

European VWD Awareness Day

1 February 2024



European
von Willebrand Disease
Community



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

The VWD 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, today, on the birthday of Erik Adolf von Willebrand, we want to raise global awareness of VWD.

In 2023, on our first-ever VWD Awareness Day, we partnered with Agate Lielpētere, a Latvian visual artist, who shined a light on one of the primary VWD symptoms – bruising – and the psychosocial impact on all PwVWD. The project 'How Did That Happen' was specifically created to raise awareness of VWD and all those impacted and affected by the condition.

In 2024, following the success of the previous campaign, we are thrilled to unveil the European VWD identity and the new motto.

Making the invisible visible

#VWDunited #VWDtogether #beVWDaware



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Artist Statement

"It was a true joy to partner with EHC last year for the first-ever von Willebrand Disease Awareness Day in the creation of the project "How Did That Happen". The heartwarming response we received from the patients and the community was inspiring. When EHC reached out to me with another collaboration proposal – for the creation of a graphical identity for the European von Willebrand Disease Community – I was happy to contribute. The symbol, a heart-shaped bruise taken from last year's project, embodies the resilience and strength of individuals within the VWD community, evoking a sense of unity and solidarity. Together with the modern yet sleek typography selected for the logo, the symbol communicates the contemporary ethos of the European VWD Community, striking a balance between professionalism and approachability. Together, these elements harmonize to form a visually compelling representation of the organisation's identity and mission."

Agate Lielpētere

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.





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On this Von Willebrand Disease (VWD) Awareness Day, the EHC wants to shed light on a condition that affects a huge part of our community. Since 2015 the EHC has been developing a platform to address the needs of these patients and to help our National Members Organisations (NMOs) to create adequate tools to fill the gaps in diagnosis, multidisciplinary care, and treatment for them. VWD impacts not only individuals but also their families in a significant way.

With that and with the creation of the VWD Committee and a comprehensive plan, a community of strength and resilience has been built.

Today, we stand in solidarity with those affected by VWD, knowing that our task is never completed and that we need to continue to advocate for advancements in research and treatment and to create empathy towards our community, so each part of it be an effective part for all.

Let us use this day to spread awareness about VWD, to educate not only our patients with the condition but also others about the signs and symptoms, and to foster a sense of understanding and empathy, with the main objective of improving the quality of life for those with VWD.

Miguel Crato, EHC President



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Jo Traunter,
EHC VWD Committee Co-chair

The VWD committee are celebrating a fruitful and industrious year. Their bruise campaign has highlighted the consequences of living with vWD, an often unrecognised and underrepresented condition. We have chosen the image of the heart tattoo from our bruise campaign to represent the work of the committee and our tireless work to support the VWD community. Our slogan, 'Making the Invisible Visible' is further symbolic of the campaign to raise awareness and educate those who encounter persons living with the disease whilst supporting those who are still fighting for diagnosis and treatment.

Our work does not end, together we are working to change the landscape, to raise awareness and to ensure that all individuals from our VWD community across Europe, gain the recognition, support and treatment they deserve.

Julia Rauscher,
EHC VWD Committee Co-chair

There are 47 countries in Europe which also means that there are just as many varying healthcare systems. Each of them runs differently but no matter how well-developed some countries may be, there are still a lot of VWD patients all over Europe who struggle to get the medical attention they need or even are undiagnosed. That's why we as the EHC VWD Committee want to put the focus on "Making the invisible visible" on this year's VWD Awareness Day. We have been working very hard for the last four years to push forward the needs of the patients within the VWD community on a European level and finally, our visions and projects start to become reality.

vwd@ehc.eu



**Cathy Verbraeken,
EHC VWD Committee member**

On February 1, we celebrate VWD Awareness Day. On this day, let us reflect on what we have achieved and what our future goals are. Let's create more awareness together, spread knowledge, educate, share what we encounter and be there for each other. We all have our stories, but we are not alone! Together we can improve our quality of life.

**Baiba Ziemele,
EHC VWD Committee member**

In light of the personalization of care, as European Union citizens, we expect harmonization of healthcare services we can receive in our countries and strive for the best available care. As the EHC VWD Committee, we hear many heartbreaking experiences and inequity in how we, the VWD community – people living with VWD, receive diagnosis and care, if any.

We teamed up with EuroBloodNet, the European Reference network which unites all excellence centres and professionals in haematology in Europe, to highlight issues and solutions for various life situations where we as patients cannot survive and live normally without professional medical help. VWD is a relatively new diagnosis, it was discovered less than 100 years ago, and many stereotypes and prejudices exist, preventing us from getting adequate help when we bleed. It is time to make a difference!

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Laura Quintas,
EHC VWD Committee member

The VWD committee works to give a voice to people with VWD, an under-recognised disease. Following the bruise campaign, a new image has been chosen to represent the work of this committee and make VWD more visible.

The celebration of VWD awareness day on 1 February with the slogan “Making the invisible visible”, launches the 2024 campaign to raise awareness and educate those living with the disease and support all those fighting for access to proper diagnosis and treatment.

The work of the VWD Committee will continue to make people with VWD visible and to ensure that all members of our VWD community across Europe have access to the treatment and care they need. Together we are stronger!

Annabel Kattai,
EHC VWD Committee member

I have been trying to make VWD heard since I was little, although I tried with words, drawings, etc. However, there was a time on the social media platform where I could make myself more visible.

I am happy that I could join the EHC VWD Committee because together with them we can make the invisible visible even bigger and more powerful. From February 1st, everyone will be able to hear what this VWD is, how it affects us, etc. I hope that everyone will find something that suits them and that the invisible will become visible.

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