Uncovering Sickle Cell Disease

A New Picture of an Old Disease

Every day, people endure the painful and life-threatening symptoms of sickle cell disease in the shadows because of fear, stigma, and isolation.[1,2,3] Now, a new picture is emerging.

Together with Novartis, Dr Alex Kumar, a global health physician and photographer, is sharing images and stories from around the globe that are intended to help inspire the sickle cell community and raise awareness of the disease to help change how the world sees it.

Sickle cell disease is a hereditary and life-threatening condition that causes ongoing vascular damage and repeated injury to the blood vessels and organs.[1,4] This lifelong illness often takes an extreme emotional, physical, and financial toll on patients and their families.[5,6]

It is a global disease. Sickle cell disproportionately affects people from Sub-Saharan Africa, however, it is also common among people with ancestry in South America, Central America, and India, as well as the Mediterranean.[7] An estimated 300,000 babies are born annually with sickle cell disease, and about 300 million people worldwide have the sickle cell trait.[5,8]

People with sickle cell disease typically experience repeated episodes of sudden severe pain (called vaso-occlusive crises) that can be associated with acute and chronic organ damage.[9] In the past, the shape of the red blood cell was the main focus. However, in recent times, researchers have come to believe that it is the adhesion, or stickiness of multiple cells and platelets to the walls of a patient's blood vessels, that leads to pain crises.[10,11]

Sickle cell pain crises can be unpredictable, severe, and life-threatening, requiring medical intervention, but many patients suffer in silence at home, and do not seek additional help and support.[3] Over time, the physical burden of pain crises often negatively affects a patient's cognitive, emotional, and social well-being, and can be associated with an increased risk of organ damage and death.[6]

More needs to be done to help raise awareness of sickle cell disease, and that is why Novartis is working together with patient support groups, and Dr Kumar and other physicians around the world to help bring sickle cell disease out of the shadows. In addition to educational resources, we have collected patient stories from around the globe on UntoldSickleCellStories.com so people may learn more about what sickle cell disease looks like in different areas of the world.

Using the power of words and pictures, this series aims to uncover the real impact of sickle cell disease and show how people are facing this debilitating illness with extraordinary courage.

References:

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