



KEEP IN MIND!

A newsletter for friends and supporters of the Massachusetts Alzheimer's Disease Research Center and The Memory Study. Visit us at: madrc.org

FALL /WINTER 2018

VOL.7 ISSUE 1

CREATIVITY IN OUR COMMUNITY



We enjoy showcasing our research participants' & patients' amazing works (when they permit us to do so!) – whether poems, paintings or even childrens' books – and are proud to present wonderful images of Mr. Charles Kellstedt's oil paintings on the cover of this issue.

Mr. Kellstedt obtained a Bachelor's Degree in Industrial Design from Syracuse University (class of 1961) and served as a First Lieutenant in the U.S. Army. He was Vice President of GUNN

Images courtesy of
Charles W. Kellstedt

DESIGN in Boston and later on, founded INOV8 DESIGN in West Concord, Massachusetts. Mr. Kellstedt received the Hatch Award for design from the Boston Design Council and holds several design patents in technology product development.

Don't you think these images set remind us of the beautiful summer season that we had this year? Can you spot other images of Mr. Kellstedt's on other pages of the newsletter?



MORE INFORMATION

If you would like to learn more about our research studies, please call: 617.643.5200 or visit us at www.madrc.org



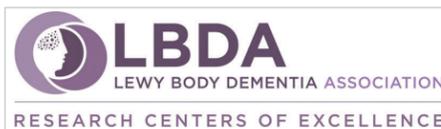
WAYS TO GIVE

For information about ways to support the clinical care, research, teaching and community health activities of the Massachusetts ADRC, please contact Liang Yap at 617.726.3987/lyap@partners.org

A MESSAGE FROM THE CHIEF

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courtesy of lbda.org

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courtesy of fcmisal.org

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After a longer-than-expected hiatus, we are delighted to produce another issue of our newsletter with an enhanced design that is distinct, creative & hopefully, pleasing to our readers' eyes. The new design is crafted by a talented graduate of MassArt (www.massart.edu), and we could not have been more pleased with the result (thanks Teresita)!

It has been another hectic yet gratifying year for all of us. During the past several months, each of my colleagues had spent close to countless hours coming together to work on our Center's 5-year grant renewal application (916 pages!) to the National Institute on Aging (NIA)! Indeed, I owe my heartfelt appreciation & thanks to each junior and senior staff who had been determined and patient throughout. Our early feedback suggest that the request has a great chance of success. We'll keep you informed as this process continues through the NIH over the next few months.

On the national news front, we have been encouraged by the increased awareness and advocacy efforts on behalf of Alzheimer's disease & related dementias (ADRD) in recent months. As some of you may already know, the National Alzheimer's Project Act (<https://aspe.hhs.gov/national-alzheimers-project-act#NAPA>) was signed into law by President Obama in 2011 and 2 members of the MGH (Katie Brandt, MM, & myself) have been honored to serve on the Advisory Council to help guide the National Plan. Katie directs caregiver support services at the MGH Frontotemporal Disorders Unit and has contributed a nice piece on NAPA and on frontotemporal dementia in this issue. A new and exciting Alzheimer's Clinical Trials Consortium (ACTC) network has also been launched across the U.S. to speed up and expand clinical trials for therapies in ADRD and we are excited that Dr. Reisa Sperling will co-direct the Consortium (<https://www.nia.nih.gov/research/dn/alzheimers-clinical-trials-consortium-actc>) together with two other renowned researchers from the Mayo Clinic and University of Southern California.

In this long-anticipated newsletter issue, we would like to highlight several recent clinical and research initiatives that would be of interest to our patients, caregivers and research participants. Dr. Stephen Gomperts – the director of the new MGH Lewy Body Dementia Clinic – has received a grant award from the Lewy Body Dementia Association (LBDA; lbda.org) to lead an LBDA Research Center of Excellence (RCOE) at MGH. With this milestone, Bostonians and visitors alike will be able to benefit from the new LBD clinical trials, community outreach and professional medical training that will be based at the MGH. In the 'A Conversation with Brad Hyman, MD' section of this issue, our readers will learn more about the MGH Interdisciplinary Brain Center



Image: The Doctor by Sir Luke Fildes. National Postal Museum/Smithsonian Institution

(IBC) that is directed by Dr. Steven Arnold. In addition to the IBC, Dr. Arnold has also established the MGH Normal Pressure Hydrocephalus (NPH) Clinic – one of a rare few NPH Clinics in the world. For our bilingual audience, we have also included a brief Spanish piece on our MGH Latino Memory Clinic that is led by Dr. Teresa Gomez-Isla.

Our Center has a distinguished history of recruiting and training talented clinician-researchers, and we are proud to feature write-ups from (i) a recent research assistant (Jessica Kloppenburg) who has now moved on to medical school, and (ii) our recent Clinical Fellow (Marta Marquie-Sayagues) who has since moved back to Spain to join a renowned Alzheimer's Treatment & Research Center in Barcelona.

Have you heard about a unique, large extended family in Antioquia, Colombia that is being studied and followed by leading investigators? Dr. Yakeel Quiroz is one such researcher who has been working with the kindred and you can read more about her fascinating work in the following pages.

Want to know more about a cutting-age project on the creation of stem cells from brain donors that is led by one of our promising young neuropathologists? Check it out amongst these pages!

In closing, I hope you will enjoy the delightful paintings of one of our ADRC family, (Mr. Charles Kellstedt) that are spread out amongst these pages. Mr. Kellstedt's work reflect the tranquility of nature, the joys of colors and our humanity. We celebrate his work in honor of the talents, gifts and resilience of each of our patients, research participants and their beloved.

Brad



Sir Luke Fildes, *The Doctor*, National Postal Museum/Smithsonian Institution

Existe una Unidad de trastornos de memoria para latinos (Latino MDU) en el MGH? La Dra. Gómez-Isla creó la consulta ambulatoria de memoria para latinos en 2013, y la ha dirigido desde entonces. Como el resto de pacientes de nuestra Unidad de Memoria, a las personas de la comunidad Latina se les realiza una evaluación neurológica y neuropsicológica completa, y vuelven para visitas de seguimiento y revisión del tratamiento aproximadamente cada seis meses. En los últimos años un número creciente de pacientes que hablan Español han sido tratados en la Unidad, y se han hecho esfuerzos para reclutar a más neurólogos que hablen español y conozcan la cultura Latina.

Las nuevas iniciativas que se desarrollan en la Latino MDU incluyen la posibilidad de participar en grupos de apoyo en Español, ser atendidos por un equipo multidisciplinar y participar en estudios de investigación y en ensayos clínicos. La latino MDU ofrece la posibilidad de realizar un fellowship clínico post-doctoral a neurólogos y psiquiatras interesados en atender a pacientes Latinos.

Estamos inmensamente agradecidos por la oportunidad de ofrecer atención multidisciplinaria de primer nivel para pacientes de habla hispana que tienen problemas con la pérdida de memoria y agradecemos sinceramente a nuestros pacientes y cuidadores que nos han confiado su cuidado.

Para programar una cita en nuestra Unidad de Trastornos de Memoria, por favor llame al 617-726-1728.



That there is a Latino Memory Disorders Unit (MDU) at the MGH? The Latino MDU outpatient clinic was established by Dr. Teresa Gomez-Isla (our Memory Division Director) in 2013 and had been directed by Dr. Gomez-Isla since then. Just as in our ‘regular’ MDU clinic, patients in the Latino MDU receive comprehensive neurologic and neuropsychological evaluations and return for follow-up treatment approximately once every six months. Over the years, an increasing number of Spanish-speaking patients have been evaluated in our Latino MDU, and efforts are being made to recruit more Spanish-speaking and culturally competent clinicians and staff to accommodate the growing number of patients waiting to be seen by Dr. Gomez-Isla and her team.

New initiatives that are in the planning stages for the Latino MDU include the opportunity to participate in Spanish-speaking support groups and in clinical trials and research observational studies. Post-doctoral clinical fellowship training opportunities for neurologists and geriatric psychiatrists who are interested in working with Latino/Hispanic patients are also being made available.

We are immensely grateful for the opportunity to offer top-notch, multidisciplinary care for Spanish-speaking patients who have concerns with memory loss and sincerely thank our patients and caregivers who have entrusted their care to us!! To schedule an appointment at our Latino Memory Disorders Unit, please call 617-726-1728.



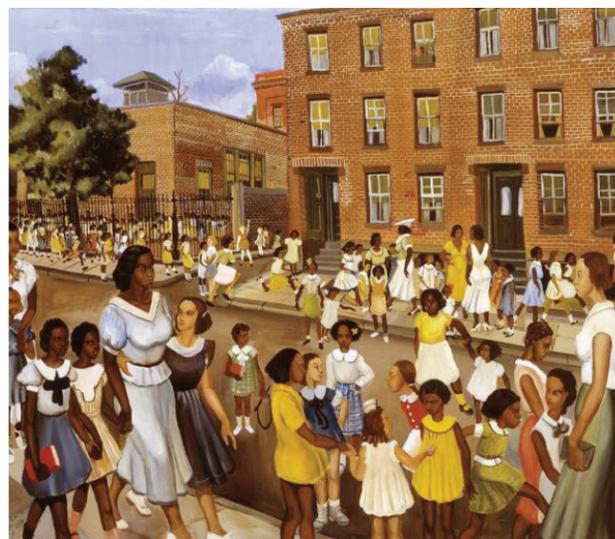
John Para. *Delicioso* Issued by U.S. Postal Service on Apr 20, 2017



A CENTRALIZED TELEPHONE NUMBER FOR INQUIRIES ABOUT OUR RESEARCH STUDIES!

INTERESTED IN LEARNING MORE ABOUT RESEARCH STUDIES AND HOW YOU CAN GET INVOLVED?

PATIENTS, CAREGIVERS, FAMILY MEMBERS AND HEALTHY VOLUNTEERS CAN CALL 617-643-5200 TO LEARN ABOUT ALL OF THE EXCITING RESEARCH OPPORTUNITIES WE HAVE GOING ON!



Allan Rohan Crite (1936). *School's Out* Smithsonian American Art Museum

We can't wait for the next school vacation!

A LOOK AT THE RESEARCH STUDIES OFFERED AT THE MGH FRONTOTEMPORAL DISORDERS UNIT

Look out for other types of studies in future issues of our newsletters!

STUDY NAME	STUDY CRITERIA	STUDY GOALS
ARTFL	AGE RANGE: 18-85 (inclusive) CLINICAL DIAGNOSES ELIGIBILITY*: FTD, PPA, CBD, FTD with ALS, or those who have a relative with a mutation in genes (MAPT, PGRN, C9ORF72) associated with FTD	THE GOAL of the study is to build a clinical research network that can support treatment and prevention studies, and to better understand the biomarkers of FTD
CAREGIVER SUPPORT INTERVENTION STUDY	AGE RANGE: 18-90 CLINICAL DIAGNOSES ELIGIBILITY*: Those with ALS or their caregivers	THE GOAL of this telephone support study is to help caregivers by providing them with support & strategies to manage challenging behaviors
CAREGIVER WELLBEING SURVEY	AGE RANGE: 18 or older CLINICAL DIAGNOSES ELIGIBILITY*: Caregivers of those with AD, FTD, PPA, PCA	THE GOAL of this survey is to help us understand how caregiving affects mental health
FTD FAMILY STUDY	AGE RANGE: 18-90 (inclusive) CLINICAL DIAGNOSES ELIGIBILITY*: individuals with family history of FTD	THE GOAL of the study is to determine if there is a preclinical FTD stage where those at risk for FTD have changes in their brain structure but do not have symptoms of FTD
IMAGING TAU, AMYLOID IN TYPICAL & ATYPICAL AD	AGE RANGE: 40-90 CLINICAL DIAGNOSES ELIGIBILITY*: typical or atypical AD, PCA, PPA	THE GOAL of the study is to examine how the proteins tau & amyloid affect brain regions and to symptoms of typical & atypical AD
LEFFTDS	AGE RANGE: above age 18 CLINICAL DIAGNOSES ELIGIBILITY*: those who have a relative with a mutation in the 3 most common genes (MAPT, PGRN, C9ORF72) associated with FTD	THE GOAL of the study is to find out if there are certain cognitive or behavioral traits that can help predict FTD
4RTNI-2	AGE RANGE: 40-80 CLINICAL DIAGNOSES ELIGIBILITY*: PSP, CBD or cognitive normal individuals	THE GOAL of the study is see if brain amyloid and tau relate to PSP and CBD symptoms

***KEY**

- AD: Mild dementia due to Alzheimer's disease
- ALS: Amyotrophic lateral sclerosis
- CBD: Corticobasal degeneration
- FTD: Frontotemporal degeneration
- PSP: Primary progressive aphasia
- PCA: Posterior cortical atrophy
- DLB: Dementia with Lewy bodies



NEW INITIATIVES AGAINST LEWY BODY DEMENTIA

BY STEPHEN N. GOMPERS, MD, PHD

In many people who develop cognitive impairment and dementia, the underlying disease is Lewy body dementia (LBD). This disease afflicts approximately 1.4 million Americans and can present either as dementia with Lewy bodies (DLB) or as dementia arising in the course of Parkinson disease. People with these illnesses develop trouble thinking in association with a constellation of clinical features including motor impairments known as parkinsonism, visual hallucinations, fluctuations of thinking or alertness, and a tendency to act out one's dreams (known as REM sleep behavioral disorder). LBD is named for protein clumps that form in brain cells, called Lewy bodies, which are also the hallmark of Parkinson disease (even without thinking problems). LBD is not usually hereditary. Like Alzheimer's disease, doctors and scientists are working hard to find a cure for LBD, to arrest, reverse, and ultimately prevent it from starting.

The over-arching mission of the LBD Unit is to improve understanding of LBD and provide comprehensive care to patients.

There is much to do to improve clinical care for patients with LBD. LBD is often misdiagnosed and this can lead to erroneous and sometimes even dangerous treatments. In addition, LBD can sometimes be hard to treat, partly because it causes such a broad range of problems. Lastly, unlike Alzheimer's and Parkinson's disease, LBD has received relatively little attention. **We seek to change that!**

To meet the significant need for individuals with LBD, we have started the MGH Lewy Body Dementia (LBD) Unit. The over-arching mission of the LBD Unit is to improve understanding of LBD and provide comprehensive care to patients. For this purpose, we work to provide an accurate diagnosis for people with problems affecting thinking and movement, to provide ongoing care for these individuals and

their families, and to offer opportunities to participate in research studies. The LBD unit is an extension of the MGH Memory Disorders Unit and also works with the MGH Movement Disorders Unit, to ensure optimal treatment of both thinking and moving, along with the other problems that can arise in this disease. Current research underway includes a brain imaging study to evaluate the contribution of Alzheimer's changes to the LBD.

Our Center has just been named a Center of the recently established Lewy Body Disease Association (LBDA) Research Centers of Excellence (RCOE) Program. A collaboration of 24 academic centers across the USA, the LBDA RCOE Program will function as a coordinated network of Centers conducting clinical trials and research related to LBD and providing expert clinical care for patients and their loved ones.

To make an appointment for the LBD Unit, please call Melanie Williams (617-726-5532).



A FEW WORDS FROM OUR NEW NEUROPATHOLOGIST

BY DEREK H. OAKLEY, MD, PHD

Neuropathology is the study of disease in the nervous system. It involves examination of human tissues under the microscope and provides the scientific basis for how we understand and treat disorders of the brain.

At the ADRC, the role of a neuropathologist is several-fold. Most importantly, we provide definitive diagnosis of dementias at the time of autopsy. This is beneficial both to our patients' families and their physicians. We also evaluate and distribute donated brain tissues from our "Brain Bank" to scientists around the country for use in cutting edge research on Alzheimer's disease and related dementias. Another growing function of the neuropathologist is to measure the effects of new disease treatments on the human brain. This is particularly exciting in the current era of emerging therapies for Alzheimer's disease and other dementias.

My name is Derek H. Oakley M.D., Ph.D. I have recently joined the staff of the Massachusetts Alzheimer's Disease Research Center as a neuropathologist after finishing my training at the Massachusetts General Hospital. Originally from the St. Louis area, I completed undergraduate studies at Washington University in St. Louis followed by medical and graduate degrees at Columbia University in New York City. While at Columbia University, I focused on using human stem cells to understand diseases of the nervous system. I came to Harvard University and MGH in 2013 for residency in anatomic pathology and a fellowship in neuropathology, which I completed in 2017. While here, I've benefited greatly from the mentorship of Dr. Matthew Frosch and Dr. Brad Hyman at the ADRC. I am very enthusiastic to be joining the team.

Dr. Oakley with his wife, Dr. Sheena Chew.
Dr. Chew is a neurologist at MGH

During this academic year, I have been fortunate enough to receive an administrative supplement from the National Institute on Aging's Alzheimer's Disease Centers. This grant allows me to have a role in overseeing the operations of the brain bank, lead conferences discussing the neuropathology of individual patients at the ADRC, and travel to other brain banks around the country to observe how they operate.

I am also involved in an exciting research project creating stem cells from brain bank donors. Starting with just a small piece of skin, we are able to generate patient-specific stem cells and then drive these stem cells to become millions of living brain cells matched to the individual donor. This gives us new ways to ask questions about what makes one person's brain cells different from another and why some people develop dementia, while others do not. We are well on our way to creating the largest matched set of stem cell lines and human brain tissues in existence. We hope that this will prove a valuable resource to the scientific community.

All the functions of the neuropathology core depend critically on the decision of patients and families to make the generous gift of brain donation after death. Through these donations, we are able to ensure that patients are receiving appropriate care and to support the development of new therapeutics. We are very grateful to each and every patient that makes the decision to become a brain donor.



INSIGHTS ON ALZHEIMER'S DISEASE FROM A LARGE COLOMBIAN KINDRED

BY YAKEEL T. QUIROZ, PHD



Image courtesy of fcmcisal.org



Dr. Quiroz assisting with fMRI scanning of a research participant

Dr. Quiroz (2nd from L) with research participants



Dr. Quiroz (2nd from L) with research participants

I am Assistant Professor in the Departments of Psychiatry and Neurology at Massachusetts General Hospital, Boston, MA. I completed my PhD in Clinical Psychology at Boston University and my Clinical Internship and Postdoctoral Fellowship at the MGH/Harvard Medical School. I established my research lab in 2015, MGH Familial Dementia Neuroimaging Lab, and also co-founded the MGH Multicultural Neuropsychology Program (MUNDOS) to provide culturally appropriate neuropsychological services to diverse patients, including monolingual and bilingual English/Spanish speaking patients.

I am interested in studying age-related cognitive disorders such as Alzheimer's disease (AD), how memory function is affected at preclinical and clinical stages of these diseases, and the differential impact these disorders may have on multicultural populations. My current research seeks to understand brain changes in presymptomatic individuals at increased risk for AD.

While attending college at a university in Colombia, I joined the Group of Neurosciences of Antioquia (GNA) to learn about memory disorders and brain function. Since then, I have worked with Dr. Francisco Lopera and colleagues in

the characterization of the world's largest extended family with a single genetic mutation (E280A in Presenilin-1) for AD. This mutation leads carriers to develop memory loss and Alzheimer's disease in their 40s. Research with these families has offered us a unique opportunity to study the progression of AD decades before onset of any symptoms because we can determine with certainty which individuals will develop AD.

My early work with these Colombian families introduced me to the power of human memory and inspired me to devote my academic life to AD research. For the past several years, I have had the privilege of working very closely with these families, and have witnessed how the possibility of preventing or even delaying the onset of the disease gives them a sense of hope that has not been present for years. I have committed myself to finding effective ways for AD early diagnosis and treatment, with the ultimate goal of delaying its onset or preventing it entirely.

Since I moved to Boston for Graduate School, I have conducted neuroimaging and clinical studies with the Colombian families. My research has provided evidence of brain abnormalities (e.g. hippocampal

dysfunction) several decades before their clinical onset, including childhood. This work has resulted in several publications that have generated considerable discussion in the field, and has achieved recognition by colleagues at the regional, national, and international level.

“Research with these families has offered us a unique opportunity to study the progression of Alzheimer's Disease (AD) decades before onset of any symptoms because we can determine with certainty which individuals will develop AD.”

In 2014, I received an NIH Director's Early Independence Award. As part of this award, in collaboration with Dr. Reisa Sperling, Dr. Keith Johnson and Dr. Dorene Rentz, my team is bringing members from these Colombian families to Boston for advanced

neuroimaging examinations (e.g. PET imaging). So far fifty-five members have visited Boston. Our initial findings provided evidence of abnormal amyloid and tau accumulation in the brains of asymptomatic carriers, several decades before symptom onset; amyloid begins to accumulate in their late 20s and tau in their late 30s, approximately six years before clinical onset.

I believe research in my lab, the MGH Familial Dementia Neuroimaging Lab (www.massgeneral.org/familialdementia) can provide key answers to many unsolved questions about preclinical AD, and therefore impact preventive treatments. We seek to provide 1) a profile of some of the earliest detectable pre-symptomatic biological changes (e.g. molecular and functional alterations) associated with the predisposition to develop memory loss and AD later in life; 2) a profile of the interaction between biomarkers in preclinical AD and their contributions to the onset of cognitive decline and progression to mild cognitive impairment and dementia.





A CONVERSATION WITH DR. BRAD HYMAN



Q: Dr. Hyman, you have led the research & clinical activities of our Research Center for more than a decade. Tell us something about your background, and how you came to develop your passion in what you do.

DR. HYMAN: I'm an MD PhD physician scientist who trained in Iowa, where there is a strong program in understanding brain function. We started studying Alzheimer disease with my mentors Gary Van Hoesen, a scientist, and Ant6nio Dam6sio, a clinician and the idea of tackling this huge problem from both a science and clinical perspective began. I moved to MGH in 1989 and John Growdon, director of the Center, did everything he could to pave the way for the new work I wanted to do to understand what went wrong in Alzheimer's, and how to fix it. We're still working hard, together.

Q: Our Research Center will soon be entering its 35th year of existence, and we have heard that the department had recruited some talented individuals to establish new collaborative entities, clinics & research centers. Tell us what's new!

DR. HYMAN: We have had the fantastic good fortune to recruit two senior researchers Dr. Steven Arnold who is a physician and scientist who came from University of Pennsylvania, and Dr. Julie Price, an expert in PET scans and similar imaging modalities, from

University of Pittsburgh. They are wonderful additions, adding new ideas and energy and strength to programs that already are among the best anywhere. Dr. Arnold is headlining new efforts in clinical trials at the newly-established MGH Interdisciplinary Brain Center that we are particularly excited about in Alzheimer disease as well as two rarer forms of dementia, normal pressure hydrocephalus, Jacob Creutzfeldt Disease, and Alzheimer disease.

Q: Dr. Arnold had also established a Normal Pressure Hydrocephalus (NPH) Clinic. Tell us more about NPH

DR. HYMAN: Normal pressure hydrocephalus is a rare cause of impairments in the elderly characterized by dementia and, often, problems walking and with bladder control. It is sometimes, but not always, helped by a special surgery. Dr. Arnold is teaming with colleagues in Neurosurgery and other departments to learn why some people are helped, and others not, and if we can do a better job of predicting who is who.

Q: What are your visions for dementia research & clinical care in the next 5 to 10 years? Any advice you would give to a young doctor who wants to pursue this line of work?

DR. HYMAN: We hope that the work we are doing, from early basic science work in the laboratory to developing ideas about how to test possible drugs and other interventions more effectively, will

contribute to a treatment and cure for these terrible diseases. I have worked with over 60 young physicians and scientists in the lab over the years, and each one knows that there is no more urgent or more important work we could be doing.

Q: Lastly, tell us something about your personal interests that most of us do not know, and that you're willing to share!

DR. HYMAN: My wife is also a physician scientist, so our kids were treated to all kinds of "interesting" conversations over the dining room table. They are doing great, one a lawyer and one in grad school, aiming for a PhD.

THANK YOU SO MUCH FOR YOUR TIME, DR. HYMAN!

Icon courtesy of kisspng.com



Image courtesy of Massachusetts General Hospital



Images courtesy of Charles W. Kellstedt



INSIGHTS ON ALZHEIMER'S PROJECT ACT (NAPA)

BY KATIE BRANDT, MM



Katie with Dr. Brad Hyman at the national Advisory Council meeting in Washington, DC in April, 2018

In 2011, the war against Alzheimer's Disease gained a new strategy when President Obama signed the National Alzheimer's Project Act (NAPA) into law. NAPA called for the National Plan to Address Alzheimer's Disease which set forth five goals, including the development of effective prevention and treatment approaches for Alzheimer's Disease and related dementias by 2025. The National Plan also established an Advisory Council on Alzheimer's Research, Care and Services. The Council convenes quarterly to advise the Secretary of Health and Human Services on federal programs that affect people with Alzheimer's Disease and related dementias and to continue the development and progress on the National Plan to Address Alzheimer's

“FTD affects an estimated 60,000 Americans and is the most common dementia for people under the age of 60.”

Disease. On September 28, 2017, HHS Secretary Tom Price, MD announced the seven new members who will serve on the Council. Two of the new members are from Massachusetts General Hospital; Brad Hyman, MD and Katie Brandt.



(L to R) Noah, Katie & Mike Brandt celebrating Noah's 3rd birthday and Mike's 32nd in March, 2011



Katie emceeding at the 2018 Rare Disease Day in Boston on February 28, 2018

As our readers know, Dr. Hyman is the Director of the Alzheimer's Disease Research Center and the Alzheimer's Unit Director of the Mass General Institute for Neurodegenerative Disease. Katie Brandt is the Director of Caregiver Support Services in the MGH Frontotemporal Disorders (FTD) Unit. Frontotemporal disorders represent a group of brain disorders caused by degeneration of the frontal and/or temporal lobes of the brain. These disorders may also be known as Frontotemporal Dementia (FTD) and Frontotemporal Lobar Degeneration (FTLD.) FTD is a progressive neurological disorder commonly striking individuals between the ages of 45 and 65, and affecting various aspects of a person's behavior, language, emotions, memory, and other abilities. Like Alzheimer's, FTD does not currently have a treatment to slow or stop the progression of the disease. Director Brad Dickerson, MD, and his team in the MGH FTD Unit, are part of the international movement to develop treatments and a cure for Alzheimer's Disease and related dementias such as FTD. We know it will take a community of patients, families, clinicians, researchers and staff members with varied roles and areas of expertise to bring the cure of tomorrow to the care of today.

Dr. Hyman and Ms. Brandt each bring a unique perspective to the Council. As a world-renowned neurologist, neuropathologist and neuroscientist, Dr. Hyman's expertise as a researcher and a clinician will bring valuable expertise to Council recommendations aimed at prioritization for research efforts

“...it will take a community of patients, families, clinicians, researchers and staff members with varied roles and areas of expertise to bring the cure of tomorrow to the care of today.”

and best practices in clinical care. Ms. Brandt brings professional experience as an advocate, educator and community event planner in the areas of best practices for dementia care and the impact of dementia on young families. Her experience as a former caregiver to her late husband, who lost his life at the age of 33 to Frontotemporal Degeneration (FTD), and as a current caregiver for her father with Alzheimer's Disease, brings hands-on expertise to Council recommendations aimed at caregiver support, community-based services and long-term care.

Alzheimer's disease currently affects 5.3 million Americans and is expected to affect more than 20 million by 2050. FTD affects an estimated 60,000 Americans and is the most common dementia for people under the age of 60. NAPA pledges to help people and families across the country whose lives are touched by Alzheimer's disease and related dementias. NAPA is a national plan, not a federal one, because to win the war against Alzheimer's Disease and related dementias, we will need participation of both the public and private sectors. By participating as members of this federal advisory council, Dr. Hyman and Ms. Brandt are demonstrating a commitment to an inclusive approach that brings together clinicians, policy makers, researchers, community-based agencies, patients and families from all sectors. Right now, patients and families need the highest quality of care and support services. Today, clinicians and researchers need funding and partnerships to develop innovative approaches to treatment that will lead to a cure. As Dr. Hyman said at the January 2018 Council meeting, “There are 3,644,640 minutes left until 2025, and I don't want to waste any of them.”

Learn more about FTD today:
www.ftd-boston.org

Learn more about the National Alzheimer's Project Act: <https://aspe.hhs.gov/national-alzheimers-project-act>



STAFF 'ALUM' MOVING ON TO BRIGHTER HORIZONS...



BY JESSICA E. KLOPPENBURG, BS

Jessica with her mom and her medical school mentor Dr. Hugh Silks

involved. How is it that after so many years of investigation we still don't have a clear answer and cure for what is going on? But even when it may seem from the outside that progress isn't being made, it is. It is your commitment to being involved in the research process, willing to put up with hours of brutal tests, unpleasant blood draws, scans, Charlestown traffic, and even the Navy Yard garage that helps keep the RA's like me excited about the work that we're doing.

Happy fall & winter! Let me re-introduce myself: my name is Jessica Kloppenburg, and I worked at the Massachusetts ADRC as a research assistant, or RA for short, for two years after graduating from Georgetown University. During that time, I had the opportunity to meet many of you while administering the big battery of neuropsychological tests and performing blood draws.

My grandmother passed away during my time at MGH due to complications from Alzheimer's Disease and my aunt has advanced early-onset Alzheimer's Disease. The disease thus holds a particularly close place in my heart and my mind. While I was in school, I came to better understand

the disease that has intimately touched my family. I learned about the destructive path that the tau tangles and beta-amyloid plaques take throughout the brain, the genes that predispose us to Alzheimer's Disease and other neurodegenerative disorders, and how many questions still remain about these disorders. The more I learned about the brain, the more interested I became and I decided to be a neurobiology major as a result. After graduation, I was thrilled to get the job at MGH so that I could be part of the team of researchers that is working towards figuring out those elements of neurodegenerative disorders that continue to puzzle us and moving closer to finding a cure. Research can be a slow process, and that can be frustrating for both the researchers and the study participants

I am now a first-year medical student at the University of Massachusetts Medical School in Worcester. I miss my coworkers, as there is certainly a close camaraderie between the RA's and study staff that comes from working in such tight quarters and seeing the hardships that so many of you go through everyday. However, I am excited to be taking the next step in my professional development. When I started at MGH, I was thinking of applying to medical school but was not 100% sure. It was only after being fully entrenched in the world of dementia every day that I was able to be unequivocal in my decision to go to medical school. My emotions varied widely over the course of a typical day and included deep respect and awe over how

so many of you handled your day-to-day, intellectual curiosity about the underlying biological processes, enjoyment in getting to meet so many interesting people, and frustration that we weren't further along in the treatment process. I always knew that I wanted to pursue something that I was passionate about, and I came to understand that I would be most satisfied in my career if I were able to help care for individuals in the present while working for better treatment options in the future. After all, this is what I saw in Dr. Hyman; Dr. Dickerson; Dr. Copeland; Dr. Koenig; Dr. Gomez-Isla; Dr. Gomperts; Dr. Okereke; Dr. Blacker; Dr. Albers; Dr. Viswanathan; Dr. Marshall; Dr. Arnold and so many of the physicians at MGH and BWH do.

While the first year of medical school has certainly been challenging, it has also been one of the best years of my life. I get to learn about the complexities of our bodies and all the nitty-gritty details of how things work all the way down to the level of cell membranes and signaling pathways. I also see when we spend time in the clinic how the medications that we prescribe for blood pressure and all other kinds of conditions are based in these kinds of nitty-gritty details. Indeed, finding the answer to Alzheimer's Disease, Parkinson's Disease, ALS, MS, and other neurodegenerative disorders will come down to this kind of understanding too. And I am excited that I have such a good basis on research principles from my time at MGH to build upon.

FORMER CLINICAL RESEARCH FELLOW MOVING ON TO PROMISING CAREER BACK IN BARCELONA

BY MARTA MARQUIE-SAYAGUES, MD, PHD

My name is Marta Marquié and I am a neurologist from Barcelona, Spain. I first came to MGH back in 2010 for a 6-month stay as part of my PhD program and I ended up staying for 7 years. My research at MGH focused on novel neuroimaging tools for the diagnosis of dementias. Specifically, I worked in a basic-science laboratory with brain tissue samples trying to validate the usefulness and specificity of new tracers designed to bind brain proteins such as amyloid and tau, known to be abnormal in Alzheimer's Disease. I was very lucky to work with awesome mentors such as Dr. John H. Growdon, Dr. Stephen N. Gomperts, Dr. Bradley T. Hyman and Dr. Teresa Gómez-Isla.



Marta with her colleagues at Fundació ACE. Marta is in floral prints in the 2nd row from the right (circled).

Continued on next page



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After a few years as a research fellow, I decided to complete my clinical training in the dementia field. I took the USMLE exams, obtained the US Medical License and in 2015 I became the 1st Growdon Clinical Fellow in Dementias at MGH. This Fellowship is named after Dr. John H. Growdon, who is the founder of the Massachusetts Alzheimer's Disease Research Center, director of the Movement Disorders Unit and former director of the Memory Disorders Unit at MGH. This 2-year fellowship combines clinical and research opportunities, which was very attractive to me as it allowed me to continue with my research activities at the laboratory. Dr. Gómez-Isla, who is the director of the Memory Disorders Unit, co-director of the Massachusetts Alzheimer's Disease Research Center Clinical Core and Anne B. Young Endowed Chair in Neurodegenerative Disease, was my mentor in this Fellowship. As a fellow, I received training in the diagnosis, management and treatment of patients with dementia. As Spanish is my native language, I was also involved with the MGH Latino Clinic that offers care to Latino patients (mainly from Central and South America), which was a very rewarding experience for me.

“*My goal is to investigate novel imaging biomarkers for preclinical Alzheimer's Disease. I am really eager to put all the knowledge I acquired at MGH during the last 7 years into practice!*”

The research I performed at MGH allowed me to complete my PhD studies at the Autonomous University of Barcelona, and Dr. Gómez-Isla was one of my PhD program directors. I defended my PhD dissertation in Barcelona on November 2016 with honors, obtaining a Cum Laude mention.

In July 2017, after finishing the 2-year Fellowship in Dementias, I decided to move back to Barcelona to start a new stage of my career. I am currently working as a clinical neurologist in the dementia out-patient clinic at Fundació ACE Barcelona Alzheimer's Disease Treatment and Research Center. I have been recently awarded a Marie Skłodowska Curie Action Research Fellowship, which is a very prestigious research award from the European Commission that will allow me to continue my research career back in Spain. My goal is to investigate novel imaging biomarkers for preclinical Alzheimer's Disease. I am really eager to put all the knowledge I acquired at MGH during the last 7 years into practice! I am very glad to be back in Spain and it did not really take me any time to re-settle down as I immediately felt like at home again. I am enjoying the nice weather, relaxed life-style and time with family and friends.

TO ALL OUR RESEARCH PARTICIPANTS

It's been a while since we produced a newsletter. I'm happy that we can send this one to you now. It gives me an opportunity to thank you, once again, for all that you do for us. Sometimes we ask you to do the same things at each visit. And sometimes we ask you to do something new and different. It's all to help us in our endeavors to better understand, treat, prevent, and even cure neurodegenerative diseases. That is our hope!

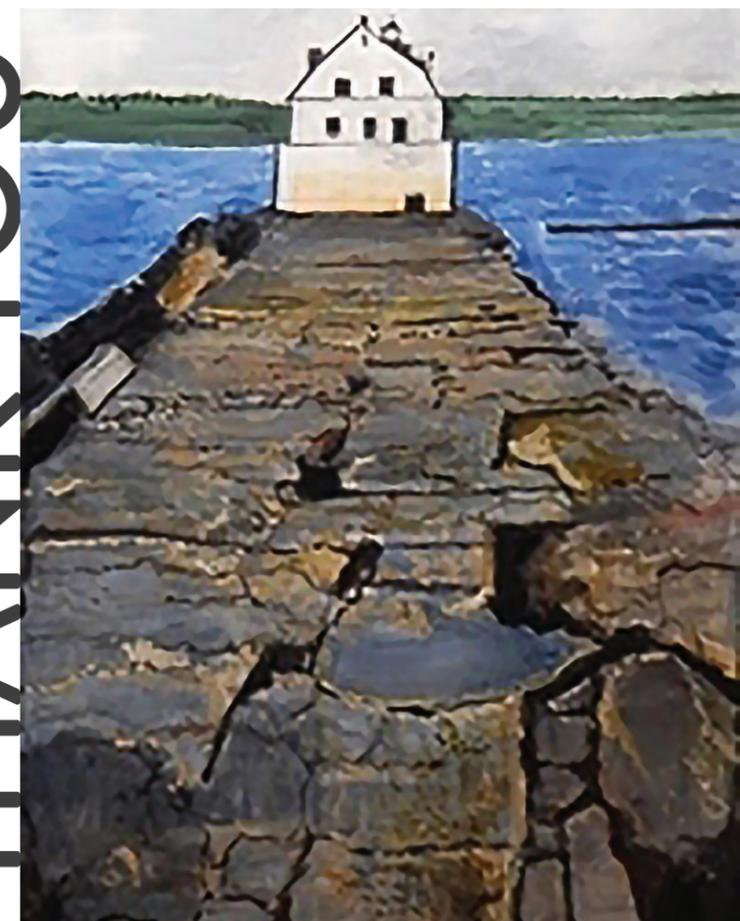
Thank you for being a special part of that hope!

Jeanette Gunther, MS
Clinical Coordinator
Gerontology Research Unit

*Hope is the thing with feathers
That perches in the soul,
And sings the tune without
the words,
And never stops at all.
-Emily Dickinson*



THANK YOU



Images courtesy of Charles W. Kellstedt



Scenes and Celebrations!



Dr. John Growdon (2nd row with pink bowtie) with other honorary awardees. Courtesy of University of Zurich

The New England Patriots won its 5th fifth Super Bowl (Super Bowl LI) and our research assistants Olivia Umoren (L), Alex Baldeon and Mikaila Christopher (R) were extremely excited when the Super Bowl Trophy was on view at the MGH



Our Research Center's Director – Dr. Hyman – was recently in Tokyo (Sept '18) when he'd met up with former members of his lab who are also good friends. In this photo, Dr. Hyman is shown with Elli Hashimoto - the wife of Dr. Tadafumi Hashimoto - and their son, Hiroto. Across from Dr. Hyman is Yuka (daughter of Dr. Hashimoto) and another former lab member Dr. Ito Kawakami Tamada. Dr. Hashimoto is now with the University of Tokyo, while Dr. Kawakami Tamade is with the Tokyo Metropolitan Institute of Medical Science.



courtesy of Tadafumi Hashimoto, PhD

KEEP IN MIND!

A newsletter for friends and supporters of the Massachusetts Alzheimer's Disease Research Center and the Memory Study

FALL/WINTER 2018 VOL. 7 ISSUE 1

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Spring Plants by Zeshin. Circa. 1800-1900. Lacquered wood, bamboo & mother-of-pearl. The Avery Brundage Collection. Asian Art Museum Chong-Moon Lee Center for Asian Art and Culture, San Francisco.

Come back soon Spring!!

NEWSLETTER ISSUE: FALL





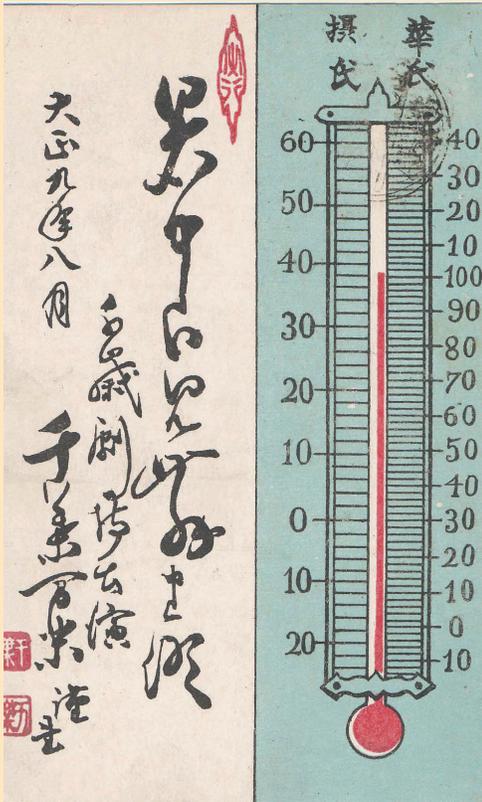
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Alzheimer's Disease
Research Center

BOSTON, MA

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TO

Empty rectangular box for an address.



WELCOME TO THE FALL / WINTER ISSUE OF **KEEP IN MIND!**

*A newsletter for friends and supporters of the Massachusetts
Alzheimer's Disease Research Center and the Memory Study*

Artist Unknown, Japanese (Circa 1919)
Summer Greeting Card: Thermometer
Taisho era Color lithograph, ink on card stock
Leonard A. Lauder Collection of Japanese Postcards
Museum of Fine Arts, Boston

Where did the Summer go?

