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On June 25th, 2021 A Light Will Shine On Vitiligo - The World's 'Forgotten' Disease

The eleventh annual World Vitiligo Day (WVD) will take place on June 25th, 2021 - with Jakarta, Indonesia playing host. This annual event unites researchers, doctors and patients to drive awareness and celebrate the diversity, resilience and determination of the nearly 100 million vitiligo sufferers worldwide.

Vitiligo causes the skin to lighten in patches across the face and body. It is an unpredictable, non-communicable, autoimmune skin disease that affects one in every hundred people to some degree. As yet, there is no known cure. 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.

World Vitiligo Day was <u>born in 2011</u> 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. The onset of the campaign has been fueled by <u>Aksenov Family Foundation</u>, whose generosity has been vital in ensuring that WVD has become a global force that's enriched many lives and brought vitiligo onto the mainstream health agenda.

Huge progress has been made. Ten years ago, two or three companies (at most) were developing vitiligo drugs – a number that now <u>stands at 30-plus</u> – with a positive outlook for <u>at least one drug</u>. And just this year the U.S. FDA held its very first public <u>meeting on vitiligo</u>, where the community had a unique opportunity to speak directly to key stakeholders in vitiligo drug development. Another indication of WVD's success is that 18 U.S. State governors and numerous city mayors <u>declared</u> June '<u>Vitiligo Awareness Month</u>'.

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 more products that satisfy the growing demand for effective treatments.

Each year WVD is officially hosted by a <u>different city</u> and in 2021 it is the turn of Jakarta to act as campaign headquarters. The honorary captain is Dr. Srie Prihianti Gondokaryono, supported by a strong team from the Indonesian Society of Dermatology & Venereology (Advisor: Dr. Yulianto Listiawan, Vice-President: Dr. Andreas Widiansyah, and Secretary: Dr. Hanny Nilasari).

Unfortunately, the large-scale, in person activities that typify WVD are not possible this year, due to COVID restrictions, so an online event will take place. This is likely to be broadcast from the offices of the dermatological society, and invites patients, doctors, volunteers, journalists and anyone who is interested to drop in and learn more. One key theme will be that patients with vitiligo have the same COVID experience as anybody else and should not fear vaccination.

As ever, the event will be a truly global affair. Other major activities on June 25th include a media event at Aula Magna of Università degli Studi Guglielmo Marconi in Rome – where the World Vitiligo Day campaign was officially announced nearly 10 years ago. This will be hosted by Dr. Torello Lotti, Full Professor and Chairman of Dermatology. Then, on June 26th, the US-based online event will take place, which is being organized by activists from VITFriends (Boston, MA), Global Vitiligo Foundation (Detroit, MI) and other vitiligo support groups.

"World Vitiligo Day is a massive event and gets bigger every year," says Yan Valle, CEO, VR Foundation. "COVID-19 may have changed things this year, but it will still be a huge day – both celebrating all we have achieved and shining a light on the prejudice and ignorance that still affects the millions of people who suffer from this poorly understood and misrepresented disease."

More information available at the WVD campaign website - www.25June.org

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