





Use of tumour materials for research: Parent`s perspective

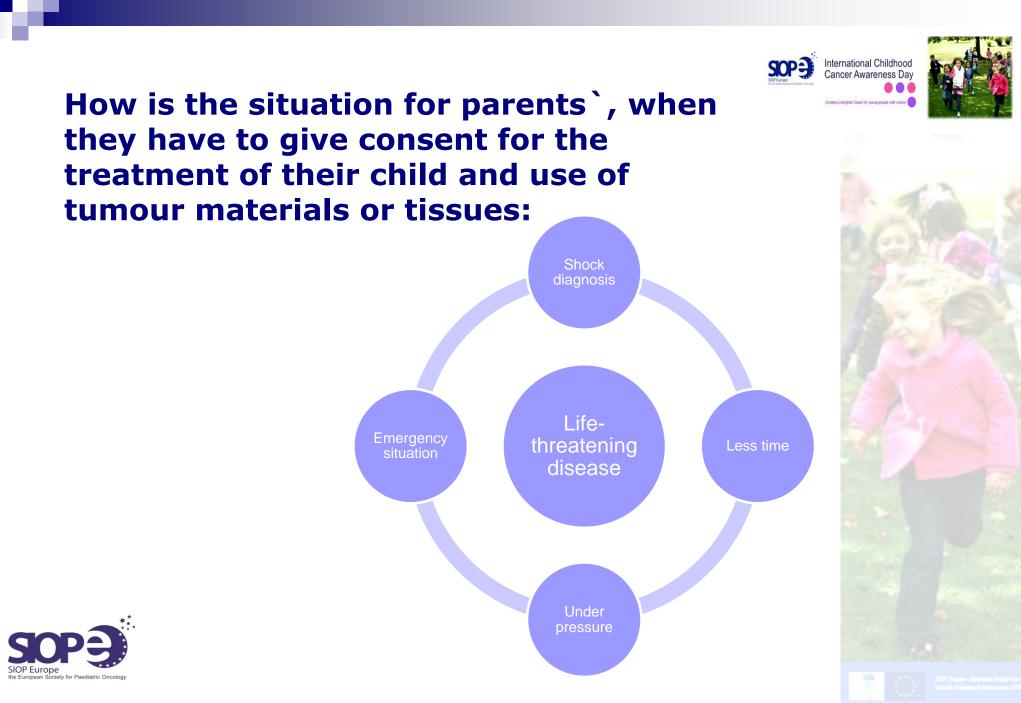
Sabine Karner

Project worker Childhood Cancer International (CCI) Representative Parents and Patients Advocacy Committee (PPAC)





Österreichische Kinder-Krebs-Hilfe Verband der Österreichischen Kinder-Krebs-Hilfe Organisationen







Parents` point of view towards research:

- Supportive towards research
- Now 80 % survival rate this would not be possible without research
- Cautious about research performed by private companies → being transparent about the research category (academic or private)







nternational Childhood Cancer Awareness Day



How is it for parents when they have to give continuously consent for their minor child:

- Family has their "normal life":
 - e.g. different emotions come up (fear, worries, fault ...)
 - e.g. this leads that the past is still topic within the family
- Don't understand the technical details of research projects → through away the letter





What are the wishes from parents` side towards the informed consent (1/2):

- To have a one-time consent "patients or in this case the parents as surrogate should have the right to give once forever their consent for their data/tissue to be processed for research purposes"
- This consent could be withdrawn by the parent/patient at any time (for any prospective research planned from the time point of withdrawal onwards).
- Therefore researchers should not ask for reconsent by parents/patients whenever new research is planned on their data and/or tissue.













What are the wishes from parents` side towards informed consent (2/2):

The **basis** for this is - **INFORMATION beforehand**:

- To be informed that the data/tissue of their child will be used for future research and
- To be informed about the conditions under which their data/tissue will be stored

Long-term wish/vision from parents` representatives:

- Involve trained and educated parents`/patients` representatives in Ethics committees
- Ethics committees should act as a gatekeeper protecting people against `unsuitable' research projects



