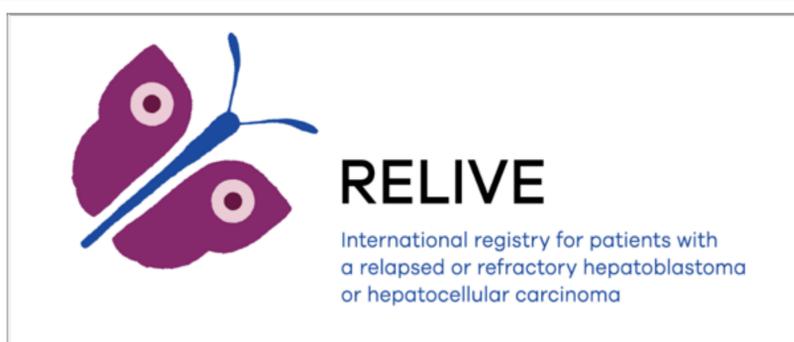


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RELIVE flash

No.5 - November 2022

RELIVE meeting during SIOP 2022 Barcelona

For the first time since the pandemic, the RELIVE community got a chance to see each other in person; it was just great to finally meet, greet, even hug, update, discuss, or simply share a laugh!

Here are the news in a nutshell:

- The study has been activated in the following countries: Canada, Hong Kong, Italy, Japan, The Netherlands, Poland, Spain, Switzerland
- Activation is ongoing in Australia/New Zealand, Belgium, France, Germany, Ireland, UK, USA
- Up to November 4, 119 patients have been registered from the following sites:

Prinses Maxima Centrum, Netherlands	34
Hospital for Sick Children, Toronto, Canada	33
Japan (11 institutions)	30
Hong Kong Children's Hospital	10
HU Regional Málaga, Spain	4
Gdansk, Poland	3
HU Virgen del Rocío Sevilla, Spain	2
HUG Geneva, Switzerland	1
Universitäts - Kinderspital Zürich, Switzerland	1
Istituto Nazionale Tumori, Milano, Italy	1

- Up to September, 126 events have been described (between 1 and 5 events per patient); 62 patients have died, highlighting the urgent need to find efficient treatments for these patients.
- Allison O'Neill from Dana Farber Cancer Institute reported on the preparations for a manuscript describing the RELIVE project as an international paradigm towards sourcing data for rare diseases.
- The procedure for uploading anonymized reports on histology, biomolecular investigations and surgery has been changed to OneDrive, see the description below.
- Remember that we aim for a total cohort size of 300 patients, therefore a substantial effort is still needed to reach our goal!

We plan the next face-to-face meeting with all of you during the SIOPEL spring meeting which is scheduled for March 23/24 at the Prinses Maxima Centrum in Utrecht, the Netherlands.

RELIVE people

Dr. Miho Kato, Department of Childhood Cancer Data Management, National Center for Child Health and Development, Tokyo, Japan

I became affiliated with the data center after working as a pediatric haemato-oncologist. Currently, at the Japan Children's Cancer Group (JCCG) Data Center for Solid Tumours, I am engaged in the centralized management of national clinical data in Japan, and the establishment of a national long-term follow-up system for childhood cancer survivors. Currently, I am involved in the RELIVE project to support the Japan Paediatric Liver Tumour Committee led by Dr. Hiyama and Dr. Watanabe.



Our data center also utilizes REDCap, and this has enabled us to set up the EDC for RELIVE in 10 seconds by importing just one file into our system!

The subsequent data exchange was also smooth thanks to the support of the core members, and we have accumulated 30 cases so far.

Thank you very much for the continued support, and we hope to have further opportunities for meaningful international collaborations.

Submission of anonymised reports

The method of sharing anonymised reports (histology, molecular analysis, surgery) for the RELIVE project with the Geneva team has changed. Instead of using the "Send-It" functionality in REDCap™, we now have a new data sharing solution: **ONEDRIVE**. You have received an e-mail lately asking you to provide us with the contact details (name, email address) of the person(s) at your site who will be in charge of uploading the reports so that you are given access to your personal folder on Onedrive. A detailed instruction will be sent to you when you receive access. Please ensure that the reports you upload are anonymised.

Any feedback from our readers?

We are curious to learn what you liked in this newsletter, or on what topic you would like to read in the future. And if you know of a colleague who should also receive the newsletter, please let us know!

