

**Patient Information**

Name: \_\_\_\_\_  
First Name: \_\_\_\_\_  
Date of birth: \_\_\_\_\_  
Diagnosis: \_\_\_\_\_

**Coordinating Study Center**

Center for Pediatrics and Adolescent Medicine  
Clinic IV: Div. of Pediatric Hematology and Oncology  
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E-Mail: [ewog-mds@uniklinik-freiburg.de](mailto:ewog-mds@uniklinik-freiburg.de)

Dear Parents, dear Patient,

The treating physician of your child / your treating physician is sending samples to the Coordinating Study Center of the European Working Group on Childhood MDS (EWOG-MDS) in Freiburg, Germany. Your child is / you are suspected to suffer from a disease involving blood and bone marrow. Possible diagnoses include bone marrow failure, myelodysplastic syndrome (MDS) or juvenile myelomonocytic leukemia (JMML). To find the correct diagnosis specific examinations on blood / bone marrow / material of other tissues (skin, hair follicles or others) are required.

Though your center is not participating in the EWOG-MDS study, we still offer support in diagnostic examinations concerning these bone marrow diseases free of charge.

We hereby ask for your written consent for the use and storage of material left over after the diagnostic procedure is completed. Your consent will enable to use this material for future research purposes. The research is non-commercial. All material will be stored at the Coordinating Study Center in Freiburg. Furthermore, we ask for your consent that the Coordinating Study Center may receive information about the clinical course of your child's / your disease.

You may retrieve information at any time about these future research results. Test results that are relevant for your child will, of course, be made available to your treating physician. You may also withdraw your consent at any time, in this case the remaining material will be destroyed. The results of our research may also benefit other patients with your child's disease in the future, allowing a deeper understanding of the disease or leading to a better treatment.

The guidelines concerning medical discretion and data protection are guaranteed. Research data will only be made accessible to specialists for scientific research purposes. If results of the research are published, your child's name / your name will not be used in any publication.

If you agree we ask you to sign the "informed consent".

I / We,

- declare of having been informed by the treating physician orally and in written form (Information Leaflet) on the diagnostic procedure and the future research purposes.
- declare that there was enough time to carefully evaluate the decision.
- declare that I/ we have read all of the above, asked questions and received answers concerning issues in the need of clarification.
- declare that I/ we give consent/assent by signing this form.

**Research Material:**

We agree that the blood and/or bone marrow and/or material of other tissues (skin, hair follicles or others) may be used not only for current diagnostic purposes but also to address open research questions. The material will be used for research concerning the cause of your / your child's disease or for optimizing treatment. This research (as molecular genetic studies) will not be commercial. All samples will be stored at the Coordinating Study Center in Freiburg, Germany, and will be analyzed for research purposes without names. The Coordinating Study Center supervises the research. Information on this research can be obtained on our website: [www.ewog-mds.org](http://www.ewog-mds.org).

**SIGNATURES**

\_\_\_\_\_  
(Patient Signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Parent / Guardian Signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Parent / Guardian Signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Physician Signature)

\_\_\_\_\_  
(Date)

By initializing in the following places, the parents / guardian and physician indicate their opinion that the patient is too young to give consent / assent to that time.

\_\_\_\_\_ Parents / Guardian

\_\_\_\_\_ Physician

\_\_\_\_\_ Age of patient