

The World's 'Forgotten' Disease Is Ready For Its Day In The Limelight

The fourth annual World Vitiligo Day (WVD) will take place this week on June 25th. This event unites researchers, doctors and leaders of patient support groups from five continents who, backed by support from two US State Governors, will speak on behalf of the nearly 100 million vitiligo sufferers worldwide.

Vitiligo is an under-investigated, non-communicable, autoimmune skin disease that affects one in every hundred people to some degree. Vitiligo causes the skin to lighten in patches across the face and body. Roughly 70% of the population carry one or more of the 30+ identified genes that cause vitiligo, although only a few develop it due to unknown triggers. The burden of vitiligo falls particularly hard on developing countries, due to misdiagnosis of the disease, little or no access to effective treatments, and widespread stigmatization and discrimination.

WVD was born from the determination of non-profit organizations VR Foundation (USA) and VITSAF (Nigeria), and their supporters across the world, to bring this 'forgotten' disease into the public eye. This is now starting to happen, particularly since Chantelle Brown-Young, who suffers from vitiligo, competed on America's Next Top Model last year. The cosmetics industry is also recognizing the needs of the vitiligo community, with New York based company Zanderm choosing June 25th to launch the world's first concealer made specifically for people with vitiligo.

However, there is still much work to be done and WVD aims to persuade major organizations such as the UN and WHO to give vitiligo the attention it deserves and instil change in the national healthcare policies of member states. Organizers are also looking to the big pharmaceutical companies to introduce products that satisfy the growing demand for effective treatments.

The event is a truly global affair and this year's activities range from a trans-Canada awareness bike ride to free skin check-ups at major hospitals in the USA, Brazil, China, India, Italy, Russia and other countries. The WVD center of operations switches countries each year, with Shenyang (China) taking its turn in 2015 and Prague (Czech Republic) next year.

Support for the event is huge and nearly half a million people from across the world have now signed a petition that asks the UN Secretary General to officially designate June 25th as World Vitiligo Day.

"World Vitiligo Day is a massive event and is growing every year," says Yan Valle, CEO, Vitiligo Research Foundation. "Healthcare policy and practice needs to change to help fight prejudice and ignorance and improve life for the millions of people across the globe who suffer from this underreported and misrepresented disease. That's why World Vitiligo Day is such a vital event."

Campaign website: www.25June.org

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Notes for editors

About the Vitiligo Research Foundation:

The VR Foundation is a 501(c)3 non-profit, disease-specific foundation. As the nation's only organization addressing every phase of vitiligo treatment development, the VRF continuously works with a diverse group of support organizations and individuals to achieve significant measurable and fast results. When it comes to finding a cure for vitiligo, the VRF firmly expects to make a real difference in our lifetime.

About Vitiligo: (pronounced vit-ill-EYE-go) is a very complex and generally unpredictable skin disease. It is characterized by a sudden loss of melanin in the skin, which turns it milky white in irregular patches and expands over the lifetime. Complete knowledge of its etiology has been elusive for decades of intense research. The current thought is that vitiligo represents a group of different immune-mediated disorders with a similar outcome: the appearance of white patches on the skin. Vitiligo is a non-lethal and it does not cause any organic harm, but it has a devastating effect on social life of the affected person and their family. The reported prevalence of vitiligo is between 0.5% to 2% of the world population on the average, but local numbers may vary greatly, depending on the region and age group. The total number of people suffering from vitiligo is estimated at around 100 million people worldwide. However, the actual number may be much higher because vitiligo is a very underreported disease. It can be treated temporarily, with varying degrees of success, but there is no cure. It can strike anyone at any age, but the condition normally develops before twenty - meaning many children are living with vitiligo.