Novartis launches "Meet The PROS" to raise awareness and support education for PIK3CA-Related Overgrowth Spectrum (PROS)

Aug 31, 2021

- PROS is a spectrum of at least 13 rare conditions driven by mutations in the PIK3CA gene, typically associated with tissue overgrowth, vascular malformations, and neurological disorders
- New initiative offers innovative educational resources for parents, caregivers, and people living with PROS, a rare disease often associated with physical and psychosocial challenges
- Novartis sought insights from an Advisory Committee of advocacy experts, patients, and caregivers to understand the community's needs and co-create content, including a comic book for children with PROS
- "Meet The PROS" reinforces Novartis commitment to supporting people affected by rare diseases

EAST HANOVER, N.J., Aug. 31, 2021 - Novartis today announced the launch of "Meet The PROS," an initiative to raise awareness and offer new educational resources for PIK3CA-Related Overgrowth Spectrum (PROS), a group of rare conditions caused by mutations in the PIK3CA gene.[1] PROS conditions are diverse, and are typically characterized by atypical, visible growths and anomalies in the blood vessels and lymphatic system.[1] People living with PROS often experience a multitude of physical, emotional, and psychosocial challenges, such as chronic pain and mobility issues, diagnosis uncertainty, and difficulty finding clothes or shoes that fit.[1-4]

Experience the interactive Multichannel News Release here: https://www.multivu.com/players/English/8928131-novartis-launches-meet-the-pros-to-raise-awareness-and-support-education/

"PROS conditions can have potentially debilitating physical impacts and are often associated with a range of emotional and social challenges for patients and their families. Through the Meet The PROS initiative, we aim to answer the community's call for more awareness and educational resources," said Reshema Kemps-Polanco, Head of Novartis Oncology, US. "We're grateful for the collaboration and insights from our Meet The PROS advisors. Their contributions are invaluable as we continue our efforts to reimagine medicine for people living with rare diseases."

Novartis collaborated with advocates, caregivers and patients to create an educational initiative to help young people with PROS learn and talk about their condition. The initiative includes an educational comic book, conversation guides, fact sheets and other resources, available now at understandingpros.com/talking-about-pros/.

Hear from "Meet The PROS" Advisors

"I've been asked questions about my PROS condition my whole life. It wasn't always easy answering those questions at a young age, but over time I've learned ways to be open and talk about my condition comfortably," said Lindsay P, a Meet The PROS advisor living with CLOVES. "I am proud to be a part of this campaign and I hope these resources help others with similar experiences to my own find new ways to talk

about their PROS condition."

"When your child is diagnosed with a rare condition, the first thing you do is search online for information. With PROS conditions, however, searching online doesn't lead to many results, which can be frustrating and isolating," said Lauren B, caregiver and Meet The PROS advisor. "I'm hopeful that these resources will help parents and families learn more, feel less alone and raise awareness about the physical and emotional impacts of these rare conditions."

"Ever since my diagnosis, I've worked hard to teach everyone willing to listen about FAVA, including doctors, medical students, my teachers, my friends, coaches and other students," said B.W., a Meet The PROS advisor living with FAVA. "It warms my heart to have helped create this comic book and other tools that will encourage kids like me to find a superhero within themselves and conquer the struggles they face because of their PROS condition."

"My daughter and I created a 'speech' she gives to her class to explain that while she was born looking a bit different, she's just like everyone else," said Robynn K, caregiver and Meet The PROS advisor. "There are limited resources for parents to help educate and empower their children to talk about PROS conditions. It's rewarding to be part of this initiative and support the community."

"I know firsthand how many questions parents and people with CLOVES and PROS have about these conditions, and it's hard to see them struggle to find answers," said Kristen Davis, Executive Director of CLOVES Syndrome Community and Meet The PROS advisor. "It is my hope that these educational materials, including the comic book, will be a resource for parents and youth seeking to learn more about these conditions."

"It's hard to meet people who understand your experiences when you live with a rare condition. Our advocacy network works to connect people impacted by PROS conditions so they can learn from each other," said Mellenee Finger, Director of K-T Support Group and Meet The PROS advisor. "It's great to have additional resources, created by and for the community, to help raise awareness and education about PROS."

About PIK3CA-Related Overgrowth Spectrum (PROS) Conditions

PROS is a wide-ranging spectrum of disorders caused by a mutation in the PIK3CA gene.[1] PROS conditions can look different from each other in size, shape, and type of growth or malformation based on where in the body the mutation is found.[1,5] PROS can disrupt mobility and cognitive function in some patients and may lead to life-threatening complications.[6-8]

The PROS classification was proposed at a National Institutes of Health workshop in 2013 to unite a group of rare overgrowth conditions caused by PIK3CA mutations.[1,5] Specific conditions associated with PROS include KTS, CLOVES syndrome, ILM, MCAP/M–CM, HME, DMEG, HHML, FIL, FAVA, macrodactyly, muscular HH, FAO, CLAPO syndrome and epidermal nevus, benign lichenoid keratosis, or seborrheic keratosis.[1,5]

About Novartis

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