

How Did That Happen?

Awareness campaign devoted to the first-ever European VWD Awareness Day

February 1, 2023



European
von Willebrand Disease
Community



Since its founding in 2020, the Von Willebrand Disease (VWD) Committee has been promoting the formation of a European community of people with von Willebrand Disease (PwVWD).

The Committee aims to provide support and 'identity' for the VWD community, whilst also promoting, building, and maintaining a network of European VWD advocates. With the ambition to increase and improve diagnosis and treatment options nationally and at the European level. And on the birthday of Erik Adolf von Willebrand, we want to raise global awareness of VWD.

For the first-ever VWD Awareness Day on February 1, 2023, we've partnered with Agate Lielpētere, a Latvian visual artist, who shines a light on one of the primary VWD symptoms – bruising – and the psycho-social impact on all PwVWD. The project 'How Did That Happen' has been specifically created to raise awareness of VWD and all those impacted and affected by the condition.

We would like to thank our Slovenian NMO – Društvo Hemofilikov Slovenije – for supporting the VWD WG in this campaign. We cannot be thankful enough to the Slovenian patients and family members for their cooperation, creativity, and willingness to make a difference for all PwVWD. Our special thanks to Matias Kavčič, Nadja, Matjaž, Nina, Janez Dolinšek, and Mojca.



About the artist

Agate Lielpētere (1995) is a Latvian visual artist living and working in Ljubljana, Slovenia. She holds a BA degree in arts and humanities from the Art Academy of Latvia (graphic art). Currently undergoing MA studies in Ljubljana in the Academy of Visual Arts (Contemporary visual practices).

She has had numerous solo and group exhibitions both locally and internationally. Her practice can be described as deeply ironic, focusing on social problems and the search for identity. The artist states: "My bad sense of humour runs in the family, blame them."





Artist Statement

Bruising, along with bleeding, is a primary symptom of von Willebrand Disease, which often comes with great distress for the patients, caused by the social implications and stigma associated with it, thus, impacting one's self-confidence. The general public commonly associates bruises with clumsiness or violence, consequently leading to feelings of shame and unease for the patients. The project 'How Did That Happen?' aims to raise awareness that bruises don't always indicate violence and encourages individuals to refrain from making assumptions about 'how that happened'. Before asking someone about their bruises, it's important to first question our own assumptions.

Even though a bruise on a VWD patient lasts longer than one on a healthy individual's body, it is only temporary. Yet it creates a life-long experience of countless episodes of embarrassment. However, raising awareness of the disease would encourage empathy and understanding in the general public.

To address this issue, the artist has made a series of temporary tattoos – realistic bruises, that people can wear in support of those with the disease. To further dissociate the bruise on VWD patients' bodies from violence or clumsiness, the bruises are made into shapes unlikely to occur naturally – a dolphin, a heart, a butterfly, a star, and a flower. It opens a conversation that converts a lack of understanding into compassion.

Agate Lielpētere has previously worked with the theme of bruises, though in a different context. In the exhibition 'Bruised and Confused' (2019, Riga, Latvia), she offered her view of the connection between youth and bruise as its symbol.



European
von Willebrand Disease
Community





European
von Willebrand Disease
Community



“It is imperative that we continue to raise awareness of VWD...”



European
von Willebrand Disease
Community

Despite multiple bleeds, extensive bruising and worrying responses to invasive dental or medical procedures my whole life, medics seemed at a loss for a diagnosis and my medical notes simply reported ‘undiagnosed bleeding disorder’. This ultimately meant that treatment options and plans were unavailable to me and every injury or procedure was fraught with anxiety and drama.

My diagnosis of von Willebrand Disease at the age of 37 ended years of discomfort, anxiety, and confusion and literally saved my life during a complicated and high-risk pregnancy and birth. I will forever be grateful to the haematology team who finally diagnosed the condition and ensured that the care and treatment I received were outstanding.

Not every patient is as lucky as I am, many women, men, and children are continuing to struggle through life with unexplained bleeding and no access to diagnosis and treatment. It is imperative that we continue to raise awareness of VWD, and advocate for effective treatment options and access to care for those affected by the disorder.

Together we can make sure that every individual living with VWD, or living with someone impacted by VWD, is supported to live long, happy, healthy lives.

Jo Traunter, EHC VWD Committee Chairwoman (as of February 2023)



“It is imperative that we continue to raise awareness of VWD...”



European
von Willebrand Disease
Community

For many years I have suffered in silence, isolated, and feeling misunderstood. I have felt maladjusted at times due to my VWD with no one to talk to, discounted from society. It is a painful memory that I have locked deep inside me for many years, until now. The misconception that von Willebrand Disease only affects the patient is untrue; it affects all those around you from a family who look after a poor child to the partner who has had sleepless nights, but “that which doesn’t break you, makes you stronger”.

I can honestly say for the first time I can see my dream come true. A dream where VWD is taken seriously, where patients work together with clinicians; both advocating and collaborating for the same cause.

As a participant in the journey in this field, I have seen the EHC act as a key catalyst in its progression and bringing change but there is so much more that can be done in regards to raising awareness. Each one of us bears responsibility but nothing can be achieved without action and the first step towards change is awareness.

The purpose of VWD Awareness Day is to break the silence that has so long darkened the lives of many and bring light and hopes to the younger generation, so they no longer have to suffer by themselves.

We aim to create a wider VWD community that can support one another and work together to bring much-needed change; with awareness comes a responsibility and a choice. Let’s choose to make things better...

Sunny Maini, EHC VWD Committee Chairman (as of February 2023)





European
von Willebrand Disease
Community

Manon Degenaar-Dujardin, Vice-President
Finance, EHC VWD Committee member
(as of February 2023)

"I wouldn't have dreamed 10 years ago that there would be a European Von Willebrand Day! And look now,...we have treatment guidelines, an EHC working group and principles of care in the making. We have been given a voice and today we are celebrating!"

Baiba Ziemele,
EHC VWD Committee member
(as of February 2023)

"For years many of us have been dismissed, untreated, and disrespected just because VWD was considered not severe enough to pay medical attention. Now we have good tools to evaluate symptom severity, distinguish various types of VWD, and provide adequate treatment. I hope one day none of us will struggle again to stop the bleeding and live a normal life".

Julia Rauscher,
EHC VWD Committee member
(as of February 2023)

"It is great to see how the awareness for VWD patients has been growing over the last few years. Although there is still a huge number of undiagnosed patients out there, we as the EHC VWD Working Group work hard to make this disorder even more visible at the European level. So let's all celebrate and share the very first European VWD Day! Together we can make a change!"

vwd@ehc.eu