Photographer Captures Patients Around the World Persevering With ITP

To showcase how people living with ITP triumph and persevere, Novartis partnered with photographer Kate T. Parker on a series of photo essays.

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“I can’t imagine my life without ITP—it has always been a part of me.” Daniela is a patient from Germany diagnosed with the rare platelet disorder at the age of 14. While she has since grown up, raised a family—and now enjoys traveling, hiking, and building memories with her husband and sons—she has also learned how to become the day-to-day manager of her own health and best handle her condition to live her life to the fullest.

ITP (immune thrombocytopenia) is a rare blood disorder in which there are too few clotting cells, or platelets, in the blood. Patients diagnosed with ITP may experience symptoms such as easy bruising, bleeding, and petechiae-sized reddish-purple spots. They are at risk for more severe symptoms, such as internal bleeding, if the condition is not managed properly. According to the I- WISh global study of ITP patients, the parts of people’s lives that are most affected by ITP (more than half of the time or all the time) are energy levels, ability to exercise, and impact on work, life, or studies.[1]

To highlight the everyday experiences of people around the world living with ITP— and their tremendous resilience—Novartis has partnered with Kate T. Parker, inspirational photographer and author.

This powerful series of photo essays brings to life the individuality of every participant, showcasing how they manage their ITP and how they triumph—and persevere.

Meet Akia

Diagnosed with ITP 6 years ago, Akia from the United States is now a leader, mentor, and advocate for other ITP patients across the country.

“The positive [of ITP] is that it has made me connect with people who are like me,” Akia says. “It has allowed me to be an advocate, a mentor, a resource, a friend, and be able to help those in the beginning stages of the disease until they’re comfortable with it and understand that they’re able to live their best life.”

Akia lives her life with the motto “YOLO: You only live once” because, in her own words, “At the end of the day, you only have 1 life to live and might as well live it to the fullest.” Her undeniable zest and enthusiasm for life comes through the first time you meet her. She loves music, art, travel, learning new things, and is a self-proclaimed foodie. Now that her ITP is under control, Akia feels grateful to be able to travel with her family and friends.

Meet Daniela

Daniela, mentioned earlier as the ITP patient from Germany, credits her parents for being the best support she could have—from that first day in the doctor's office to now. She is fulfilled as an architect for Hamburg's administration and finds joy coming home to her family and indulging in the little things like sewing, knitting, and painting. Like her fellow ITP patients, she understands that while she can't do everything with ITP, what she can still do is worth the world.

"I tell people I have to be careful. I can't do certain things sometimes. If they ask me to go on a roller coaster or something like this, I tell them no, I won't," she laughs. "My hobbies…I'm painting, I'm drawing when I'm at home. I also like some needlework, I'm knitting and sewing, things like this. When I go outside, I like hiking in the mountains with my kids and my husband."

Despite her ITP diagnosis, Daniela wouldn't change anything about her life. "I want everything to be the way it is now," she says. "I'm really happy now!"

To check out Kate T. Parker’s signature photography style, uplifting patient video testimonials, and inspirational ITP patient stories, visit ITP in Focus.

References:

1. Novartis I-WISh Survey Dashboard, https://www.livingwithitp.com/i-wish-survey/index.html.

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