



## **GRANT AGREEMENT**

This Agreement ("Agreement"), effective as of **1<sup>ST</sup> OCTOBER 2023**, is entered into between Takeda Pharma A/S, "Delta Park 45, DK- 2665 Vallensbæk Strand - Denmark (Takeda)", CVR 16406899 and Sjældne Diagnoser ("Organization") (collectively, the "Parties").

(1) **Background.** The Organization is dedicated to improve lives of patients, relatives and people supporting persons living with rare diseases and Takeda is a manufacturer of pharmaceutical and diagnostic products focusing on research, development, manufacture, distribution, marketing and sale of pharmaceutical products. Therefore, in consideration of the mutual promises, covenants and agreements hereinafter set forth, the sufficiency of which is hereby acknowledged, and intending to be legally bound, the Parties agree as follows:

(2) **Contribution.** Takeda agrees to support the Organization in the form of a restricted grant as set out in **Exhibit A** (the "**Contribution**").

(3) **Use of Contribution.** The Organization shall use the Contribution exclusively for the purpose of conducting an awareness campaign for rare diseases related to the Rare Disease Day 2024 event (the "Purpose"). Without prejudice to the generality of the foregoing, the Organization shall not use the Contribution for the provision of any hospitality, entertainment and/or leisure time programmes and/or subsistence to any healthcare professionals, appropriate administrative staff and/or members and appropriate staff of the Organization unless and to the extent permitted by applicable laws, regulations, codes and guidelines (including, without limitation, the IFPMA and EFPIA codes and any corresponding, equivalent or similar applicable national codes such as – but not limited to – the Danish Ethical Rules for Promotion of Medicinal Products towards Healthcare Professionals (the "**ENLI Code**") and the Danish Ethical Rules for Collaboration between Patient Groups, etc. and the Pharmaceutical Industry (the "**Patient Association Code**")) (the "**Applicable Laws**").

(4) **Terms of Payment.** Upon signature of this Agreement, the Organization shall submit to Takeda an invoice for the Contribution which shall be payable within forty-five (45) days upon receipt and acceptance of the duly issued invoice by Takeda. Any invoice submitted by the Organization to Takeda must, as a minimum, include the information set out in **Exhibit B** (the "**Minimum Information for Invoices**").

(5) **No Other Sum Payable.** Unless otherwise expressly agreed in writing between the Parties, the Contribution shall constitute the entire sum payable by Takeda under this Agreement.

(6) **Conduct of Activities.** The Organization shall carry out all activities in relation to which it uses the Contribution in a professional manner using all due skill, care and diligence, and in conformity with the Applicable Laws.

(7) **Reporting and Approval of Activities.** The Organization shall provide Takeda with a brief report on the contemplated activities to be carried out by or on behalf of the Organization in relation to which the Contribution is planned to be used. An activity to be carried out must be approved by Takeda. In this regard, Takeda's review and assessment of any such activity is limited solely to ensure that the activity can be carried out in accordance with the Applicable Law. The report shall be provided to Takeda by email, or in such other format and by such other method as Takeda may specify, and at a point in time where it is still possible to amend or cancel the contemplated activities, if Takeda cannot approve them.

(8) **Accounting.** The Organization shall keep records and books of account showing all expenditure made, and costs incurred for the purposes of the Purpose. The Organization shall make its records and books of account available for inspection by Takeda, at Takeda's option, an independent professional advisor appointed by Takeda, at any time during the term of this Agreement and during the period of one (1) year following expiry or termination of this Agreement, on reasonable notice and during normal business hours, for the purpose of verifying the purposes for which the Organization has used the Contribution and the level of expenditure made and the costs incurred for the purposes of the Purpose.

(9) **Representations and Warranties.** The Organization represents and warrants that, the Contribution will be used in full compliance with the Applicable Laws and ENLI Codes. Moreover, the Organization represents and warrants that the terms of this Agreement do not conflict with or violate the terms of any policies or procedures of the Organization or any other contractual or legal obligations the Organization may have.



(10) Declarations by the Organization. The Organization shall make such declarations in relation to the provision of the Contribution by Takeda, and the use of the Contribution by the Organization, as Takeda may require and/or as may be required under the Applicable Laws. All declarations shall be in the form requested or approved by Takeda and must accurately reflect the nature of Takeda's relationship to the Organization. The Organization shall submit any such declarations to Takeda for review and shall delay its disclosure as required in order to correct any eventual inaccuracy or incorrectness. The Organization shall take into account any changes reasonably requested by Takeda.

(11) Declarations by Takeda. Takeda and/or its affiliates shall be entitled to make such declarations in relation to the provision of the Contribution by Takeda, and the use of the Contribution by the Organization, as may be required under the Applicable Laws, and to use the name, logos or trademarks of the Organization in relation to such declarations. Without prejudice to the generality of the foregoing, the Organization agrees that Takeda shall be entitled to identify itself as a donor of the Organization on websites, in literature and/or in other company material of Takeda and/or its affiliates and the Organization acknowledges and agrees that Takeda and/or its affiliates are making publicly available the information required to be disclosed under applicable laws, including, but not limited to, information to the Organization and the Contribution given to the Organization by, or on behalf of, Takeda and/or its affiliates. Promptly on request, the Organization shall provide Takeda with any further information as Takeda considers necessary to enable Takeda and/or its affiliates to make such declarations.

(12) No Inducement or Influence. The Parties acknowledge and agree that this Agreement is concluded independently from any business transactions and decisions in relation to the supply or purchase of goods or services from Takeda or its affiliates and that the provision of the Contribution shall not in any way (i) constitute any inducement to, or reward for, recommending, prescribing, purchasing, supplying, selling, administering or taking any decisions favourable to, any products or services of Takeda or its affiliates, or (ii) have any influence on the content of any materials authored by or on behalf of the Organization.

(13) Other Donors. Takeda has not, and the Organization acknowledges and confirms that Takeda has not, in any way requested or required that it be the exclusive donor of the Organization or any of its programmes or activities.

(14) Relationship of the Parties. The Parties acknowledge and agree that no joint venture, association, partnership or agency relationship is created hereby. Each Party shall be conclusively deemed independent of the other and neither Party shall have any right or authority to bind the other hereto.

(15) Liability. The Organization shall be solely responsible and liable for all activities in relation to the use of the Contribution.

(16) Indemnification. The Organization shall fully indemnify, defend and hold harmless Takeda, its affiliates and their respective personnel from and against any and all liability, losses, claims, actions, proceedings, injuries, demands, fees, penalties, judgments, fines, damages, costs and/or expenses (including reasonable attorneys' fees and costs) sustained or incurred by Takeda and/or its affiliates arising as a result of (i) any misrepresentation or breach of this Agreement by the Organization, (ii) any third party claim brought against Takeda and/or its affiliates in relation to any activities in relation to which the Organization uses the Contribution, and/or (iii) any breach of the Applicable Laws in the performance of any activities in relation to which the Organization uses the Contribution.

Term. This agreement shall come into force on the Effective Date and shall expire upon achievement of purpose.

(17) Termination for Breach. Each Party may terminate this Agreement at any time for a material breach of the Agreement by the other Party by giving written notice of immediate termination to the other Party, including, without limitation, a termination pursuant to section (18) and (19).

(18) Termination for Inappropriate Use. If the Organization uses the Contribution for any purpose other than the Purpose, Takeda shall be entitled to immediately terminate the Agreement for material breach pursuant to Article 17 above. In case of such termination the Organization shall return to Takeda the Contribution.

(19) Termination for Lack of Completion and Repayment of Unused Funds. In case the Purpose is not completed within a reasonable timeline, Takeda shall be entitled to immediately terminate the Agreement for material breach pursuant to Article 17 above. In case of such termination the Organization shall immediately return to Takeda the portion of the Contribution that has not been expended, applied or committed for the Purpose as at the date of such



termination. If the Purpose is cancelled for any reason or the Contribution otherwise exceeds the actual costs for the Purpose after its completion, the Organization undertakes to repay any remaining part of the Grant to Takeda. Such payment shall be made within ninety (90) days of the cancellation or completion of the Purpose.

(20) Survival. Any provision, which by its intent or content is meant to have validity beyond expiry or termination of this Agreement, shall survive the expiry or termination of this Agreement.

(21) Business Identifiers. Neither Party shall use the name, logos or trademarks of the other Party and/or its products or services, nor make any announcement, comment upon or originate any publicity or otherwise disclose any information relating to this Agreement to any third party except: (i) to the extent required by the Applicable Laws; (ii) with the prior written consent of the other Party; and/or (iii) as otherwise provided in this Agreement.

(22) Disclosure of Agreement. The Agreement shall be published on the websites of the Parties at the time when the Agreement is made and must be accessible for Takeda for at least six months after the termination of the Agreement and for the Organization for at least two years from the receipt of the Contribution.

(23) Independence and impartiality. By their' signatures, the Parties declare that the Organization shall be free to incorporate with and receive grants from other pharmaceutical companies, just as Takeda shall have the right to collaborate with and grant contributions to one or several organizations. Further to this, Takeda declare not to lay down conditions for the Organization's view on professional and political issues.

(24) Waiver. Failure or delay by either Party to exercise any right or remedy under this Agreement shall not be deemed to be a waiver of that right or remedy or prevent it from exercising that or any other right or remedy on that occasion or on any other occasion. No single or partial exercise of any right or remedy shall preclude or restrict the further exercise of that or any other right or remedy.

(25) Entire Agreement. This Agreement constitutes the entire agreement and understanding between the Parties with regard to all matters herein and supersedes all prior agreements and understandings, oral and written, between the Parties with respect to the subject matter hereof and the transactions contemplated hereby. The Parties acknowledge that in entering into this Agreement they do not rely on any statement, representation (excluding any fraudulent misrepresentation), warranty, course of dealing, custom or understanding except for those expressly set out in this Agreement.

(26) Applicable Law and Jurisdiction. This Agreement shall be construed in accordance with, and governed by, the laws of Denmark. The place of jurisdiction shall be the relevant court of Glostrup.

**SIGNATURES**

**TAKEDA PHARMA A/S**

Date:

Date:

\_\_\_\_\_  
Name: Louise Herbild  
Title: Head of Patient, Value & Access

\_\_\_\_\_  
Name: Roland Kurney  
Title: General Manager



**ORGANIZATION**

Date:

Date:

DocuSigned by:

*Lene Jensen*

21-sep-2023 | 10:10 CEST

9AAEAE0061E246C

Name: Lene Jensen

Name:

(Project responsible)

Title: Head of Secretariat of  
Sjældne Diagnoser

Title:



**Exhibit A**

**Contribution & Other information**

Takeda will support the Organization in the total amount of DKK 30.000,- (thirty thousand Danish Kroner)

Name/Title of person responsible for the activity/project: Head of Secretariat of Sjældne Diagnoser, Lene Jensen

Name/Title of person responsible for the account: Regnskabskonsulent Kim Andersen

The Contribution is to be used for conducting an awareness day of rare diseases on the Rare Disease Day 2024, 29th February. The Organization will create a professional and political awareness event concentrated on Christiansborg / The Folketing and subsequently invite all rare citizens, their relatives and everyone else who wants to support the Rare Day to a public event in the public space, where the Rare Prize will be handed-out.

In addition, Sjældne Diagnoser will in the period up to the Rare Disease Day and during the day raise awareness of rare diagnoses via SoMe activities, emails, newsletters etc.

It must be noted, that it is required that the "Organisation" publishes the economic support from Takeda (inclusive the amount) on their homepage no later than one month after receipt of the support and keep the information on their website for at least two years.



## **Exhibit B**

### **Minimum Information for Invoices**

Any invoice submitted by the Organization to Takeda must include the following:

- full name and address of patient organization
- Organisations VAT registration number
- the Contribution to which the invoice relates;
- Invoice number
- Invoice amount specified as the net amount, VAT amount (if any) and the gross amount. If there is no VAT, please still specify net amount and gross amount (the numbers will be the same)
- the date on which the invoice was issued;
- the name and address of Takeda; Takeda Pharma A/S, Delta Park 45, 2665 Vallensbæk Strand
- the name and e-mail address of Takeda's contact person; Britta Smedegaard Andersen, [Britta.smedegaard.andersen@takeda.com](mailto:Britta.smedegaard.andersen@takeda.com)
- Takeda's tax number: 16406899;
- invoice name, address and name of bank, bank account number, SWIFT and IBAN to which the Contribution is payable; and
- all other information and details as may be reasonably requested by Takeda from time to time (e.g. Takeda's cost center and/or purchase order number, as given by Takeda, if applicable).



## Exhibit C

### **Privacy Notice and Transparency Rules**

Takeda Pharma A/S (“**Takeda**”), being strongly committed to protecting your privacy, will make efforts to protect your Personal Data in accordance with the following Privacy Notice (“**Notice**”).

#### **Personal Data Takeda Collects and Source**

In accordance with applicable laws Takeda collects and processes Personal Data about you. The types of Personal Data that Takeda collects and processes about you depends on your relationship with Takeda as well as applicable laws, but may include the following categories of information:

- Basic personal details such as identity and contact information;
- Educational and professional details e.g. qualifications, organizational or institutional affiliations;
- Payment related information, where necessary;
- Information about your interactions, engagements and activities in relation to Takeda.

This information may come directly from you or from public or third-party information sources.

#### **Legal Basis for Processing**

Takeda processes Personal Data based on the following:

- The processing of your Personal Data may be necessary in order to comply with the applicable law, regulations, governmental orders or for the performance of the Agreement. You may not be able to opt-out of this processing, or your choice to opt-out may impact our ability to comply with the Agreement.
- In certain cases Takeda may ask for your consent in order to process your Personal Data. At any time you may withdraw your consent as described in the “How to Reach Us” section. Please note that the withdrawal of consent will not affect processing which has already occurred.

#### **How Takeda Uses the Personal Data**

Takeda and/or its affiliates may process Personal Data about you for administration, statistical analysis, payment, internal evaluation and/or in order to comply with the Agreement.

#### **With Whom Takeda Shares Your Personal Data**

Personal Data about you may be shared by Takeda with its affiliates for the purposes stated above. Takeda and/or its affiliates may engage service providers, agents, contractors or other third parties (“**Third Parties**”) to perform services for or on its behalf, including, but not limited to, the Processing of Personal Data about you for the purposes stated above, and, as a result, Takeda and/or its affiliates may share Personal Data about you with such Third Parties. Takeda has executed appropriate contracts with such Third Parties that define the legitimate use or sharing of Personal Data in accordance with this Notice.

Some of Takeda's group companies and/or service providers may be located in countries outside of the European Economic Area (“**EEA**”) whose laws may not afford your Personal Data the same level of protection. Takeda will ensure that all adequate safeguards are in place and that all applicable laws and regulations are complied with in connection with such transfers.

#### **How Takeda protects your Personal Data**

Takeda will take reasonable and appropriate physical, administrative and technical safeguards to protect the Personal Data about you from loss, misuse, unauthorized access, disclosure, alteration or destruction.

#### **Your Rights**

Individuals in the EU have certain data subject rights which may be subject to limitations and/or restrictions. These rights include the right to: (i) request access to and rectification or erasure of their Personal Data; (ii) obtain restriction of processing or to object to processing of their Personal Data; and (iii) the right to data portability. If you wish to exercise one of the above mentioned rights, please use the contact information below. Individuals in the EU also have the right to lodge a complaint about the processing of their Personal Data with their local data protection authority.



### **How long Takeda retains the Personal Data**

Personal Data will only be stored as long as necessary for the purposes for which it was collected subject to local laws and regulations and legitimate business needs.

### **How to Reach Us**

You can contact us in order to exercise your rights, make inquiries or submit complaints concerning Takeda's processing of your Personal Data. Takeda will take appropriate steps to address requests, inquiries and complaints. Takeda will respond to such requests within thirty (30) business days.

Contact Details: Takeda Pharmaceuticals International AG, Attn: Data Protection Officer, Legal Department, Thurgauerstrasse 130, CH-8152 Glattpark-Opfikon (Zurich), Switzerland. Email: [dataprivacy@takeda.com](mailto:dataprivacy@takeda.com).

### **Important Information**

The Danish Data Protection Authority (Datatilsynet) is responsible for making sure that privacy law is followed in Denmark. For more information about your privacy rights, or if you are not able to resolve a problem directly with us and wish to make a complaint, contact: Datatilsynet (the Danish Data Protection Agency), Carl Jacobsens Vej 35, DK-2500 Valby, phone: +45 3319 3200, email: [dt@datatilsynet.dk](mailto:dt@datatilsynet.dk), website: [www.datatilsynet.dk](http://www.datatilsynet.dk).



**Certifikat for færdiggørelse**

Kuvert-id: A2293641ADBB432EB1DBB99BF785861B

Status: Sendt

Emne: Complete with DocuSign: Contract\_Takeda Pharma AS\_SDsjælddag\_Grant2023.pdf

Kildekuvert:

Dokumentsider: 8

Underskrifter: 1

Kuvertskaber:

Certifikatsider: 5

Initialer: 0

Britta Smedegaard Andersen

Autonavagation: Aktiveret

40 Landsdowne Street

Kuvertstempling: Aktiveret

Cambridge, MA 02139

Tidszone: (UTC+01:00) Brussels, Copenhagen, Madrid, Paris

britta.smedegaard.andersen@takeda.com

IP-adresse: 165.225.195.124

**Sporing af poster**

Status: Original

Ihændeher: Britta Smedegaard Andersen

Sted: DocuSign

21-09-2023 08:29:51

britta.smedegaard.andersen@takeda.com

**Hændelser for underskriver****Underskrift****Tidsstempel**

Lene Jensen

DocuSigned by:

Sendt: 21-09-2023 08:46:11

lj@sjældnediagnoser.dk



Vist: 21-09-2023 10:10:12

Sikkerhedsniveau: E-mail, Kontogodkendelse  
(ingen)

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Signeret: 21-09-2023 10:10:45

Vælg underskrift: Forudvalgt stil

Brug af IP-adresse: 152.115.40.130

**Oplysninger om elektroniske poster og underskrifter:**

Accepteret: 21-09-2023 10:10:12

Id: 513d7eaa-3549-44a6-ac3a-892d687f35a6

Louise Herbild

Sendt: 21-09-2023 10:10:46

louise.herbild@takeda.com

Head of Patient Value Access

Takeda Pharmaceuticals - Default

Sikkerhedsniveau: E-mail, Kontogodkendelse  
(ingen)**Oplysninger om elektroniske poster og underskrifter:**

Tilbydes ikke via DocuSign

Roland Kurney

Roland.Kurney@takeda.com

Sikkerhedsniveau: E-mail, Kontogodkendelse  
(ingen)**Oplysninger om elektroniske poster og underskrifter:**

Tilbydes ikke via DocuSign

**Hændelser for personlig underskriver****Underskrift****Tidsstempel****Hændelser for redaktørlevering****Status****Tidsstempel****Hændelser for agentlevering****Status****Tidsstempel****Hændelser for midlertidig levering****Status****Tidsstempel****Hændelser for certificeret levering****Status****Tidsstempel****Hændelser for kopi (cc:)****Status****Tidsstempel****Vidnehændelser****Underskrift****Tidsstempel**

<b>Notarhændelser</b>	<b>Underskrift</b>	<b>Tidsstempel</b>
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<b>Hændelser for kuvertoversigt</b>	<b>Status</b>	<b>Tidsstempler</b>
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Kuvert sendt	Med hash/krypteret	21-09-2023 08:46:11
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<b>Oplysninger om elektroniske poster og underskrifter</b>		
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## **ELECTRONIC RECORD AND SIGNATURE DISCLOSURE**

From time to time, Takeda Pharmaceuticals - Platform (we, us or Company) may be required by law to provide to you certain written notices or disclosures. Described below are the terms and conditions for providing to you such notices and disclosures electronically through the DocuSign system. Please read the information below carefully and thoroughly, and if you can access this information electronically to your satisfaction and agree to this Electronic Record and Signature Disclosure (ERSD), please confirm your agreement by selecting the check-box next to 'I agree to use electronic records and signatures' before clicking 'CONTINUE' within the DocuSign system.

### **Getting paper copies**

At any time, you may request from us a paper copy of any record provided or made available electronically to you by us. You will have the ability to download and print documents we send to you through the DocuSign system during and immediately after the signing session and, if you elect to create a DocuSign account, you may access the documents for a limited period of time (usually 30 days) after such documents are first sent to you. After such time, if you wish for us to send you paper copies of any such documents from our office to you, you will be charged a \$0.00 per-page fee. You may request delivery of such paper copies from us by following the procedure described below.

### **Withdrawing your consent**

If you decide to receive notices and disclosures from us electronically, you may at any time change your mind and tell us that thereafter you want to receive required notices and disclosures only in paper format. How you must inform us of your decision to receive future notices and disclosure in paper format and withdraw your consent to receive notices and disclosures electronically is described below.

### **Consequences of changing your mind**

If you elect to receive required notices and disclosures only in paper format, it will slow the speed at which we can complete certain steps in transactions with you and delivering services to you because we will need first to send the required notices or disclosures to you in paper format, and then wait until we receive back from you your acknowledgment of your receipt of such paper notices or disclosures. Further, you will no longer be able to use the DocuSign system to receive required notices and consents electronically from us or to sign electronically documents from us.

### **All notices and disclosures will be sent to you electronically**

Unless you tell us otherwise in accordance with the procedures described herein, we will provide electronically to you through the DocuSign system all required notices, disclosures, authorizations, acknowledgements, and other documents that are required to be provided or made available to you during the course of our relationship with you. To reduce the chance of you inadvertently not receiving any notice or disclosure, we prefer to provide all of the required notices and disclosures to you by the same method and to the same address that you have given us. Thus, you can receive all the disclosures and notices electronically or in paper format through the paper mail delivery system. If you do not agree with this process, please let us know as described below. Please also see the paragraph immediately above that describes the consequences of your electing not to receive delivery of the notices and disclosures electronically from us.

#### **How to contact Takeda Pharmaceuticals - Platform:**

You may contact us to let us know of your changes as to how we may contact you electronically, to request paper copies of certain information from us, and to withdraw your prior consent to receive notices and disclosures electronically as follows:

To contact us by email send messages to: [ad.ministrayter@mail.com](mailto:ad.ministrayter@mail.com)

#### **To advise Takeda Pharmaceuticals - Platform of your new email address**

To let us know of a change in your email address where we should send notices and disclosures electronically to you, you must send an email message to us at [ad.ministrayter@mail.com](mailto:ad.ministrayter@mail.com) and in the body of such request you must state: your previous email address, your new email address. We do not require any other information from you to change your email address.

If you created a DocuSign account, you may update it with your new email address through your account preferences.

#### **To request paper copies from Takeda Pharmaceuticals - Platform**

To request delivery from us of paper copies of the notices and disclosures previously provided by us to you electronically, you must send us an email to [ad.ministrayter@mail.com](mailto:ad.ministrayter@mail.com) and in the body of such request you must state your email address, full name, mailing address, and telephone number. We will bill you for any fees at that time, if any.

#### **To withdraw your consent with Takeda Pharmaceuticals - Platform**

To inform us that you no longer wish to receive future notices and disclosures in electronic format you may:

- i. decline to sign a document from within your signing session, and on the subsequent page, select the check-box indicating you wish to withdraw your consent, or you may;
- ii. send us an email to [ad.ministrayter@mail.com](mailto:ad.ministrayter@mail.com) and in the body of such request you must state your email, full name, mailing address, and telephone number. We do not need any other information from you to withdraw consent.. The consequences of your withdrawing consent for online documents will be that transactions may take a longer time to process..

### **Required hardware and software**

The minimum system requirements for using the DocuSign system may change over time. The current system requirements are found here: <https://support.docusign.com/guides/signer-guide-signing-system-requirements>.

### **Acknowledging your access and consent to receive and sign documents electronically**

To confirm to us that you can access this information electronically, which will be similar to other electronic notices and disclosures that we will provide to you, please confirm that you have read this ERSD, and (i) that you are able to print on paper or electronically save this ERSD for your future reference and access; or (ii) that you are able to email this ERSD to an email address where you will be able to print on paper or save it for your future reference and access. Further, if you consent to receiving notices and disclosures exclusively in electronic format as described herein, then select the check-box next to ‘I agree to use electronic records and signatures’ before clicking ‘CONTINUE’ within the DocuSign system.

By selecting the check-box next to ‘I agree to use electronic records and signatures’, you confirm that:

- You can access and read this Electronic Record and Signature Disclosure; and
- You can print on paper this Electronic Record and Signature Disclosure, or save or send this Electronic Record and Disclosure to a location where you can print it, for future reference and access; and
- Until or unless you notify Takeda Pharmaceuticals - Platform as described above, you consent to receive exclusively through electronic means all notices, disclosures, authorizations, acknowledgements, and other documents that are required to be provided or made available to you by Takeda Pharmaceuticals - Platform during the course of your relationship with Takeda Pharmaceuticals - Platform.