

DystoniaDiary Mobile Application Privacy Policy

Effective date: April 2021

Last reviewed: April 2021

INTRODUCTION

Ipsen Pharmaceuticals Ltd (“Ipsen”, “we”, “us”, “our”) has worked with patientMpower to develop this application (“App”) to empower users to manage their health condition. This Privacy Policy relates to the collection and use of information (also referred to as “data”) by us in connection to this App. Ipsen is data controller in relation to the use of this App. patientMpower is the data processor.

WHEN DOES THIS PRIVACY POLICY APPLY

This Privacy Policy and accompanying Terms of Service (“Terms”) apply to your use of The DystoniaDiary mobile application, which is available through the Apple, Google Play, and any other App stores.

WHO WE ARE

IPSEN PHARMACEUTICALS LIMITED incorporated and registered in the Republic of Ireland with company number 173934 whose registered office is at Blanchardstown Industrial Park, Blanchardstown, Dublin, 15, Republic of Ireland.

patientMpower Ltd, with registered office and business address of: 21 Denzille Lane, Dublin D02 EY19, Ireland.

OUR VALUES

Ipsen takes protecting personal data seriously. We are committed to ensuring that we comply with data protection legislation across all our activities. This includes having robust technical and organisational measures in place to take care of personal data. We are committed to ensuring that we provide clear information to individuals about how we use their data, in Privacy Notices. We will only process personal data and special category personal data when we have a lawful basis and relevant conditions or processing to do so. We will also ensure that we restrict the use of personal data to the specified purposes and minimise data processing to only that which is required. We will keep personal data accurate and up to date and we will limit how long we keep personal data in line with our retention policy.

WHAT INFORMATION WE COLLECT

This App may obtain information about you in two ways. The first relates to information that is manually entered by you and the second relates to information that the App collect automatically. Information collected automatically may come from your smartphone.

We collect and process data to register your use of the App and then to support you in recording health information, as follows:

Registering your user account

We collect your name and email address to facilitate your access to the App. You may also be given a unique code and be asked to set up a password to access and maintain access to the App. We may also collect information when you make requests for support when you want some help using the App or need patientMpower to troubleshoot the service. The legal basis for this is to provide you with a service, under Article 6 1b of GDPR.

Information gathered when using the App

You can use the App to manage and document information about you, your health, how you're feeling and your symptoms by entering e.g.:

- Demographic data e.g. gender, age, etc.
- Health result data e.g. which botulinum toxin you receive and clinic appointment dates etc.
- Information on your Dystonia symptoms and how they are managed

This information is used to help you to manage your condition and to keep records that will help you and your healthcare providers to better manage your condition. The legal basis for processing this information is your explicit consent (Articles 6 1 a and 9 2 a of GDPR).

We will also ask for your explicit consent to share any of your data with your healthcare professional.

We may ask for your feedback about the App in surveys from time to time, based on our legitimate interests and your agreement to take part.

Information that is automatically collected

We process technical information from your smartphone or computer e.g. operating system, device type, features used on the App, dates and times of interaction with the App. This would be used to facilitate functionality and manage usage within the application, as necessary for our legitimate interests in providing the App to you (Article 6 1 f).

To sign up to our App you may choose to use your Google account or other social media accounts to complete the sign-up process. If you choose to do this, you are authorising patientMpower to collect, store, and use information that you agreed these sites may share with us through their API. Such information may include name, email address, profile picture, etc.

HOW INFORMATION IS TRANSFERRED AND STORED

The information that we collect from you will be transferred, stored, and processed within the European Economic Area ("EEA"). By using the App, you consent that information may be transferred, stored and processed outside your country of residence (if you currently reside outside the EEA).

Your data will be stored for a period as long is deemed reasonably necessary by patientMpower on behalf of Ipsen for legitimate business and legal reasons.

DE-IDENTIFIED AND AGGREGATED INFORMATION

De-identified information refers to information that does not allow us to identify you. We may use de-identified information to understand, improve, and customize your experience for this App.

De-identified information may be shared with third party affiliates, agents or business partners. For example, aggregated information may be shared with researchers to better understand health conditions or with companies developing treatments.

Aggregated information refers to de-identified information that is combined with that of other users' de-identified information to give an aggregate overview of certain statistics. We may use aggregated information to understand, improve, and customize our users' experience. Aggregated information may be shared with third party affiliates, agents or business partners.

Third party affiliates, agents, or business partners – we may engage with other third-party companies or individuals to perform certain business functions on our behalf. Examples may include providing technical assistance, order fulfilment, customer service and improving your experience of this App or developing marketing materials. These third-party organisations will only have access to the de-identified and aggregated information necessary to perform their functions.

BUSINESS TRANSFERS AND LEGAL REQUIREMENTS

In the event of a corporate sale, merger, reorganisation, sale of assets, dissolution or other business-related event, your information may be part of the transferred assets. Ipsen and patientMpower will inform their customers of any proposed change of control as soon as possible.

If we receive a legal request for access to your information (e.g. from a court order, law enforcement authority, regulatory agency, etc.) we may disclose your information to the extent permitted by law. We may also share your information with legal advisors, consultants, or courts in order to protect and defend our rights and users of the App.

USE OF COOKIES OR SIMILAR ANALYTICS TECHNOLOGIES

patientMpower use essential cookies to ensure that the App is reliable and works correctly and securely. This technology is used to track how users use the App. The purpose of these cookies is to help patientMpower maintain and support users' using the app safely and effectively as part of treatment or recording of symptoms. patientMpower does not use cookies or similar technologies for marketing analytics or related activities.

HOW WE PROTECT YOUR INFORMATION

We place great importance on the security of all personal data associated with our users. We have security measures in place to attempt to protect against the loss, misuse and alteration of personal information under our control.

On behalf of Ipsen, patientMpower has designed the DystoniaDiary with stringent security protocols. patientMpower uses state-of-the art electronic surveillance and multi-factor access control systems. All data transport between your App and our servers is encrypted.

No data is stored on your mobile phone device. If you were to lose your phone, there would be no health-related data available for anyone else to see. If you wish to have information corrected or deleted from the patientMpower App this can be done on request by contacting patientMpPower, dataprotection@patientmpower.com.

patientMpower use a risk management process based on a Health Insurance Portability and Accountability Act (HIPAA) template. It allows them to conduct an accurate and thorough assessment of the potential risks and vulnerabilities to the confidentiality, integrity, and availability of electronic protected health information held via the App, and also implement security measures sufficient to reduce risks and vulnerabilities to a reasonable and appropriate level to comply with HIPAA standards.

patientMpower collects and processes Electronic Protected Health Information (ePHI). ePHI is defined as 'Individually identifiable health information transmitted by electronic media and/or maintained in electronic media'. Periodic reviews of patientMpower's security standards are carried out and their software development process has a checkpoint to identify any new risks when new features are defined / developed.

However, with any electronic transmission and storage of data comes risks and we cannot guarantee that our databases, or those of our third-party affiliates, will be 100% secure. There is also a risk of data being intercepted while being transferred over the internet. If there is a personal data breach, Ipsen will work with patientMpower to ensure that we manage the risks effectively and communicate with you and the Supervisory Authority in line with the requirements of Data Protection Legislation.

YOUR RIGHTS

You have a number of legal rights under the EU's General Data Protection Regulation (GDPR). The following section explains your rights:

- You have a right to request a copy of your personal data
- You have a right to erasure (delete), rectify (correct), restrict, and object to the processing of your personal data
- We are obliged under the GDPR to provide any requested information within one month of receiving a request. However, if a large number of requests are received or requests are complex, the time limit may be extended by a maximum of two further months.
- You have a legal right to access, rectify, erasure and object to the use of your data free of charge. However, a reasonable fee may be charged for "repetitive requests", 'manifestly unfounded or excessive requests" or "further copies".

- You have a right to the rectification (correction) of inaccurate personal data.
- You have a right to receive a copy of your personal data in a structured, commonly used, machine readable format that supports re-use. You also have a right to transfer your personal data from one controller to another without hindrance, and to store your personal data for further personal use on a private device.
- If your personal data was shared with a third party, then you have a right to request information about the identities of those third parties.
- You have a right to object to the processing of your personal data for the process of direct marketing, including profiling.
- You have a legal right to not be subject to a decision based solely on automated processing which may significantly affect you, unless it is authorised by law or you explicitly consent and the appropriate safeguards are in place.
- You have a right to complain to the EU's Data Protection Authority (DPA) if you think your rights have been infringed upon

HOW TO CORRECT or DELETE YOUR DATA or WITHDRAW CONSENT

No data is stored on your mobile device from the DystoniaDiary App therefore deleting the App from your mobile device is not sufficient to delete your data. Your data will remain on patientMpower's servers for 1 year after you stop using the DystoniaDiary application. However, you can contact patientMpower to request the deletion of your data.

Please contact patientMpower to request any changes, or deletion or to withdraw your consent at dataprotection@patientmpower.com

CHILDREN

We do not knowingly collect Information from children under the age of 14 through the App. This App is intended for use by persons 18 years of age and older. If you discover that your child has been using the App without your consent, or someone has been using the App on behalf of your child without your consent, please contact patientMpower using via the Contact Us page on their website - contact us — patientMpower and they will take steps to delete the information from our databases.

CHANGES TO THIS PRIVACY POLICY

This Privacy Policy is effective as of the date listed previously at the start of this document. This Privacy Policy may be changed or updated at any time in the future without notice to you. This Privacy Policy is available for you to review at all times via the link in the App and it is recommended that you regularly review it. By using our App after we have updated our Privacy Policy, you are deemed to have accepted any changes.

CONTACTING US

For support questions and issues related to the App, please contact patientMpower in the first instance, dataprotection@patientmpower.com.

If you have any questions or comments about this Privacy Notice or how your data is processed, please contact Ipsen's Data Privacy Officer at dataprivacy@ipsen.com.

If you are not satisfied with the response to your queries, or you wish to make a complaint or believe the processing of your information does not comply with data protection law, you can make a complaint to the data supervisory authority, the Data Protection Commission (Homepage | Data Protection Commission).

