

Carolina Sommer & The Born A Hero Research Foundation

Carolina Sommer downplays her accomplishments as an advocate, lobbyist, author, founder & co-founder, board member, and researcher, saying “as a rare disease patient or caregiver, you’re just put into all these different roles that you never thought you would do, but you know, that’s what we do for our kids and it’s the best community to be part of.”

Carolina's daughter has a rare genetic disorder called Pfeiffer syndrome. In the first five years of her daughter's life, Carolina spent up to six times a month in the hospital with her, describing it as a "lonely" and "isolating" experience. Despite the immense challenges, Carolina's daughter showed remarkable resilience and "glow" and "happiness" that inspired Carolina to fight alongside her, thus her creation of Born a Hero Research Foundation. The foundation provides support not only for Pfeiffer syndrome but also 15 other disorders associated with mutations in FGFR1, FGFR2, or FGFR3 genes, all of which encode fibroblast growth factor receptors (FGFR).

An early Foundation initiative was a partnership with the Seattle Children’s Research Institute to create The Seattle Rare Disease Fair; an annual event which provided visibility and resources for the rare disease community. The fair brought rare disease stakeholders – patients, caregivers, researchers, physicians, legislators, insurers, and manufactures – to an open and welcoming environment to have tough discussions. Through this, all stakeholders could view each other not as impediments but rather as collaborators.

“...one thing that I learned from the fairs. Everyone’s trying to do the right thing -- pharma’s trying to do the right thing, payers are trying to do the right thing. We have to learn how to see the positive in people, how to love people, how to like meet people, where they’re at.”

Out of this movement, the Northwest Rare Disease Coalition was born. This Coalition supports all those affected by rare disease. The coalition has ongoing work to ensure the patient voice is represented in individual state and federal policies, while also leading specific research initiatives with pharmaceutical companies, with biotechnology companies, and with insurers. One current effort is to fund an evidence-based study of complex care coordination, a major challenge for caregivers to manage.



Patients with Pfeiffer Syndrome, craniofacial conditions, and rare disease patients often have complex needs that affect multiple systems, making coordinated care essential. Carolina is fortunate to have her daughter under the care of a multidisciplinary Craniofacial team made up of 16 specialists. However, she recognizes that not all families have access to this level of comprehensive support. The reality is that many caregivers struggle to know who to contact, where to turn for help, and how to ensure that vital information is shared across the various healthcare providers involved in their child’s care. Rare disease families and complex pediatric patients urgently need a voice in the hospital setting—a central point of contact to help navigate care coordination and ensure that every aspect of their child’s health is addressed.



The NW Rare Disease Coalition and TFA Analytics are working on an evidence-based study to demonstrate the positive outcomes of complex care coordination for rare disease families—and the potential cost savings for healthcare systems. This pilot study aims to highlight the value of integrated care models that prioritize patient outcomes and efficiency.

“Time is everything for our families... if you’re not treating in the right time, then that’s when you get secondary conditions... and it gets big really fast”

As a step towards optimal outcomes and efficiency, Carolina’s efforts through Born a Hero have led to the creation of Centers of Excellence—specialized hubs of care designed to expand access to critical services and promote collaboration among healthcare providers. These centers bring together a network of experts, including doctors, surgeons, and other specialists, all with the knowledge and experience to treat patients with FGFR Syndromes, including Pfeiffer Syndrome.

“The more you collaborate, the more successful you are... It’s not just about receiving, it’s about giving back.”

For families with a member affected by an FGFR Syndrome, these Centers of Excellence offer second opinions, connect patients with the right specialists, and streamline access to hospital resources, including financial aid for travel, lodging, surgeries, and navigating insurance. This comprehensive support system ensures families have the help they need, both medically and logistically. In areas where specialized knowledge is scarce, the centers also play a pivotal role in training healthcare providers, helping to equip them with the expertise to better serve their communities. As part of this effort, the Born a Hero Foundation and the PROS Foundation are bringing surgeons from Africa’s first Craniofacial Center to the U.S. for advanced training, strengthening the global network of care for craniofacial conditions.

In addition to all of these initiatives, Carolina has been actively involved in research efforts to advance the understanding of FGFR Syndromes. Together with Ellen Morgan, Carolina has established a research registry to collect real-world data and generate evidence to improve treatment strategies.

At the heart of Carolina’s work is a simple yet powerful approach: communication, inclusion, and cooperation. These values have driven her efforts to build a more collaborative, effective system of care for rare disease families. Her perseverance has led to meaningful advances, providing better care and support for families who need it most.

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To learn more about these foundations, organizations, and initiatives working to improve lives for those with rare disease, please go to:

- Born a Hero Foundation - bornahero.org
- Northwest Rare Disease Coalition - nwrare.org
- PROs Foundation - prosfoundation.org
- FGFR Research Registry - fgfr.aimrare.org
- Principled Research Resources - principledresources.com
- Rare Awareness Radio - rareawarenessradio.org