gorlin
SYNDROME ALLIANCE

ANNUAL REPORT

2024

A letter from our Board President

As we reflect on the past year, I am proud to share just how far the Gorlin Syndrome Alliance has come—thanks to the strength of our community, the dedication of our leadership, and the generosity of our supporters. In 2024, we made measurable strides in our mission to support, educate, and advocate for individuals and families living with Gorlin syndrome.

We expanded our reach through record-setting engagement in our community programs, launched our second year of research grants, and continued growing our Patient Registry—our community's most powerful tool for shaping research and care. We awarded $30,000 in direct research funding and saw our end-of-year fundraising campaign grow by over 56% from the year before. These numbers reflect more than growth—they reflect trust, connection, and the momentum of a community working together toward a better future.

One of our most exciting milestones was being selected to join the Chan Zuckerberg Initiative Rare As One Network, a five-year capacity-building partnership designed to equip patient-led organizations like ours with the tools, funding, and strategic support to drive scientific progress. This moment validates years of groundwork and propels us into a new era—one where patients and families are not only at the center of research, but leading it. Through this partnership, we will expand the Patient Registry, set research priorities with our community, and invest in programs that move the needle for those affected by Gorlin syndrome.

In 2024, we also experienced a smooth transition in leadership. As we welcome Meredith Weiss as our new Executive Director and look ahead to this next chapter, we want to express our deepest gratitude to Julie Breneiser for her remarkable leadership during her tenure, and to all of you—our donors, volunteers, partners, and families—for being the heart of this organization.

The future is bright, and together, we will make it even brighter.

Kevin Gullatt

2024 BY THE NUMBERS

Grew Research Fund to: **$386,604**

Direct Research Funding: **$30,000**

Raised in End of Year Campaign: **$36,000**
+56% over last year

Income: **$514,311**

Expenses: **$441,185**

3 GRASSROOTS FUNDRAISERS

1,298 COMMUNITY FACEBOOK GROUP MEMBERS

A Celebration of Leadership

After 5 years, Julie Breneiser stepped down from her role as Executive Director in September, 2024. As a person living with Gorlin syndrome and the mother of two grown children also diagnosed, she brought personal insight and fierce advocacy to every aspect of her leadership.

During her tenure, Julie spearheaded the organization's first **Patient-Focused Drug Development (PFDD)** meeting with the FDA, resulting in the **Voice of the Patient** report now featured on both the FDA and GSA websites. She was also selected to serve on the FDA's Patient Engagement Collaborative from 2021–2023, amplifying patient voices in national policy.

Julie helped grow GSA's reach to over 3,400 community members. She launched the Gorlin Syndrome Patient Registry and built a robust library of educational resources for healthcare professionals.

In 2024, thanks in large part to Julie's vision, the GSA was honored to join the **Chan Zuckerberg Initiative Rare As One Network**. Julie's legacy lives on in the progress she made possible and the community she empowered.

Thank you, Julie!

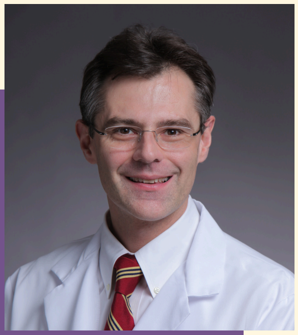
> *The Gorlin Syndrome Alliance was 1 of 31 organizations chosen to join the Rare As One (RAO) Network. The RAO Project aims to "lift up rare disease communities, providing them with resources and tools to be more effective advocates for—and partners in—research."*

Rare As One

Gorlin Syndrome Research

In 2024, the GSA Research Grant Program received more than twice the number of applications than in its inaugural year. The award committee was deeply impressed by the quality and vision of submissions.

This year's GSA Research Grant was awarded to Dr. John Carucci for his proposal:



John Carucci , MD

"Defining the BCC microenvironment change in response to smoothened inhibition: Identification of a role for addition of checkpoint inhibitor to optimize antitumor therapy for overwhelming disease."

Clinical Trials

The GSA collaborated with drug companies advancing therapies that target symptoms of Gorlin syndrome to incorporate the patient voice & perspective at critical points of drug development.

We support recruitment in clinical trials by disseminating information through our communication channels and acting as an unbiased hub for opportunities to participate in research.

GSA PR

GORLIN SYNDROME ALLIANCE PATIENT REGISTRY

Our Patient Registry is our most valuable tool for bridging the gap between the patient experience and scientific research. It allows us to elevate the patient voice, advance research and accelerate patient-centric priorities.

Patient participation grew in 2024, helping guide future research and enabling precision approaches to care.

> I *participate in clinical trials to help encourage doctors and clinicians to continue their efforts to find relief, help, information, and ultimately a cure.*
>
> -Maria

Medical & Scientific Advisory Committee

The MSAC plays a vital role in the GSA by shaping research efforts, guiding our research grant program, providing physician-reviewed educational materials, delivering community presentations, and supporting our staff. *Their expertise and commitment make our work possible.*

In 2024, we expanded our MSAC with the addition of three accomplished oral surgeons: Dr. Shravan Renapurkar, Dr. Kelly Kennedy, and Dr. Zachary Peacock. They join an exceptional team of experts on our MSAC, as well as our Oral and Dental subcommittee, to advance research and improve care for the oral and dental challenges associated with Gorlin syndrome.

2024 MSAC Advisors

Addy Alt-Holland, Ph.D.
Skin Cancer Researcher & Associate Professor,
Tufts University School of Dental Medicine

Allen E. Bale, M.D.
Professor of Genetics & Scientific Director,
Cancer Genetics & Prevention
Yale University

Liz Billingsley, MD
Professor of Dermatology
Staff Dermatologist & Mohs Micrographic Surgeon
Penn State Hershey Medical Center

Ervin Epstein, MD
Senior Scientist
Children's Hospital Oakland Research Institute (CHORI)

Jed Gorlin, MD
VP of Medical and Quality Affairs, Medical Director,
Memorial Blood Centers of Minnesota Center

Elena Hawryluk, MD, PhD
Committee Co-Chair Faculty Director of Pediatric
Dermatology Boston Children's Hospital,
Massachusetts General Hospital,
Dana Farber Cancer Institute
Harvard Medical School

Dr. Kelly Kennedy, DDS, MS, FACS
Oral and Maxillofacial Surgeon-- Professor and Oral &
Maxillofacial Surgery Residency Program Director at
The Ohio State University

Dr. Zach Peacock, DMD, MD
Chair, Oral and Maxillofacial Surgery,
Harvard School of Dental Medicine
Co-Director, Cleft and Craniofacial Clinic,
MGfC and Shriners Hospital for Children

Dr. Shravan Renapurkar MD
Associate Professor and Program Director
Department of Oral & Maxillofacial Surgery
Virginia Commonwealth University

Amy Tasca, DDS, PhD
Clinical Associate Director & Course Director,
Orthodontist in the Cleft & Craniofacial Clinic
University of Minnesota

Joyce Teng, MD
Director of Pediatric Dermatology,
Stanford University School of Medicine
Lucile Packard Children's Hospital at Stanford

Jim Swift, MD
Committee Co-Chair Oral & Maxillofacial
Surgery Director, Advanced Specialty Education
Program in Oral & Maxillofacial Surgery
University of Minnesota

with tremendous gratitude for our

Donors & Partners

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SOL-GEL

SUN PHARMA

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INHIBITOR THERAPEUTICS

Rare As One

PeDRA

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

COALITION OF SKIN DISEASES

NORD®
National Organization for Rare Disorders

Your unwavering support and commitment of our mission has a lasting impact on the entire Gorlin syndrome community.

2024 Board Members

At the end of September 2024, our Board of Directors welcomed Alix Alderman, FTOPRA, to the board. Alix is a seasoned leader in the biopharmaceutical industry with experience building regulatory affairs and research strategy, securing global approvals and patient access for therapies across various medical fields, including rare diseases.

Alix Alderman
Stacy Bissell
Sam Breneiser
Kevin Gullatt, JD
Elena Hawryluk, MD, PhD
Taylor Hodge
Beth Speigel
Mike Rainen
Roni Rubenstein, JD
Jim Swift, MD

Staff

Executive Director: Meredith Weiss, JD
Director of Clinical Trial Engagement: Julie Breneiser
External Relations Director: Dina Scalone
Patient Registry Director: Jean Pickford
Operations Manager: Samantha Maher

Charity Navigator
✦✦✦✦
✦ FOUR-STAR ✦

Gold
Transparency
2024
Candid.

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Please consider staying involved by volunteering your time, donating to our mission, or exploring other ways to partner.