

# Instructions

## International Living Donor Liver Transplant Registry

[LDLTregistry.org](http://LDLTregistry.org)



International  
**ILDLT Group**  
Living Donor Liver Transplantation



# Instructions contents

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- About LDLTregistry.org
- Platform navigation
- Register for an account
- Form your local team / assign a data auditor
- Audit / Quality Improvement Program / Ethics / IRB registration
- The electronic Case Report Form (CRF) / submit cases
- Access submitted cases for editing
- Contact us

# About LDLTregistry.org

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## **Aim**

- Capture outcome data on all LDLT donors and recipients worldwide
- Identify the true morbidity, mortality and independent predictors of outcome
- Allow evidence-based evolution of LDLT practice

## **Data**

- Data will belong to all LDLTregistry.org members.
- Local data monitors will ensure completion and quality.

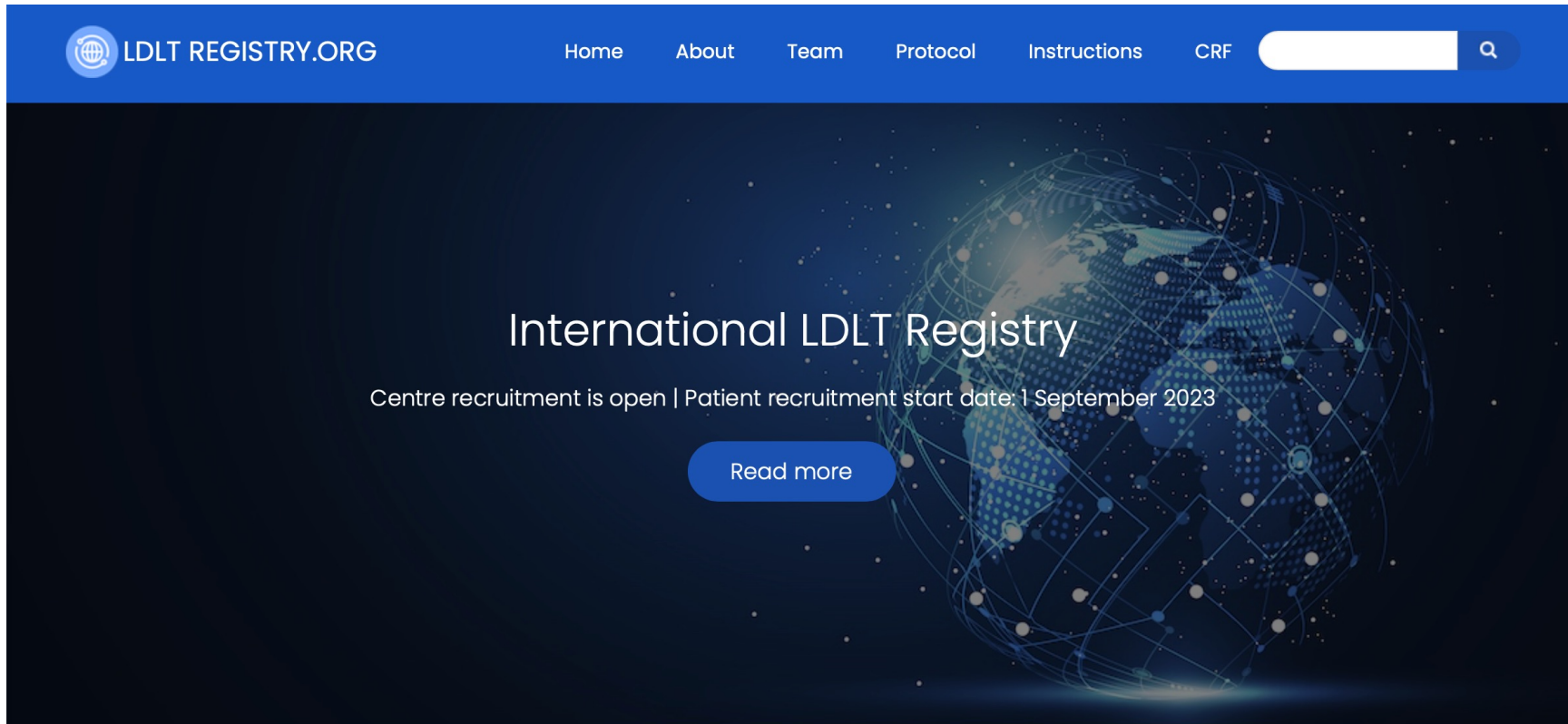
## **Authorship**

- All members will be PubMed cited as group authors in all publications.

## **Ethics**

- This project can be approved as an audit, quality improvement program, may require formal ethics / IRB approval by the local institutions. It is the responsibility of the local PI to receive approval

# LDLTregistry.org Platform




Please type [LDLTregistry.org](https://LDLTregistry.org) at your browser address bar to access the LDLTregistry.org platform.

You may use the top menu bar to access the “About”, “Team”, “Protocol”, “Instructions”, etc. pages.


More useful links are also available at the right sidebar and footer of the platform.



# Protocol


 LDLT REGISTRY.ORG

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## Registry Protocol

**International Living Donor Liver Transplant Registry | LDLTregistry.org**






Click on the relevant icon above to download the short version of the protocol in different languages.

**Background:** Living donor liver transplantation (LDLT) was introduced in the early 90's to overcome an increasing shortage of available diseased donor organs for transplantation. LDLT remains the main source of grafts for liver transplantation in Asian countries, however, reports on donor morbidity and even mortality have hampered the uptake of the procedure in Western countries. Outcome data are available from developed countries, but outcomes in developing countries remain unknown. There is a need to collect data from all parts of the world, to create a single prospective registry and allow meaningful comparisons, as well as standardization of the procedure, across the globe.

**Center eligibility:** Any center worldwide involved in LDLT is eligible to participate in this registry. There are no minimum number of cases to be submitted or selection criteria for centers.

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Log in

**Please read the short version of the registry protocol.**

**This is available in 12 different languages from the countries that perform the most LDLT.**

# Protocol

Full protocol: [Click on the icon below to access the complete version of the LDLRegistry.org protocol.](#)



- [Register your participation](#)
- [IRB waiver or approval](#)
- [Submit cases](#)

- [Donate](#)
- [List of funders](#)
- [Sponsorship](#)

## [Recruitment – 9 Apr 23](#)

### [Committees](#)

- [Members: 83](#)
- [Cities: 46](#)
- [Countries: 27](#)
- [Continents: 6](#)

### [Members](#)

- [TBA](#)

### [Submitted Cases](#)

- [TBA](#)

**The full version of the registry protocol is available for download at the end of the page.**

**This is currently available only in English however it will be translated in different languages soon.**

**This protocol can be used to request audit, quality improvement program, ethics and IRB approval.**

# Protocol



## Registry Protocol

**International Living Donor Liver Transplantation Outcomes Registry – LDLTregistry.org**

*The LDLTregistry.org Collaborative*


### **Summary**

**Background:** Living donor liver transplantation (LDLT) was introduced in the early 90's to overcome an increasing shortage of available diseased donor organs for transplantation. LDLT remains the main source of grafts for liver transplantation in Asian countries, however, reports on donor morbidity and even mortality have hampered the uptake of the procedure in Western countries. Outcome data are available from developed countries, but outcomes in developing countries remain unknown. There is a need to collect data from all parts of the world, to create a single prospective registry and allow meaningful comparisons, as well as standardization of the procedure, across the globe.


**Please read the full version of the registry protocol before starting recruiting patients.**

**This is available for download in PDF format.**

# Registration


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## International LDLT Registry

Centre recruitment is open | Patient recruitment start date: 1 September 2023

[Read more](#)

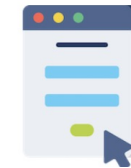
About LDLTregistry.org



Access the Registry Protocol




Register your Participation



Please register your participation by clicking on this icon.



# Registration

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## Create new account

Log inCreate new accountReset your password

Email address

*The email address is not made public. It will only be used if you need to be contacted about your account or for opted-in notifications.*

Username

*Several special characters are allowed, including space, period (.), hyphen (-), apostrophe ('), underscore (\_), and the @ sign.*



Picture


Choose Fileno file selected

*Your virtual face or picture.  
One file only.  
2 MB limit.  
Allowed types: png gif jpg jpeg.*

▼ Contact settings

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Log in

Member Menu

**This is the registration form available at LDLTregistry.org. Please complete it accurately.**

**This information will be used for future publications and authorship.**

# Registration

Would you like to become the country or regional leader?

- None -

*he role of the country / regional leader is to recruit and co-ordinate collaborators in their own country or region as well as to provide additional scientific and administrative support to their collaborators. If you agree, you will receive credit for your contribution as a country leader in all publications.*

Full name of your SECOND additional local collaborator at your institution (if known)

*You may now form a team of up to three collaborators per senior surgeon at your institution (multiple teams allowed for the same institution, in this case please ask them to register separately). Please indicate above and below the details of the two additional members of your team to also receive PubMed citable co-authorship from the PancreasGroup.org publications. If you are not sure yet, please leave them blank.*

Email address of your SECOND additional local collaborator at your institution (if known)

Full name of your THIRD additional local collaborator at your institution (if known)

Email address of your THIRD additional local collaborator at your institution (if known)

Full name of your Auditor (data monitor) at your institution

*Auditors (data monitors) will be assigned to monitor the adherence to the registry protocol as well as auditing the quality of data collection of the participating centers. Auditors are typically senior physicians of any type of speciality but not surgeons (to minimise bias and conflict of interest).*

Email address of your Auditor (data monitor) at your institution

**Select yes if you would like to become a country leader. Country leaders' additional responsibility is to recruit centers from their own country.**

**Please add here the full name of the 2<sup>nd</sup> local collaborator of your institution. These details will be used for authorship in future publications.**

**Each local team will be comprised of 3 investigators and one independent data auditor (monitor, non-surgeon).**

**Add here the email address of the 2<sup>nd</sup> local collaborator.**

**Add here the full name of the 3<sup>rd</sup> local collaborator.**


**Add here the email address of the 2<sup>nd</sup> local collaborator.**

**Add here the full name of the data auditor.**


**Add here the email address of the data auditors. See below for more information.**



# Registration

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## Account pending approval



**Thank you for applying for an account.**


Your account is currently pending approval by a member of the LDLTRegistry.org administration team.

In the meantime, a welcome message with further instructions has been sent to your email address.

**Please check your spam / junk folder if you have not received the email.**

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**Once you submit the form to request for a new account, you will receive an automated email.**

**Please check your spam folder if you have not received it.**


**A member of our Administration team will review the information and activate your account within 48 hours. This is for security purposes. Please check your spam folder again to ensure that you access this email; It will prompt you to create your password and allow you to login to the platform.**

**You can only access the electronic Case Report Form (eCRF) / case submission page only if you are logged in to the platform.**

# Local team


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## Formation of the local team

### Local Investigators + Auditor






**Local teams** will represent their participating centre in the LDLT Registry.

Each center may form a team of 4 members in total:

- **3 local investigators** and
- **1 independent local Auditor** (data monitor, non-surgeon).

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Log in

**Local teams will represent their participating center in the LDLT Registry.**

**Each center may form a team of 4 members in total:**

- **3 local investigators** and
- **1 independent local Auditor** (data monitor, non-surgeon).

**In high volume centers, it is allowed to create more than one local team of 3 per senior surgeon after request by email to our administration and management committee (see contact page).**

# Local team

## Auditor



An additional member of the local team, the **Auditor** (also called data monitor) (n=1) will be assigned to monitor the adherence to the registry protocol as well as auditing the quality of data collection of the participating centers.

**Auditors** should not be members of the surgical team to minimise bias.

Auditors are typically senior or middle grade physicians in other fields of medicine rather than surgery.

Quality control includes ensuring all consecutive cases are being submitted as well as ensuring that major complications for the donor and mortality for the recipient is correctly captured.

**Auditors** will be contacted by our administration team to confirm that the data submitted are complete and accurate.

If you have not yet included your local **Auditor** into your account when you registered with LDLTregistry.org, please do so by clicking [here](#). Alternatively, you may click on the "My account" link at the right side bar of the website and then "Edit".

Towards the end of the form, you are asked to enter the "Full name of your Auditor (data monitor) at your institution" as well as his/her email address. Please ensure that their details are correct, this is how he/she will appear on co-authorship in future publications.

## Recruitment - 9 Apr 23

### Committees

- Members: 83
- Cities: 46
- Countries: 27
- Continents: 6

### Members

- TBA

### Submitted Cases


- TBA

**Auditors, also known as data monitors, will be assigned to monitor the adherence to the registry protocol as well as auditing the quality of data collection of the participating centers.**

**Auditors should not be members of the surgical team to minimize bias.**

**Please read the following page for more information:** [https://ldltregistry.org/formation\\_local\\_team](https://ldltregistry.org/formation_local_team)

# Approval

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## Institutional Review Board (IRB) & Ethics

ViewEditDeleteRevisions


The International LDLT Registry - LDLTregistry.org is an observational cohort without affecting the patient management.

Data collection is fully anonymised without any patient identifiers.



In many countries this study is considered as an Audit (UK / Australia / New Zealand) or Quality Improvement Program (USA, Canada), without necessitating a formal ethics approval. However, each country, state, region or institution may have different regulations for gaining ethics permission.


In the UK, LDLTregistry.org does not require formal ethics approval and can be registered as an audit.

Please click on the icon below to [download](#) the Ethics Committee Decision Letter from the Canton of Zurich, Switzerland, where our academic headquarters are situated:



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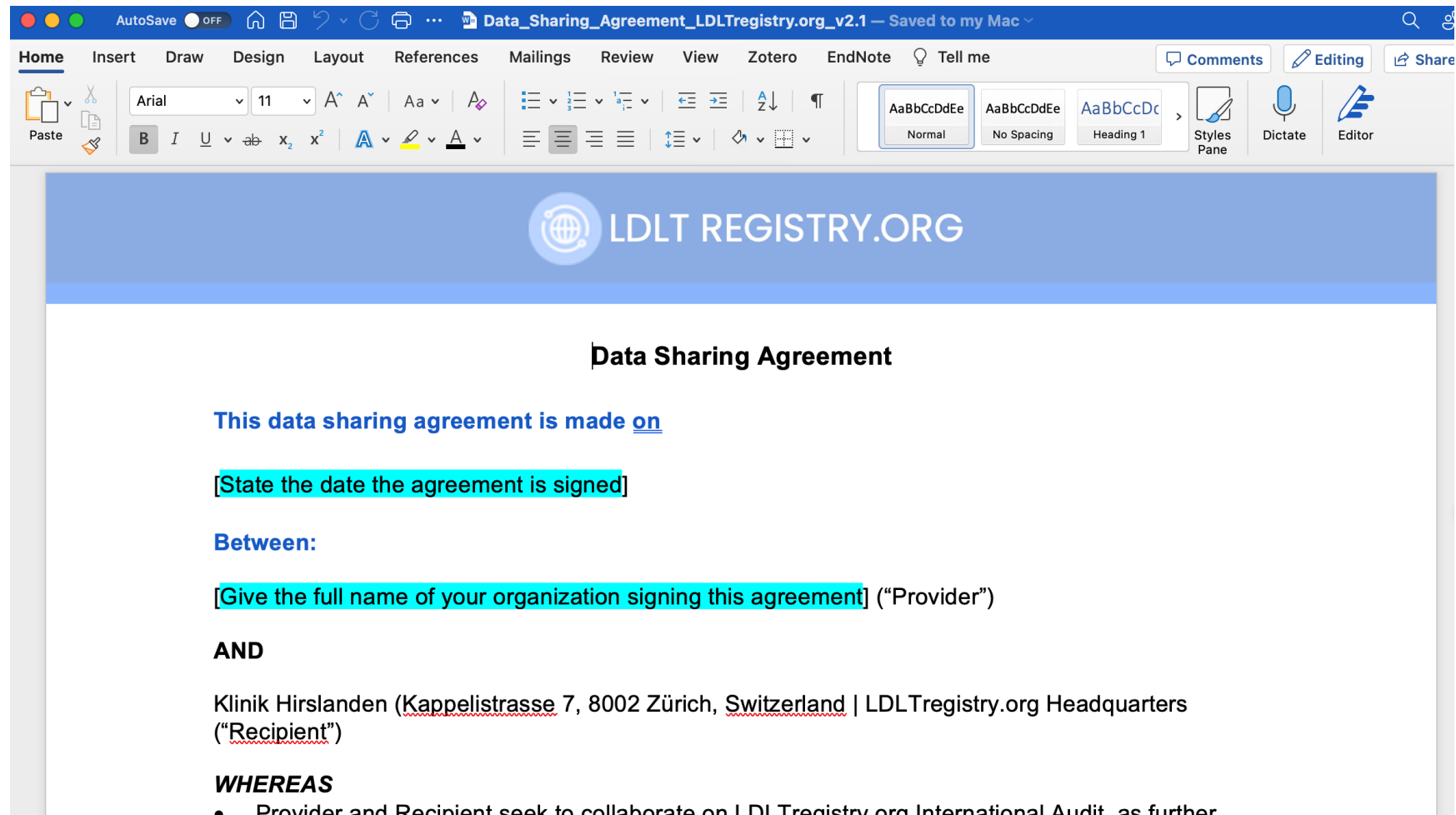
Admin Menu

**LDLTregistry.org is an observational cohort without affecting the patient management.**

**Data collection is fully anonymized without any patient identifiers.**

**In many countries this registry is considered as an Audit (UK / Australia / New Zealand) or Quality Improvement Program (USA, Canada), without necessitating a formal ethics approval. However, each country, state, region or institution may have different regulations for gaining ethics permission.**

# Data sharing agreement



**Under the "Instructions" page you will find a lot of useful information, such as the Data Sharing Agreement template, available for download in Microsoft Office format.**

**Our Administration team is available to help and support you with preparing your audit / ethics approval documents if required.**

# Instructions



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## Instructions

### Steps for Participation



1. Access the study protocol
2. Form a team of up to 3 people to collect data.
3. Identify an additional local auditor (data monitor, not a surgeon)
4. Register your participation
5. Obtain necessary local approvals (if required)
6. Submit cases to our electronic Case Report Form (eCRF)

**The official LDLT Registry recruitment start date is 1<sup>st</sup> of September 2023.**

### Information & Instructions



- Access the Frequently Asked Questions (FAQ)
- Institutional Review Board (IRB) & Ethics
- Patient Information and Consent form (only if required)
- Formation of your local team
- Becoming a country leader
- The study protocol short version in different languages
- Using your desktop, laptop, tablet or smartphone
- Conversion Calculators (height, weight, blood values)

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[Member Menu](#)

**The "Instructions" page is available at the top main menu bar at LDLTregistry.org**



# Login



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## Log in

[Log in](#)[Create new account](#)[Reset your password](#)

Username

Dimitri Raptis



*Enter your LDLT registry.org username.*

Password

.....



*Enter the password that accompanies your username.*

Log in

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## Funding

- [Donate](#)
- [List of funders](#)
- [Sponsorship](#)

**After having your account activated by our admin committee and you have successfully set your password, you will be able to login to your account by clicking on the "Log in" button available at the right sidebar of the platform.**

# Login

**Apart from being able to access the eCRF, additional functions and links will appear at the right sidebar of the platform.**

**There are shortcut links to the eCRF, your submitted cases for editing, calculators, and information about the terminology used at the CRF.**

## Member Menu

- My account
- Statutes
- Disclaimer
- FAQ
- Search
- Submission & Case ID Template
- Case Report Form
- Local team formation
- Contact us
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## Case Submission

- Paper CRF (PDF)
- Electronic CRF (submit cases)
- **My submitted cases (edit)**

## Calculators

- Height & Weight
- Bilirubin & Creatinine
- Date duration
- ACLF score calculator
- MELD score calculator

## Terminology

- ASA Status
- Performance Status Scores
- Intraop adverse events
- VAS pain scores
- Clavien-Dindo Classification

## Funding

- Donate
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- Sponsorship

## Recruitment – 9 Apr 23

### Committees

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### Members

- TBA

### Submitted Cases

- TBA

# Electronic Case Report Form



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## Case Report Form

### Paper version of the Case Report Forms (CRF) available for download:



(Will be available soon)

We strongly suggest to extract and record the data first on a **paper CRF** and then submit them online using the electronic CRF (see below). This may be useful to record all data prospectively and submit them only when all mandatory data are available (e.g. 90 day morbidity and mortality).

For your convenience, please use our "Submission & Case ID" excel file template (optional) stored safely at your institution to help you anonymize and de-anonymize the cases when you wish to identify them in the future in order to edit their submitted information.

Note that all fields marked with an asterisk (\*) are mandatory.

### Electronic Case Report Form (eCRF) for online case submissions:



The **electronic Case Report Form (eCRF)** was specially designed to support the online data collection of the LDLTregistry.org study. This CRF is an online data collection form where you can submit your cases.

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- [Submission & Case ID Template](#)

**The Case Report Form (CRF) / Data Submission Form will be available soon in PDF for download. The electronic Case Report Form / Data Submission Form is open, cases submitted from 1 Sep 2023 onwards will be included in the registry.**

# Electronic Case Report Form

The screenshot shows the LDLT Registry eCRF form. The top navigation bar includes the LDLT Registry logo and links for Home, About, Team, Protocol, and Instructions. The main heading is "Electronic Case Report Form (eCRF)". Below this is a progress bar with four steps: 1. Submission Information, 2. Donor Characteristics (current step), 3. Recipient Characteristics, and 4. Complete. The "Donor Characteristics" section is titled "Donor Characteristics" and includes a note: "Fields marked with an asterisk \*\* are mandatory". The form fields are: Donor ID \* (text input), Donor age \* (text input with a unit dropdown set to "years"), Donor sex\* (dropdown menu set to "- Select -"), Donor height\* (text input with a unit dropdown set to "cm"), and Donor weight\* (text input with a unit dropdown set to "kg"). Each field has a help icon (?) and a link to the unit conversion calculator.

## Donor

- Preop characteristics
- Workup data (medical / surgical)
- Anesthesia characteristics
- Operation characteristics
- Postoperative outcomes 90d | 12m

## Recipient

- Preop characteristics
- Operation characteristics
- Postoperative outcomes 90d | 12m

**The parameters above will be captured for each donor as well as recipient.**


**First you are required to complete the donor information and then the recipient information before you submit the joined case submission.**

**You may submit incomplete cases, but you will need to edit them in the future to ensure no missing data. Mandatory parameters are labelled with an "\*\*".**

# Electronic Case Report Form

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## Electronic Case Report Form (eCRF)

1

2

3

4

Submission InformationDonor CharacteristicsRecipient CharacteristicsComplete

1 of 4


Submission ID \* 


Please assign above a submission identification number related to both the donor and recipient. Please ensure that you keep this "Submission ID" in your records (excel file or any other database) if you would like to access this submission in the future and perform changes. Your excel file or any other database should include a) the submission ID, b) the donor ID and c) the recipient ID. [Click here to download the Submission and ID database template.](#) Please keep this file safe at your institution. Please ensure that the "Submission ID" does not contain any patient identification information, such as date of birth, hospital number, case number, etc.

Please click on the **"Next"** button below to proceed with the submission of the **Donor electronic Case Report Form (eCRF)**.

Save DraftNext >

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**The submission ID will link both donor and recipient cases.**

# Electronic Case Report Form

	A	B	C	D	E	F	G	H	I
1	<b>Submission ID</b>	<b>Donor ID</b>	<b>Donor Hospital Number</b>	<b>Recipient ID</b>	<b>Recipient Hospital Number</b>		<b>Submission ID</b>	Random number	Patient cannot be identified
2	334036	567948	51365	148313	52391		<b>Donor ID</b>	Random number	Patient cannot be identified
3	805469	444384	24424	427845	28574		<b>Donor Hospital Number</b>	Patient actual hospital number	Only for your records
4	550762	809696	42620	248646	32825		<b>Recipient ID</b>	Random number	Patient cannot be identified
5							<b>Recipient Hospital Number</b>	Patient actual hospital number	Only for your records
6									
7							<b>Random number generator</b>	<a href="https://g.co/kgs/AQ2kn7">https://g.co/kgs/AQ2kn7</a>	
8									
9									
10									
11									

**We strongly recommend you downloaded and used the excel template that links the Submission ID with the Donor ID and Recipient ID. These IDs should not include any patient identifiers. Please keep this file safe at your institution and link each Donor and Recipient ID to their hospital number. This way you may edit each submission later for completion of data.**

**Google has a random number generator; you may use this one to create Submission, Donor and Recipient IDs.**

Google search results for "google random number generator". The results show a random number generator tool with the number 418944 displayed. The tool has input fields for Min (1) and Max (999999) and a GENERATE button.

**These files are available for download at the Instructions page.**



# Electronic Case Report Form

**The Donor CRF captures morbidity until hospital discharge using the Clavien-Dindo Classification of postoperative complications.**

**This table will capture both the type and the grade of complications. The first column represents the type of complication, the remaining columns indicate the grade of the complication severity. By clicking on 3b under Abdominal wall dehiscence for example, this indicates a reoperation to manage this complication.**

**Please ensure you are familiar with the Clavien-Dindo Classification of postoperative complications before you submit any cases.**

**This classification, among others, is available under the “Terminology” right sidebar menu of our platform.**

	NO	1	2	3A	3B	4A	4B	5
Abdominal wall dehiscence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bile leak	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biliary stricture	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biloma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bowel obstruction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiac	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Deep vein thrombosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gastrointestinal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intra-abdominal fluid collection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurologic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pleural effusion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Portal vein stenosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Portal vein thrombosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Postoperative bleeding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonary embolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Renal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respiratory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Small for size syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Surgical site infection (SSI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Urinary tract infection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other infection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vascular	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other complication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Electronic Case Report Form

## Donor Postoperative Outcomes from Discharge up until 1 Year of follow up

*Please report all complications up to 12 months postoperatively excluding those already stated above (i.e. those during hospitalization)*

### Donor complications from hospital discharge until 12 months of follow up\*

☐ 12 month follow up not complete yet ☐ Yes ☐ No ☐ Unknown / no follow up

### Donor hospital readmission until 12 months postoperatively\*

☐ 12 month follow up not completed yet ☐ Yes ☐ No ☐ Unknown / lost to follow up

### Post-donation mental health status within 1 year of follow up

☐ Not assessed ☐ Lost to follow up ☐ Anxiety disorders ☐ Post-Traumatic Stress Disorder (PTSD) ☐ Depression

☐ Schizophrenia ☐ Bipolar disorder ☐ Eating disorders ☐ Disruptive behaviour and dissocial disorders

☐ Neurodevelopmental disorders ☐ Deliberate self-harm ☐ Suicidal ideation ☐ Other...

### Donor submission data completion

☐ Donor data complete until hospital discharge

☐ Donor data complete until 1 year of follow up

**Additional morbidity is captured in retrospect from hospital discharge until 1 year of follow up.  
Only cases with complete data until hospital discharge will be included in the registry analysis.**

# Electronic Case Report Form

You have now reached the **end** of the **Donor electronic Case Report Form (eCRF)**.

Please click on the the **"Next"** button bellow to proceed with the completion of the **Recipient eCRF**.

Furthermore, by clicking on the **"Save Draft"** button below, you may return to this form later and it will restore the current values.

**You will not be able to submit another case until you click on the "Submit" button, even if you have missing data. You may accesse and edit your submitted cases by clicking on the link "My submitted cases (edit)" available under the Case Submission right side bar menu. Complete submissions are considered only those without missing data of mandatory fields marked with a "\*".**

Save Draft

< Previous

Next >

**You may start completing a case at the eCRF and if you get interrupted or provided all available data, you will be able to save a draft of your submission by clicking on the "Save Draft" button.**

**When you return, the data will be available for completion. However, you will not be able to create a new case submission until you click on the "Submit" button available at the end of the eCRF.**

**If you have missing information (e.g. follow up data, etc.), please submit the case and access the "My submitted cases (edit)" page to view all your submission and choose the one you would like to edit. If anything is not clear, please feel free to contact us at any time.**

# Electronic Case Report Form

By clicking on the **"Save Draft"** button, you may return to this form later and it will restore the current values. You will not be able to submit another case until the current form is submitted.

By clicking on the **"Submit"** button, your case will be saved, even if it has missing data, and you will be able to fill out and submit the next case.

**You may access and edit your submitted cases by clicking on the link ["My submitted cases \(edit\)"](#) available under the Case Submission right side bar menu. Complete submissions are considered only those without missing data of mandatory fields marked with a "\*".**


Save Draft

< Previous


Submit

**The case is submitted by clicking on the "Submit" button in order to be able to submit another case in the future.**

# Electronic Case Report Form

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## Electronic Case Report Form (eCRF)

•

1

2

3

4

Submission Information

Donor Characteristics

Recipient Characteristics



Complete


4 of 4

New submission added to Electronic Case Report Form (eCRF).

[Back to form](#)

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Log out

**As soon as you submit a case, you will be prompted to this confirmation page.**

# Access submitted cases


## Case Submission

- Paper CRF (PDF)
- Electronic CRF (submit cases)
- **My submitted cases (edit)**

The Case Submission Menu Bar is available on the right side of the platform.



# Access submitted cases

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## My submitted cases

Action 

Lock submission


Apply to selected items

<input type="checkbox"/>	DRAFT	CREATED ▾	CHANGED	SUBMISSION ID *	DONOR ID *	RECIPIENT ID *	DONOR DISCHARGE	DONOR 1 YEAR	RECIPIENT DISCHARGE	RECIPIENT 1 YEAR	EDIT
<input type="checkbox"/>	No	4 May, 2023	1 minute 35 seconds ago	Test 19			No	No	No	No	Edit
<input type="checkbox"/>	Yes	6 February, 2023	3 months ago	Test 6			No	No	No	No	Edit

Apply to selected items

This is an example of two previously submitted cases. By clicking on the "Edit" link on the right, you will be able to make changes to your submission. By clicking on each parameter title, you will be able to sort your submissions accordingly for your convenience, e.g. when looking at those cases with incomplete data submission until hospital discharge.

# Conversion calculators

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## Conversion calculators

Please wait for a few seconds for the calculator widget below to load. Thank you.

Conversion Calculators

Height

Weight

Bilirubin

Creatinine

Dates

rBiostatistics.com

Height



Feet:


Inches:

Conversion Results

6 feet and 1 inches = 185 cm

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**We have developed conversion calculators to ensure uniform data collection. Please use them when converting height, weight or laboratory units.**

**The "Dates" link on the left will provide you with the number of days between two dates for your convenience.**

# Terminology

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## Performance Status Scores Information and Conversion



**Karnofsky score**


- 100 – Normal; no complaints; no evidence of disease.
- 90 – Able to carry on normal activity; minor signs or symptoms of disease.
- 80 – Normal activity with effort; some signs or symptoms of disease.
- 70 – Cares for self; unable to carry on normal activity or to do active work.
- 60 – Requires occasional assistance, but is able to care for most of their personal needs.
- 50 – Requires considerable assistance and frequent medical care.
- 40 – Disabled; requires special care and assistance.
- 30 – Severely disabled; hospital admission is indicated although death not imminent.
- 20 – Very sick; hospital admission necessary; active supportive treatment necessary.
- 10 – Moribund; fatal processes progressing rapidly.
- 0 – Dead

**ECOG/WHO score**

- 0 – Asymptomatic (Fully active, able to carry on all predisease activities without restriction)
- 1 – Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)
- 2 – Symptomatic, <50% in bed during the day (Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours)
- 3 – Symptomatic, >50% in bed, but not bedbound (Capable of only limited self-care, confined to bed or chair 50% or more of waking hours)
- 4 – Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair)
- 5 – Death

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The “Terminology” menu at the right sidebar will provide you with information regarding the different scores and classifications used in the eCRF. This is an example of the performance status.

# Terminology



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## CLIF-C ACLF (Acute-on-Chronic Liver Failure) ☆

Predicts mortality in acute-on-chronic liver failure.

### INSTRUCTIONS

Use in adult patients with decompensated chronic (cirrhotic) liver disease; it does not predict outcome in acute liver failure.

When to Use ▾

Pearls/Pitfalls ▾

Why Use ▾

Age  years

WBC count  × 10<sup>9</sup> cells/L ↗

Liver

Bilirubin  +1

### About the Creator



Dr. Rajiv Jalan

[Are you Dr. Rajiv Jalan?](#)

### Also from MDCalc...

#### Related Calcs

- [Child-Pugh Score](#)
- [MELD Na \(UNOS/OPTN\)](#)
- [UKELD Score](#)

### Content Contributors

- Callum Wood, MB, BChir, MRCP (UK)

This is an example on the Acute-on-Chronic Liver Failure score used in our CRF.

# Terminology

## Clavien-Dindo Classification of postoperative complications

Grades	Definition
<b>Grade 1</b>	Any deviation from the normal postoperative course without the need for pharmacological treatment or surgical, endoscopic and radiological interventions Allowed therapeutic regimens are: drugs as antiemetics, antipyretics, analgetics, diuretics and electrolytes and physiotherapy. This grade also includes wound infections opened at the bedside.
<b>Grade 2</b>	Requiring pharmacological treatment with drugs other than such allowed for grade I complications. Blood transfusions and total parenteral nutrition are also included.
<b>Grade 3</b>	Requiring surgical, endoscopic or radiological intervention
- 3a	Intervention not under general anesthesia
- 3b	Intervention under general anesthesia
<b>Grade 4</b>	Life-threatening complication (including CNS complications)* requiring IC/ICU-management
- 4a	single organ dysfunction (including dialysis)
- 4b	multiorgan dysfunction
<b>Grade 5</b>	Death of a patient

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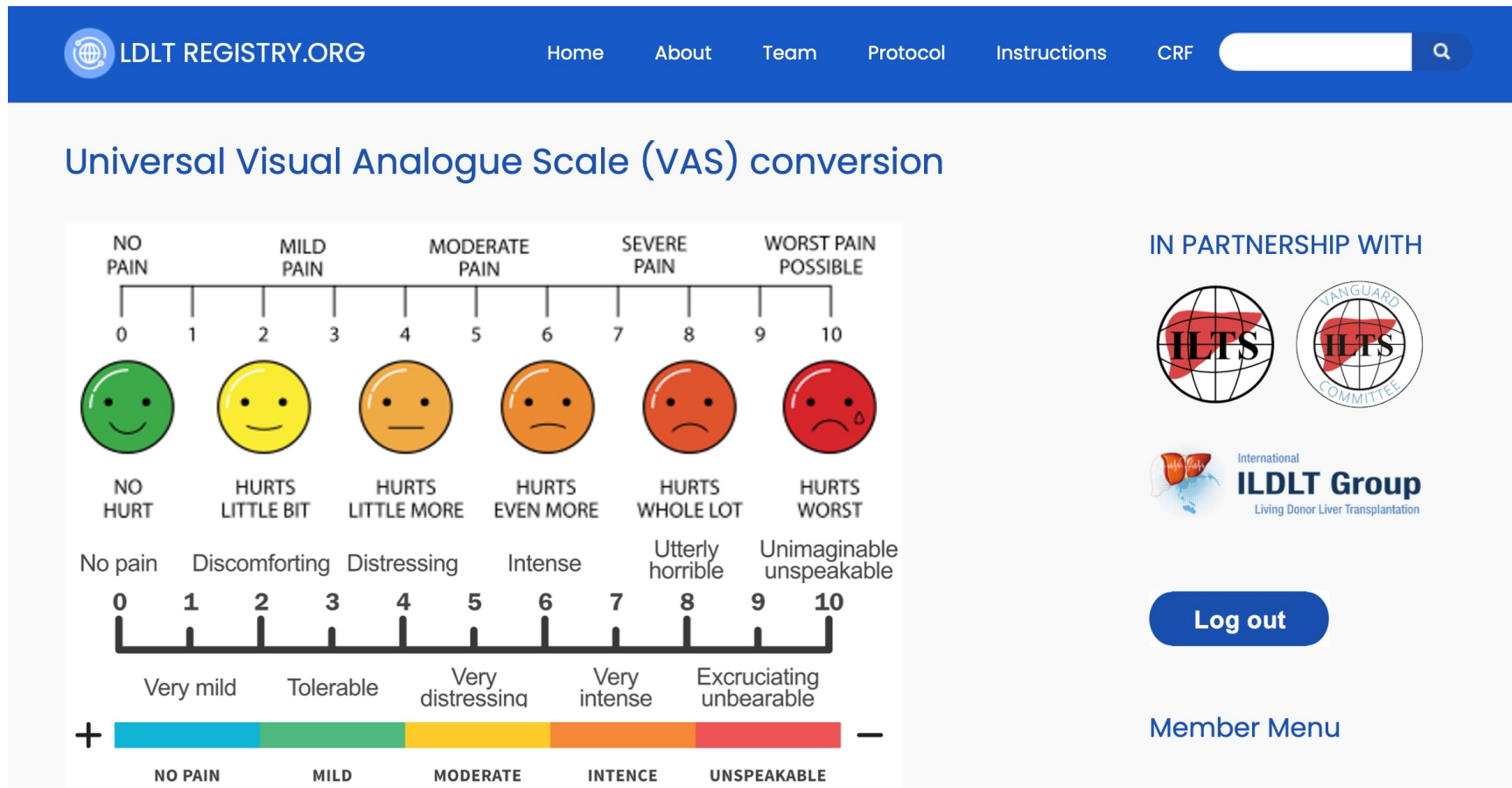
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Here is the Clavien-Dindo Classification of postoperative surgical complications

# Terminology



Since there are many Visual Analogue Scales, here is a universal conversion (0-10) for data uniformity purposes. This is also available under the “Terminology” right sidebar menu.

# Contact us



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## Contact

### Administration Office

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- ✉: [admin@ldltregistry.org](mailto:admin@ldltregistry.org)

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### Join our WhatsApp and/or Telegram Chat Groups

You may ask questions as well as be up-to-date with our developments:

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**Please feel free to contact us at any time. There will be soon a 24/7 support line for urgent questions and trouble shooting.**



# Thank you!

## International Living Donor Liver Transplant Registry

[LDLTregistry.org](http://LDLTregistry.org)



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