

Our Journey To A Higher Level

HDYO Annual Report 2018



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**



Message from Cat Martin – Executive Director

2018 has been another amazing year for HDYO with lots of new emerging partnerships and projects coming to fruition.

My highlights have to be increased interest in research surrounding young people, more services and projects being developed specifically for young people and the voices of young people being heard at an international level...positively.

HDYO is a key influencer and we will continue to ensure that young people are central to those organizing or developing research studies and trials, patient services, educational resources, events and conferences specific to Huntington's Disease.

Our mission remains to ensure that young people have access to education and support regardless of where they are in the world or their economic status. We are making a difference, we have achieved a huge amount for a small organization but we won't rest until we achieve what we were set up to do.

Every penny of your donations is invested in improving the lives of children, young people and young adults around the world impacted by HD. We can't do this without your donations and are forever grateful to our amazing supporters. I look forward to welcoming more of you to the team as we work towards our biggest project ever, the inaugural Young Adults Congress on HD taking place in Glasgow, Scotland 9th-11th May 2020.

-Catherine@HDYO.org

Message from B.J. Viau - Board Chair

As the global leader for young people impacted by HD, entering 2019 we have much to be proud of and thankful for as an organization. However, the list of projects to accomplish continues to grow exponentially. Time has flown but HDYO's accomplishments in 7 years exceed all expectations, even as the bar rises.

Fifteen years ago, if you suggested, "supporting young people" in the HD world, you'd likely get a blank stare in return. In fact, just eight years ago, HDYO was nothing more than an idea in Matt Ellison's (HDYO Founder) mind. There was no money, no professional assistance, a minuscule network. Fortunately, a handful of young people had a deep passion to make a difference...and HDYO was born!

We continue to grow, mature and lead the way for the future HD community. Our progress in 2018 speaks volumes to our dedicated staff team, board of directors, global volunteer network and supporters of all kinds. Since our founding in 2012, HDYO has spent just \$1.4M US Dollars on all our programs, camps, website, videos, staff costs and overhead. SO much has been accomplished, I don't believe there is a non-profit that stretches money further.

I could not be more excited for what 2019 will bring! It's time for HDYO to take the next step, grow exponentially to fill the ever-present gap in youth services needed around the world. We have a host of projects and plans with a common goal: expand opportunities for more people to use the HDYO platform to get what they need and/or give what they want.

- **Research!** HDYO will impact acceleration of future treatments through the creation of two unique, but complimentary international registries focusing on Juvenile HD & young adults 18-35 years old.
- **Translation!** HDYO has incredible educational videos available through hdyo.org, which we are hoping to have translated into multiple languages. Expect more educational access for regions that need it most!
- **Community Expansion!** Until now, HDYO has operated as a very small group. We are excited to welcome more enthusiastic and dedicated volunteers to help HDYO expand critical services: young adult councils, medical advisers, youth mentors, new board members, community liaisons, congress committee, volunteer projects and more.

Will you join me in keeping our mission possible? In 2019, I am personally looking for 1,000 people to join our \$10/month donation campaign.

Just \$10/month is enough to provide an HDYO camp attendee food & housing for 5 days at our signature international camps. Sign up here: <https://en.hdyo.org/eve/donate>

On behalf of myself and all on the HDYO team, **THANK YOU** to everyone who contributes to fulfill our mission!

-BJ@HDYO.org



HDYO Team 2018

HDYO Staff Team

Cat Martin - UK
Executive Director

Matt Ellison - UK
Founder/Project
Coordinator

Chandler Swope - USA
Director of Youth Services

HDYO Volunteer Board

BJ Viau – Chairperson - USA

Dr Bonnie Hennig-Trestman - USA

Bethanie Downing - UK

Clarissa Trujillo - USA

Lindsay Morrison - USA

Lysle Turner – S Africa

Seth Rotberg - USA

Our 2018 Mission & Goals

HDYO's ambition is 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.

HDYO goal 1	HDYO goal 2	HDYO goal 3	HDYO goal 4
Establish HDYO as a sustainable and leading organization in the HD community	Increase awareness about HDYO to the international HD community	Continually produce educational and supportive materials and opportunities for young people and their supporters	Collaborate with other organizations and HD associations globally to provide the best support possible to young people impacted by HD
<i>What has happened as a result?</i>	<i>What has happened as a result?</i>	<i>What has happened as a result?</i>	<i>What has happened as a result?</i>
7 policies 4 protocols in place such as Child Protection Policy, Lone Working Protocols, Data Protection & Privacy Policy. (reviewed and updated annually as required)	4,000+ young people/ families in contact with service	7 clinics with an HDYO service and 600+ families who can then access support	4 research partnerships in place
Year to date funding in place	Increased number of national services offering support to young people	Most viewed HD video on YouTube	7 funding avenues explored because of partnerships
Full capacity workforce in place	5 new partnerships in place	Increased number of families participating in research because of HDYO	Increased youth services because of partnerships
Fully compliant governance in place for both UK and USA non-profit requirements	7 clinical partnerships	3 international camps in 2018	Presented at 14 partner events
Participated in 26 conferences	3 research papers submitted for	Webinar and personalised	4 global partners naming HDYO as

Premier Camp Supporter



HDYO Camps

HDYO Youth Camps are one of our favourite projects. We love everything about them (except maybe organising all those flights!) but especially getting to see the difference a few days of education, support and friendship can make in the lives of people who thought they were on their own in this!

HDYO has held nine international youth camps over the last six years allowing over 550 young people to come together, meet new lifelong friends, learn about HD with peers and professionals, share experiences, get some respite and have lots of fun! The average cost of sending one young person to camp is \$800, but it is **TOTALLY FREE** for every young people.

“Organising a camp starts with securing the funding, then we find and book a camp location that suits our needs, prepare an application form for campers and volunteers, collect the data from incoming applicants, review applicants and decide who to take and who not to take unfortunately as it’s a popular event, then considering our campers we develop the content and schedule for camp. From there we have calls with staff and volunteers, book flights for everybody, plan meeting at the airport, then hold the camp and hopefully have an amazing time. It’s a lot of hours of work but we know how valuable camp is to those young people who attend” – Matt Ellison





Australia & New Zealand Camp

The 2nd HD Youth Camp for young people from Australia and New Zealand was another success in February 2018. The second year brought in 51 applications and saw 42 campers attend the 4-day event on the beautiful (and very HOT) Sunshine Coast in Queensland Australia. The campers engaged in small group sessions as well as larger educational sessions to discuss all things HD. The group also engaged in recreational activities such as: swimming, indoor rock climbing, caving and other games.

The feedback on the event was overwhelmingly positive without any post camp feedback rating lower than “good,” the second highest rating on the scale. A majority of the campers expressed that the educational content was excellent or good and that they felt they had more skills to cope post-camp.

North American Camp



The 4th North American Youth Camp came with one big change but stayed consistent with a successful outcome. After three years of hosting camp in the Washington DC metro area, in 2018 we moved camp across the country and used a facility right outside San Diego.

Camp Cedar Glen provided a stunning backdrop for five days of education, support, healing and laughs. Camp was primarily funded by a grant from TEVA Pharmaceuticals and supported by donations from the Jake E. Hoffman Foundation & Gimbel Family Scholarship. We had 48 campers attend: 60% were first time campers and 40% were returning campers.

South American Event



This was quite a big project for us in 2018. HDYO has made a significant impact in many regions around the world such as North America, Europe and Australasia but we haven't done much in South America. This is a region we know is in dire need of support but providing that for HDYO is not so simple. However, we made a significant step this year by holding an event for young adults from across South America to attend. This was no camp though, we wanted to learn about the needs of young people from HD families in this region and we wanted the young people to create a 3-year plan of action for HDYO and South American HD Associations to work towards to improve the lives of young people.

How did this take shape? Well, we had an opportunity to hold the event in Colombia during July as Factor H (a wonderful organization helping families in South America) had set up its first conference for the region. So we tagged our event on to the beginning of this conference. Then we spoke with all the HD Associations in the region about the project and that we needed young adults who were engaged in their HD community and keen to do more with HDYO.

Participants applied over the course of months and we actually had a really good amount of interest with almost 40 applicants. In the end we took 26 young people to Barranquilla, Colombia. We paid for their travel and accommodation. We set an agenda where we could learn their experiences and then get them thinking about how to improve support for young people in their countries. On the last day we spent 2-3 hours creating the 3-year plans for each country, driven by the young people and the HD Associations. We now have some plans to work together towards. Some goals have been achieved already and others are in the process. Altogether this was a really beneficial event for us to put on and we aim to do more in South America soon.

2018 Camper Feedback

Camp allowed me to feel what I was putting away for a long time. I was able to do this while also being very happy and having fun at the same time. I felt serene and not stressed at all.



It's helped me tremendously emotionally. I felt so lost and alone before camp and now I have so many friends who I can relate to about everything we're going through. We have so many similar experiences I sometimes can't believe it. I loved camp so much and the worst part of it was when it ended.

I loved the experience! Being able to connect with peers so deeply on things I have never felt understood about was such a surreal experience. I felt like I have made some friendships that will continue to grow deeper provide future support for me and from me. Thank you for being so willing to talk and provide information and a listening ear. It was been encouraging and hope building, and I feel like maybe all is not lost and something good might happen in research. I have never felt so understood in all my complexities in my entire life! Thank you from the bottom of my heart, it really makes me feel less isolated. The way you have cared for us all has been incredible.

One of the best and most beneficial decisions I've made in my life. So valuable – hope this can continue for many years to come!

I barely even have the words to describe it. I am forever going to remember this experience and am very grateful that I had the opportunity. It makes me sad that others going through this don't have the same opportunities especially if they live in developing countries.

I really enjoyed being able to listen to other people's story's and know that I'm not the only one going through similar situations. I was also happy that I was able to gain more information about HD and how it works.



USA Youth Service



The United States Youth Service continues to be an evolving project, but one that adds an important level of professional support for young people in the US that was lacking prior to the project's inception. In 2018, we expanded the service to include virtual support (via text, phone, social media and video calls) to ensure that all young people have access to support. This change allowed more young people and families to access the services and obtain much-needed support. We continue to partner with other HD Community groups to ensure that young people impacted by HD know of HDYO, our services and how to obtain support.

The USA database grew from 351 contacts to 603 in 2018, a 58% increase from 2017. This significant increase was due to the addition of the virtual service as-well-as changing our data management approach. This number includes young people, parents and professionals. Contacts range from answering questions that come in via the website on genetic testing, HD 101, caregiving, coping and grieving to on-going support for young people engaging in the genetic testing process to dealing with the loss of a loved one.

In 2018, there were more than 350 direct individual contacts with young people, parents and professionals; over 500 interactions with young people and families at conferences and HD educational events.

Director of Youth Service is also responsible for NA Youth camp.

The last 5 years have been a lot of learning about the project: how to best work with existing services, how to ensure families/clinics/young people know the service exists, how young people are most comfortable accessing the service and how to ensure that as many young people are supported as possible with one youth worker on staff. The use of virtual methods has expanded our reach and our ability to ensure that young people who are more geographically isolated are supported and has allowed us to case a wider net for services. The big area for growth in 2019 is ensuring that all HD care centers and professionals know of the youth service, what our scope of services are and how to refer families. Our goal for 2019 is to ensure that HD Community partners, healthcare practitioners and other support services are aware of the youth service and how to access services.

Youth Service Partnerships

The HDYO youth service continued to partner with several community partners to ensure that young people were able to access peer and professional support along with appropriate education.

Help4HD

The HDYO youth worker attended 2 of the 3 Help4HD H.I.P.E Days as well as their annual symposium to provide youth breakout sessions. HDYO and Help4HD continue to discuss how to best market these sessions and ensure teens and young adults know they can attend and there are sessions specifically for them. Overall, there were 23 young people that attended the three days. The two agencies will continue to look developing this program so that young people have access to high-quality, age-appropriate sessions.

National Youth Alliance (NYA)

The youth worker attended 2 of the 4 NYA youth retreats as well as NYA Day at the HDSA National Convention to provide support. The youth worker and Senior Manager of Advocacy and Youth Programs at HDSA continue to work together to maximize opportunities for young people and ensure that topics are relevant and continuously being updated based on feedback from young people and what they are seeking.

Young People Affected by Huntington's Disease (YPAHD)

The youth worker and Executive Director of HDYO attended the 2018 Huntington's Society of Canada Conference in November 2018. The youth worker was there to provide extra support during YPAHD Day and be available to speak about camp to interested young people and families. YPAHD continues to grow each year with a record 71 young people registered for the day. The young people were excited about camp and families were happy to learn more about the event and how to get their young people engaged. HDYO continues to work closely with YPAHD and HSC to support young people impacted by HD.



Educational Projects

Dealing with a Diagnosis section

This is a new section on our site focused on helping young people who are dealing with a diagnosis of HD. Most of our audience are at risk or not yet symptomatic, but we do have plenty of young people who are experiencing symptoms when they contact us so we aimed this section at that group. It's a difficult topic to face, but we don't shy away from such topics. The process for the creation of this article begun as they always do for the website, we researched the topic and made some pointers on what areas we felt were useful to cover and what order to put that all in. From there we wrote the content following the pointers, then it goes for feedback from the feedback team along with some individuals who have valuable experience on this topic (young people and professionals), it then gets a 2nd draft from us after feedback is all in and then once more out for final feedback before being released on to the site. <https://en.hdyo.org/you/articles/568>

Helping someone with HD

Another new section for the site, this time we looked at providing care tips for young people who provide care for a loved one with HD, which is essentially most young people in HD families. On this project we didn't have the experience to do it justice in the style we wanted (we wanted to provide very specific caregiving tips on what sort of tools and resources are available for people with HD). So we recruited two Occupational Therapists, Michaela Crutsinger and K. M. Knewstep-Watkins, who both work in HD. We had a briefing call with both about what we wanted to achieve and the tone of the project and then they provided a 1st draft for us to review, it then went to our feedback team and from there we eventually had our final version for release. We actually have 3 different versions of this article on the site, one in kids, teens and young adults – all different based on the age group. <https://en.hdyo.org/you/articles/571>

Matt Ellison – matt@hdyo.org



History of HD Website Section

Another new section for the site. We created a history of HD section for children as part of HDYO Land a couple of years ago but we didn't have one for young adults/teens we wanted to change that as we thought that knowing the history of this condition is important for young people. Creating this section wasn't too difficult for us as we had already done the research for HDYO Land previously and just needed to refresh it a little before creating the 1st draft. This went for feedback to young people and professionals, and from there we were good to launch!

<https://en.hdyo.org/you/articles/577>

HDYO Feedback Video

This video was initially created for EHDN's conference in Vienna but is also available on YouTube and our site and we could use it elsewhere in the future. We wanted to create a video in which young people were simply giving their thoughts about HDYO, and we wanted to use this video at our booth at EHDN Vienna. We created an interview plan and we put the word out once again for participants. We ended up with about 20 participants and we filmed using skype as we wanted to do this one on a budget as it wasn't an educational video and this allowed us to interview many more young people globally for a loss in quality which we were happy to do. This was very much an international project and the feedback from participants about HDYO was extremely positive but also very insightful for us and for our supporters.

<https://www.youtube.com/watch?v=QKlaGpXPDHY&t=836s>

Genetics of HD Video

Our next project was a video to explain the genetics of HD. Many people are not completely familiar so we wanted to create this to help. After some discussion we decided to go for an animated video. We then needed to create a script for the video which took some time and plenty of feedback until we were happy. We then recruited a company to do the video and they sent drafts through after we provided feedback on the last version. Eventually we got to where we wanted it to be. A nice simple explanation of what the genetics of HD is.

https://www.youtube.com/watch?v=aRt_G7lXjRQ&t=3s



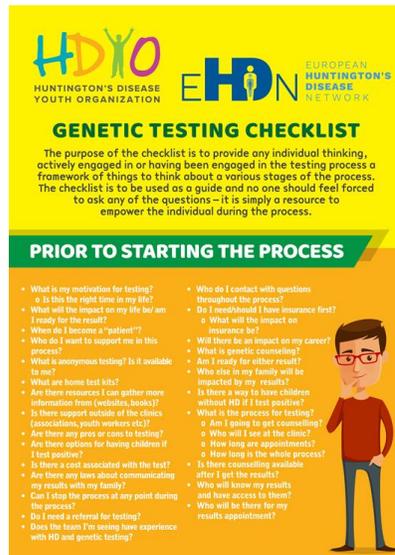
**What impact has
HDYO had on you?**

Educational Resources



Genetic Testing Checklist (page and brochures)

This project was a dual project between HDYO and the Young Adult Working Group (YAWG) at EHDN. Together we wanted to create a checklist for those thinking about testing (to help them consider things they may not have thought about yet). The YAWG created the draft after some time and once we were both happy with the final version that was then added to our site as an article. But we also used this content to create a genetic testing checklist brochure in which we had a company put the design together and then we printed it in English. We then got the file translated by our volunteers and will now be able to print the checklist in several languages. This checklist has been popular among genetic counsellors and HD Associations as having available to hand out to those they come in to contact with. <https://en.hdyo.org/you/articles/570>



Brochure and flyer into new languages

Having our materials available in as many languages as possible is important for us as we want to make people aware of HDYO globally. So we spent some funds on putting our brochures in to some new languages such as Russian and Mandarin. The process to do this is fairly simple; we have the English versions on PDFs and translations, so we then hire a company to produce the new languages versions. Once we have the PDFs we just send them to a printing company to get them done!

If you would like copies of any of our brochures or flyers please email info@hdyo.org and we will happily sending these over to you.



Webinars

In 2018 we wanted HDYO to hold educational webinars for our audience, so we did some research in to the types of webinar systems we could use and which would be best for our purpose. We then created a range of topics and speakers to take part in the webinars. A test webinar was done in September, then our first one which was about HDYO in October and a 2nd on talking to children about HD with **Dr Bonnie Hennig-Trestman**. Our next webinar is lined up for 6th February with Bill Beckett (Genetic Counsellor, Manchester University Hospital) on genetic testing. We intend to keep these going regularly with topics such as:

Upcoming Webinars

- Genetic testing (February 2019)
- Caregiving (March 2019)
- HDYO International Congress Details (May 2019)

Heroes project

This project will launch on 24th January 2019 but all the work has gone in to it in 2018. HDYO Heroes is a brand new youth engagement programme. It will offer young people a chance to take part in various challenges all focused on creating awareness for HD and HDYO, whilst engaging the young person in some fun challenges. When a young person completes a set of challenges they will get a reward and a certificate as a thank you for their efforts. The whole premise here is to try and entice young people to join in, take part, make contact with us and most importantly provide a positive way for them to engage with HD. Heroes will launch at the end of Jan 2019.

To create this project we had to discuss what we wanted to achieve as our overarching goal, then I began working on how to structure the challenges so that it was engaging, achievable and worked across the age groups. It then went through several rounds of feedback, one with a large group of young people who were all very positive about the project, before we then created a consent form for those under 18 to fill in. <https://en.hdyo.org/you/articles/583>



Young Adult Congress Glasgow 2020



In May we announced that HDYO is going to host our 1st International Young Adult HD Congress in Glasgow, May 2020. This is the FIRST ever international event of it's kind for young adults aged 18-35 impacted by HD. The goal of the event is to meet the needs of our young adult audience who are too old to make use of our camps but want something for them. This event will be available for young adults worldwide to attend and we hope to have a scholarship fund available to help get people there. The event itself will take place over 3 days and will be full of educational and support sessions/speeches, whilst being a very fun experience for attendees. We're hoping for 500 young adults to attend this event, which is a lot! We can actually take a maximum of 900 but we would love to see as many young adults from the HD community at this event!

Keep an eye out for updates and start saving to attend!

<https://en.hdyo.org/eve/news/576>



HDYO On The Road

HDYO has spent a lot of time on the road in 2018 and we have racked up a lot of miles!



Conferences:

- Orphan Drugs - April
- Enroll-HD - May
- HDSA National Convention – June
- Factor H Latin American Conference – July
- EHDN Conference – September 2018
- Romanian Association Family Event – September 2018
- Global Genes – October
- Scottish Association Conference – October
- England and Wales Association Conference - October
- Huntington’s Society of Canada – November
- Huntington Study Group - November
- Italian (Rome)

Association Family Conference – December

Training Events

- Police Scotland – February
- Police Scotland – March
- Police Scotland - May
- Vanderbilt Clinic Team – November

Education Days & Events

- New Jersey Chapter Education Day – February
- Help4HD H.I.P.E Day, Riverside, CA – March
- Virginia Commonwealth University Education Day – March
- HD Reach Education Day – April
- Carers Training Course with HAD England &

- Wales - May
- Indiana University Education Day – May
- National Youth Alliance Retreat, Des Moines, IA – May
- Help4HD H.I.P.E Day, San Juan, Puerto Rico – August
- Vanderbilt Education Day – August
- National Youth Alliance Retreat, New Orleans, LA – September
- Help4HD Annual Symposium, Des Moines, IA – October



Spent over \$1.4 million on supporting young people impacted by HD worldwide



Since launching in 2012 HDYO has:

4000 90+



Supported 4,000 young people and families from over 90 countries



Spent \$430,000 on 9 unique youth camps in North and South America Europe and Australasia, bringing 550 young people from HD families to our camps at no cost to them or their families



7,000,000



Created a website (hdyo.org), which has over 7 Million views, and has the best HD educational content for young people impacted by HD, which has been shared over 200,000 times



1,000,000+



Created a vast amount of HD educational videos which have been viewed over 1,000,000 times

If you like the impact we have made and want to support our mission to improve the lives of young people impacted by HD worldwide, then donate to the cause.

Feedback

I am so sorry for this long rant but HDYO is the only place i feel comfortable coming to about this. This is the only place that I can be completely honest about my fear and know I wont be judged. – Young Adult, USA

Thank you so much, Matt! You are magic! I cannot tell you how important the HDYO network has been to me the past several months. Thank you for all your hard work,
Young Adult, USA



You and the organisation you have created are truly amazing.” – Melanie, Young Adult, UK



Brilliant in what you do, inspirational for what you do for these young people my heart goes out to them. – Adult, UK

Amazing to hear these young couples talking openly and sharing their different perspectives on the impact of HD has on their relationships. Great video for anyone or any couple living with the impact of HD. – Huntington’s Victoria (young couples video)

Thank You To Our AMAZING Supporters

Griffin Foundation

Huntington's Society of Canada

Huntington's Association England & Wales

Huntington's Association of Ireland

Deutsche Huntington-Hilfe

HDA Belgium/Franco

Gimbel Family Scholarship

James E "Jake" Hoffman Memorial Fund

Georgetown Huntington's Disease Centre of Excellence

Huntington Study Group

CHDI Foundation

TEVA Pharmaceuticals

WAVE Life Science

Charles River

Garbage Trail Pickers Walk

The Teva logo, featuring the word "teva" in a blue, lowercase sans-serif font with a green leaf-like graphic element above the 'v'.

GRIFFIN
FOUNDATION

The Huntington Society of Canada logo, featuring a stylized blue and green plant icon.

Huntington Society of Canada
HUNTINGTON
Soci t  Huntington du Canada

Adam Liebhoff	Chloe Carr	Felicia Doane	Karen Clark	Melanie Costa	Simone Watt
Alexander Soderlund	Chris Brown	Gail & Bryan Viau	Karen Lenard	Melissa Barnes	Solweig Karlsson
Alexandra Bucci	Christopher Storgards	Ganda Setiakurnia	Kari Hess	Michael & Laurel Schnitman	Sonia Cruz
Alan Rotberg	Clarissa Vandersteen-Trujillo	Gil Lewis	Kari Vinal	Michal Nowicki	Stacey Saladin
Angelique Marie	CM Moore	Gillian Watts	Kendell Harrington	Monica Cazzolli	Stacey Smith
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Catherine Martin	Emma Burris	Jessie Gumbs	Matt Ellison	Savannah Moore	
Chad Sipes	Emma Fickle	Joann Lemasters	Matthew Conlon	Seth Rotberg	
Chandler Swope	Erik Sanches	Jon Krus	Megan Carroll	Shannon Dotson	
Charles Austin	Fan wu	Kaisa Eklumd	Megan Killegass	Shiana Darrow	



Our AWESOME Team Volunteers



Aus/NZ Camp

Monica

Amy

Melanie

Shandelle

Deb

Kimberley

Leanne

Lauren

Lambrina

Malcolm

North American Camp

Lindsay

Lisa

Natalie

Jaclyn

Doug

Erika

Dr Bonnie

Dr Bob

Gwen

Michael

Adam

MaryAnn

Sierra

Jennifer

Corey

Lisa H

South America

Nacho

Laura

Translators

German Team

Michaela

Anne

Clara

Sonja

Clara

Eugen

Julia

Marleen

Janine

Rebecca

Nicole

French Team

Johan

Joel

Portuguese Team

Sandra

Filipa

Romanian Team

Andrea

Ramona

Dutch Team

Dirk

Dr Luces

Elisabeth

Monique

Tijl

Wilma

Sanne

Martjin

Social Media

Megan

Rebecca

Doug

Tasha

Book-keeping

Jessica