Patient´s

Background

- As you already know from information received on the EWING 2008 trial, we are aware of many risk factors for patients with Ewing sarcoma. This allows us to classify patients into risk groups and to establish risk-adapted therapy options.
- In addition to the EWING 2008 trial, there are other international research projects instrumental in improving the prognosis and therapy of patients with Ewing sarcoma.
- Recent findings indicate that certain characteristics (genes, proteins) in tumour, blood and bone marrow enable a more comprehensive stratification of risk groups. These analyses have already been carried out on a small number of patients. In order to see if these markers are helpful in the estimation of individual patient risk profiles, these analyses need to be performed on a large number of patients.

Aim of the study

- In the context of PROVABES and EEC, leading scientists from many European countries collaborate in order to find novel biomarkers that aid in improving the therapy and prognosis of Ewing sarcoma patients.
- As patients enrolled in current studies profit from former studies, the results of PROVABES and EEC will also be helpful to future patients. Participation in the study does not result in any personal or financial advantages.

Analyses

- In addition to markers that aid in the categorization of tumours, there are also changes in the surface markers, proteins and genes that play a role in risk profiling.

  <u>Tumour material</u>

  In the context of the EWING 2008 trial, tumour material from a subset of patients was closely examined. We would now like to analyze tumour material from all patients. We will use remaining material, which was collected during initial biopsy surgeries. By paying special attention to the possibility of chromosomal relocations or unusual transcription and translation, this will enable us to evaluate our findings more precisely.

  <u>Blood</u>

  In the course of therapy, routine blood extractions are necessary. We would like to draw an additional 5-15ml of blood at the regularly scheduled collection times. Extractions will occur prior to the onset of therapy, before and after induction therapy cycles, before and after surgery, and at therapy conclusion. The additional blood will be examined for minimal tumour traces, through the isolation of mRNA, microRNA and DNA.

  <u>Bone marrow</u>

  In the context of staging, there is a scheduled aspiration of bone marrow. At this point, we would like to aspirate an additional 5ml in order to detect

minimal tumour traces through the isolation of circulating mRNA, microRNA and DNA.

Required material (tumour, 5ml bone marrow, 12 times 5-15ml blood) will be extracted in the context of regularly scheduled diagnostic biopsy, bone marrow aspiration and blood extractions. No additional procedures are necessary to obtain these materials!

Voluntary participation

- Participation is voluntary. Consent may be cancelled at anytime without reason. This also holds true for patients who have reached the legal age of majority.
- The cancellation of, or refusal to participate does not result in negative consequences for further care.

Use of personal data

- No additional clinical or personal data will be collected. Data previously collected from the EWING 2008 trial is used to link new findings from PROVABES and EEC trial with the patient´s clinical condition.

- All rules concerning data protection are observed. All persons involved in the trials maintain confidentiality. There is no transfer of data to unauthorized personnel.

- Data is saved in a pseudonymous way. Names are replaced by a code, and therefore secure patient identity.
- In order to optimize the care of future patients, data is saved in the database long after the end of the trial, until such time that a revocation is necessary.

Contact persons

Professor Uta Dirksen (oncologist and project director), Dr. Andreas Ranft (psychologist) and Meybrit Rasper (physician) are your contact persons throughout the trial.
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