HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

ANNUAL REPORT 2017

Another year of incredible achievements

HDYO – ABOUT US

Our Purpose

HDYO is a youth-minded organization that focuses its efforts on providing and improving support for children, teens and young adults. HDYO provides educational resources and supports opportunities for young people impacted by HD globally. We provide educational resources both online through the website and offline through many different outlets. It is HDYO's ambition to reach every young person impacted by HD so that they have a good standard of support available to them no matter their circumstances, language or culture.

HDYO seeks collaboration on an international scale with young people, families, associations, healthcare providers, corporations and any other groups looking to positively change the Huntington's Disease Community. By working together, we can improve support for young people at a more progressive and productive rate.

Our Goals

1. Establish HDYO as a sustainable and leading organization in the HD community
2. Increase awareness about HDYO to the international HD community
3. Continually produce educational and supportive materials and opportunities for young people and their supporters
4. Collaborate with other organizations and HD associations globally to provide the best support possible to young people impacted by HD

A MESSAGE FROM OUR CHAIRPERSON

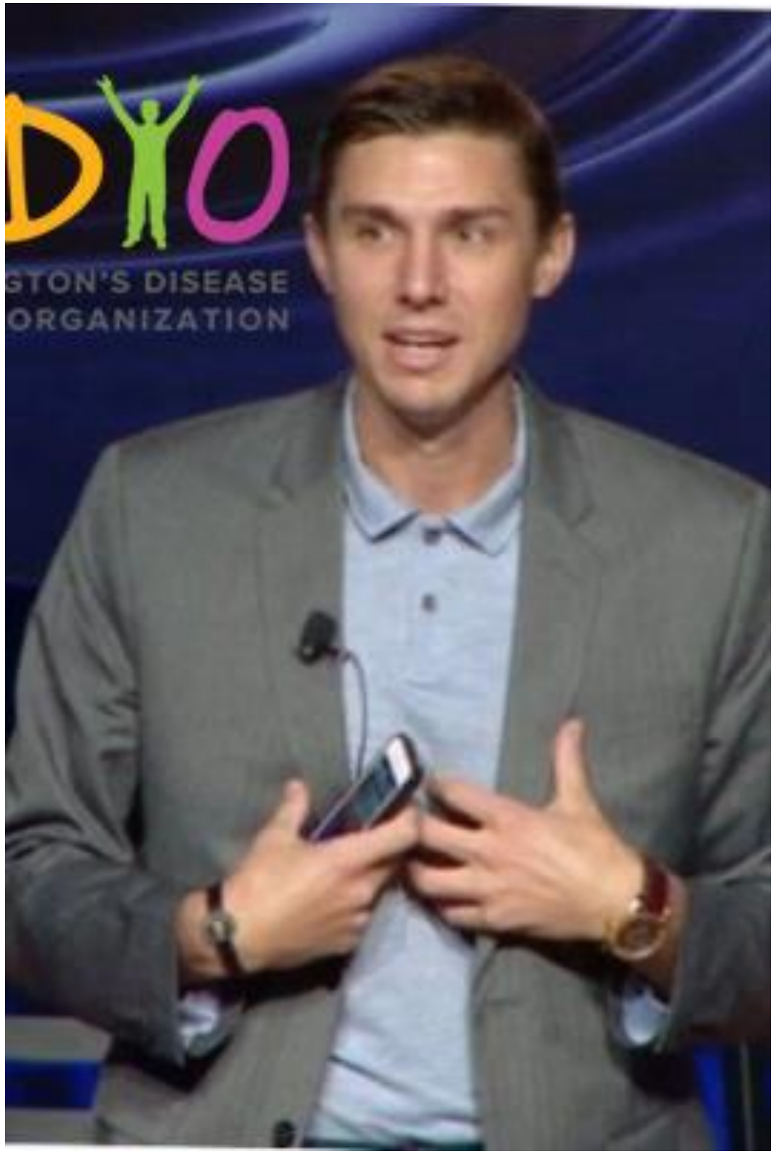
The power of young people in the HD community continued to grow in 2017 and we are proud to be a part of the growth. The passion of our staff, volunteers and partners is truly incredible and without the collaboration efforts from everyone, many young people would be without the needed support. The paradigm shift over the past six years continues to bring more resources and opportunities that didn't exist before and here are a few highlights that stick out to us:

- HDYO website or video content was visited/viewed over 1M times. www.HDYO.org now available in 14 languages!
- HDYO camps were held in Australia for the 1st time and the 3rd annual in N. America!
- HDSA & NYA hosted four youth retreats, full of support!
- HSC & YPAHD hosted a tri-city education day for young people throughout Canada!
- Youth retreats held by HD associations in Germany, Norway, USA, England, Scotland and Australia!
- More young people than ever before became advocates, fundraisers and research participants and overall are now living happier and healthier lives!
- HDYO attended 14 medical conferences raising awareness about youth support to HCPs.
- HDYO brought on Executive Director, Cat Martin, allowing her to utilize her passion to support young people on a day-day basis while providing HDYO the resources for continued growth through collaboration!

We have plenty of accomplishments as a community to be proud of for 2017 and much to be excited for in the future. 2018 will be a monumental year for the HD community as hope for continued research progress grows. Until any treatment is a reality, we promise to do everything in our power to provide the support, education and motivation that young people in HD families desire. Please keep pushing us, believing in us and partnering with us to create continued successful programs for the young people that need us!

BJ Viau & HDYO Board

bj@hdyo.org



A MESSAGE FROM OUR NEW EXECUTIVE DIRECTOR

Hi everyone

2017 has been another incredible year for us at HDYO. I was honoured to be appointed HDYO's first Executive Director in April of this year after 5 years as a board member and volunteer.

My role has been another milestone in the journey of HDYO and one that has helped increase our focus on delivering against our strategic goals. This year we have surpassed our expectation's and have made huge strides towards achieving these goals.

You will see from the report that we have had a much larger international presence in 2017 than we have had previously along with delivering new educational projects, expanding the US youth service and establishing a new Facebook support group.

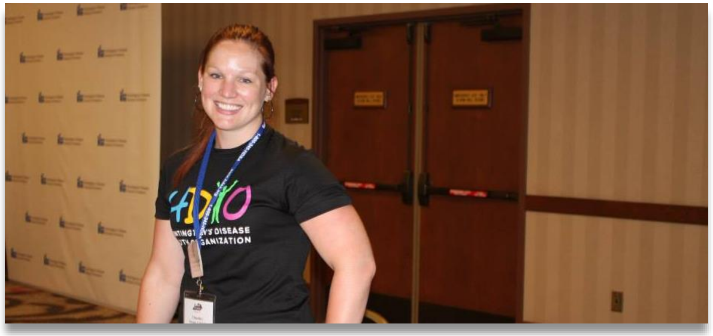
2018 is setting up to be even busier and we look forward to expanding our reach with our partnership projects in South America, Europe, North America and Australia & New Zealand.

As always HDYO would not be possible if it wasn't for our incredible supporters and superhero volunteers. Thank you to all of you.

Cat Martin

catherine@hdyo.org

MEET THE STAFF TEAM



Cat Martin

Executive Director

Catherine@hdyo.org

+44 7555 178340

UK Based

Matt Ellison

Project Co-ordinator & Founder

Matt@hdyo.org

+44 7821 799554

UK Based

Chandler Swope

Director of Youth Services for USA

Chandler@hdyo.org

+1 202-674-4848

USA Based

MEET THE BOARD


BJ Viau


Lindsay Morrison


Seth Rotberg


Bethanie Downing


Lysle Turner


Dr Bonnie Hennig-Trestman

2017 HIGHLIGHTS

- Produced Living with JHD video
- Produced Diagnosing JHD Video
- Published Talking to JHD as a Family Article
- Published Coping Article
- 4 New Languages for website
- Launched the HDYO Happenings quarterly newsletter
- New HDYO Brochure
- 2 International Camps
- Expanded US Youth Service
- New Partnerships
- New Facebook Support Group
- New Social Media Accounts
- 22 Conferences & Events attended worldwide
- New regular blog site

LIVING WITH JHD VIDEO

At the beginning of the year we filmed and edited a video project focused on Juvenile HD (JHD). We interviewed four families on camera with the goal of creating a video that would enlighten people about what JHD is and how it impacts young people and families. We launched the video at the end of March and in that time it has become by far our most viewed video on Youtube which is interesting. It currently has **420,000 views** and is amongst the most viewed HD videos on Youtube. Views are still coming in for the video. We would like to thank the families you bravely shared their experiences with us to raise awareness of JHD and hope they are glad they did. Here is the link:

- https://www.youtube.com/watch?v=Sb6YjAfB1H0&t=144s

TALKING ABOUT JHD AS A FAMILY

We added to our JHD section content by producing an article on talking about JHD with your children and family. A very difficult topic but one we wanted to approach for families in this challenging position. We aimed to cover the challenges they face and provide ideas for talking about JHD with their children and family.

https://en.hdyo.org/jhd/articles/551

DIAGNOSING JHD

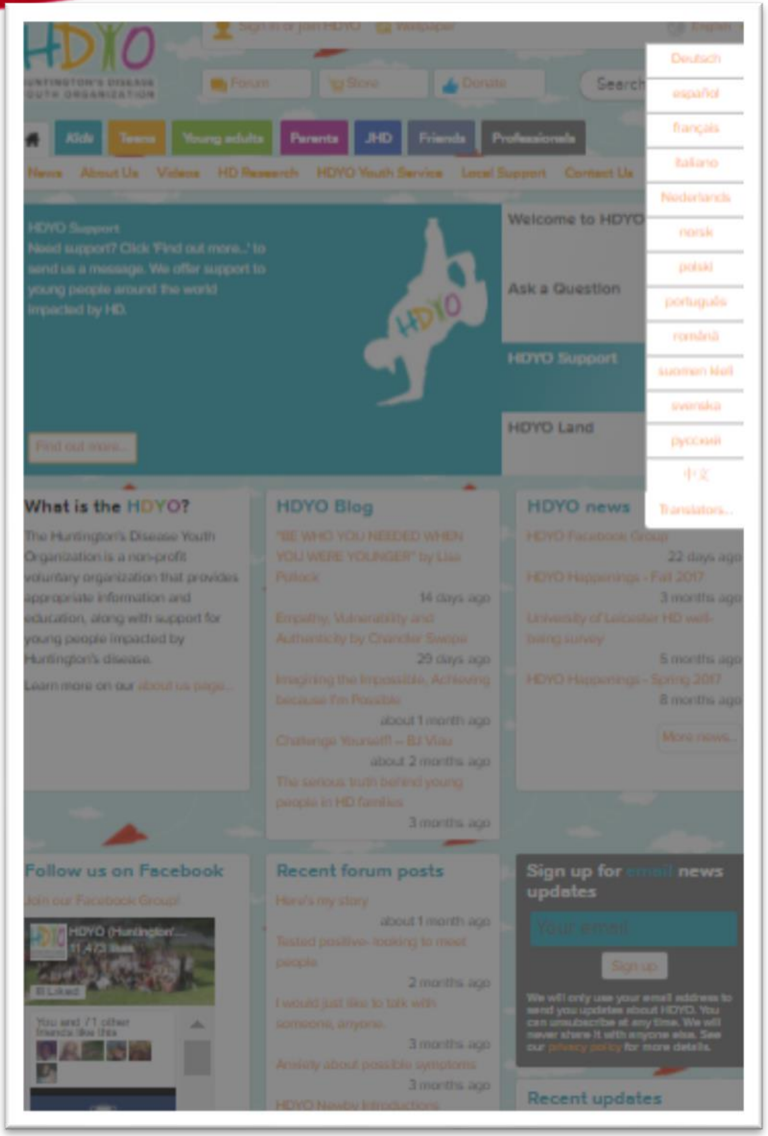
We also created a video focused on diagnosing JHD and the challenges that brings for professionals and families alike. Dr Martha Nance was happy to help us with this video project and we did this at the same time as the other JHD video. This video now sits in the difficulty in diagnosing JHD section on our website to provide some insight into this issue for families. Here’s the link:

https://www.youtube.com/watch?v=0oNc5NT4b0Q

COPING

We added a section to our site looking at coping with HD in a young person's life. We've highlighted the barriers to being able to cope, what coping means, how to cope better and to be aware of any bad ways of coping that young people may be using. Coping is one of the biggest topics young people want help with in the HD community and so it is only right that HDYO has a section on coping for them.

https://en.hdyo.org/tee/articles/550



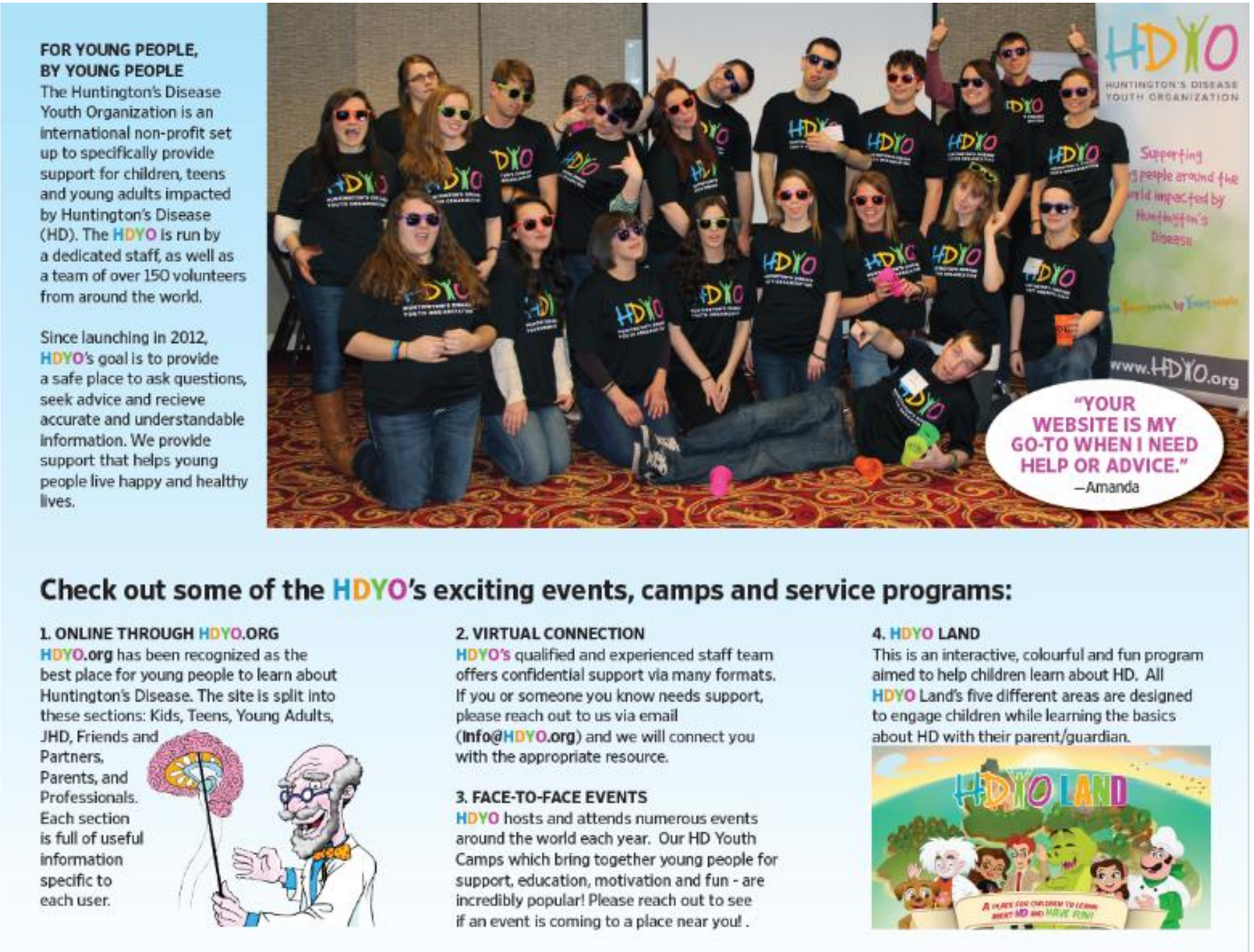
4 NEW LANGUAGES

We were delighted to add 4 new languages to the website this year. We added Russian, Chinese, Finnish and Romanian, taking our total to 14! We received grant funding for two of the languages (Chinese and Russian) and the other two were done by volunteer teams. Thank you to the Finnish HDA and the Romanian team who helped us get those languages up and running!

www.hdyo.org

NEW HDYO BROCHURE

We created an updated HDYO brochure as our previous one was published in 2012 when we launched! So we've gone through and updated the brochure to better reflect what we offer now and have given it a redesign also. If you would like some HDYO brochures please contact us, we are happy to send them out.



FOR YOUNG PEOPLE, BY YOUNG PEOPLE

The Huntington's Disease Youth Organization is an international non-profit set up to specifically provide support for children, teens and young adults impacted by Huntington's Disease (HD). The HDYO is run by a dedicated staff, as well as a team of over 150 volunteers from around the world.

Since launching in 2012, HDYO's goal is to provide a safe place to ask questions, seek advice and recieve accurate and understandable information. We provide support that helps young people live happy and healthy lives.

"YOUR WEBSITE IS MY GO-TO WHEN I NEED HELP OR ADVICE."
—Amanda

Check out some of the HDYO's exciting events, camps and service programs:

1. ONLINE THROUGH HDYO.ORG

HDYO.org has been recognized as the best place for young people to learn about Huntington's Disease. The site is split into these sections: Kids, Teens, Young Adults, JHD, Friends and Partners, Parents, and Professionals. Each section is full of useful information specific to each user.

2. VIRTUAL CONNECTION

HDYO's qualified and experienced staff team offers confidential support via many formats. If you or someone you know needs support, please reach out to us via email (**Info@HDYO.org**) and we will connect you with the appropriate resource.

3. FACE-TO-FACE EVENTS

HDYO hosts and attends numerous events around the world each year. Our HD Youth Camps which bring together young people for support, education, motivation and fun - are incredibly popular! Please reach out to see if an event is coming to a place near you! .

4. HDYO LAND

This is an interactive, colourful and fun program aimed to help children learn about HD. All HDYO Land's five different areas are designed to engage children while learning the basics about HD with their parent/guardian.

YOUTH CAMPS 2017

Australia & New Zealand

We were thrilled to host our first Australia and New Zealand HD Youth Camp in January 2017! We've been hoping to get a camp to this region for a few years and we're very thankful to Teva for their support in helping us put this camp in place. We underestimated the interest in a camp in this region, we planned for 25 places given the population is a lot smaller than the North American camp population, but we ended up with 40+ applications so had to find more funding to almost double the amount of attendees. Thanks to the Griffin Foundation we were able to achieve this and we held a beautiful camp event in Queensland, Australia, in January.

The 3rd North American HD Youth Camp took place in Maryland, USA, with over 50 campers and 20+ volunteers/staff in attendance it was a great success once again! This camp was a day longer than previous camps, with 4 full days available for young people to get to know each other and share experiences or concerns. The 4th North American camp is already confirmed for 2018 and we will be moving locations from Maryland to California to see if we can get some new faces to apply.

North America

U.S. YOUTH SERVICE

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

The fourth year of the United States youth project was another year of development and growth. The project continues to evolve as the years progress and the feedback continues to be positive from young people, families and partners. We've continued to partner with the Huntington's Disease Society of America, Huntington's Society Canada, Huntington's Study Group, Help4HD International and local efforts to provide support and information regarding youth support and services.

The youth project has seen a lot of growth after incorporating virtual work into the project. There are over 351 individuals (young people, parents and professionals) reaching out to the youth service since its inception. The youth worker provides supportive services in person, via text, Facebook messenger, Skype, e-mail and over the phone. Using a variety of mediums has had a positive impact on the growth of the service.

US YOUTH SERVICE PARTNERSHIP

This year the youth worked to partner with clinics, chapters and other providers to offer youth-focused programming in conjunction with education days. HDYO attended five educational days to speak about the HDYO youth service and well as providing youth-specific programming at three of them. We have a number of partnering requests for 2018 as well as HDYO will be partnering with Help4HD International at their four H.I.P.E days and annual symposiums to offer support and education for young people.

The youth worker also attended three of the four National Youth Alliance (NYA) Youth Retreats as well as NYA day at the national convention. NYA day at convention had a record 97 attendees and there were many individual support sessions held throughout the weekend. The youth retreats each had approximately 20 attendees and it was a great opportunity for the youth worker to connect with former campers, assist with any concerns that arose and meet new families. We look forward to continuing to work with the NYA to support young people across the United States.

US YOUTH SERVICE

- **351** individuals receiving support
- **15-20** individual contacts per week
- **65** families supported at clinics
- **572** individuals reached via workshops, groups or events

"It was a rare opportunity to get close to other HD families. He is often shy with new people but was able to make new friends.." – Parent

"Thank you so much for this incredible experience! I learned so much about HD and how to cope with the illness. I feel more prepared emotionally and physically for coping with HD in my family and the community. I'm so happy I was able to build friendships and connect with so many strong individuals."– Young Person

FACEBOOK SUPPORT GROUP

In November we launched a Facebook group especially for young people, with the idea being to have a place for peer support. Our website forum is quiet and we wanted to try and create a new space for young people globally to connect. We did some planning to figure out the best approach to setting the group up. We made a closed group and trained some volunteers to help us moderate the group, with importance placed on making sure young people only get into the group and nobody else from the HD community. Since launching we have been able to get 753 young people into the group with more requesting to join each day. The interaction since we launched the group has been wonderful, with 221 posts, 1900 comments and 7500 likes/reactions in the group over the first couple of weeks. This is really positive and it's great to see young people connecting so easily over Facebook in our group setting.

Contact matt@hdyo.org if you would like to join the group or find out more details.

2018 PROJECTS WE'VE ALREADY STARTED

Educational Content

Dealing with a Diagnosis Section

- Matt has been developing a dealing with a diagnosis section for the website which is essentially finished but we are getting some personal experiences of dealing with a diagnosis into the section to give it that personal touch and experience so until we have those we are holding off uploading to the site. So expect it to be up on the site in early 2018!

Young Caregiver Video

- Another video project in the works is our young carers video. Once again we've been recruiting for the project in previous months and will begin filming early next year. The goal will be to have an insightful video into the experiences of young carers in HD families.

Genetic Testing Results Video

- We've also started work on a video project to assess young people's feelings to testing positive and negative after having time to adjust and accept their results. So we are recruiting young adults who have tested around 5 years ago or longer to this project. We have had a strong response for participants to this project and will begin filming next year and have a finished video towards the end of the year hopefully.

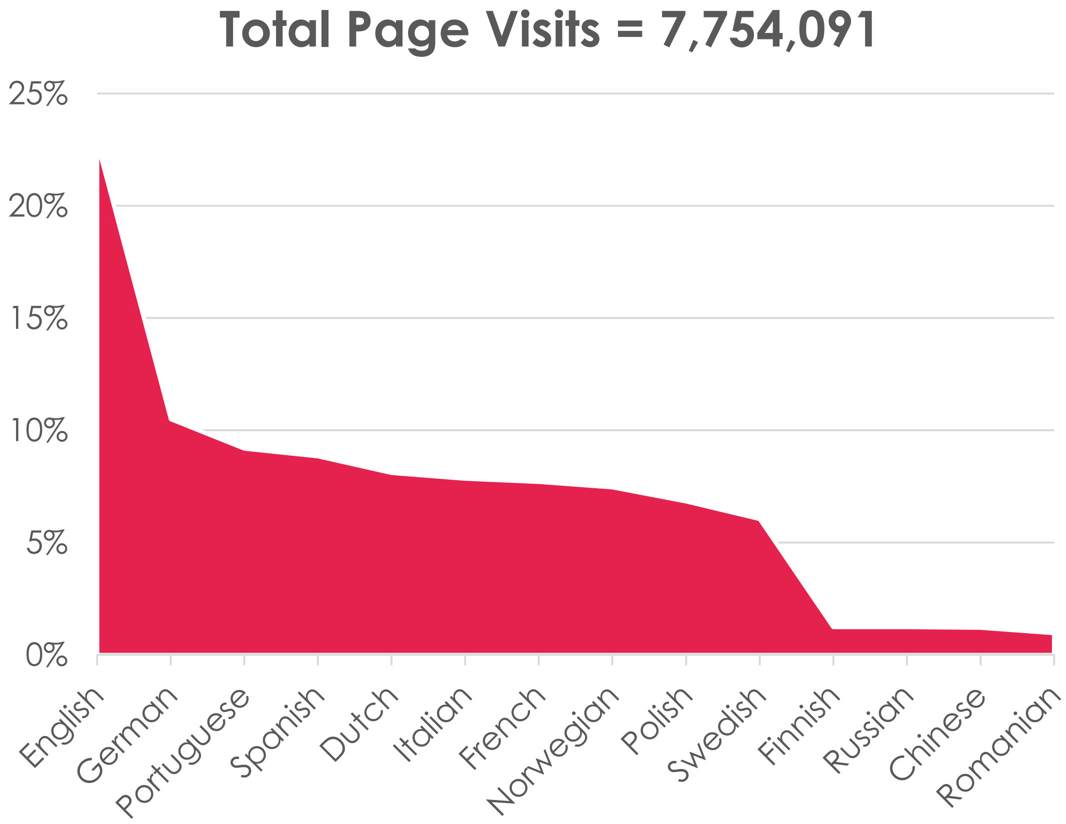
Support & Training

- European Youth Engagement Training
- South American Camp Training
- Webinar Based Support Programme

Camps & Events

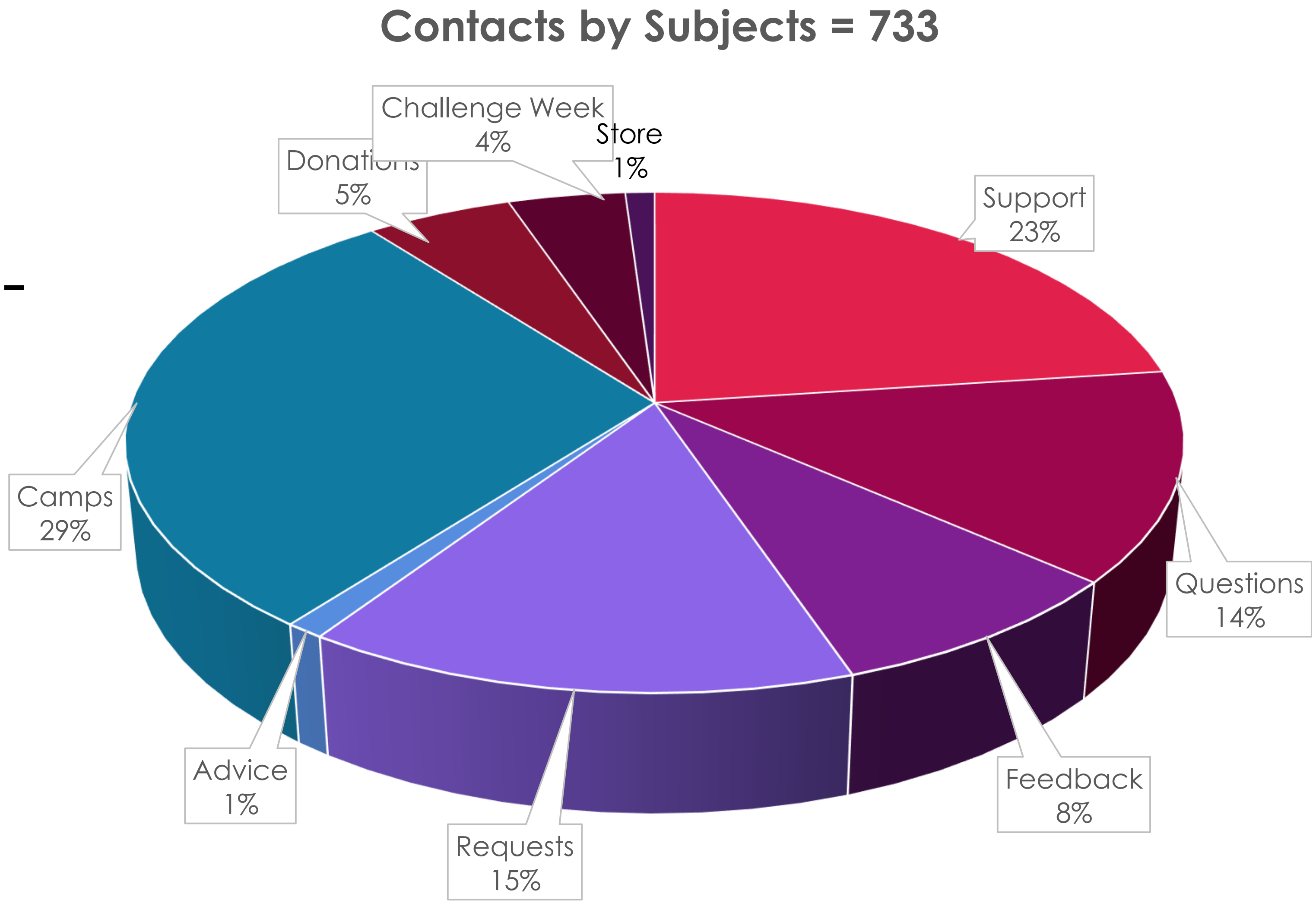
- Australia & New Zealand Camp
- North American Camp

HDYO IN NUMBERS - WEBSITE

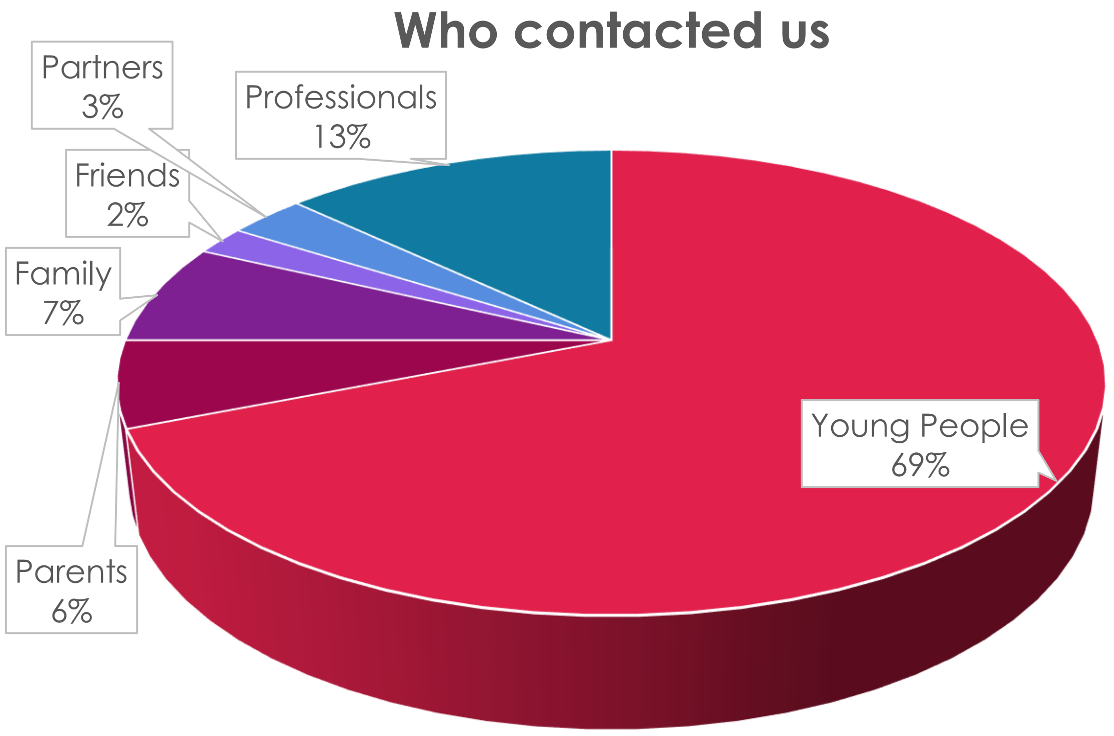


HDYO IN NUMBERS - CONTACTS

We have had 733 individuals contact us via www.hdyo.org in 2017. 29% of this comes from camp applications and questions however 37% are looking for support or to ask a question about HD.



HDYO IN NUMBERS - CONTACTS



NEWS TEAM

2017 has seen us change how we share and interact with everyone. HDYO has multiple social media platforms as well as quarterly newsletter and bi-weekly blogs.

HDYO is committed to open engagement with our users and supporters and this year we have seen a huge increase in interactions.

For instance:

- HDYO Youtube channel has now had its content viewed **760,000**
- Our new Facebook Support group had **2,500** posts in its first week from **651** members.
- Our Instagram challenge in May helped to increase our reach **693** followers
- We have a new regular blog page http://blog.hdyo.org
- HDYO Happenings is now delivered directly to mail boxes every quarter

2018 will see us recruit new volunteers to the news team to help us continue to deliver and engage across all platforms. Contact info@hdyo.org is you would like to get involved.

A WORLD OF CONFERENCES

This year HDYO have been travelling the global to raise awareness of our services and the need to support children and young people impacted by HD. Thanks to CHDI Foundation we were able to attend 7 conferences in 2017.

1. American Academy of Neurology
2. CHDI Therapeutics Conference
3. Movement Disorder Society Congress
4. 6th International Neuropsychiatry Conference
5. National Society of Genetic Counsellors Conference
6. European Huntington's Association Family Conference
7. Huntington's Study Group Conference

On top of the 7 conferences we also attended or participated in an additional 15 HD related events around the world excluding our two youth camps.

One of the most extraordinary events we were privileged to be at was HDdenNoMore Audience with Pope Francis. This was an unforgettable event and one that we need to, as a community, continue the momentum of raising awareness of HD and helping people to feel safe to be able to actively participate in the global HD community.

THANKS TO OUR FUNDERS & DONORS

- Griffin Foundation
- Huntington’s Disease Society of America
- Huntington’s Society of Canada
- TEVA Pharmaceuticals
- Huntington’s Study Group
- Gimbel Family Scholarship
- James E “Jake” Hoffman Memorial Fund
- HDA Belgium/Franco
- Deutsche Huntington-Hilfe
- Huntington’s Disease Association of Ireland
- Georgetown Huntington’s Disease Centre of Excellence
- CHDI Foundation

- Tamara Miller
- Phyllis Gimbel Schnitman
- Gail & Bryan Viau
- Mark Murphy
- Lindsay Morrison
- Susan Kelly
- Jamie Levey
- BJ Viau
- Michael & Laurel Schnitman
- Yarragon Primary School
- Emilie Liebhoff
- Kari Hess
- Deena Schnitman
- Karen Clark
- Seth Rotberg
- Savannah Moore
- Margaret Andrews
- Laura Crabtree
- Melanie Costa
- Jared Piaggione
- Brooke Harlowe
- Richard Shiffrin
- Stacey Saladin
- CM Moore
- Susan Karp
- Samuel Karp
- Trent Berrier
- Chandler Swope
- Kirk Oates
- Monica Cazzolli
- Jason Potash
- Megan Killegass
- Ganda Setiakurnia
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- Betsy Ratner
- Dale & Viki Henry
- Regina Silver-Koplo
- Sylvia Pasieka
- Barbara Bradshaw
- Laura Marinari
- Daniel Mizrachi
- Deborah Sharpe
- Alexandra Bucci
- Harry Rosenberg
- Catherine Martin
- Stacey Smith
- Gill Lewis
- Blue Coat School
- Adam Liebhoff
- Anna Lunsford
- LuLaRoe
- Gwen Johnson
- Kaisa Eklumd