



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Translator Team

October 14, 2015

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

www.hdyo.org

HDYO's mission is to support young people affected by Huntington's disease all over the world. In order to provide support, HDYO produces a huge amount of informative and educational content for young people and their families affected by Huntington's disease. All of this content has to be translated into as many languages as possible to ensure that young people have access to the information that may help them live positively despite Huntington's disease being in their lives. The translations for HDYO are done by the HDYO Translator Team, which consists of many people who share a desire to help. Many of them are in fact young people affected by Huntington's disease themselves, who want to do their part for the cause. All HDYO's translators are volunteers, giving up their time freely. HDYO is always looking for more translators. If you feel you have the ability to translate for HDYO and would like to do so, then [contact HDYO](#) and let us know. Who knows, maybe you could join the team you see below!

Spanish

Juanma

Hello! My name is Juanma Melgar Jiménez. I was born in a small beautiful spot of Andalucía, Spain called Arriate and currently live in Boston, MA. My family has known about Huntington's disease for several generations. I first learned about it when my mother and uncles had symptoms and I saw its devastating effects up close. One way to pay tribute and at the same time help other people who are going through the same thing is through translations into Spanish so that they have an updated knowledge about the disease, all the scientific advances and strategies to support their families and thus improve the quality of life of people affected by this disease.

Norwegian

Marthe



I'm 21 years old and live in Trondheim where I study to be a pre-school teacher. I grew up with HD in my family. For the last couple of years I have wanted to do something for the HD community, by translating for HDYO I feel like I'm giving something back for those who need it, and at the same time it is helping me through my own coping process.

Eline



My name is Eline and I am 18 years old. We have Huntington's disease in our family. I translate for HDYO because I feel that I can take part in helping others in the same situation. I am also translating for HD buzz. I am in my last year in high school, but I haven't figured out exactly what to do next.

Maria



Hi I am 20 years old and live in Ålesund, where I am studying to become clinical social worker. I grew up with Huntington's disease in my family, and want to contribute and give something back to the Huntington's disease community. I am part of HDYO's Norwegian translation team because I want everyone to have the opportunity to get right and good information about HD in their own language, which they can understand.

German

Michaela



I'm 36 years old and live in Stuttgart, Germany. I grew up in a Huntington's disease family. I learned about Huntington's disease at the age of 15. My Dad died of Huntington's 9 years ago. Huntington's disease was always part of my life. I know the fears of those at risk and their sorrows but also their strength and ways of fulfilling their lives with joy. Translating is not a big effort for me and the results are very valuable. It's

an extremely good feeling doing something for young people in Huntington's disease families.

Clara



Hello, my name is Clara and I'm from Germany. I translate for HDYO because I think it is important that all the young people affected by HD have the possibility to get high-quality information in their language and can communicate with other young people from HD-families.

Eugen

I'm Eugen, I live in Germany, 31 years old. I'm happy to have an opportunity to contribute to the HD community and support other young persons impacted by HD. Due to the personal motivation based on family background I try to be active in HD research as well as in social work.

Currently, I'm finishing my PhD on this topic and I'm also passionately involved into the documents translation. I'm excited about the people here and the strong solidarity between them, and I'm proud to be a part of this network.

Polish

Marianna



My Dad suffers from Huntington's disease. Taking care of him is difficult but gives me a lot of satisfaction at the same time. I feel that I must help others because all of us need support (and yes, this is the way to help myself too). Cooperating with HDYO is the best way of doing it. Besides I feel that it's only when we do things together we can really help the Huntington's disease community. HDYO is such a great idea. Together we're creating a completely new reality. I know that because I can see a difference. It's

unbelievable how much we are able to do! For those whom we love and for ourselves. It makes me so happy! This work and satisfaction it brings are worth our every effort :)

Ewa



Hello everyone!

My name's Ewa, I was born in Poland in 1989, the time of the fall of the Berlin Wall, to my beautiful mum and hero dad. They'd been long waiting for children too, so after having my older sister Marianna and me, our family life showed great promise. It was, however, only a little later that my loving dad started behaving not really caring anymore. Now I know it has a name: behavioural problems and depressive episodes. Finally my great dad started chorea-dancing, which did not turn out to be anything to do with joy at all. We found out it was Huntington's disease. My mum had to take over the role of the hero and become dad's carer and I with my sister Marianna are there to help her.

My connection to HD is, therefore, the fact that I'm my daddy's girl. I know the difficulties, dilemmas, fears and well, everyday life that a carer and, previously, a person at risk goes through. Also, as mentioned before, I'm from Poland and even though the communist regime is over, people are still too inhibited and there is, in fact, little awareness as regards neurodegenerative diseases like HD. Seriously ill people and their families don't get enough understanding or support or even information about the disease either. Therefore, I found the whole idea of the HDYO just invaluable. Especially the HDYO website, with its straightforward, clear and simply-put information, colourful design and, above all, atmosphere of support and comfort, is an endeavour that I'd love to spread in my country. That's why I started translating the articles from the HDYO website into Polish and speak about HD openly, too. I do it in between teaching English, walking with my dog, swimming, cooking and, of course, looking after my dad.

Anna



My name is Anna. I lost the two most important people in my life to HD, my grandmother and recently my mom. I'm positive as well. Until there is a cure for HD we simply need to rely on one another. I met many wonderful people through HDYO, and I encourage you to join our team to have a great time!

Kinga



I'm 26 years old and live in Warsaw. When I first heard about HDYO through my friend whose dad suffers from HD I offered my help with making translations because I was very impressed with the entire concept of HDYO. HD is a very sad disease so if there's even a tiny little possibility that our work could help even one person then it's totally worth the effort. I'm proud that I could be a part of the team and hope that young Polish people would also find here the much needed information and support.

Swedish

Marina



My connection to Huntington's is through my mother, who's at this point at a late stage of Huntington's disease. She started showing symptoms very early, and after my parents got separated when I was 9 years old, the disease progressed very fast. My older brother, younger sister and I, didn't understand what was going on with mom until about 4 years later, when our dad told us about Huntington's disease. But even after mom got her diagnosis she kept denying it and refused to get help. So my siblings and I took care of her all through our teenage years, some of us more than others. We felt like we were alone in the world until my sister and I started up a youth support group in Gothenburg with a few others and got a chance to hear others' stories and share ours with others who for once understood.

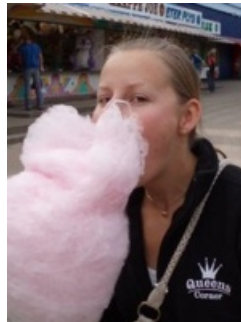
I got that support through other young people and I believe it's the best support you

can get, after knowing each other for five minutes you feel like you've known each other for years. That's why I really believe in the HDYO, it's a great way to reach young people and give them the opportunity to meet with others who will understand and support them.

I've wanted to reach and help other young people for quite some time, and I never really knew how to, so I'm glad and thankful for getting the opportunity to translate for the HDYO so I can finally help out the way I can.

Danish

Helle



My name is Helle, and I am 24 years old. I live in Aarhus where I study chemistry and mathematics at the university. My mother has Huntington's disease and she lives at a nursing home only for people with Huntington's disease.

When I was a child I did not know anything about Huntington's disease, although my grandfather was affected by the symptoms. Around my 18 years birthday in January 2005, my mother called me just to tell me about Huntington's disease. I lived alone at this time, so I got the message alone in my little dorm room over the phone. At this point my brother, who is five years older than me, knew nothing. I had to call him and pass him the message, which was very hard for me. After this we started the process to get tested together, and in the summer 2005. My brother was tested positive and I was tested negative, we followed the statistics one of each unfortunately.

During the test process I did read a lot about Huntington's disease, but I thought it was a bit difficult to find something 'just for me'. That is the reason I work for HDYO, to help develop something about Huntington's disease just for people like me: young, alone, afraid and unaware of the different sides of Huntington's disease. I believe that if this site in Danish helps just one person, all my translation work has been a success.

Italian

Marica

Hi, My name is Marica, i'm 22 years old, and i'm from Milan.

In my family my grandma (she is death before I born) my mum is sick since when I was born, and now she is in vegetative state by 2002, I'm only child and I've been testing positive last year.

My dad is involved in Milan 's Huntington disease association by twenty years and he had always took me in association' s meeting, and I know about this disease since when I was very little, and also about the test. Now I'm a part of administration' s association as my dad.

I've decided doing test when I was 18, but everybody told to me I was too young, and so I did it last year.

I'm a basketball player since when I was 7, and I like it very much!

I really believe in the HDYO, it's a great way to reach young people and give them the opportunity to meet with others who will understand and support them.

Claudia



My name is Claudia, and I first heard of Huntington's Disease while studying Pharmacology at the University. At that time there was not much awareness of this disease, and it was called Huntington's Chorea. I thought I would have never heard about that disease anymore. I could clearly remember the disease onset and the precise

genetic this disease showed. All I thought was that it was a cruel disease. It was 1995.

Exactly 10 years after, I started to work as a researcher in a company, Siena Biotech, a small company based in Siena. And during my job interview, I was told that the main goal of the company was to study and eventually develop a molecule for curing Huntington's disease. I was asked if I knew it, and of course I rattled off quotations of pharmacology and genetic about Huntington's disease – which I still clearly remembered.

I worked in this company for 8 years, during which I have worked on a range of projects delivering clinical and preclinical candidates, including Selisistat, currently in Phase II clinical trials for Huntington's disease. It has been flattering when the EHDN (European Huntington's Disease Network) asked me to join them as Language Area Coordinator for Italy. It is what I am doing now, and I have the fortune to see a global overview on the different trials ongoing - there are so many things going on for HD!

I am volunteering as translator for HDYO because in my past life as researcher, I only knew how molecules could “aggregate” in a research lab, but since I have started my work for the EHDN, I have learnt how important is to aggregate people bearing this pain of having HD in their families. And I believe HDYO is one of the most powerful tool that is helping this process worldwide. Congratulations to these Youth: you are doing a massive effort and ultimately a great job!

Dutch

Lucre

Hello everyone,

My name is Lucre and I am 41 years old. I became involved with HDYO through a dear friend of mine who is affected by the disease himself. I've seen him struggle with the dilemma of getting tested or not, how to care for his affected parent and where to get the right information and help. Also, being a researcher in the field of child- and adolescent psychiatry, I have seen how it can affect children and adolescents when their parents suffer from serious illnesses, especially when they are at risk of developing the illness themselves. I find it immensely important for children, adolescents and young adults to have easy access to information that is understandable and relevant for their own age. I am therefore very excited about HDYO and I did not hesitate for one second to join the translator team! It is my wish that you all will find the information that you need on HDYO, and please don't hesitate to give us feedback, also when you feel important issues are not covered, because it will help us to develop HDYO as a reliable and relevant source of information for you and all other young people affected by HD.

Jaco

Hello all,

My name is Jaco, 47 years old and I married into a family with Huntington Disease. My mother in law passed away several years ago. For some years the disease seemed relative absent but now it kicks in dramatically into the next generation. My wife doesn't have the symptoms herself but 3 of her brothers/sisters do. It is terrible to see how the disease takes away the future and hope of these young people. Being healthy myself, I feel that I need to do whatever I can to help. Translation of the articles is one aspect where I can help and I am very happy to do so. Reliable information and good advice is very important. Being able to read that in your own language is in my view essential. I am sure that the articles will help those who are affected by this disease.

Martijn

Hi everyone,

My name is Martijn. I am 23 years old and currently finishing my studies at the University of Groningen. Several years ago I heard that my aunt was affected by HD. Soon after, we found out that my father carries a faulty gene as well. As I grew older and wanted to know more about HD, I applied for the World Congress of HD in Vancouver, 2009. It was there that I came into contact with HDYO and decided to join them. As of today, I am still a member and happily translating parts of the website such that everybody affected by HD is able to read about it in his or her own language. Last but not least, last March I have taken the predictive test and tested negative :) I hope you will enjoy reading this website and that it might help you!

Dirk

Hi all,

My name is Dirk. I am 43 years old (but I used to be younger). I've tested gene positive and I'm in the early stages of the disease. Twenty years ago we suddenly heard that my mother was affected by HD. We were shocked and tried to find some information about how to care for my mother or whether us children should do the predictive test or not. In the library there was only one little book (and no internet). The Dutch HDA could provide some more information and especially the opportunity to talk to young adults in the same situation. This helped us a lot in making decisions for my mother's and my personal situation. I'm so thrilled that at this moment it is possible to have worldwide access to the latest information from HD specialists, written in a language that young people understand, and to have a chance to discuss with young adults from all over the world. Also working for HDYO is a great experience, by meeting many different people and really making a difference by sharing the best possible information and your own knowledge and experience. So, I really hope you get some answers on your questions from HDYO, and please let us know if you feel there's a topic that's missing on HDYO.

French

Jean-Paul alias "Polosunshine"



For 73 years I have happily ignored Huntington, nothing in me, nothing in my family and nothing anywhere. One day I saw the movie "The Octopus" showing something. I do not have delivered. Wickedness and arbitrary destruction of this dirt shocked me to the highest degree. I am more than happy to do something against this thing. My wife Lily feels a deep sense of solidarity with all those facing it; she takes care of polishing the translations.

Johan & Olivier

I'm Johan, I'm from Belgium and I grew up in a HD family. I decided to translate for HDYO after the HDYO camp in Bastad (Sweden) in summer 2012. But I soon realized I wouldn't be able to do it on my own, so I asked my cousin Olivier to help me out. Since, we're translating together HDYO material to French.

Portuguese

Filipa



My name is Filipa, I'm a psychologist and I am currently doing my PhD in Neuropsychology, developing a research project in Huntington and Parkinson diseases.

I'm the President of the Huntington's Portuguese Association (APDH) since 2009. I started working with Huntington's patients and families in the beginning of 2007, when I became a research assistant at IBILI - Institute for Biomedical Imaging and Life Sciences (Faculty of Medicine of University of Coimbra). One year later, I've met the founder of the Portuguese Association, Ursula Anna Kleibrink, at the Huntington's Portuguese

Association national meeting. I think it was then that I truly became more aware of the real impact that this disease has not just in the patient but in the entire family. By the end of that year, I became APDH's delegate for the central region of Portugal.

In 2009, I was elected president of APDH. The volunteer work that I do at the Association includes promoting and orienting training sessions about HD in the community (clinical units, day centers and schools); giving individual counseling to patients and relatives; guiding families to the clinical, legal and social resources that exist in the Portuguese community (and that are sometime, unfortunately, very scarce); maintaining and updating APDH's Website and Facebook page; translating brochures, books and other educational material about HD to Portuguese; collaborating with several academic works and institutions; organizing fund raising events to help APDH finances; and, in general, raising awareness about HD and helping in every possible way the HD families in my country.

In 2011, I have become member at large of the International Huntington Association board. That year, I also started doing the HDBuzz translations to Portuguese. In the next year, 2012, I have joined the European Huntington Association board, as secretary. I started helping with the HDYO site translation into Portuguese since the very beginning because I realized, over the years, that the internet is currently the main source of information for the young (and not so young) people. I deeply believe in the goals and mission of HDYO and I'm very proud to be part of this global effort.

Sandra



I do translations because I am a carrier of Huntington's disease and because besides learning with translations, I'm helping other people, since very young, and this is a way to disclose all information about Huntington's disease to a greater number of people in the world.

I am 36 years and hope that together we can all find a cure, and have a 5 year old daughter who gives me all the strength to continue, and I would like to see my daughter grow up, with health.

Náthaly



A few years ago I met a girl that is now one of my best friend. That time she told me her mum had the Huntington's disease and as I had never heard about it she explained to me. As the years went by I watched her and her family union and strength to deal with the disease. It was a beautiful thing to see and to take as example of love and how we all should be thankful for our lives.

One day I started to look for more stuff about the Huntington's disease and found HDYO and they were looking for translators. I remember I thought 'OMG, my English is not that good', but even so I e-mail Matt and he told me I could help. I started to translate although my difficulties and this make me feel so good about myself and the fact that maybe I'm helping some young people.



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<https://www.hdyo.org/a/33-translator-team>

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