

Pigmented BCCs blanket the back and neck of a 9-year-old after radiation therapy for a medulloblastoma as an infant, prior to being diagnosed with GS. Medulloblastoma is a malignant brain tumor, and is a manifestation of this syndrome.



**8-year-old after undergoing
general anesthesia for laser
ablation of multiple BCCs
AND
removal of odontogenic
keratocyst.**



**5-year-old three days after
undergoing general
anesthesia for laser ablation
and PDT treatment of
multiple BCCs.**



These two men who had Gorlin syndrome died from metastatic BCCs to the lungs.

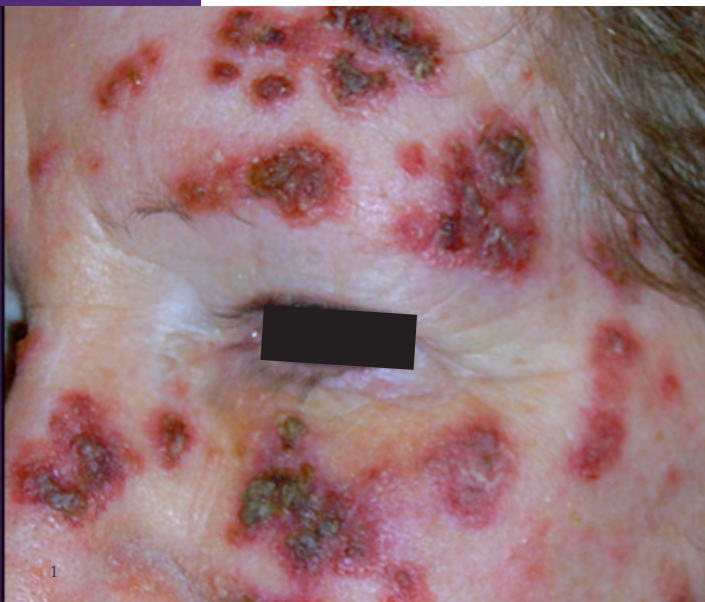


Having Gorlin syndrome is like “living with a ticking time bomb”.

Treatments can limit one's ability to function at home and in public.



After photodynamic therapy (PDT) treatment of multiple facial BCCs.



After 6 weeks of treatment with topical 5-FU.



**8-year-old boy
after undergoing
6-weeks of daily
application of
topical Imiquimod
for multiple BCCs.**



24-year-old male during PDT treatment of multiple BCCs on scalp. This was his 4th PDT treatment since age 7.



Woman in her 20's
with multiple
untreated facial BCCs
along with
disfiguring scars
from prior BCC
surgery.



Same woman with a
large, untreated BCC
on scalp.



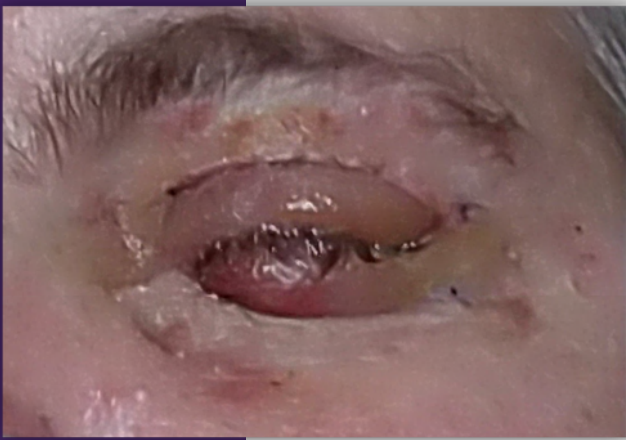
9-year-old boy two days after having 139 BCCs removed under general anesthesia.

There were more to be removed from scalp, neck, and arms but dermatologist felt that further excisions were intolerable at that time.

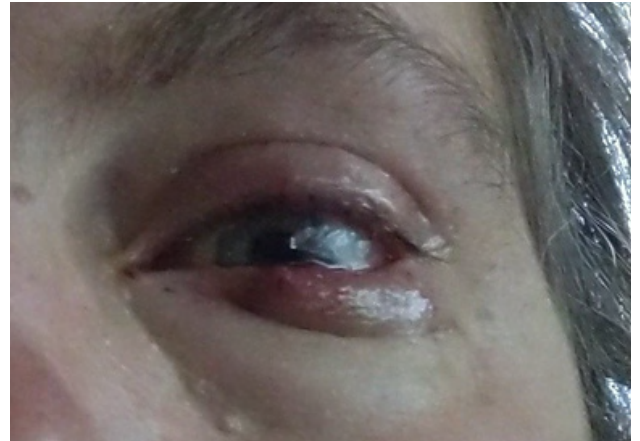


**Defect after two
(on top) and five
cuts (on bottom)
during Mohs
surgery of 52-
year-old woman
with Gorlin
syndrome.**





Surgery to repair defect necessitated eye being sewn closed for 12 weeks to heal. This significantly impacted daily life for her, as well as her husband and family.



It resulted in permanent loss of muscle function of lower lid in that it does not move down as far as that on the right.



8-year-old after
undergoing PDT (top)
and laser ablation (bottom)
of multiple BCCs.



A long day... Patient departed 9 hours after arriving for 3-hour drive home.



Pre-op. June 2020.



Mohs after 1st cut.



After 2nd cut.



After 3rd cut.



Clean after 4th cut.



Wound closed.

Same patient.



Post-op day 3.



Post-op day 10.



**2nd Mohs
procedure in 10
days – after 4 cuts.**



**17 days post-op 1st Mohs,
and 7 days post-op 2nd
Mohs.**



Two separate Mohs procedures. These individuals found sleeping and wearing glasses to be challenging for over 6 months.





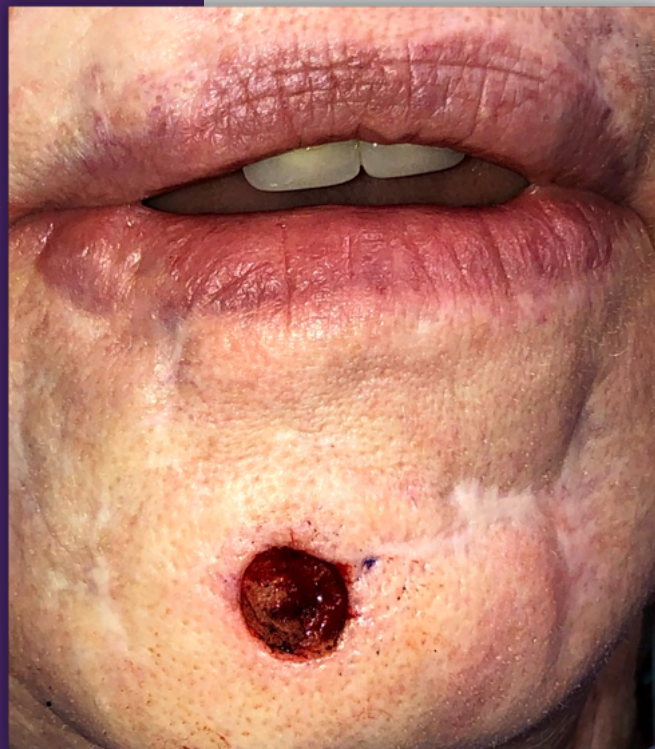
Extensive closure of Mohs defect. Due to its size, it was not possible to completely close. Borders were not clear and further treatment was required.





Multiple BCCs on the back and arm of three men.

Patients with breakthrough disease while on hedgehog inhibitors may require Mohs procedures for treatment of resistant lesions.





Individuals in their 20's already showing significant BCC burden and scarring. The woman below with sutures on the cheek and right side of her nose had a cleft lip and palate repaired as an infant. Cleft lip and palate are manifestations of Gorlin syndrome.





**Permanent
disfigurement &
scarring from years
of BCC removal
treatments.**





**Pits on the
palms and soles
are unique to
Gorlin
syndrome.**





7-year-old one day after removal of right maxillary OKC.



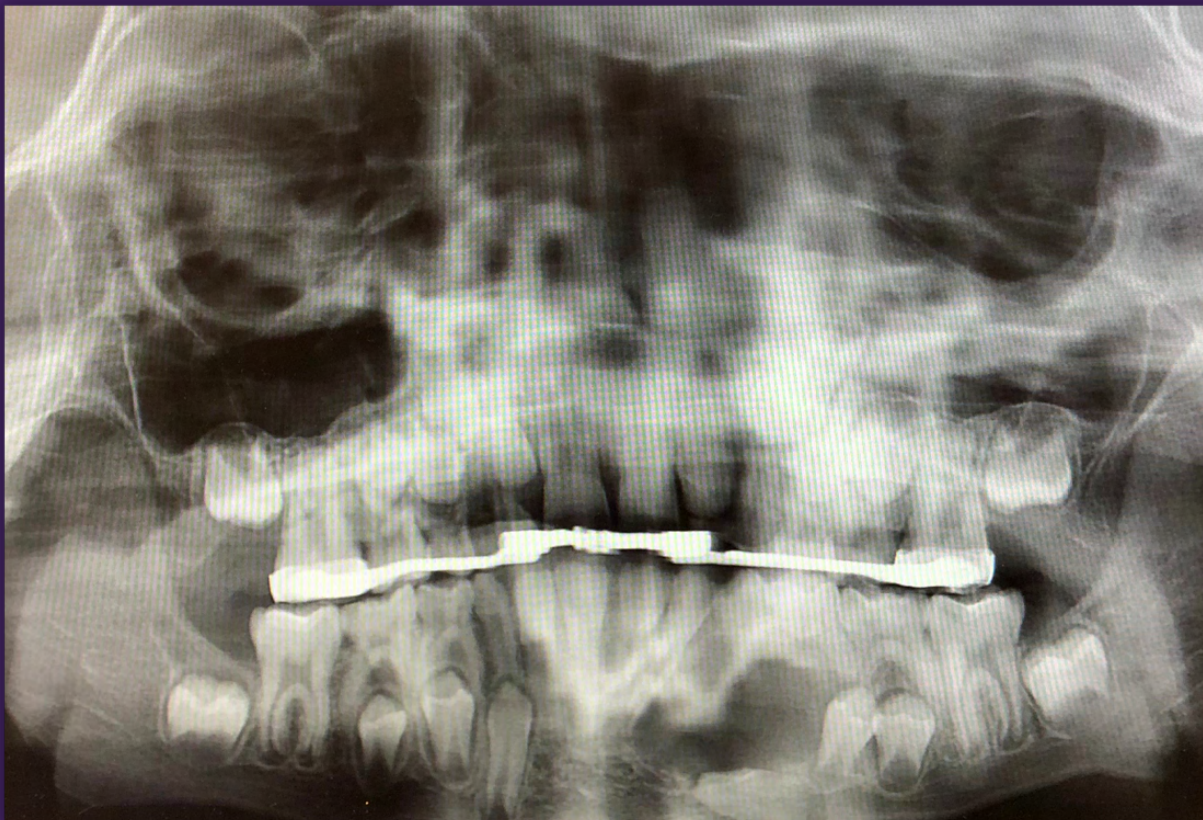
Now 15, the same boy four months after surgical removal of recurrent OKC in right maxilla. Thus far, he has had 9 surgical procedures to remove OKCs and lost 6 permanent teeth.



11-year-old on her way home from having four OKCs surgically excised. Now 14, she has had nine OKCs removed since age 9 and has lost 2 permanent teeth. Since birth, she has had 11 surgical procedures for a variety of Gorlin⁶ syndrome manifestations including hydrocephalus, strabismus, and hundreds of BCCs.



Since his first surgical procedure to remove an OKC at the age of 9, he has felt self-conscious about doing an open mouth smile. Other manifestations thus far include macrocephaly (wears his hair down on his forehead to hide this), hydrocephalus requiring VP shunt, scoliosis, and Sprengel deformity of shoulder blades.

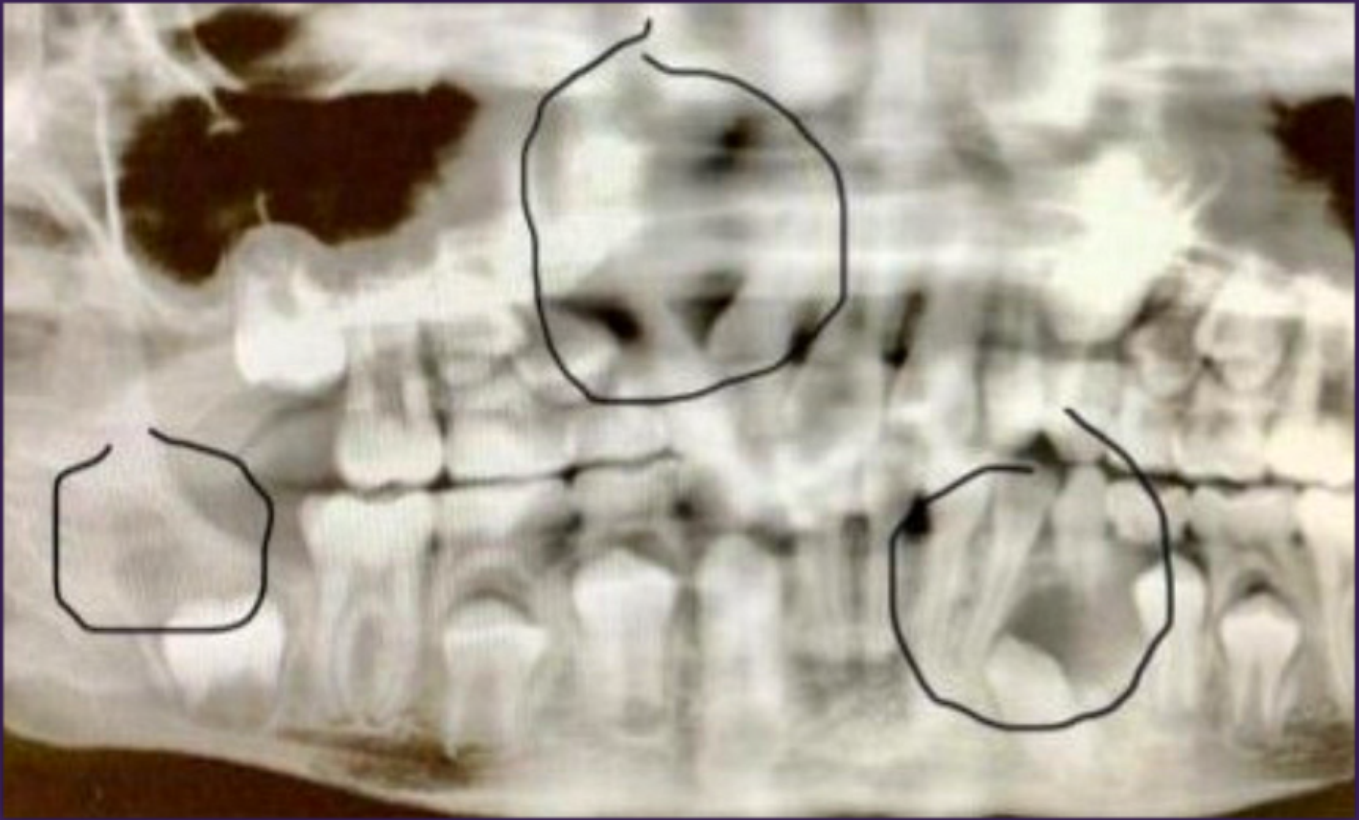


Left Mandibular OKC.



One day post-op.

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18 months later he had a recurrence of the left mandibular OKC along with two others.



One day post-op.

Other manifestations thus far include over 150 BCCs removed, cranial synostosis, cerebral ventriculomegaly, macrocephaly, bilateral hyperopia, hypertelorism, hypotonia, growth anomalies due to low growth hormone levels, strabismus, trichotillomania/anxiety, ADHD (inattentive).



**18-year-old with OKC
in left maxillary
sinus.**



**21-year-old with
recurrent OKC in
left mandible. Two
sets of braces set
the family back
financially.**



**17-year-old with
recurrent OKCs in
right & left
maxillary sinuses.**



Individuals with hydrocephalus or ventricular asymmetry that required surgical intervention.





Twin boys. Mom, who has Gorlin syndrome, knew immediately that one son did as well based on his head size.



Individuals affected with Gorlin syndrome who have had cleft lip and or palate.



On left, 7-month-old prior to surgery for cranial synostosis. On right, one day after surgery. Post-operative skull infection necessitated a month-long hospital stay and a 2nd cranial surgery. Infection was in the skull and required insertion of a PIC line to administer IV antibiotics for an additional 2 months after hospital discharge.



L to R: Waking up from surgery to remove medulloblastoma, undergoing chemotherapy, requiring oxygen for support during chemotherapy. Now 5 years old, he has had general anesthesia 20 times for Gorlin syndrome related manifestations including cleft palate and fetal rhabdomyoma on a rib. Other manifestations have included macrocephaly, enlarged brain ventricles, torticollis, motor and speech delays necessitating regular Physical and Speech Therapy.