



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

HDYO Survey Series

March 31, 2023

HDYO has more information about
HD available for young people,
parents and professionals on our
site:

www.hdyo.org

Share Your Voice to Help ALL People Impacted by HD!

HDYO strives to support, educate and empower young people (18-35) and their families impacted by Huntington's disease. To accomplish this goal, we have launched a series of surveys to better understand different aspects of our community's lives as they continue their journey with HD.

What will we do with this data? We want to use this information and share findings/analytics in peer-reviewed publications, poster presentations, formal presentations at conferences, educational materials for partners and associations and encourage use of this information to better serve the HD community. While this is led by our Research Committee and facilitated through Monash University, this is a community-based project that we want to be helpful for all who cares about this community.

Surveys are currently in **English, Portuguese, Spanish, Polish, Italian, French, Norwegian, Romanian, Lithuanian, Greek, Finnish and Czech**. We are working on translating each one in additional languages. **

[Read the Latest Report](#)

Open Surveys

NEW Survey: Mapping Milestones

Aim Understanding the needs of young people can't be a one size fits all. HD-related milestones (learning about HD, genetic testing, etc) can happen at different times in one's own journey. We are striving to understand how HD milestones affect life milestones and how the community can best provide interventional support. Additionally, there may be information to help guide what is needed to make young people more equipped for informed decision-making.

Launch Date: March 14, 2025

Who Can Participate: Anyone who is impacted by HD at least 18 years and older. This is a global study - you can participate no matter where you live. This includes people directly affected (Gene positive, at-risk, diagnosed with HD) and also those who love someone affected (Gene negative, care partner, friend, professionals).

Data: Surveys are anonymous and no personal information will be collected or distributed.

[Complete this Survey](#)

Survey: Understanding Educational and Social Stigmas and Feelings Around Research

Aim: We already know some of the barriers of participating in research, like burdens with work, family, etc. This is not replicating those findings, but it is diving deeper in feelings and knowledge around different research initiatives. We want to use this information to enhance educational initiatives for HDYO and other organizations to better equip young people and community members about research.

Data: Surveys are anonymous and no personal information will be collected or distributed.

Launch Date: January 16, 2024

Who Can Participate: Anyone who is impacted by HD at least 18 years and older. This is a global study - you can participate no matter where you live. This includes people directly affected (Gene positive, at-risk, diagnosed with HD) and also those who love someone affected (Gene negative, care partner, friend, professionals).

Data: Surveys are anonymous and no personal information will be collected or distributed.

[Complete this Survey](#)

Past Surveys

How the Community Seeks Support

Aim: The pandemic has changed the way people seek and access support. We want to better understand how our community is currently seeking support and resources. This will help the advocacy and scientific community prepare and communicate with the latest happenings in HD.

Acknowledgments

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This document was downloaded from the HDYO website at
<https://www.hdyo.org/a/752-hdyo-survey-series>

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