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**MINUTE of the GRELL Meeting “ Toronto guidelines for staging childhood cancers” , Lisbon 31 May 2019.**

Participants:

Gabriela Caldas, Lisbon, Portugal

Rafael Marcos Gragera, Girona, Spain

Eva Ardanaz, Navarra, Spain

María-Dolores Chirlaque, Murcia, Spain

Marine Castaing, Siracusa, Italy

Fabiano Sabrina, INT Milan, Italy

Giovanna Tagliabue, INT Milan, Italy

Riccardo Capocaccia, E&P Journal, Milan, Italy

Laura Botta, Fondazione IRCCS “INT”, Milan, Italy

Gemma Gatta, Fondazione IRCCS “INT”, Milan, Italy

Rejane de Souza Reis, Hospital Fundação do Câncer, Rio de Janeiro, Brazil

Nathalie Balmant, INCA Rio de Janeiro, Brazil

Maria Paola Curado Camargo Center , Sao Paolo, Brazil

Brief presentation of each participants.

**Gemma** presented the agenda and objectives of the meeting (PP presentation attached) .

**Laura** presented the results of the JARC pilot study on stage for neuroblastoma and Wilms tumours (sample) in the countries whose registries contributed cases. Stage was reconstructed according to the Toronto guidelines on childhood cancers (TSGL). (PP presentation if requested)

Registries attended the meeting explained how they were able to reconstruct stage according to TSGL .

**Marine Castaing** (Sicily East Coast):

Thanks to a pediatric oncology Andrea di Cataldo (he got all cases, east coast of Sicily). A proposal to include him for the routine collection on stage, he will be more involve and willing to do routinely prospectively.

**Rafael Marcos Gragera**, Girona Cancer registry (CR):

Very low number of cases, no difficulties from clinical records, information included in the clinical record. In the region there are no pediatric oncologist unit, children with cancers go to be treated in Barcelona. Easy to obtain clinical information from the hospitals. For Tarragona CR it is the same. Very good centers and stage was easily reconstructed.

**Eva Ardanaz** (Navarra CR):

We had good experience, everything was in the clinical record. We have to speak with Rafael Peris in the middle of June (REDECAN, national network of Spanish CRs) at the meeting to discuss what to do next. We have pediatric oncologists that participate and send the data to RETI (Spanish Network of Childhood Tumors). Rafael Peris commented the possibility to complete the TNM staging in the RETI, thus, most of pediatrics cancer in Spain will have available the staging according with Toronto Guidelines. Thus, it could be possible a good collaboration between RETI and population based cancer registries in Spain. Populations small, we dedicate a specific person to do this kind of stage.

Gemma: informed that soon will be available a Spanish translation of the Toronto Guidelines Manual. Actually, at the Congress of the SEHOP (the Spanish Society of Haemato and Paediatric Oncologists), there was a meeting of the Working Group of the SEHOP for the RETI, which is the team responsible of doing the Spanish translation of the guidelines. The details of the organization of the work were completed and they hope that the translation would be ready in a short time. The University of Valencia will get a DOI for the translation, which will be accessible. Gemma stressed the relevance of the agreement between RETI and SEHOP to facilitate the use of the guidelines.

**Gabriela Caldas**: Today Pediatric oncologists care more about the stage also because its link with survival.

**María-Dolores Chirlaque** (Murcia CR):

Not easy to reconstruct stage, no information necessary to reconstruct childhood cancer stage available at the registry. Since the agreement with RETI there is an optimistic hoping for the routinely collection of stage.

**Nathalie Balmant and Rejane de Souza Reis (Rio de Janeiro, Brazil)** :

We had the authorization to translate in Portuguese the TSGL from the Australian group (Joanne Aitken). The manual is available for all the Portuguese language registries. The first pilot study on the application on the TSGL was done in the Belo Horizonte population-based tumor registry (southeast region). The incidence rate for cancer is 132 per million (children/adolescents 0-19 aged). For these pilot we selected cases during the period from 2012-2013 (244 cases) from only one institution. (65 cases). We apply the guidelines on all the tumors included in the TSGL. Neuroblastoma was the most difficult tumor to stage, that was necessary help of a pediatric oncologist. Three reviewers were able to stage every cases and there was good agreement. Average time to collect was 13 minutes. 12,3 % of missing in Tier 1 and 18,5% of missing in Tier 2, with the help of pediatricians the proportion of missing reduced to 7,7% (Tier 1) and 10,7% (Tier 2).

These first pilot was very small with only 65 cases but we believe the TSGL is feasible to be collected in Brazil. However, some difficulties were found for the hematological tumours, because of the lack of information on CNS invasion, so for these cases stage were missing. The Pediatric oncologists informed that the CNS exam was sent to a centralized lab and results were scarcely available. Training is required to improve a correct codification of stage according to the TSGL.

During a meeting with the participation of Linsday Frazier, all Brazilian population tumor registries (32) were invited and it was selected 5 with good quality to continue our pilot project. The 5 population-based tumor registry represents the 5 different geographic area from Brazil.

In Brazil, all public hospital must have a hospital based cancer registry (HBCR), actually more than 180 hospital have a registry. It is difficult to include the Toronto stage as new variable for these HBCRs, however it will necessary to try to do it. In the next meeting the TSGL will be proposed to both PBCR and HBCR. A collaboration with pediatric oncologists to support the TSGL is ongoing with the support of the Brazilian Pediatric Oncology Society (SOBOPE).

Gemma explained the linkage done in Spain between the clinical national neuroblastoma database ( Adela Canete) and the national database on childhood cancers.

SIOPE should endorse the TSGL . Regarding the collaboration with the national Societies: in Spain the collaboration is good, and for Portugal, Gabriela Caldas is the Vice president of the society.

Importance of **training course** in Italy to reinforce the collaboration with the Italian Pediatric Oncologists Society.

Gemma will contact Florencia (Argentina) director of the national childhood cancer registry. For expand the collaboration and the geographical comparison.

**Giovanna** **T and Sabrina F** (Varese Cancer registry) will translate, together with the colleagues of the Childhood Cancers Campania CR, the manual in Italian. The colleagues from the Varese CR also explained that for the Varese province, the information were available and complete for the TSGL stage.

To **conclude** from participants of the meeting emerged a great interest and availability to collect stage in childhood according to TSGL. Within the GRELL group, large number of registries will contribute from France, Belgium, Spain, Portugal, Italy and the Switzerland. Possible collaborative study with the use of stage will be considered as a **GRELL collaborative study**.

All agreed the organization of a **training courses**, that will be supported by the GRELL. In Italy, the Palermo registry will host the first course that will be realized in November 2019 (date to be defined).

The **manual** will be translated in Italian and soon will be available in Spanish, the Portuguese one is already available. it is expected to have in each GRELL country a training initiative within the next GRELL.

Gemma suggested to include the translated manual of TSGL in the **GRELL website**.

