



Presented By
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AGENDA

- Where it all began
- Who We Are
- What We Do
- How to get Involved





WHERE IT ALL BEGAN



- The inspiration behind the NYA sprouted in 2000, at the 15th Annual HDSA National Convention in Orlando, FL.
- After being presented to HDSA the following year in 2001, the National Youth Alliance was born.
- In 2003, the NYA held our very first NYA Day and Silent Auction in Houston, TX. This was the same year in which the NYA Scholarship Fund began.
- The first NYA Talent Show was held in 2004 in St. Louis, MO.



WHO WE ARE



- The NYA, is a group of children, teens and young adults who are impacted by HD & JHD
- Members are ages 9-29
- Members are from all over the United States
- We are volunteers, dedicated to the vision of becoming the last generation with HD & JHD!



WHAT WE DO

- We provide support to the children, teens and young adults of HDSA
- We come together each year for NYA Day & Convention
- We fundraise to provide members with scholarship opportunities to attend convention
- We have become an integral part of HDSA's Chapters and Affiliates in fundraising, advocacy, and education





HOW TO GET INVOLVED

- Becoming a member is the first step!
 - www.hdsa.com/nya
- Get involved locally in HDSA's Chapters & Affiliates
- Join an NYA Committee
- Become a part of the NYA Board
- Attend Convention (we've got scholarships!)





GETTING INVOLVED LOCALLY

- Become involved in your local Support Group, Chapter or Affiliate
 - Take part in Team Hope Walks, Hoop-a-thons, Bake Sales, and Car Washes
 - Ask leadership to help the NYA by donating a portion of the proceeds to the NYA Scholarship Fund
 - Help to engage other young people and get them involved with the NYA



NYA COMMITTEES

- Advocacy Committee
- Fundraising Committee
- Research Committee
- Youth Services & Recruitment Committee
- Communications Committee
- NYA Day & Convention Committee



NYA ADVOCACY COMMITTEE

- The NYA Advocacy Committee works closely with HDSA's Advocacy efforts for the HD Parity Act H.R. 842 & S. 968
- Work with HDSA's Advocacy Team, Jennifer Simpson and Jason Gromley
- Bi-monthly conference calls within the committee (1 hour per call x 6 calls per year= 6 hours)





NYA FUNDRAISING COMMITTEE

- The Committee will oversee all fundraising efforts on behalf of the NYA and will lead community outreach efforts for NYA donations
- Will engage the NYA member population to motivate them to become more involved in fundraising efforts by the NYA
- Bi-monthly conference calls within the committee (1 hour per call x 6 calls per year= 6 hours)





NYA RESEARCH COMMITTEE

- Works alongside HDSA research initiatives and assists in the promotion of trials and studies that NYA members are able to partake in
- Committee members will receive training as Research Champions through HDSA's George Yohrling, PhD
- Will have quarterly updates conference calls within the committee (1 hour per call X 4 calls per year= 4 hours)





NYA YOUTH SERVICES AND RECRUITMENT COMMITTEE

- Responsible for overseeing support services for youth's impacted by HD/JHD nationally and assisting in HDSA Chapters/Affiliates and their support groups to further and continue support efforts for young people.
- Manage NYA Representatives and ensuring that they are functioning effectively and working towards established goals, such as providing an optimum level of support through information and referrals to appropriate resources in their local HD communities.
- Recruitment shall work to support current volunteers in their efforts and cultivate new relationships with active participants in events and expanding the NYA family and membership.
- Bi-monthly conference calls within the committee (1 hour per call x 6 calls per year= 6 hours)



NYA COMMUNICATIONS COMMITTEE

- The committee is responsible for ensuring the development and maintenance of social media accounts: Facebook, Twitter, Pinterest, and Instagram
- As well as established programs: Faces of NYA and the We Are the NYA Newsletter
- The committee must communicate NYA's mission and must consistently create announcements for the NYA's Fundraising, Advocacy, Research, YS & R, NYA Day & Convention Committee's efforts
- Bi-monthly conference calls within the committee (1 hour per call x 6 calls per year= 6 hours)





NYA DAY AND CONVENTION COMMITTEE

- The NYA Convention Committee is lead by the NYA Chairperson. The NYA Convention Committee oversees the planning of NYA Day, the NYA Night activity, NYA/Youth Sessions, NYA Table Auction/Raffle and the Talent Show at the HDSA National Convention.
- The Committee shall work in relationship with the Communications Committee to help promote activities and services available during NYA Day and Convention.
- Committee publishes the agenda, and works alongside HDSA National and the Convention Planning Committee to provide the best NYA/Youth program possible.
- Focused from January to July
- Monthly conference calls within the committee during convention planning season (1 hours per call x 7 calls per year= 7 hours)



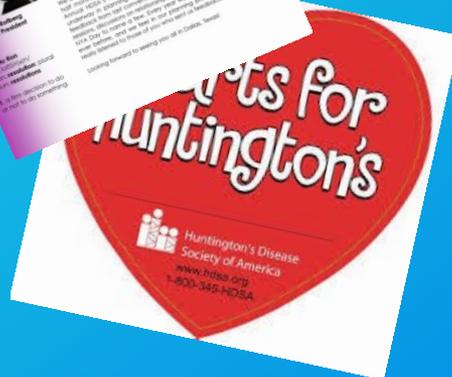
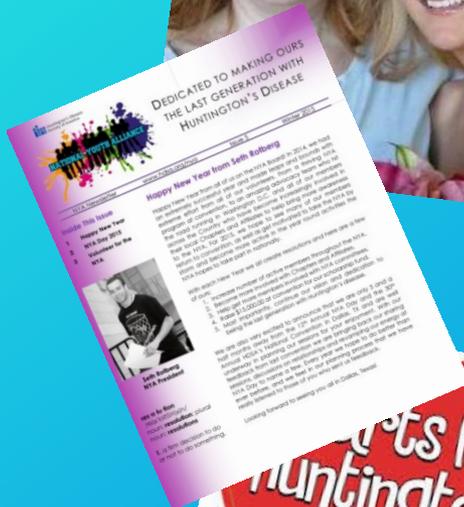
BECOME A BOARD MEMBER

- The NYA Board is made up by the NYA Committee Chairs.
- The Committee Chairs report to the NYA Board Chair and to one another year round once per month via conference calls for a minimum of one hour each call.
- This allows for Committee Chairs to come together, update one another, share ideas and continue our efforts in working together as a team of volunteers.
- The NYA works together as a collective whole, and without cooperation from each member we are not able to maintain the goals we have set through the NYA Strategic Plan for 2016-2018.



WHAT ELSE CAN YOU DO?

- Becoming an active member is simple.
 - What do you like to do?
 - How do you see yourself getting involved?
- Become an important part of your HDSA Chapter or Affiliate and speak up for the NYA at their events.
- Do you think you would be good at fundraising, why not set up a Hearts for Huntington's event at your school?



There is something for everyone here in the NYA!



ANY QUESTIONS?

Contact the NYA:

www.hdsa.org/nya

nyaboard@gmail.com