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Crouzon syndrome

orphan**anesthesia**

a project of the German Society
of Anaesthesiology and Intensive Care Medicine

SUPPLEMENT NR. 19 | 2026

OrphanAnesthesia –

ein krankheitsübergreifendes Projekt des Wissenschaftlichen Arbeitskreises Kinderanästhesie der Deutschen Gesellschaft für Anästhesiologie und Intensivmedizin e.V.

Ziel des Projektes ist die Veröffentlichung von Handlungsempfehlungen zur anästhesiologischen Betreuung von Patientinnen und Patienten mit seltenen Erkrankungen. Damit will OrphanAnesthesia einen wichtigen Beitrag zur Erhöhung der Patientensicherheit leisten.

Patientinnen und Patienten mit seltenen Erkrankungen benötigen für verschiedene diagnostische oder therapeutische Prozeduren eine anästhesiologische Betreuung, die mit einem erhöhten Risiko für anästhesieassoziierte Komplikationen einhergehen. Weil diese Erkrankungen selten auftreten, können Anästhesistinnen und Anästhesisten damit keine Erfahrungen gesammelt haben, sodass für die Planung der Narkose die Einholung weiterer Information unerlässlich ist. Durch vorhandene spezifische Informationen kann die Inzidenz von mit der Narkose assoziierten Komplikationen gesenkt werden. Zur Verfügung stehendes Wissen schafft Sicherheit im Prozess der Patientenversorgung.

Die Handlungsempfehlungen von OrphanAnesthesia sind standardisiert und durchlaufen nach ihrer Erstellung einen Peer-Review-Prozess, an dem eine Anästhesistin bzw. ein Anästhesist sowie eine weitere Krankheitsexpertin bzw. ein weiterer Krankheitsexperte (z. B. Pädiaterin bzw. Pädiater oder Neurologin bzw. Neurologe) beteiligt sind. Das Projekt ist international ausgerichtet, sodass die Handlungsempfehlungen grundsätzlich in englischer Sprache veröffentlicht werden.

Ab Heft 5/2014 werden im monatlichen Rhythmus je zwei Handlungsempfehlungen als Supplement der A&I unter www.ai-online.info veröffentlicht. Als Bestandteil der A&I sind die Handlungsempfehlungen damit auch zitierfähig. Sonderdrucke können gegen Entgelt bestellt werden.

OrphanAnesthesia –

a project of the Scientific Working Group of Paediatric Anaesthesia of the German Society of Anaesthesiology and Intensive Care Medicine

The target of OrphanAnesthesia is the publication of anaesthesia recommendations for patients suffering from rare diseases in order to improve patients' safety. When it comes to the management of patients with rare diseases, there are only sparse evidence-based facts and even far less knowledge in the anaesthetic outcome. OrphanAnesthesia would like to merge this knowledge based on scientific publications and proven experience of specialists making it available for physicians worldwide free of charge.

All OrphanAnesthesia recommendations are standardized and need to pass a peer review process. They are being reviewed by at least one anaesthesiologist and another disease expert (e.g. paediatrician or neurologist) involved in the treatment of this group of patients.

The project OrphanAnesthesia is internationally oriented. Thus all recommendations will be published in English.

Starting with issue 5/2014, we'll publish the OrphanAnesthesia recommendations as a monthly supplement of A&I (Anästhesiologie & Intensivmedizin). Thus they can be accessed and downloaded via www.ai-online.info. As being part of the journal, the recommendations will be quotable. Reprints can be ordered for payment.

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Projektleitung

**Dr. med. Christine Gaik,
DESAIC, FESAIC**

Oberärztin
Klinik für Anästhesie und
Intensivtherapie
Universitätsklinikum Gießen
und Marburg GmbH,
Standort Marburg
Baldingerstraße
35033 Marburg, Deutschland
E-Mail:
gaikc@med.uni-marburg.de

**Priv.-Doz. Dr. med.
Philipp Gude, MHBA**

Geschäftsführender Oberarzt
Klinik für Anästhesiologie und
Intensivmedizin
Universitätsklinikum
St. Elisabeth-Hospital
Bleichstraße 15
44787 Bochum, Deutschland
E-Mail:
philipp.gude@ruhr-uni-bochum.de

orphan**a**nesthesia

Anesthesia recommendations for Crouzon syndrome

Disease name: Crouzon syndrome

ICD 10: Q75.1

ORPHAcode: 207

Synonyms: Craniofacial dysostosis, first branchial arch syndrome

Disease summary: Crouzon syndrome is a congenital disorder characterized by premature closure (synostosis) of the coronal sutures, and less frequently of the sagittal or lambdoidal skull sutures. This results in a dysmorphic appearance of the skull and face, with a high forehead, flattened occiput and brachycephaly. In addition to the craniosynostosis, affected children may also have abnormal fusion of the bones of the skull base and midface, resulting in maxillary hypoplasia, high arched palate and shallow orbits, causing pronounced exophthalmos [1].

Severity is variable. The combination of a reduced intracranial volume and a growing brain may result in raised intracranial pressure (ICP), optic atrophy, hearing loss, seizures, and rarely, cognitive impairment.

Extended dysostosis of the facial and cervical bones and subsequent soft tissue abnormalities may compromise the upper airway. Obstructive sleep apnea (OSA) is common in Crouzon syndrome. Spine abnormalities may also be present and can reduce cervical mobility.

Crouzon syndrome may also be associated with a patent ductus arteriosus (PDA) and aortic coarctation (AoC). Crouzon, Apert, and Pfeiffer syndrome are among the most recognizable of the syndromic craniosynostoses [2,3].

Crouzon occurs in approximately 1 in 25,000 births and is due to a mutation in the fibroblast growth factor receptor (FGFR) 2 gene on chromosome 10. It may be inherited in an autosomal dominant fashion or occur sporadically as a spontaneous mutation. It has a male-to-female ratio of 3:1.

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Diagnosis may be incorrect; if uncertainty exists, the diagnosis should be re-evaluated.

Every patient is unique; individual circumstances must always guide clinical care.

Medicine is in progress; new clinical knowledge may not be yet reflected in this guideline Perhaps new knowledge.



Recommendations are not rules or laws; they provide a framework to support clinical decision-making. Although this recommendation has passed a structured review process, it does not meet the formal criteria of a guideline.

Translations may not always reflect the most recent updates of the English version.



Find more information on the disease, its centers of reference and patient organizations on Orphanet: www.orpha.net

Emergency information

A	AIRWAY / ANESTHETIC TECHNIQUE	Anticipate difficult mask ventilation and upper airway obstruction (OSA). Have a supraglottic airway available. Video laryngoscopy is the preferred option. Intubation can be easier than mask ventilation. However, be fully prepared for difficulty! Both general and regional anesthesia are feasible.
B	BLOOD PRODUCTS (COAGULATION)	No intrinsic coagulopathy! Major craniofacial surgeries = potential massive blood loss!
C	CIRCULATION	Crouzon syndrome can be associated with PDA and aortic coarctation. OSA and hypoventilation can lead to pulmonary hypertension.
D	DRUGS	Avoid strong opioids and benzodiazepines in OSA patients. Consider short acting agents and opioid sparing strategies.
E	EQUIPMENT	Difficult airway cart: video laryngoscope! Prepare for postoperative ventilation needs.

Typical surgery and procedures

Cranial vault expansion: Infants often require surgery to relieve raised ICP and allow brain growth. Posterior cranial vault expansion (with or without spring-assisted techniques) may be done in early infancy (as early as 3-6 months) if ICP is elevated. Fronto-orbital advancement (FOA) is usually performed in late infancy (app. 9-12 months) to correct skull shape and protect the eyes by enlarging the orbital volume [4].

Midface advancement: Severe midface hypoplasia causing exorbitism or airway obstruction (OSA) is addressed with a Le Fort III osteotomy, often with distraction osteogenesis using a rigid external distraction (RED) frame. This is typically done in childhood (around 5-12 years old, depending on severity).

Tracheostomy and Ear-Nose-Throat (ENT) procedures: Neonates with severe upper airway obstruction (e.g., severe choanal stenosis or micro airway) might need tracheostomy. Adenoidectomy or adenotonsillectomy is commonly performed in early childhood to palliate OSA symptoms.

Orthognathic and cosmetic surgeries: In adolescence or adulthood, patients may have corrective jaw surgery (Le Fort I maxillary advancement, mandibular surgery) or cosmetic revisions.

Multistage approach: Definitive management is staged across childhood.

Neurosurgical shunts: Hydrocephalus occurs in a subset of patients.

Other: For patients with a PDA or AoC, pediatric cardiac surgery may be necessary.

Type of anesthesia

There are no known contraindications to specific anesthetic drugs, and surgery can proceed with regional or general anesthesia [5].

Both inhalational and total intravenous techniques are feasible. In the case of increased intracranial pressure, the use of nitrous oxide is not advised; any further increase in ICP should be avoided.

Avoiding general anesthesia and systemic opioids may be advantageous in patients with airway obstruction (e.g., OSA). There have been reports of successful neuraxial blocks, although the presence of scoliosis may make neuraxial anesthesia difficult.

Be very cautious with deep sedation for procedures in Crouzon patients as sedation can precipitate airway obstruction. Dexmedetomidine has emerged as a valuable alternative in this scenario as it provides sedation and analgesia with minimal respiratory depression. However, data are very limited.

Necessary additional preoperative testing (beside standard care)

Look for indicators of a difficult airway during preoperative anesthetic assessment: Evaluate possibilities for alternative airway devices (e.g., supraglottic airway); assess mouth opening [6].

The personal, surgical, and anesthetic history may help guide anesthetic management or prompt further investigations: description of snoring and/or sleep apnea, history of difficult bag-valve-mask ventilation and any adjuncts used.

Corrective craniofacial surgery must be considered genuine major surgery, and an extended preoperative assessment is advisable (including blood work such as full blood count and coagulation studies, planning for transfusion requirements, postoperative intensive care arrangements, etc.).

In suspected or confirmed PDA or AoC, an echocardiogram and assessment for heart failure should be performed.

Also investigate for any history of seizures and the use of anticonvulsant medication.

Particular preparation for airway management

When anesthetizing a patient (adult or child) with Crouzon syndrome, it is advisable to anticipate and prepare for a difficult airway. In children, airway obstruction may occur early during induction due to the tongue blocking a hypoplastic oral cavity; thus, airway adjuncts such as a nasopharyngeal or oropharyngeal airway or a laryngeal mask may be required. The mandible is usually not affected by the disease, and therefore (direct) laryngoscopy is often feasible. In accordance with current guidelines, video laryngoscopy is the preferred option [7,8].

However, there are special situations where laryngoscopy may be more difficult. Following a series of mid-facial distraction procedures to achieve midface advancement (which enlarges the nasopharyngeal space), difficult laryngoscopy may be encountered – particularly during anesthesia for removal of the distraction device. This can occur even if intubation was uneventful during the device insertion.

The anesthetist should be familiar with how to remove the RED frame quickly in case of an emergency. Removal is accomplished by cutting the horizontal wires and using a screwdriver to remove the remaining screw and vertical central bar. The necessary tools must, of course, be immediately available whenever a patient with a RED frame is anesthetized.

A difficult airway trolley, with equipment such as a range of oropharyngeal and nasopharyngeal airways, laryngeal mask airways, a video laryngoscope, cricothyroid puncture (cricothyrotomy) sets, and a fiberoptic bronchoscope, should be kept ready nearby. Prepare correctly sized airway adjuncts in advance.

In any doubtful case, management of the airway by an awake fiberoptic intubation (planned a priori) is advisable.

Particular preparation for transfusion or administration of blood products

Crouzon syndrome is not associated with a bleeding diathesis, and there is no evidence to suggest any specific issues related to blood product administration. However, craniofacial procedures can be associated with significant blood loss, particularly when surgery is prolonged and in younger, lower-weight children [9]. As such, patients should have a full blood count, coagulation screen, and cross-matched blood available prior to surgery. If possible, optimize hemoglobin levels pre-op.

Employ strategies to reduce blood loss. Measures such as the use of anti-fibrinolytics (e.g., tranexamic acid), surgical adrenaline infiltration, meticulous surgical hemostasis, and cell salvage are effective and recommended to reduce transfusion requirements [10]. Invasive monitoring is indicated for craniofacial surgery, and regular sampling for arterial blood gas analysis or a thromboelastogram (TEG) will help guide fluid and blood product management.

Particular preparation for anticoagulation

There is no evidence of any increased risk of venous thromboembolism in the perioperative period, compared to the normal surgical population.

Particular precautions for positioning, transportation and mobilization

Extra care should be taken to protect the patient's eyes intraoperatively. Exophthalmos may be present and full eyelid closure may not be possible. The use of lubricating eye ointment and carefully applied eye pads is advisable.

Interactions of chronic disease and anesthesia medications

None known.

Anesthetic procedure

Once the airway is secure, anesthesia can proceed with either inhalational or intravenous agents, as appropriate. A multimodal analgesic approach may help to reduce opioid requirements in patients with OSA. At the end of craniofacial surgery, the airway should be re-assessed prior to extubation.

Particular or additional monitoring

The type of surgery will dictate the extent of additional monitoring required. Craniofacial surgery will require large-bore peripheral IV access (or central venous access), invasive arterial blood pressure monitoring, and urinary catheterization. Regular sampling for blood gas analysis or TEG will help guide fluid and blood product management during such cases. For other types of surgery, an arterial line may also be useful to allow monitoring of blood gases and hemodynamics in the recovery period.

Cerebral near-infrared spectroscopy (NIRS) can be used to monitor regional cerebral oxygenation during cranial vault surgeries – a drop in NIRS could indicate low cardiac output or significant venous air embolism (VAE) affecting cerebral perfusion.

Possible complications

Children or adults with Crouzon syndrome and suspected or diagnosed OSA may not tolerate a spontaneous-breathing anesthetic technique. This is due to a rightward shift of the CO₂ response curve under anesthesia, compounded by the respiratory depressant effect of opioids. As such, following securement of the airway, positive-pressure ventilation should be used. Consider the use of shorter-acting agents, such as desflurane, propofol, and remifentanyl, to facilitate a reliable return of airway reflexes and spontaneous ventilation at the end of the procedure. Avoid benzodiazepines.

In craniofacial procedures, as with any surgery during which the anesthetist does not have immediate access to the airway, be vigilant for evidence of endobronchial intubation, accidental extubation or disconnection, or blockage of the endotracheal tube by blood or secretions. There are no reports of other disease-specific manifestations intraoperatively.

Vigilance for VAE: In surgeries where the head is elevated and venous sinuses opened (like cranial vault expansions), be vigilant for VAE [11].

Postoperative care

Plan for a controlled, awake extubation in most cases. Consider an airway leakage test. Children who used nasal or face-mask CPAP preoperatively should have it available in the recovery area or intensive care unit (ICU). Plan for post-op ICU or high-dependency monitoring for the youngest, major cases and advanced pathology.

Disease-related acute problems and effect on anesthesia and recovery

There are no known syndrome-specific acute emergencies.

Be vigilant for post-extubation airway obstruction and respiratory compromise. Monitor and prevent secretions, swelling, or positional asphyxia.

Ambulatory anesthesia

Children without significant comorbidity or sleep apnea – for example, those with mild manifestations of the syndrome or those who have had successful corrective craniofacial surgery – and who are undergoing minor procedures may be suitable for day-case surgery. Caution is advised for adults with partially treated or suspected sleep apnea, particularly those who require opioids.

Obstetrical anesthesia

Crouzon syndrome is not known to be associated with complications in pregnancy. There is no contraindication to neuraxial techniques, although scoliosis may pose practical problems for neuraxial block placement. If general anesthesia is required, supraglottic airway edema may impede mask ventilation and laryngoscopy. Special consideration should be given to performing an awake fiberoptic intubation in this subgroup of patients [12].

Breastfeeding and genetics: Not directly an anesthetic issue, but the FGFR2 mutation has 50% chance of passing to child (if mother has it). Ensure pediatrician is aware that baby might have the syndrome for any immediate newborn care differences.

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This recommendation was prepared in 2014 by:

Author(s)

Emily Haberman, Anesthesiologist, Great Ormond Street Hospitals, London, United Kingdom

Co-Author

Johannes Prottengeier, Anesthesiologist, Klinikum Klagenfurt, Austria
johannes.prottengeier@kabeg.at

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This recommendation was reviewed by:

Reviewer(s)

Sukhminder Bajwa, Anesthesiologist, Gian Sagar Medical College and Hospital, Ram Nagar, Banur, Patiala, Punjab, India
sukhminder_bajwa2001@yahoo.com

Christopher R. Forrest, Division of Surgery, SickKids Centre For Craniofacial Care & Research, University of Toronto, Canada
christopher.forrest@sickkids.ca

Disclosure: The reviewer(s) have no financial or other competing interest to disclose.

Update and revision (2026)

Johannes Prottengeier, Anesthesiologist, Klinikum Klagenfurt, Austria
johannes.prottengeier@kabeg.at

Reviewer

Beate Küppers, Anesthesiologist, University Hospital Pisa, Italy

Editorial Review

Christine Gaik, Anesthesiologist, Department of Anesthesiology and Intensive Care Medicine, University Hospital Giessen and Marburg, Campus Marburg and Philipps University of Marburg, Germany
gaikc@med.uni-marburg.de

Herausgeber



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Redaktion/Editorial Staff

Korrespondenzadresse:

Neuwieder Straße 9 | 90411 Nürnberg |

Deutschland | Tel.: 0911 9337812

E-Mail: redaktion@ai-online.info

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Geschäftsführung

Wolfgang Schröder | Jan Schröder |

Tel.: 09522 9435-0 | Fax: 09522 9435-67

E-Mail: info@aktiv-druck.de

Anzeigen | Vertrieb

Pia Müller | Tel.: 09522 9435-70

E-Mail: anzeigen@aktiv-druck.de

Verlagsrepräsentanz

Jürgen Distler

Neuwieder Straße 9 | 90411 Nürnberg

Tel.: 0171 9432534

E-Mail: jdistler@bda-ev.de

Herstellung | Gestaltung

Robert Kux | Tel.: 09522 9435-71

E-Mail: ai@aktiv-druck.de

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3D Arts GmbH

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E-Mail: rmehl@3darts.de

www.3darts.de

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German Society of Anaesthesiology and
Intensive Care Medicine
Neuwieder Straße 9 | 90411 Nuremberg | Germany
Tel.: +49-911-933780
Email: info@orphananesthesia.eu