



IN PARTNERSHIP WITH



### WHO WE SERVE

The Gorlin Syndrome Alliance serves all those affected with and by Gorlin syndrome.



### OUR VISION

The three pillars to the work of the Gorlin Syndrome Alliance are to provide support, share information on this rare disease to all who need it, and support research through opportunities to participate in clinical trials and the funding of grants.



### OUR MISSION

The mission of the Gorlin Syndrome Alliance is to thoughtfully support, comprehensively educate, and aggressively seek the best treatments and a cure for those affected by Gorlin syndrome.

### How skin conditions **IMPACT** patients



The three most burdensome manifestations of Gorlin Syndrome are Basal Cell Carcinomas (some will have over 1,000), aggressive cysts of the jaw bones which have a high recurrence rate, and the emotional and physical burdens of this disease which includes a lifelong cancer risk.

# OUR STORY

Founded in 2000 as the Basal Cell Carcinoma Nevus Syndrome Life Support Network, the Gorlin Syndrome Alliance as a 501c-3 non-profit, is the only such organization in the world working vigorously to improve the quality and quantity of the lives of people with Gorlin syndrome.

## HOW WE MAKE AN IMPACT

The Gorlin Syndrome Alliance makes an impact in many ways. Information on this rare disease is shared with health care providers, support is given to affected individuals and their care partners, and through collaboration with pharmaceutical companies, affected individuals have the opportunity to participate in clinical trials. The GSA also funds research into finding better treatments and ultimately a cure for the many, varied and challenging manifestations of Gorlin syndrome.

The GSA has an ongoing comprehensive patient registry / national history study. All affected are encouraged to participate by completing the questionnaires. The incidence of Gorlin Syndrome is approximately 1 in 27,000.




**SCAN TO LEARN MORE ABOUT GORLIN SYNDROME ALLIANCE**





## AT A GLANCE HOW WE PROVIDE SUPPORT

We connect people to give personal support, conduct quarterly community group and town hall meetings, and have an in-person conference every two years. Our private Facebook groups are supportive and active. Posts on LinkedIn and Instagram help as well.

## GET SOCIAL WITH US

 @gorlinsyndromealliance

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