



# HDSA National Update

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By: Melissa Worthington  
HDSA Great Lakes Regional Director





# National Overview

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- **Who I am**
- **Overview of the Organization**
  - Staff and New CEO
  - Mission
  - 501c3 Status
- **Regional Structure**
- **Working Chapter Relationship**
  - Reporting Structure
  - Cohesive Fundraising Efforts
- **My Role**
  - Other Regional Staff



# Great Lakes Region

## Staff Breakdown



Regional Development Coordinator



## Chapter/Affiliate Breakdown

### •Central Ohio Chapter



### •Indiana Chapter



### •Kentucky Chapter



### •Northeast Ohio Chapter



### •St. Louis Chapter



### •Michigan Chapter



### •Ohio Valley Chapter



### •Wisconsin Chapter



### Budget Projections 07/08FY

Revenue	\$801,582
Expense	\$655,355
Net	\$146,227

### Number of Centers





# National Convention



- **2009 Convention**
  - Phoenix, Arizona
  - June 5<sup>th</sup> – 7<sup>th</sup>
  - 750 Attendees
  - Highest Attended Convention to Date
  - Presentations can be found at [www.hdsa.org](http://www.hdsa.org) for review and download
- **2010 Convention**
  - Raleigh, North Carolina
  - June 25<sup>th</sup> – 27<sup>th</sup>
  - 3<sup>rd</sup> Annual NYA Day



# National Youth Alliance



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- **History and Overview**
  - **Mission**
  - **NYA Board**
  - **NYA at Convention**
    - Scholarship
    - NYA Day
    - Scholarship
    - NYA Auction
  - **NYA Presence**
  - **NYA Advisors**



# National Youth Alliance



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## National Youth Alliance Board

### **President**

Cathy Harrel Colyer  
[cat4acure4hd@yahoo.com](mailto:cat4acure4hd@yahoo.com)

### **Vice President**

Katie Moser  
[katharine\\_moser@hotmail.com](mailto:katharine_moser@hotmail.com)

### **Secretary-**

Melinda Wagner  
[melinda8181@hotmail.com](mailto:melinda8181@hotmail.com)

### **CFO-**

### **Silent Auction Chair**

Staci Nicholas  
[spacystace9@yahoo.com](mailto:spacystace9@yahoo.com)

### **Fundraising Chair**

Mindy Maher  
[curehd2006@aol.com](mailto:curehd2006@aol.com)

### **Talent Show Chair**

Scott Nicholas  
[hilikus\\_2005@yahoo.com](mailto:hilikus_2005@yahoo.com)

### **NYA Volunteer Social Workers**

Leo Rafail, BSW  
Social Worker  
Email: [Info@iuhdclinic.org](mailto:Info@iuhdclinic.org) or  
[info@hdsaindiana.org](mailto:info@hdsaindiana.org)



# National Youth Alliance



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## National Youth Alliance Advisors/Contacts

### Bill Marsch

Email: [wrmarsch@earthlink.net](mailto:wrmarsch@earthlink.net)

Phone: 732-821-5522 Ext. 35

### Mynelly Perez

Email: [mperez@hdsa.org](mailto:mperez@hdsa.org)

Phone: 1-800-345-4372 Extension 214



# Juvenile HD

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- Percentages
- Symptoms and Onset Variances
- Testing Considerations
  - Age
  - Symptoms
  - Specialists and COHs
  - Other Underlying Conditions
  - Testing Non-Symptomatic Children
- Care After a Positive Diagnosis
- Family Assistance
  - SSI
  - Medicaid
  - Schools
  - In home Care



# Advocacy

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- Sign up online at [www.hdsa.org](http://www.hdsa.org)
- HR 678 Huntington's Disease Parity Act
  - All tools are online to get involved
  - Sign the petition
- Facebook and MySpace
- GINA
  - What it is
  - Effective Dates



# Getting Involved



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- **Plan a Fundraiser**
    - Team Hope Walks
    - Firstgiving
  - **Serve on a Local Board or Committee**
  - **Sign up to be an Advocate**
  - **Sign up to be an Event Volunteer**
  - **Register to be a Speaker with the Chapter**
  - **Sign Up for a Study**
  - **Matching Funds**
  - **Family Funds**
  - **Planned Giving**
  - **Tributes and Memorials**
  - **Shop at HDSA Affiliates**
  - **Vehicle Donations**
  - **Grass Roots Initiatives**
    - Toner
    - Cell Phones
    - Hearts for HD



**A National Walk Campaign**



## Campaign Description

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Team Hope Walk for HD is the Huntington's Disease Society of America (HDSA) signature fundraising campaign designed to provide hope and support for those touched by this devastating disease. Team Hope is a way for the HD community to mobilize and show the nation how a team of inspired individuals can unite to make a difference. Funds raised support the mission of HDSA. More than a fundraiser, it is a time for the entire HD community to join together in a day of camaraderie, inspiration and above all, hope.



## Team Hope Benefits

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- Allows for vision achievement
- Mobilizes HD Community to get involved
- National identifier
- Cost effective purchasing power: T-shirts, brochures, posters, incentives
- Allows for strategic and planned growth
- Diversified revenue stream: Teams, Partners, Top FR
- Engage volunteers for committees and day of event
- Increased community awareness



## What can you do?

- **Start a Walk** – Team Hope has all the tools to help you start a walk in your area. Simply contact Cindy Messerle – National Walk Director at 1-877- WALK-4-HD (1-877-925-5443) or [cmesserle@hdsa.org](mailto:cmesserle@hdsa.org).
- **Volunteer** – HDSA and Team Hope need you! As part of the planning committee and/or a day of event volunteer – your help is invaluable!
- **Become a Team Captain** – A team is 4 or more people who collectively raise funds in support of the same team. An average team is 10 people and raises \$1000!
- **Walk for HD** – register for your local walk today and begin fundraising. Challenge yourself with a fundraising goal! Online registration and fundraising are available.
- **Questions???** Contact Cindy Messerle 1-877-WALK-4-HD; [cmesserle@hdsa.org](mailto:cmesserle@hdsa.org)



# Getting Involved



- **Support Regional Events**
  - **Great Lakes Gala**
    - Annual Event in September
    - 9-11-09, 4<sup>th</sup> Year
    - Honorees
    - Format
    - \$20K Gross
    - How you can help
  - **Logrolling Event**
    - Shana Martin
      - [Shana@shanamartin.com](mailto:Shana@shanamartin.com)
    - Annual Event in June
    - How you can help



# Conclusion

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- Questions
- Contact
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