The North Carolina Center for the Care of

Huntington's Disease

PROVIDING assistance
and improving
access to CARE FOR
North Carolina
PATIENTS *and*
family members
WITH
HUNTINGTON'S DISEASE

The North Carolina Center for the Care of Huntington's Disease
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Huntington's Disease

Dear Friend,

Huntington's Disease (HD) is a fatal, genetic, disorder of the brain. HD causes great suffering not only in those it strikes, but also in their families. Despite promising research and unprecedented financial support for drug development, medical care for HD patients and their family remains inadequate, inaccessible, and poorly coordinated. At a time in history when human suffering is being reduced in growing ways, HD sufferers and their families in North Carolina receive little more than sympathy. Families find that they must manage acute psychiatric symptoms and life-threatening medical complications—to say nothing of financial ruin—with little or no help. After generations of misunderstanding and inadequate care, it is no wonder that many families can barely utter the words – Huntington's chorea. They do not want any reminder of a miserable past and the prospects of an unchanged, equally miserable future.

Fortunately, the situation in North Carolina is not global. In major cities around the world, centers have been established to provide specialized care for HD patients and their families. Although current treatments neither slow the disease's progression nor prevent death, appropriate medications can offer relief while care-giving techniques and support are available that allow an afflicted person to remain at home longer. Timely access to appropriate information, government programs and charitable resources benefit patients, families and society. Equally as important, these centers provide a necessary resource for evaluating drug candidates that provide the best possibility for a near-term treatment an eventual cure for HD.

North Carolina urgently needs such a center to aid those suffering from HD in our state. The North Carolina Center for the Care of Huntington's Disease (NC-CCHD) has been formed to address this pressing need. The NC-CCHD will leverage existing world-class clinical expertise from leading medical research centers to build a communication network that connects HD patients and their families with expert medical care and available resources. The Center will provide access to expert care, crisis intervention services, caregiver support and education, establish partnerships with existing government and charitable programs, and offer education and outreach to community care providers, hospitals and nursing homes throughout our state. Despite the magnitude of the task of establishing the NC-CCHD, our funding goals are modest.

We hope you will join us in building a Center for HD Care in North Carolina. There is an urgent need to aid North Carolinians who suffer from this devastating disease and to create a better environment in our state for research participation, drug discovery and treatment advancements. While aiding people and families now who suffer from Huntington's Disease, we hope to play a role in ultimately bringing that suffering to an end.

Sincerely,

Mary C. Edmondson, MD
President

Francis O. Walker, MD
Medical Advisor

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Huntington's disease: a family legacy

Huntington's disease is a devastating and fatal inherited brain disorder that results in chorea—a type of involuntary movement—psychiatric symptoms and loss of muscular control and mental functions. Lying dormant for years, symptoms typically begin to appear in mid-life, often after the childbearing years. The illness progresses over a 10-25 year period and is always fatal.

The most painful aspect of HD is its inheritance. Each child of an HD affected individual has a 50% chance of inheriting the disease. A teenager watches a trusted parent become depressed and lose occupational abilities. Putting her own life on hold, a young adult cares for her parent who has lost independence. Decisions about career, marriage and parenthood are constantly colored by the worry of a foreshortened life, burdened loved ones and abandonment. Parenting for people at risk is haunted by fears of having passed the gene on to a child, often while watching a suffering parent slip further and further away.

For some at risk, they will have the good fortune of not personally having the disease. They will nonetheless share in the care and suffer many losses—a parent, one or more siblings, a favorite cousin, a niece or nephew—all to Huntington's Disease.

But for the person who develops the disease, he knows what fate will hold as he follows his affected parent's path. The simplest task becomes an adventure—and a nightmare. Eating will include choking, falling will accompany walking and the inability to communicate, think and use remaining abilities are constant obstacles. It's hard to know how the person with HD experiences his final days. Without language, it often feels to those left behind that separation came long before death.

This is the legacy left to future generations of HD sufferers. Huntington's disease affects entire families, from birth to death, generation after generation.

North Carolina Huntington's Disease Families: an under-served population

Based on national estimates, there are approximately 550 affected NC HD patients and 2,750 affected family members (at-risk children and caregivers) in North Carolina. In total, there are an estimated 3,300 individuals in North Carolina affected by HD.

Although Huntington's Disease is uncommon, geography and social isolation limit the care for HD families more than prevalence. It is estimated that 3-7 out of every 100,000 people suffer from HD in the US; this is similar to the prevalence rates for ALS (Lou Gehrig's disease) and Cystic Fibrosis. The *true prevalence* of HD, however, is widely believed to be many-fold greater than these estimates, as many families are hesitant to divulge their family illness because of hopelessness, stigmatization and the fear of genetic discrimination. Community awareness of Huntington's Disease is much less than other illnesses of a similar incidence, which serves to further isolate HD families from each other and their communities. HD families are spread throughout distant geographic regions in states without high population urban areas. Because of these social and geographic factors, families find that they must manage serious psychiatric symptoms, life-threatening medical complications and dwindling financial resources with minimal help.

In North Carolina, community physicians provide medical treatment for most HD patients. Caring for a patient with Huntington's Disease is a prohibitively time intensive and complicated process for an inexperienced care provider. The average patient is misdiagnosed for seven or more years after the onset of the disease. Medications can have paradoxical effects, misinformation about the

disorder can hinder good decision making and lack of preparation for the financial consequences and predictable problems of the disorder maintain the cycle of crises often seen in Huntington's Disease. It is hard for the community physician to maintain hope in the face of these challenges.

Currently, there are clinicians in North Carolina located at Wake Forest University, Duke University and the University of North Carolina at Chapel Hill, with the experience and resources to provide high quality care to HD families. However, in the absence of an interconnected web of care for HD in our state, fewer than 200 patients are followed at these institutions, and only 20 patients undergo predictive genetic testing each year. In fact, most HD families do not even know that expert care is available in North Carolina since few social networks connect patients and their families with these care sites. At a time when HD families are most in need, there is no easy way for families to access expert medical care or vital support resources.

A Sad Reality: Alec's story

At 33, Alec was enjoying multiple successes, in his work, marriage and personal life. A handsome Mediterranean dancer and GQ model, he was the Cellermaster of a profitable restaurant located in the World Trade Center. He and his wife, Lisa, had just had their second child, a beautiful daughter. The only flaw in the fabric of his life was his mother's illness, as she had been diagnosed with Alzheimer's Disease.

In 1993, the World Trade Center was bombed, and Alec and his co-workers were trapped in the building for more than four hours. Afterward, Alec began having several problems. He struggled with time management, planning and the execution of simple tasks. His employer made many accommodations for him, but things continued to get worse. He began to have jerking movements during presentations and lost more and more initiative. He tried computer classes, business writing classes and toastmaster speaking classes, thinking he had a skill deficit. His work continued to deteriorate, and on Dec. 31, 1999, he was terminated. Lisa was pregnant with their third child.

Alec and Lisa's youngest daughter. Lisa is committed to preserving her children's childhoods.

As newlyweds, Alex and Lisa saw older couples helping one another with walking and other simple tasks and thought "that'll be us someday" They never expected that "someday" would come so soon.

Friends and family helped him try all sorts of jobs, but within days or weeks, he was repeatedly fired. For four years, Lisa worked up to three jobs at once to keep them afloat. When Alec began acting odd and delusional, Lisa finally sought medical help.

A psychiatrist diagnosed him with Social Anxiety Disorder and PTSD, and placed him on medications. His symptoms did not improve. His psychiatrist began to tell Lisa that she was causing his symptoms, and that she needed to reduce her expectations. To compound the burden, the doctor would not help them obtain disability for Alec. In the meantime, they spent all $200,000 of their savings, amassed $40,000 in debt and lost the support of family who felt they were being financially irresponsible.

Seven years after his symptoms began, Alec's brother developed some of the same symptoms. Lisa began to realize that Alec, his brother and mother all had similar symptoms. Alec's primary care physician, an advocate for them during these difficult times, researched Alec's odd movements, and mentioned a disease called Huntington's Disease. By this time, Alec was paranoid and delusional, and refused testing.

To prevent impending bankruptcy, Lisa made the decision to sell their home in New York, consolidate what money they had left, and move to a less expensive part of the country. It seemed their only option, even though they were leaving behind their families and a large social support system.

After arriving in North Carolina, Alec became delirious and was admitted to the hospital. Lisa demanded testing for Huntington's Disease. The testing proved that he carried the expanded gene. Thirteen years after his symptoms began, they finally had a definitive diagnosis. Naming his illness was both a relief and a nightmare, since Lisa's intuition about inheritance was true. All three children are at a 50 percent risk to someday develop HD. However, at least Lisa could make plans for the future and optimize Alec's treatment. A medication regimen was finally helpful, but Alec was nothing of his former self.

At times, Lisa can even find humor in the chaos of their life together. A poignant, tragically funny memory for her was the day she had to take Alec to the Disability Determination office. After years of preparing disability applications, there was a finally proof—a diagnosis—that qualified him. But she still had to take him, actively psychotic, to the disability office to prove he was unable to manage his affairs.

Now 48 years old, Alec leads a very simple, quiet existence in order to manage his symptoms. For Lisa, it is a very difficult way to raise a seven year-old girl and two teenagers. Lisa is committed to preserving their childhood and the fun and new experiences they deserve, but it is becoming increasingly difficult for Alec to handle any kind of stimulation. Because of short-term memory loss, Alec requires her attention every 10 minutes. She has had to reduce her workload, and they barely make ends meet on her income. One option is short-term unemployment benefits for Lisa, but she doesn't know what she will do when those benefits run out.

The pain of Alec's illness colors all of their moments together. Lisa wants to keep him at home, knowing that no one will care for him the way she does. She lives in constant fear—that he will choke to death in front of her and the children, that the stress of his illness will kill her, or that they will lose their home, their only remaining asset.

One of the hardest parts for Lisa—aside from the fact that the love of her life is dying in front of her eyes, that she has constant nightmares about her children's future and that she doesn't have a single moment to take care of any of her own needs—is that she has always been an incredibly resourceful woman. If she just had time, she could organize a solution, she knows how to get things done. If she just had time…if she just had some help…

Now is the Time for Optimism

The main concern raised by researchers is that there will not be enough study participants to test all promising drug candidates!

Although there is presently no cure or treatment to slow down progression, this is a time of great hope for Huntington's Disease families, greater than at any time in history.

In 1967, only 12 scientists attended the International Congress of Neurogenetics to discuss the state of HD research. In 2008, more than 220 individuals participated in the 15th annual Huntington's Study Group (HSG) meeting in Florida. The **Huntington's Study Group** includes more than 390 active clinical

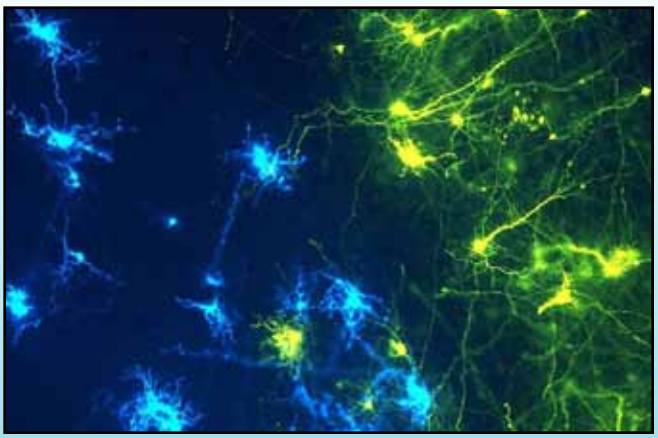
Discovering how to halt, slow down, or reverse the damage caused by the abnormal HD gene will be applicable to many progressive neurodegenerative diseases, like Alzheimer's Disease, Parkinson's Disease and other trinucleotide disorders.

approximately 80 research sites in the United States, Canada, Europe and Australia. Since 1993, the HSG has conducted 20 multi-site studies.

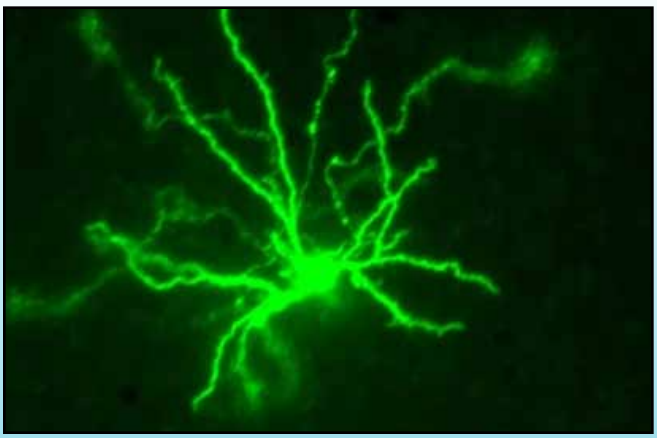
After a ten-year search involving extensive recruitment of families in the United States, Europe and Venezuela, **HD gene** was discovered in 1993. An expanded number of trinucleotide repeats on the short arm of Chromosome 4 was identified as the underlying cause. This made pre-symptomatic, predictive testing of at-risk individuals available.

The identification of the HD gene creates an entire new avenue of investigation in the **basic sciences**. HD is one of ten neurodegenerative trinucleotide repeat disorders, so advances in understanding one of these disorders is likely to apply to all. The development of a wide range of laboratory and preclinical tools in HD research has advanced the ability of scientists to understand diseases beyond Huntington's Disease. Uncovering the function of the protein made by the HD gene has identified new pathways in the production and regulation of cellular mechanisms. In particular, several neurodegenerative disorders share a common pathway on the way to regulated cell death, so finding a way to stop cell death in Huntington's Disease is likely to prevent cell death in many other neurodegenerative diseases.

The **Huntington's Disease Society of America** is the main grassroots organization that supports HD families today. HDSA promotes and supports both clinical and basic HD research, provides aid to families coping with the multi-faceted problems



Healthy Brain. Green=neurons in the cortex which feeds information into the striatum; Blue=neurons in the striatum where Huntington's Disease hits.



A healthy neuron in the striatum

presented by HD and educates families, the public and heath care professionals about Huntington's disease. With the help of HDSA funding, a multi-disciplinary system of caring for HD families was developed and implemented in the Center of Excellence Program. Each Center is focused around a clinical team that approaches the extensive problems facing HD families in a multi-disciplinary way by coordinating effective support and services. Currently, 21 clinical sites have been designated as Centers of Excellence in the US, with plans to expand the program in the near future.

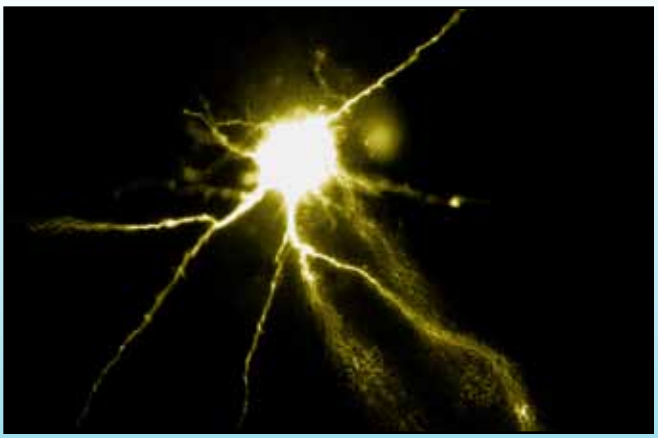
The North Carolina Chapter of HDSA was formed in 2000. It carries out many fundraising, educational and awareness efforts throughout the state. The main focus of their efforts over the past decade has been to raise money for research, while creating opportunities for families to interact and share information about common challenges.

The **Cure Huntington's Disease Initiative** (CHDI) Foundation was established in 2002 as a private philanthropic foundation with the mission of bringing together academia, industry, governmental agencies and other organizations in the search for a cure for Huntington disease. The Foundation supports numerous projects related to HD, including basic research, drug discovery programs and clinical studies. Because of the CHDI Foundation, research in HD is now funded at unprecedented levels. There is hope that this large-scale, collaborative approach will bring us an effective treatment for Huntington's disease in the near future.

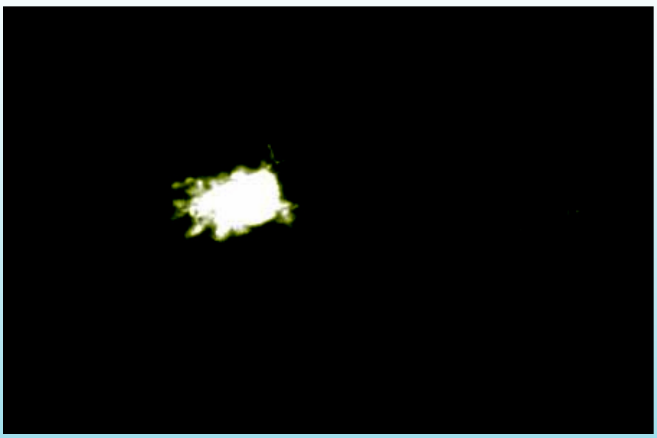
On November 24, 2008, **Tetrabenazine**, the first FDA-approved treatment for the symptoms of Huntington's disease, was released in the United States. Although Tetrabenazine does not slow the progression of the disease or offer relief of all symptoms, it is a hopeful first start. Thanks to HDSA, the Hereditary Disease Foundation, Prestwick Pharmaceuticals—and the many families who testified at the FDA public hearings—the path has been blazed from clinical trials to FDA approval for new drugs to treat HD.

Fear of discrimination has been a major deterrent preventing at-risk individuals from coming forward for medical care and genetic testing. With the passage of the **Genetic Information Discrimination Act** (GINA) in 2008, at-risk individuals can no longer fear excessive health insurance premiums or employment discrimination based on their genetic information.

With all these reasons for hope, North Carolina families are ready to join others around the world in creating a better environment in our state for research participation, drug discovery and treatment advancements. Now is the time to help them make this significant step!



A mid-stage neuron degenerating from the mutant Huntington gene



A terminal stage neuron degenerating from a juvenile-onset form of mutant Huntington's

Our Vision of Hope

As HD families wait for a cure or treatment, they want to do all that can be done to manage symptoms, help an affected person live with dignity, and experience life to the fullest in every healthy moment. But Huntington's Disease creates years of hard work. Any system of health care must be based upon the need to reduce the heavy burden of work HD families face.

Our vision of helping families achieve their goals includes:

Families need a way to access **timely help** that is easy, efficient, and available to them by phone, Internet, and in person.

Accurate information about symptoms, course of disease, and treatment strategies can help set the stage for future planning.

HD families need **leadership** from their medical care team. Collaboration and communication between all members of the health care team, including ancillary care, primary care, and community providers, is critical.

Improvement in **preventive and general medical care** across the lifespan can reduce complications of HD.

Psychiatric manifestations of HD are often treatable at multiples stages of the illness. Treatment of these psychiatric symptoms can greatly improve quality of life for HD patients and families.

Most at-risk individuals rarely seek out medical care or genetic testing until they believe they have symptoms of HD. A window of opportunity for **prevention of complications** is lost without the active involvement of this population in care.

At-risk individuals work hard to manage **psychological factors**, related to their family member's illness and personal risk. Opportunities to address these issues in a psychotherapeutic relationship may mend wounds that otherwise haunt some at-risk individuals and HD patients.

Families are hardest hit and most vulnerable around the time of **diagnosis**. Crisis intervention and multiple social supports are necessary to help a family recover their footing.

Social work interventions are critical in addressing **financial and legal needs**, especially when an individual loses occupational skills.

Patients with juvenile HD—and **children in HD families** in general—are uniquely affected. They may lose both of their parents, one to HD and the other to the care of their affected parent. Special interventions, including a community approach to meeting the family's needs, may be needed.

Research offers patients and families hope for a cure or treatment for HD. It also increases the time they spend with their care team, and fosters a collaborative, personal and therapeutic relationship.

Would you want to know you would someday develop Huntington's Disease?

Most at-risk individuals do not seek out medical care or genetic testing until they believe they have symptoms of HD. They are a highly under-served population, represent very small numbers in observational clinical studies of HD families, and will be the most important population to study in future drug trials aimed at preventing onset of symptoms. Attracting the at-risk population into care will require compassion, commitment, and creativity!

Wendy' Story: Homework for Hope

Wendy and her two sisters moved with her parents from England to the United States when they were young. When Wendy was 14, she and her family were in a terrible car accident, which killed both of her parents. In hindsight, her father was suffering from Huntington's Disease, which may have contributed to the crash.

The three girls were sent to live with an abusive uncle, and learned the hard knocks of taking care of themselves. They formed a bond that held them together through the hardest of times, and holds them together still today.

In the late 1990s, Wendy began to develop symptoms of depression. Medications helped some, but her symptoms never completely resolved. Knowing that Huntington's Disease was in her family, she pursued genetic testing which confirmed that she indeed had the gene for HD.

Wendy worked as a nurse, but found her work more and more difficult. Her depression worsened, until the only thing she was able to do was her job. Bills were lost or left unpaid, and housework accumulated. She began to drop things, stumbled occasionally and hit the sides of her garage while parking her car. Her neurologist suggested that she inform her employer that she had HD and consider disability. When she informed her employer, she was abruptly terminated, losing all of her benefits. She took a nursing job answering questions by phone, but continued to have problems at home, resistant depressive symptoms and even some temper outbursts which were very much out of character for her.

In 2007, she began to see a member of the HD Clinics on a monthly basis. The mountain of problems she felt she faced was separated into individual monthly goals, and she was assigned "homework" after each clinical visit. First, a new antidepressant regimen was started, and applications to drug companies for compassionate use were made. She went on short-term disability and—after many applications and countless phone calls—finally saw long-term disability approved. She allowed her sister to help with management of her finances, and eventually moved into her sister's home for safety as well as financial reasons. Without work, she created a new daily routine that included predictability, exercise, good nutrition and enjoyable activities. The hardest decision was surrendering her driver's license and creating new transportation options, but she did so with grace. Communications with her family about her wishes began with conversations about the loss they all experienced with her illness. She enrolled in HD studies at Wake Forest University, and recruited her adult children to participate as well. Her current "homework" is to evaluate what activities and goals will make the next stage of her life worthwhile to her. Fourteen months into treatment in the HD Clinic, with depressive symptoms and the pressing social issues behind her, she is free to determine what makes life with Huntington's Disease worth living. It's not that there aren't bad days, but there is also hope for good times to come.

Our Mission Statement:

Providing access to care, education and social assistance for patients and families affected by Huntington's Disease in North Carolina.

Recognizing the long-standing need in our state, North Carolina clinicians, scientists and members of the Board of Directors of the NC Chapter of HDSA came together in March 2008 to discuss how to improve care and support for HD families in North Carolina.

The resources were available: the HD Clinical Sites at Wake Forest University and Duke University were already providing expert clinical care to patients and families. Psychiatric care geared to meet the needs of HD families was available. Ancillary care providers had important skills to offer, and research opportunities were available. Predictive genetic testing services was well organized at the University of North Carolina at Chapel Hill.

However, the obstacles were clear: Each of the three main tertiary care centers with HD expertise could make a unique contribution to clinical care, but full collaboration at a single location was precluded by institutional and geographic separations. Care was being provided, but not in an integrated fashion, and not in conjunction with necessary social services support.

There is both the need and the opportunity to improve access to the expert care that is so urgently needed by HD patients and their families in the state of North Carolina, by creating the NC Center for the Care of Huntington's Disease. Because all core areas of medical care already exist at various clinical sites in the state, the NC-CCHD will be able to leverage these invaluable resources with only a modest level of additional support in order to bring expert care to all—care that is currently beyond the reach of most who suffer from HD in our state.

From these discussions, the concept of a "Virtual Care Center" was created in order to collaborate and share resources. The mission of the North Carolina Center for the Care of Huntington's Disease (NC-CCHD) was established. The creation of the NC-CCHD provides the ability to join our state's resources together in a coordinated fashion and to bring these services to HD patients and families throughout the state. The NC-CCHD focuses on integrating:

Clinical Services:

- Crisis Intervention
- Coordinated intake into NC-CCHD
- Streamlined collaboration among members of the HD care team
- Referrals to programs that can provide financial, housing, pharmaceutical, and other means of support necessary to manage HD
- Caregiver Support and Education
- Web-based resources for home-bound families and community physicians

Advocacy Efforts:

- Partnership creation with existing programs that provide clinical services needed by HD families
- Advocacy to government programs, such as NC Disability Determination, Hospice programs, and other organizations to develop guidelines to make services and benefits more accessible to HD patients and families
- Education and outreach to community clinicians, hospitals and nursing homes

Huntington's Disease

Family

Government Resources

SSDI, Medicare, Medicaid

Crisis Intervention

Duke HD Clinic

WFU HD Clinic

UNC Genetic Testing Clinic

HD Psychiatry Clinic

Ancillary Care

NC HDSA

Support Groups, Educational Meetings

Support Organizations

Hospice, Respite Providers, Long-Term Care Facilities

Community Providers

MDs, Therapists, Ancillary Professionals

Charitable Organizations

Drug Assistance Programs, etc.

NC-CCHD Founding Medical Leadership

The core clinical personnel have been actively involved in the formation of the Center. Their leadership will direct the clinical activities and programs of the North Carolina Center for the Care of Huntington's Disease.

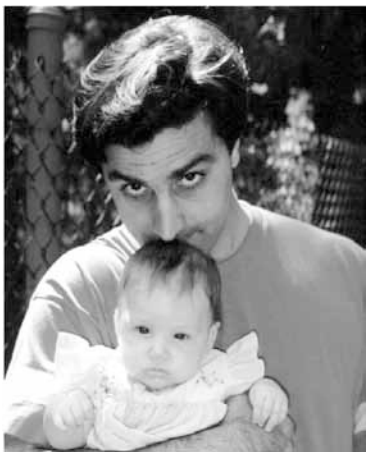
Francis O. Walker, MD, Professor Of Neurology and Director of the Movement Disorder Clinic at Wake Forest University, has had significant involvement in clinical care and research in Huntington's Disease for over 25 years. In addition to his extensive involvement with the Huntington's Study group as a leader and site investigator over the years , he is currently the Principal Investigator of CHDI's Global Database Project. Dr. Walker also provides clinical care for 150 HD patients per year, participates in six ongoing active clinical trials for Huntington's disease, and serves on steering committees that review and coordinate two additional multi-center clinical trials. His leadership, experience and participation in the NC Center for the Care of Huntington's disease are invaluable.

Mary C. Edmondson, MD is a Clinical Consultant in Psychiatry at Duke University and Director of the Consult-Liaison Psychiatry service at Duke Raleigh Hospital. She has been involved in the care of Huntington's disease for most of her life. In 1981 she organized the first meeting of NC HD families at Duke University. She provides ongoing psychiatric care to HD patients and their family members through her private practice and the HD clinics of both the Duke and Wake Forest University Medical Centers. After her father lost his battle with Huntington's disease in 1995, Dr. Edmondson personally underwent genetic testing. Although fortunate to have tested negative for the gene, her experience with her family's illness continues to provide a unique perspective in the care of Huntington's disease.

Burton L. Scott, PhD, MD, Associate Clinical Professor of Neurology at Duke University is a member of the Duke Movement Disorders Clinic. After the completion of his residency at Duke University and fellowship training in movement disorders at Baylor College of Medicine, he joined the Duke faculty in 1995. Over his career, he has been very active in the care of HD patients and their families. As a new member of the Huntington's Study Group, he participates in two ongoing clinical trials. He leads a dedicated group of clinicians who will provide the opportunity for expanded HD care in North Carolina.

Debbie Keelean-Fuller, MS, CGC, developed the HD Genetic Testing Program at the University of North Carolina at Chapel Hill. In addition to managing this program, Debbie serves as Chairman of the Family Services Committee for the NC Chapter, organizes the annual NC HDSA meeting each fall, participates in the Triangle Support Group as a speaker and facilitator, and incorporates teaching about HD to second year medical students in her genetics class each year.

Victoria P. Hunt, RN, BSN recently retired after 21 years as a Nurse Clinician in the Movement Disorders Clinic in the Department of Neurology at Wake Forest University School of Medicine. Although her work was diverse, her love has always been HD patients and their families. She contributed to the Huntington's Study Group, serving on the executive committee, steering committee and as a site study coordinator in numerous clinical trials. She has been a speaker at state and national meetings and has published manuscripts dealing with the dilemma of being at risk for HD and the problems of dysphagia in HD. Although recently retired, Mrs. Hunt participates in the HD clinic at Wake Forest University as a volunteer. Her vast experience with the day-to-day problems facing HD patients and families makes Mrs. Hunt's expertise an invaluable resource for North Carolina families and The North Carolina Center for the Care of Huntington's Disease.



Huntington's Disease, although tragic for its victims, provides an opportunity to make a huge difference in the lives of others. The North Carolina Center for the Care of Huntington's Disease can offer hope and dignified solutions to the challenges facing HD families. With your generosity, we can directly and immediately change today's sad reality into a life worth living for current victims, and a future without fear for their children.

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