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## Join the Rare Disease Day with the BCM Families Foundation on February 29, 2020!

Take Action!

- 1) [Join the BCM Patient Registry](#) on Rare Disease Day 2020 or talk to your relatives affected by BCM and invite them to [join the BCM Patient Registry](#).
- 2) On February 29, decide [to test your DNA](#) or inform your relatives who are diagnosed as having BCM about how to test it.



## Join the BCM Registry!

If you, or you son, have received a genetic diagnosis of Blue Cone Monochromacy, you are invited to join the BCM Patient Registry. You can do that on your own or on your son's behalf if he is diagnosed to have BCM. The information collected in the Registry is expected to advance our understanding of the disease and to foster research into the treatment of BCM. Find out more by clicking on the link below!

<https://www.bcmregistry.org/>

On 29 February 2020 join the BCM Registry or invite your relatives to enroll by giving them the **Flyer** you can find [here](#).

*'Rare Disease Patient Registries constitute key instruments for increasing knowledge on Rare Diseases and Patient Registries should be recognised as a global priority in the field of Rare Diseases.'* **Eurordis**



The BCM Patient Registry has been funded by [Otto per Mille Chiesa Valdese](#)

## Test your DNA to find your BCM causative mutation!

On 29 February 2020, if you have a clinical diagnosis of BCM, there are many reasons to perform a DNA test, for example, to have a genetic confirmation of the diagnosis or to help scientific research to find all the possible genetic mutations that lead to disease and identifying treatment options including clinical trial.

In 2020 the BCM Families Foundation, through its longstanding collaboration with the University of Tübingen, guarantees to you and your relatives access to [BCM DNA test](#).

*"The development and maintenance of tests for rare genetic diseases must continue to be encouraged.*

*Because of the rarity of many diseases, only one or a few laboratories in the United States, or the world, accurately perform tests for them".*

*National Human Genome Research Institute*

You can find more information on how to test  
your DNA [here](#)



**NORD®**  
National Organization  
for Rare Disorders



Check out this year's [NORD Activities of Rare Disease Day!](#)

*'The zebra is the official symbol of rare diseases in the United States and is noted for its black and white stripes, which are central to its uniqueness. In the spirit of raising the profile of the rare disease community at large and celebrating Rare Disease Day, this year NORD will promote specific ways that individuals, organizations and groups can show their stripes'.*

**During medical training, future doctors and nurses are taught: "When you hear hoof beats, look for a horse." Recognition is needed that sometimes it will be a zebra, when it's a rare disease (us)!**



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