

2025 Leanne Storch Support Group Guidelines

About Leanne Storch and the Fund

Leanne Storch was diagnosed with pulmonary fibrosis (PF) in January 2003. With a desire to positively impact the PF community, she joined the Pulmonary Fibrosis Foundation (PFF) in 2004 and ultimately served as the Foundation's Executive Director from 2008 until 2010. Ms. Storch provided countless hours advocating on behalf of the PF community, including leading a support group for ten years. She received a lung transplant in 2014 and was a dedicated champion for the PF community. The Pulmonary Fibrosis Foundation is sad to report that Leanne passed away in 2019, but her spirit and work live on through the Leanne Storch Support Group Fund (LSSGF). The Leanne Storch Support Group Fund, established in 2012, proudly honors the commitment of Ms. Storch.

The PFF is dedicated to assisting the PF support group community. The Leanne Storch Support Group Fund enhances the PFF Support Group Leader Network by providing funds to assist leaders in meeting the objectives of their support group, including establishing new support groups and hosting meaningful educational events.

Leanne Storch Support Group Fund Grants

Support group leaders may apply for the following types of grants:

- New Support Group Grant (\$500) a grant to establish a new pulmonary fibrosis support group
- Support Group Development Grant (\$750) a grant to help an existing PF support group expand and extend its impact.

Groups are limited to one grant per funding year. Support group leaders can request funds to cover expenses such as site rental fees, printing costs, refreshments, honoraria for non-healthcare professionals, and other costs related to starting and/or running a PF support group. Groups must meet at least quarterly to qualify for a LSSGF grant.

2025 Application Cycle

Applications for this year's cycle will be accepted beginning January 17, 2025 until February 28, 2025.

Submission of Applications

- All applications for the LSSGF must be submitted online. Visit the <u>Lead a Support</u> <u>Group page</u> on the PFF website to access and submit an application. Emailed submissions will not be accepted.
- All applications for the Leanne Storch Support Group Fund must provide a detailed quarterly or monthly plan on how the funds will be used.
- Applications for New Support Group Grants will be accepted no earlier than 60 days before the group's first meeting.
- Support Group Development Grants, where funds are to be partially used to support a planned event, must be submitted at least 60 days prior to the event.

Review and Notification Process

- All applications will be reviewed and scored by the LSSGF Review Working Group, which is made up of PFF Support Group Leader Network members and PFF staff.
- A member of the Working Group will reach out to each applicant to conduct a phone interview to discuss the application.
- Funding decisions will be made based on the overall quality of the application and interview.
- Applicants will be notified about the status of their application by a member of the PFF staff. If funded, applicants will then receive a Letter of Agreement. *Please note that an individual must be named on the Letter of Agreement. The PFF is not able to make grant payments directly to an institution or healthcare organization.*
- Funds will be released after the PFF has received a signed copy of the Letter of Agreement and other forms needed to complete the payment.

This process is in place to ensure that all applications are evaluated equally and fulfill the PFF's mission, vision, values, and strategic plan.

Post-Award Guidelines

- Funded support groups are asked to acknowledge the PFF on all print and electronic materials pertaining to activities of the support group by using an approved PFF logo found in the PFF Style Guide and language describing the support group as being "supported by the Pulmonary Fibrosis Foundation." The PFF Style Guide will be sent to each awardee with their letter of agreement.
- Funded support groups receive the benefit of no-cost access to PFF educational materials and are asked to make these available in their support group meetings. The materials may be obtained by contacting the PFF Help Center at 844.TALKPFF (844.825.5733) or help@pulmonaryfibrosis.org or fill out the online order form here.
- Funded support groups are asked to conduct meetings at least quarterly to ensure the needs of the local PF community are being met.
- Funded support groups should keep the PFF informed on any changes to their group through the <u>Support Group Meeting Information survey here</u>.
- Funded support groups are asked to offer a virtual or hybrid format meeting at least once quarterly. Many support group participants are at high risk for severe illness from COVID-19 and are <u>encouraged to take extra precautions by the Centers for Disease</u> <u>Control & Prevention (CDC)</u>, such as avoiding crowded areas. Additionally, some support group participants are limited in their ability to travel to in-person meetings for other health reasons. We ask funded support groups to continue to offer meetings in a virtual or hybrid format to meet the needs of all group members.
- The LSSGF grant can be used to cover expenses such as site rental fees, printing costs, refreshments, virtual meeting platform subscription, honoraria for non-healthcare professionals, and other costs related to starting and/or running a pulmonary fibrosis support group. Please reference the <u>LSSGF FAQ</u> for a list of other acceptable uses of the grant funds.
- The grant funds may not be used for stipends/honoraria for healthcare professionals, to
 pay a healthcare organization, for coverage of costs related to an individual's medical
 care, or for donations to nonprofit organization that exceed \$50. This is not an
 exhaustive list of expenses for which the funds may not be used. Contact Molly Abrams
 at mabrams@pulmonaryfibrosis.org if you have any questions about the acceptable use
 of LSSGF award funds. Grant recipients may be asked to return any funds spent that

were not considered an acceptable use of the LSSGF award.

- The deadline to use all grant funds is December 31, 2025.
- The PFF requires that grant recipients submit either an official expense report or receipts to document all grant expenditures made during the grant year. Submission of receipts and/or an expense report is separate from the report on fund use. Receipts can be emailed to Molly Abrams at <u>mabrams@pulmonaryfibrosis.org</u> or mailed to the PFF office. If mailing receipts, the PFF office address will be provided closer to the 2025 deadline. Receipts must be received by December 31, 2025.
- Grant recipients are asked to submit a report of how the funds were used and how they benefited the group. This report is separate from the submission of receipts. **The deadline to submit the report is January 15, 2026.** The report is required for your support group to be considered for future grants. You can find this report here.
- Groups must use all funds granted to them. Any unused grant funds, exceeding the amount of \$50, will need to be returned to the PFF by January 15, 2026. Checks for unused funds should be made out to the Pulmonary Fibrosis Foundation and mailed to the PFF office. The PFF office address will be provided closer to the 2025 deadline.

For questions or more information, please contact Molly Abrams, Coordinator, Volunteer Programs, at <u>mabrams@pulmonaryfibrosis.org</u> or 312.854.1940.