

Publication on anaesthesia in patients with rare diseases

- Get information on the rare disease
- Plan the anaesthesiological process together
- Create the case report / recommendation together

Checklist:

- No relevant or only few publications so far covering this focus
- Consent of patient/legal guardian
- Medical history, physical exam and preoperative work up for the special case done?
(ECG, echocardiography, lung function test, laboratory test, ENT-counseling, information of other physicians)
- Intra-operative: Relevant diagnostic process done (blood gas analysis, laboratory tests, ...)
- Information for further care units / physicians
- Documentation complete

For the patient/legal guardian

Declaration of Assent to a case report

Dear *patient/legal guardian*,

You/your child are diagnosed with a rare medical condition and will be requiring anaesthesia for a procedure which this condition may impact on.

We ask for your consent to us writing a case report on this anaesthetic. This case report is to provide information (data, X-ray, picture of air way, etc.) to other anaesthesiologists or physicians who may need to treat similar patients with this rare disease in future. Sharing this information is important and may help to improve the anaesthetic and medical care and safety of other patients with this condition.

Your/your child's name and any personal data will be deleted, including any details that might make you/them identifiable. Pictures will be changed so that recognition is not possible.

Your assent is voluntary and neither refusal nor assent will influence the treatment of you/your child in any way. You can retract your assent any time.

For any question about this, please contact us.

Your contact person:

Name

Signature

For the study doctor/physician

Declaration of Assent to a case report

I declare herewith my assent that the anaesthesiologist caring for me/my child

Name, date of birth, bar code etc.

may see and publish all data and all pictures referring to the anaesthetic care, and receive information from other medical parties involved (current clinic, family doctor, other physicians, other clinics etc.) for scientific purposes. This includes the presentation on expert conferences and congresses and the publication in scientific medical journals and educational books, digital media and online data bases.

I am aware that this assent is voluntary and that I will not be put at any disadvantage if I refuse. I am also aware that I can retract my assent any time with effect to the future. I am aware furthermore that already published texts cannot be withdrawn when the retraction takes place after publication.

There will be no costs for me connected with this assent, and there is no allowance possible.

I have been informed in detail and clearly about the case report by

_____ (name).

I have read and understood the text of this declaration of assent. My questions have been answered to my satisfaction. I have had all the necessary time to decide about this.

.....
(name of the assenting person in capital letters)

.....
Date

.....
Signature of the assenting patient/legal guardian