SEVBI: Stichting Effectief Voorschrijven Buiten Indicatie (Foundation for effective off-label prescription)

- SEVBI, a nonprofit organisation, creates an enabling basis for off-label prescription treatment options for patients with neuromuscular and neurological diseases – such as amyotrophic lateral sclerosis (ALS) - based on sound scientific and medical information.
- All within the guidelines for off-label prescribing, and in collaboration with patients, patient advocates, physicians, pharmacologists, pharmacists, legal experts and relevant governance boards.

PRIVACY POLICY

INTRODUCTION

We at SEVBI are convinced that the protection of the privacy of users of the information on our website is critical to our activities and the trust of our users. Personal information of our users of the website is treated with the greatest care and secured accordingly. SEVBI adheres to the Data Protection Act and other relevant legislation relating to the protection of personal information.

PROCESSING OF PERSONAL INFORMATION

We at SEVBI may capture information in the framework of our information exchange. This happens as soon as a user visits our website and subsequently when a user asks for more information through our contact form, or when you have other contact with SEVBI. This pertains to information that is necessary for contact or the sharing of information. You never need to provide more information than is necessary for the purpose of the data processing. You are free to share more information on the website's comments section with other users in regards to your knowledge and experiences.

SEVBI uses the information exclusively for the purposes of the exchange of information. Your information will not be made available to third parties without your prior consent. If you consent to share information with designated third parties, you can also withdraw this permission at any time.

SEVBI stores information only as long as necessary to realize the objectives of the data processing, i.e. responding to the user's enquiry and exchange of information. The information is then subsequently filed for future reference only.

SEVBI secures the website and the information it processed in an appropriate manner, as prescribed by international law.

USER'S E-MAIL ADDRESS AND CONTACT INFORMATION

If user has provided SEVBI with e-mail address and/or other contact information, or entered it onto the SEVBI website, for example if user has subscribed for a newsletter or requested information, it can be used by SEVBI to send user relevant or interesting information about SEVBI and its developments. If user does not wish to receive such information, user can specify this at any time by sending SEVBI an e-mail about this or click on the provided button in the e-
mail user may receive from SEVBI. SEVBI does not give user's e-mail address or other contact information to any third party, unless at user's request.

ACCESS AND CORRECTION OF USER INFORMATION

SEVBI is responsible for the information that it captured, which is processed via the website and e-mail, within the context of the Data Protection Act. User can take note of the data that are processed via a request to SEVBI. User has the right to correct and have the information removed. User can direct requests for access or correction of user's information to SEVBI. User will also be assisted here if user has additional questions about how SEVBI handles user's information.

NOTIFICATION OF PERSONAL INFORMATION

In accordance with the Data Protection Act, the processing of personal data may be registered with the Global Supervisor, the International Personal Data Protection Authority in The Hague.

CLICK BEHAVIOUR AND IP ADDRESS

General information is stored on SEVBI's website statistics, without the visitors being identified. The purpose of this is to optimize and monitor the user experience of the website. This information can also be used to put more specific information on the website in order to optimize the exchange of information to users in this way. SEVBI therefore also makes use of the IP address of user's computer. It can be used to see which usage of the website is used and for the preparation of analyses and reports. The IP addresses are not linked to identifiable information.

WEBSITE LINKS

There are links to other websites on SEVBI's website. SEVBI will take no responsibility regarding the manner that these parties make use of your information. Please read the privacy policies of the sites that you visit.

AMENDMENTS

SEVBI reserves the right to make changes to this privacy statement. Therefore, regularly check this privacy statement for SEVBI's privacy policy. Existing users can be informed about relevant changes in the privacy statement.