

Uncovering profound and under-reported effects on people living with sickle cell disease

Results of the Sickle Cell World Assessment Survey (SWAY) highlight the impact this debilitating disease has on patients and their families.

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Novartis recently presented interim findings from the Sickle Cell World Assessment Survey (SWAY) at the 2019 American Society of Hematology (ASH) annual meeting this year, which highlighted new data around the global burden of the disease. Insights collected from over 2,100 patients and 360 health care providers evaluated the impact of the disease on patients and families, helping to inform the management of this debilitating disease.

Notably, patients reported a much higher number of vaso-occlusive crises (VOCs) than current published data, which suggests that VOCs may be substantially underreported. The survey found that on average, individuals with sickle cell experienced more than 5 VOCs per year, and more than 90% surveyed experienced at least one VOC in the past 12 months.

Not only did patients report the physical burden of the disease, but also the impact on quality of life. Over half of respondents said they believe their income would be higher if they didn't have the disease, and nearly 60% believe that sickle cell disease has negatively impacted their education.

To learn more about the global survey and its findings, hear from members of the survey's international steering committee as they discuss the impact of this devastating disease.

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