



ACTION TOOLKIT

**A GUIDE TO HELP YOU SHARE, ADVOCATE AND
ENGAGE TO MAKE A DIFFERENCE FOR THOSE
AFFECTED BY HUNTINGTON'S DISEASE**



Dear HD advocates,

After the success of *Pope Francis' Special Audience for the HD community in solidarity with South America* on May 18th, our initiative has blossomed into a movement.

Since the conclusion of the event, international media outlets have continued to write news stories and generous contributions have been donated from those who want to help make a difference for the HD community . We must seize this moment and sustain the momentum.

To do so, we need your help in raising awareness around the plight of those affected by HD and their families.

Together, we can achieve more for the HD community. We updated this toolkit to help you continue to spread the word in your own communities.

The materials below are starting points and can be adapted to suit your needs, so be sure to make them your own.

This kit includes:

1. Simple **key messages** to reference when speaking or writing about the issue and the legacy of the event. Use these to keep the conversation fresh.
2. Sample **letters/e-mails** for your local government, community and religious leaders, as well as other relevant community organizations
3. **Media tips** to help you effectively educate local press and share stories from families in your association
4. Supporting **content** to bring your message to life, including an HD fact sheet, infographics, videos and photos
5. Sample **social media posts**

Together, we made Huntington's Disease Hidden No More! Now, the next chapter of our work begins.

- The HDdenommore team

Find us on...



HDdenmore.com



@HDdenmore



/HDdenmore



HDdenmore Channel

1. KEY MESSAGES

The following messages include key information about HD and the HDdenmore initiative. They are designed to help you communicate consistently and effectively when writing or speaking about the issue and the lasting impact of Pope Francis' Special Audience .

These messages are not intended to be exhaustive; rather, they should be used to supplement your or your organization's existing work.

KEY MESSAGES

- 1. Huntington Disease (HD) is an incurable genetic brain disorder affecting nearly one million people globally. It is among the most common hereditary brain disorders, yet few people know about it and no cure exists.**
 - HD causes the progressive breakdown of nerve cells in the brain, deteriorating a person's physical and mental abilities.
 - It begins with personality changes and progresses to loss of body function, eventually robbing the person of the ability to talk, walk, swallow, think and reason.
 - The Huntingtin gene was identified nearly 25 years ago thanks to the participation of families in the region of Lake Maracaibo in Venezuela.
 - Despite two decades since the discovery of the gene, HD has no cure, nor are there treatments to slow the progression of the disease.

- 2. Stigma around HD has forced those affected by the disease to hide in shame for generations, hindering the availability of services to improve their daily lives.**
 - People with symptomatic HD have uncontrolled, irregular, rapid, jerky movements called chorea, cognitive challenges such as loss of speed and flexibility in thinking and memory loss, and psychiatric disorders including depression and anxiety.
 - These symptoms have forced families affected by HD to hide in shame for fear of public criticism, discrimination and unfair treatment. They feel alone, marginalized and rejected.

- 3. A global coalition of patient advocates has initiated a campaign called HDdenomore (Oculita Nunca Mas' in Spanish or 'Mai Piu Nascosta' in Italian) to raise awareness of HD and end the stigma and shame around the disease that has persisted for generations.**
 - What began as a request for a one-on-one meeting between an HD patient and Pope Francis. This soon blossomed into a special papal audience at which more than 150 HD patients and their families were received and 1,500 supporters participated.
 - In addition to the audience with His Holiness, the HDdenomore initiative included a series of events in Rome to shine an even brighter light on HD and create an enduring legacy for HD community.
 - Physicians from Latin America met with physicians from Gemelli University Hospital, Rome to exchange experiences in treating HD patients and to form a lasting network of exchange to improve the care and treatment of those affected by HD around the world.
 - After the event's conclusion, the Initiative shifted its focus towards ensuring that HD remains out in the open and that those affected are not neglected by the global community again.

- 4. The HDdenomore initiative will continue by building on the momentum the event generated in order to remove the stigma from Huntington's disease and empower those living in its grip. In the days ahead, we will work with the global HD community to shape the future of the initiative.**
 - Keeping Huntington's disease hidden is severely detrimental to the health, hope and dignity of people affected by the disease.

- Action is needed at all levels – from advocates to governments to researchers and community organizations including religious organizations – to improve the lives of HD patients and their families.
- By working together, we can raise awareness, increase understanding and mobilize action to ensure that HD is Hidden No More.

5. Visit hddenomore.com to learn more about the impact of the event, see original multimedia content and find opportunities to get involved.

2. SAMPLE LETTERS/EMAILS

These letters/emails can be distributed to local government representatives, religious leaders and other local organizations to bring attention to Huntington's disease and the plight of those affected.

We encourage you to customize the letter with local information – or information about your organization's efforts – to make it most relevant to the community leaders to whom you are contacting.

LETTER TO LOCAL GOVERNMENT AND COMMUNITY REPRESENTATIVES (SOUTH AMERICA FOCUS)

“People often say that, as a mother, there’s nothing more heartbreaking than hearing that your child is sick. Dilia knows this tragedy all too well: four of her children and one grandchild have already passed away from HD, four more are living with HD and several grandchildren have started showing symptoms.” Watch her story [here](#).

Dear [INSERT NAME],

On May 18, 2017, Pope Francis recognized Huntington’s Disease – the first of any global leader to do so – and brought those affected out of the shadows.

This inspirational moment not only put a spotlight on HD, it also started a global movement that will continue beyond the event in order to reduce stigma around the disease and empower those who live in its grip.

Huntington’s disease impacts the lives of hundreds of thousands of people globally. In regions of South America – specifically parts of Venezuela and Colombia – the prevalence of HD is up to 1000 times higher than the rest of the world, making the local impact substantial.

HD is a neurodegenerative disease that begins with personality changes and progresses to loss of body function, eventually robbing the person of the ability to talk, walk, swallow, think and reason. Its symptoms have forced those affected to hide the disease for fear of public criticism, discrimination and unfair treatment. Currently, there is no cure and only limited options exist for managing symptoms. The disease continues unabated globally.

[INSERT INFORMATION ABOUT LOCAL IMPACT OF HD IF AVAILABLE OR STORY OF LOCAL PERSON OR FAMILY AFFECTED BY HD].

Your help is critical to improve the lives of those affected by HD in our community. How can you help?

- Help provide much needed resources for increased access to basic needs and medical support to ensure Huntington’s disease patients have the highest quality of life possible
- Let your constituents or members know about Huntington’s disease in our area (insert specifics) and about why people with this disease need support
- Utilize social media (or other methods available to you) to share important information about HD and the plight of families living with the condition (you may find content for sharing on our website and social channels listed below)

Every action counts. We hope that you will join us to reverse the stigma and improve the lives of people affected by HD.

Thank you in advance for your support. Huntington’s Disease is Hidden No More!

Best Regards,
[INSERT NAME]

HDdenmore.com | Facebook: /Hddenmore | Twitter: @hddenmore | YouTube: HDdenmore channel

LETTER TO LOCAL GOVERNMENT AND COMMUNITY REPRESENTATIVES (GENERAL COMMUNITY FOCUS)

Dear [INSERT NAME],

On May 18, 2017, Pope Francis recognized Huntington's Disease – the first of any global leader to do so – and brought those affected out of the shadows.

This inspirational moment not only put a spotlight on HD, it also started a global movement that will continue beyond the event in order to destigmatize the disease and empower those affected.

Huntington's disease impacts the lives of hundreds of thousands of people around the world. Currently, there is no cure for this fatal genetic disorder.

HD is a neurodegenerative disease that begins with personality changes and progresses to loss of body function, eventually robbing the person of the ability to talk, walk, swallow, think and reason. Its symptoms have forced those affected to hide the disease for fear of public criticism, discrimination and unfair treatment.

[INSERT INFORMATION ABOUT LOCAL IMPACT OF HD IF AVAILABLE OR STORY OF LOCAL PERSON OR FAMILY AFFECTED BY HD].

There are no treatments to slow the progression of the disease and only limited options exist for managing symptoms. The disease continues unabated globally.

Your help is critical to improve the lives of those affected by HD in our community. How can you help?

- Help provide much needed resources for increased access to basic needs and medical support to ensure Huntington's disease patients have the highest quality of life possible
- Let your constituents or elected officials know about Huntington's disease in our area [insert specific] and about why people with this disease need support
- Utilize social media (or other methods available to you) to share important information about HD and the plight of families living with the condition (you may find content for sharing on our website and social channels listed below)

Every action counts. We hope that you will join me to reverse the stigma and improve the lives of people affected by HD.

Thank you in advance for your support. It's time for Huntington's Disease to be Hidden No More!

Best Regards,
[INSERT NAME]

HDdenmore.com | Facebook: /Hddenmore | Twitter: @hddenmore | YouTube:
HDdenmore channel

LETTER TO RELIGIOUS LEADERS

Dear [INSERT NAME],

On May 18, 2017, Pope Francis recognized Huntington's Disease – the first of any global leader to do so – and brought those affected out of the shadows.

This inspirational moment not only put a spotlight on HD, it also started a global movement that will continue beyond the event in order to destigmatize the disease and empower those affected.

Huntington's disease impacts the lives of hundreds of thousands of people around the world. Currently, there is no cure for this fatal genetic disorder.

HD is a neurodegenerative disease that begins with personality changes and progresses to loss of body function, eventually robbing the person of the ability to talk, walk, swallow, think and reason. Its symptoms have forced those affected to hide the disease for fear of public criticism, discrimination and unfair treatment.

[INSERT INFORMATION ABOUT LOCAL IMPACT OF HD IF AVAILABLE OR STORY OF LOCAL PERSON OR FAMILY AFFECTED BY HD]

There are no treatments to slow the progression of the disease and limited options exist for managing symptoms. The disease continues unabated globally.

Your help is critical to improve the lives of those affected by HD in our community. While Pope Francis' support showed the world that HD patients deserved to be 'hidden no more,' more action is needed. How can you help?

- Let members of your congregation know about the event and what it achieved
- Speak to your congregation about the importance of accepting others and the need to end stigma around HD
- Ensure that the resources of Catholic organizations already deployed on the ground in most affected regions and respond to the needs of these families by providing access to basic healthcare services and essential medicines
- Advocate for the basic right of access to healthcare with the national and local governments, in solidarity with these families
- Help educate and train local community leaders about HD so these families are less stigmatized and the community becomes supportive.

Every action counts. We hope that you will join me to reverse the stigma and improve the lives of people affected by HD.

Thank you in advance for your support. It's time for Huntington's Disease to be Hidden No More!

Best Regards,
[INSERT NAME]

Hddenomore.com | Facebook: /Hddenomore | Twitter: @hddenomore | YouTube: HDddenomore channel

3. MEDIA ALERT AND TIPS

Local media can be a helpful tool for educating the community about HD. Use the media tips included below to connect with your local newspapers, television and radio stations.

IMPORTANT: Should you receive any media inquiries as a result of your outreach, please forward those inquiries to HDdenmoremedia@gmail.com immediately. We encourage you not to answer any media questions directly. Our media team will be responsible for answering media questions and arranging any interview request.

MEDIA TIPS

- **Make it easy.** It is best to reach out to local media via email. Your email should include a short 2-3 sentence introductory note explaining why you are reaching out to them, as well as the media alert (pg. 11) copied and pasted within the body of the email (not attached).
- **Target your pitch.** Look for a journalist who has previously covered Huntington's disease or health in general as they are more likely to be interested in the story. You can do so by searching relevant key terms on the media outlets website. If you are not able to find their email address, visit their website for a general editorial email address, or contact their editorial desk via phone.
- **Find a local angle.** Are you part of a local HD or HD-related organization? Are you personally affected by HD or know someone who is? Include this information in your outreach to your local media. A few ways to do so are included below:
 - Change headline of media alert. For example:
 - Local HD organization goes to the Vatican on May 18 to join what is expected to be the world's largest gathering of the HD community
 - Make your role clear in your introductory email. For example:
 - "My name is Emma Smith and I am the Director of the HD group in Toronto and I am writing to make you are of..."
 - Integrate local stats in your media pitch. For example:
 - "There are more than 100 families in our community that are affected by HD"
 - Include your experience or family's experience
 - Use personal or family photos, creative writing content or other impactful forms of communication to highlight the impact of HD on your life
- **Make the story visual and provide extras.** Help them enhance the story by providing helpful links as well as photos, videos, graphics and fact sheets. You can direct them to the following locations for this information:
 - Hddenomore.com
 - [Facebook.com/ HDddenomore](https://www.facebook.com/HDddenomore)
 - [Twitter.com/HDddenomore](https://twitter.com/HDddenomore)
 - YouTube: HDddenomore channel
 - [Electronic Press Kit \(EPK\)](#)
 - Your own photos, videos or other extras

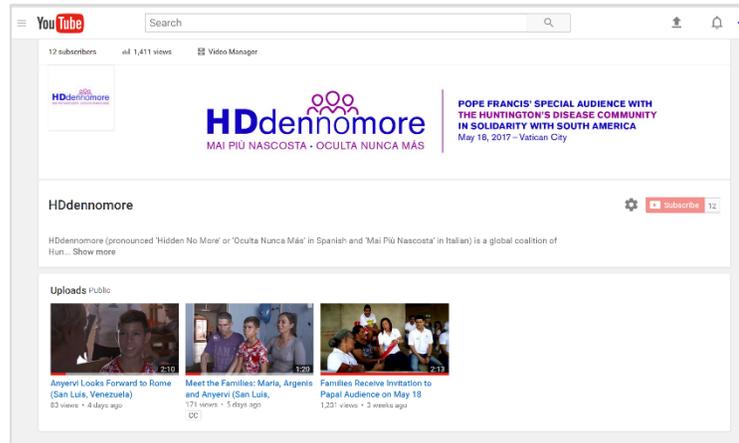
1. CONTENT

Photos, videos and graphics for you to share as part of our outreach to local community leaders, media or within your own social channels

IMPORTANT: We will be providing new content via our website and social channels, so please stay tuned to these platforms.

VIDEOS

You can find all our videos on our [HDdenmore YouTube Channel](#), including several videos detailing the journey of the 5 South American families affected by HD who made the journey to Rome on May 18.



GRAPHICS

You can view or share directly any of our HD graphics via our website. You can also save each graphic to attach in an email by right clicking on the graphic and select 'save image as,,.'



HD FACT SHEET

Learn the facts and pass them on. Use this simple tool to educate your friends, family and community on HD.

- [English](#)
- [Español](#)
- [Italiano](#)



2. SOCIAL POSTS

Suggested Facebook posts, tweets and more to help you get the word out

Remember to always use the hashtag #HDdenmore in every social post related to this initiative so that others may track the conversation.

KEY POINTS TO SHARE ABOUT	SUGGESTED POSTS	MEDIA
Meet affected families	Meet the #HD families from South America who traveled to meet with Pope Francis on May 18 #HDdenmore http://bit.ly/2osGIUb	Multiple videos available on the HDdenmore YouTube Channel
HD Awareness	Learn the facts. Pass them on. Help shine a light on Huntington's disease #HDdenmore	HD fact sheet or infographics available on HDdenmore.com
Visit our website	Visit the #HDdenmore website for the latest updates on the movement and more! http://bit.ly/2ozMCXC	HDdenmore.com