BRINGING THE VOICE OF THE PATIENT TO THE DEVELOPMENT OF NEW THERAPIES
Dear Valued Industry Partner,

Thank you for expressing interest in our Patients as Partners program. As the leading patient advocacy organization, we are proud to be able to offer your company the opportunity to engage our community to help advance the care for those suffering from scleroderma.

Patients as Partners provides you with patient advocates who will wield a significant impact in:

- protocol reviews
- advisory boards
- clinical trial design
- patient-centered outcomes
- marketing development

The National Scleroderma Foundation has a multi-year track record of working successfully with numerous industry partners on national and global initiatives. I am proud to share that together through Patients as Partners we are able to collectively advance the development of therapies and enhance patient experiences including quality of life.

Thank you for your commitment to helping those with scleroderma.

Mary J. Wheatley
Chief Executive Officer
Bringing the Voice of the Patient to You

Partners Program is designed to work in concert with industry on a variety of needs across all areas of drug development, from clinical trial protocol development through FDA approval and post-approval activities.

Roles for Patient Advocates

Clinical Trial Design & Recruitment
- Share unique insights related to living with the disease including the impact of major disease manifestations.
- Patient Advocates can assist with defining important clinical questions.
- Provide practical feedback on clinical trial protocols.
- Disseminate information about clinical trials through the patient network.
- Provide insights/feedback about informed consent language.
- Working through the organization, help to recruit patients into trials.

Approval
- Participate in legislative and regulatory processes by providing patient-centered testimony.
- Provide access to opinion leaders.

Brand Insights
- Provide a patient perspective of market dynamics that data do not always describe or explain.
- Share insights with the industry on patient needs

Adherence
- Provide peer-to-peer education to enhance the understanding of the treatment.
- Reinforce the importance of adherence for best patient outcomes.

Policy Information
- Participate in the creation of screening and treatment guidelines.
- Function as the “consumer voice” on regulatory and healthcare advisory panels
- Provide patient perspective as companies deal with policy issues.
- Assist in the formulation of strategies that impact public decision-making.

Access and Reimbursement
- Serve as representatives to provide testimony to government and regulatory advisory boards.
- Share personal experience with the product to help regulators and payers understand patient needs and perspectives to assist in the creation of appropriate access and reimbursements.

To ensure that the Scleroderma Foundation has an informed and prepared group of advocates, its program trains interested advocates in preparation for their involvement with industry partners.

Each Patients as Partners collaboration is unique to your company. We take the time to discuss your deliverables, timeline, and requirements at an intake meeting.
Industry Benefits

Your company will benefit from the following by working with well-informed patient advocates.

Our patient network can provide **Clinical Trial Awareness** through our powerful group of passionate, well-informed patient advocates.

**Competitive advantage** by differentiating your self from other companies/competitors working in the same therapeutic space

Foster greater **brand awareness** and **credibility**

**Engagement** with relevant patient communities in which the company may not yet be well known

**Advance drug development** while learning about the needs and challenges of the patient

**Defining patient-center outcomes** through well-informed patient advocates clarifying disease-specific issues and outcomes that are most specific to individuals affected by scleroderma
If you are interested in exploring next steps with Patient as Partners, please schedule an intake meeting.