

HDSA National Youth Alliance (NYA)

Membership Application

Please fill out the below application and submit it via email or snail-mail it to:
 Huntington's Disease Society of America [HDSA]
 505 Eighth Avenue, Suite 902
 New York, NY 10018
 Attention: Mynelly Perez
 Email Address: mperez@hdsa.org

Required Information - Pages 1 and 2					Today's Date:		
Name:							
Nickname:		<i>[only if this is the name you go by]</i>					
Street Address:							
City:					State:		Zip:
Home Phone:	Area Code []	-	Cell:	Area Code []	-		
Current Age:		Birth date:	Month:	Day:	Year:		
How do you want to receive HDSA notices on NYA activities:			Email		Mail		Both
Email Address:	@						
Alternate Email	@						
Personal Website:	<i>[only if you want to share]</i>						
IM's You Want To Share:							
In Case of An Emergency		Provide the person or physician to be contacted in an emergency.					
Name:							
Relationship to you:							
Street Address if different from above:							
City:					State:		Zip:
Home Phone:	Area Code []	-	Cell:	Area Code []	-		
Email Address:	@						
Tell Us About Your Membership in a HDSA Chapter or HD Support Group							
Do you currently belong to an HDSA Chapter? [] Yes [] No							
If yes, what is the name of the Chapter?							
If no, do you belong to a HD Support Group? [] Yes [] No							
If yes, what is the name of the Support Group?							
Do they have special sessions for youth? [] Yes [] No							
If no, would you attend if they started one? [] Yes [] No							
Your Previous Attendance At An HDSA National Convention							
The only time the members of NYA are able to get together <i>in person</i> is during the Huntington's Disease Society of America (HDSA) annual HD convention. The HDSA plans special convention activities and sessions to meet the needs of the NYA and all young people living with HD. Please help us by answering the following questions:							

Have you attended an HDSA convention in the past?		<input type="checkbox"/> Yes <input type="checkbox"/> No	
If yes, did you attend any sessions designed for young adults?		<input type="checkbox"/> Yes <input type="checkbox"/> No	
Please add any comments about your convention experience you'd like to share:			
Do you have any suggestions for sessions specifically for children and/or young adults that you would like to see at future HDSA national conventions? Please share them here:			
Do you plan on attending the next HDSA convention?			<input type="checkbox"/> Yes <input type="checkbox"/> No
If yes, will you be applying for the NYA Convention scholarship?			<input type="checkbox"/> Yes <input type="checkbox"/> No
Does your HDSA Chapter or HD Support Group offer a scholarship?			<input type="checkbox"/> Yes <input type="checkbox"/> No
Your Support to the NYA			
Please write your thoughts on what you feel the NYA's primary goal(s) or purpose should be:			
If asked, how do you feel you could best support the NYA:			
Fund Raising:	<input type="checkbox"/> Yes <input type="checkbox"/> No	Letter Writing:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Emotional Support:	<input type="checkbox"/> Yes <input type="checkbox"/> No	Silent Auction Items:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Media Attention:	<input type="checkbox"/> Yes <input type="checkbox"/> No	Education/Awareness:	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other:			
Level of support you can provide: [time]			
Best time to contact you <i>[please indicate EST, CST, MST, etc.]</i> :		<input type="checkbox"/> AM	<input type="checkbox"/> PM
If you have any questions about the NYA please ask them here:			

The following pages contain Optional questions only and your responses are not required to become a member of the HDSA National Youth Alliance.

HDSA NYA-Youth Survey – *Optional Information*

The below information **will not** be shared or made available to anyone outside of the HDSA. Your responses to this survey will only be used to help the HDSA develop specific programs or educational material for young people living with HD. Any material developed will be used both for a HDSA National Convention and/or to help the HDSA Chapters in setting up support groups or educational programs for young people ages 9 to 29 living with HD.

Names are **not** necessary on this survey. Thank you for your help and support!

Information About You

	Yes	√	No	√
Are you at-risk for Huntington's Disease?				
If no, have you tested negative?				
If no, have you tested positive?				
If yes, are you symptomatic?				
I am not at-risk but have a relative or friend with HD				

Information About Your Parents & HD

Have your parents been open about discussing HD with you?	Yes		No	
If no, please briefly describe how has this made you feel?				
If no, where have you gone to find answers to any questions you've had about HD?				
If you could, what questions would you ask your parent about HD?				
What is the #1 thing about HD that you are most afraid to discuss with a parent and why?				

Information About Siblings

Do you any have brothers or sisters living at home?	Yes		No	
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Are they at-risk for inheriting HD?				
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Has any sibling tested HD positive?				
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If yes, please describe how this has affected you, your relationship with your sibling, your parents and school?

Information on How HD May Affect Your Daily Life

What issues do you deal with every day that are the hardest on you?

Has living with HD affected your education?	Yes		No	
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If yes, please describe how: [absenteeism, lack of concentration, missed school days, failing, dropping out, delayed college, etc.]

Has living with HD affected your long-term friendships?	Yes		No	
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If yes, please describe how those changes have affected you:

Has living with HD affected your peer relationships [at school or work]	Yes		No	
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If yes, please describe how those changes have affected you:

Financially, how has living with HD affected you, personally?
[No or little allowance, can't attend college, clothing, school supplies, vacations, etc.]

Information on Providing Care to Someone With HD

Do you help with the daily care of a parent or sibling with HD?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
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If yes, describe what type of things do you do to help:

Do you feel having to help with these things is fair?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
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How does helping with this care affect you personally, socially or financially?

Information on Abuse, Anger or Violence

Has there been any violence or abuse in your home directed at you or other family members that you've been afraid to talk about?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
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Have you've tried to talk to other family members or school counselors about this? If yes, how have they been helpful?

What advice would you give to other young people living in a volatile HD family home?

Do you feel any resentment or anger having to live in a HD home?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
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If yes, please describe how have you handled this anger. What has worked best for you, what hasn't?

Is there anything else you would like to share to help people understand what it is like for a young person living with HD in their life?

If you had one chance to talk to a scientist doing research on HD, what would you like to say to them?

Permission to contact you if:

Do you want to be contacted if a HD Youth Support Group is started near you?	Yes		No	
Do you want to be contacted by other NYA members or young people from your state who are near your age?				

Only if you answered yes to either question, please complete the following:

Your Name or Parent Contact:				
Street Address:				
City:		State:		Zip:
Phone:		Email:		

Thank you!

Please submit your survey responses via email or snail-mail it to:

Huntington's Disease Society of America [HDSA]
505 Eighth Avenue, Suite 902
New York, NY 10018
Attention: Mynelly Perez
Email Address: mperez@hdsa.org