



## PRIVACY POLICY

The Pulmonary Hypertension Association of Canada (“PHA Canada”) is committed to protecting the privacy of the personal information of its employees, volunteers, constituents, and other stakeholders. We value the trust of the members of the PH community and of the public. We also recognize that maintaining this trust requires that we be transparent and accountable in how we treat the information that members choose to share.

During various projects, programs, conferences, and other ways in which members may interact with us, PHA Canada gathers and uses personal information. Anyone from whom we collect such information shall expect that it will be carefully protected. Further, any use of, or other dealing with, this information is subject to consent. PHA Canada’s privacy practices are designed to ensure protection of all such information.

### 1. Defining Personal Information:

Personal information is any information that can be used to distinguish, identify, or contact a specific individual. This information can include an individual’s opinions or beliefs, as well as facts about or related to the individual. Exceptions: business contact information, such as names, addresses, and telephone numbers as published in telephone directories, are not considered personal information. Information in the public domain is not subject to privacy legislation, and as such, is not included in this policy.

Where members of the PH community and other stakeholders in PHA Canada provide us their home contact information as business contact information, PHA Canada considers the contact information as business contact information. This is therefore not subject to protection as personal information.

We consider donor, employee, and volunteer information always to be personal information and do not disclose information about donors, volunteers, or employees (other than in their capacity as a PHA Canada employee) without consent.

As per patient confidentiality regulations, PHA Canada considers any disclosure about personal medical information or health status made by any of our constituents as personal information. We will not share any such information without explicit consent of the constituent.

PHA Canada observes the following practices concerning consent, data collection, and online data security when collecting, maintaining, and using personal information:

### 2. Consent:

PHA Canada requires consent from individuals regarding the proposed use of personal information. Consent can either be expressed or implied, depending on the purpose of the use and type of information collected. Expressed consent can be given either electronically or in writing. Implied consent is consent that can be reasonably be inferred from an individual’s action or inaction. An individual’s consent is required before information is released to outside parties.



At PHA Canada, we require expressed consent for any photography, videography, or audio recording of our constituents. Expressed consent is also required for releasing names and other contact information to other constituents for the purposes of mutual support. Implied consent is sufficient with regards to mailing of PHA Canada materials and other such items that can be reasonably inferred may be of interest to an individual who has shared his/her contact information with us.

### 3. Data Collection

#### *Security Safeguards*

PHA Canada maintains all personal information collected from our constituents in a secured database. This information is kept strictly for the purposes of communication with our constituents and is never shared unless expressed consent is given.

Personal information gathered by PHA Canada shall be kept in confidence. PHA Canada staff and relevant volunteers shall be authorized to access personal information based only on their need to deal with the information for the reason(s) for which it was obtained.

We have put in place appropriate physical and electronic policies and procedures to safeguard and secure the information we collect through both physical and online means to protect privacy, ensure data accuracy, and assure correct use of information. Special protection shall be given to all records pertaining to anonymous donors. The confidentiality of donor and volunteer records shall endure after the relationship with the individual has ended.

All personal information is stored in PHA Canada's secure database and/or a secured online database, using industry standard technology. Access to either of these databases is limited to authorized staff and select authorized volunteers. All staff and volunteers sign a confidentiality agreement.

#### *Third Party Release Protection*

We do not sell or share this information in any way with third parties (except as noted below). The Pulmonary Hypertension Association of Canada may allow access to database information by third parties providing technical services, such as email or IT support. In those instances, the third party is bound by the above terms and has agreed to hold information in confidence.

#### *Limited Collection*

The collection of personal information is limited to that which is relevant and necessary to our programs, member services, and fundraising efforts. PHA Canada shall not make any unwarranted or intrusive inquiries into a donor or prospect's gift history or personal life. PHA Canada attributes all data it collects.

#### *Limited Use, Disclosure, and Retention*

PHA Canada shall only use or disclose personal information for the purposes for which it was collected, unless expressed consent of the individual is given or as required by law. Personal information shall be retained only as long as necessary for the fulfillment of those purposes.



### ***Accuracy***

Personal information shall be as complete, accurate, and up-to-date as possible. Constituents are encouraged to review, correct, and update personal information on a regular basis. Information may be updated via email at [info@phacanada.ca](mailto:info@phacanada.ca) or by calling the PHA Canada office at 1-877-774-2226.

## **4. Online Data Security**

### ***Discussion Board, Email Groups***

Please note that PHA Canada does not control who participates in online community discussions (patients, members, third parties, etc.). While the forums may be monitored to control inappropriate content being posted, we cannot control the information being divulged by our members. If members choose to reveal any sort of personal information (contact information, medical information etc.) in these forums, they do so at their own risk.

### ***Links to Other Sites***

PHA Canada may provide on its website links to external sites that we believe may be useful or educational to our members. Please note that we are not responsible for the privacy policies or actions of the parties operating these linked sites. We suggest that members access the online privacy policies of these web sites or contact the relevant parties concerning their policies.

### ***Confidentiality***

Members may request that their name, the amount of any gifts that they have made, or any other relevant information, not be publicly released but remain anonymous.

### ***Openness***

Upon request, members shall be given access to the information in their member profile and/or donor record.

### ***Questions or Concerns?***

Further information on privacy rights can be found on the website of the Privacy Commissioner of Canada at [www.privcom.gc.ca](http://www.privcom.gc.ca). If members have questions, comments, or concerns about our privacy policies or practices, please contact us at [info@phacanada.ca](mailto:info@phacanada.ca) or call us at 1-877-774-2226.

This policy was last reviewed and approved by the Board of Directors of PHA Canada on August 9, 2021. The Board reserves the right to make changes to this policy at their discretion from time to time.

A copy of this Policy shall and will be made available at: <https://phacanada.ca/About-Us/Accountability>