# DATA PROCESSING POLICY FOR THE PATIENT SUPPORT PROGRAM IN COLOMBIA OF SAREPTA THERAPECUTICS INC.

SAREPTA THERAPECUTICS INC. ("SAREPTA") in compliance with the Personal Data Protection Regime, is committed to the protection of the Personal Data it collects and processes in Colombia, therefore, has adopted this Policy for the Processing of Information and Personal Data, which aims to establish the standards to be followed for the Processing and the purposes to which the database of the Patient Support Program it manages in Colombia, the Personal Data included therein, the rights of the Data Controllers and the mechanisms through which they can be enforced.

The rules of this Policy apply to the Processing of Personal Data of patients who are part of SAREPTA's Patient Support Program, which collects, stores, uses, circulates or deletes, and must be followed by all Workers or Agents who carry out the Processing of Personal Data on behalf of SAREPTA.

#### 1. **DEFINITIONS**

For the purposes of the application of the Policy and in accordance with the provisions of the Personal Data Protection Regime, the following definitions shall apply:

Authorization	It is the prior, express and informed consent given by the Data Subject
	to the Controller or the Processor that allows him/her to carry out the
	Processing of his/her Personal Data.
Claim	
Claim	It is the request submitted by the Data Subject, its assignee or
	representative, in the cases in which he/she considers that the
	information contained in a Database should be corrected, updated or
	deleted; or in the cases in which the alleged breach of a duty under
	the Personal Data Protection Regime is noticed.
Consultation	Is the consultation made by the Data Subject, the assignee or his
	representative about his Personal Data contained in the Database(s).
Controller/Responsible	It is SAREPTA, who decides on the Databases and/or the Processing
for the Processing	of Personal Data.
Data Base(s)	It is the organized set of Personal Data that are subject to Processing
	and that are in physical or digital media.
Data Processor	Is the natural or legal person, public or private, who by himself or in
	association with others, performs the Processing of Personal Data on
	behalf of the Controller.
Data Processing Policy	This is the present SAREPTA's Information and Personal Data
	Processing Policy.
Data Subject	Is the natural person whose personal data is processed by SAREPTA.
Personal Data(s)	Is any information associated or that may be associated to one or
	several determined or determinable natural persons.
Personal Data	Refers to the general regulations governing the protection of personal
Protection Regime	data in Colombia, which includes Statutory Law 1581 of 2012,
	Regulatory Decree 1377 of 2013, Decree 886 of 2014, Single
	Regulatory Decree 1074 of 2015, Title V of the Single Circular of the
	Superintendence of Industry and Commerce and any others that
	complement or modify it.
Privacy Notice	It is the verbal or written communication that the Controller shall
	make available to the Data Subjects, by means of which they shall be
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	informed about the existence of the applicable information processing
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	policy, the way to access it and the purposes to which their Personal
	Data shall be subject.
Processing	Is any operation or set of operations carried out on Personal Data,
	such as the collection, storage, use, circulation or deletion thereof.
Public Data	Is data that is not semi-private, private or sensitive. Public Data are
	considered, among others, the data related to the marital status of
	individuals, their profession or trade and their status as merchant or
	public servant.
Sensitive Data	Are those Personal Data that affect the privacy of the Data Subject or
	whose improper use may generate discrimination. Among others,
	racial or ethnic origin, political orientation, religious beliefs, health,
	sex life and biometric data.
Transfer	It occurs in cases in which the responsible and/or Processor located
	in Colombia, sends the Personal Data to a recipient, who in turn is
	responsible for the Processing and who is located inside or outside the
	country.
Transmission	It is the Processing of Personal Data that involves the communication
	of the same within or outside Colombia for the purpose of a Processor
	to process it on behalf of the Controller.
Workers	Are all natural persons who are linked to SAREPTA, and who
	develop activities aimed at developing the purpose of SAREPTA in
	Colombia, regardless of the type of relationship. Likewise, Workers
	shall be understood as all those natural persons linked to the Agents.
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## 2. PRINCIPLES FOR THE PROCESSING OF PERSONAL DATA

SAREPTA will apply the following principles during the Processing of the Databases and the Personal Data included therein:

- 2.1 <u>Access Principle:</u> the collection and processing of Personal Data must be adequate, relevant and limited to authorized personnel.
- **2.2** <u>Confidentiality principle:</u> the confidentiality and integrity of personal data shall be guaranteed by means of technical and administrative controls.
- **2.3** <u>**Principle of purpose:**</u> consent for the collection and processing of Personal Data must obey legitimate and authorized purposes in an express, prior and informed manner in accordance with the Constitution and the Personal Data Protection Regime.
- 2.4 <u>Legality Principle:</u> the Processing of Personal Data shall comply with the provisions applicable to the Personal Data Protection Regime.
- **2.5** <u>Principle of security:</u> all technical, preventive and administrative measures will be implemented to ensure the security of the files that hold the Personal Data processed by SAREPTHA (Data Controller) or the Processor.
- **2.6** <u>**Principle of truthfulness or quality of information:**</u> the Personal Data subject to treatment must be truthful, complete, accurate, current and understandable.

**2.7** <u>Principle of truthfulness or quality of Information:</u> the Personal Data subject to Processing shall be truthful, complete, accurate, current, verifiable and understandable. Partial, incomplete, fractioned or misleading data shall not be processed.

## **3** GUIDELINES FOR THE PROCESSING OF PERSONAL DATA

SAREPTA establishes the following guidelines for the Processing of Personal Data carried out directly or through its Agents:

- **3.1** Treat Personal Data only with the prior, express and informed authorization of the Data Subject, unless it is in one of the cases in which the Personal Data Protection Regime expressly states that this authorization is not necessary.
- **3.2** Request the Authorization for the Processing of Personal Data to the Data Controllers, at the latest at the time of their request, and inform the Data Controllers clearly and expressly of the Processing to which the Personal Data will be subject, the purpose thereof and the rights they have as Data Controllers.
- **3.3** To keep the copy of the Authorization for the Processing of Personal Data granted by the Data Subject.
- **3.4** To keep the information under the security conditions necessary to prevent its adulteration, loss, consultation, use or unauthorized or fraudulent access. As well as to prevent the Processing of Personal Data by unauthorized third parties that may violate, modify and/or destroy the information.
- **3.5** To treat Sensitive Data in all cases in which the Data Controller has given its explicit authorization for the Processing, in a free and voluntary manner. As well as to refrain from conditioning any service to the provision of Sensitive Personal Data by the Data Subject.
- **3.6** Guarantee the Data Subject, at all times, the full and effective exercise of the right of habeas data, which consists of knowing, updating and rectifying the information that has been collected about them in databases or files.
- **3.7** To process queries and claims formulated in accordance with the Personal Data Protection Regime and the internal information management manuals.
- **3.8** Inform the data protection authority when there are violations to the security codes and there are risks in the Processing of the Personal Data of the Data Holders.

## 4 PROCESSING OF PERSONAL DATA OF THE PATIENT SUPPORT PROGRAM

The Patient Support Programs that SAREPTA develops in Colombia ("PSP") will be managed and developed by the legal person designated by SAREPTA for this purpose, who for the purposes of the Processing of Personal Data will have the quality of Agents, and in that sense, will have all the obligations and rights established under the Personal Data Protection Regime.

#### 4.1 Collection of Personal Data

The administrator of the PSP shall collect the Personal Data of the patients that are linked to it, either by means of direct contact with the patient or by means of the contact made by the patient to the PSP, but in any case, after the request for the Authorization for the Processing of the Personal Data.

#### 4.2 Processing of Personal Data

The Data Processor is obliged to Process the Personal Data in accordance with the provisions of the Personal Data Protection Regime and this Policy. During the Processing of Personal Data, the Data Processor is obliged to the following:

- a) Carry out the Processing of the Database and the Personal Data included therein, within the limits established by SAREPTA, corresponding to those authorized by the Data Subject.
- b) Carry out the Processing of the Database and the Personal Data on behalf of SAREPTA, in accordance with the principles that protect them, the Personal Data Protection Policy and the Personal Data Protection Regime.
- c) Refrain from using the Database or the Personal Data included therein for purposes other than those authorized, for their own benefit or that of a third party.
- d) Maintain the information under the security parameters established by SAREPTA and others considered necessary to prevent its adulteration, loss, consultation, use or unauthorized or fraudulent access and keep the confidentiality of the Database and the Personal Data included therein.
- e) Guarantee that the information subject to processing is truthful, complete, accurate, updated, verifiable and understandable.
- f) Inform the Data Subject how to access or consult the Personal Data processing policy of SAREPTA and the Data Processor, inform him/her about the use given to his/her data and guarantee the Data Subject, at all times, the full and effective exercise of the right of habeas data.
- g) Refrain from disclosing, disseminating or publishing, by any means, the Database or the Personal Data included therein, to any third party, regardless of their legal relationship or name.
- h) Refrain from circulating information that is being disputed by the Data Subject and whose blocking has been ordered by the Superintendence of Industry and Commerce, as well as to comply with the instructions and requirements issued by the latter.
- i) Allow access to the information only to those persons who may have access to it and ensure that its employees, contractors, personnel.

## 4.3 Specific purposes for the Processing of Personal Data collected within the framework of the $\ensuremath{\mathsf{PSP}}$

Without prejudice to the purposes specifically authorized by the Data Subjects by means of the Authorization and those set forth in section 4 of this Policy, the PSP shall process the Personal Data of the patients for the following purposes:

a) to make visits with nursing support to the Patient to provide education about the disease and support for monitoring adherence to treatment;

- b) to provide guidance on the procedures to be followed in order to have effective access to the medication;
- c) provide educational or informative material related to the disease, the medication and the treatment;
- d) to provide support to patients in taking medical and laboratory tests;
- e) refer the Patient's Personal Data to health sector actors (EPS, IPS, health services insurers, among others) to provide education on general aspects of the disease and the medication. Referral information excludes promotional activities;
- f) report adverse events or generate quality complaints where the Patient's Personal Data are related in accordance with the formats provided by SAREPTA or the person in charge;
- g) to prepare the request for authorization to import vital not available before the authorities in Colombia, as well as to carry out any management or administrative procedure in relation to commercial, logistic, customs issues, etc., for the effective delivery of the medicine to the Patient;
- h) to transfer the Patient's Personal Data to its subsidiaries located outside Colombia, provided that they comply with the adequate levels of protection of personal information required by Colombian law; and,
- i) to develop all the activities related to the proper execution of the Program and to provide all the services that may be necessary by virtue thereof for the benefit of the Patient.

#### 4.4 Processing of Sensitive Data

Within the framework of the PSP, the Data Controller shall collect Personal Data related to health, treatment, medications prescribed by the treating physician, racial or ethnic origin, which may affect the Patient's privacy or whose improper use may generate discrimination, which have the character of Sensitive Personal Data. These will be treated with the purpose of achieving the purposes mentioned in numbers 4 and 6.3 of this Policy, subject to the authorization granted by the Data Subject in a free and voluntary manner.

In these cases, SAREPTA, through its Agent, will comply with:

- a) Inform the Data Subject that since it is Sensitive Data, it is not obliged to authorize its Processing.
- b) Inform the Data Subject explicitly and previously, in addition to the general requirements of the Authorization for the collection of any type of Personal Data, that the data that will be subject to Processing, have the quality of Sensitive Data and the purpose of the Processing.

#### 4.5 Processing of Personal Data of children and/or adolescents.

SAREPTA will only collect the Personal Data of children under 18 years of age, in the cases in which their representative authorizes the Processing, when necessary for the development of the purposes set forth in section 6.3. The foregoing always in consideration of: (i) respect for the best interests of children and adolescents; and, (ii) respect for their rights.

## 4.6 Procedures and channels for handling queries or claims related to the Processing of Personal Data

Inquiries, claims or requests related to the Processing of Personal Data provided within the framework of the PSP shall be submitted by the Data Subjects, their representatives or assignees in the following manner:

### • Procedure

The Data Subject, his/her representative or assignees may submit Queries and/or Claims in exercise of his/her rights, as follows:

- i. The Query or Claim must be addressed to any of the channels established in section 4(b), and must clearly describe its request for correction, update or deletion. In case the Complaint is related to a possible breach by SAREPTA or its Responsible Party of any of its duties, the reason for the breach must be stated in detail.
- ii. The Claimant must clearly and accurately identify himself/herself. Likewise, he/she must demonstrate the relationship that identifies him/her as representative or assignee in case he/she is acting on behalf of the Data Subject.
- iii. In the event that the Claim is incomplete, the Data Controller shall require the interested party within five (5) business days following receipt of the Claim to correct the deficiencies. After two (2) months from the date of the request without the applicant submitting the required information, the Person in Charge will understand that the claim has been withdrawn.
- iv. In the event that the Person in Charge receives a Claim that he/she is not competent to resolve, he/she will transfer it to the appropriate person within a maximum term of 3 business days and will inform the interested party of the situation.
- v. Once the complete request has been received, the Processor shall include in the corresponding Database a legend stating "claim in process" and the reason for the same, which shall be maintained until the Claim is decided.
- vi. The Processor shall respond to the request within a maximum term of 10 business days from the day following the date of its receipt in case it is a Query about the Personal Data contained in the Database. The Data Processor will respond within a maximum term of 15 business days, in case it is a Claim, related to the correction, updating, deletion or an alleged breach is noticed.

Data Processor	Valentech Pharma Colombia S.A.S.
Person or area in charge of	Área legal
the Personal Data	
Address	Carrera 7 # 77 – 07 Of. 801
	Bogotá, Colombia
E-mail	programapacientes@valentechforlife.com

## • Channels of attention

## **5** RIGHTS OF THE OWNERS OF THE INFORMATION

In accordance with the Personal Data Protection Regime, the Personal Data Holder has the following rights:

- **5.1** Access, know, rectify and update their Personal Data.
- **5.2** Request proof of the Authorization granted, except in those cases where it is exempted as a requirement for the Processing of Personal Data, in accordance with the exceptions set forth in the Personal Data Protection Regime.
- **5.3** Receive information, upon request, regarding the Processing that has been given to their Personal Data.
- **5.4** To go before the authorities and file complaints for breaches of the provisions of the Personal Data Protection Regime, prior consultation or complaint process before SAREPTA.
- 5.5 Modify and revoke the Authorization and/or request the deletion of the data.
- 5.6 To have knowledge of and access to the personal data that have been subject to Processing.
- 5.7 Any other rights recognized in the Personal Data Protection Regime.

#### **6 EFFECTIVENESS**

- **6.1** This document is effective as of October 30, 2019.
- **6.2** The Databases under the administration of SAREPTA shall have a validity equal to the time in which the Personal Data is used for the purposes described in this Policy; and, they shall be kept as long as the Data Subject does not request their deletion and there is no legal or contractual duty to keep the information.
- **6.3** SAREPTA informs that any substantial change in the Personal Data Processing Policy, will be communicated in a timely manner through its website and through the means generally used to contact the Data Subjects, during the 10 working days prior to its entry into force.

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