

Newsletter of the Gallbladder Cancer Registry

Dear (potential) members of the IHPBA Gallbladder Cancer Registry,

First of all, we're very excited to see so much renewed interest for the registry. Since the IHPBA meeting, we've had centres from all over the world join our effort. We're glad to welcome all new team members amongst our midst and we're looking forward to our future collaboration. Additionally, we'd like to congratulate dr. Jagannath and his colleagues on the publication of the expert consensus statement in HPB. The paper is a great example of the opportunities that international collaboration can provide and can serve as inspiration for future papers using data from the registry. In this letter, we'd like to provide an update on the progress of our study and our future plans.

Sincerely,

Dr. Philip de Reuver and dr. Elise de Savornin Lohman

On behalf of the Gallbladder Cancer Registry steering committee.

Castor EDC

The new Castor database is up and running. We'd like to thank dr. Subasinghe (University of Colombo) for the inclusion of the first patients in the registry. In the upcoming months, we're expecting many more inclusions yet to come! We're working on translating the Castor database to Spanish to facilitate participation of Spanish-speaking colleagues, and are planning to finalize the Spanish database by the end of this month.

Data completion

During the I-AHPBA meeting in Cape Town, we've established that the retrospective data needed proper completion in regards to follow-up. The past few months, many of you have been working hard in order to improve data completion, for which we're very grateful. We'd like to issue a special thanks to dr. Prieto Calvo (Spain), who's been successful in coordinating the completion of the data of the fifteen Spanish centers. We'd like to use this opportunity to request you to **complete follow-up of your patients by the end of September**, if you have not already done so. Your aid is instrumental in ensuring the success of the registry.

Aims for the coming year

As stated above, we're aiming to complete follow-up on the retrospective patients by the end of the summer. This fall, we'd like to use the retrospective data to write a paper on survival outcomes of patients stratified by the definitions as provided by the delphi consensus guideline paper. All participants from centers who've contributed patients will be mentioned as an author in the collaborative. In addition, we'd like to invite all participants to write their own research proposals using the data from the retrospective dataset. Proposals will be screened by the Steering Committee and data will be provided if the research proposal is found suitable.

New partners

Thirteen centers from across the world have joined the renewed registry, and another twelve have showed definitive interest in participating. We're aiming to increase this number significantly in the coming months. If any of your colleagues are interested in joining, please refer them to our website <http://www.gbcregistry.com>.

Use of own data

The new data management system allows all local investigators to track their number of inclusions live, and compare it to the others in the database. Moreover, every investigator is able to download their own data for personal use. In order to utilize data from other centers, a research proposal needs to be sent to the steering committee and approved by all members.

Interested?

Please visit our website: www.gbcregistry.com, or send an e-mail to the study coordinators (Philip.dereuver@radboudumc or elisedesavorninlohman@gmail.com)