



Flatley Discovery Lab, LLC

PRIVACY STATEMENT

EFFECTIVE 1 AUGUST 2017

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1. Acceptance of Terms

By visiting www.FDL.org (“the Site”) or using our Services, you agree to the terms of this Privacy Statement and our accompanying Terms of Use.

2. Privacy Statement

Flatley Discovery Lab LLC (FDL) is committed to protecting your privacy. This Privacy Statement explains the types of personal information we may collect from visitors, including donors, to this Site, why we collect it, and with whom we may share it. It also describes how we protect your personal information and how you can contact us with any questions.

This Privacy Statement applies to personal information we collect from website visitors, as well as personal information we may gather outside this site, such as through mobile applications, social media and written correspondence with FDL.

3. Our Mission

FDL is a nonprofit organization whose mission is to cure cystic fibrosis (CF) and to provide all people with the disease the opportunity to lead full, productive lives by conducting research and drug development via clinical trials.

Our focus is supporting the development of new drugs to fight the disease, improving the quality of life for those with CF, and ultimately finding a cure.

4. What We Do That May Involve Personal Information

A. What's in the Scope of this Privacy Statement

The following services are among those FDL is currently providing or may provide to website visitors, members of the public, patients and families who contact us, those who register at the Site, and other individuals.

We may:

- provide public information about CF, including educational resources about CF
- help connect CF patients and families who want to communicate with other CF patients and families via blogs or forums where individuals can learn and post their own content
- conduct surveys of visitors to FDL and users of FDL services
- help patients find clinical trials
- help patients find accredited care centers

Any additional online services that we may provide involving the collection of personal information will be described on the Site.

B. What's Not in the Scope of this Privacy Statement

- *Employment-related information.* Information regarding potential employment opportunities is not covered by this Privacy Statement, even if you submit your application electronically or through the Site.
- *Services we provide to clinicians.* FDL provides certain services to CF clinicians and care centers intended to help them improve clinical care. Any health information we receive or process when providing these services to care centers is subject not to this Privacy Statement but to state privacy laws, the federal data privacy and security law called HIPAA (Health Insurance Portability and Accountability Act), or its European Union equivalent.

5. Information You Provide to FDL and Your Choices

A. Personal Information

You are welcome to make use of the educational content on the Site without providing any personal information. However, you may choose to provide us with personal information via the Site. For example, if you choose to register for a FDL account to get involved as a volunteer, request information, or similar activities, you will need to provide certain personal information such as your name, address, telephone number, and email address.

If you submit your personal information to register, send us questions and/or let us know that you would like updates about CF or FDL, we may later send you follow-up communications related to CF or CF-related developments, events, or updates. If you wish to stop these communications, please see the section below titled “**How to Unsubscribe from FDL Communications.**”

We use personal information collected through the Site only for purposes consistent with this Privacy Statement. If we wish to use or disclose your personal information for an additional or inconsistent purpose (like, for example, publicizing your story), we would obtain your consent before doing so.

We may aggregate and/or anonymize personal information provided by our visitors and users to improve, measure, or expand our services.

B. Nonpersonal Information We Collect

Like other websites, we collect non-personal web usage information about visitors to our site. This may include information about your browser type, geographic location, IP address, and pages you visit. We may use web beacons in email or other communications with you to assure proper operations of the Site or analyze our effectiveness, such as determining if a message to you was delivered or opened. We may also use cookies, web beacons, and/or third-party web analytic tools to analyze website traffic.

Cookies are small text files or data placed by your web browser on your hard drive to store information that allow a website to recognize whether a certain computer or device has been used to visit the site in the past. Cookies enable websites to keep track of online patterns and preferences and make the personalization of web experiences possible. We may make use of session-based and/or “persistent or memory based” cookies, which remain on your computer's hard drive until you delete them. You can adjust your browser settings to remove or block cookies, although if you do so, it may not be possible to utilize all our services if you reject cookies. **If you visit our site, you have consented to our use of cookies, as described in this Privacy Statement.**

A web beacon is a graphic on a web page or in an email that gathers non-personal web log information about pages visited or emails opened. We use web analytics services, such as Google Analytics, to record non-personal data such as browser type, operating system, the date and time of a visit, where visitors came from, the pages visited on this website, the time spent viewing site, where visitors went when they left the site, and return visits to the site. Please see [here](#) to learn more about how Google Analytics collects and processes data and to learn how to opt out of cookies set by Google Analytics.

We may aggregate this non-personally identifiable data to better understand how visitors use our site, and to help manage, maintain, and report on use of our website.

We may store IP addresses for fraud detection and prevention purposes.

C. California “Do Not Track” Disclosure

California recently enacted a law requiring websites to explain certain online practices regarding tracking of visitors.

Some web browsers have a “Do Not Track” feature that lets a user have the browser notify websites that the user does not want to have his or her online activities tracked. FDL's website currently does not respond to such browser-initiated signals. Regarding any potential external tracking, please consult external website policies regarding their tracking practices and their responses to Do Not Track signals.

D. Social Plug-in Data

The Site may use interfaces with social media sites like Facebook, Google+, LinkedIn, Twitter, or others. If you chose to “like” or share information from the FDL Site through these services, you should review their privacy policies. If you are a member of a social media site, the interfaces may allow the social media site to connect your Site visit to your personally identifiable information.

E. Personal Information We May Share

If you provide personal information to us via the Site, we may share it with service providers who assist us in activities such as technology or communications management. These providers are not authorized to use or disclose the information except as necessary to perform services on our behalf or to comply with legal requirements.

We might share personal information if we were to sell, assign, license, or transfer all or a portion of our organization or its assets, in which case we would make commercially reasonable efforts to contractually require the recipient to treat the information in accordance with this Privacy Statement. We might also disclose information about you (i) if required by law, subpoena, court order, or legal process, (ii) to law enforcement or other government authorities, or (iii) if we believe disclosure is necessary or appropriate to prevent serious physical harm or in connection with an investigation of or legal action involving illegal or fraudulent activity or conduct that violates our [Terms of Agreement](#).

F. Protecting Personal Information

We take commercially reasonable steps to protect the personal information and Other Information from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. Please understand, however, that no security system is impenetrable. We cannot guarantee the security of our databases, nor can we guarantee that the information that you supply will not be intercepted while being transmitted to and from us over the Internet. E-mail sent to or from the Platform may not be secure and you should therefore take special care in deciding what information you send to us via e-mail.

If you register with FDL, we encourage you to take strong precautions to protect your username and password. While we strive to protect your personal information, we cannot ensure or warrant the security of any information you transmit to us or receive from us. This is especially true for information you transmit to us via email. We review our data security arrangements from time to time as we deem appropriate.

6. Links to Other Sites

We may provide links to other websites for your convenience and information, but we do not operate these websites and are not responsible for their privacy practices or content. Please contact those websites directly if you have any questions about their practices.

7. Children

This Site is intended for use by adults. If you are between the ages of 13 and 18 years old, you may use this Site only if: (i) your use has been approved by your parent or legal guardian, (ii) you use the Site under his or her supervision, and (iii) he or she has agreed to the Terms (and any additional registration agreements, if applicable) on your behalf.

If you are the parent of a minor, you may use the Site and agree to the Terms on behalf of the minor. By doing so, you warrant that you have the legal capacity to act on the minor's behalf and you agree that the provisions of the Terms (and any additional registration agreements, if applicable) that are applicable to you are equally applicable to the minor.

Under no circumstances may a minor under the age of 13 use the Site. If you have reason to believe that a child under the age of 13 has provided personal information to us, please contact us, and we will endeavor to delete that information from our databases.

8. International Data Transfers

It is important to note that the platform and our servers are operated in the United States. If you are located outside of the United States, please be aware that any personal information you provide to us will be transferred to the United States. By using the Platform and by providing us Personal Information in any manner, you consent to this transfer and our use of the information and data provided by you in accordance with this Privacy Statement. .

9. Changing and Accessing your Information

If you would like to access or change information you have submitted to us online, you may be able to update it through the registration process. If you are unable to do so, please email us at info@flatleydiscoverylab.com or write to us at

Flatley Discovery Lab, LLC.
529 Main Street, Suite 115
Charlestown, MA 02129
Attn: Compliance

If you would like to request the deletion of personal information you have previously submitted to FDL, please email us at info@flatleydiscoverylab.com or write to us at

Flatley Discovery Lab, LLC.
529 Main Street, Suite 115
Charlestown, MA 02129
Attn: Compliance

Subject to applicable law and best practices, we will make commercially reasonable efforts to delete or suppress your personal information. Please be advised that we are required by law to retain certain records, such as donation and other records.

10. How to Unsubscribe from FDL Communications

If you do not wish to receive further emails, postal mail, or other communications from FDL, please use the unsubscribe mechanism described in the communication you received, call us at **617-242-0720**, email us at info@flatleydiscoverylab.com or write to us at

Flatley Discovery Lab, LLC.
529 Main Street, Suite 115
Charlestown, MA 02129
Attn: Compliance

It is our policy to honor any no-solicitation request as quickly as possible.

11. Changes to this Notice

We may update this Privacy Statement at any time and, if so, we will post the new effective date below. We expect that most changes will only be editorial in nature or reflect changes in the services we provide. However, in the unlikely event that we would ever make material changes that would permit us to share your information more broadly than we have previously described, we would post a prominent announcement on this site and/or ask for your consent.

Your continued use of the Site after the effective date of the new Privacy Statement would constitute your consent to the new Privacy Statement.

12. Contact Us

FLD welcomes your comments. If you have any questions or comments about our Privacy Statement or our information practices, please email us at info@flatleydiscoverylab.com or write to us at

Flatley Discovery Lab, LLC.
529 Main Street, Suite 115
Charlestown, MA 02129
Attn: Compliance
Effective Date

13. Effective Date

The effective date of this Privacy Statement is **August 1, 2017**.