

Movement Disorder Digest

News from the Johns Hopkins Parkinson's Disease and Movement Disorders Center

Fall 2015

Moving for Parkinson's

Pacing 4 Parkinson's Team Highlight: "Stan's Fans"

Pacing for Parkinson's (P4P) is a charity team that participates in the Baltimore Running Festival and raises money for the *Johns Hopkins Parkinson's Disease and Movement Disorders Center.* The team has raised over \$500,000 and attracted over 300 annual runners and walkers. This event has become a family affair with many



individuals and teams running in honor of or for someone living with Parkinson's disease (PD).

Stanley Morris, a beloved husband, father, grandfather, and friend, has been on his journey with Parkinson's disease for over 8 years. His three daughters (now committee members) created **Team Stan's Fans** to show their support and will be participating for the 3rd year with over 15 team members. Read more about the Morris family on *page 6*.

Join us for the **7th Annual Pacing 4 Parkinson's on Saturday, October 17, 2015** by participating in the 5k, half marathon, marathon, or team relay. Visit the website at **www.pacing4parkinsons.org** or call Bailey Vernon at 410-616-2811 to learn more about the team or support the cause.

Moving Day DC®

Team Highlight: "Team Shake it Off"

Stephanie Stull decided she wanted to challenge herself to do something big, and she did! PD had taken over her life, but the **National Parkinson Foundation Moving Day** provided a new chance for her to move forward. She lives each day with her mantra "be brave, be strong, be you", which she shared on stage at the walk. She embraces those words and now lives life fully with PD.

When Stephanie finally shared her diagnosis, she was overwhelmed with support and quickly became the top fundraiser by raising over \$16,000. Stephanie's family, friends, and co-workers walked with her on June 7, 2015 as Team Shake it Off. Pictured to the right is Stephanie and her mother, Shirley Boon, accompanied by our team members Bailey Vernon and Nadine Yoritomo.



Program Highlights

Long-Term Care Ombudsman Parkinson's Disease Advocacy Training - April 16, 2015

The Maryland Department of Aging Long-Term Care Ombudsman office invited our Center to train their employees on PD. Ombudsman specialists serve as advocates for residents in long-term care facilities and train volunteer advocates throughout the state. The curriculum was created by Becky Dunlop, with input from the following team members: Arita McCoy, Bailey Vernon, Jenna Zehler, and Stevanne Ellis. Attendees emphasized that this program will greatly enhance their PD advocacy.

Ataxia Wellness Program -March & April 2015

For six weeks, seven individuals with ataxia and their care partners attended the Ataxia Wellness Program created by Bailey Vernon. The program provided exercise, education, and social support. Each participant was given a specialized home exercise program and had the opportunity to try yoga, Qi gong, Pilates, and dance.



PD Educational Series - Coming Soon!

3rd Wednesday of Every Month October 2015 - December 2016 7:00 p.m. - 9:00 p.m. St. Thomas Episcopal Church, Towson, MD

Those with PD and their families and friends are invited to attend these free informational sessions that will feature a guest speaker each month.

Please refer to page 7 to learn more about the center's outreach & education programs.

SPECIALTY CENTERS

Ataxia Center

Liana S. Rosenthal, MD, Director of the Johns Hopkins Ataxia Center

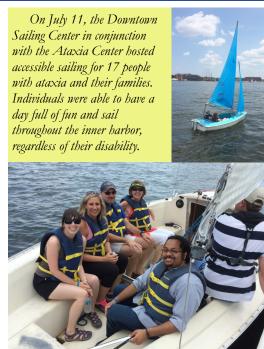
Ataxia is defined as the presence of abnormal, uncoordinated movements and may result from abnormalities in different parts of the nervous system. The Ataxia Center offers a multidisciplinary approach to the identification and treatment of cerebellar ataxia.

With the support of the **Gordon and Marilyn Macklin Foundation** and the **National Ataxia Foundation**, the center has added new faculty and allied health professionals to the multidisciplinary clinical team, initiated new outreach programs for both the patients and their care partners, and expanded research initiatives. The multidisciplinary team includes 4 neurologists, 2 fellows, 4 specialists, a center coordinator, a genetic counselor, a nurse, a health educator, 2 occupational therapists, 4 physical therapists, and 2 speech therapists.

There are 5 research laboratories conducting cutting-edge ataxia research to help develop better treatments and diagnostic tools.

- ♦ Cognitive Neuropsychiatric Research Lab
- ♦ Eye Movement and Vestibular Research Lab
- Study of Motor Learning
- ◆ Lab for Medical Image Computing, which includes the *Natural History of Genetic Modifiers in Spinocerebellar Ataxia*
- ♦ Motion Analysis Lab at Kennedy Krieger

The Ataxia Center has a robust outreach and education program that includes support groups, seminars, social clubs, and more. To learn more about these programs or request educational information, please contact Bailey Vernon at 410-616-2811 or bvernon1@jhmi.edu. To reach the Ataxia Center Clinic Coordinator, please call 410-502-0133, option 1.



Atypical Parkinsonism Center

Alexander Pantelyat, MD, Director of the Johns Hopkins Atypical Parkinsonism Center



A Center Update

By Alexander Pantelyat, MD

The atypical parkinsonian disorders include **corticobasal syndrome** (CBS), **dementia with Lewy bodies** (DLB), **progressive supranuclear palsy** (PSP), and **multiple system atrophy** (MSA). These "cousins" of Parkinson disease (PD) share some of the same symptoms, but generally do not

respond well to available PD treatments and progress faster than PD. This leads to significant disability and shortens patients' lifespans.

While these disorders are less common than PD, they are often more difficult to diagnose, leading to delays in access to necessary care. The Johns Hopkins Atypical Parkinsonism Center is dedicated to the provision of the best care possible to the patients and families living with atypical parkinsonism. We endeavor to provide multidisciplinary, state of the art care to these individuals while advancing the science and knowledge of atypical parkinsonism through research initiatives and

professional education.

Our community outreach and educational programs offer additional support, and aid in raising much-needed awareness of these disorders in our society. Our monthly multidisciplinary atypical parkinsonism research clinic is truly patient centered: as the patients and their family members stay in the same room, they are seen by members of a dedicated team.

First they see our nurse outreach coordinator Becky Dunlop who discusses a number of quality of life issues and helps arrange available support. They then see me and discuss medication management and the overall plan of care. After this they have sessions with physical, occupational, and speech/swallow therapists who are experienced in atypical parkinsonism. There is also time for discussion and enrollment in several ongoing research studies at our center. Finally, the day ends with a multidisciplinary meeting when the overall plan of care is discussed with each team member.

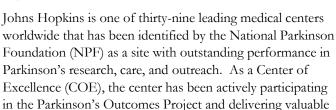
It is our goal to establish the model for an Atypical Parkinsonism Center of Excellence that would be replicated throughout the world.

SPECIALTY CENTERS

A National Parkinson Foundation Center of Excellence

Zoltan Mari, MD, Director of the Johns Hopkins NPF COE

educational resources.



Parkinson's Outcomes Project - The center has been participating in this initiative since 2009 to help develop the best patient outcomes. *See page 4 for more information.*

Aware in Care - The NPF Aware in Care kit helps a person with PD advocate for better care during a hospital stay.



Rainbow Series - NPF's educational books and new caregiver handbook are free to the community and provide valuable information.



Visit www.parkinson.org or call the NPF Helpline at 1-800-4PD-INFO (1-800-473-4636) to learn more about the resources available.

The Morris K. Udall Parkinson's Disease Research Center of Excellence

Ted Dawson, MD, PhD, Director of the Johns Hopkins Udall Center



Congress created the Morris K. Udall Centers of Excellence for Parkinson's Disease Research to help develop new clinical treatments for PD. One of 10 sites nationwide, the JHU Udall Center engages in a wide range of research initiatives to study the disease process. The **Udall Center Longitudinal Study** and **Brain Donation Program** are currently enrolling those with PD or atypical PD and those without a neurological diagnosis. *See page 4 for more information*.

Dystonia Center

Zoltan Mari, MD, Director of the Johns Hopkins Dystonia Center Dystonia is a neurological condition defined as a sustained muscle contraction with a very broad range of manifestations. There are many treatment options for dystonia that the center explores with patients, including botulinum toxin injections, pharmacological treatments, and in some cases, deep brain stimulation. The NIH Dystonia Coalition research project seeks to better understand dystonia. See page 5 for more information.

Deep Brain Stimulation Center

Kelly Mills, MD, Associate Director of the Johns Hopkins DBS Center



What's New at the DBS Center By Kelly Mills, MD

Movement disorders including Parkinson's disease, dystonia, and essential tremor, can be treated with surgery when medications are ineffective at suppressing movement symptoms of these diseases. In Deep Brain Stimulation (DBS) surgery, a small electrode is placed deep into the brain to help "reset" the abnormal

circuitry that causes movement symptoms such as tremor, slowness, stiffness, and/or dystonia. In dystonia and essential tremor, this procedure is typically used when the movement symptoms are refractory to medications. In PD, DBS helps the movement symptoms that respond to medications but reduces the "wearing-off" that some patients feel between their medication doses. Patients are evaluated for DBS candidacy by our multidisciplinary team, including specialists from neurology, neurosurgery, neuropsychology, psychiatry, nursing, and other allied health providers.

The DBS procedure has traditionally been done with the patient awake so that symptoms could be tested during the surgery to ensure appropriate placement of the electrode. Johns Hopkins DBS Center now offers some patients surgery using **Clearpoint® Interventional MRI system** (iMRI- DBS), which allows patients to undergo DBS surgery while under general anesthesia using real-time MRI guidance. Patients can stay on medications and do not have to be awake during surgery.

At Johns Hopkins, we have also expanded the number of neurologists caring for DBS patients and the locations at which we provide this care. In addition to the DBS clinic at the East Baltimore campus, we now offer a DBS-related clinic at our Auburn Avenue location in **Bethesda**, which is affiliated with **Suburban Hospital**.

As part of our educational mission, the center arranges bi-annual **DBS Information Sessions** in the evenings to educate patients and their families on DBS and its uses. These sessions are open to the public, regardless of whether patients are seen at our center or elsewhere. For more information, please refer to *page 7* or contact Bailey Vernon at **410-616-2811** or **bvernon1@jhmi.edu**.

RESEARCH

Enrolling Research Studies

Please contact Becky Dunlop, RN, MS, *Associate Director* at **410-955-8795** if you are interested in research at the Johns Hopkins Parkinson's Disease & Movement Disorders Center or have any questions.

Condition	Title	Objective	Eligibility	PI	Contact
Parkinson's disease	National Parkinson Foundation Patient Registry	Develop quality care standards for PD	All PD patients and care partners seen at the center	Zoltan Mari, MD (NA_00036863)	Becky Dunlop 410-955-8795
Parkinson's disease	MARK-PD	Identify biomarkers for PD and PD-related cognitive impairment	Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis	Liana Rosenthal, MD (NA_00031749)	Nadine Yoritomo 410-616-2822
Parkinson's disease	Genetic Cohort	Identify genetic links to PD and learn how the LRRK2 mutation affects certain populations of people (Part of the Michael J. Fox Foundation Parkinson's Progression Markers Initiative)	1.) Individuals diagnosed with PD who are of Ashkenazi Jewish decent 2.) Individuals without PD who are of Ashkenazi Jewish decent AND have a first degree relative with PD	Zoltan Mari, MD (NA_00039232)	Arita McCoy 410-955-2954
Parkinson's disease	STEADY-PD	Determine if isradipine alters disease course	Individuals with PD who are not treated	Kelly Mills, MD (NA_00038373)	Becky Dunlop 410-955-8795
Parkinson's disease	Adamas 302 (blinded) and 304 (placebo control)	Determine safety and effectiveness of new extended release formulation of Amantadine (Amantadine HCL) to treat dyskinesia	Individuals with PD who have untreated dyskinesia	Kelly Mills, MD (NA_00056431) (NA_00056432)	Becky Dunlop 410-955-8795
				Shawn Smyth, MD (ADS-AMT-PD304) (Adjunct Faculty, PDMD Center in Howard County)	Erica Stacy 443-755-0030
Parkinson's disease	Anxiety in Parkinson's	One day visit to assess anxiety symptoms in PD	All individuals diagnosed with PD	Gregory Pontone, MD (NA_00092051)	Kate Perepezko 410-614-1242
Parkinson's disease	MRI PD Study	One day visit to explore the relationship between cognition (e.g. memory) and emotion in PD	Individuals diagnosed with PD and those without PD	Gregory Pontone, MD (NA_00087276)	Kate Perepezko 410-614-1242
Parkinson's disease and related disorders	Udall Center Longitudinal Study	Examine the relationship between the clinical symptoms of PD and the disease process in brain tissue (participation includes eventual brain donation)	Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis	Liana Rosenthal, MD (NA_00032761)	Catherine Bakker 410-616-2814
Parkinson's disease and related disorders	Udall Center Brain Donation Program	Examine the pathological changes in the brain tissue of individuals diagnosed with PD or related disorders as compared to controls	Individuals diagnosed with PD or atypical PD and those without a neurological diagnosis	Liana Rosenthal, MD (NA_00032761)	Catherine Bakker 410-616-2814

RESEARCH

Enrolling Research Studies

Please contact Becky Dunlop, RN, MS, Associate Director at 410-955-8795 if you are interested in research at the Johns Hopkins Parkinson's Disease & Movement Disorders Center or have any questions.

Condition	Title	Objective	Eligibility	PI	Contact
Parkinson's Disease	Parkinsonics	Study of group singing for quality of life and voice outcomes in PD	All individuals diagnosed with PD	Alex Pantelyat, MD (NA_00065196)	Becky Dunlop 410-955-8795
Parkinson's disease	Transcranial Direct Current Stimulation	Test the therapeutic relevancy of non-invasive brain stimulation for improving motor symptoms	All individuals diagnosed with PD	Reza Shadmehr, PhD (NA_00081426)	Yousef Salimpour 410-350-6241
Parkinson's Disease	Cerebellar Hyperactivity in PD	Study how cerebellar hyperactivity influences gait and balance in individuals with PD with transcranial direct current stimulation	Individuals with PD who have gait and balance difficulties	Amy Bastian, PhD (NA_00052263)	Tjitske Boonstra 443-923-2716
Movement Disorders	Genetic Characterization	To study the genetic risk factors involved in movement disorders	Individuals with PD, atypical parkinsonisms, dystonia, ataxia, and Lewy body dementia	Jeffery Rothstein, MD, PhD (NA_00055442)	Sonja Scholz, MD 240-271-5297
Dystonia	Dystonia Coalition	Create repository to learn more about dystonia	Individuals over the age of 18 who have primary dystonia	Zoltan Mari, MD (NA_00074297)	Becky Dunlop 410-955-8795
Sialorrhea (drooling or excessive salivation)	Mysticol	Investigate the efficacy of Botulinum toxin type B injection to treat troublesome sialorrhea	Individuals who have untreated excessive salivation due to any cause	Zoltan Mari, MD (NA_00084484)	Becky Dunlop 410-955-8795
				Joseph Savitt, MD, PhD (SN_SIAL_301) (Adjunct Faculty, PDMD Center in Howard County)	Erica Stacy 443-755-0030

New Research Initiatives

Parkinsonics - Alexander Pantelyat, MD

The loss of voice volume and clarity is a common problem in Parkinson's disease, and several studies have evaluated the effects of singing in a choir on patient's voice quality and several other outcomes. While results so far have not been conclusive, the proliferation of PD choirs throughout the world and in the U.S. indicates that patients are experiencing benefits. A study of group choir-based singing for PD at Johns Hopkins, the **Parkinsonics** is under way.

This research study is supported by the Dunlop Outreach & Education Fund and Pacing 4 Parkinson's. If you are interested in participating, please contact Becky Dunlop at 410-955-8795.

Cognition & DBS - Kelly Mills, MD

Deep brain stimulation (DBS) is a FDA-approved neurosurgical procedure that can help alleviate the symptoms caused by Parkinson's disease and other movement disorders.

Dr. Mills is investigating how DBS might affect memory, language, problem-solving, or changes in thinking or behavior. A questionnaire is conducted after DBS surgery to assess cognitive changes. Those with Parkinson's disease who have received DBS at Johns Hopkins Hospital are eligible to participate. If you are interested in learning more, please contact Becky Dunlop at **410-955-8795**.

A Family Affair - Parkinson's Disease Dementia

Judy Morris and her three daughters, Dodie, Laurie, and Cheryl, share their experience in caring for their beloved Stanley Morris.



The Morris Family - (From left to right) Judy Morris, Cheryl Manser, Stanley Morris, Laurie Kimbel, and Dodie Syzmanski

Stanley was diagnosed with Parkinson's disease (PD) in 2007 at age 72. Married for 52 years at the time, his wife Judy noticed signs of change in his personality and daily habits which were inconsistent with his normal behavior. He was always very busy around the house and very social. He started to seem withdrawn and was not participating in conversations as much, which family and friends also noticed.

The disease progressed slowly over the first few years and then Judy started to notice more changes in his mental ability than in his physical movement. In 2009, he was diagnosed with dementia associated with his PD. The progression has been faster than hoped and the dementia is now the bigger issue.

In Judy's words, "It's like caring for a 150 pound baby. I see that medications are given on time, his personal hygiene is maintained, his nutritional needs are met and these are just a few issues that are faced daily. The dementia creates a whole new perspective for the primary caregiver. It takes constant monitoring throughout the day and night, and takes an enormous toll emotionally and physically on the caregiver as the disease progresses."

Stanley and Judy's daughters (Laurie, Cherie, and Dodie) take turns walking with him or engaging him in a conversation that will jog old memories. They also stay with their dad when their mom takes a few days away with her sisters or an evening out. Judy has also tapped into home care and day care facilities for respite care. Family events are also very important and it's crucial that Stanley remains a part of these gatherings.

He has always been an exercise enthusiast. Laurie says, "At 5 years old I remember sitting on Daddy's feet while he did his sit-ups and I jogged around the house behind him with my hands in his back pockets. He always had a weight bench and stationery bike in the basement. I know my Dad has influenced my dedication to live a healthy lifestyle."

Dodie says, "It may be cliché but my Daddy inspires me. It just happened to take me quite a while to realize his impact. He was my first fitness role model. I can't remember a time he didn't workout and his workouts were old-school to include homemade chin-up bar, boxing bag, sit-ups, and push-ups. To this day at 80 years old with 8 years of PD my Dad still exercises every day, whether it be a few toe touches, a walk, bicep curls, and always at least one push-up. If he can do it, I can too, and that is why he inspires me, therefore my involvement in Pacing 4 Parkinson's."

Cheryl says her work ethic comes from her dad. "From the time I was very young, my Dad worked shift-work at Bethlehem Steel, only taking time off for a family vacation. And when he was home, there was always a home project that we helped him with – he was always working on something, from building a carport to remodeling a bathroom – he kept his hands busy all the time and he was always so good at what he did."

Exercise has been the constant in Stanley's life and it has kept him mobile to this point. Though the falls are more frequent and his balance and gait are worse, he is still able to stand on his own two feet.

The family became involved with the JHU PDMD Center by joining Pacing 4 Parkinson's and creating team Stan's Fans. The Morris family has been participating annually in the Baltimore Running Festival since 2013 and all three daughters have joined the committee. They have been an invaluable asset to the team by raising thousands of dollars and recruiting dozens of team members. For race day, Cheryl and her husband, John, bring their RV, which allows Stanley and Judy to participate in the festivities, and join the rest of the P4P team. The Morris Family, including grandchildren, make their participation in P4P a fun family affair.

Judy says, "Our constant support is our family, including our grandchildren and my two sisters whom without their love and understanding, we could not have made it through this journey. I cannot say how important this is to anyone suffering a disease of this magnitude. Our connection to our local Senior Center and the Johns Hopkins Support Groups has been invaluable."

"Our family is grateful for the JHU PDMD Center team and the work they do to promote a better understanding of PD, support families, and actively engage in important research to improve care and treatment of this devastating disease."



Parkinson's Outreach & Education Programs

These programs are presented by the *Johns Hopkins Parkinson's Disease and Movement Disorders Center* and made possible through the center's Dunlop Outreach and Education Fund, Pacing 4 Parkinson's, and our generous donors. Pre-registration is required for all programs listed below. Please contact Bailey Vernon at **410-616-2811** or **bvernon1@jhmi.edu** to register or learn more about these programs. Visit our website at **www.hopkinsmedicine.org/neuro/movement** for a full listing.

♦ Parkinson's Disease Educational Series - NEW!

3rd Wednesday of Every Month October 2015 - December 2016 7:00 p.m. - 9:00 p.m. St. Thomas Episcopal Church 1108 Providence Road, Towson, MD 21286

♦ Pacing 4 Parkinson's Saturday, October 17

7:00 a.m.

Baltimore Running Festival M&T Bank Ravens Stadium www.pacing4parkinsons.org



♦ Newly Diagnosed Parkinson's Disease Educational Forum Friday, October 23

9:00 a.m. - 12:00 p.m. St. Thomas Episcopal Church 1108 Providence Road, Towson, MD 21286 Register online - http://tinyurl.com/PDNewlyDiagnosed

♦ Support Group Leader Networking Meeting Thursday, October 29

10:00 a.m. - 2:00 p.m. St. Thomas Episcopal Church 1108 Providence Road, Towson, MD 21286

♦ Deep Brain Stimulation Information Session Wednesday, November 4

6:00 p.m. - 8:00 p.m.

Green Spring Station, Pavilion II, 1st Floor Conference Room 10753 Falls Road, Lutherville, MD 21093

Register online - http://tinyurl.com/JHUDBS

Support Groups

A diagnosis of PD or a related movement disorder can lead to many difficult emotions. It is a challenge to learn how to cope with those feelings along with the stress of diagnosis and treatment. Education and support groups can be an essential key to successfully coping and managing the disease.

If you are interested in finding a group locally, starting a new group, joining a specialty group for those with atypical parkinsonism, or volunteering; please contact Bailey Vernon at **410-616-2811** or **bvernon1@jhmi.edu**.

Fundraisers

♦ Poppin' Pigeons for Parkinson's

Saturday, September 12

Trapshooting and pig roast to benefit Pacing 4 Parkinson's Newark, DE Elaine Keys, 856-332-3380 http://pigeons4parkinsons.whindo.com

♦ Walk Off Parkinson's

Sunday, September 13

To benefit the PFNCA
Nationals Park, Washington, D.C.
PFNCA, 703-734-1017
www.parkinsonfoundation.org

♦ Bev Battles Parkinson's

Saturday, October 10

Evening fundraiser with entertainment and raffles to benefit Parkinson's research at Johns Hopkins & University of Maryland Parkville American Legion 2301 Putty Hill Avenue, Baltimore, MD 21234 Mike Bruno, 443-250-5470

Dancing with Parkinson's

♦ Dancing with PD

Every Monday, 2:00 - 3:20 p.m. (Starts Sept. 21) Roland Park Place, Baltimore, MD

Every Thursday, 4:30 - 6:00 p.m. (Starts Sept. 10) Goucher College, Decker Sports and Recreation Center - Todd Dance Studio, Towson, MD Ellen Talles, 410-878-7164 or ellentalles@comcast.net

Local Parkinson's Organization

♦ Maryland Association for Parkinson's Support (MAPS)

www.marylandparkinsonsupport.org info@marylandparkinsonsupport.org 443-470-3223

MAPS is a local non-profit organization dedicated to providing meaningful programs that will support the entire PD community. Contact MAPS if you are interested in supporting the cause, volunteering, or receiving updates.

The Johns Hopkins Parkinson's Disease and Movement Disorders Center

The Johns Hopkins Parkinson's Disease and Movement Disorders Center is dedicated to the tripartite mission of education, research, and excellent care of those living with movement disorders.

Johns Hopkins Outpatient Center 601 North Caroline Street, Suite 5064, Baltimore, MD 21287

410.502.0133 www.hopkinsmedicine.org/neuro/movement

Zoltan Mari, MD, *Director* Becky Dunlop, RN, MS, *Associate Director*

Please consider supporting our center! The work of the Johns Hopkins Parkinson's Disease and Movement Disorders Center would not be possible without the generous support from our patients and the community. For more information about supporting the center, please contact the Development Office at 443-287-7877.

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Disclaimer: The Movement Disorder Digest is published by the Johns Hopkins Parkinson's Disease and Movement Disorders Center to provide timely and useful information. Every effort has been made to verify the accuracy of the content. However, this newsletter is not intended to provide specific medical advice, and individuals are urged to follow the advice of their physicians. The PDMD Center is not responsible for the information or opinions expressed in its articles. If you prefer not to receive fundraising communications from Johns Hopkins Medicine, please contact us at 1-877-600-7783 or FJHMOptOut@jhmi.edu. Please include your name and address so that we may honor and acknowledge your request.

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