

## **Personal Information**

**Full Name:** Claudia M. Testa, M.D., Ph.D.

**Title:** Founder and Director of the VCU Huntington Disease Program, Joan Massey Clinical Chair in Parkinson Disease, Medical Director of the VCU Parkinson's and Movement Disorders Center

**Business Name:** Virginia Commonwealth University Parkinson's and Movement Disorders Center

**Business Address:** 1101 East Marshall Street, Richmond, VA 23298

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**Email:** claudia.testa@vcuhealth.org

**Languages Spoken:** English

## **Professional Summary**

### **Primary Departmental Specialization Area/Field**

Movement Disorders

### **Areas of Expertise and Interest**

Clinical and translational research in movement disorders

Huntington disease, essential tremor, dystonia, ataxia, Parkinson disease

Interaction of phenotypes and genetic risks in neurodegenerative disorders

Essential tremor impact of phenotyping on clinical care and molecular genetics

## **Education**

### **Post Graduate**

Movement Disorders Fellow, Emory University, Atlanta GA  
07/2000 - 09/2001

Chief Resident, Neurology, Partners Program, Boston MA  
07/1999 - 07/2000

Resident, Partners Program, Departments of Neurology, Massachusetts General Hospital and Brigham and Women's Hospital, Boston MA  
06/1997 - 07/1999

Intern, Department of Internal Medicine, Beth Israel Hospital, Boston MA  
06/1996 - 06/1997

Summer Institute in Statistical Genetics  
Dept of Biostatistics, University of Washington

Module One: Probability and Statistical Inference  
06/2008

Academic Healthcare Finance for Faculty  
Six week faculty development series  
Course director: Melinda Hancock, CFO VCU Health Systems  
02/2018 - 03/2018

## **Graduate**

Masters of Science in Clinical Research (MSCR), Emory University, Atlanta GA  
Movement Disorders in Galactosemia; Dr. Judith Fridovich-Keil and Dr. Stewart Factor  
09/2007 - 05/2012

MD, University of Michigan, Ann Arbor MI  
Cum Laude; Fellow, Medical Scientist Training Program  
08/1988 - 06/1996

PhD Neuroscience, University of Michigan, Ann Arbor MI  
Metabotropic glutamate receptors in the basal ganglia; Dr Anne B Young  
Cum Laude; Fellow, Medical Scientist Training Program  
1993 The Nancy Myers Anderson Fellowship, Parkinson's Disease Foundation  
1994 Individual Predoctoral National Research Service Award, NIMH  
08/1988 - 06/1996

CPGS Certificate of Postgraduate Study (Masters), Engineering, Cambridge University,  
England UK  
A software interface for a parallel processing network; Dr.Simon Garth  
Completed under a Winston Churchill Foundation Scholarship for advanced study in  
math, science and engineering at Churchill College of Cambridge University  
08/1987 - 08/1988

## **Undergraduate**

BA, Biophysics, The Johns Hopkins University, Baltimore MD  
General and Departmental Honors, Student Activities Senior Service Award with BA  
Phi Beta Kappa and Alpha Epsilon Delta  
08/1984 - 05/1987

## **Certification & Licensure**

### **Licensure**

Virginia Medical License  
06/2011

### **Certification**

Board Certified in Neurology, American Board of Psychiatry and Neurology  
Certification # 50112; Board recertification passed 3/2011, expires 2021

05/2001

## **Hospital Appointments**

Medical College of Virginia Hospitals of Virginia Commonwealth University  
09/2011 - Present

## **Academic Appointment History**

Professor (non tenure track), Department of Neurology, School of Medicine, Virginia Commonwealth University, Richmond, VA with joint faculty appointment in the VCU Parkinson's and Movement Disorders Center.

2/2012-present, Joan Massey Clinical Chair in Parkinson's Disease (endowed position)

9/2016-present, Adjunct faculty appointment, Department of Physiology and Biophysics

07/2018 - Present

Associate Professor (non tenure track), Department of Neurology, School of Medicine, Virginia Commonwealth University, Richmond, VA

09/2011 - 06/2018

Assistant Professor (non tenure track), Department of Neurology, School of Medicine, Emory University, Atlanta GA

09/2002 - 08/2011

9/2001-9/2002 Associate, Neurology, Emory University

09/2001 - 09/2002

## **Employment History**

Medical Director, VCU Parkinson's and Movement Disorders Center

07/2012 - Present

Founder and Director, VCU Huntington Disease Program

2015-present Director, Huntington Disease Society for America Center of Excellence at Virginia Commonwealth University

09/2011 - Present

Associate Director, Clinical Research, VCU Parkinson's and Movement Disorders Center

09/2011 - 07/2015

Medical Director, Huntington Disease Society of America Center of Excellence at Emory University

09/2005 - 08/2011

Director, Movement Disorders Fellowship, Emory University

07/2004 - 09/2005

Co-Director IBS 506R Basic Mechanisms of Neurological Diseases, Emory University Neurosciences Program, with Co-Director Dr. Yoland Smith, head of the Graduate Neurosciences Program

01/2005 - 12/2007

## **Special Awards & Honors**

Huntington Disease Society of America designation of the VCU Huntington Disease Program as an HDSA Center of Excellence for Huntington Disease  
Designation achieved first year HDSA accepting applications for new Centers  
Renewed annually 2015 - present  
2015

Attendee (accepted after application process), American Academy of Neurology's Women in Leadership program at the 2016 AAN annual meeting  
2016

2012-2014: MCVP Leadership Institute initial cohort  
Selected VCU medical directors and clinical leaders  
2012

Tremor Research Group, Nominated junior investigator attendee, TRG meeting on Essential Tremor  
2005

2002-2005 Dr. George C. Cotzias Memorial Fellowship,  
American Parkinson Disease Association  
2002

Individual Predoctoral National Research Service Award, NIMH  
1994

8/1987 - 8/1988 Winston Churchill Foundation Scholarship for advanced study in math, science, and engineering at Churchill College, Cambridge University, England  
1987

The Johns Hopkins University, General and Departmental Honors, Student Activities Senior Service Award with BA (Biophysics)  
Phi Beta Kappa and Alpha Epsilon Delta  
1987

## **Society Memberships**

Virginia Neurological Society  
01/2013 - Present

Tremor Research Group (TRG)  
07/2005 - Present

International Parkinson and Movement Disorders Society (MDS)  
07/2002 - Present

Huntington Society Group (HSG)  
02/2001 - Present

American Academy of Neurology (AAN)  
2000 - Present

Society for Neuroscience (SfN)  
01/1992 - Present

International Basal Ganglia Society  
06/2004 - 06/2010

## **Scholarly Activities**

### **Expert Services**

Virginia Commonwealth University site PI, first in human phase 1/2 trial novel genetic therapeutic for Huntington disease, uniQure and Huntington Study Group. Site qualification visit December 2018. (in progress)

Scientific advisory committee for protocol development, first in human phase 1/2 trial novel genetic therapeutic for Huntington disease, uniQure and Huntington Study Group.  
04/2018 - 10/2018

Virginia Commonwealth University site PI, SIGNAL, Vaccinex Pharmaceuticals and Huntington Study Group  
2018 - Present

Medscape expert panel CME program videotaped discussion: Best Practices in Huntington Disease: Exploring the Role of the Multidisciplinary Team. Discussant for roles of physical therapy, occupational therapy, and speech language pathology in HD care, and how these providers interact with patients, other HD team members, and community providers.  
2017

Medscape Live Town Hall/Symposium lecture speaker plus panel discussion of cases for "Symptomatic Treatment in Huntington Disease: Making a Positive Impact" at the 2016 American Neurological Association meeting; talks recorded for web based program.  
2016

WebMD Global MedScape expert panel videotaped discussion for a web based internationally available educational program  
2016

Invited discussant, Essential Knowledge Gaps in the field of Essential Tremor, NIH workshop meeting, Bethesda, MD, May 11-12, 2015  
05/2015

Advisor for PCORI study "Intervention and Outcomes in Duarte Glactosemia", Emory University  
2015 - Present

Steering Committee member, Transgenic Huntington's Disease Monkey Resource; PI

Anthony Chan, Emory University, funding NIH / ORIP  
2015 - Present

Virginia Commonwealth University site PI, Open-PRIDE, Teva Pharmaceuticals and the  
Huntington Study Group  
2015 - 2017

Virginia Commonwealth University site PI, PRIDE-HD, Teva Pharmaceuticals and  
Huntington Study Group  
2014 - 2016

Virginia Commonwealth University site PI, Enroll-HD, CHDI Foundation  
2013 - Present

Chairperson of Study Monitoring Committee for "Erythromycin in Parkinson's disease:  
a pilot study of its effects on levodopa pharmacokinetics and pharmacodynamics" VCU  
protocol #HM15105, Dr. Leslie Cloud PI  
2013 - 2015

Virginia Commonwealth University site PI, Clinical Studies of Dystonia and Related  
Disorders, Dystonia Coalition  
2010-2011 Emory University Co-PI, Clinical Studies of Dystonia and Related Disorders  
2013 - Present

Co-Principal Investigator, multicenter clinical trials (US, Canada, Australia) First-HD and  
ARC-HD, investigational drug for chorea in Huntington disease with Auspex  
Pharmaceuticals (now a whole owned subsidiary of Teva Pharmaceuticals) and the  
Huntington Study Group  
2012 - 2017

HopeNET (Hope for No more Essential Tremor), 501c foundation  
Board member (unpaid) 2011-2013, Medical Advisory Board member 2013-present  
09/2011 - Present

Founder, North American Essential Tremor Consortium focusing on advancing ET  
phenotyping/epidemiology and genetics. Organized and hosted initial Consortium  
meeting in Atlanta, GA August 7, 2010, attended by US and Canadian collaborators  
representing fourteen groups.  
2010 - Present

International Essential Tremor Foundation medical advisory board member, includes  
annual scientific grant application reviewing  
2008 - Present

Expert rater for European Huntington's Disease Network UHDRS-TMS video exam  
project: Expert ratings of the United Huntington Disease Rating Scale (motor section)  
were used to make consensus scores for a large library of videotaped exams,  
subsequently used to train and certify new motor raters primarily in clinical research /  
clinical trials.  
2007

Discussant, NIH F03A Neurodevelopment, Synaptic Plasticity and Neurodegeneration Fellowship Study Section  
2006

American Academy of Neurology, Neuroscience Research Prize Ad-Hoc Judge  
2004 - 2006

**Scientific Abstract Reviewer:**

American Academy of Neurology annual meetings: 2011, 2013, 2014, 2017  
Program Committee, Huntington Disease Clinical Research Symposium 2013, 2014, 2015

**Manuscript Reviewer:**

|                                    |                                   |
|------------------------------------|-----------------------------------|
| American Journal of Human Genetics | Movement Disorders                |
| Developmental Neuroscience         | Neurology                         |
| Experimental Neurology             | Neuropharmacology                 |
| Journal of Neuroscience            | Neuropsychopharmacology           |
| Parkinsonism and Related Disorders | Expert Opinion on Pharmacotherapy |
| Journal of Huntington's Disease    | PLOS ONE                          |
| JAMA Neurology                     |                                   |

**Grants and Contracts: Active**

Title: A Phase 2, Multi-center, Randomized, Double-blind, Placebo Controlled Study in Subjects With Late Prodromal and Early Manifest Huntington's Disease (HD) to Assess the Safety, Tolerability, Pharmacokinetics, and Efficacy of VX15/2503 (SIGNAL)

Role: Site PI

Estimated total direct costs \$1,085,000

Clinical Trial, Vaccinex with Huntington Study Group

Specifically solicited as expansion site for recruitment of second cohort

2018 - Present

Title: Essential tremor.

The purpose is to accelerate phenotype/genotype research with VCU as a collaborative team leader, to increase progress in understanding essential tremor and in generating effective new treatments.

Role: PI

Private bequest. Family members participated in research with Dr. Testa at Emory University and in clinical care with Dr. Testa at VCU.

Total commitment \$500,000

Direct funds = total minus MCV Foundation 4% flat rate charge

2016 sale of real estate establishes initial fund.

Summer 2017 initial funds >\$300,000 available; research coordinator hired

2016 - Present

Title: VCU Huntington Disease (HD) Program Center of Excellence (CoE)

Interdisciplinary clinical care and research providing local and regional HD families with outstanding resources to fulfill the HDSA mission of "help for today, hope for

tomorrow”.

Competitive annual renewal for both designation and (when funds available) general grant to support areas of need in clinical care programs for HD.

Role: PI

Nonprofit foundation: Huntington Disease Society of America (HDSA)

2015 designation = first opportunity to apply to new HDSA CoE program;  
no funds available.

2016 \$10,000 (\$9000 direct).

2017 \$17,500 (\$16,625 direct)

2018 \$20,000 direct

2015 - Present

Title: Dystonia Coalition Projects

Role: Site PI

NIH/NORD 5 U54 NS065701 04, subcontract to VCU

ongoing; 1% effort (variable)

2013 - Present

Title: Enroll-HD

A longitudinal multicenter multinational observational trial to understand the progressive phenotype of Huntington’s Disease (HD) and develop biomarkers leading to improved treatments.

Role: Site PI

CHDI Foundation, private non-profit

ongoing, 4% effort (variable)

2013 - Present

Title: RQ-00000010 for gastroparesis and constipation in Parkinson’s disease

This phase 1 study of a potential gastrointestinal prokinetic agent aims to test safety, tolerability, and pharmacokinetics of the agent in Parkinson’s disease patients.

Role: co-investigator; Dr Leslie Cloud principal investigator

Michael J Fox Foundation, private non-profit

ongoing, no salary support

03/2016 - Present

*VCU Parkinson's and Movement Disorders Center (PMDC) start up funding*

Title: Parkinson’s and Movement Disorders Center data registry

Role: PI. Founded registry for entire movement disorders group.

Research database driven off of PMDC clinical care visits. PMDC patients are offered the option of joining the data registry. The PMDC research team transfers relevant data fields to the data registry. Consent also includes an option to be contacted for potential participation in future research. Established initial IRB protocol, hired and paid research coordinator for further development such as REDCap database programming, continue to oversee registry.

2017 Over 1000 participants

2011 - Present

Title: A HIPAA compliant digital library for movement disorders  
Role: PI. Founded digital library for full movement disorders group.  
Repository of digital video and still clips of movement disorders cases. Consent includes yes/no options for digital material to be used for clinical care and consultation, teaching, research, and/or publication. Purchased initial video editing software and video camera, established IRB protocol, hired and paid research coordinator for further development.  
2017: over 170 entries; transitioning teaching and clinical aspects to Dr. Jon Snider  
2011 - Present

### **Grants and Contracts: Pending**

Virginia Commonwealth University site PI, first in human phase 1/2 trial novel genetic therapeutic for Huntington disease, uniQure and Huntington Study Group (HSG). Organized initial VCU site visit with scientific consulting; successfully proposed Drs Holloway and Broaddus, VCU Neurosurgery as part of site visit, neurosurgical advisory committee and now clinical trial team. Site qualification visit December 2018, site PIs meeting with sponsor at November 2018 HSG meeting. (in progress)

### **Grants and Contracts: Past**

Title: A Randomized, Double-Blind, Placebo-Controlled Study of SD-809 Extended Release for the Treatment of Chorea Associated with Huntington Disease: First Time Use of SD-809 ER in HD (First-HD)

Role: global Co-PI

Clinical Trial, Auspex Pharmaceuticals, through Huntington Study Group (HSG)

- Initial contract negotiations and protocol discussions started 9/2011
- Top line data out 12/2014
- Formal % effort ended as of 1/2015, data analysis and publication work ongoing
- Lead publication out 6/2016 in JAMA with editorial
- FDA approval 4/2017 for chorea in Huntington disease

Co-PI duties include: one of three people (with PI, Auspex CMO) drafting study protocol, and writing first drafts of key manuscripts; with PI responsible for forming steering committee, site selection, leading safety monitoring, leading internal (HSG, CRO) and full team meetings, leading site meetings, training and on boarding new HSG sites, oversight of all study conduct, participating in HSG independent data analyses.

First clinical trial for HSG as an independent non-profit; first clinical trial for Auspex as a start-up. Auspex was purchased by Teva Pharmaceuticals just prior to completion of First-HD. Sites for First-HD and ARC-HD combined covered US, Canada, Australia.

Based on this pivotal trial, the compound SD-809 or deutetrabenazine achieved FDA approval in April 2017. This is the second compound approved for a Huntington disease indication. The first, tetrabenazine, was approved about 10 years prior.

Deutetrabenazine is the first approved deuterium containing therapeutic compound.  
2012 - 2017

Title: An Open Label Long Term Safety Study of SD-809 ER in Patients with Chorea Associated with Huntington Disease: Alternatives for Reducing Chorea in HD (ARC-HD)

Role: global Co-PI

Clinical Trial, Auspex Pharmaceuticals, through Huntington Study Group

2017 ongoing 15% effort

- Initial contract negotiations and protocol discussions started 9/2011

- Initial data cut analysis out 12/2014

- Lead publication for "switch" cohort accepted 6/2017 in JAMA Neurology

Formal % effort completed December 2017, further manuscripts in process.

ARC-HD covers *two* protocols and participant cohorts: participants who completed First-HD and then chose to join the open label study; and participants who were never in First-HD, were being clinically treated with tetrabenazine, and switched overnight to open label deutetrabenazine based on a set conversion table.

Open label study participants converted to commercial product across summer to end 2017.

2013 - 2017

Title: Case management and outreach for Huntington disease (HD)

Role: PI

The Griffin Family Foundation, private non-profit

Funds targeting 40% (2 days a week) effort for social worker specifically for Huntington disease patients and families. Includes direct case work, facilitating support groups, conducting visits for staff education at long term care facilities, facilitating ability to participate in clinical research for interested families. PI role includes participating in hiring process, training in HD, interfacing with care coordination supervision, integrating social work into full Parkinson's and Movement Disorders Center (PMDC) activities.

2015 HD funds commitment secured by Dr. Testa

2015 successfully advocated for full time social worker for all PMDC patients

2016 Full time licensed clinical social worker hired for PMDC including HD

2016 Funds received from Griffin Foundation to MCV Foundation

2016 New \$10,000 donation (separate donor) to PMDC: Parkinson disease social work

2016 - 2017

Title: A Phase 2, Dose-Finding, Randomized, Parallel-Group, Double-Blind, Placebo-Controlled Study, Evaluating the Safety and Efficacy of Pridopidine 45 mg, 67.5 mg, 90 mg, and 112.5 mg Twice-Daily versus Placebo for Symptomatic Treatment in Patients with Huntington's Disease (PRIDE-HD)

Role: Site PI

Clinical Trial, Teva Pharmaceuticals with Huntington Study Group

Final direct costs approx \$112,000

2014 - 2016

Title: A Multi-Center, Open-Label Study Evaluating the Safety, Tolerability, and Efficacy of Pridopidine in Patients with Huntington's Disease (Open PRIDE-HD)

Role: Site PI

Clinical Trial, Teva Pharmaceuticals and Huntington Study Group

2015 - 2018

Title: Digital substudy arm of Open-PRIDE clinical trial.  
One of limited initial pilot sites for Teva international project on wearable technology for outcomes in movement disorders clinical trials. This pilot is attached to Open-PRIDE (above).

Role: Site PI

Clinical Trial, Teva Pharmaceuticals

*Dec 2016: VCU was site with first participant in.*

2016 - 2017

*Support transferred to other investigators at Emory University*

Title: Creatine Safety Tolerability and Efficacy in HD (CREST-E)

Role: Site PI; 2% effort while at Emory

NIH/NINDS/Huntington Study Group, Emory subcontract

09/2008 - 2014

Title: Neurobiological Predictors of Huntington's Disease (PREDICT 2.0)

Role: Motor Rater; 2% effort while at Emory

NIH/NINDS /Huntington Study Group, Emory subcontract

09/2010 - 2016

Title: The Safety and Effectiveness of Aripiprazole for Treating Irritability and Aggression in Huntington Disease

Investigator initiated double-blind placebo-controlled phase 2b clinical trial

Role: PI, in collaboration with Dr. Adriana Hermida, Emory Psychiatry (Co-PI)

Huntington Society of Canada/Huntington Study Group, private foundation funding; no industry funding but

donated investigational drug from Bristol-Myers Squibb

Total \$125,000 for entire study cost (direct plus 10% indirect); 15% effort while at Emory

9/2009 start; 10/2014 database closed; 2016-17 acting as unpaid off site collaborator for data analysis

09/2009 - Present

Title: Neurological complications in classic galactosemia

Role: PI

Atlanta Clinical and Translational Science Institute (ACTSI) PHS Grant UL1 RR025008

NIH / National Center for Research Resources, Intramural peer-reviewed competitive funding

University Research Committee (URC) pilot (funds only expended at Emory University)

Time frame compressed for move to VCU

\$15,300 for research technician time

01/2011 - 06/2011

*Support at Emory University*

Title: Validation of the TRG Essential Tremor Rating Scale (TETRAS)

Tremor Research Group (TRG), private non-profit, Emory subcontract  
Role: Site PI  
Investigator-initiated award to Dr Rodger Elble (PI) and TRG from GlaxoSmithKline  
01/2010 - 08/2011

Title: Cooperative Huntington's Disease Observational Trial (COHORT)  
Role: Site PI  
HighQ Foundation, Huntington Study Group, Emory subcontract  
2006 - 2011

Title: A Phase 3, Randomized, Double-Blind, Placebo-Controlled Safety and Efficacy Study of Dimebon in Patients with Mild-to-Moderate Huntington Disease (HORIZON)  
Role: Site PI  
Clinical Trial, Medivation  
2010 - 2011

Title: Establishment of a transgenic monkey model of Huntington's disease  
Role: Co-PI  
2R24RR018827-05A1 NCR/NIH  
2009 - 2011

Title: Neurobiological Predictors of Huntington's Disease (PREDICT-HD)  
Role: Motor Rater  
NIH/NINDS 1R01NS40068-01A1, Huntington Study Group  
09/2005 - 08/2010

Title: Emory Alzheimer's Disease Research Center (ADRC)  
Role: Co-investigator  
P50 AG025688, NIH/NIA  
09/2008 - 05/2010

Title: Pilot Huntington At Risk Observational Study (PHAROS)  
Role: Site PI  
Huntington Study Group, NIH/NHGRI/NINDS, 1R01HG02449-01  
07/2002 - 09/2009

Title: Essential tremor disease mechanisms  
Role: PI  
Emory URC via PHS UL1 RR025008 ACTSI  
Pilot funds to cover subject enrollment and some genetics costs; no salary support.  
2008 - 2008

Title: Mitochondrial dysfunction in neurodegenerative disease  
Role: PI  
K08 Mentored Clinical Scientist Development Award, NINDS, NS044267-01  
09/2002 - 08/2007

Title: Molecular genetics of essential tremor  
Role: PI  
Pilot funding awarded out of NIH PHS M01-RR00039, Emory University General Clinical

Research Center (GCRC)

One time pilot funds to partially cover linkage analyses costs; no salary support  
09/2006

Title: Mitochondrial dysfunction in Parkinson disease

Role: PI

Research Grant, American Parkinson Disease Association, nonprofit foundation  
09/2002 - 06/2006

Title: Open-label 24-week extension study of tetrabenazine for the treatment of Huntington's chorea

Role: Site PI

Clinical Trial, Prestwick Pharmaceuticals, Inc with Huntington Study Group  
06/2004 - 06/2006

Title: A randomized, double-blind, placebo-controlled, study of tetrabenazine in patients with Huntington's disease (TETRA-HD)

Role: Site PI

Clinical Trial, Prestwick Pharmaceuticals, Inc with Huntington Study Group  
04/2003 - 06/2004

Title: An open-label extension study of remacemide hydrochloride 300 mg bid in subjects with Huntington's disease

Role: Site PI

Clinical Trial, AstraZeneca, Inc with Huntington Study Group  
04/2000 - 04/2002

### **Advising and Mentoring**

Mentor, Amy Harper MD, associate professor Neurology, VCU

Supporting Dr. Harper's efforts to build a clinical research program as a new faculty member at VCU including identifying potential collaborations and mentors outside our shared department; supporting efforts to integrate clinical research and interdisciplinary clinical care programs within VCU and VCU Health.

2016 - Present

Mentor, Kelly Andrzejewski, DO, PhD, assistant professor Neurology, University of Buffalo.

Asked to support Dr. Andrzejewski's efforts to found a new Huntington disease clinical care and research program in her first post-fellowship faculty position.

In person meetings at Huntington Study Group and Movement Disorders Society conferences, periodic phone meetings.

2015 - Present

Founder and organizer, Neurology faculty human subjects research support group. Monthly 1-2 hour meetings. This has grown into an informal mentoring forum for new and mid-level faculty. Across 2016 secured invited guests (ex: head of research for VCUHealth; leadership from neurosurgery and pediatrics).

2015 - 2018

Mentor, VCU undergraduate Leena Penumalee, Guaranteed Admissions Program in Medicine. Clinical research experience and clinic shadowing.

01/2018 - Present

Mentor, Junghoon Ha, VCU MD PhD student (M4).

Currently working on proposal for clinical research experience in early spring 2019, to compliment bench science based PhD training.

Sponsored Huntington Study Group (HSG) CME4HD scholarship application.

His successful application enables Mr Ha to travel to the November 2018 HSG meeting education and mentoring sessions.

2018 - Present

Mentor, Kaitlyn Riley, VCU genetic counseling masters degree thesis project "Social Media and Sharing Genetic Testing Results".

As Director of the VCU Huntington Disease Program, hosting diverse clinical and research trainees. Facilitating contact with patient/family groups including registration for student at 2017 annual HDSA meeting as part of VCU HD Program table. Poster presentation of work accepted for November 2018 Huntington Study Group meeting.

2017 - Present

Mentor, summer volunteering, Wei-Li Suen, VCU M2 medical student.

Working with research databases, research study enrollment, and shadowing in movement disorders clinics. Class schedule permitting will participate in Dystonia Coalition observational study research visits in fall 2017.

Sponsored Huntington Study Group New Member scholarship application.

His successful application enabled Mr Suen to travel to the 11/2017 HSG meeting education and mentoring sessions.

06/2017 - 12/2017

VCU Advocates for MD-PhD Women (organizer graduated 2016)

Informal phone and in person discussions with students, facilitating connections to other MD-PhD women in their fields

12/12/2014 Lunch meeting / seminar "Career paths: choosing your own direction"  
7 students, 2 hours contact time

12/08/2015 Invited panelist for panel discussion on success in MD/PhD careers  
30 students, 1 hour contact time

07/2014 - 2016

Sponsored Huntington Study Group New Member scholarship application for VCU MD/PhD student (2017 graduate) Julie Suyama (nee Bonano).

Her successful application enabled Ms Bonano to travel to 10/2015 HSG meeting education and mentoring sessions. Current status: OB/Gyn resident at HUP, goal of research in the overlap of neuroscience and urology.

2015

Thesis committee member, Melissa Holman (nee Beyer), genetic counseling masters degree. Topic: "The Changing Demographics of Individuals Seeking Presymptomatic Genetic Testing for Huntington Disease". Graduated May 2015 from Virginia

Commonwealth University. In addition, as Director of the VCU Huntington Disease Program, mentor for IRB submission, facilitated contact with patient/family groups and HDSA Centers of Excellence for data collection, sought funds for project. Manuscript published 2018.

2013 - 2015

Supervisor for spring semester research rotation, VCU CCTR PhD candidate Eiman Aboaziza

2014

Thesis Committee member, Jim Bogenpohl, PhD candidate in Neuroscience. Topic: Mechanisms of disease in non-human primate animal models of neurodegenerative movement disorders. Graduated from Emory University. Current position: neuroscience postdoctoral fellow.

06/2007 - 06/2011

Oral dissertation exam proposal mentor, Jennifer Johnson, PhD candidate in the Graduate Division of Biological and Biomedical Sciences, Emory University.

2009

Mentor, laboratory rotation, Jaime Hatcher-Martin (nee Hatcher), MD, PhD student. Graduated from Emory University. Current position: movement disorders faculty, Emory University (under Dr. Martin).

2002

Mentor and supervisor, Lisa Miyatake, research assistant / study coordinator, Emory University. Subsequently completed medical school and residency.

2007 - 2009

Mentor and supervisor, Michael Bryant. 2004 Undergraduate student; 2004-06 Research specialist, Emory University. Subsequently completed Emory University medical school and residency.

2004 - 2006

Mentor, Emory University undergraduate honors thesis course, Sherri Rauenzahn. Subsequently completed VCU medical school (2010) and residency.

2004 - 2005

## **Presentations**

### **Invited**

#### **Internal/VCU**

*Huntington disease research update*, special Neurology grand rounds / research presentation

03/2018

*New Tremor Classification System: Advancing clinical care and research*, Neurology grand rounds

10/2017

*Spinocerebellar ataxia 19/22: Science one case at a time*, Neurology grand rounds  
10/2016

*Huntington Disease New Therapeutics for HD and Beyond*, Neurology grand rounds  
09/2015

*Huntington Disease New Therapeutics*, Neurology grand rounds  
02/2014

*Movement disorders genetics research*, Virginia Institute for Psychiatric and Behavioral  
Genetics seminar series  
02/2013

*Huntington Disease*, Medical Genetics seminar series  
02/2012

*Huntington Disease*, Neurology grand rounds  
12/2011

### **Local/Regional (Virginia but Non-VCU)**

Ask the Doctor roundtable and HD Program Updates roundtable, HDSA DC Metro  
conference, Georgetown MD  
Lead organizer: Huntington Disease Society of America (HDSA) DC Metro support  
group chapter.  
11/2017

Progressive Supranuclear Palsy patient/family event at Sheltering Arms. Invited panel  
discussant, 3 hours discussion around topics proposed by patients and families.  
Organizer: Robert Hand, DPT, Sheltering Arms.  
05/2017

Faculty, 2nd Huntington Disease education day for patients and families: Making a  
Difference. Sponsored by the HDSA Centers of Excellence at University of Virginia,  
Charlottesville VA. *Update on HD research* 30 min talk with slides; panel Q&A summary  
session.  
04/2017

Ask the Doctor roundtable and Clinical Trials Updates roundtable, HDSA DC Metro  
conference, Georgetown MD. Lead organizer: Huntington Disease Society of America  
(HDSA) DC Metro support group chapter.  
02/2016

*Essential tremor*, lecture, Virginia Association of School Nurses annual conference,  
Virginia Beach, VA (sponsor: Deb Zeller)  
11/2015

*Neurogenetics: Lessons from neurodegenerative and movement disorders*, platform  
presentation, Virginia Association of Genetic Counselors 9th Annual Virginia State

Genetics Education Conference, Richmond, VA  
05/2015

*Huntington Disease: New Therapeutics*, Eastern Virginia Medical School  
neuropathology grand rounds, Norfolk, VA  
04/2015

*Essential tremor treatment and research update*, 6th Annual Reasons for HOPE co-hosted by the International Essential Tremor Foundation Richmond Virginia support group, VCU PMDC, and the Richmond Veterans Administration Medical Center PADRECC. 60 min talk with slides, handout.  
03/2015

Ask the Doctor roundtable and HD Program Updates roundtable, HDSA DC Metro conference, Georgetown MD  
Lead organizer: Huntington Disease Society of America (HDSA) DC Metro support group chapter.  
11/2014

*Huntington Disease Therapeutics: new concepts for HD and beyond*. Virginia Beach HDSA support group guest lecture series. 15 patients and family members, 1.5 hours, handout, talk with slides and demonstration of on line clinical trial resources, and Q&A  
03/2014

*Essential tremor clinical update*, 3rd Annual Reasons for HOPE co-hosted by the International Essential Tremor Foundation (IETF) Richmond Virginia Essential Tremor support group, VCU Parkinson's and Movement Disorders Center, and the Richmond Veterans Administration Medical Center PADRECC. 50 min talk with slides, handout  
03/2012

*Huntington Disease*, University of Florida Movement Disorders Center grand rounds, Gainesville FL  
03/2012

*Clinical care and clinical research programs at the VCU Parkinson's and Movement Disorders Center*, Movers & Shakers support group invited lunch talk, handout, hour for talk and extended Q&A, 12+ attendees, Richmond, VA  
02/2012

*Essential tremor and genetics research*, IETF Richmond Essential Tremor Support Group meeting invited speaker, handout, hour and a half talk plus open discussion, 20+ attendees, Richmond, VA  
01/2012

*Update on Essential Tremor*, Meet the Experts series hosted by St Mary's Woods, Richmond, VA; 80 patient/family community members  
10/2011

*Huntington Disease Treatment*, lecture, Third Low Country HD Group conference, Savannah GA

Lead Organizer: Low Country Huntington Disease support group  
09/2010

*Juvenile Huntington Disease*, lecture, Second Low Country HD Group conference,  
Savannah GA  
09/2009

*Update on basic research in Huntington Disease*, lecture, Low Country HD Group  
conference, Savannah GA  
05/2004

## **National**

*Recent Advances in Huntington Disease*, in Recent Advances in Movement Disorders  
interactive lunch session: 15 minute talk, questions, panel discussion, American  
Neurological Association annual conference, Atlanta, GA  
10/2018

*Using economic creativity to build an HDSA Center of Excellence program*, talk and  
Q&A, with Dr Sandra Kostyk  
First in person meeting for directors of Huntington Disease Society of America (HDSA)  
Centers of Excellence in the new HDSA CoE program, Schaumburg, IL. 30+  
attendance, CoE directors and HDSA leadership  
06/2017

*Juvenile Huntington disease*: talk and Q&A, Huntington Disease Society of America  
annual national meeting, Baltimore MD  
06/2016

Galactosemia Foundation biannual conference, Atlanta GA:  
*Movement Disorders 101*: lecture and Q&A  
Faculty panel open Q&A sessions for "Generation G" teens with galactosmia  
Faculty panel open Q&A for full meeting attendance  
06/2016

Galactosemia Foundation biannual conference, Orlando FL:  
*Movement Disorders 101*: lecture and Q&A  
*Advanced movement disorders*: lecture and Q&A  
Moderator, participatory session on directions in galactosemia research  
for full meeting attendance  
Faculty panel open Q&A sessions for "Generation G" teens with galactosmia  
Faculty panel open Q&A for full meeting attendance;  
07/2014

*Movement Disorders 101*: lecture and Q&A, Galactosemia Foundation biannual  
conference, Dallas TX  
07/2012

*Motor symptom treatment*: lecture and roundtable discussion, Huntington Disease  
Society of America annual national meeting, Atlanta GA

06/2004

## **International**

National Institute of Mental Health and Neurological Sciences (NIMHANS), Bangalore, India, March 13-24, 2017 visiting professorship.

Requested seminar for neurology services, attendance approx 120: *The new Movement Disorders Society Tremor Task Force tremor classification system: impact on research and clinical care.*

Requested formal case discussant, attendance approx 60: *Siblings with cerebellar and thalamic degeneration.*

03/2017

*First Time Use of SD-809 in Huntington Disease (First-HD) and Alternative for Reducing Chorea in Huntington Disease (ARC-HD): Results from the Switch Cohort.*

Invited platform presentation, European Huntington Disease Network biannual meeting, The Hague, The Netherlands. Attendance approx 600.

09/2016

*Our Journey to the FDA: A phase III trial from start to FDA submission* invited speaker, with Sam Frank, MD.

Platform presentation to closed HSG membership portion of meeting, Huntington Study Group annual meeting, Nashville TN. Attendance approx 300.

11/2016

Invited panel discussant: *First-HD and ARC-HD initial results* as part of "HD Clinical Trials Roundup" panel; and panelist for "Lessons Learned: So You Want to be a Study PI", Huntington Study Group annual meeting, Tampa FL

10/2015

## **Posters or Other Unsolicited Presentations**

### **National**

Testa CM, Jones KC, Slobodnikova Z, Wood-Siverio C, Jones RS, Factor SA, Hermida AP. (2015) The safety and effectiveness of aripiprazole for treating irritability and aggression in Huntington disease (HD): a double-blind placebo controlled pilot study. Ninth Annual Huntington Clinical Research Symposium (Huntington Study Group).

10/2015

Johnson JM, Yu T, Jones DP, Testa CM, Chan AWS (2009) Metabolic profiling in non-human primate model of Huntington's disease reveals early disruptions in tryptophan metabolism. Third Annual Huntington Clinical Research Symposium (Huntington Study Group) November 2009.

11/2009

Rosen AR, Levey AI, Bouzyk M, Wichmann T, Factor SA, Testa CM (2006) Essential tremor phenotyping and molecular genetics. Twentieth Annual Symposia on Etiology, Pathogenesis and Treatment of Parkinson's Disease and Other Movement Disorders, Chicago, IL.

## Teaching Experience

### **Didactic and Clinical**

Director of monthly interdisciplinary Huntington disease (HD) clinic hosting trainees across multiple disciplines. This includes acting as supervisor for the HD clinic as a formal standing rotation site for VCU genetic counseling masters degree students (2016-present), leading monthly one hour staff meeting prior to clinic, communicating with faculty/trainee teams across all disciplines in clinic.

2018 to date: genetic counseling students, physical therapy student, occupational therapy student, nurse trainee

2017: social work masters student, nursing trainee, genetic counseling students

2016: physical therapy students, social work masters student, nursing trainee, genetic counseling students, psychiatry nurse practitioner trainee

2016 - Present

National Institute of Mental Health and Neurological Sciences (NIMHANS), Bangalore, India, two week visiting professorship. Supervised clinical PhD students (equivalent of specialized neurology resident), neurology residents, and movement disorders fellow in outpatient clinics. Contributed to case discussions on inpatient rounds. Contributed as faculty discussant to weekly neurology resident live patient presentations and lectures. Mentored VCU neurology chief resident on similar resident level exchange program. This was the first neurology faculty and resident exchange under a VCU - NIMHANS memorandum of understanding, and the first site in a global neurology educational program founded by Dr Soundarya Gowda, VCU neurology.

03/2017

Supervising trainees in attending movement disorders outpatient clinics, at least weekly. General movement disorders, botulinum toxin injection clinic, monthly Huntington disease clinic.

2013 to present, neurology resident PMDC movement disorders outpatient rotation

2014 onward faculty for formal integrated integrated VCU PMDC interdisciplinary clinic block

2016 onward added monthly movement disorders clinic at main hospital campus to increase resident access,

resident participation whenever resident(s) on general outpatient clinic rotation or movement rotation

2015 to present neurosurgery residents

2011 to present M3 and M4 students movement disorders clinic rotation

2011 - Present

Staffing neurology resident continuity clinic, on average twice a month with 3 residents per clinic half day

2011 - Present

Attending, inpatient neurology ward (with open ICU) and consult services, 3 to 6 weeks a year, per team up to 2-3 neurology residents, psychiatry intern, medicine

resident, neurosurgery resident, 2-4 medical students.

2011 - Present

Lectures for Neurology residents didactic education program, residents and medical students on VCU inpatient services and (by remote dial-in) VA services; 1-2 one hour sessions per academic year. Topics: Huntington Disease, Demystifying tremors, Parkinson disease, Genetic testing in adult neurological disorders.

2013 - Present

Lecturer and discussion leader, MD PhD Science and Disease (PHIS 691-002): "Finding an ataxia diagnosis". 2 hours contact time each year, with video case presentation and literature, 5-9 students.

11/2014, 11/2015, 11/2017, (scheduled 11/2018)

11/2014 - Present

Presenter, Parkinson's and Movement Disorders Center monthly educational meeting: Monogenetic Parkinson disease. Faculty, staff, medical students, residents. 30 minutes presentation time, selected references provided.

10/2018

Faculty, Medical Genetics (HGEN 527), "Neurogenetic disease". Per fall semester 3 hours contact time, 7-10 students, lecture prep, handout, also prior to lecture advising student assigned to the same day on their own 15 minute presentation topic and slides.

2013 - 2016

Supervisor, Doctorate in Physical Therapy students and genetic counseling students participating in the neurology and/or genetic counseling sections of PMDC movement disorders outpatient clinic at Reynolds Crossing (site closed 2016)

2013 - 2016

Seminar presentation, MD-PhD Program seminar series: "Movement disorders (genetics) research: opportunities to move the field forward", one hour, all MD-PhD students, open seminar series.

09/2014

VCU speaker for Kiwanis of Ashland, VA: "Tremors". Talk, discussion, handouts provided; 33 people.

03/2013

VCU Virginia Institute for Psychiatric and Behavioral Genetics seminar series, "Movement disorders genetics research"

02/2013

CME VCU talk at Southside Regional Hospital to medical faculty, Petersburg VA; "Demystifying Tremors" 1 hour talk with handout

01/2013

VCU Medical Center Seminar Series at Ginter Gardens: "Tremor: Myths, New Understanding, Taking Action". 130 attendees, hour talk plus Q&A.

07/2012

Lecture for Messina VCU exchange program students, "Huntington disease"

03/2012

VCU Medical Genetics seminar series, "Huntington Disease"

02/2012

Faculty, Emory University IBS 506R Basic Mechanisms of Neurological Diseases. Full semester course.

A neuroscience graduate program course with PhD candidate students from diverse fields (psychology, pharmacology, genetics, biomedical engineering) from Emory University and Georgia Tech. Option for advanced neurosciences undergraduates to petition to attend.

Each week 2 hour clinical overview lecture and (live) patient presentation, and 2 hour highlights of basic science lecture and graduate student presentation of key journal article and summary of week.

Recruited patient/family guests, gave disease focused lecture and patient presentation, either recruited faculty partner or gave basic science lecture, met with graduate student assigned to topic week and advised on paper review.

2005 through 2007 also Co-Director of course, with Co-Director Dr. Yoland Smith, head of the Graduate Neurosciences Program: In addition to regular faculty duties, recruited other faculty, attended all lectures, created student feedback forms, made annual letters to faculty acknowledging service and providing teaching feedback. Annually gave introductory lecture including course structure, basics of neurology terms and etiquette for interacting with volunteer patients. Graded weekly student one page write-ups of journal article. Graded final exam: a mock grant proposal covering neurobiology of a disease. Supervised teaching assistants. 2006-07 Incorporated neurology residents as well as graduate students.

*2006 student evaluation: "This is one of the best courses I have ever taken"*

01/2005 - 2011

Attending, Emory University neurology inpatient ward and consult services, 1 to 3 months per year, teams included up to 3 neurology residents, 2-3 medical students. Teaching duties included faculty supervisor of daily morning report, once a week at least. 2010 to 2011 also covered newly formed separate stroke inpatient service at the same time as covering regular ward service, supervising nurse practitioner and stroke fellow in addition to neurology residents and students.

2002 - 2011

Supervising Emory University trainees in attending movement disorders clinics, including movement disorders fellows, neurology housestaff, medical students.

2001 - 2011

Lecturer, Emory University Geriatric psychiatry fellowship lecture series: Huntington disease, one hour contact time, psychiatry fellows, faculty, and rotating students

2011

Faculty, Emory University IBS 799R MD/PhD Program Clinical Research Conference  
2007 - 2010

Lecturer with live patient presentation Emory University PHT 543C (physical therapy program) Neurologic Rehabilitation: Analysis of Dysfunction. Topic: Pathophysiology and Medical Management of individuals with Huntington's disease  
2009 - 2010

Lecture for Emory Neurology residents didactic education program, one hour contact time. Topic: Differential diagnosis of tremor  
2010

Faculty, NBB 470 Special Elective in Clinical Neurology, Emory University undergraduates: students shadowing in clinic weekly, editing weekly patient write-ups, mentoring one student through the semester and final oral presentation  
2008 - 2010

Emory University neurology residency mock oral boards judge  
2004 - 2010

Lecturer NBB 370S The Path to Discovery AD & PD, Emory University undergraduate course  
2009

Lecturer, Neuroscience I Module, Emory University medical students, topic: The basal ganglia and cerebellum, 3 contact hours  
2009

Lecturer, Medical Biochemistry, MEDI 515, Emory University medical students, topic: PD/mitochondrial disease  
2005 - 2008

Lecturer, Medical Genetics, MEDI 545, Emory University medical students, topic: HD genetics and genetic testing)  
*Course director 2007 review: "easily one of the best clinical sessions of the year"*  
2005 - 2008

Lecture for Emory University Neurology residents didactic education program, one hour contact time. Topic: essential tremor  
2007

Lecturer, BAHS 501, Emory University physician assistant course, topic: PD/mitochondrial disease  
2003 - 2005

Small Group Leader, Emory University first year medical school Neuroscience course  
2002 - 2007

## **Educational Innovations**

HIPAA compliant, IRB approved digital libraries for movement disorders.

As faculty at Emory University, assisted Dr Stewart Factor in building out a searchable modern digital library with video editing capabilities, including making associated video contributor forms, usage forms. Used this experience to found the VCU Parkinson's and Movement Disorders (PMDC) digital library in 2011, now used by multiple faculty for teaching. 2013-2016 the digital library was also used as an immediate resource by trainees rotating in PMDC outpatient clinics, when all PMDC core activities outside of bench science were housed in the same building area. 2017 mentoring Dr Jon Snider in further development of teaching arm of this resource, working with him to transition over teaching and clinical care sections and connect those with digital teaching materials held by other neurology divisions.

2011 - 2017

## **Service Activities**

### **Clinical Service**

#### **Outpatient Activities**

Attending neurologist VCU Huntington Disease Program, a Huntington Disease Society of America Center of Excellence. Integrating in-person interdisciplinary team visits for Huntington disease: neuropsychiatrist, nurse navigator, genetic counselor, social worker, nutritionist, physical therapist, speech language pathologist (services previously available as separate referral appointments only).

06/2016 - Present

Attending neurologist, VCU Parkinson's and Movement Disorders Center. Outpatient visits and botulinum toxin injections.

09/2011 - Present

Attending neurologist for summary visit, Emory Parkinson Disease Comprehensive Care Clinic. Full movement disorders neurologist visit plus integrating results from sleep neurology, geriatrics, psychiatry, neuropsychology, physical occupational and speech therapies, and medical social work assessments occurring over the one and a half days preceding the neurologist summary visit.

06/2010 - 09/2011

Attending neurologist, Emory University Movement Disorders and Huntington Disease Clinics. Outpatient visits and botulinum toxin injections.

09/2002 - 09/2011

#### **Inpatient Activities**

VCU Medical Center Neurology ward and consult attending

09/2011

Attending Neurologist, Emory University Hospital, Grady Memorial Hospital, and Wesley Woods Geriatrics Center, all Atlanta, GA

09/2002 - 09/2011

### **Service to the Profession**

Member, MDS Tremor Study Group (appointed post), 14 member international task force. Co-Chairs: Günter Deuschl (EU), Rodger Elble (US)  
06/2017 - Present

Member, MDS Task Force on Tremor (appointed post), 14 member international task force. Co-Chairs: Günter Deuschl (EU), Rodger Elble (US)  
6/2017 task force transitioned to standing study group  
09/2011 - 06/2017

Member, International Parkinson's and Movement Disorders Society (MDS) Task Force on the Definition of Huntington Disease (appointed post), 17 member international task force. Co-Chairs: Ralf Reilmann (EU), Christopher Ross (US), Francisco Cardoso (Brazil)  
03/2015 - Present

Member, Society for Neuroscience (SfN) Neurobiology of Disease Workshop Advisory Committee (appointed post)  
2007 - Present

Neurobiology of Disease Workshop (NDW): Gene Therapy to Address Unmet Needs in Neurology  
1/2017: core NDW committee group for detailed topic development  
8/2017: invited coach/mentor for in person formal faculty rehearsal  
01/2017 - Present

co-Chair, 2014 Neurobiology of Disease Workshop (NDW): Stroke Recovery: Connecting Neuroimmunology, Regeneration, and Engineering to Restore Functional Circuits  
279 attendees, international faculty and audience, lectures and discussion sections  
2013 successfully pitched topic and initial faculty proposal to NDW committee  
9/2014 formal rehearsal led by co-Chairs and NDW committee chair  
5/2015 moderated follow-up webinar after developing webinar with faculty  
11/2013 - 05/2015

Vice President, Tremor Research Group (TRG), non-profit with US and Canadian membership of faculty in tremor research. Elected post; re-elected 12/2016.  
02/2013 - Present

Member, Huntington Study Group Scientific Advisory Committee (4 year term, invited post)  
02/2015 - Present

"Champion" of HSG Mentoring, invited post  
2015

Investigator member, Huntington Study Group Executive Committee (elected post)  
09/2011 - 11/2014

Member, Huntington Study Group Nominating Committee (invited post)  
07/2013 - 11/2014

Member Huntington Study Group 2014 annual meeting planning committee  
03/2014 - 11/2014

Member, Huntington Study Group PREDICT-HD Motor Scientific Section  
2009 - 2013

co-chair, American Academy of Neurology 69th annual meeting scientific session  
"Movement Disorders: Beyond oral levodopa in Parkinson disease"  
04/2017

Guided Poster Tour leader for "Tremor" session, 1.5 hours, 30+ attendees,  
International Parkinson's and Movement Disorders Society 19th International Congress  
06/2015

co-chair, American Academy of Neurology 66th annual meeting scientific session  
"Movement Disorders: Huntington disease, ataxia, and Wilson disease"  
04/2014

Member, Juvenile Huntington Disease Workgroup (invited post), Huntington Disease  
Society of America. Two day meeting attached to the annual HDSA meeting, state of  
current knowledge and recommendations for advancing research.  
2012

### **Service to the Community**

Interactions with congress in collaboration with HopeNET founder Peter Muller:  
5/2014 Invited speaker, congressional briefing on essential tremor organized by  
HopeNET: "Overview of essential tremor" and "Goals of briefing"; Q&A panel  
participant. About 30 participants  
2016 Drafted letter that became memorandum from Congressman Van Hollen to NIH  
2/2017 in person meeting, Washington DC: Educating senior legislative aide to Senator  
Van Hollen on essential tremor, ways to move research in tremor forward.  
2014 - Present

Invited presenter, live webinar *Huntington disease clinical trials* for HD Support and  
Care Network, a national organization. 60 minutes with slides, recorded and posted to  
HDSCN YouTube channel for further member viewing  
06/2018

Huntington disease (HD) regional education day organized and hosted by VCU  
Huntington Disease Program.  
Speakers from across region and multiple HD centers and related organizations.  
Faculty member: *Research Updates* 30 min talk with slides; Speakers Panel open  
question session.  
68 attendees; 23 evaluation forms completed all scores 4.5 or higher (1-5 scales).  
03/2018

*Time with Testa* mini-lectures (3-5 minutes) for VCU Parkinson's and Movement  
Disorders Center YouTube channel  
Range of Symptoms in Essential Tremor >8200 views

Differences Between Essential Tremor and Parkinson disease >4200 views  
Movement Disorders and Understanding a Clinical Diagnosis; What is Huntington  
Disease?; Huntington Disease and Genetic Testing; Genetic Testing and Movement  
Disorders  
2016

2nd biannual Huntington disease education day hosted by VCU Huntington Disease  
Program and the University of Virginia Huntington Disease Center. "Update on HD  
research" 50 min talk with slides  
10/2015

Program Committee for the Ninth Annual Huntington Disease Clinical Research  
Symposium (HDCRS). Primarily geared to Huntington disease patients and families.  
Attendance also open to Huntington Study Group (HSG) membership, industry and  
governmental partners and local clinicians attending annual HSG meeting.  
02/2015 - 10/2015

Program Co-Chair and Program Committee for the Eighth Annual Huntington Disease  
Clinical Research Symposium  
03/2014 - 11/2014

Program Committee for the Seventh Annual Huntington Disease Clinical Research  
Symposium.  
03/2013 - 11/2013

Society for Neuroscience (SfN) poster tour host for patient / family community  
members. 3 community support group members, 5 posters plus general orientation to  
SfN, one hour walking tour  
11/2014

Speaking as VCU Huntington Disease Program Director on HD clinical trials. Invited to  
attend Richmond VA HD support group meeting. 6 patients and family members, 1.5  
hours, handout, talk and Q&A  
04/2014

PD101 (Parkinson Disease 101) series: on planning team for series, and presenter for  
"Overview of symptoms and treatments: Concepts and Categories". 15 patients and  
family members, 3 hours contact time on lecture date, handout, talk and Q&A in  
addition to overall planning team work  
2014

VCU Huntington Disease (HD) Program helps form Richmond area HD support group,  
independent open group hosted at the VCU PMDC clinical area and facilitated by VCU  
HD Program staff  
2013

Moderator for panel discussion and Q&A on Clinical Trials, Davis Phinney Foundation  
Victory Summit event in Richmond VA  
05/2012

Huntington disease advocacy day, Washington D.C.: attended training and then participated in direct lobbying of congressional offices regarding legislation HR 678, closing two year gap from disability approval to disability benefits payments for Huntington disease patients  
03/2010

Organizer of quarterly essential tremor (ET) educational series for patients, family and medical community, Atlanta, GA, with unrestricted educational grant sponsorship by Medtronics and International Essential Tremor Foundation (IETF) support. In addition to organizational contributions, served as faculty member:

*Overview of essential tremor*, January 26, 2008, Attendance: 130

One of four speakers April 26, 2008 event on Treatment of ET, Attendance: 110

Event evaluations: 100% 5/5 quality of speakers, 93% 5/5 event organization

*Clinical and translational research in essential tremor*, July 26, 2008, Attendance: 60

Final event October 2008 on Physical Therapy and Exercise in ET (by movement disorders physical therapist)

2008

Established Emory essential tremor support group, Atlanta, GA, which transitioned to independent member-run status same year.

2008

Organizer of IETF patient education day, Atlanta, GA, including giving *Basic and clinical research in essential tremor* lecture

01/2006

## **Service to the University**

Medical Director, VCU Parkinson's and Movement Disorders Center

Includes working on overall PMDC structure to integrate clinical care between disciplines, as well as integrated research, outreach/education, and clinical care missions; strategic planning; implementing programs.

Develop PMDC clinical care programs including: building out the botulinum toxin injection program, establishing pilot movement disorders telemedicine clinic (staffed by Dr Leslie Cloud), expand deep brain stimulation program.

Help recruit and on board new clinical care faculty, including neurologist, neuropsychologist, physician assistant.

Training resource for junior faculty, physician assistant, interdisciplinary team members, nurse navigators.

Facilitate patient access, track clinic availability and rate of referrals, referral sources.

Contribute to successful moves of clinical care programs:

- 2011 to initial Reynolds Crossing evaluation center, 2012 led transition of Reynolds Crossing VCU evaluation center to MCVP clinic status including transition to VCUHS electronic medical record system and modifying clinic for regulatory compliance

- 2013 designed new integrated clinical care, clinical research, education programs and academic office space in different area of Reynolds Crossing building, coordinated move into the new space, successfully advocated for nurse manager for PMDC clinics at Reynolds Crossing

- 2015-2016 facilitated move of clinical care programs to new VCUHealth NOW building including attending meetings on building design, staffing structure; 2016 clinical care programs moved to NOW center and Reynolds site closed
- 2017 continued collaboration with NOW building leadership to grow PMDC programs in this space; grew new ACC5 movement disorders clinic with resident teaching, established interdisciplinary partners for ACC5 clinic location
- 2018 advocate for interdisciplinary clinical care space and integration of clinical research in new outpatient building designs, attending 6 week VCUHS Academic Healthcare Finance for Faculty course

07/2012 - Present

Member, Promotion and Tenure Committee for Dr. Rachel Waller, Internal Medicine  
2017

Member, VCU CCTR Endowment Fund Research Advisory Committee (appointed).  
Includes quarterly review of grant applications.  
Spring 2017 coordinator for reviews of application to CCTR Endowment Fund Multi-School Award RFA:  
review application, coordinate summary of evaluations by two outside VCU reviewers.  
11/2014 - 11/2017

Chair, Promotion and Tenure Committee for Dr. Leslie Cloud, Neurology  
2016

Abstract reviewer for VCU Residents/Fellows Research Day: 55 abstracts reviewed and scored. One of 3 total reviewers.  
2016

Associate Director, Clinical Research, VCU Parkinson's and Movement Disorders Center  
Initial PMDC leadership team (PMDC Director Dr Bennett retired 7/2015).  
Strategic planning, facilitate interdisciplinary projects across all PMDC areas, mentor junior faculty growing clinical research programs, track clinical research programs including enrollment across PMDC. Actively support initiatives that promote research across PMDC: Founded clinic research registry, which has grown to over 1000 participants; developed one page permission to contact about research for use at educational and outreach activities; founded movement disorders digital library.  
2013 designed new integrated clinical care, clinical research, education programs and academic office space in different area of Reynolds Crossing building, coordinated move into the new space.  
2015 facilitated 2016 move of clinical research programs to new VCUHealth NOW building including collaborating with NOW center, VCUHealth and VCU CCTR leadership on integrating research programs into a clinical care building.  
09/2011 - 07/2015

Interviewer, VCU Neurology residency  
2014 - Present

Interviewer, VCU MD PhD Program

2015

Interviewer, VCU CCTR PhD Program  
2014

Member, VCU Neurology residency education committee  
2012 - 2013

Member, Emory University Neurology residency education committee  
2005 - 2011

Member, Parkinson Disease and Movement Disorders Research Subcommittee and  
Parkinson Disease and Movement Disorders Teaching Subcommittee, Emory University  
Comprehensive Neuroscience Center  
2005 - 2008

### **Service to other Affiliated Institutions**

Medical Directors committee on no show/cancellation rates (appointed)  
2016 - Present

Physician Wellness Committee VCUHealth (appointed)  
2015 - 2016

Speaker for the VCUHealth Community Health Education Center (CHEC) Library lunch  
lecture series for VCUHealth employees: "Demystifying Tremor". 20+ attendees, hour  
talk with slides, handout, and Q&A.  
06/2013

## **Publications**

### **Papers Published in Peer Reviewed Journals**

1. Testa CM, Jankovic J (2018 in press) Huntington disease: A quarter century of  
progress since the gene discovery. J Neurol Sci  
<https://doi.org/10.1016/j.jns.2018.09.022> available online

2. Holman MA, Quillin J, York TP, Testa CM, Rosen AR, Norris VW (2018) The changing  
age of individuals seeking presymptomatic genetic testing for Huntington disease. J  
Genetic Counseling 2018 Feb 20. doi: 10.1007/s10897-018-0233-9. [Epub ahead of  
print] PMID: 29460111

3. Bhatia KP, Bain P, Bajaj N, Elble RJ, Hallett M, Louis ED, Raethjen J, Stamelou M,  
Testa CM, Deuschl G and the Tremor Task Force of the International Parkinson and  
Movement Disorder Society (2018) Consensus statement on the classification of  
tremors, from the Task Force on Tremor of the International Parkinson and Movement  
Disorder Society. Mov Disord 33(1):75-87. doi: 10.1002/mds.27121. PMID: 29193359.  
*Named author based on contributions to manuscript. First new consensus tremor  
classification since 1998.*

4. Frank S, Stamler D, Kayson E, Claassen DO, Colcher A, Davis C, Duker A, Elmer L,

Furr-Stimming E, Gudesblatt M, Hunter C, Jankovic J, Kostyk SK, Kumar R, Loy C, Mallonee W, Oakes D, Scott BL, Sung V, Goldstein J, Vaughan C, Testa CM on behalf of the Huntington Study Group / ARC-HD investigators (2017) Safety of converting from tetrabenazine to deutetabenazine for the treatment of chorea. *JAMA Neurology* 74(8):977-982. doi: 10.1001/jamaneurol.2017.1352. PMID: 28692723

*One of 3 authors responsible for manuscript first draft plus final revisions.  
Global Co-PI of study.*

5. Hopfner F, Haubenberger D, Galpern WR, Gwinn K, Van't Veer A, White S, Bhatia K, Adler CH, Eidelberg D, Ondo W, Stebbins G, Tanner CM, Helmich R, Lenz FA, Sillitoe RV, Vaillancourt D, Vitek JL, Louis ED, Shill HA, Frosch M, Foroud T, Kuhlenbaumer G, Singleton A, Testa CM, Hallett M, Elble R, Deuschl G (2016) Knowledge gaps and research recommendations for essential tremor. *Parkinsonism Relat Disord* 33:27-35. DOI: 10.1016/j.parkreldis.2016.10.002. PMID: 27769649

*Proceedings of NIH meeting on knowledge gaps in essential tremor; invited discussant, contributed to consensus manuscript.*

6. Norriss SA, Jinnah HA, Espay AJ, Klein C, Bruggemann N, Barbano RL, Malaty I, Rodriguez RL, Vidailhet M, Roze E, Reisch SG, Berman BD, LeDoux MS, Piro Richardson S, Agarwal P, Mari Z, Ondo W, Shih LC, Fox S, Berardelli A, Testa CM, Chang FCF, Troung D, Nahab F, Xie T, Hallett M, Rosen AR, Wright LJ, Perlmuter JS (2016) Clinical and demographic characteristics related to onset site and spread of cervical dystonia. *Movement Disorders* 31(12):1874-1882. DOI: 10.1002/mds.26817. PMID: 27753188.

7. Haubenberger D, Abbruzzese G, Bain PG, Bajaj N, Benito-Leon J, Bhatia KP, Deuschl G, Forjaz MJ, Hallett M, Louis ED, Lyons KE, Mestre TA, Raethjen J, Stamelou M, Tan EK, Testa CM, Elble RJ (2016) Transducer-based evaluation of tremor. *Mov Disord*. 2016 Sep;31(9):1327-36. DOI: 10.1002/mds.26671. PMID: 27273470.

*output from International Parkinson's and Movement Disorders Society Task Force on Tremor*

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*First major paper from the North American Essential Tremor Consortium, in collaboration with a similar European consortium*

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## **Corporate Authorship or Multicenter Trials**

### 1. *Selected examples*

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*One of 3 authors responsible for manuscript first draft plus final revisions. Global Co-PI of study.*

2. Huntington Study Group PHAROS Investigators (2016) Clinical-Genetic Associations in the Prospective Huntington at Risk Observational Study (PHAROS): Implications for Clinical Trials. *JAMA Neurol.* 73(1):102-10. DOI: 10.1001/jamaneurol.2015.2736. PMID: 26569098

*Site investigator, contributed to manuscript review and editing*

3. The Huntington Study Group TETRA Investigators (2006) Tetrabenazine as antichorea therapy in Huntington's disease: A randomized controlled trial. *Neurology* 66: 366-372.

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## **Editorials, Reviews, Commentaries, Proceedings, Invited Published Papers in Peer Reviewed Journals**

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2. Deb A, Frank S, Testa CM (2017) New Symptomatic Therapies for Huntington Disease. *Handb Clin Neurol* 144:199-207. doi: 10.1016/B978-0-12-801893-4.00017-1. PMID: 28947118

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### **Books, Book Chapters and Monographs**

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### **Published Abstracts or Proceedings**

## 1. *Selected examples*

Testa C, Edmondson M, Agarwal P, Blindauer K, Gray C, Jankovic J, Kumar R, Shprecher D, Siragusa P, Whaley J, Frank S, on behalf of the Huntington Study Group First-HD and ARC-HD Investigators and Coordinators. (2017) Assessment of capacity to consent in a Huntington disease clinical trial: implications for future clinical trial design in neurodegenerative disease populations. American Academy of Neurology annual meeting, Boston MA, April 2017  
*co-PI for both trials; presenting author*

2. Frank S, Eberly S, Oakes D, Stamler D, Walker F, Testa C on behalf of the Huntington Study Group First-HD and TETRA-HD Investigators (2017) Reducing variability in the measurement of chorea. American Academy of Neurology annual meeting, Boston MA, April 2017  
*co-PI for First-HD trial; site PI for TETRA-HD*

3. Testa, C on behalf of the Huntington Study Group. Deutetrabenazine: update on first time use of SD-809 in Huntington's disease (First-HD) and alternative for reducing chorea in Huntington's disease (ARC-HD). (2016) J Neurol Neurosurg Psych 87(Suppl 1): A101. DOI: 10.1136/jnnp-2016-314597.286.  
*Invited platform presentation submission, peer reviewed published abstract*

4. Frank S, Claassen DO, Stamler D, Sung V, Janicki S, Oakes D, Vaughan C, Testa CM and on behalf of the First-HD HSG Investigators. Evaluating Swallowing Function in Patients with Huntington Disease Enrolled in the First-HD Study. (2016) Mov Disord 31(Suppl 2): S370.  
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5. Claassen DO, Oakes D, Stamler D, Sung VW, Testa CM, Frank S and on behalf of the First-HD HSG Investigators. Maintenance of balance function in patients with HD treated with deutetrabenazine, as measured by Berg balance test (BBT) in First-HD. (2016). Mov Disord 31(Suppl 2): S365.  
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*study co-PI*

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10. Sharma VD, Jones R, Alexander G, Testa C, Factor S (2015) Psychodynamic and reality therapy for psychogenic movement disorders: report on 9 cases. Mov Disord 30 (Suppl 1): S286.

11. Huntington Study Group/ARC-HD Switch Investigators (2015) Alternatives for reducing chorea in Huntington disease (ARC-HD): Results from the switch cohort. Mov Disord 30(Suppl 1): S531.

*co-PI for trial*

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*study co-PI*

13. Khandker N, Ganeshalingam N, Vota S, Testa C (2015) Isolated Hypoglossal Nerve Palsy as Initial Presentation of Pancreatic Cancer. Poster Session IV - Neurodiagnostics. Neurology 84(14 Supplement): P4.169.

14. Testa CM, Miyatake L, Wilson M, Bouzyk M, Factor S (2008) Longer REP1 repeat lengths are associated with both essential tremor (ET) and Parkinson disease (PD). Mov Disord 23(S1): S35.

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## **Lay Press Interviews or Publications**

1. NeurologyLive video interview on emerging therapeutics in Huntington disease (in press)

2. 6/2017 Huntington Study Group press release  
<http://huntingtonstudygroup.org/news/overnight-switch-from-tetrabenazine-to-deutetrabenazine-safe-trial-shows/>

3. 4/2017 Huntington Study Group press release  
<http://huntingtonstudygroup.org/news/fda-approves-second-drug-for-huntington-disease-symptom/>

4. Interviewed for and quoted in:  
Schmidt C (2017) First deuterated drug approved, Nature Biotechnology 35(6):

493–494 doi:10.1038/nbt0617-493

5. HD Insights volume 17, Spring 2017: Interview on Austedo (deutetrabenazine)  
<http://huntingtonstudygroup.org/hd-insights-volume-17/>

6. 7/2017 Huntington Study Group press release  
<http://huntingtonstudygroup.org/news/chorea-reduced-by-deutetrabenazine-in-study-led-by-hsg/>

Re-released by University of Rochester on Eurekalert  
[https://www.eurekalert.org/pub\\_releases/2016-07/uorm-crb070116.php](https://www.eurekalert.org/pub_releases/2016-07/uorm-crb070116.php)

7. Help4HD blog radio interviews:  
11/21/2013; 5/27/2014 hour panel discussions, Huntington disease clinical trials  
6/17/2014 Biographical interview, one hour

8. 2013 “Study indicates progress toward better diagnostic tests, offers evidence that ET and TAD may be separate conditions” invited review of scientific article for the International Essential Tremor Foundation’s patient/family publication Tremor Talk

9. 2011 “Talking About Driving in Huntington Disease” authored article for Huntington Disease Society of America’s patient/family publication

10. Emory Health Magazine Fall 2008 write up on essential tremor research project.  
[http://whsc.emory.edu/\\_pubs/hsc/08fall/hs08\\_clinical\\_care.html](http://whsc.emory.edu/_pubs/hsc/08fall/hs08_clinical_care.html)

11. International Essential Tremor Foundation Bulletin Fall 2007 article

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