Dear Friends of HDSA,

Are we where we want to be? **NOT YET.** Are we getting closer? **YES!**

Putting all the great advancements in research aside, it is important to be reminded that there are still thousands of families impacted by Huntington’s disease that are in dire need of support right now. Although we are excited to report on promising research news — there is still no treatment for HD and our work is not done. In 2019 we worked hard to expand these services to provide world-class support to families from coast to coast.

This year we expanded our Centers of Excellence program to 47 facilities and 6 clinical sites across America where more families can receive expert care. With near Centers in California, Illinois, New York and North Dakota, HDSA now offers care locations in 31 States plus the District of Columbia. This year, HDaSA awarded a total of $1.4 million to the Centers of Excellence program, an almost eleven percent increase in funding from 2018.

The Huntington’s Disease Society of America also added new staff positions to play integral roles in supporting HD families. In June, we welcomed Allison Bartlett, Esq. to serve as HDSA’s Manager of Disability Programs. Allison has been able to assist countless families through the complex disability process as well as host Disability Chats to provide valuable insight into social security and what is needed for approval.

We know youth are a powerful voice in the fight against HD. Young adults and children from HD families continue to be wonderful advocates and their passion is never overlooked. However, we knew we needed to create more support programs for youth impacted by HD which is why we welcomed, not one, but two youth social workers to the HDSA team. Thanks to the Griffin Foundation, Katie Dykman, LISW and Jessica Marsolek, LGSW are professionals trained to serve young people and respond to the unique needs of children, teens and young adults impacted by HD.

With more hands on deck, we are able to improve our tremendous support programs even more, such as HDaSA’s Telehealth program, online support groups, HD Trialfinder and helpline — All Free. All the time.

HDSA is on the forefront of supporting promising HD research. In 2019, we funded more HD science than ever before including more than $1.4 million in direct grants to scientists. We also continued to cultivate strong relationships with leading bio-pharmaceutical partners.

As our founder Marjorie Guthrie said, “We must continue to search for HD families everywhere.” Through strategic outreach and engagement efforts, HDaSA has generated more awareness than ever before. We are getting more influencers involved who are using their platforms to bring HD families together and let them know how to find the help they need.

Once again, our work is not done, but because of you we are able to let HD know — we are never giving up this fight until we are in a world free of Huntington’s disease.

Sincerely,

Louise Vetter
President & Chief Executive Officer
In 2019, HDSA announced that forty-seven outstanding Huntington’s disease care facilities with six satellite sites were awarded the designation of HDSA Centers of Excellence. This was an increase from 43 in 2018, and from just 20 in 2015. The four new 2019 Centers of Excellence are OSF HealthCare Illinois Neurological Institute (Peoria, IL), Sanford Health (Fargo, North Dakota), University of Buffalo (New York) and University of California, Irvine. The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington’s disease that share an exemplary commitment to bringing comprehensive care. The strategic expansion of the Center of Excellence program allows HDSA to increase access to expert HD clinical care and clinical trial opportunities to more families across the United States. With new Centers in California, Illinois, New York and North Dakota, HDSA now offers care locations in 31 states plus the District of Columbia. This year, HDSA awarded a total of $1,418,684 to the Centers of Excellence program, an almost eleven percent increase in funding from last year.

OSF HealthCare Illinois Neurological Institute (Peoria, Illinois)
Sanford Health, (Fargo, North Dakota)
UBMD Neurology, University of Buffalo (New York)
HDCARE Clinic, Gottschalk Medical Plaza, University of California, Irvine

“HDSA is deeply committed to helping families affected by Huntington’s disease have access to experienced and family-focused care,” said Louise Vetter, HDSA’s President & Chief Executive Officer. “The recognition of new Centers of Excellence means that more families will benefit from comprehensive care and the life-changing treatment and research opportunities that drive us forward towards finding a cure for this disease.”

The HDSA Centers of Excellence provide an expert team approach to Huntington’s disease care and research. Patients benefit from expert neurologists, psychiatrists, social workers, therapists, counselors and other professionals who have extensive experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease. Applications for this grant mechanism were open to all 47 HDSA Centers of Excellence and their six partner sites. Ultimately, grants were awarded to four research teams on the following projects:

- HDSA Center of Excellence Partner Site at Oregon Health & Science University, Dr. Amie Hiller: Measuring Cortisol Levels in Persons with Huntington’s Disease
- HDSA Center of Excellence at Rush University Medical Center, Dr. Deborah Hall: Optimization of Tele-Genetic Counseling for Huntington’s Disease
- HDSA Center of Excellence at the University of Texas Health Science Center, Dr. Erin Furr-Stimming: Melatonin for HD Gene Carriers with HD Related Sleep Disturbance
- HDSA Center of Excellence at the University of Virginia, Dr. Madaline Harrison: Training in Primary Palliative Care for Huntington’s Disease

“Our HDSA Centers of Excellence are at the epicenter in the search for better HD care and treatments. HDSA is pleased to support these pilot programs in the confidence that our investment today will provide a brighter future for all HD families,” said Louise Vetter, HDSA’s President and Chief Executive Officer.

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On Saturday, September 28th, four hundred guests attended the 5th Annual Freeze HD Gala in the Hollywood where more than $420,000 was raised to support HDCA’s fight against Huntington’s disease. The star-studded event was hosted by actor Lamorne Morris and honored Keays and Scott Porter. Some notable guests included Seth Green, Topher Grace, Jason Bitter, Katherine McNamara, Marianna Palka, Kate Miner, Rachel Bilson, Wilson Bethel, Jaime King and the Allie LaFosse. The event featured incredible live performances from Brian Logan Dales and The Dales Hotel, Tyson Bitter from The All American Rejects, DJ bees, DJ Prophet, Emma Hutton, Leslie Powell and Scott Porter. Actor Will Ferrell donated $10,000 to support this wonderful night!

“The 5th Annual Freeze HD was the largest fundraising event ever hosted to support our organization and we couldn’t have done it without our incredible honorees, Scott and Kelsey Porter, sponsors, event committee and everyone who attended as well as bid on the amazing auction items,” said Louise Vetter, HDCA’s President and Chief Executive Officer. “Thank you everyone — this was truly a showcase of the extraordinary strength of the HD community.”

The incredible auction included exciting trips, signed TV / movie & sports memorabilia, once-in-a-lifetime experiences, exclusive tickets, gaming equipment and so much more! Freeze HD was supported by a wonderful event committee that included Rachel McAdams, Jason Bitter, Jaime King, Marianna Palka, Simon Helberg, Bryce Dallas Howard, Kenneth and Diane Mayfield, Blake and Jamie Coler-Dark, Brian Logan Dales, Matt and Courtney Hamilton, Jamie Linden, Justin and Katie Miner, Elliott and Tracy Owen, Carm Bitter, Nancy Morgan Bitter, Tyler and Leila Ritter, Jamie Zonne, Allegro Cate, Fabian Moore and Britt Logan, Gentle Kissed, Kyle Newman, Adam Sandler, Jessica Cainer, Emily and Jamie Rodgers, and Alana Yankowitz.

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HDSA FILMS DEBUT

In 2019, HDSA produced three powerful short films — Carol & Richard: A Love Story, The Hodgsons, and The Vaughts. All were directed by Ken Macwell. The films are featured on HDSA’s YouTube Channel and each has received thousands of views.

September 18: HDSA’s Founder’s Day of Giving

On September 18th, HDSA launched the Founder’s Day of Giving to pay tribute to our founder, Marjorie Guthrie. It was on September 18, 1967 our organization was founded. In just its first year, Founder’s Day of Giving raised more than $10,000 to support the first-time attendee.

GILLETTE TREO™ RECEIVES POSITIVE REVIEWS FROM HD FAMILIES

This year, HDSA partnered with Gillette to test a new product with HD caregivers. The Gillette TREO™ razor features a built-in safety comb that helps protect the skin and prevent clogging, an ergonomic handle for great comfort and control, and a special non-foaming gel that hydrates the hair with no clogging. The razor provides great partnership to bring useful products to HD families.

Starting a Family Amid HD Concerns Discussed on NBC’s The Today Show

HD facts and statistics provided by HDSA were featured on The Today Show in February when our dear friends, TNT basketball reporter Allie LaForce and husband Joe Smith of the Houston Astros appeared for an exclusive interview. The couple shared their concerns about starting a family since Joe’s mother suffers from HD. Dr. Joe E. Rum-Stimmen, a neurologist from the University of Texas HDSA Center of Excellence, whose team was recently awarded a Clinical Research Pilot Grant by HDSA, also appeared.

Gillette TREO™ razor features a built-in safety comb that helps protect the skin and prevent clogging, an ergonomic handle for great comfort and control, and a special non-foaming gel that hydrates the hair with no clogging, an ergonomic handle for great comfort and control, and a special non-foaming gel that hydrates the hair with no clogging.

Celebrity Rod Man hosts HD fundraiser — ‘Main Street Live’

Comedian Rod Man, who comes from an HD family, hosted his annual talent show — Main Street Live — in Georgia to raise funds and awareness for HD. Rod has appeared on NBC’s Last Comic Standing. This year his charitable event raised more than $3,000 to support HDSA’s mission.

Comedian, Rod Man

‘Bike for the Cure’ featured in Bicycling magazine

After 20 years and 20,000 miles, Bike for the Cure was featured in Bicycling magazine. Over the past 20 years, Charlotte Reicks age 83, and Marie Nemec, 74, rode more than 20,000 miles for Huntington’s Disease Awareness. They crossed 48 of the 50 contiguous states, connecting people and communities while growing their mailing list — their main source of donations. As of December, 2019 they have raised over $743,000 to fight HD.

Bicycling magazine

‘Here’s the Deal’ Video Series

HDSA’s Jennifer Simpson, LCSW continues to host Here’s the Deal, an online video series that features insightful conversations with members of the HD community. This past year’s topics included isolation, Family Planning, Caregiving While Positive and Parenting a Child With HD.

Visit HDSA’s YouTube Channel to watch Here’s the Deal to host conversations with members of the HD community. This past year’s topics included isolation, Family Planning, Caregiving While Positive and Parenting a Child With HD.

Gillette TREO™ razor

and Rachel Nichols are among many more celebrities who continue to generate much-needed HD awareness through ListenTalkAboutHD public service announcements.

Gillette TREO™ razor

#letsTalkAboutHD

HDSA’s mission.
HDSA’S 34TH ANNUAL CONVENTION IN BOSTON SETS ATTENDANCE RECORD

The 34th Annual Huntington's Disease Society of America (HDSA) Convention was held in Boston, Massachusetts on June 27th-29th at the Boston Marriott Copley Place. With 1,225 guests, the Convention set a new attendance record breaking the previous record (1,046) in Los Angeles, California held last year. The 35th Annual HDSA Convention will be held in New Orleans, Louisiana on June 4th-6th, 2020.

“The 34th Annual HDSA Convention not only set a new attendance record, but it also confirmed the momentum of the HD community that is actively working to improve the lives of everyone affected by Huntington’s disease,” said Louise Vetter, HDSA’s President and CEO. “With the incredible advancements in HD research and care, HD families are engaged and invigorated to go out and do something. We could not put an event of this magnitude together without the help of our amazing sponsors who we are grateful to call our friends in the fight against HD.”

The festivities kicked-off on Thursday with the Team Hope Walk through the historic streets of Boston, which led to the carnival-themed Welcome Reception. During the Opening Ceremony on Friday morning, Dr. Jang-Ho Cha, Dr. Marcy McDonald and Cheryl Sullivan-Stavely led a moving panel discussing the dynamic relationship between research and HD families.

Friday afternoon featured the Cheers-themed VolunCheer Luncheon where the Society cheered the extraordinary efforts of the HDSA volunteers.

Friday night’s HDSA National Youth Alliance Talent Show raised more than $35,000 for the NYA Scholarship Fund which sends children and young adults impacted by HD to the HDSA Convention each year.

The education tracks were jam-packed with workshops from world-class speakers, including Nobel Laureate Dr. Craig Mello who delivered the Keynote Address during Saturday’s Research Forum.

Also during the Research Forum, Dr. Ed Wild and Dr. Jeff Carroll from HDBuzz gave an in-depth and entertaining update on HD research and promising clinical trials entitled “HD Avengers — Endgame.”

The Convention culminated with Saturday night’s elegant Gala Reception where HDSA honored individuals and groups for outstanding achievements with the HDSA 2019 National Awards (see list at right).

The 34th Annual HDSA Convention was made possible by the generous support of all its sponsors:

PRESENTING SPONSOR
• Genentech
• Teva Pharmaceuticals

PLATINUM SPONSOR
• Lundbeck

GOLD NONPROFIT SPONSOR
• CHDI Foundation / Enroll-HD

SILVER SPONSORS
• Ionis
• uniQure

BRONZE SPONSORS
• MassMutual SpecialCare
• Voyager
• Wave Life Sciences

FRIEND SPONSORS
• Archare
• BioTek mMEDys
• Brain
• Next Step Healthcare
• PTC Therapeutics
• Sanofi
• Spark Therapeutics
• UMass Medical School
• Vaccinex
• WilmerHale

HDSA 2019 NATIONAL AWARDS

Wendy Goldstein
Advocacy Award
Suft Riefberg and
Theresa-Catherine-Marin
HDSA Youth Award
Hallie Kile
Researchers of the Year
Dr. Darrin Mountcastle and
Dr. Vanessa Wheeler
HDSA Chapter of the Year
HDSA New Jersey Chapter
HDSA Affiliate of the Year
HDSA-Connecticut Affiliate
Inaugural Long-Term Care Award
Stow Health Care Center
HDSA Excellence in Care Award
Dr. Samuel Frank
Marjorie Guthrie Award
Patricia McLean and
Morgan McLean
HDSA Person of the Year
Alexandra Brodsky
E.L. Gehr, HDSA Board of Directors’ First Place Creative Writing
HDSA President’s Award
HDSA Field Staff
HDSA National Awards
HDSA MD Award
HDSA Award for Lifetime Achievement
HDSA Person of the Year Award
Alexandra Brodsky
HDSA 2019 National Awards (see list at right).

As is tradition, the Convention closed with the emotional candle lighting ceremony paying tribute to the entire HD community.
HDSA ADDS THREE TRUSTEES TO NATIONAL BOARD

The Huntington’s Disease Society of America is excited to welcome three new members to the Society’s national Board of Trustees.

Wendy Erler and Jay Hughes are appointed Trustees, and Jonathan Klein is Chair of the Mergers and Acquisitions Group at DLA Piper in New York City. Jonathan has extensive experience in merger and acquisition transactions, private equity, corporate finance, securities matters and restructuring for both domestic and international clients. Jonathan received his J.D. from Georgetown University Law Center and his B.S. from Cornell University.

Wendy Erler is the Vice President of STAR and Patient Advocacy at Alexion Pharmaceuticals. She leads the executive leadership team at Wave Life Sciences where she led Patient Advocacy and Commercial. She leads the patient insights throughout the drug development holistic solution model to gather and incorporate where she is responsible for building an enterprise insights and advocacy at Alexion Pharmaceuticals.

Jay Hughes is MGIC’s Executive Vice President of Sales and Business Development. He began his career with MGIC in 1987 as an Account Executive in Wisconsin. In his current role as Executive Vice President of Sales and Business Development, Jay is responsible for MGIC’s five regions, our National Account relationships and Marketing. He holds a Bachelor of Science degree in Finance from the Villanova School of Business.

“HDSA is thrilled to welcome Wendy, Jay and Jonathan to HDSA’s Board of Trustees,” said HDSA’s President & Chief Executive Officer. “Their diverse skills and experiences will contribute to the Society’s ability to achieve our mission and support families affected by HD.”

In other Board-related news, Louise Vetter, Jonathan’s representative on HDSA’s Board of Trustees, said, “We are excited to welcome Wendy, Jay and Jonathan to HDSA’s Board of Trustees.”

The Huntington’s Disease Society of America is grateful for the exceptional volunteer leadership that guides our mission work! We are grateful for the exceptional volunteer leadership that guides our mission work!

HDSA’S NYC MARATHON TEAM RAISES MORE THAN $133,000

HDSA’s 2019 New York City Marathon team featured twenty-five runners from twenty different States across the US all willing to take on 26.2 miles to support the fight against HD. To date, the team raised more than $133,000 finishing in the top 18 among all NYC Marathon Charity Partners!

COUNTRY STAR CHRIS STAPLETON SUPPORTS HDSA

After being introduced to HDSA’s rich musical history and incredible mission, singer-songwriter Chris Stapleton donated $5,000 to improve the lives of people with HD and their families.

Samantha Cox, Kari Baker, and Janine Lind Trembicki are a few of the many who contributed to the success of HDSA’s 2019 New York City Marathon team. Special thanks to the accounting firm EisnerAmper for being the team’s Presenting Sponsor. The team’s fastest runner was Craig Robinson who finished with an impressive time of 2:34:55 – good enough for 118th overall! The team’s top fundraiser was Kari Baker from Florida who raised more than $10,000!
HD LEGACY — THE GIFT TO FUTURE GENERATIONS

In response to a growing need to study exactly what Huntington’s disease (HD) does to the human brain, HDSA and CHDI Foundation announced a new collaboration in 2019 called HD LEGACY to support brain and other organs donations from families affected by HD who would like to make a vital contribution to research. This new program encourages the donation of brain and other tissues from HD gene-expansion carriers, at-risk individuals, and healthy family controls. The Harvard Brain Tissue Resource Center (HBTRC) will assist interested families throughout the process, and families will bear no costs associated with the donation.

“The decision to donate one’s body to science is an amazingly selfless act,” said Louise Vetter, President and CEO at HDSA. “Participating in HD LEGACY is truly a gift for future generations. The brains and other organs donated through this program will leave a ‘legacy’ of hope, inspiring new knowledge that will someday stop HD in its tracks.”

“Science still has a quite rudimentary understanding of how the human brain works,” said Robi Blumenstein, President of CHDI Management, Inc. “Researchers need more brain donations from HD-affected individuals to better understand how HD affects the human brain, what happens to the different cell types and circuits that make up the brain over time. HD LEGACY will give us new insight into how to intervene therapeutically.”

INSPIRATIONAL RUNNER SUPPORTING HDSA HIGHLIGHTED IN RUNNER’S WORLD MAGAZINE

Gabby McNary, who has tested positive for the HD gene, ran the Chicago Marathon (her first) to honor her mother who she lost to the disease five years ago. She also raised over $4,000 for HDSA. Her inspiring story was featured in the October 14 edition of Runner’s World.

CHARITY NAVIGATOR AWARDS HDSA 4 STARS — ITS HIGHEST RATING — FOR THE FOURTH CONSECUTIVE YEAR

“We are proud to announce Huntington’s Disease Society of America has earned our fourth consecutive 4-star rating. This is our highest possible rating and indicates that your organization adheres to sector best practices and executes its mission in a financially efficient way. Attaining a 4-star rating verifies that Huntington’s Disease Society of America exceeds industry standards and outperforms most charities in your area of work.

Only 20% of the charities we evaluate have received at least 4 consecutive 4-star evaluations, indicating that Huntington’s Disease Society of America outperforms most other charities in America. This exceptional designation from Charity Navigator sets Huntington’s Disease Society of America apart from its peers and demonstrates to the public its trustworthiness.”

Michael Thatcher, President & CEO, Charity Navigator

HDSA LISTED IN TOP 10 VOLUNTEER OPPORTUNITIES IN NEW YORK CITY BY GREAT NONPROFITS

A woman whose mother was diagnosed with Huntington’s disease forwarded the following comment to greatnonprofits.org about HDSA:

“I am a daughter whose mother was diagnosed with HD, which I knew nothing about until I found this organization. If not only answered the billions of questions I had, but also provided me with emotional support from real friends. It gave me a sense of security knowing I am not the only person in the world going through this. This organization is a way saved my life. I was overwhelmed and ready to give up and they would NOT let that happen. For that I will always be truly thankful. This is an organization that helps people in every way possible. Thank you for all you have done and continue to do every day. I will always be a proud volunteer HDSA.”

Gabby McNary comforts her Mom.

Runner's World Magazine.
Every year, HDSA’s 50+ Chapters and Affiliates host more than 300 events across the country thanks to the amazing leadership of HD families & volunteers. Here are just a few!

**NEW ENGLAND REGION**
- New England Region Celebration of Hope Gala
  - New England Region
  - $62,500
- 21st Annual Cure HD Golf Tournament
  - Tennessee Chapter
  - $16,500
- Twin Cities Team Hope Walk
  - Illinois Chapter
  - $27,000

**UPPER MIDWEST REGION**
- Twin Cities Team Hope Walk
  - Minnesota Chapter
  - $42,400
- South Dakota Team Hope Walk
  - South Dakota Chapter
  - $37,000
- Iowa Hoop-a-Thon Tour
  - Iowa Chapter
  - $127,000

**GREAT LAKES REGION**
- Sparkle Celebration of Hope
  - Northeast Ohio Chapter
  - $185,000
- Chicago Celebration of Hope
  - Illinois Chapter
  - $114,000
- Illinois Team Hope Walk
  - Greater New York Chapter
  - $90,850

**NEW YORK / NEW JERSEY REGION**
- New York City Team Hope Walk
  - Greater New York Chapter
  - $116,300
- Celebration of Hope Dinner
  - New York/New Jersey Region
  - $83,000

**PACIFIC REGION**
- San Diego Team Hope Walk
  - San Diego Chapter
  - $115,000
- San Francisco Team Hope Walk
  - San Francisco Chapter
  - $65,000
- Los Angeles Team Hope Walk
  - Los Angeles Chapter
  - $65,000

**SOUTHEAST REGION**
- 25th Annual Cure HD Golf Tournament
  - Tennessee Chapter
  - $32,500
- Atlanta Team Hope Walk
  - Georgia Chapter
  - $38,203
- Pittsburgh Team Hope Walk
  - Pennsylvania Chapter
  - $30,000

**SOUTH CENTRAL REGION**
- Fairways for Hope
  - Rocky Mountain Chapter
  - $38,320
- Denver Team Hope Walk
  - Rocky Mountain Chapter
  - $34,700
- Anita Sabedra Team Hope Walk
  - South Central Region
  - $28,100

**MID-ATLANTIC REGION**
- Team Hope Walk
  - Delaware Affiliate
  - $32,000
- Philadelphia Team Hope Walk
  - Eastern Pennsylvania Chapter
  - $30,000
- Massanassa Team Hope Walk
  - Mid-Atlantic Region
  - $30,000

**NEW ENGLAND REGION**
- New England Region Celebration of Hope Walk
  - New England Region
  - $42,000
- Boston Team Hope Walk
  - Massachusetts Chapter
  - $20,000
- Sparkle Celebration of Hope
  - Northeast Ohio Chapter
  - $185,000
- Illinois Team Hope Walk
  - Illinois Chapter
  - $114,000
- Chicago Celebration of Hope
  - Illinois Chapter
  - $114,000
- Illinois Team Hope Walk
  - Greater New York Chapter
  - $90,850

**SOUTHWEST REGION**
- New Mexico Team Hope Walk
  - South Central Region
  - $24,000
- Arizona Team Hope Walk
  - Arizona Chapter
  - $24,000
- Texas Team Hope Walk
  - Texas Chapter
  - $28,100

**2019 REGIONAL EVENT HIGHLIGHTS**

Special thanks to our National Team Hope Sponsors
In October of 2019, HDSA awarded five grants under the Society’s largest research initiative, the HDSA Huntington’s Disease Human Biology Project. These grants, totaling $575,000, represent HDSA’s patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington’s disease science in the human condition. Applicants worldwide proposed projects addressing HD through small clinical studies or donated human samples. This year’s winners hail from Scotland, Spain, and the United States.

Danielle Larson, MD
Northwestern University Feinberg School of Medicine
Dr. Larson will study whether remote “telemedicine” visits with a neurologist could be just as helpful as in-person visits for an HD patient or family.

Osama Al Dalahmah, MD
Columbia University
Dr. Al Dalahmah will examine how astrocytes, the brain’s support cells, change over the course of HD to become harmful versus helpful.

Vilija Lomeikaite, PhD candidate
University of Glasgow
Vilija will work on improving the existing methods to detect an increase in CAG repeats in certain cells of the body and brain during the course of HD.

Ricardo Moure-Pinto, PhD
Massachusetts General Hospital and Harvard Medical School
Dr. Moure-Pinto will focus on the biology of CAG repeat expansion in hopes of developing drugs to stop this process.

Saúl Martínez-Horta, MSc,
Sant Pau Hospital, Barcelona
Saúl will examine what kinds of changes are happening in the brain and blood when HD patients begin to have difficulty with planning and memory.

Madeleine Sharp, MD
2016 Human Biology Fellow, Postdoctoral Research Fellow, McGill University
The overall goal of Madeleine’s project was to uncover the mechanisms underlying common cognitive and behavioral symptoms of HD. She designed tasks to detect subtle changes in learning and memory, even in pre-symptomatic carriers of the HD gene. She exceeded her enrollment goals with a total of 70 HD patients, some of whom were recruited at HDSA’s National Convention. This work is impactful from the perspective of early diagnostics as well as potential interventions. Certain cognitive tasks shown to create long-lasting improvements in memory and reward processing could potentially be powerful and safe approaches to treating early changes in thinking.

Marina Papoutsi, PhD
2017 Human Biology Fellow, Postdoctoral Researcher, University College London
Marina is a skilled statistician whose project focused on the concept of “cognitive reserve,” the idea that intelligence, education, or an intellectually stimulating lifestyle can be protective or delay cognitive problems for people with the HD gene. In 2019, she completed an analysis showing that HD patients with higher levels of education or a higher IQ had a slower rate of decline in mental abilities. This knowledge could be applied to design stimulating interventions, encourage young people in HD families to follow intellectual pursuits, or to stratify patients in clinical trials.

In 2016, HDSA Human Biology Fellow Madeleine Sharp studied the impact of subtle changes in learning and memory on HD patients. Her work, which exceeded enrollment goals, showed potential for early diagnostics and interventions.

Richard Hickman, MD
2018 Human Biology Fellow, Neuropathology Fellow, Columbia University
Richard’s HDSA funding is allowing him to work closely with Dr. Jean-Paul Vonsattel to learn the art of HD brain banking, an invaluable skill that enables researchers to use donated human brain tissue. His HDSA fellowship also helped him to transition to an assistant faculty position at Columbia University. He is working with autophagy expert Dr. Ai Yamamoto to explore how the brain’s waste disposal systems handle toxic huntingtin protein. Beyond potential discoveries that could help harness the power of the cell’s clean-up crew to combat HD, the skills required to make use of precious brain donations from HD families are highly sought after.

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In April of 2019, four exceptional undergraduate students were awarded HDSA’s Donald A. King Summer Research Fellowships. These awards are named in honor of Donald King, who served as HDSA Board Chairman from 1999 to 2003 and worked tirelessly to advocate for HD families until his death in 2004. In order to further meaningful discoveries about Huntington’s disease and ensure that bright young scientists are steered towards the field, this program supports undergraduates who have committed their summers to training in an HD research lab. Applications are accepted between December and March each year and are reviewed by HDSA’s Scientific Advisory Board. The 2019 Donald A. King Summer Research Fellows completed focused HD research projects under the supervision of senior scientists.

Zach Cooke  
Brown University  
Zach spent the summer working with Dr. Marc Tatar, testing effectiveness of drugs in a fruit fly (Drosophila) model of Huntington’s disease.

Chloe LaRoche  
University of Central Florida  
Chloe worked under the guidance of Dr. Amber Southwell on a project investigating aggression in HD mice.

Alexandra Putka  
Duke University  
Alexandra worked in the laboratory of Dr. Audrey Dickey to elucidate how altered function of a protein called PPAR contributes to HD pathology.

Colleen Strohlein  
University of Pittsburgh  
Colleen spent the summer working in the laboratory of Dr. Robert Friedlander, to investigate whether phosphorylation of huntingtin protein affects its localization to mitochondria.

As part of HDSA’s commitment to developing the next generation of passionate and innovative Huntington’s disease scientists, the Berman-Topper Family HD Career Development Fellowships provide up to $80,000 of funding per year for three years to young scientists and clinicians who desire to make HD part of their long-term career plan. These prestigious awards are made possible due to the generosity of the Berman and Topper families and CHDI Foundation. HDSA’s Scientific Advisory Board reviewed applications from researchers from all around the world, and HDSA was able to award two scientists the 2019 Berman-Topper Fellowship — Dr. Lauren Byrne and Dr. Nicholas Caron. Dr. Byrne is working under the guidance of Dr. Ed Wild at University College London. Her project will better prepare the field for future disease prevention studies by researching how early in life we can detect changes in the neurofilament light (NFL) protein in persons with the HD mutation. Dr. Caron is guided by Dr. Michael Hayden at the University of British Columbia. He will investigate novel ways to enhance the delivery of huntingtin lowering antisense oligonucleotides across the blood-brain barrier.
By Dr. Craig Mellis and colleagues, the formation of a new company that will try to treat HD. This is one of dozens now currently pursuing HD as a primary indication in their business plan. While the light of hope now shines brighter for all of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. That work requires the voices of us, much work remains before HD becomes a thing of the past. 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2019 was an exceptional year for HDSA educational efforts. Thanks to a generous unrestricted educational grant from Genentech, HDSA was able to support 59 educational events that ranged from full day conferences to half-day meetings to support group guest speakers. This compares favorably with 2018 when HDSA supported 49 educational events. Our thanks to the creativity and budget savvy of our event organizers who used every one of our grant dollars wisely.

In addition to outstanding programming in the areas of care, advocacy and youth, several larger conferences received a clinical final update from Genentech as well as information about advances in HD research. Every attendee received an HDSA information packet that contained valuable materials about support groups, HDSA Centers of Excellence and chapters/affiliates in their region. Almost 2,700 HD family members and healthcare professionals attended these events with six multi-track state conventions attracting more than 100 family members to each. HDSA thanks Genentech for their generous unrestricted educational grant which made these events possible. In the area of professional education, HDSA launched a new three year continuing education program in partnership with the American Occupational Therapy Association (AOTA). We anticipate that it will be as well received as the prior three year course which awarded more than 2,200 Continuing Education Units (CEUs) to community-based occupational therapy specialists. In early 2020, HDSA will launch a new three year continuing education course with the American Society of Genetic Counselors (NSGC) that will provide the information community-based genetic counselors will need to counsel and assist at-risk individuals contemplating HD genetic testing. HDSA was invited to present two posters at the annual Huntington Study Group meeting in Sacramento CA. Each poster focused on HDSA’s professional education efforts and partnerships with AOTA and Medscape (which awarded more than 5,000 CEUs to healthcare professional in 2018). As always, HDSA is pleased to have featured so many of our HDSA Center of Excellence staff in these continuing education efforts.

2019 saw the expansion of HDSA’s stable of youth support programs, rolling out our Youth Social Worker Pilot Program and the integration of these two social workers into the world of youth work. In 2019, the HDSA National Youth Alliance (NYA) held their four youth retreats around the country, returning to Pittsburgh and New Orleans and introducing Chicago and Sacramento as new sites. As we look to 2020, expect more new cities to be added to our rotating sites for NYA Youth Retreats. With our Youth Social Workers joining us in Chicago and Pittsburgh, young people can anticipate even more support in 2020 as we bring on two additional youth social workers. HDASA and the NYA brought nearly 90 young people out to our youth retreats in 2019, providing them with information from experts at HDSA Centers of Excellence, support from social workers, and integrated improv and art therapy workshops. The NYA also funded more than 60 young people to attend HDSA’s largest ever National Convention in Boston through full and partial scholarships. The NYA also supported their Regional Lead Program, encouraging chapters and affiliates, as well as local social workers, support groups and youth social workers, to utilize them for peer outreach and support. Regional Leads also took center stage during a 2019 advocacy trip to Washington DC, using their stories to influence leaders to advance legislation important to the HD community. Here’s to more incredible experiences, growth and support for young people impacted by HD in 2020!
In 2019, HDSA unveiled its new disability program thanks to the addition of disability attorney, Allison Bartlett, Esq., who specialized in the representation of clients with rare, chronic conditions, like Huntington’s disease, to navigate them through the complex disability system. She works directly with families and social workers to provide advice, assistance, and resources for the Social Security disability process. We have assisted and provided educational resources to approximately 91 social worker requests and 222 HD families via phone and email regarding the Social Security disability process and the appropriate next steps for the disability application in the areas including: when to start the disability process, tips for submitting a disability application, health insurance, work credits and disability eligibility, and case specific disability questions. HDSA launched the Disability Chat Webinar Series in September 2019 to cover a wide range of disability topics for families and social workers. Disability chat webinars are hosted every other month and provide an in-depth look at different aspects of the Social Security disability process, including eligibility criteria, work credits, and the 5-step disability evaluation process. To date, Disability Chat has had 119 live views and 441 recorded views. HDSA has also expanded the ‘Disability Benefits and HD’ section (under Find Help, Healthcare & Future Planning) on its website to include new disability resources. Several new resources were created for families and social workers this year to help with the Social Security disability application process, including a Disability Booklet, Wellness Journal, and Social Security Disability Application Tips. If you have questions about Social Security disability or general disability topics, please contact Allison Bartlett, Esq. at 212-242-1968, ext. 218.
Please Join Us!

Join us for the 35th Annual HDSA Convention in the Big Easy at the Sheraton New Orleans Hotel.

JUNE 4-6, 2020, NEW ORLEANS, LA

Save the Date!

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