

January 4th, 2023

INTO-HLH Registry eConsent User Guide

Insight into the Natural History and Treatment Outcomes of
Hemophagocytic Lymphohistiocytosis (HLH)



Join the INTO-HLH Registry

Welcome to INTO-HLH Registry Guide!

There are **three documents** that we need to help you Join the Fight against HLH:

- (1) **consent** to participate for yourself (or as parent/legal representative), adolescents will also need to assent (see below)
- (2) a **medical records release form** to gather information from hospitals/doctors, and
- (3) a list of the medical institutions/doctors where you or your child has received treatment for HLH (the **next steps** form).

We will also need your contact and some other general information, as well as your (or your loved ones) initial date of diagnosis for HLH. Having this and a list of doctors/hospitals handy before you start is a great idea.

Let's get started!

On the Getting Started page, click **Continue** to begin.

- At the bottom of each page of the consent, you will see a slider bar that looks like this



- Place your finger or mouse on the button and slide to the **Right** to indicate you understand or to the **Left** if you have a question. Continue reading and acknowledging each page until the end.

If you have a question at any time during the consent process, the system will stop at that point and you will be directed to contact the INTO-HLH Registry Team (IHRT). Please either call 513-636-2908 or email intohlh@cchmc.org



Sign the Consent but you're not done yet!

Once you have read through each page and expressed your understanding, a Summary will show the list of the items you need for participation.

- You will need to **fill in all required fields** which are marked with a red asterisk (*).
- You will also be asked if you are interested in completing **optional** quality of life questionnaires for you or your loved one that will periodically be sent to you over the course of our 5 year study.
- Then click on the **Sign the Document green box** followed by a **Click** on the Signature Box as shown below.



Signature Box

The image shows a 'Patient' consent form. It includes a 'Required' label, an 'Agreement to take part in the study' section with bullet points, and a signature box with the text 'Tap or click here to sign your name'. There are fields for 'Patient' and 'Date' at the bottom.

Join the Fight by following the steps below to sign the Consent but you're not done yet!

The image shows the signature box with a hand cursor pointing to the text 'Tap or click here to sign your name'. There are fields for 'Patient' and 'Date' at the bottom.

Click in the gray box.

The image shows the signature box with a handwritten signature. There are 'Clear' and 'Next' buttons at the bottom.

Use your mouse to sign and then click the Green Next button

The image shows the full name input field with the name 'John Doe' entered. There is a 'Save' button at the bottom right.

Please type your name then click the Green Save button

You're Almost There!

Before you EXIT, **please click on [Read Another Document](#)** as it will take you to the final **two documents** needed for requesting medical records as we move forward towards the building of our Community of Hope.

*(Note: If you are consenting for a child between the ages of 11 and 17, they will also need to sign the Assent Form similarly to how you signed the consent form. This adolescent assent form will appear first in the list of documents to review.)

The screenshot shows a user interface for reviewing documents. At the top, a grey box contains the text "You have signed this document." Below this text are three green buttons: "Read Another Document", "Print", and "Exit". A large blue arrow points down from the "Read Another Document" button to a list of documents. The list is titled "Select a document to review" and contains four items: "Main Consent Form" (Required) with a green checkmark, "Assent for Adolescents Form" (Required), "Records Release Form" (Required), and "Next Steps Form" (Required). Below the list are two green buttons: "Back" and "Exit".

Sign the **'Records Release'** form followed by the **'Next Steps'** form. You will then automatically exit the system. Look for your Welcome email within the next couple of days!

Thank you for your participation!