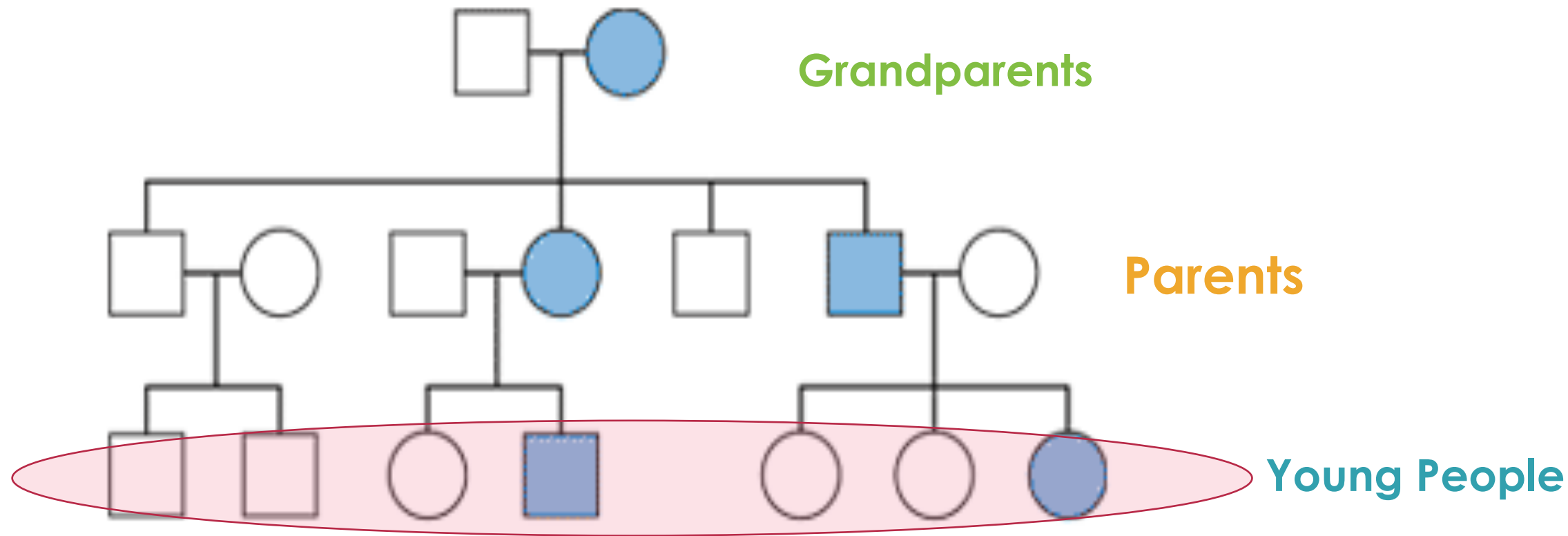




**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Engaging Young People with Rare
Diseases Around the Globe

11 May 2019



- affected male
- unaffected male
- affected female
- unaffected female



HDYO MISSION:

Support YOUNG PEOPLE around the world living in families IMPACTED by Huntington's Disease.

- HDYO's Definition of YOUNG PEOPLE:

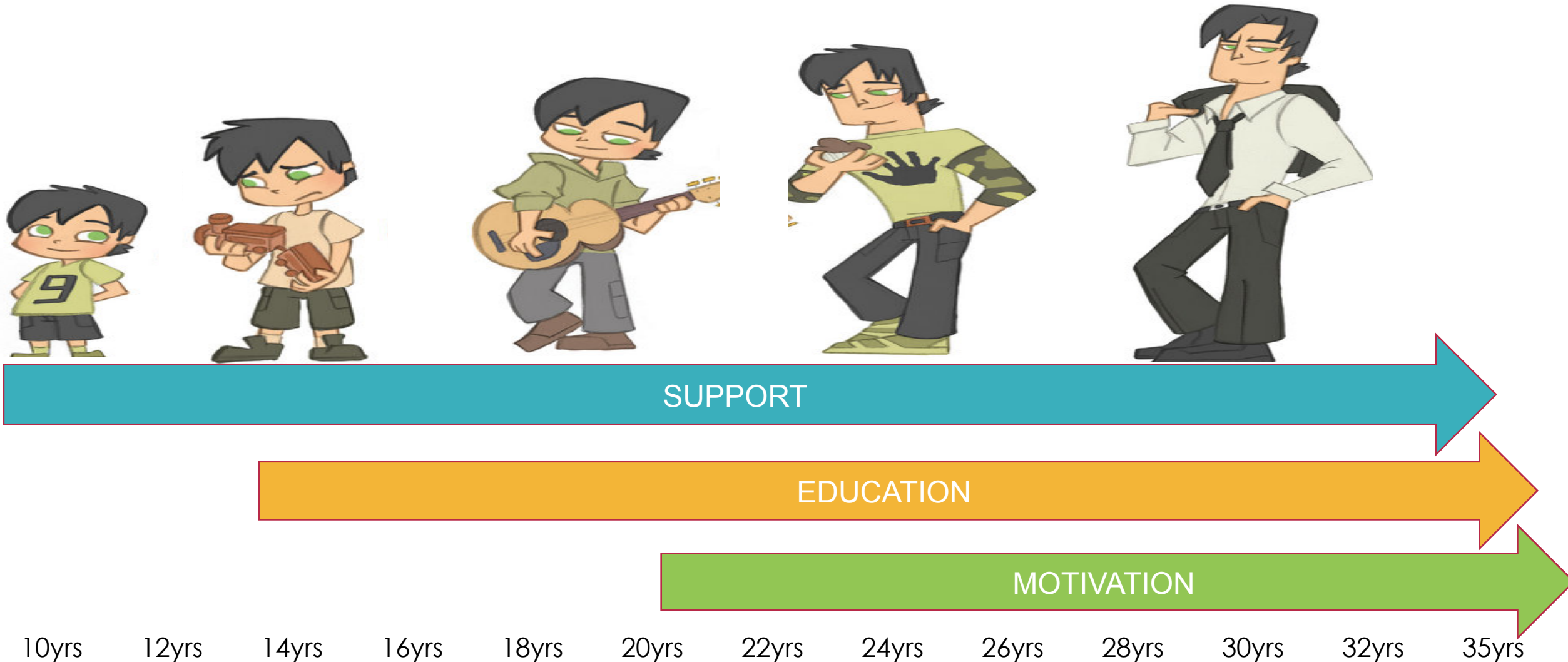
- Kids: 10-13 years old
- Teens: 14-17 years old
- Young Adults: 18-35 years old

- HDYO's Definition of IMPACTED:

- At-Risk of HD
- Gene Tested with positive or negative result
- Caregivers of family members that might not be at risk. (cousins, friends etc.)



THE HDYO MODEL





TIMELINE OF ACHIEVEMENTS

2010

The idea

2011

Creation & Funding

2012

Hdyo.org launched

UK and USA Charitable status achieved

2013

Hired 1st employee

2014

Launched USA Youth Service

Hired 2nd Employee

Held 3rd European Youth Camp

2016

Website available in 10 languages

4th European Youth Camp

2nd North American Camp

2018

2nd Australian/New Zealand Camp

4th N. American Camp

Vanderbilt Youth Worker Project

HD-GEM

2015

1st North American Youth Camp

2017

1st Australian/New Zealand Youth Camp

3rd Employee recruited – Executive Director

4 new languages launched (14 now)

3rd North American Youth Camp

2019

Young Person Worldwide Registry

J-HD registry

Re-launch www.HDYO.org website

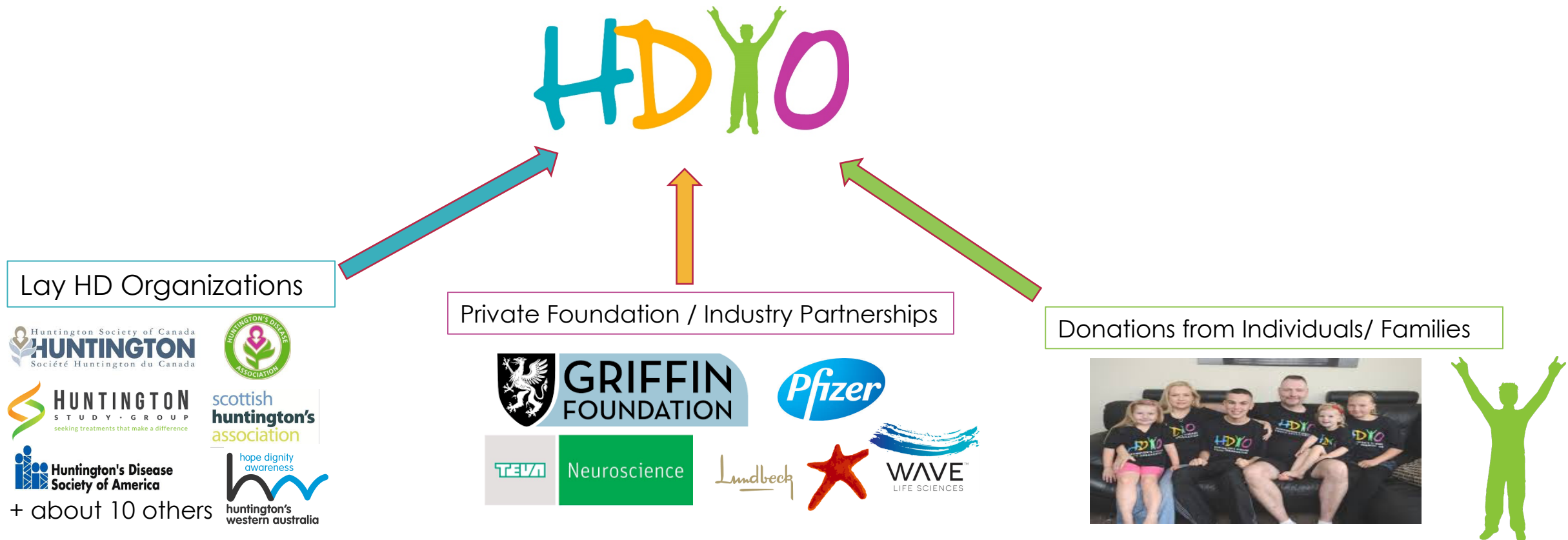
2020

Inaugural Congress - Glasgow

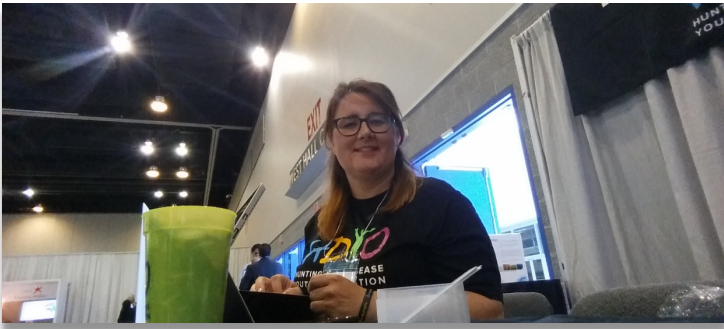


THE HDYO BUSINESS MODEL

- Registered Not-For-Profit in both USA & UK.
- 501c(3) & UK Charity Commission
- Three simple strategies for funding our work.



HDYO STAFF TEAM



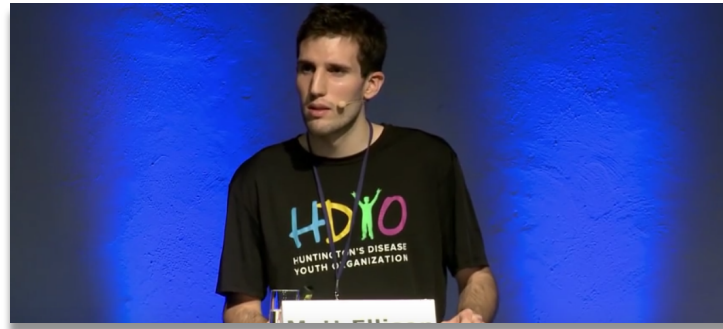
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USA Based



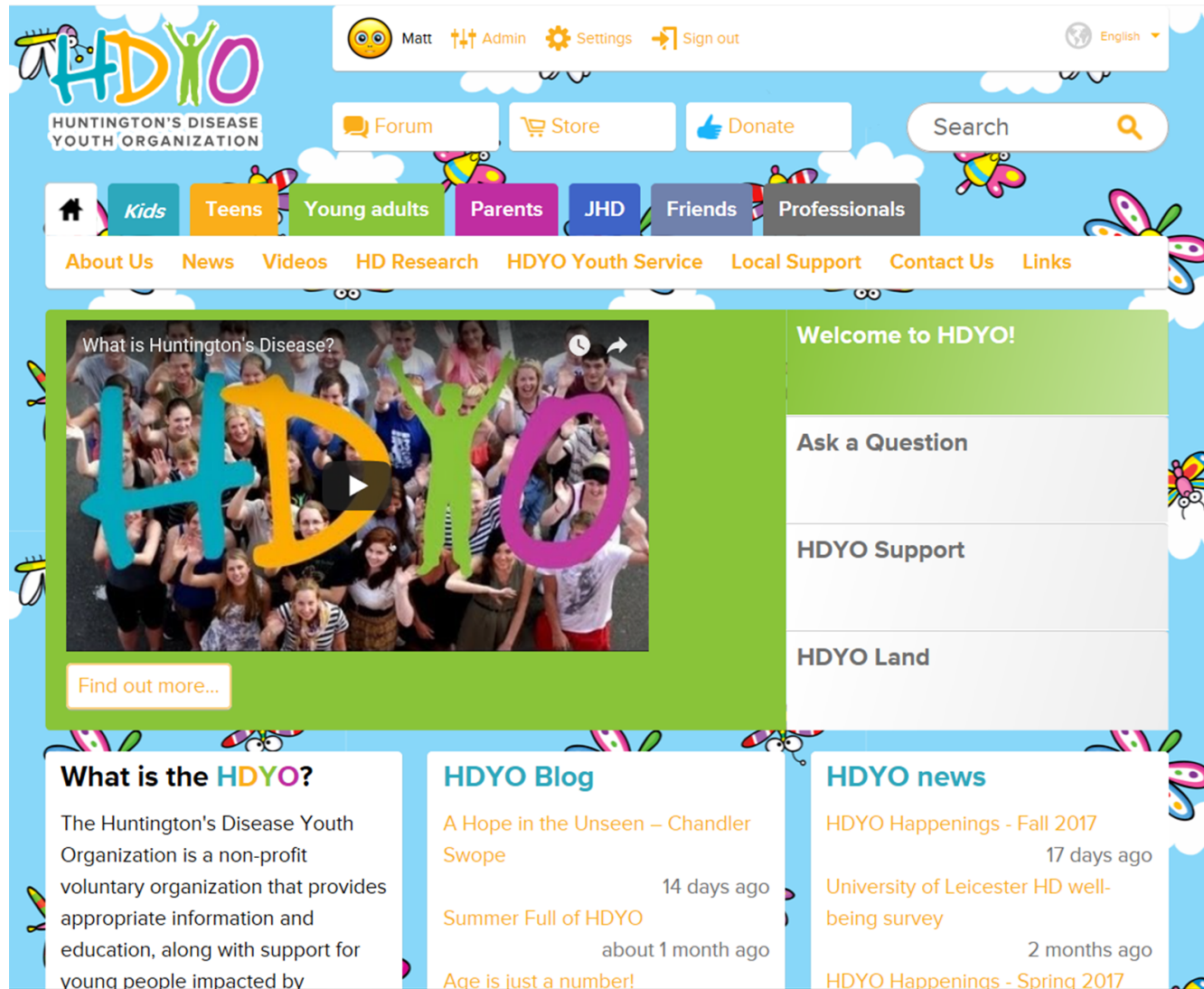
HDYO VOLUNTEERS



- Board of Directors
- Translation team
- News team
- Social Media team
- International Reps team
- Camp staff & volunteer team
- Professional Feedback team
- Family & Young People Feedback team
- Forum & Support Group Moderator team



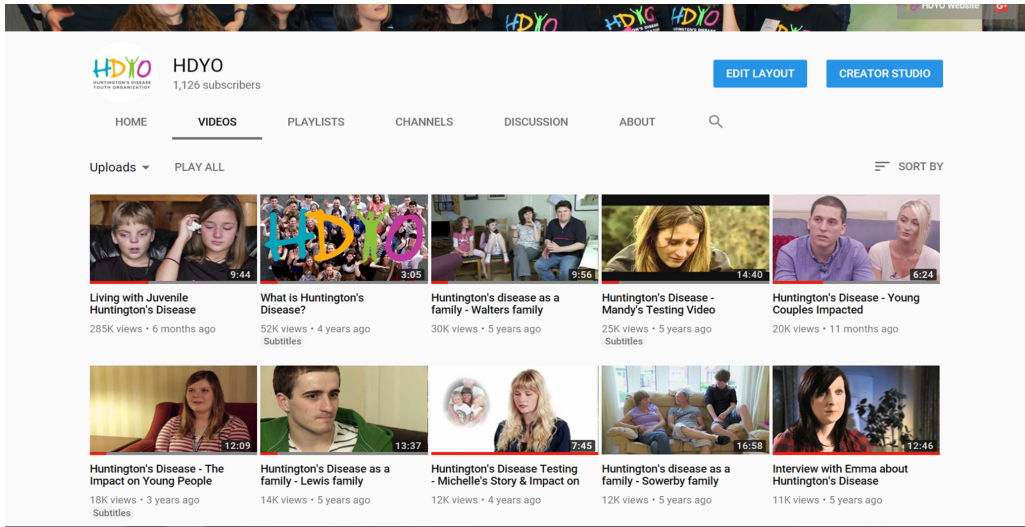
HDYO.ORG WEBSITE



- Age & Stage Appropriate
- Personalized
- Open Source Licence
- 14 languages languages



YouTube Channel: 50 videos w/ over 1M views!

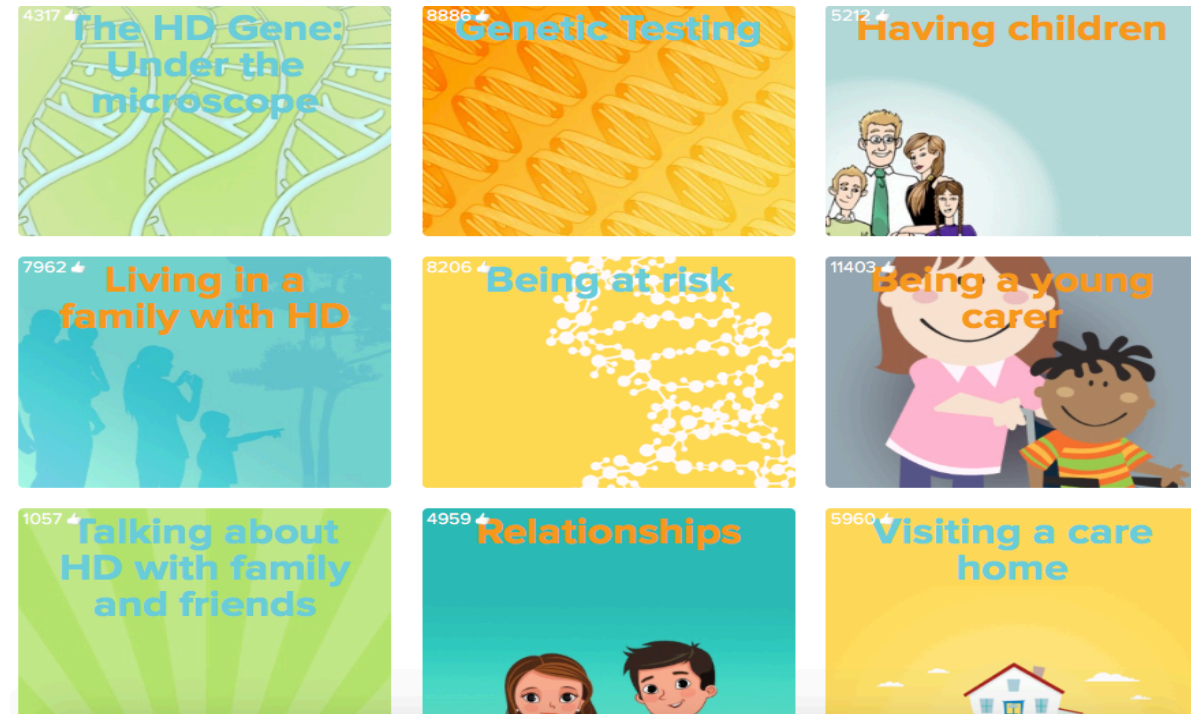


HDYO Land: teaching kids about HD Basics.



EDUCATIONAL PROJECTS

Variety of website sections geared for YP





CANADIAN YOUTH SERVICES

- HDYO partners with HD organizations such as the Huntington Society of Canada (HSC) to encourage local support of young people
- Canadian young people have formed a virtual Chapter of the HSC
 - Young People Affected by Huntington Disease (YPAHD)
 - Created in 2008
- HSC Youth Mentorship Program
- YPAHD Day
- YPAHD Representatives in local Chapters



USA YOUTH SERVICE

Created in 2014

Addressed the lack of individualized, professional support for young people.

The aim is:

- 1) Provide support to YP when needed
- 2) Provide resource for YP's questions with HD
- 3) Connect YP with resources



<https://www.youtube.com/watch?v=YCnbCXO-KQ8&t=1s>



YOUTH WORKER SERVICES



Individualized Support

Available for young people in-person, phone, video chat, text, social media etc..

This should not replace any weekly counseling a young person may need.

Event/Conference Support

Provide youth-specific programming at educational events.

Speak to parents and professionals about addressing youth needs.

Setup table/booth at events to spread awareness of HDYO services.



North American Camp

Plan and facilitate the North American Youth Camp.

Approximately 50 young people together for 5-days of support, education, motivation, relaxation and FUN!

August 2018 Camp in California.

HEALTHCARE PROFESSIONAL SUPPORT

1. HDYO has professional toolkits on a variety of topics related to young people.
2. Host online or in-person trainings for professionals and families about engaging with young people and addressing the specific needs of young people.
3. Professionals can reach out if they have concerns related to young people in a family and we can work together to provide support.
4. <https://en.hdyo.org/eve/service/274>





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