interviews, and meetings with leadership, volunteers and staff.

The implementation process of the plan will be comprehensive, with the Foundation focusing its current work and programs in concert with the new strategic priorities. During the implementation stage, the Foundation will continuously share updates, as well as seek input and feedback from stakeholders on defining the programs and activities the Foundation undertakes, as well as concrete outcomes within each set of goals and objectives.

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