

Dear HDSA Leaders

As the fall chill hits the air, we begin our new fiscal year and prepare for our annual Guthrie Dinner, I would like to report on the array of successful activities that took place in late August and September. I thank you all for making these events so successful.

Celebration of Hope Dinners made headlines around the country. Over 200 people attended the inaugural Illinois Celebration of Hope Dinner in downtown Chicago on September 8th, whose honorees included Dr. Morimoto of the Rush Center of Excellence, Clarence and Sharon Wiese and Alan Thicke. The LA Celebration of Hope Dinner was a smashing success, netting over \$35,000 to support the newly-dedicated Center at UCLA. Over 320 people attended the star-studded gala hosted by Craig Ferguson of the Late Late Show, which featured a performance by Anita Pointer. The producer and cast of “Everwood,” who have done a great deal to bring HD to the general public through their story line, were among several distinguished honorees including Louis J. Horvitz 4-time Emmy award winning producer/director; Victor Doolan, past president of Volvo Cards and BMW North America; and Dana Reeve, who received the HDSA John Ritter Humanitarian Leadership Award. Ms. Reeve will accept the award at the Guthrie Dinner in New York.

Over 500 people attended the Denver Celebration of Hope Gala on August 17. More than \$50,000 was raised to support the HDSA Center of Excellence at the Colorado Neurological Institute. Honorees included Leslie Nielsen, Shelly and Walt DeHaven, Faye Tate, and DC Veio. Rita Coolidge entertained the crowd. A video featuring the Krivanek family was produced by CBS for the occasion.

On September 10, despite the devastation of Hurricane Katrina and Rita, and the migration of 225,000 citizens of New Orleans, HDSA’s Texas Affiliate held their fourth annual Walk for Hope, chaired by local anchor Lisa Faronda. Participants were asked to bring non-perishable food items, baby goods, cleaning supplies or first aid kits – and the event was able to net approximately \$30,000 – and a ton of good will and promises from people to make next year’s walk bigger and better than ever. The Houston Celebration of Hope Dinner has been rescheduled for February 9, and I have no doubt it will be a great success.

HDSA mobilized to help our families in the wake of Hurricane Katrina in several ways. Contact was made with all of the major relief agencies to make them aware of the services offered at the Centers of Excellence; Chapter officers were asked to contact their local relocation facilities to confirm that they were aware of resources for any displaced person with HD, and their family; and HDSA acted as an intermediary to put several people with HD into contact with alternative doctors and facilities.

HDSA scored big on the fairways last month as well. The HDSA Celebrity Golf Classic sponsored by Intralinks (thank you Diane Carlson) raised over \$23,000 at the Trump Golf Center in Westchester New York. On September 16, the Annual Fiore Golf Tournament

was held in Illinois. The Fiores came through once again, accounting for \$100,000+ in donations.

Northern California's 4th Annual HDSA Golf Classic held September 21, raised over \$35,000 for research, with additional donations still coming in. Lob wedges imprinted with the HDSA logo were among the prizes.

Congratulations to the NE Ohio Chapter for the event they held at Stan Hywet Manor Hall (home of the Goodyear founders). More than 160 guests attended the most successful event in the Chapter's history, raising \$33,000 for HDSA.

On August 7th, the South Florida Chapter led by Debbie Gomberg took to the land and sea on behalf of our families, with their 14th annual Triathlon. Over 650 hearty souls, swam, biked and ran to raise over \$100,000 to support our research initiatives.

Our Central Florida Affiliate held its first walkathon in Jacksonville last month, and the Long Island Affiliate held their annual event on September 25, with over 140 participants.

September brought a "Run to Rid HD" Walk/Run to Minnesota, which was a resounding success, with a record number of donations collected. This was followed by their annual ADE for HD Auction, Dinner and Dance in Belle Plaine, sponsored by the Fahey and Stier families, capping off a great month of fundraising activities.

The Orange County Walk was a resounding success, with an increase in revenue of \$7,000 over last year, netting over \$33,000. New volunteers and corporate support were key to the success of this effort. The emotional highlight was clearly the opening program, where a young woman entertained the crowd with her beautiful singing voice – and then shared the fact that she had recently tested positive. The walk honored HDSA researchers Dr. Leslie Thompson and Dr. Larry Marsh, as well as the medical Director of the new HD Clinic at University of California at Irvine, Dr. Neal Hermanowitz.

The Mid-Atlantic Region and Center of Excellence at the University of Virginia added a new event to the HDSA roster, with their first annual Polo Event

More than \$100,000 was raised to support the Center of Excellence at the Ohio State University as over 300 guests convened for the Celebration of Hope Martini Blast on September 30. Pat and Delores Meeker were honored at this great event.

The Wisconsin Chapter held its annual Education Conference with a large turnout and a well-put together program on September 17th. On October 7th, Iowa's Music at the Mill was held to benefit the Iowa Center of Excellence, which included great entertainment and a silent auction.

At HDSA final preparations were being made for the new fiscal year and two Direct Mail Programs were implemented. A "Research Investors Report" was sent with a

personalized letter to major donors from me. The report outlined the aggressive program of research that HDSA has funded, and how our scientists' work is progressing through the translational phase into clinical trials. Follow-up phone calls completed the effort, which has already yielded a stream of donations. At the end of September a new direct mail campaign was dropped in two parts: Part one spoke to previous donors about the importance of their past contributions and the need for them to continue to support HDSA. Part two was the first step in a new effort to build awareness and a larger donor base, with a more information-oriented letter sent to four different lists compiled by our marketing department and Hoffman York, our new pro bono advertising/communications agency. The result of this mailing will help us refine our list-purchasing methodology for future direct mail.

Among the highlights of the past two months were the formal dedications of the new HDSA Centers of Excellence at Rush University Medical Center and at UCLA. To witness the culmination of years of hard work and dedication on the part of the Chapters, volunteers and staff pay off in tangible benefits for our HD community was very moving and very rewarding.

The 9th Annual Guthrie Awards Dinner will be held on October 20, honoring Richie Havens, Nina Hill of Pfizer, Megan Tingly and the AOL Time Warner Book Group, who have provided us with advertising space for many years, and Joe Pardavila of WPLJ Radio. The San Diego Celebration of Hope Dinner will be held on November 18. On November 19, Kari and Tim Baker are hosting Picasso's Prom at their home in Orlando. It will be a very special evening of dining, dance, celebration and fundraising.

I would like to acknowledge and thank all of the Chapter and Affiliate officers who went that extra mile over the last two months to help HDSA meet our research and center care commitments so that we can continue to serve our families.

Let's start this new fiscal year with high expectations and a renewed dedication to our mission. I know that the work in the months ahead will bring us closer to our goal of making this the last generation with HD.

I look forward to hearing from you soon

With appreciation for all your efforts,

Barbara

Barbara T. Boyle
National Executive Director/CEO
Huntington's Disease Society of America
212-242-1968 ex. 16

