

Effective: April 1, 2019

THIS NOTICE DESCRIBES YOUR RIGHTS TO ACCESS AND CONTROL YOUR PERSONAL DATA AND HOW YOUR PERSONAL DATA MAY BE COLLECTED, STORED, USED, OR DISCLOSED BY THE BRAIN DONOR PROJECT IN ACCORDANCE WITH GDPR. PLEASE REVIEW THIS NOTICE CAREFULLY.

The General Data Protection Regulation (“GDPR”) is a regulation that protects the personal data of individuals located in the EU and the European Economic Area (collectively the “EU”) from possible privacy and data breaches. The GDPR allows individuals to control of their personal data that is held or processed by data controllers, which includes The Brain Donor Project and any affiliates, subsidiaries, or aligned partners (“BDP”).

The GDPR defines “personal data” as:

“any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.”

BDP is committed to protecting and maintaining the privacy of personal data. As a data controller, BDP is

responsible for explaining to you how and why it processes personal data. BDP will collect and process your personal data lawfully, fairly, and in a transparent manner; process, use, and disclose your personal data only for valid purposes; keep the personal data it collects and maintains accurate and up to date; keep your personal data secure in accordance with applicable law and regulations; and store personal data only as long as necessary to meet BDP’s legitimate needs.

This GDPR Privacy Notice outlines BDP’s collection, use, processing, and disclosure of personal data that you provide to BDP. **When you submit personal data to BDP, communicate with BDP, or you use BDP’s websites or other services, you consent to BDP’s collection, use, processing, and disclosure of your personal data as described in this GDPR Privacy Notice.** In the event of a data breach that poses a high risk to your personal data, BDP will notify you of the breach without undue delay.

COLLECTION AND USE OF INFORMATION

BDP collects, receives, and records your personal data any time you contact BDP or interact with BDP, such as using BDP’s services, operations, or websites. BDP may also combine personal data you provide to BDP with information from BDP’s affiliates or third parties from time to time.

You are not required to provide your personal data to BDP. Any personal data you provide to BDP is voluntary.

BDP also collects certain information when you use its websites, which is recordable anytime you use the internet or other means of communication. This information, includes the Internet Protocol (IP) address used to connect your computer to the internet; your domain name, if any; and computer and connection information, such as a browser type and version.

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Like other websites, BDP's websites use "cookies" to record your activity while visiting BDP's websites.

BDP uses this information to learn how you use BDP's websites, to remember your preferences, and to diagnose problems. You can learn more about how BDP uses these systems and technology in BDP's Privacy Policy which is available at:

<https://braindonorproject.org/wp-content/uploads/2019/08/bdp-privacy-policy-rev-08.06.2019.pdf>

BDP collects, records, and processes your personal data as necessary to accomplish BDP's legitimate interests, purposes, functions, and responsibilities. For example, BDP collects and processes personal

data from individuals who access benefits through BDP programs.

Information collected from such persons may be used to: register or enroll you in BDP programs or membership; conduct BDP's operations; alert persons to BDP programs and products, and other BDP functions.

USE AND DISCLOSURE OF INFORMATION

BDP only uses or discloses your personal data if it has your consent, or it is otherwise authorized to do so by the GDPR or other applicable international, Federal, State, and local law or regulation. BDP may also use or disclose your personal data as follows:

- **Emergency Circumstances:** BDP may share your personal data when necessary to protect your interests if you are physically or legally incapable of providing consent.
- **Necessity:** BDP may share your personal data when necessary in accordance with applicable law, provided that your personal data is protected by appropriate safeguards to prevent further unauthorized use or disclosure.
- **Public Information:** BDP may share your personal data if you have manifestly publicized your personal data.
- **Archiving:** The may share your personal data for archival purposes such as public interest needs, public health, and for other historical research and statistical purposes.
- **Performance of a Contract:** BDP may share your personal data if it is necessary to administer a contract you have with BDP.
- **Legal Obligation:** BDP may share your personal data if disclosure is required or permitted by international, federal, and state laws and regulations.
- **Service Providers:** BDP may use affiliate and third party service providers who have entered into a contract with BDP to assist BDP in performing its services, duties, functions, and operations. In these cases, BDP may share your personal data with such party provided that your personal data is protected by appropriate safeguards to

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prevent further unauthorized use or disclosure individual brain banks contracted to the NeuroBioBank of the NIH or other biorepositories to which a case is being referred.

- **BDP-Affiliated Programs:** BDP may share your personal data with parties that are affiliated with BDP for the purpose of contacting you about products, services, or benefits that may be of interest to you.
- **De-Identified and Aggregate Information:** BDP may use and disclose personal data in de-identified or aggregate form without limitation. However, this information will not include personally identifiable information, is purely statistical in nature, and cannot be tied to you.

BDP may use and disclose your personal data on its own behalf, share it with its affiliates and other third

parties, or share it with other individuals or third parties to whom you have authorized BDP to disclose your personal data for the purposes of processing information; communicating with you on behalf of BDP; providing services or products that you have requested; or for other authorized activities or functions. BDP may also use or disclose your personal data to conduct general demographic and statistical research to improve BDP programs and operations, to enforce BDP policies, and to comply with applicable laws and regulations.

Where your personal data is disclosed to BDP's affiliates or third parties, BDP requires the recipient to agree to process and use personal data based on instructions from BDP and in compliance with BDP's contracts with the third party, and other appropriate confidentiality and security measures.

SECURITY

BDP uses appropriate technical and organizational security measures to protect your personal data from unauthorized access and unauthorized alteration, use, disclosure or destruction.

These measures include internal reviews of BDP's data collection, storage and processing practices and security measures, including appropriate encryption and physical security measures to guard against unauthorized access to systems where BDP stores data. You can learn more about BDP's data security by reading BDP's Privacy Policy.

Personal data created in the European Union will be transferred out of the European Union to BDP in compliance with appropriate safeguards and applicable law, including the GDPR and Federal, State, and Local information privacy laws.

If you feel BDP has not complied with applicable EU laws regulating such personal data, you have the right to file a complaint with the appropriate supervisory authority in the EU in accordance with your rights listed in this GDPR Privacy Notice.

RETENTION AND DESTRUCTION OF INFORMATION

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Your personal data will be retained by BDP in accordance with applicable state and federal laws, and the applicable retention periods in BDP's records management policy. Your personal data will be destroyed upon your request unless applicable law or regulation requires destruction after the expiration of an applicable retention period. The manner of

destruction will be appropriate to preserve and ensure the confidentiality of your personal data given the level of sensitivity, value, and importance to you and to BDP.

YOUR RIGHTS

At any point in which BDP is in possession of or is processing your personal data, you have the following rights, subject to applicable laws and regulations:

- **Right of access** – you have the right to request a copy of the information that BDP hold about you.
- **Right of rectification** – you have a right to correct data that BDP hold about you that is inaccurate or incomplete.
- **Right to be forgotten** – in certain circumstances you can ask for the data BDP holds about you to be erased from its records.
- **Right to restriction of processing** – where certain conditions apply, you have a right to restrict BDP's processing of your personal data.
- **Right of portability** – you have the right to have the data BDP holds about you transferred to another organization.
- **Right to object** – you have the right to object to certain types of processing such as direct marketing.
- **Right to object to automated processing, including profiling** – you have the right to not be subject to the legal effects of automated processing or profiling.
- **Right to judicial review:** in the event that BDP refuses your request under any of the above rights, it will provide you with a reason as to why. You have the right to complain as outlined in this GDPR Privacy Notice.
- **Right to withdraw consent:** You have the right to withdraw your consent to BDP's collection, recording, use, processing, or disclosure of your personal data at any time. However, your withdrawal of consent will not affect BDP's lawful use or disclosure of your personal data while your consent was in effect.

Any exercise of the above rights can also be forwarded to any third party involved in the processing of your personal data. Your rights may differ depending upon the location within the world where your personal information was created or shared. The erasure of your information may also be subject to BDP's records retention and management policies. Should your personal data fall within one of the areas where BDP is legally required to retain your personal data for a certain period of time, BDP will retain that personal data in accordance with its legal obligations.



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Please note that your rights in this GDPR Privacy Notice are not absolute and BDP may refuse certain requests where exceptions apply. Should BDP determine that you are not entitled to exercise a certain right, BDP will provide you with the reason(s) for the denial.

REQUESTS FOR PERSONAL DATA HELD BY BDP

At any time, you may request that BDP provide you with the personal data BDP collects about you and to transmit your personal data to another data controller where possible. You may also request that BDP confirm what personal data it possesses about you and whether or not your personal data is being processed by BDP; is subject to the use of automated

decision-making; and how BDP processes your personal data.

Similarly, you can request confirmation whether BDP received your personal data; if it disclosed your personal data to a third party; and how long BDP will store your personal data under its records management policy.

UPDATES TO THIS GDPR PRIVACY NOTICE

BDP may update or change this GDPR Privacy Notice at any time. Your continued use of BDP's websites or third party applications, or continued

interaction with BDP or submission of personal data to BDP, after any such change indicates your acceptance of the changes.

COMPLAINTS AND CONTACT INFORMATION

In the event that you wish to make a complaint about how your personal data is being processed by BDP or its authorized third parties, or how your complaint has been handled, you may to lodge a complaint directly with the GDPR supervisory authority and BDP.

If you wish to contact BDP or file a complaint concerning BDP's collection, recording, use, processing, or disclosure of personal data please contact us at: The Brain Donor Project,
P. O. Box 111002
Naples, FL 34108-1929