

PAP FOUNDATION PRIVACY POLICY

Individuals may view our website without providing any information to us and we do not collect any personal information about you without your consent.

Privacy Policy

Patient privacy and confidentiality is of the highest priority at The PAP Foundation and we are committed to protecting your privacy when you visit our website. The information we collect is used to respond to your questions and requests and to help keep you informed about state-of-the-art knowledge and current clinical research efforts related to PAP.

Personal Information Provided by You

We collect email addresses and other personal information only when you provide it to us. If you fill-out a form or survey, request information or make a donation, we collect your name, address, city, state, zip code, telephone number and email address.

Use of Personal Information

We do not sell, rent or otherwise release our website visitor's personal information to any other individuals or organization. When you provide us with personal information, the PAP Foundation may use it in the following ways:

Requests for Information Requests / Questions - When we respond to your email request or questions, we collect your information and directly place you on our mailing list to receive publications and other mailings via regular mail or email.

Donations - When you make a donation to us you are placed on our mailing list to receive publications and other mailings either via regular mail or email. As a donor, you may request to have your name removed from these mailing lists.

Joining the RLDC Contact Registry - The Contact Registry provides an opportunity for individuals with PAP to register themselves to receive information about clinical research that is or will be conducted by the Rare Lung Diseases Consortium (RLDC). You may also learn about progress being made towards treatment advances by researchers who specialize in your disease or disorder. By joining the Contact Registry, you will be asked to provide information about you (or your child) and how you can be contacted. The registry will use that information to contact those registered individuals who might qualify for participation in a clinical research study. We may also use your contact information in order to communicate with you about treatment information and sources.

Joining PAP Foundation Mailing List - The PAP Foundation's mailing list provides an opportunity for the us to send you to information about PAP, either by email or regular post. Such information may include advances in our understanding about the cause of PAP, methods to diagnose or treat the disorder or clinical research efforts to evaluate new and better treatments for PAP.

Consent to Use Your Information

When you provide us information to us through the PAP Foundation's online forms, you consent to the collection and use of this information as described above, unless you specify otherwise.

Removal from the PAP Foundation Mailing List

We understand that you may wish be removed from the Foundation's mailing list or to limit the ways in which the Foundation uses your personal information. If so, please send an email to colleen.morrone@papfoundation.org and provide your: 1) full name, current email address, mailing address and a sentence indicating your request, e.g., "Please, remove my name from the PAP Foundation mailing list.", etc.

Updates and Changes to Your Personal Information

To review or correct your personal information with the PAP Foundation, please provide your name and a sentence explaining the review and/or correction.

Security

We take every precaution to protect your personal information. At the PAP Foundation, your personal information is kept confidential and stored in a secure environment, and access to your information is restricted only to authorized staff with a legitimate and specific business purpose. For example, we may need access to your information to process your online donations. Our website "www.papfoundation.org" is owned and maintained by the PAP Foundation. If you have any questions about your privacy, the use of information collected, or the security of our website, send an email to the website manager at colleen.morrone@papfoundation.org.