

Privacy Policy

Last Updated: August 20, 2025

The Boston London Toronto Rare Disease Consortium (“BLT,” “we,” “our,” or “us”) is committed to protecting your privacy. This Privacy Policy explains how we collect, use, store, and protect your information when you interact with our website and services.

1. Scope

This Privacy Policy applies to visitors of our website and to research partners who engage with BLT through our digital platforms. It does not cover patient or medical data, as BLT does not collect or store patient information through this website.

2. Information We Collect

We may collect the following types of personal information:

- **Names**
- **Email addresses and contact details**

We do not collect medical histories, scans, or other patient health information through our website.

3. How We Use Your Information

We use the information you provide to:

- Respond to inquiries and correspondence
- Facilitate collaboration with research partners

- Maintain accurate contact records for our consortium activities
-

4. Sharing of Information

We do not share your personal information with third parties without your consent, except where required by law.

5. Legal Compliance

BLT complies with applicable privacy and data protection laws, including the Health Insurance Portability and Accountability Act (HIPAA).

6. Data Storage & Security

- Personal data is stored on secure servers.
 - We employ appropriate technical and organizational measures to safeguard your data from unauthorized access, alteration, or disclosure.
-

7. Your Rights

You have the right to:

- Request access to the personal data we hold about you
- Request correction of any inaccurate information
- Request deletion of your information (subject to applicable laws)

To exercise these rights, please contact us via the details provided below.

8. Cookies & Analytics

Our website uses cookies and Google Analytics to improve user experience and understand how visitors engage with our site. Cookies may collect non-identifiable information such as browser type, location, and usage patterns.

You can adjust your cookie preferences through your browser settings.

9. Updates to This Policy

We may update this Privacy Policy from time to time. Updates will be posted on this page with a revised “Last Updated” date.

10. Contact Us

If you have any questions about this Privacy Policy or how we handle your information, please contact us through our website:

[Insert BLT website contact form link or email address]