

Attn: Editor's Desk

____, 2024



Dear Editor,

This Letter seeks to update medical news editors, as well as clinicians, health ministries, insurance companies, philanthropic institutions, patients and their caretakers on vitiligo, a rare skin disease, and the [World Vitiligo Day](#) campaign.

WHAT IS IT?

Vitiligo (pronounced *vit-ill-EYE-go*) is a non-contagious, life-long and generally unpredictable autoimmune [disease](#) with heavy psychological [burden](#). It causes milky white patches to develop randomly on the skin. Initially, the vitiligo may start as a patch that is slightly paler than the rest of the skin but will gradually become completely white. In many cases, white patches eventually enlarge to cover the nearly whole body.

WHO IS AFFECTED?

Vitiligo can strike anyone, at any time. The average [prevalence](#) of vitiligo approximately 1.5% of the world population, but local numbers may vary from 0.004% to 9.98%, depending on the region and age group. Half of all cases begin in childhood, often popping up in springtime without warning, and women are 25% more likely than men to develop vitiligo.

The total number of people suffering from vitiligo is estimated at around 65-95 million people worldwide. However, the actual number may be much higher because vitiligo is an underreported disease. The disease severity seems to be higher in the industrialized regions – thus suggesting a substantial role of chemical or environmental triggers in vitiligo development.

WHY IT HAPPENS?

The complex nature of vitiligo is still poorly understood. Researchers know the cause is pre-wired in one's genes, just waiting for a specific trigger or an unfortunate combination of benign conditions. An obscure event creates stress in the pigment-producing cells of the skin. An over-reactive immune system mistakenly identifies these stressed-out cells as intruders. Specialized cells called 'killer' T-cells neutralize these 'enemies,' driving autoimmune response and progressive skin depigmentation.

Prolonged contact with certain chemicals may directly induce or worsen pre-existing vitiligo. These harsh chemical agents are commonly found in products from low-cost stores, which include hair dyes, perfume, cosmetics, cleansers, insecticides or rubber slippers. Often, these contaminated products make their way to corporate supply chains and mass market, as well.

HOW IS IT TREATED?

Simply put, patients can do one of three things with vitiligo: (a) try to stop lesion spread and restore pigmentation, (b) camouflage the white patches, or (c) destroy the remaining color to have all-white skin. The problem is that there's currently neither a cure for vitiligo, nor a universally accepted method for limiting the spread of the disease. Although many [treatments](#) are being used for its management, only [one](#) is licensed specifically for vitiligo, in the US and the EU. The good news are, there are over 30 [biotech](#) companies with R&D programs in vitiligo that will result in a handful of drugs in the nearest 3-5 years.

Still today, it is not always easy to predict what will work best for which patient, as each one requires an individualized treatment approach. Halting the disease progression and re-establishing pigmentation are two different phases that require different treatment strategies working alongside. Existing treatments seldom induce lasting repigmentation: an average relapse time even after successful treatment is just under five years.

A narrowband ultraviolet type B light therapy (commonly, UVB) remains a 'golden standard' for treatment but it may take one or two years to restore the natural skin color. UVA therapy is no longer recommended. Experimental treatments for vitiligo like afamelanotide, HSP70i, JAK inhibitor, prostaglandin, or simvastatin might work for some people, but researchers just haven't figured out exactly who that is yet. Dietary supplements or vitamins can only mildly enhance phototherapy effectiveness and are incapable of creating prolonged effect on their own.

Vitiligo should ideally be treated within two or three months of its first appearance. As the disease progresses it becomes harder – although not impossible – to treat. Unfortunately, new patients often get trapped between physicians, dermatologists, insurance companies and their daily activities, and typically lose this best window of opportunity. Home phototherapy devices offer a faster beginning and more economical treatment, compared to clinic-based treatments, with similar efficacy.

WHAT'S THE IMPACT?

The overall humanitarian, social and economic costs of vitiligo are immense. Vitiligo has severe psychological and socio-economic [impact](#) on nearly 100 million people worldwide. Developing countries bear the greatest economic burden due to the risk for misdiagnosis of the disease, little-to-no access to effective treatments, widespread stigmatization and discrimination.

According to the [estimates](#), vitiligo costs to the healthcare system about three times more than rosacea and twice as much as acne. Average out-of-pocket expenses by patients for vitiligo treatments at the clinic often exceed \$4,000 per year, yet expenditures vary greatly between ethnic groups and skin types.

WHAT IS WORLD VITILIGO DAY?

World Vitiligo Day (WVD) is celebrated annually on 25th of June, since 2011. WVD was [born](#) from the determination of the non-profit organizations from USA and Nigeria and its supporters across the world. In small but effective steps, the WVD campaign has brought this ‘forgotten’ disease into the public eye.

The original goal was to raise awareness, to portray the true nature of vitiligo, and to eradicate common myths about the disease. Over the years, its purpose has broadened to include recognition of the bullying, social neglect, psychological trauma and disability of millions of people affected by vitiligo.

Local vitiligo support groups organize walks, picnics, other events around the WVD. Half a dozen US State governors and numerous city mayors have declared June a ‘Vitiligo Awareness Month.’ Thousands of participating clinics and volunteer doctors offer a free skin screening program, education and consultations to the public. For more information, please visit 25June.org

The headquarters of the WVD campaign are moved across the globe every year: it was envisioned in Nigeria, started in Italy, then moved to India, China, Czech, Brazil, the United States, Vietnam, Serbia, Indonesia, Mexico, Kazakhstan and Colombia in 2024.

There is still much work to be done. WVD supporters aim to persuade major organizations such as the UN and WHO to give vitiligo the attention it deserves and instill 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.

With best regards,

Yan Valle
CEO Vitiligo Research Foundation

For more information about World Vitiligo Day, please visit website www.VRFoundation.org
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